

# **Communicating about Cancer Risk with Health Information Seekers:**

## **Results of Focus Groups and Key Informant Interviews**

**National Cancer Institute  
Office of Education and Special Initiatives**

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# Executive Summary

The National Cancer Institute’s (NCI) Office of Education and Special Initiatives (OESI) is developing educational material to help cancer information seekers<sup>1</sup> accurately interpret numerical expressions of risk and increase their ability to put such information into context. Guided by a review of the risk communication literature and materials, plus input from risk communication experts, OESI drafted a series of cancer risk scenarios, each as a short, one-paragraph story a person might tell another during a conversation. One scenario also had four questions and answers to address the issues raised.

To explore information seekers’ reactions to these materials and some visuals and to determine whether the same scenarios can be used with various populations, OESI commissioned eight focus groups (with 67 participants). Most focus group members were between the ages of 40 and 59, were health information seekers, had sufficient literacy and language skills to read and discuss materials written in English, and had graduated from high school or college. Participants were not cancer survivors or employed in a medical setting. Four computer-assisted telephone focus groups were conducted with African Americans and Caucasians; members came from large and small communities across the United States. Four in-person focus groups were conducted with English-speaking Hispanics, two in Bethesda, Maryland and two in Chicago. All focus groups were segregated by gender.

To obtain input from other population groups, six key informant interviews were conducted. Three were with health educators or health activists who work with Asian, Native Hawaiian, and Pacific Islander (API) communities; three were with similar professionals who work with American Indian or Alaska Native communities.

The following materials were discussed in the focus groups and key informant interviews:

- Four sets of vignettes—each introduced particular genetic/family history, behavioral, or environmental cancer risk concerns; three included multiple scenarios; and one contained questions and answers to guide readers through relevant risk concepts
- A list of possible topics for a risk publication
- Three visual representations of risk likelihood to refer to during the telephone discussions.

As with all qualitative research, findings reported here are directional in nature and cannot be considered representative of or generalizable to some known population.

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<sup>1</sup> “Cancer information seekers” were defined as members of the general public engaged in interpreting cancer risks or making cancer risk-related health decisions.

## **General Risk Findings**

Focus group participants mentioned a range of health risks that concerned them, and said they tended to think about these health risks anywhere from several times a day to weekly. They had taken actions to reduce health risks, such as improving their eating habits, getting more exercise, seeking medical care for chronic conditions, drinking bottled water, and taking vitamins. Participants looked for information about health from a variety of sources, including various sites on the Internet.

## **Cancer Risk Findings**

Focus group participants thought that many things cause cancer, such as environmental, lifestyle, and genetic factors. They generally thought that a person's risk of developing cancer could be reduced (especially through lifestyle changes), but not eliminated. If they read or heard a news story about a new means of reducing cancer risk, their reaction depended upon the action involved and the source of the information. Some took actions if they seemed safe and were easy to do; others waited until multiple credible sources suggested the same action.

Key informants emphasized that attitudes towards cancer risk vary dramatically by education, culture, and region. In some cultures, asking questions about or discussing cancer could be viewed as bad luck. Some perceived that it is more appropriate to seek health information for others than for oneself. The degree to which individuals are concerned about cancer risk may depend on the severity and number of other health challenges they face.

## **The Scenarios**

Participants and key informants reviewed 1-paragraph anecdotes that used first-person stories to set up three types of common risk situations: those involving a family history of cancer, those involving behavioral risk factors, and those involving potential environmental risk factors. Participants generally found this approach engaging and easy to follow.

Focus group participants liked characters who take control of their lives by doing what they could to prevent cancer or detect it early. This desire appeared to hold across cultures. Stories with sentiments like "there's nothing I can do" tended not to be well-received. Scenarios about topics for which there is uncertainty or confusion (e.g., cancer appearing in young people with no family history of it, neighborhood cancer clusters), were well received—readers both identified with the topics and found them engaging. They seemed to resonate because participants had wondered about such things or knew friends who had similar situations. Key informants cautioned that some details in the scenarios may not be applicable for many members of the populations they serve.

Participants did not like stories that presented myths as facts, which are later dispelled. This approach made the storytellers appear ignorant. Since health information seekers are not ignorant, they did not identify with the stories and would not see the publication as relevant. The approach disturbed some participants, who expressed concern that readers might stop before reading the accurate information.

Focus group members pointed out the need to pay attention to certain words. They recommended that terms such as “prevention,” “at-risk,” and “clinical trials” be clearly defined. Men recommended avoiding the word “worry,” because men may be concerned, but they do not think of themselves as worrying about cancer.

The one scenario that discussed clinical trials interested focus group members, but distracted them from the risk concepts. The scenario generated a lot of discussion and questions, but the questions were equally likely to be about clinical trials and about cancer risk.

## **Scenario Responses**

Participants received a two-page document with an introductory scenario, followed by four questions and answers that presented key risk concepts. In general, this approach to walking participants through risk concepts appeared to work well. Participants suggested reordering the questions and making some editorial changes.

## **Visually Communicating Numeric Expressions of Risk**

Participants were given three graphic representations of risk. They preferred one that depicted human forms (in this case, females) and recommended that the images should look like “real” women rather than stylized figures. Participants thought portrayals of women humanized and personalized risk information.

## **Risk Topics of Interest**

Based on initial research, OESI had proposed developing cancer risk material focused on concepts related to understanding risk. When asked to choose risk topics of interest from a list, however, participants were clearly interested in information related to risk-reducing behaviors. Their top four choices were: what to do to decrease the risk of getting cancer, information to help decide about taking action, types of cancer risk that can and cannot be controlled, and understanding what cancer is.

Although most focus group participants said they would be interested in a booklet on cancer risk, some expressed concern that it would be too elementary. They said that many health information seekers think they already know a lot about cancer and the risks for it and would not be satisfied with basic information. Instead, they are looking for information that is somewhat more sophisticated, yet presented in an easy-to-understand format.

## **Recommended Next Steps**

The findings and conclusions reported here suggest the following next steps for OESI in developing educational materials on cancer risk for health information seekers.

1. Revise and draft additional scenarios according to the findings summarized above and additional input from the Risk Working Group.
2. Pretest the revised scenarios and perhaps a draft of the educational materials with larger numbers of people, in one-on-one settings to facilitate gathering individual reactions. Include health information seekers from various ethnic groups, recognizing that the definition of “health information seeker” may have to be somewhat fluid depending upon predominant cultural norms.

# 1. Background

The National Cancer Institute's (NCI) Office of Education and Special Initiatives (OESI) plans to develop educational material for cancer information seekers<sup>2</sup> that will increase their ability to accurately interpret numerical expressions of risk and put such information into context for themselves.

In preparation for developing the educational materials, OESI conducted several activities that are detailed elsewhere,<sup>3</sup> including reviewing the risk communication literature, analyzing relevant NCI initiatives and grants, examining cancer risk education materials, consulting with risk communication experts, convening a Risk Working Group (with experts from several NCI divisions), and consulting with NCI's Division of Cancer Control and Population Sciences' Health Cognition Group. Guided by these sources, OESI and risk experts crafted a series of cancer risk scenarios and responses to help people understand cancer risk concepts.

To explore information seekers' reactions to these materials and determine whether the same scenarios can be used with various populations, OESI commissioned eight focus groups and six key informant interviews. Other objectives of the study were to:

- Explore the effect of presentation formats (e.g., message framing, visual aids) on the public's understanding of cancer risk terms and concepts
- Assess the public's understanding of placing risk information into a personal perspective
- Learn whether the public prefers risk information presented in qualitative or quantitative formats
- Explore public perceptions of behaviors that may reduce cancer risks
- Identify cancer risk-related myths and misconceptions

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<sup>2</sup> Cancer information seekers are members of the general public engaged in interpreting cancer risks or making cancer risk-related health decisions.

<sup>3</sup> Office of Education and Special Initiatives, National Cancer Institute. (Undated). *Cancer Risk Communication Project to Develop Educational Materials that Communicate Cancer Risks to the Public*.

## 2. Methods

To gain insights into ways that information seekers think about cancer risk and their reactions to materials addressing cancer risk, qualitative methods were used:

- Four telephone focus groups were conducted, segmented by race (African American and Caucasian) and gender. Focus group participants were from large and small communities across the United States.
- Four in-person focus groups were conducted with Hispanics, segmented by gender. Two groups were convened in Chicago and two in Bethesda, Maryland.
- Key informant telephone interviews were conducted with health educators, activists, providers, or researchers—three from the Asian and Pacific Islander (API) communities and three from the American Indian and Alaska Native (AI-AN) communities.

Table 1 summarizes key characteristics of focus group participants. The focus groups were conducted in November 2002. Each focus group session was audiotaped and transcribed; transcripts were analyzed to capture the range of opinions and major themes that emerged.

**Table 1. Focus Group Participant Characteristics<sup>a</sup>**

Characteristic	Number	Percent of Total
African American	16	24
Caucasian	16	24
Hispanic	35	52
Female	33	49
Male	34	51
High school	10	15
Some college	22	33
College graduate	25	38
Some graduate coursework or graduate degree <sup>b</sup>	9	14
Look for information on medical conditions. . .		
Monthly	24	36
Every few months	37	56
1-2 times a year <sup>b</sup>	6	9
Touched by cancer	21	32
Often think have health problems	2	3
Fatalistic about cancer risk	3	5

<sup>a</sup> Demographic characteristics were not available for one participant at the time this report was written, so all percentages except race/ethnicity and gender are based on n = 66, not 67.

<sup>b</sup> Bethesda Hispanics only.

Additional information about the methods used to select participants and collect information is presented in Appendix A.

Focus groups and key informant interviews are exploratory research techniques, useful for gaining insights into the thoughts, feelings, and perspectives of target populations. Participants are not drawn from a random sample of a defined population, and data take the form of conversations rather than answers to identically worded questions. For these reasons, the research findings reported here may not be representative of or generalizable to the populations from which participants were drawn.<sup>4</sup>

Below, findings from focus groups and key informant interviews are presented.<sup>5</sup> Findings are grouped, with results from focus group preceding lessons from key informant interviews. The report first discusses respondents' opinions about health risks and their knowledge and behaviors regarding cancer risk. Reactions to the materials—scenarios, scenario responses, visual graphics, and risk topics of interest—are presented next, along with feedback regarding interest in a booklet on cancer risk concepts. The report concludes with a summary of findings and recommendations.

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<sup>4</sup> Additionally, color was used differently in the materials participants reviewed, so participant preferences may have been affected by the way information was presented or the colors used.

<sup>5</sup> There are distinctions between focus group and interview participants, namely (1) focus group participants were health information seekers, but key informants had professional or personal expertise in cancer issues; (2) the focus groups had 67 participants, whereas key informant interviews were conducted with six people; and (3) the focus group reports include a broad range of views from African American, Caucasian, and Hispanic health information seekers, while key informant interviews reflect the perspectives of a few AI-AN and API individuals who work with members of these populations.

## 3. Findings

Within each section below, reactions from African American, Caucasian, and Hispanic participants are presented first, followed by comments from the API and AI-AN key informants. Verbatim comments from focus group members are italicized and identified as to type of participant; statements from key informants are presented as quotations in the text.

### 3.1 Perceptions of Health Risks

To start the focus groups, focus group participants were asked basic questions to determine thoughts about health and cancer risks, and key informants were asked to respond to these questions in terms of health information seekers in their populations. Responses are summarized in this section.

#### 3.1.1 Health Risks and Actions to Reduce Them

##### Focus Groups

Focus group participants thought of health risks as things that make people sick, can shorten their lives, or are potentially dangerous to people's health. The specific "things" they thought of as health risks varied from group to group, although every group mentioned behavioral risk factors. The lengthy list of health risks they mentioned include: tobacco use, obesity, poor eating habits and diet, use of alcohol and drugs, stress, unprotected sex, toxins in food, hereditary conditions, and major life-threatening diseases, including cancer, breast cancer, high blood pressure, diabetes, and heart attack.

In terms of personal health risk concerns, participants mentioned breast cancer (for women), stress, high blood pressure, heart attack, stroke, congested traffic, not getting enough exercise, being overweight, being exposed to biological contaminants that may be released by a terrorist, and the West Nile virus.

The frequency with which focus group participants thought about these health risks varied from several times a day to weekly. Some participants said they think about these health risks when another person mentions them or when they see or hear a news story. Participants said they try to reduce health risks by eating healthy foods (such as more fruits and vegetables and less red meat and pork), drinking bottled water, taking vitamins, exercising, and seeking medical care for high blood pressure and cholesterol control.

To get information about health risks, participants consult a variety of sources: the Internet, books, magazines, healthcare professionals (including clinics and hospitals), and pharmacies. The Internet and printed information from books and the mass media were mentioned most often. Some look for health information only when it concerns them:

*Usually I go searching after I've had a doctor's visit and he's said something that I just wasn't clear about. [African American female]*

*Sometimes some unusual thing you hear on the radio or television will prompt me to look for some articles or some information. [Caucasian female]*

## Key Informants

One informant who works mostly with Native Hawaiian and Pacific Islander populations said that tobacco, diet, and other behavioral risk factors are the major health risks of concern to API groups. She noted that illness is viewed from the perspective of how it affects family members. Another API informant, who is a cancer patient, said the major risk had been heart disease, but increasingly it is cancer.

Two AI-AN informants said that diabetes, cancer, and heart disease were issues of major concern in their populations; other health risks include obesity, alcoholism and depression. One informant said that among Alaska Natives, oral, lung, breast, and colon cancers are most common.

