

# **I.5 Key Focus Group Findings on I-131 Exposure from the Nevada Test Site: Preliminary Findings from Public and Physician Groups**

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**KEY FOCUS GROUP FINDINGS ON I-131 EXPOSURE FROM THE  
NEVADA TEST SITE: PRELIMINARY FINDINGS FROM  
PUBLIC AND PHYSICIAN GROUPS**

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## **I. INTRODUCTION**

The National Cancer Institute (NCI) and Centers for Disease Control and Prevention (CDC) are designing a national campaign to implement Institute of Medicine (IOM) recommendations to communicate to Americans the potential health effects of Iodine-131 (I-131) radiation released during atmospheric testing in Nevada during the 1950s and 1960s. To inform this effort, Office of Cancer Communication (OCC) conducted six focus groups during December 1999 with members of the higher-exposure public, the lower-exposure public, and primary care physicians. Primary objectives of this research were:

- To gauge participants' awareness and knowledge of I-131 radiation fallout from the Nevada Test Site (NTS), as well as the potential risk for thyroid cancer and other non-cancerous thyroid conditions resulting from this exposure;
- To determine whether participants perceive themselves or anyone else as being at-risk for health problems resulting from I-131 exposure and, if so, how concerned participants are about such risk;
- To evaluate participants' reactions to IOM recommendations which discourage mass screening for thyroid cancer, but advocate for an educational campaign to communicate to Americans the potential health effects of I-131; and
- To gain a better understanding of the information needs and wants of the general public and health care professionals.

Preliminary findings from the focus groups are presented in this report. These findings will be used to help determine the direction and scope of further research for the campaign.

## **II. Methodology**

### **Audience Segments**

A total of six focus groups were conducted with three audience segments, referred to as the "higher-exposure public," the "lower-exposure public," and "physicians." The higher-exposure public was defined as adults ages 39-64 who had lived in at least one of 18 states exposed to high levels of I-131 for at least 5 years from birth to age 15.<sup>1</sup> The lower-exposure public was defined as adults 34-64 years of age who had NOT lived in one of the 18 higher-exposure states from birth to age 15. Conducting research with both the higher- and lower-exposure public was done to obtain a

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<sup>1</sup> The higher-exposure and lower exposure public definitions were extracted from NCI's report, "Estimated Exposures and Thyroid Doses Received by the American People from Iodine-131 in Fallout Following Nevada Atmospheric Nuclear Bomb Tests: A Report from the National Cancer Institute" (NIH Pub #97-4264), which outlined the key risk factors due to I-131 exposure. Participants had to be ages 39 to 64 because that is the present age of the individuals who were ages 0 to 15 during the time of the Nevada testing. The 18 states designated as high exposure by the report were: Arkansas, Colorado, Idaho, Illinois, Iowa, Kansas, Minnesota, Missouri, Montana, Nebraska, Nevada, North Dakota, Oklahoma, South Dakota, Utah, Vermont, Wisconsin, and Wyoming.

preliminary sense of how risk status might affect one's awareness, knowledge, and concerns about the Nevada Test Site and I-131 health implications.

Physicians were defined as general practitioners, family physicians, or general internists who had been practicing medicine for at least three years in a high-exposure state. The three-year criterion ensured that physician participants had been in practice long enough to have some chance of seeing patients with radiation issues or health effects, and that they had been practicing in the surrounding area long enough to be familiar with their communities. Research was conducted with primary care physicians, because past research has shown that they are the most trusted source of both health care and health information.

A total of 51 people participated in the focus groups: 33 were members of the higher-exposure or lower-exposure public and 18 were physicians. The six focus groups were structured as follows:

Location	Date and Time	Audience Segment	Number of Participants
Philadelphia, PA	December 7, 1999 6:00-7:30 PM	Lower-exposure public	9
Philadelphia, PA	December 7, 1999 8:00-9:30 PM	Lower-exposure public	7
Omaha, NE	December 13, 1999 5:30-7:00 PM	Higher-exposure public	9
Omaha, NE	December 13, 1999 7:30-9:00 PM	Physicians	9
Burlington, VT	December 14, 1999 5:30-7:00 PM	Higher-exposure public	8
Burlington, VT	December 14, 1999 7:30-9:00 PM	Physicians	9

### Focus Group Sites

The higher-exposure public and physicians groups were conducted in two states exposed to higher levels of I-131 radiation. Omaha, NE, was chosen because of its close proximity to the Nevada Test Site, and Burlington, VT, was included because it is farther away from the site. These locations were selected to provide an initial reading of whether geographic proximity to the Nevada Test Site would affect focus group responses, particularly perceived risk to health problems due to I-131 exposure.