## 3.2 Perceptions of Cancer Risks

Participants were asked what it would mean if their doctor said, “You may be at increased risk” of a health problem such as cancer. They said, “*It sounds like you have a good chance*” and “*It sounds like I’m in a statistical grouping that might matter.*” One Hispanic man tied it to current behavior: “*It means that you’re close. If you could continue doing whatever you’re doing, you will get cancer if you don’t take care of yourself.*”

If they got this message from their doctor, focus group participants said they would first talk to the doctor to gain greater understanding of what s/he meant and to ask what could help them avoid the problem. Many also said they would research the issue in more detail.

*Not to be flippant, but I think I would ask my doctor what his definition of increased risk meant.* [Caucasian male]

*I would try to make the changes to avoid falling into the category and getting sick.* [Hispanic female]

*I would use the beautiful technology existing today to prevent.* [Hispanic female]

### 3.2.1 Causes of Cancer

#### Focus Group Participants

Participants thought that many things cause cancer. As one participant put it, “*What doesn’t?*” Members of all groups mentioned genetic, lifestyle, and environmental factors without prompting. One man said he thought it was viral, and another said he thought it was something wrong with the immune system. Some Hispanic women said they thought stress caused or at least contributed to cancer; a couple mentioned hormones as a cause of breast cancer. Another woman said she thought it was caused in part by how food is processed these days. Some thought it was a combination of genetics and then a trigger from something related to the environment or lifestyle.

*This is my opinion...I feel like all of us have cancer inside. It’s just that it doesn’t grow. It all depends on lifestyle ...something in our lifestyle will trigger it.* [Hispanic female]

## Key Informants

Two API informants asserted that most Asians do not want to talk about cancer risk. One said, “People just pretend they do not exist.... It’s seen as bad luck” to mention topics such as cancer

and death. Another said many Asian Americans think cancer is a curse and do not tell friends when they have it. A third API informant said that Native Hawaiians and Pacific Islanders believe diet, behavior, smoking, and “power” play a role in cancer risk. Explaining the concept of power, she noted, “It has to do with what your ancestors have done in the past. It’s similar to the idea of karma.”

All AI-AN informants mentioned that American Indians and Alaska Natives believe environmental contaminants cause cancer. Two felt there is growing awareness about the relationship between lifestyle and risk; one noted that she frequently hears smoking mentioned as a health risk. One said that Alaska Natives do not couple their belief that environmental contaminants cause cancer with a realization or acceptance that behavioral patterns such as diet can contribute to cancer. She emphasized that AI-AN belief systems vary, and some ill AI-AN individuals experience guilt, thinking their health condition is due to something they have done.

### **3.2.2 Reducing Cancer Risk**

#### **Focus Groups**

Participants generally thought that a person’s risk of developing cancer can be reduced but not eliminated because some risks, such as genetics and certain environmental factors, cannot be controlled. To reduce cancer risk, most focus groups discussed lifestyle choices, but a couple of Hispanic women mentioned other means, such as “*going to the doctor for the treatment or something that he could give you to prevent the disease*” and “*probably spirituality*.” Participants generally thought it was hard to measure how much risk could be lowered; one or two people guessed about 50 percent.

Participants did not agree on the greatest cancer risk. Some said lifestyle factors, such as smoking; others cited genetic predispositions; and still others noted that it depends on the type of cancer because various behaviors will put people at greater risk of developing different cancers (e.g., smoking leads to lung cancer, too much sun exposure leads to skin cancer).

#### **Key Informants**

One API informant was ambivalent about reducing cancer risk. She felt that because genetics play a large role in whether a person will develop cancer during his or her lifetime, cancer risk cannot always be reduced, but it can often be lowered through behavior change. Another informant held the view that, “To some point, a person’s risk can be reduced, especially by changing smoking and eating habits.”

### 3.2.3 Reactions to News Stories about Reducing Cancer Risk

#### Focus Group Participants

Participants varied in their likelihood of taking action in response to a news story about being at increased cancer risk or something they could do to decrease cancer risk. Some said they would take the action if it seemed safe and was easy, such as eating more broccoli.

*Yeah, you have to think of practical advice. I mean, if it's something like you have to walk 20 miles a day to minimize your risk, well, obviously, you're not going to do that. But if it's—you know, you should eat more salmon and you like salmon—I like salmon, that's one thing I've done. I eat more salmon. [Hispanic male]*

Some said if they get information from a mainstream news source, they will check into it, usually via the Internet, but not take action until they get information from a source they deem more trustworthy. Some wait until multiple sources suggest action—they are skeptical because new findings from studies are issued frequently, and one study often contradicts another.

*I will research further sources and compare sources. Because then there's so much information, and sometimes it's not accurate. And you need to compare it and get your own conclusion. [Hispanic male]*

Others commented on the credibility of the source. One Hispanic male asked, “*Is the information the result of some kind of experiment?*” and another asked whether the recommended action was “*approved by a community of scientists.*”

### 3.2.3 Most Trustworthy Source

#### Focus Groups

Many participants did not name a single source of cancer information as the one they found most trustworthy. Sources mentioned were WebMD, the Gary Knowles show, the Mayo Clinic, NIH, CDC, the American Medical Association, and the *New England Journal of Medicine*. Several look for multiple sources—such as the Internet, doctors, books, medical journals, and the mass media—that have the same conclusions or recommendations. Some said they do not trust the government.

Participants' remarks demonstrate their limited trust in doctors.

*I don't necessarily think they [scientists or doctors] could give me a good enough response. They don't know anything that is actually proven that is definitely going to stop me from getting cancer. I mean, there are things we can do to help reduce the risk. However ... 'if you do this, you're not going to get cancer.' They can't give me that, either. So anything that they said wouldn't really have much weight, unfortunately. [African American male]*

*If somebody told me that I'm high risk [for cancer], I would want to be very well informed, not only by my doctors but also with literature—all the literature I can get. [Hispanic female]*

*...here in this country, I don't trust doctors because they don't have time to discuss with me the things that I want to ask. In my country ...I can spend with my doctor 15 minutes and ask many questions. And they have the patience to explain to me. But here, I trust more research and [written materials] and I share this information with all my family members, with my friends, and with other persons who can benefit from that information, too. [Hispanic female]*

## **Key Informants**

Two API informants thought a doctor, other healthcare practitioners, and staff from community-based organizations could be trusted sources of information for the populations they serve, although both qualified their remarks. One said a doctor would be trustworthy especially if s/he is of the same ethnicity; the other noted that many Asians trust alternative treatments, such as acupuncture or herbs. She thought people who grew up in the United States would be more inclined to trust western medicine. The third API informant believed the question was not particularly relevant to this population: "They won't even look into it, unless someone is more educated or acculturated."

Two AI-AN key informants mentioned trust as a critical issue for disseminating health information. One said American Indians and Alaska Natives will trust someone who is known to them, such as another Native person or someone who has lived in the community for a long time. "Within the community there aren't a lot of distinctions between who you are and what your role is. You must be 'one of them' to be credible... An outsider is seen as not trustworthy." The other informant suggested that doctors and the media are viewed as trusted information sources, with a great deal of education done via radio and television. The third AI-AN informant has found through focus groups she moderates that a lot of people view the National Cancer Institute as a credible source for this type of information, but she thought most people would prefer to hear information from their tribal government. She emphasized that because many AI-AN individuals do not trust the Indian Health Service, some tribes are now providing their own health services.

### **3.2.5 Current Questions about Cancer Risk**

Participants were asked if they had any questions about cancer risk. Some, particularly in the Hispanic focus groups, posed questions about cancer, but relatively few focused on cancer risk. Their questions included: Is it really true that the hormones are going to cause cancer;<sup>6</sup> is there any technical way to discover cancer cells in the body, whatever the affected organ; what is cancer; and why hasn't a cure for cancer been discovered?

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<sup>6</sup> These focus groups were conducted about four months after results of two studies, one a large clinical trial and one an observational study, were released showing an increase in breast and ovarian cancers among women using combined hormone replacement therapy or estrogen replacement therapy. The results received widespread media coverage.

### 3.3 Reactions to Scenarios

To test the type of cancer risk scenarios that would resonate with participants, OESI developed four sets of materials, with each containing between one and five scenarios. Each scenario was a brief paragraph that set up a cancer risk situation by presenting it as the beginning of a first-person story. The sets and their focus are as follows:

- Group A: Types of cancer risk related to family history (3 scenarios)
- Group B: Types of cancer risk related to behavior (5 scenarios)
- Group C: Types of cancer risk related to environmental factors (3 scenarios)
- Group D: A person at higher risk of developing cancer enrolls in a clinical trial of a prevention therapy.

#### Focus Groups

When reviewing each set of scenarios, participants in the first few groups were asked to choose the scenario that interested them the most or spoke to them the most. When it became apparent that they were using diverse criteria to make their choices, this instruction was refined in later groups to encourage more consistent responses: participants were asked to select the scenario that most reflected people they knew. Focus group participants tended to choose scenarios either because they found them personally relevant or because they addressed a question they had wondered about.

*It [Group A, Bill's story] just simply applies to me. And so I picked that one because it strikes home...[Caucasian male]*

*I went with Jane's story because ...I had a friend that acquired cancer. And that's the same question that I asked myself at the time that I found out that this person had acquired cancer. [African American male]*

With the exception of John's story (in Group D, relating the removal of a polyp and subsequent recommendation to enroll in a clinical trial), focus group participants had no questions about any particular aspects of the stories. The few questions tended to focus on why cancer occurs and it can be prevented, sometimes using the story to recall how they felt in a similar situation. For example, one man said in response to Jane's story:

*...basically, my question is, why? Why surprise—why after a healthy life and a really healthy way to eat, to eat well, good exercise, why stomach cancer, why neck cancer? [Hispanic male]*

#### Key Informants

Key informants were asked to select the story that would be of most interest to health information seekers in their populations. They selected scenarios that they believed API and AI-AN health information seekers would find most relevant to their circumstances.

### 3.3.1 Group A—Family History

After they made their selections, all focus groups and key informants were then asked to discuss what appealed to them about the scenarios they chose. They discussed the believability of all scenarios, whether they could imagine people they knew making similar comments, and any questions they had about the information presented. The sections below discuss their comments.

#### Focus Groups

Focus group participants had no questions about any particular aspects of the three scenarios addressing the role of family history (or lack thereof) in developing cancer. Participants found all stories believable and thought they had heard or could imagine people they know making similar comments. When asked whether they would want to continue reading the stories, a number of participants said yes, particularly if the story provided a solution or information about prevention.

*I would like to read more of the stories if there was a solution that came after each one of the stories. [African-American male]*

They did not think the scenarios were confusing or difficult to comprehend:

*Simply as materials, [these are] not hard to understand and not too complicated to take in and something that people could relate to. [Caucasian female]*

Focus group participants were asked which scenario they preferred (see Table 2). Of the 60 who stated a top choice, about half chose Jane's story, about 40 percent chose Lisa's (for women) or George's (for men), and 10 percent chose Bill's. Preferences were generally consistent across ethnicity and gender, although men were more evenly divided in their preferences for Jane's story or Lisa's/George's, and fewer women than men chose Bill's.

**Table 2. Summary of Focus Group Reactions to Family History Scenarios <sup>a</sup>**

Scenario	Top Choice <sup>b</sup>	Reasons for Choosing and Positive Feedback	Negative Feedback
<p><b>Jane's Story</b> My neighbor just found out her grown son has cancer, but cancer doesn't run in her family. How can it be that someone young and healthy can get cancer?</p>	30	<ul style="list-style-type: none"> <li>➤ Emphasis on how cancer can strike seemingly at random</li> <li>➤ Reminder of people they know</li> </ul>	<ul style="list-style-type: none"> <li>➤ Most participants did not mention particular dislikes.</li> </ul>
<p><b>Lisa's Story (for women)</b> My mother got breast cancer when she was 55, and my sister got it when she turned 49. I'm 40 years old now. I figure that by the time I'm 50 or 60, I'll probably get breast cancer, too.</p> <p><b>George's Story (for men)</b> My mother-in-law got breast cancer at age 55. My sister-in-law just got it when she turned 49. My wife, Lisa, is 40 years old now, and I'm worried that she's going to get it by the time she's 50 or 60. I love my wife, and I want to know if this is something we should worry about.</p>	23	<ul style="list-style-type: none"> <li>➤ Reminder of people they know</li> </ul>	<ul style="list-style-type: none"> <li>➤ Use of the word "worry" in George's story bothered some of the men in one African American and Caucasian group.</li> </ul>
<p><b>Bill's Story</b> Cancer just seems to run in my family. Every time I look around someone else is getting it. I'm beginning to think there's nothing I can do to keep from getting it. But no one in my wife's family has gotten cancer, so she doesn't have to worry about cancer as much as I do.</p>	7	<ul style="list-style-type: none"> <li>➤ Little discussion, since relatively few picked this story. One man said it applied to him; another said it reflected his belief about genetics relative to cancer.</li> </ul>	<ul style="list-style-type: none"> <li>➤ Focus group participants did not like the lack of control conveyed by "there's nothing I can do to keep from getting it"</li> </ul>

<sup>a</sup> Discussion focused on why particular scenarios were selected. There was little discussion of scenarios that were not chosen (or chosen by few) or why they were not chosen.

<sup>b</sup> Column indicates the top choice among focus group participants, of whom 60 designated a top choice.

Participants were interested in scenarios that raised unsettling questions. Many chose Jane's story, which raises such a question.

*I guess it's the unknown. People can maybe process it better if they know it's hereditary. Or they know it's the environment. But these things do happen. They come out of nowhere ...you just scratch your head on that one...that it can happen*  
[Caucasian female]

They were drawn to scenarios that reminded them of people or stories they know. Focus group participants and key informants selected Jane's story and Lisa's/George's story because the situation portrayed was familiar.