The lower-exposure public groups were held in Philadelphia, PA, a lower-exposure state.

**Participant Recruiting Criteria**

Higher-exposure and lower-exposure individuals were recruited in advance of the focus groups. The screening questionnaire was designed to separate out people with a personal history of thyroid cancer or disease, individuals having an immediate family member with a history of thyroid disease, or individuals who self-reported that they were familiar with the issue of radioactive fallout from nuclear testing. The reason for excluding these individuals was the desire to talk with people for whom the I-131 issue is not already salient because of personal knowledge or experience. Clearly, any information campaign which is developed will have to address those who are already concerned about the issue, but it will also need to address the concerns and information needs of a potentially much larger number of people who will become aware (through the campaign) they may have a health risk due to I-131 exposure. It is this latter group – those not already knowledgeable or savvy about their potential risk – that the focus groups sought to speak with<sup>2</sup>.

In addition to the above criteria, the screening criteria ensured that the groups would contain a mix of women and men, a mix of races, and participants whose educational levels ranged from a high school graduate through college graduate. Copies of the recruitment screeners for the public and physician groups can be found in Attachment A.

	<b>Number of Participants (Higher- exposure)</b>	<b>Number of Participants (Lower- exposure)</b>	<b>Number of Participants (TOTAL)</b>
<b>Gender</b>			
Female	8	9	17
Male	9	7	16
<b>Race or Ethnicity</b>			
White	11	11	22
Black	4	5	9
American Indian	2	0	2
<b>Education</b>			
High school degree	3	5	8
Some college or technical school	8	8	16
College degree	5	3	8
Not specified	1	0	1

<sup>2</sup> It should be noted that earlier research, in the form of in-depth interviews, was conducted in November 1999 with advocates, scientific experts, and public health experts to obtain the viewpoint of those more cognizant of the I-131 health issue.

## **Topic Guide Development**

The moderator's guides for the general public and physicians' groups were designed to: a) measure initial awareness, knowledge and concern about the Nevada nuclear testing in the 1950s and 1960s; b) assess reactions to information presented during the groups about the I-131 exposure and its possible relationship to thyroid cancer and other non-cancerous thyroid disease; and c) gather opinions about the IOM screening recommendations as well as suggestions about implementing a communication campaign.

After participants were asked about their general awareness, knowledge and concern, they were shown a newspaper article from the *Chicago Sun-Times* dated August 2, 1997, along with a fact sheet and map illustrating exposure patterns across the U.S. They were then asked questions to elicit their reaction to the information. The newspaper article was selected from a sample of press coverage appearing after the release of the NCI report, "Estimated Exposures and Thyroid Doses Received by the American Public from Iodine-131 in Fallout Following Nevada Atmospheric Nuclear Bomb Tests." Potential articles were judged on their objectivity in communicating basic facts about the I-131 exposure and its potential relationship to thyroid cancer.

Each focus group was two hours in length and was conducted by a male moderator in his forties. Participants were paid for their participation. A copy of the topic guide, as well as the stimulus materials, can be found in Appendices B and C.

## **Limitations**

It should be noted that focus groups are a qualitative research technique which provide useful, detailed insights into the target audience's perceptions and motivations. Findings from qualitative research, however, cannot be projected to a larger audience. Rather, they are intended to provide guidance and direction in determining the best approach for communicating with key audiences about cancer risk research. In addition, findings from focus groups should be considered preliminary, laying the groundwork for further research with key target audiences.

## **III. KEY FINDINGS**

The remainder of this report presents the main findings from the focus groups. Findings related to the lower-exposure public, the higher-exposure public, and the physicians' groups are presented separately in order to give the reader an overall profile of each audience. However, it should be noted that there were many similarities across the three audience segments, particularly between the lower- and higher-exposure groups.