*I picked [Jane's story] because recently I did hear a couple of stories from neighbors or friends about someone who got some type of cancer or disease, and it just came out of nowhere. They didn't know how they got it . . . no one in the family had it.* [Caucasian female]

*I'm going with the George story because my mother-in-law died of breast cancer. So it did hit home.* [African American male]

Focus group participants liked scenario subjects who took action to reduce their risk of cancer and were uncomfortable with the lack of control they inferred from some scenarios:

*[George is] at least taking a realistic approach to what's happening, whereas Bill seems like, it seems like a very emotional response, which I think is probably real for a lot of people. But it didn't strike me. [Caucasian male]*

*Lisa's story and Bill's story kind of seem like they have no outlet. It's like, "I'm going to get it and that's it. There's nothing I can do about it. And I don't think that's so. I kind of figure if you do research and you catch it early enough, there is something you can do. [African American female]*

Several suggestions were raised about words and situations used in the scenarios. One group of male participants said the word “worry” should be avoided.

*...maybe women are a little more worried about [cancer] on a regular basis, but most guys have other things to worry about. [Caucasian male]*

*I guess the term “worry”—I reacted to that because like with what was said earlier ... I mean, I don't really think about cancer unless something comes up that causes me to think about it. [African-American man]*

### **Key Informants**

One AI-AN key informant chose Jane's story as the top choice because it talks about “someone other than yourself,” which can be a less threatening way to convey information. She explained, “Sometimes it's easier to worry about others and more appropriate to worry about others.” Another chose Lisa's story because of the frequency of breast cancer in the AI-AN population. One AI-AN informant who chose Jane's story noted, however, “I don't hear people talking about cancer that much. I mean, when three people in your family are amputees because of diabetes, cancer isn't the first issue for them.”

All three API key informants preferred Bill's story. One said it was “because people won't think about it [cancer] until it happens,” “because it's my story,” and because she had heard stories like this in the community. Another chose Bill's story it because she believed that cancer runs in the family.

Both an API and an AI-AN informant cautioned about accurate depictions for their populations. Both suggested, for example, lowering the age in Lisa's story: The first said, “In [the Native Hawaiian] population, the person who gets breast cancer won't be 50-60 years old ... They get it young,” and the second said, “You talk about genetic cancers, but the age is wrong. It's too high. The age should be younger, maybe 43.”

### **3.3.2 Group B—Behavioral Risks Focus Groups**

This group of scenarios generated the most controversy and contradictory reactions. Some focus group participants said they could imagine people they know making similar remarks, so many found them believable. Other participants, however, did not personally identify with the stories because they saw them as unrealistic, thought the storytellers were “in denial,” or felt the endings were not consistent with their beliefs or possible actions. A number of focus group participants did not like the stories because, with the exception of one story, no characters take proactive steps.

Participants were asked to select their top two choices. Of those with preferences, about half selected Lee’s story as their first or second choice, about one-third selected Kevin’s story, and about one-third selected Ted’s and Tina’s stories (see Table 3). Preferences were generally consistent across ethnicity and gender for Lee’s and Kevin’s stories, but Ted’s, Tina’s, and Phillip’s stories received differences in preferences according to ethnicity and gender. Reactions to Tina’s story were the most markedly divergent, mainly because Hispanic women tended to choose it and others did not. Ten of 17 Hispanic women selected Tina’s story as their first choice in this set of scenarios, as did four Hispanic men. In contrast, only three African American or Caucasian women (but no men) selected Tina’s story as their top choices.

**Table 3. Summary of Focus Group Reactions to Behavioral Risk Scenarios <sup>a</sup>**

Scenario	Top 2 Choices <sup>b</sup>	Reasons for Choosing and Positive Feedback	Negative Feedback
<p><b>Lee's Story</b>                      "I love my cell phone, and everyone I know uses one. I keep hearing that they can cause brain tumors. But I can't stop using my cell phone... I need it for my job. Sometimes I think I may have a tumor from using my cell phone because I get a lot of headaches. How do I know what the truth is about cancer and cell phones?"</p>	27	<ul style="list-style-type: none"> <li>➤ Many chose because they use cell phones and wondered if they could cause cancer.</li> <li>➤ Brought to mind other instances where an association between some type of device and cancer was suspected, but never proven.</li> <li>➤ Some chose because they found it the most—or only—believable story in the set.</li> </ul>	
<p><b>Kevin's story</b>                      "My grandfather smoked his whole life, and he lived to be 93 years old. He never got lung cancer or had any breathing problems. If he was able to live so long, why should I worry about getting cancer from smoking?"</p>	23	<ul style="list-style-type: none"> <li>➤ Reminder of people they know.</li> <li>➤ Reflected, to some extent, their beliefs that "everything causes cancer" or that what causes cancer in one person may not cause cancer in another.</li> </ul>	<ul style="list-style-type: none"> <li>➤ Some did not like that Kevin was not taking responsibility for his actions</li> </ul>
<p><b>Ted's Story</b>                      "I read that eating low-fat food can reduce a man's chances of getting prostate cancer. But last year, my father got prostate cancer, and he's always eaten healthy—mainly fruits and vegetables and no junk food. I don't believe what you eat has any effect on whether you get cancer. So, I'm going to go on eating the food I like, since it's not going to help anyway."</p>	21	<ul style="list-style-type: none"> <li>➤ Chosen by African Americans and Caucasians about three times as often as by Hispanic participants; most often rated first or second by African Americans and Caucasians, and least often rated that way by Hispanics. Preferences among men and women generally consistent across ethnic categories.</li> </ul>	
<p><b>Tina's Story</b>                      "I'm 52, and my doctor checks my breasts and I get my mammogram every year. I know I'm doing what I should to prevent getting breast cancer. Preventing breast cancer is easier than women think. All women have to do is get their mammograms and they'll be fine."</p>	19	<ul style="list-style-type: none"> <li>➤ Reactions to this story were the most markedly divergent, largely because Hispanic women tended to choose it but others did not.</li> <li>➤ Some Hispanic participants who selected it said they did so because it was the only story where the person took action or tried to gain some control of the situation.</li> </ul>	<ul style="list-style-type: none"> <li>➤ Some found it misleading or not believable, because getting mammograms is not enough.</li> </ul>
<p><b>Phillip's Story</b>                      "I am so tired of all of the TV ads warning me about smoking. Yes, I smoke. But I also exercise everyday. I eat healthy. I know other people in my family have gotten lung cancer, but I don't have to worry about that because I live a healthy life."</p>	13	<ul style="list-style-type: none"> <li>➤ None selected it as their top choice</li> <li>➤ Rated second by one-third of Hispanic participants, compared to just two African American and Caucasian participants.</li> </ul>	

<sup>a</sup> Discussion focused on why particular scenarios were selected. There was little discussion of scenarios that were not chosen (or chosen by few) or why they were not chosen.

<sup>b</sup> Column shows top 2 choices among 67 focus group participants.

Scenarios about topics for which there is public uncertainty or confusion engaged participants. They brought up instances where an association between cause and cancer was suspected, but never proven.

*When I read Lee's story, I immediately thought of the years ago they were talking about people that lived near high wires and electrical wires and towers and generators and so forth, having all kinds of effects. I think that's pretty much slipped away because it's never been proven beyond the shadow of a doubt ... [Caucasian male]*

Scenarios that reminded participants of people or stories they know were of interest. As with the family history scenarios, focus group participants and key informants chose some behavioral risk scenarios because the situation portrayed was familiar or part of their life history. One API informant said, "When you're working in the [Native Hawaiian] community, you get a sense that there are people who live unhealthy lifestyles, who live for a long time." An AI-AN informant noted often hearing statements like "My grandfather smoked tobacco until he was in his 90s and he's fine" from members in her community.

Scenarios that reflected the unknowns about cancer and who will develop it were consistent with some health information seekers' beliefs:

*[Kevin's story and Phillip's story] sort of resonate with me because [they] kind of like illustrate ... well, what causes cancer in one person does not necessarily have to cause cancer in another person. And so it makes me think about the fact that we just don't know enough about cancer to be able to say for sure exactly what causes it. But that doesn't mean to say that we shouldn't worry about the things that we know that could exacerbate the conditions that will make you most likely to get cancer. [African American male]*

*I picked Ted as number two, but both [Kevin's story and Ted's story] basically say that we don't know what causes it—that some people are just healthy and can deal with whatever other people can't. And so that's the part that kind of appealed to me. Basically I believe that if you do things in moderation you can be better off. Even if some of the things you do might be things that might cause other people problems. [Caucasian male]*

Participants were drawn to scenarios that featured people taking action to reduce their risk of cancer. As with the family history scenarios, some mentioned they wanted the scenario subjects to do what they can to reduce their cancer risk.

*I didn't like [Kevin's story], either. It's the same thing that my mother-in-law used to say, "My grandfather in Cuba used to smoke a lot, and he never got cancer, so why should I quit?" And it's a cop out. It's a way of saying I'm not strong enough or responsible enough to quit smoking. [Hispanic female]*

*I like Tina because she is humble. And they were aware of the risk and she is responsible. She is disciplined. She goes every ... year. Have a mammogram and she*

*can live better, more relaxed because you don't have to be worried that maybe you are developing some tumor or something. [Hispanic female]*

*If I had to choose, I only chose [Tina's story] because it's the most proactive—I mean, I know something and I try to find the solution. [Hispanic male]*

Participants did not like scenarios with people portrayed as “ignorant,” which is how several described the subjects of many behavioral risk scenarios. They found the last sentence of each story (except Lee's) particularly bothersome.

*I have heard people say these things, although I wouldn't say these things because ...I wouldn't turn around at the end and say, “well, because this happened to this person and I'm not going to worry about it because it won't happen to me.” So I guess in all the stories, for me it was the ending that kind of bothered me the most, where people are saying, “Well, so I'm not going to worry about it,” or “I'm not going to concern myself with it.” [African American male]*

*I selected Lee's story, because to me that seems like the only story that doesn't have a blatant rejection and ignorance about the situation. [Hispanic male]*

Some participants, particularly in one group of African American and Caucasian females, were disturbed by false statements in the scenarios, even if they were later resolved.

*Now, we're talking about ...cancer education materials, and there's so much misunderstanding, ignorance, and confusing information about cancer already that to put out materials based on the “what's wrong with this picture” school of thought is just such a goofy way to go about it...Some people won't read the whole brochure. They'll get this far and say, “well, then I can smoke. Okay.” [Caucasian female]*

*There's sort of an implication in Tina's story that you do the mammogram and you're fine. And that's like saying, you know, if you don't eat candy, you'll never get a cavity in your teeth. [Hispanic male]*

One participant's reaction to Lee's story illustrates that this concern has merit, in that people may not read far enough or may read so quickly that they come away with erroneous conclusions:

*I ... actually was not aware that there was research out there that said [cell phones] could cause brain tumors. [Male, race unknown]*

### **Key Informants**

All three API key informants were drawn to Kevin's story because it is relevant to their populations. Two also liked Ted's story because it reflects the common perception that lifestyle will not affect risk, and one liked Phillip's scenario. One said that Lee's story was not relevant to the population she works with, which have relatively low levels of cell phone use. The AI-AN informants preferred Phillip's story, although two of them mentioned liking Kevin's story also. Several key informants were concerned about Tina's story because they found it misleading or untrue.

Some aspects of the scenarios were particularly relevant to special populations. Because exercise is consistent with many American Indian and Alaska Native lifestyles (such as fishing, camping, and carrying water), two AI-AN informants were drawn to Phillip’s story. One respondent suggested paying close attention to the wording of the scenario: in Philip’s story “relatives” would be better than “people in my family” and the word “so” should be deleted.

### 3.3.3 Group C—Environmental Risks

#### Focus Groups

Participants generally reacted positively to these stories, although they had some concerns, particularly about Janet’s story. A couple of groups said these stories were much more believable than the preceding set. As with the behavioral risk scenarios, preferences among these stories were influenced to some degree by the presence or absence of false information.

When asked to choose the one story they found most appealing, like themselves, or people they know, about 4 in 10 participants chose Rosa’s story, about one-third chose Damon’s story, and about one-fourth chose Janet’s story (see Table 4). **Table 4. Summary of Focus Group Reactions to Environmental Risk Scenarios**<sup>a</sup>

Scenario	Top Choice <sup>b</sup>	Reasons for Choosing and Positive Feedback	Negative Feedback
<b>Rosa’s Story</b> “My neighbor just found out he has cancer. It’s the third family on the block that has been affected by this disease. I think that people get cancer because of the air we breathe and the water we drink. Until we clean up our environment, more and more people will get cancer.”	25	<ul style="list-style-type: none"> <li>➤ Identified with it</li> <li>➤ Brought to mind other similar situations (e.g., Love Canal, neighborhoods in Mexico where many got sick, and the movie <i>Erin Brockavich</i>)</li> <li>➤ Reflected general concern about environmental causes of cancer.</li> </ul>	<ul style="list-style-type: none"> <li>➤ A couple thought the emphasis was political (cleaning up the environment), rather than on cancer risk</li> </ul>
<b>Damon’s Story</b> “My family is so excited about buying our first house. The only problem is that the house we are looking at is right next to these huge power lines, and they cross over into the backyard. We heard on the news that kids can get leukemia if they live in places with a lot of electrical wires. So what should we do now? Could living near power lines increase our son’s chance of getting cancer? We love the house, and it’s a good deal, but it’s not worth our son’s life.”	19	<ul style="list-style-type: none"> <li>➤ Reflects a personal concern of theirs or one they think many people have.</li> </ul>	
<b>Janet’s Story</b> “There’s a new ‘Sun Protection’ program at my kids’ school. They’re teaching the kids that getting too much sun can cause skin cancer. The teachers sent home a note telling the kids to bring sunscreen and hats to school for when they play outside. I didn’t bother to buy that stuff for my kids though. They have dark skin—they don’t get suntans or sunburns. It’s really the children with lighter skin who the school needs to worry about.”	15	<ul style="list-style-type: none"> <li>➤ Thought topic was of interest</li> </ul>	<ul style="list-style-type: none"> <li>➤ Participants were concerned about presenting inaccurate information</li> <li>➤ Some did not know whether information was accurate or not</li> </ul>

<sup>a</sup> Discussion focused on why particular scenarios were selected. There was little discussion of scenarios that were not chosen (or chosen by few) or why they were not chosen.

<sup>b</sup> Column shows top choice among 67 focus group participants, of whom 59 indicated a top choice.

Preferences among these stories differed by ethnicity and gender. About equal proportions of African Americans and Caucasian participants preferred each story; in contrast, about half of Hispanic participants preferred “Rosa,” about a third preferred “Damon,” and the remainder chose “Janet.” Women were evenly divided between “Rosa” and “Damon” as their first choice, with about half as many choosing “Janet.” The same proportion of men chose “Rosa,” but a few more chose “Janet” as compared to “Damon.”

The reactions of focus group participants and key informants to the environmental risk scenarios suggest that scenarios presenting potential environmental risks are of interest to health information seekers in part because they reflect common concerns or beliefs.

*I think that it's a real story ...I have been looking for a house, and I have been to research areas where there is a lot of concern about cancer cases. [Hispanic female]*

*I went with Rosa's story just because it mentioned the environment specifically, and ...in terms of cancer, I think of outside factors as well as what we do and don't do ourselves and diet and genetics and all that. [African American male]*

*I think this expresses a valid and realistic concern. I think this is something that people do think about, and I also think that the way that this is constructed would appeal to people and make them interested in what's a good decision here, and how will these people make their decision. [Caucasian female]*

Again, scenarios about topics on which there is public uncertainty or confusion were appealing to participants:

*I chose [Damon's story], too, because also from all the things that I have been reading about possible causes of cancer, in probably 15 years, the power lines have been ...one of the strongest that you can find. It has been continuous. [Hispanic male]*

Scenarios that are perceived as too political turned off some readers, as did false statements in the stories:

*I think Rosa's story feels more like political propaganda that is using the fear of cancer to get people to clean up the environment as opposed to educate people about cancer...to me, this seems like a piece of propaganda wrapped around a very weak health story. [Hispanic male]*

*I picked [Janet's story] because I like sun protection. I think it's a good idea to introduce the idea to children. I think that's a real good point. But then the second part of the story goes on to where it's false information. [Caucasian female]*

Although some participants, such as the one above, clearly knew that the latter half of Janet’s story presents a myth, others seem to think it was but did not seem to be completely sure:

*I don’t bother to buy that stuff, “they are dark-skinned and they don’t get sunburned, it’s really [only] the children with lighter skin”...If she said that “I believe that people with dark skin are not as susceptible and so I don’t take as much stock in it,” or something like that. [Caucasian female]*

*I don’t think there’s enough knowledge as to whether lightness or darkness of skin can alleviate the probability of skin cancer. [Caucasian male]*

### **Key Informants**

Two API and all AI-AN informants selected Rosa’s story as their favorite, reflecting beliefs or likely reactions in their communities. One thought that Chinese who grew up outside the United States would never think about cleaning up the environment without prompting, so the scenario’s last sentence would not affect them. One API informant thought the scenario was important because “Asian families live close to each other, so if a lot of people in an area get sick, they panic.” Another API informant liked Rosa’s story because communities she works with express concern about cancer clusters. She explained that people in her community, “may think [getting cancer] has to do with the air, food, water—some even think it’s a conspiracy.”

Damon’s story produced mixed reactions: one said that the topic of power lines is of interest to the population, another said that power lines are not an issue in rural AI-AN communities, and a third said that buying a house is not relevant to many members of their populations. No key informant chose Janet’s story as the top pick.

Key informants noted that situations depicted in the scenarios might not match experiences in their populations. One API and one AI-AN informant mentioned that “buying a house” is not an appropriate framework for relaying information to their populations (the API informant suggested changing the words to “renting a house,” and the AI-AN informant said that reservation-based residents may live in subsidized housing). Another pointed out that “villages” or “communities” would be more appropriate terminology than “blocks.”

### **3.3.4 Group D—Clinical Trials**

#### **Focus Groups**

Group D had one story, shown below. Although many participants generally found the story believable, a fair number thought the story made some big, unsupported leaps in the process, from removing a polyp to assuming the person was at risk of getting cancer and then to participating in a clinical trial to test a drug.

#### **John’s story**

“I got a test for colon cancer. The doctor found and removed a growth inside. He called it a polyp. He said it was not cancer, but because of it, he thinks that I am ‘at risk’ for cancer. Now he’s asking me if I want to join some kind of study—called a clinical trial—to test a drug that may keep me from getting colon cancer. Why should I be in a study? Am I really at risk?”

The clinical trials component of the scenario generated a great deal of discussion, usually regarding the potential risks of participation and what participants would want to know before agreeing to participate—but distracted participants from the topic of cancer risk. Some wondered who was sponsoring the story. One said if he read it, he would believe a drug company was “pushing this” as a way of testing drugs that may not be needed or wanted, or that the doctor recommending the clinical trial might have a vested interest in the study.

Some participants thought having one non-cancerous polyp removed would not put a person at sufficient risk of developing cancer to warrant the potential risks of enrolling in a clinical trial and taking an untested drug. One group of African American and Caucasian women questioned whether a doctor would bring up a clinical trial so quickly.

*I just wanted to say that it is believable, except, honestly, I don't think too many doctors would come out with a statement about a clinical trial. [African American female]*

Some thought John needed to know his degree of risk before committing to a clinical trial:

*The only concern I have is that last question, “am I really at risk?” Risk is something that should be measured in terms of probability. And I will say 40 percent or 50 percent probability would be enough to do something... Otherwise, it seems to be there is too quick of a jump from being at risk for cancer to jumping straight into the clinical trial. I think there needs to be some sort of in-between stuff to see how viable you are [for a clinical trial]—and for the clinical trial, because the trial in itself can present its own set of risks that may be more likely than the colon cancer risk. [Hispanic male]*

Others were concerned about being encouraged to enter an experiment so quickly.

*It's kind of alarming to me that immediately they want to use you as a guinea pig. And that's how I would relate to it ... [Caucasian female]*

One group of Hispanic men thought perhaps John really did have cancer, and the doctor was just using an alternative way to describe it:

*...I believe that instead of saying you got cancer, they change the word. That's all he did. Because it's still, whatever kind of growth you got, in it, in your system ... [Hispanic male]*

*Why, if he took it away—he took it out of your system, why our risks went up if it's not there anymore? [Hispanic male]*

The topic of clinical trials engaged focus group participants, piqued their curiosity, generated discussion, and produced detailed questions they would want a doctor to address, including:

- What are the side effects of the drug?
- What are the drugs and what are they supposed to be doing?
- Why do you want me to try a new drug to prevent colon cancer if you know I don't have it?
- What is a clinical trial?
- What is a polyp?
- Why am I more at risk because of a polyp?
- How are non-cancerous growths related to cancer?
- What does it mean to be in a higher risk group?

### **Key Informants**

All key informants liked John's story and generally found it believable, but some had concerns about aspects of it. Two had concerns about the question, "Am I at risk?" but for different reasons. One API informant said people she works with would not ask whether they are at risk. Because Asian doctors are so highly trusted, especially among Asians who have recently immigrated, "if the doctor says they're at high risk, they will worry. If the doctor asks them to join the clinical trial, they will say OK." An AI-AN informant said that posing the question as worded was problematic: "'At risk' is a medical term and a professional term. I never really hear people say that."

Some terminology raised issues. "Clinical trials" may need to be explained. An AI-AN key informant commented that clinical trials are not accessible for the AI-AN population. She thought materials focusing attention on clinical trials were important "to explain how trials shape the art of cancer care and treatment."

### **3.4 Reactions to Scenario Responses**

To explore the type of information people might want in response to the scenarios, participants were given a 2-page handout that began with George's story (men's groups) or Lisa's story (women's groups), and then had four questions about cancer risk and their answers. The questions were:

1. How does family history (having a person in her family with breast cancer) affect Lisa's risk?
2. Can Lisa do anything about her risk for breast cancer?
3. Can anyone tell Lisa outright whether or not she will get breast cancer?
4. What questions should Lisa ask her doctor?

Participants were instructed to focus on the questions and think about whether they were the ones readers would want answered.

## Focus Groups

Most focus group participants said the questions shown were the ones they would want answered. While acknowledging that there probably were other questions to ask, most could not think of what they would be. Some said they would need to read more information before knowing what to ask.

Most focus group participants thought all four questions should be included. Some thought that “Can anyone tell Lisa outright whether or not she will get breast cancer?” could be deleted, but others thought it should be kept. It appeared that the term “outright” was the problem; as stated in one group of Hispanic men:

*It's like ...it takes a black and white approach. And that's what I'm not comfortable with in the wording of that question. [Hispanic male]*

*...the basic answer is no one can tell her outright. So that kind of would discourage someone from further trying to understand the situation. [Hispanic male]*

In the same group of Hispanic men, participants suggested that the question could be re-worded along the lines of, “is breast cancer predictable?” or “what’s the chance of getting it?” A couple of focus group participants said they did not think the response under “Can Lisa do anything about her risk for breast cancer” really answered the question.

Participants were asked about the order in which the questions were presented. Many said it was fine. Three recommendations regarding the questions were made by multiple people: (1) Put “Can Lisa do anything about her risk for breast cancer” first, followed by “How does family history affect Lisa’s risk?” (2) put “Can anyone tell Lisa outright whether or not she will get breast cancer?” at the beginning; and (3) shorten the answer to the first question, since the length might “turn some people off” (from a couple of participants in one group of African-American and white men).

- One woman wanted statistics based on her genetic makeup and family history versus what she termed “environmental.”
- More detail on Lisa’s history: what type of periods she had, when she went through menopause, what body shape she has, and answers to some myths that have been perpetuated.
- Information on the foods Lisa ate, whether she exercised, and how that affected her risk.
- How often Lisa should see her doctor.
- Lisa’s probability of getting cancer.
- What Lisa could do differently from her mother and sister to prevent cancer.
- How often Lisa should get a mammogram.
- Should the participants worry about Lisa getting cancer?
- Break down the information into (1) What are the things you do that could increase your risk of getting cancer? and (2) What are the things around you (in your environment) that could increase your risk of getting cancer?

- What is breast cancer, and do only women get it?
- Some information on the current state of the science regarding breast cancer, especially information about the kind of treatments that are more efficient.

### **Key Informants**

Two API informants and all three AI-AN informants said the questions in the story were the ones they would want to have answered. One AI-AN informant characterized the questions as “great,” noting that dietary change is very important, given a huge increase in consumption of fast food among AI-AN groups in the past ten years. One API informant did not find the questions particularly relevant, largely because in the population she serves, “Lisa is not going to look for her risk of getting breast cancer unless she has it or someone in her family has it.”

Echoing a concern expressed by focus group participants, the word “outright” in question #3 was problematic for two key informants. One AI-AN informant said it was confusing.

The key informants suggested several changes to the content of the questions and answers:

- Tell people what they can do proactively.
- Use the term “healthcare provider,” not doctor, because the doctor may be infrequently seen.
- Re-phrase the “For Information” section at the end of the piece as a question, such as “What are my options to find out more?”
- Keep the questions as simple as possible and present the information in ways that are less clinical, more personal, and shorter.

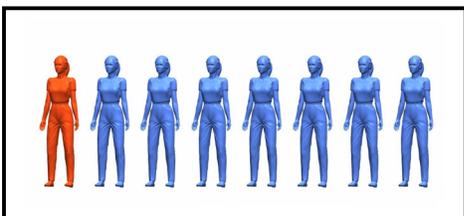
### **3.5 Reactions to Visuals**

Focus group participants and key informants were asked to choose among the three visuals shown in the box on the following page. Each visual was presented on a separate page, with the text in the box on each page.

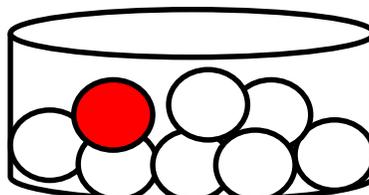
Over two-thirds of all focus group participants chose the visual depicting a line of women (labeled Choice 1). Just over one-sixth chose the pie chart (Choice 3). A number of participants, especially Hispanic ones, said they were more comfortable with information presented in a graph, as in the third choice. Although some clearly understood the content of the pie chart, comments from others suggested some did not comprehend it. Only about one-twelfth of the focus group participants chose the visual depicting eight balls (labeled Choice 2).

### What is Lisa's risk of getting breast cancer, even if she doesn't have a family history?

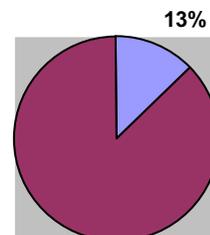
Whether Lisa has a family history or not, she already has some risk of getting cancer. Every woman does. And this risk naturally gets higher with age, no matter what you do. The risk of getting breast cancer in a lifetime is about 1 in 8 or 13%. This estimate is for the *average* woman and is stretched out over an entire lifetime, which for the average woman is about 85 years.



(Choice 1)



(Choice 2)



87%(Choice 3)

1 in 8 women or 13% will develop breast cancer over a lifetime.

### Focus Groups

Both men and women liked Choice 1 because its use of female figures was more personal than the images used in Choices 2 and 3.

*We're women and [Choice 1] shows women. Choice two look like something in a Petri dish in a biology lab. And choice number three looked like what the accountant is going to tell you. [Caucasian female]*

*When you're reading ... a study like this, you want to see actual women as opposed to like a chart or anything like that. Because it's more personalized. And it seems more like you're actually talking about human beings. [African-American male]*

Some focus group participants commented negatively on the stylized women depicted in Choice 1, saying that they looked like soldiers or crash-test dummies, and that images of real women would work better.