## A. Lower-Exposure Public

### Awareness, Knowledge & Concern **Before** Reading Newspaper Article and Fact Sheet

- Participants were concerned about a broad range of environmental concerns, including noise and water pollution, trash disposal, power plants, power lines, exhaust from vehicles, and “radiation” from computers.
- Participants were generally aware or had some vague recollection of the tests conducted at the Nevada Test site. The tests in Nevada were brought up by a few participants and then seemed to “ring a bell” for others who indicated a vague awareness of them.
- Several participants in each group knew the tests were conducted around the time of the 1950s or 1960s, but one thought tests had continued throughout the 1980s.
- Although participants were aware of the Nevada Test Site, they had little specific information about where their knowledge came from. No one knew about the NCI or IOM reports, or any other government reports on the issue. A couple of participants recalled seeing a movie about the Nevada Test Site called “Black Rain.” Other participants mentioned television, and one got more specific and mentioned documentaries on programs like *Nova* and *60 Minutes*.
- None of the participants had specific knowledge of different types of radiation or radiation-induced health effects. Most expressed health concerns about “deformities” or “genetic alterations.” One participant said the tests left people “crippled.” Another said it could cause skin problems similar to those that resulted from “Agent Orange.” Participants were particularly concerned about radiation-related illnesses being “passed through the genes.”
- Participants felt little or no concern that they would suffer any negative health effects from the Nevada tests. Most did not consider themselves to be at risk and felt it was more of a concern for other people. One participant said, “If I lived out there I’d be concerned.” Another said it was a problem for “those military people who were there at the time.”

### Concerns & Perceptions of Risk **After** Reading Newspaper Article and Fact Sheet

- Participants were provided with a newspaper article and additional facts regarding the association between the Nevada tests and thyroid cancer, risk factors that increase the likelihood of exposure, examples of higher and lower exposure areas, and possible associations between I-131 and two other types of non-cancerous thyroid disease: hypothyroidism and hyperparathyroidism.

Questions were then asked to gauge their level of concern, perceptions of risk, and opinions about actions that should be taken.

- The newspaper article and fact sheet raised levels of suspicion among many respondents. When asked about their initial reaction to the materials, many made comments like “there must be a big lawsuit coming” or referred to the newspaper article as a “scare tactic” no different from what they usually see in the news.
- Responses to the actual content of the material varied and included responses such as “frightening,” surprise about the fact that “everyone was exposed” or the problem was so “widespread” and feelings of “sadness because children were affected.” Others said the information was just “another thing to worry about.”
- Even after reading the newspaper article and fact sheet, participants still did not feel a high level of personal concern about their risk of thyroid cancer or other non-cancerous thyroid disease from the Nevada Test Site 1-131 exposure. A few said there were more important health risks to worry about like stroke and heart attack. One respondent who stated that she has hypothyroidism said the information made her wonder about the possible connection to the Nevada Site, but even she did not seem overly concerned. Another said that the radiation had a “short half life” and no longer posed a risk because it was “long gone.”
- When asked who is most at risk, participants thought the exposure posed a significant problem primarily to people living closer to the site. One said it was just not “plausible” that the radiation could cause problems in people thousands of miles away, and the rest of the group agreed. One person emphasized that she was still concerned about “other people being sacrificed.”
- Few participants seemed to make the connection that *they* are the people who were children at the time of the tests and therefore at some level of risk. The length of time that has passed since the tests occurred and the aging of those who may be at greater risk seemed to make this a difficult concept for people to comprehend.

#### Actions Needed

- While some participants said they would like more information about I-131 exposure from the Nevada Tests, few seemed to want it out of concern for their own health. Most wanted more information in order to clear up what they perceived as discrepancies in the newspaper article. More participants in the first group wanted additional information than did those in the second group. A few participants said they didn’t want more information because the issue “does not affect me” or “it is someone else’s problem.” One participant said it

was like “AIDS” in the sense that “sometimes you just don’t want to know if you have a problem or not.”

- Among the few who wanted more information, interest focused primarily on more conclusive information on the association between I-131 and development of thyroid cancer, why the study took 14 years, and why it was still going to take more time to know whether people are “going to get cancer from the tests or not.”
- In general, thyroid screening and the false positives associated with screening were difficult concepts for people to understand.
- Reactions to the IOM recommendation not to conduct screening were mixed. Reasons for not supporting the IOM recommendation included statements like “If there is anything the government can do, it should be done” or “It sounds like the government is copping out.” Participants who supported screening stressed the individual’s right to choose, rather than concern about whether they themselves should (or might elect to) be screened.
- Proponents of the IOM recommendation expressed other views. One participant said screening would just cause a “panic.” Another suggested screening in “limited areas.” And one, who inaccurately thought cancer could be detected by a blood test, kept asserting that blood tests should be conducted because they would not cause anyone any harm.
- Regardless of whether or not they agreed with the IOM screening recommendation, many thought each individual should have the final say in whether or not to be screened.