Compared to Choice 1, some focus group participants interpreted Choice 3 as illustrating lower risk, or focusing on the positive (those who don't get cancer) rather than the negative. The latter reaction may be due in part to the colors used: in Choice 1, red was used to depict the one female out of eight who will develop breast cancer; in Choice 3, maroon was used to depict the percentage of women who will *not* get breast cancer.

*I chose number three just because it represents the population as whole, and the smaller part of the population over a lifetime might have a risk for that. [Caucasian male]*

*I liked the picture on the first one best. But I think, after looking at them more closely, the third one helps me understand it better ... I guess it made me feel a little bit better. Like seeing all that red, those are the people who aren't going to get cancer. Whereas the first one, it's like one out of eight ... maybe I'm being naïve. Maybe 13 percent is a lot. But to me it made me feel better. It made me feel like I don't have that much of a chance to get cancer. [Caucasian female]*

*I definitely agree...do you want to scare people into doing something, or do you want to pacify people into thinking that they're going to be okay? ...If you don't want to scare anyone, then yeah, you would go with three. But if you really want people to do something and pay attention to what is going on with their bodies ... then the first one is much more—I don't want to say depressing, but it look more striking. Like, "hey, I better do something." [African American female]*

### **Key Informants**

All key informants selected Choice 1, but none were enthusiastic about it. Instead, they seemed to view it as the least problematic of several undesirable options. They believed the images of the women conveyed a clearer message than the other, more abstract visuals. An API informant said, "People can see one person in one color, and seven in another color. The pictures of the women are easier to relate to than the other images." An AI-AN informant said, "The picture of people is easiest to understand. It's not a bowl of balls or a pie-chart." As with focus group members, key informants expressed discomfort and some amusement with the figures, describing them as "stiff" and "like plastic soldiers, Barbie dolls." One API key informant suggested that the graphic should depict "real, multi-cultural, multi-ethnic women of different body sizes." One API informant commented that, "a lot of first generation Asian Americans don't know how to read a graph." She thought they wouldn't know what was being represented in Choice 2.

Although key informants were not asked to comment specifically on the text accompanying the visuals, one API respondent disliked the explanation of the graphic, saying that "It says nothing about the life of a woman; it also doesn't clarify that as you age, risk rises."

### **3.6 Risk Topics of Interest**

Participants were given a list of nine topics, told that it was a list of other information the cancer risk booklet could include, and asked to choose three topics they would like to see included (telephone groups and key informants) or five topics (in-person groups).<sup>7</sup>

#### **Focus Groups**

Among focus group participants, topic preferences were generally consistent across ethnic and gender categories. They were most interested in information related to risk-reducing behaviors. The following topics were the most popular, selected by between 30 and 34 of the 67 participants:

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<sup>7</sup> Telephone group participants chose a smaller number of topics due to time constraints.

- What you can do to decrease your risk of getting cancer.
- Information to help you decide when to take some action, such as changing a behavior or getting genetic counseling.
- What types of cancer risk you can control versus those beyond your control.
- Understanding what cancer is.

Fewer focus group participants said they would like information on the remaining five topics, with between 13 and 20 of the 67 participants selecting each of the following:

- How to understand scientific studies about cancer risk.
- Understanding the limitations of science in estimating cancer risk.
- Myths about what puts you at risk for developing cancer.
- How to understand news stories about cancer risk.
- How to understand what risk statistics mean

### **Key Informants**

Among key informants, there was no consensus regarding which topics should be included in a booklet on cancer risk. Actions to decrease the risk of getting cancer and information to help make decisions about actions were selected by two AI-AN key informants; information to help make decisions about actions and understanding what cancer is were selected by two API key informants; and understanding risk statistics was chosen by two AI-AN respondents.

### **3.7 Interest in a Booklet on Cancer Risk Concepts**

At the end of each focus group session, participants were asked if they would be interested in a 10-20 page booklet containing the type of information they had been discussing. Key informants were asked if they thought the health information seekers in their populations would be interested in such a booklet.

### **Focus Groups**

Most focus group participants were interested in such a booklet, although some qualified their interest in various ways. Several noted that a booklet should present information simply, but with sufficient sophistication to appeal to health information seekers. A couple of Hispanic participants said they would be interested in a 10-20 page booklet on cancer risk written in plain English. A couple of focus group participants said a booklet on cancer risk would be a starting point, although if they were truly interested they would want more information than what a booklet could contain. Some participants said they did not think such materials would be useful to them because they were too basic:

*...some of these questions and these stories seem to be very elementary to me and maybe it's because I am interested in it more, and try to learn about it more than most. [Caucasian male]*

*Statistics, based on, I guess, whatever research they've been doing with groups of women ...Because I think just reading what we're reading—it's like—to me it sounds more elementary. Not saying that it's bad, but it's like basically someone with absolutely no knowledge might pick this up and maybe get a little something out of it. But I think from just my basic knowledge that I have acquired throughout the years*

*and just reading and seeking information—this isn't really giving me anything.*  
[African American female]

Participants had difficulty grasping the idea that the booklet would be for people like them—other health information seekers. It is unclear if their trouble was because they thought the material was too simple or if they instinctively think of materials as being for all kinds of audiences.

Hispanic focus group participants were divided about whether the risk booklet should be produced in Spanish and English. Some said yes; a few said it was not necessary because health information seekers in the United States will speak English. A number of Chicago-area Hispanic men said that they could read it in either language, but they would want it in Spanish for their wives or other relatives.

*The reality is, if you're a health seeker that happens to be Hispanic, you will speak English.* [Hispanic male]

*For myself...for my own personal knowledge, I look for it in either one, whichever comes first, I take it.* [Hispanic male]

Some Hispanic women did not think a 10-20 page booklet on cancer risk would be particularly helpful and suggested a different communications channel:

*Because in the cancer issues, there is a lot of denial—emotional denial. Because people don't like to read bad news—we have the tendency to deny bad things. I think it would be more useful to have some kind of other educational approach, [such as a televised] soap opera.* [Hispanic female]

Focus group participants suggested the following as additional information or topics they would like to see covered in such a booklet. Several people mentioned the first item, resources; most other items were mentioned by only one participant.

- Resources, including web site addresses, not just the 1-800-4-CANCER number. Many of them expressed a desire to read more, not necessarily talk to someone.
- Ways to find reliable sources of information.
- What to discuss with the doctor, when, and how often.
- Something about cancer and gender and race.
- Information about products such as coffee and toothpaste, which receive news media reports as causes of cancer.
- Communicating the fact that people can take steps to avoid the chance of getting cancer, and that these steps should be taken early in people's lives.
- Statistics on risk reduction (e.g., “if you stop smoking, you'll reduce your probability of getting cancer by x percent”).
- Cancer risks that can be controlled versus those that cannot.
- Understanding the limits of science and estimating cancer risk.
- Holistic methods of prevention.

## **Key Informants**

The three API informants appeared to have mixed feelings about the usefulness of such material. One said it would be helpful only if designed appropriately, and thought that the content should be broken up into shorter brochures. She said, “It should use images of API women. It also should not be so dense, and should include more personal stories and lots of graphics... [Twenty pages is] too long for this type of booklet.” A second was unsure that members of API populations would look for this type of information unless they actually have cancer. The third thought the booklet would be great, but also seemed to think people who had recently been diagnosed with cancer would be the publication’s audience.

All three AI-AN informants thought a cancer risk publication would be helpful because risk is not well understood. “The consumer is now better-informed,” said one, “but people need this information.” The second informant agreed that the publication would be very useful, especially if converted to web-accessible versions. One suggested providing a list of Native American resources and commented that the worst way to distribute this brochure would be through the Indian Health Service, while the best way would be through the Association of Native American Physicians or tribal web sites.

Key informants perceived several target audiences for a booklet, from people recently diagnosed with cancer (an API informant) to community health aides (an AI-AN informant).

## 4. Conclusions and Recommendations

The focus groups summarized here provide a wealth of insights into how African American, Caucasian, and Hispanic health information seekers think about cancer risk and the ways in which they would like information on cancer risk presented. The discussion made clear that health information seekers are likely to be much more interested in risk-reducing behaviors than in understanding risk concepts.

The six key informant interviews provide suggestions regarding the ways that American Indian-Alaskan Native and Asian and Pacific Islander health information seekers may think about the topics. The suggestions demonstrate the range of opinion and knowledge likely to be present in these diverse populations, underscoring the importance of including larger numbers of AI-AN and API health information seekers in future testing of cancer risk materials.

### 4.1 Constructing the Scenarios and Responses

The basic approach to introducing risk concepts explored in the focus groups appears to be useful: create a scenario with a brief (1-paragraph) anecdote that uses a first-person story to set up a common risk situation, then use a question-and-answer format to guide readers through key risk concepts. Participants generally found this approach engaging, informative, and easy to follow.

Although most focus group participants said they would be interested in a cancer risk booklet containing this type of information, some expressed concern that it would be too elementary. Their reasons underlying that concern are not entirely clear, but may be due to their reactions to some characters (with whom they did not identify) and that they spent most of their time reviewing short, simple scenarios rather than more complicated risk information. Many health information seekers think they already know a lot about cancer and risks, so they would not be satisfied with basic information. Instead, they are looking for information that is more sophisticated, yet presented in an easy-to-understand format.

#### 4.1.1 Introductory Scenarios

Focus group findings suggest a number of principles for constructing the introductory stories that will precede a discussion of risk concepts:

**Health information seekers wanted scenarios featuring characters who take control of their lives by doing what they can to prevent cancer or at least detect it early** (although they do not necessarily distinguish between those two concepts). This desire appeared to hold across cultures and is not surprising. Stories expressing sentiments along the lines of “there’s nothing I can do” tended not to be well-received. Even if participants had concerns about parts of the scenarios they reviewed, they noted when the subject was trying to do something.

**Scenarios on topics about which there is public uncertainty or confusion, such as neighborhood cancer clusters, are likely to be well received**, with readers both identifying with the topics and finding them engaging. In each set of scenarios focus group participants reviewed, the top-ranking choices tended to fall in this category.

**Scenarios that remind readers of people or stories they know are of interest.** Both Jane’s story and Lisa’s/George’s story were selected by focus group participants and key informants because the situation portrayed was familiar to them. Interestingly, it is not clear which was of paramount importance to focus group participants: the topic of the scenario or the way the characters act.

**Stories should not present myths as facts, which are later dispelled.** This approach makes storytellers appear ignorant. Because health information seekers consider themselves informed, they may not identify with the stories or see the publication as relevant. The myth-then-fact approach disturbed some focus group participants who were concerned that readers might stop before getting to accurate information.

**Terminology must be carefully considered.** Words such as “prevention,” “at-risk,” and “clinical trials” must be clearly defined. Even among relatively savvy health information seekers, it was clear some did not understand (or accurately express) the difference between prevention and early detection. Scenarios should avoid using the word “worry.” Males may be concerned, but they do not think of themselves as worrying about cancer.

**Stories discussing clinical trials may interest readers but distract them from the risk concepts.** John’s story, which presented someone who had a polyp removed and was then approached about participating in a clinical trial, generated a lot of discussion and questions, however, the questions were as likely to be about clinical trials in general or the clinical trial raised in the story in specific as they were to be about cancer risk.

#### **4.1.2 Presenting Risk Concepts in the Response**

In general, the question-and-answer approach to walking participants through key risk concepts appears to work well, although participants had little time to review or comment upon the answers in their examples. For the four questions used in the example, participants recommended that the first question should center on any action readers could take; they also suggested avoiding dense wording and paying close attention to terminology.

#### **4.2 Visually Communicating Numeric Expressions of Risk**

Depicting humans in illustrations of cancer risk statistics is likely to be well received, especially if the ones used look like “real” people, rather than stylized figures. In the samples they reviewed, participants thought portrayals of females humanized and personalized the risk information, and doing so was important.

### **4.3 Risk Topics of Interest**

Based on initial research, OESI had proposed developing cancer risk material that focused on concepts related to understanding risk. When asked to choose risk topics of interest from a nine-item list, however, participants made clear that they are interested in information related to risk-reducing behaviors. Consistent with their preferences for scenarios that feature characters taking some action to control or reduce cancer risk, their top choices centered on information that would help them control or reduce cancer risk—what can be done to decrease the risk of getting cancer, information to help decide when to take action, and types of cancer that can be controlled vs. others that cannot—plus the general topic of understanding what cancer is. Fewer participants said they would like information on the remaining topics they were presented, most of which address understanding cancer risk:

### **4.4 Recommended Next Steps**

The findings and conclusions reported here suggest the following next steps for OESI in developing a cancer risk primer.

1. Revise and draft additional scenarios according to the information summarized above and additional input from the Risk Working Group.
2. Pre-test the revised scenarios and perhaps a draft of the entire booklet, with larger numbers of people, in one-on-one settings to facilitate gathering individual reactions. Include health information seekers from various racial and ethnic groups, recognizing that the definition of “health information seeker” may have to be somewhat fluid depending upon predominant cultural norms regarding the frequency of looking for health information.

# **Appendix A**

## **Study Methods**

The goal of this study was to gain insights into how information seekers think about cancer risk and how they would react to materials addressing cancer risk. Therefore, qualitative methodologies were used:

- Four 90-minute telephone focus groups were conducted with African Americans and Caucasians. Of the four groups, two were with men and two with women. Computer-assisted telephone focus groups were used so that participants from large and small communities across the United States could participate.
- Four 90 to 120 minute in-person focus groups were conducted with Hispanics. Two groups were convened in Chicago, Illinois; the other two were held in Bethesda, Maryland. In each city, one group was conducted with men and one with women. In-person focus groups were conducted because experience shows that many Hispanic participants are more comfortable with face-to-face discussion.
- Six telephone interviews were conducted, three with key informants from the Asian and Pacific Islander communities, and three with key informants from the American Indian-Alaska Native communities.

### **Focus Groups**

To most efficiently allocate limited resources, the focus groups were limited to the three largest racial/ethnic populations in the United States, because they will form the bulk of the population using the risk publication OESI envisions. Subsequent stages of this project will include testing revised materials with health information seekers from all population groups.

Based on reviewing the literature, Cancer Information Service data, and expert advice, the following initial requirements for participation in the focus groups were developed:

- Age 40-59
- Not cancer survivors, employed in a medical care setting, or non-believers in Western medicine
- Health information seekers (i.e., people who seek out information on taking care of their health by purposefully looking for information in newspapers, magazines, or on television or the Internet)
- Comfortable reviewing written material (e.g., literate)
- High school graduates through college graduates (bachelor's degree), with each group containing a mix of people with education in this range
- English dominant or comfortable speaking and reading English and Spanish (for Hispanic groups)

Because recruiters in the Washington, DC area had trouble identifying Hispanics with these characteristics, some recruiting criteria had to be relaxed: the age range was lowered to 32, health information seeking was increased to include those who look for health information as

infrequently as one or two times per year, and education was raised to include graduate coursework or degrees.

In addition to the individual participation criteria outlined above, each focus group session had certain specifications:

- No more than half of the participants recruited for each group could be touched by cancer (e.g., close to someone in the past 5 years who was undergoing cancer treatment)
- No more than half of the participants recruited for each group could be the “worried well” (i.e., people who often think they have health problems)
- Less than three participants recruited for each group could be people who believe there is nothing one can do to change one’s cancer risk
- For Hispanic groups: a mix of people whose families originate from the major Hispanic groups present in the United States

African American and Caucasian participants live in California, Connecticut, the District of Columbia, Florida, Georgia, Illinois, Massachusetts, Minnesota, New Jersey, New York, South Carolina, Texas, and Wisconsin. All Hispanic participants live in the Washington, DC and Chicago, Illinois metropolitan areas; their countries of origin are Bolivia, Chile, Columbia (6 participants), Ecuador, Guatemala, Mexico (9 participants), Nicaragua (3 participants), Paraguay, Peru, Puerto Rico (8 participants), Venezuela (2 participants), and 1 unknown.

Professional recruitment firms called potential focus group participants and used a screener developed with OESI (see Appendix B) to determine whether a person was eligible to participate. Qualified individuals were offered a \$50 incentive for participation. The recruitment firms used a variety of methods to identify potential participants. All began by contacting people in their databases of potential focus group participants who appeared to meet at least some screening criteria; they then supplemented their databases in the following ways. For the telephone focus groups, the recruitment firm asked individuals who did not meet the screening criteria for referrals of friends or associates. For the Chicago focus groups, the recruitment firm used local-area phone books, calling people with Hispanic surnames. For the Washington, D.C. groups, the recruitment firm contacted agencies and community organizations in the area, asked them to let people know about the focus groups, and asked that announcements be placed in their facilities. They also contacted Spanish-language media, resulting in a popular radio station’s morning show hosts reading the announcement on the air, and the Telemundo television network adding information about the focus groups to its daily community calendar.

All individuals who agreed to participate were sent a letter confirming participation and the date and time of the scheduled group. Telephone focus group participants received a package containing materials to be discussed during the focus group, which they were instructed not to open until told to do so by the group’s moderator. One day before the focus groups, all recruited individuals were called and reminded about the session; telephone focus group participants received an additional reminder call one half-hour before the session began.

All focus group discussions were led by one of two experienced moderators working from a topic guide focused on the objectives outlined in the background section of this report and developed in consultation with OESI staff (see Appendix C). Major topics were as follows:

- General risk concerns
- Perceptions of cancer causes and risk factors
- Understanding of, using, and seeking risk information
- Reactions to (1) four groups of scenarios, (2) one scenario accompanied by explanatory information illustrating key risk concepts in a question-and-answer format, and (3) three visual representations of risk
- Preferences among additional topics they would want in a booklet about cancer risk

African American and Caucasian focus groups were conducted by a Caucasian moderator as computer-assisted telephone conference calls. Two calls (one with males and one with females) took place on November 4, 2002, and the other two took place on November 13, 2002. Telephone focus groups encourage and facilitate participation, as they can accommodate participants from all areas of the country, not just a few large metropolitan areas, and people can participate from their home, office, or other convenient location. Computer technology allowed the moderator to track who was speaking and receive notes from observers. Toward the end of each discussion, the moderator gave the focus group participants a brief task, and then entered a separate telephone conference with observers to identify areas for further discussion. She then returned to the participants and covered any remaining topics. Each focus group was followed by a debriefing session between the moderator and the observers.

Hispanic focus groups were conducted by a Hispanic moderator in commercial focus group facilities. The first two focus groups, one with females and one with males, took place in Bethesda, Maryland (a suburb of Washington, DC) on November 6 and 7, 2002; the other two sessions (again, one with males and one with females) were held in Chicago, Illinois on November 12, 2002.

Each focus group session was audiotaped and subsequently transcribed. The transcripts were analyzed to capture both the range of opinions and the major themes emerging across the discussions.

### **Key Informants**

NCI developed a list of Asian American and Pacific Islander (API) and American Indian-Alaska Native (AI-AN) contacts for the key informant interviews by consulting OESI's database of organizations that work with these populations. Matthews Media Group contacted individuals from this list, inviting them to participate in a 30-minute interview to discuss their reactions to the cancer risk materials (see Appendix D).

Three interviews were conducted with API health educators or activists who have served API communities, and three were conducted with AI-AN professionals who have worked with AI-AN communities in addressing health issues. One API informant does cancer prevention and

control work with community groups, including Native Hawaiian and Pacific Islander populations; another does cancer work with community members, including Asian populations, in the San Francisco Bay Area; the third is a cancer survivor who volunteers with cancer organizations and coordinates support groups for Chinese-Americans with cancer. Among the three AI-AN informants, one works for an organization that addresses cancer among Alaska Natives; another works for a women's wellness project that serves AI-AN populations; and the third is a qualitative researcher who has conducted extensive research with members of a range of tribes on a variety of health issues.

## **Appendix B**

### **Screening Criteria**

**Matthews Media Group**  
**National Cancer Institute Office of Education and Special Initiatives**

**Risk Communications**

**Focus Group Recruitment Screener: African American and Caucasian Participants**

RECRUIT 11 FOR 8 TO SHOW

ENSURE A MIX OF PARTICIPANTS FROM ACROSS THE UNITED STATES

Hello, my name is \_\_\_\_\_ and I'm calling from  
\_\_\_\_\_. We're conducting a study about health issues.

1. Are you, or is anyone in your household or immediate family, a doctor, nurse, or other health professional?

Yes [THANK AND TERMINATE]  
 No [CONTINUE]

2. Are you, or is anyone in your household or immediate family, employed in any of the following settings: hospital, doctor or dentist's office, health clinic, health insurance company or agency, or pharmacy?

Yes [THANK AND TERMINATE]  
 No [CONTINUE]

3. Have you ever participated in a focus group, or been paid to participate in a discussion group?

Yes [CONTINUE]  
 No [SKIP TO Q.6]

4. When did you participate?

In the past year [CONTINUE]  
 More than one year ago [SKIP TO Q.6]

5. What was/were the topic(s)?

---

IF ANY TYPE OF HEALTH ISSUE, THANK AND TERMINATE

6. Which of the following best describes your age? [READ RESPONSES]

- Under 40 [THANK AND TERMINATE]
- 40-59 [CONTINUE]
- 60 or older [THANK AND TERMINATE]
- Refused [THANK AND TERMINATE]

7. Which of the following statements best describes the highest level of education you have completed? [READ RESPONSES; RECRUIT MIX FOR EACH GROUP]

<input type="radio"/>	I did not graduate from high school	[THANK AND TERMINATE]
<input type="radio"/>	I am a high school graduate	[CONTINUE]
<input type="radio"/>	I took some trade school, junior college, community college, or college classes but did not graduate	[CONTINUE]
<input type="radio"/>	I graduated from a trade school, junior college, or community college	[CONTINUE]
<input type="radio"/>	I graduated from a four-year college	[CONTINUE]
<input type="radio"/>	I have taken post-graduate courses or have a post-graduate degree	[THANK AND TERMINATE]
<input type="radio"/>	Refused	[THANK AND TERMINATE]

8. Which of the following best describes your race or ethnicity? [READ LIST]

<input type="radio"/>	White	[RECRUIT HALF PER GROUP]
<input type="radio"/>	Black or African-American	[RECRUIT HALF PER GROUP]
<input type="radio"/>	Hispanic or Latino	[THANK AND TERMINATE]
<input type="radio"/>	Asian	[THANK AND TERMINATE]
<input type="radio"/>	Native Hawaiian or other Pacific Islander	[THANK AND TERMINATE]
<input type="radio"/>	American Indian or Alaskan Native	[THANK AND TERMINATE]
<input type="radio"/>	Refused	[THANK AND TERMINATE]

9. I'm going to read you a series of statements. For each, I'd like you to tell me if you strongly agree, somewhat agree, somewhat disagree, or strongly disagree.

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	
A. I'm more concerned than most of my friends about getting particular diseases.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	NO MORE THAN 4 PER GROUP WHO "STRONGLY AGREE" WITH ANY TWO OF STATEMENTS A THRU C
B. My doctor doesn't take my health problems seriously enough.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
C. Every time I hear about a new disease, I worry that I may get it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
D. There is nothing I can do to reduce my risk of getting cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	"STRONGLY AGREE" -- NO MORE THAN 3 PER GROUP

10. Have you ever been diagnosed with cancer?

- Yes [CONTINUE]  
 No [SKIP TO Q.13]

11. Was it skin cancer, or another kind of cancer?

- Skin cancer [CONTINUE]  
 Melanoma [THANK AND TERMINATE]  
 Another kind of cancer [THANK AND TERMINATE]

12. Was it melanoma, or another kind of skin cancer? [CLASSIFY SQUAMOUS OR BASAL CELL AS "ANOTHER KIND" OF SKIN CANCER]

- Yes, melanoma [THANK AND TERMINATE]  
 Another kind [CONTINUE]  
 Don't know [THANK AND TERMINATE]

13. Have you ever needed to have follow-up tests or procedures to ensure you didn't have cancer after a possible problem was detected?

[EXAMPLES: A BIOPSY, SIGMOIDOSCOPY FOLLOWING A SUSPICIOUS STOOL TEST/FECAL OCCULT BLOOD TEST, COLONOSCOPY FOLLOWING SUSPICIOUS SIGMOIDOSCOPY, MORE SENSITIVE OR ADDITIONAL MAMMOGRAMS FOLLOWING ROUTINE SCREENING MAMMOGRAMS, COLPOSCOPY FOLLOWING SUSPICIOUS PELVIC OR PAP EXAM.

ROUTINE SCREENING TESTS CONDUCTED IN THE ABSENCE OF SYMPTOMS—SUCH AS MAMMOGRAMS, PSA TESTS, PAP TESTS, STOOL TEST/FECAL OCCULT BLOOD TESTS, SIGMOIDOSCOPIES, COLONOSCOPIES—DO NOT CONSTITUTE A “YES” RESPONSE TO THIS QUESTION]

- Yes [CONTINUE; NO MORE THAN THREE PER GROUP]  
 No [CONTINUE]

14. During the past five years, have any of your close family members or other loved ones been treated for cancer?

- Yes [CONTINUE; NO MORE THAN FIVE PER GROUP]  
 No [CONTINUE]

15. When you are sick, do you usually turn to a doctor or nurse, or some other type of person?

- Doctor, nurse, nurse practitioner, physician's assistant [SKIP TO Q.17]  
 Some other type of person [CONTINUE]  
 Don't know [CONTINUE]  
 Refused [THANK &

TERMINATE]

16. Would you ever seek care from medical doctors or nurses?

- Yes [CONTINUE]  
 No [THANK AND TERMINATE]

17. About how often do you look for information on a particular illness or medical condition in newspapers, magazines, or books, or on television or the Internet? Would you say . . . [READ RESPONSES]

- Never [THANK AND TERMINATE]  
 Less than once a year [THANK AND TERMINATE]  
 One or two times a year [THANK AND TERMINATE]

- Every few months [CONTINUE]
- Monthly or more often [CONTINUE]

18. In your opinion, what is the biggest health care problem in America today?

19. What about that problem makes it so important?

[RECORD EXACT RESPONSE; THANK AND TERMINATE ANYONE WHO CANNOT ARTICULATE CLEARLY OR SPEAK LOUDLY ENOUGH TO BE UNDERSTOOD.]

20. RECORD GENDER [DO NOT ASK UNLESS UNABLE TO TELL]:

- Female
- Male

21. We would like to invite you to participate in a telephone discussion about some health issues with about seven other people like yourself from across the United States. The session is sponsored by the National Cancer Institute, one of the National Institutes of Health. It will last about an hour and a half and will include reading some short materials about cancer and then discussing them. Are you comfortable reading written materials?

- Yes [CONTINUE]
- No [THANK AND TERMINATE]

22. Since these discussions take place over the phone, you can participate from your home, your office, or anywhere else you need to be. All that we ask is that you participate from a regular telephone, not a cell phone. A conference operator will call you at the number of your choice. When everyone is on the line, a discussion leader will introduce everyone by first name only, and will then lead the group through several topics. You will receive \$50 as a token of appreciation for your participation.

[ENTHUSIASTICALLY] Will you be able to join us on [DATE] at [CONVERT TIME INTO PARTICIPANT'S LOCAL TIME]?

- Yes [CONTINUE]
- No [THANK AND TERMINATE]

IF NECESSARY, EXPLAIN THAT THE DISCUSSION IS NOT A SALES PITCH.

Men Group 1 – Monday, November 4, 9 PM ET

Men Group 2 – Wednesday, November 13, 7 PM ET

Women Group 1 – Monday, November 4, 7 PM ET

Women Group 2 – Wednesday, November 13, 9 PM ET

23. At what phone number shall we call you then? \_\_\_\_\_

24. We will send you a confirmation letter and some materials that you will need during the group. Can I have your name and mailing address, please?

PARTICIPANT'S NAME:

\_\_\_\_\_

STREET ADDRESS:

\_\_\_\_\_

CITY: \_\_\_\_\_ STATE: \_\_\_\_\_ ZIP:

\_\_\_\_\_

HOME PHONE: \_\_\_\_\_

WORK PHONE: \_\_\_\_\_

That's all of my questions. Thank you for your time; you should receive our materials shortly.

**Matthews Media Group**  
**National Cancer Institute Office of Education and Special Initiatives**

**Risk Communications**  
**Focus Group Recruitment Screener: Hispanic Participants**

ALL PARTICIPANTS MUST BE COMFORTABLE SPEAKING AND READING ENGLISH.

Hello, my name is \_\_\_\_\_ and I'm calling from \_\_\_\_\_ . We're conducting a study about health issues.

1. Are you, or is anyone in your household or immediate family, a doctor, nurse, or other health professional?  
  
 Yes [THANK AND TERMINATE]  
 No [CONTINUE]
  
2. Are you, or is anyone in your household or immediate family, employed in any of the following settings: hospital, doctor or dentist's office, health clinic, health insurance company or agency, or pharmacy?  
  
 Yes [THANK AND TERMINATE]  
 No [CONTINUE]
  
3. Have you ever participated in a focus group, or been paid to participate in a discussion group?  
  
 Yes [CONTINUE]  
 No [SKIP TO Q.6]
  
4. When did you participate?  
  
 In the past year [CONTINUE]  
 More than one year ago [SKIP TO Q.6]
  
5. What was/were the topic(s)?

---

IF ANY TYPE OF HEALTH ISSUE, THANK AND TERMINATE

6. Which of the following best describes your age? [READ RESPONSES]

- Under 40 [THANK AND TERMINATE]
- 40-59 [CONTINUE]
- 60 or older [THANK AND TERMINATE]
- Refused [THANK AND TERMINATE]

7. Which of the following statements best describes the highest level of education you have completed? [READ RESPONSES; RECRUIT MIX FOR EACH GROUP]

<input type="radio"/>	I did not graduate from high school	[THANK AND TERMINATE]
<input type="radio"/>	I am a high school graduate	[CONTINUE]
<input type="radio"/>	I took some trade school, junior college, community college, or college classes but did not graduate	[CONTINUE]
<input type="radio"/>	I graduated from a trade school, junior college, or community college	[CONTINUE]
<input type="radio"/>	I graduated from a four-year college	[CONTINUE]
<input type="radio"/>	I have taken post-graduate courses or have a post-graduate degree	[THANK AND TERMINATE]
<input type="radio"/>	Refused	[THANK AND TERMINATE]

8. Do you consider yourself to be Hispanic or Latino/a?

- Yes [CONTINUE]
- No [THANK AND TERMINATE]

9. What country are you or your family originally from? [RECRUIT MIX, WITH MAJORITY FROM MEXICO, PUERTO RICO, AND SOUTH AMERICA]

\_\_\_\_\_ [RECORD COUNTRY]  
 Refused [THANK AND TERMINATE]

10. I'm going to read you a series of statements. For each, I'd like you to tell me if you strongly agree, somewhat agree, somewhat disagree, or strongly disagree.

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	
A. I'm more concerned than most of my friends about getting particular diseases.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	NO MORE THAN 4 PER GROUP WHO "STRONGLY AGREE" TO ANY TWO OF STATEMENTS A THRU C
B. My doctor doesn't take my health problems seriously enough.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
C. Every time I hear about a new disease, I worry that I may get it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
D. There is nothing I can do to reduce my risk of getting cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	"STRONGLY AGREE" -- NO MORE THAN 3 PER GROUP

11. Have you ever been diagnosed with cancer?

- Yes [CONTINUE]
- No [SKIP TO Q.14]

12. Was it skin cancer, or another kind of cancer?

- Skin cancer [CONTINUE]
- Melanoma [THANK AND TERMINATE]
- Another kind of cancer [THANK AND TERMINATE]

13. Was it melanoma, or another kind of skin cancer? [CLASSIFY SQUAMOUS OR BASAL CELL AS "ANOTHER KIND" OF SKIN CANCER]

- Yes, melanoma [THANK AND TERMINATE]
- Another kind [CONTINUE]
- Don't know [THANK AND TERMINATE]

14. Have you ever needed to have follow-up tests or procedures to ensure you didn't have cancer after a possible problem was detected?

[EXAMPLES: A BIOPSY, SIGMOIDOSCOPY FOLLOWING A SUSPICIOUS STOOL TEST/FECAL OCCULT BLOOD TEST, COLONOSCOPY FOLLOWING SUSPICIOUS SIGMOIDOSCOPY, MORE SENSITIVE OR ADDITIONAL MAMMOGRAMS FOLLOWING ROUTINE SCREENING MAMMOGRAMS, COLPOSCOPY FOLLOWING SUSPICIOUS PELVIC OR PAP EXAM.

ROUTINE SCREENING TESTS CONDUCTED IN THE ABSENCE OF SYMPTOMS—SUCH AS MAMMOGRAMS, PSA TESTS, PAP TESTS, STOOL TEST/FECAL OCCULT BLOOD TESTS, SIGMOIDOSCOPIES, COLONOSCOPIES—DO NOT CONSTITUTE A “YES” RESPONSE TO THIS QUESTION]

- Yes [CONTINUE; NO MORE THAN THREE PER GROUP]  
 No [CONTINUE]

15. During the past five years, have any of your close family members or other loved ones been treated for cancer?

- Yes [CONTINUE; NO MORE THAN HALF PER GROUP]  
 No [CONTINUE]

16. When you are sick, do you usually turn to a doctor or nurse, or some other type of person?

- Doctor, nurse, nurse practitioner, physician's assistant [SKIP TO Q.18]  
 Some other type of person [CONTINUE]  
 Don't know [CONTINUE]  
 Refused [THANK &

TERMINATE]

17. Would you ever seek care from medical doctors or nurses?

- Yes [CONTINUE]  
 No [THANK AND TERMINATE]

18. About how often do you look for information on a particular illness or medical condition in newspapers, magazines, or books, or on television or the Internet? Would you say . . . [READ RESPONSES]

- Never [THANK AND TERMINATE]  
 Less than once a year [THANK AND TERMINATE]  
 One or two times a year [THANK AND TERMINATE]

- Every few months [CONTINUE]
- Monthly or more often [CONTINUE]

19. In your opinion, what is the biggest health care problem in America today?

20. What about that problem makes it so important?

[RECORD EXACT RESPONSE; THANK AND TERMINATE ANYONE WHO CANNOT ARTICULATE CLEARLY IN ENGLISH OR SPEAK LOUDLY ENOUGH TO BE UNDERSTOOD.]

21. RECORD GENDER [DO NOT ASK UNLESS UNABLE TO TELL]:

- Female
- Male

22. We would like to invite you to participate in a discussion about some health issues with about seven other people. These discussions are sponsored by the National Cancer Institute, one of the National Institutes of Health. The session will last about an hour and a half and will include reading some short materials about cancer and then discussing them. Are you comfortable reading materials written in English?

- Yes [CONTINUE]
- No [THANK AND TERMINATE]

23. [ENTHUSIASTICALLY] Will you be able to join us on . . . [READ APPROPRIATE LINE AND CIRCLE BELOW]?

- A. [DC MEN GROUP 1] Thursday, November 7, at 7 PM? You will receive dinner and \$50 as a token of appreciation for your participation.
- B. [DC WOMEN GROUP 1] Wednesday, November 6, at 7 PM? You will receive dinner and \$50 as a token of appreciation for your participation.
- C. [CHICAGO MEN GROUP 2] Tuesday, November 12, at 8 PM? You will receive \$50 as a token of appreciation for your participation.
- D. [CHICAGO WOMEN GROUP 2] Tuesday, November 12, at 6 PM? You will receive dinner and \$50 as a token of appreciation for your participation.

- Yes [CONTINUE]
- No [THANK AND TERMINATE]

IF NECESSARY, EXPLAIN THAT THE DISCUSSION IS NOT A SALES PITCH.

24. We will send you a confirmation letter and directions to our facility. Can I have your name and mailing address, please?

PARTICIPANT'S NAME:

\_\_\_\_\_

STREET ADDRESS:

\_\_\_\_\_

CITY: \_\_\_\_\_ STATE: \_\_\_\_\_

ZIP: \_\_\_\_\_

HOME PHONE: \_\_\_\_\_

WORK PHONE: \_\_\_\_\_

That's all of my questions. Thank you for your time; you should receive our confirmation letter shortly.

## **Appendix C**

### **Moderator's Guides**

**National Cancer Institute  
Office of Education and Special Initiatives**

**Risk Communications  
Moderator's Guide: Telephone Groups**

*Study objectives are to explore, with health information seekers:*

- 1. Which of a series of risk scenarios communicate best*
- 2. Whether the same scenarios can be used to communicate across various special populations and medically underserved groups*
- 3. Types of risk information (quantitative/qualitative) the public desires*
- 4. Ability to accurately interpret numerical expressions of risk (e.g., probabilities, percentages, frequencies)*
- 5. Understanding of how to put numerical risk information into perspective for oneself*
- 6. Cancer risk-related myths and misconceptions*
- 7. Relationships between cancer risk perceptions and cognitive and social biases*
- 8. Effect of different presentation formats (e.g., message framing, visual aids) on understanding of cancer risk terms and concepts*

**I. Introduction**

(10 minutes)

**A. Welcome and audiotaping notification**

Good evening everyone, this is \_\_\_\_\_, can everyone hear me clearly? First, thank you for taking the time to join us. As a reminder, the National Cancer Institute, one of the National Institutes of Health, has convened this discussion in order to learn more about your cancer information needs.

Our call tonight is being audiotaped. The tapes will be used only for research purposes, and your individual comments remain confidential. They will be written down and used by me to prepare a report. In the report, none of you will be identified by name or organization.

Presence of observers

**B. Introduce topic, moderator, participants**

Let's introduce everyone on the line, so we all know who is here. Then I'll talk about more about the nature and purpose of this discussion. And then we'll get right into the fun, discussion part of your session as quickly as possible. When I call your first name -- LET'S USE FIRST NAMES -- please tell us if there is some other name you prefer to be called, and the city and state where you're located [FOR HISPANICS/LATINOS, ALSO ASK FOR COUNTRY OF ORIGIN].

[CALL NAMES]

### **C. Describe process**

1. When you have something to say, jump right in, don't wait to be called on. I can't see you raising your hand. However, I'm looking at a computer screen that shows me the name of the person who's talking, so sometimes if two people talk at once, I may notice on my computer screen
2. When you speak, please say your first name in the first sentence, so people can respond to you.
3. My role is to guide our discussion by asking some questions, and keep us on track to end on time. As you know, we are planning on the discussion taking about 90 minutes.
4. Your role is to speak to the topics raised based on your own opinion or viewpoint. Agree, disagree, expand on what people say. That's why we're talking in a group: to get your reactions to each other's ideas. AGREE? LET'S HEAR A CHORUS.
5. Let's hear from as many people as possible.
6. Hopefully you're all sitting somewhere private, where you won't be interrupted and none of us will be distracted with background noise, like barking dogs, televisions, or people talking.
7. Does everyone have the package of information we sent? Don't open it yet, but please have it, a pen or pencil, and your reading glasses, if you need them, right next to you so you can open up the package and read it when I ask you to do so.
8. Call waiting or another line. Please try to stay with us during the discussion, and don't take other calls. But if you must, we'll ignore the clicks. Get back ASAP. Then please interrupt us if you can't figure out what we're talking about. Better to have you back participating.

### **D. Any questions?**

## **II. General Risk Concerns**

(10 minutes)

### **A. Thinking About/Using Risk Information in Daily Life**

1. What do you think of when you hear the words *health risk*? [PROBE FOR SPECIFICS, EXAMPLES]
2. What are some of the health risks that you are personally concerned about?

3. How often would you say you think about these health risks?  
(PROBE: Occasionally? Daily?)
4. What do you do about them? [PROBE: Have you made any changes in your life? Such as . . .?]

**B. Let's say your doctor told you that you *may be at increased risk of getting something like cancer.***

1. What does "may be at increased risk" mean to you?
2. What, if anything, would you do in response? [PROBE FOR SPECIFICS]

**III. Perception of Cancer Causes and Risk Factors**

(10 minutes)

**A. Possible Causes of Cancer**

1. What do you think causes cancer? PROBE AS NEEDED: What about:  
Your lifestyle (what you eat, how much exercise you get, how much you weigh, whether you smoke or use smokeless tobacco, whether you drink alcohol)  
Family history or genetics  
Your environment (power lines, pesticides, radiation, etc.)
2. What puts you at greatest risk for cancer? (REVIEW LIST FROM ABOVE IF NECESSARY)

**B. Risk reduction**

1. Do you think that a person's risk of cancer can be reduced? [IF NO: What makes you say that?]
2. How?
3. Is it possible to eliminate risk, or just lower it? How much?
4. Are there types of risk that are beyond ones' control?

**IV. Understanding of, Using, and Seeking Risk Information**

(10 minutes)

**A. At times you may hear something on the news or read something in the paper that talks about cancer risk. For example, a news story might report that you're two times more likely to get colon cancer than some other cancer, or that if you eat more of a certain food, it will reduce your cancer risk.**

1. What, if anything, would you do in response to such news stories?

a) PROBE FOR SPECIFICS, AND UNDER WHAT CIRCUMSTANCE

b) What is it about a news story that convinces you to take action?

2. Can you think of any particular questions you have about cancer risk right now? Any information that would help you understand cancer risk better?

B. [BRIEFLY] Do you ever look for information on health risks—cancer or otherwise—for yourself or anyone else?

1. Where did you find the information? (TV, MAGAZINES, WEBSITES, ETC.)

2. What did you do as a result of the information you found? [FOCUS ON THIS]

C. In your opinion, who or what is the most trustworthy source for information about cancer risk? [PROBE: doctors, researchers/scientists, friends/family, other?]

V. Scenarios  
minutes)

(40

The National Cancer Institute is thinking about developing a 10-20 page booklet to help people understand cancer risk. We'll spend the remainder of our time tonight looking at some of their ideas for what might go in that booklet. They aren't finished yet, and your comments will help shape the final booklet. Also, you don't have to worry about hurting my feelings because I did not create any of the pieces we're going to talk about.

A. Reactions to Group A Scenarios

Now I'd like you to open the package you were sent, and take out the sheet of paper labeled Group A. It should be on top. Leave the others in the envelope for now.

One of the ideas they are considering is using people's stories to begin a discussion of cancer risk. This sheet contains the beginnings of three stories. Please look over each of them for a moment, and select the one you feel is most like you or the people you know. [USE POLLING TO GET TOP RATINGS]

REPEAT FOLLOWING QUESTIONS FOR ALL SCENARIOS RATED MOST INTERESTING. DON'T HAVE TO GO THRU WHOLE LIST FOR EACH STORY SEPARATELY, JUST MAKE THEM CLARIFY WHAT STORY THEY'RE DISCUSSING AS NECESSARY.

1. I noticed a lot of you chose [NAME OF SCENARIO FREQUENTLY CHOSEN]. What about [NAME OF SCENARIO] makes it the one that speaks to you the *most*? [PROBE: Topic? Something about the person? Something else?]
2. Is this story believable, or not? What makes you say that?
3. Do you want to read more of this story, or not? Why?
4. If there were scientists or your doctor in the room with us tonight, what would you ask them to help you understand this information better?
  - a) [EVERYONE] Is there anything you particularly like—or dislike—about this story? [IF NECESSARY, FOCUS THEM ON THE STORY, NOT THE PERSON IN IT]
5. Have you heard people you know make comments like those in these stories, or not?

#### B. Reactions to Group B Scenarios

Now I'd like you to open the package you were sent, and take out the sheet of paper labeled Group B. It should be on top. Leave the others in the envelope for now.

This sheet contains five stories. Please look over each of them for a moment, and select the two that interest you the most or speak to you the most. Decide which is your top choice and your second choice. [USE POLLING TO GET TOP 2 RATINGS]

REPEAT QUESTIONS IN SECTION A FOR ALL SCENARIOS RATED MOST OR SECOND MOST INTERESTING

#### C. Reactions to Group C Scenarios

Now I'd like you to open the package you were sent, and take out the sheet of paper labeled Group C. It should be on top. Leave the others in the envelope for now.

This sheet contains three stories. Please look over each of them for a moment, and select the one that interests you the most or speaks to you the most. [USE POLLING TO GET TOP RATINGS]

REPEAT QUESTIONS IN SECTION A FOR ALL SCENARIOS RATED MOST INTERESTING

D. Reactions to Group D Scenario

Now I'd like you to open the package you were sent, and take out the sheet of paper labeled Group D. It should be on top. Leave the others in the envelope for now.

This sheet contains one story. Please look it over for a moment, and then we'll discuss it

REPEAT QUESTIONS IN SECTION A

E. Now I'd like you to take out the sheet labeled "Topics." This is a list of other types of information that could be included in the materials we've been looking at. What I'd like you to do is look over the list and choose up to five topics you would most like to see included. An easy way to do this is to put a plus sign next to the topics you find interesting. [USE POLLING TO RECORD VOTES]

M. Myths about what puts you at risk for developing cancer

I. Information to help you decide when to take some action, such as  
changing a behavior or getting genetic counseling

R. How to understand what risk statistics mean

N. How to understand news stories about cancer risk

S. How to understand scientific studies about cancer risk

D. What you can do to decrease your risk of getting cancer

C. What types of cancer risk you can control versus those beyond your  
control

L. Understanding the limitations of science in estimating cancer risk

U. Understanding what cancer is

F. Reactions to Lisa's Story/George's Story (2 pages)

[INSTRUCT PARTICIPANTS TO REVIEW 2 PAGES LABELED "LISA'S STORY" (WOMEN'S GROUPS) OR "GEORGE'S STORY" (MEN'S GROUPS), FOCUSING ON THE FOUR QUESTIONS ASKED, NOT THE ANSWERS. TELL THEM THERE IS ONE QUESTION ON THE FIRST PAGE AND THREE ON THE SECOND, ALL IN BOLD PRINT]

1. Were these the questions you would want answered?
2. Do you have other questions that you would like to see included?  
[PROBE: If there were scientists or your doctor in the room with us tonight, what would you ask them to help you understand this information better?]
3. Are the questions in the right order? Or would you prefer to see them ordered differently?
4. Is there anything confusing or hard to understand?
5. Is this information believable, or not?
  - a) What makes you say that?
  - b) What, specifically, did you find hard to believe?
6. Was any of this information unnecessary to you? [IF YES: What?]
7. What additional information would you like to have?

**VI. Visuals**  
minutes)

(5

Now I'd like you to take out the last three sheets of paper. As before, please feel free to comment honestly because I did not create these.

- A. Please look over the three pictures, and select the one that communicates most clearly to you. [USE POLLING TO RECORD RESPONSES; CHECK WITH OBSERVERS WHILE PARTICIPANTS REVIEW MATERIALS]
- B. FOR EACH VISUAL CHOSEN AS MOST APPEALING, PROBE: What about this graphic made it most appealing to you?
- C. Would putting these graphics into the two-page Lisa's/George's story be helpful, or not?

**VII.** Wrap-up  
(minutes)

(5-10)

- A. As I mentioned earlier, we've been reviewing these materials because the National Cancer Institute is thinking about putting together a 10-20 page booklet that would contain personal stories, such as those we were looking at earlier, followed by explanations, possibly in the question-and-answer format you saw in Lisa's story/George's story. This booklet is also likely to include some of the other topics we asked you about earlier, either in separate sections or integrated into the stories.
1. [IF APPROPRIATE: It sounds like many of you already know a lot about cancer risk from what you read in articles and on the Internet, what you see on television, and what you hear from doctors, friends and family members.] How useful would such a booklet be to you? What type of person do you think would find it most useful?
  2. Thinking about what you already know about cancer risk, and what we've discussed tonight, what topics would you want to make sure were described clearly or in detail in such a booklet?
- ADDRESS ANY ISSUES RAISED BY OBSERVERS
  - Any final comments?
  - THANK PARTICIPANTS.
  - SAY CHECK WILL COME FROM RECRUITING COMPANY -- 1 WEEK.

**Appendix D**  
**Key Informant Interview Guides**

**National Cancer Institute  
Office of Education and Special Initiatives**

**Risk Communications  
In-depth Interview Guide**

*Study objectives are to explore, with health information seekers:*

- 1. Which of a series of risk scenarios communicate best*
- 2. Whether the same scenarios can be used to communicate across various special populations and medically underserved groups*

I. Introduction (5 minutes)

A. Welcome and audiotaping notification

Hello, this is \_\_\_\_\_ I'm calling on behalf of the National Cancer Institute, to discuss the materials we sent. Is this still a good time for you to talk?

1. Our call today is being audiotaped. The tapes will be used only for research purposes. Your individual comments during our discussion are confidential. What you tell me will be used to prepare a report, however, you will not be identified by name in it. Your participation in this interview is voluntary; you may skip any questions you do not feel comfortable answering. You may also stop participating at any time.
2. We are seeking your feedback and opinions based on your knowledge of and experience with [\_\_\_\_\_]POPULATION]..
3. Do you have the package of information we sent? {Please have it in front of you, along with a pen or pencil, so you can read the materials when I ask you to do so.

B. Any questions before we get started?

II. Introducing Risk

- A. What would you say are the major health risks of concern to members of the [POPULATION]?
- B. What do you think most [POPULATION] believe puts one at greatest risk for cancer?
- C. Risk reduction
  1. Do you think that a person's risk of cancer can be reduced? [IF NO: What makes you say that?]

2. How do you think members of the [POPULATION] generally feel about cancer risk?
3. In general, who or what do you think [*Asian Americans & Pacific Islanders/ Native Americans*] would consider to be the most trustworthy source for information about cancer risk? [PROBE: doctors, researchers/scientists, friends/family, other?]

### III. Scenarios

The National Cancer Institute is thinking about developing a 10-20 page booklet to help "health information seekers" understand cancer risk. **"Health information seekers" are people who tend to look for information about particular illnesses or medical conditions on the Internet, or in newspapers, magazines, or books, at least every couple of months.** [*If clarification is needed --This booklet is not intended for low-literacy audiences.*] The package I sent you contains some of NCI's ideas for what might go in a booklet about cancer risk. They aren't finished yet, and your comments will help shape the final booklet. Please be honest in your comments, both positive and negative. You don't have to worry about hurting my feelings because I did not create any of the pieces we're going to talk about.

#### A. Reactions to Group A Scenarios

Now I'd like you to open the package you were sent, and take out the sheet of paper labeled Group A. It should be on top. Leave the others in the envelope for now.

One of the ideas they are considering is using people's stories to begin a discussion of cancer risk. This sheet contains the beginnings of three stories. Please look over each of them for a moment, and tell me which one you think the health information seekers in your population would be most interested in, or which one they would identify with the most.

1. What made you choose that one? [PROBE: Topic? Something about the person? Something else?]
2. Is this story believable, or not? What makes you say that?
3. Is there anything you particularly like—or dislike—about this story? [IF NECESSARY, FOCUS THEM ON THE STORY, NOT THE PERSON IN IT]
4. Have you heard people in [POPULATION] communities make comments like the ones in these stories, or not?

**B. Reactions to Group B Scenarios**

Now I'd like you to take out the sheet of paper labeled Group B. Leave the others in the envelope for now.

This sheet contains five stories. Please look over each of them for a moment, and tell me which TWO you think the health information seekers in your population would be most interested in, or which one they would identify with the most.

REPEAT QUESTIONS IN SECTION A FOR SCENARIO RATED FIRST AND SECOND

**A. Reactions to Group C Scenarios**

Now I'd like you to open the package you were sent, and take out the sheet of paper labeled Group C. It should be on top. Leave the others in the envelope for now.

This sheet contains three stories. Please look over each of them for a moment, and tell me which one you think the health information seekers in your population would be most interested in, or which one they would identify with the most.

REPEAT QUESTIONS IN SECTION A FOR SCENARIO RATED MOST INTERESTING

**B. Reactions to Group D Scenario**

Now I'd like you to open the package you were sent, and take out the sheet of paper labeled Group D. It should be on top. Leave the others in the envelope for now.

This sheet contains one story. Please look it over for a moment, and then we'll discuss it

REPEAT QUESTIONS IN SECTION A

- C. Now I'd like you to take out the sheet labeled "Topics." This is a list of other types of information that could be included in the materials we've been looking at. What I'd like you to do is look over the list and choose up to three topics you think health-information seekers in your population would most like to see included. An easy way to do this is to put a plus sign next to the topics you find interesting. [CIRCLE INTERVIEWEE'S CHOICES]

M. Myths about what puts you at risk for developing cancer

- I. Information to help you decide when to take some action, such as changing a behavior or getting genetic counseling
- R. How to understand what risk statistics mean
- N. How to understand news stories about cancer risk
- S. How to understand scientific studies about cancer risk
- D. What you can do to decrease your risk of getting cancer
- C. What types of cancer risk you can control versus those beyond your control
- L. Understanding the limitations of science in estimating cancer risk
- U. Understanding what cancer is

**D. Reactions to Lisa's Story (2 pages)**

[INSTRUCT PARTICIPANTS TO REVIEW 2 PAGES LABELED "LISA'S STORY", **FOCUSING ON THE FOUR QUESTIONS ASKED, NOT THE ANSWERS.** TELL THEM THERE IS ONE QUESTION ON THE FIRST PAGE AND THREE ON THE SECOND, ALL IN BOLD PRINT]

1. Were these the questions you would want answered?
2. Do you have other questions that you would like to see included?  
[PROBE: If there were scientists or your doctor in the room with you right now, what would you ask them to help you understand this information better?]
3. Is there anything confusing or hard to understand?
4. Was any of this information unnecessary to you, or is there additional information that should be there? [IF YES: What?]

**IV. Visuals**

Now I'd like you to take out the last three sheets of paper. As before, please feel free to comment honestly because I did not create these.

- A. Please look over the three pictures, and select the one that communicates most clearly to you.
- B. FOR VISUAL CHOSEN AS MOST APPEALING, PROBE: What about this graphic made it most appealing to you?

## V. Wrap-up

- A. As I mentioned earlier, we've been reviewing these materials because the National Cancer Institute is thinking about putting together a 10-20 page booklet that would contain personal stories, such as those we were looking at earlier, followed by explanations, possibly in the question-and-answer format you saw in Lisa's story/George's story. This booklet is also likely to include some of the other topics we asked you about earlier, either in separate sections or integrated into the stories.
    1. How useful would such a booklet be to the health-information seekers in your population? What type of person do you think would find it most useful?
    2. How might you use this resource with members of the [POPULATION]?
- Any final comments?
  - AS A WAY OF THANKING YOU FOR TAKING TIME OUT OF YOUR DAY, WE WOULD LIKE TO SEND YOU A \$50 INCENTIVE, OR SEND IT TO THE CHARITY OF YOUR CHOICE. CAN I VERIFY YOUR MAILING ADDRESS?

THANK AND TERMINATE