#### Educational Effort: Who Should Conduct It?

- Most participants thought government should be involved in an educational effort because the government was “responsible” for what happened. Many individuals thought the American Cancer Society would be appropriate. Other groups mentioned included the Red Cross, Greenpeace, local and city health centers and other medical groups. A few thought a combination of government and non-government groups would be best.
- When asked what organizations should not be involved, some said the federal government because it “caused the problem” and therefore would not be trusted. A few said that only the part of government which caused the problem (i.e., “the military”) should not be involved. One participant expressed distrust of the Environmental Protection Agency (EPA) and said that agency should not take part.

- When probed about the appropriateness of the National Cancer Institute’s involvement in an educational effort, participants said they had never heard of the institute. One participant said he thought the National Cancer Institute might be part of the National Institutes of Health, which may be associated with Johns Hopkins. Another participant then said the National Institutes of Health was a “research organization” that might be affiliated with that “group out of Atlanta,” prompting another respondent to mention the “CDC.”

### Ethical Considerations

- Participants were generally divided over whether there was good reason for conducting the Nevada bomb tests during the 1950s and 1960s. Some said the tests were necessary to ensure the safety of Americans during the Cold War. Others said that it is “never right to sacrifice anyone” and that the nuclear testing “should not have been done because of the problems it caused.” One participant also mentioned that the public could have been better protected from the radiation fallout at the time of the nuclear testing.
- Several participants expressed the opinion that “the government” (no agency specified) will always keep secrets and will never disclose the “full story” about nuclear testing pertaining to the past, present, or future.
- A couple of participants said that, in addition to being informed about the Nevada bomb testing and its resultant health effects, they would want assurance that nuclear testing would never happen again. Most of the other participants, however, took the viewpoint that the nuclear testing was over and that nothing could be done about it. In the words of one participant, “You can’t right a wrong.”

## **B. Higher-Exposure Public**

### Awareness, Knowledge & Concern **Before** Reading Article and Fact Sheet

- Participants expressed a broad range of general concerns about environmental hazards, from air and water pollution to lead paint, but provided few specifics. One participant said she was worried about “carcinogens...that are just everywhere nowadays.”
- Participants had little knowledge about nuclear testing in general or the Nevada Test Site in particular. A few participants could name locations in the U.S. where nuclear testing has been conducted, including “the Pacific,” “the West,” and the state of Nevada. A couple of these participants thought testing was still going on in these locations. Only a few recalled specific dates of the nuclear testing, expressing a vague recollection that “there was some nuclear testing that went on in the 1950s and 1960s.” Participants had no specific knowledge of different types of radiation or radiation-induced health effects from the

Nevada Test Site. Several expressed the view that the government has kept secrets about nuclear testing.

- Most participants could not recall the source of their information about the Nevada nuclear tests. A few vaguely recalled hearing something in “the news” or through “a documentary.” One participant, for example, recalled seeing a program on the History Channel that “had something to do with radiation exposure and military men.” Another said she thought the Discovery Channel might have run a documentary about the issue in the not too distant past. Another participant remembered some media coverage happening “when people were invited to watch some above-ground testing with special glasses.” Although she couldn’t recall the specifics, she characterized the event as “a real big deal.”
- Participants initially expressed little concern about suffering any negative health effects from the Nevada tests. One participant, describing the tests as “underground tests,” said he hoped the people conducting the tests now were protecting the environment to avoid any “contamination of the atmosphere or water supply.” Another participant responded by saying it was more important to be concerned about the effects of such tests on people and animals than the environment. Another emphasized that people should worry more about the present than the past. One Vermont participant expressed little concern because of living far away from the Nevada Test Site (Note: this perception later changed when participants saw a map illustrating that radiation fallout had been carried from the West to the East).

#### Perceptions of Personal Risks & Concerns **After** Reading Article and Fact Sheet

- Prior to seeing the article and fact sheet, participants were asked whether they remembered hearing anything in the news about two years ago. None remembered anything too specific. A couple of participants said they remembered hearing something, but they either could not recount the details or mentioned other events such as the nuclear testing in India and Pakistan.
- The newspaper article and fact sheet initially evoked an emotional reaction from some participants. Some Nebraska and Vermont participants said they were “shocked” and that the information made them feel “unsafe.” However, these emotional reactions dissipated quickly after the first few minutes of conversation.
- When asked who in the population is most at risk, most participants in Nebraska and Vermont immediately noted that people living in their own geographical areas were exposed, often referring to the color map of exposure levels. Comments like, “We are in the red” or “It is right over us” were fairly frequent during the course of the groups. Few participants, however, fully

comprehended that they might also be at risk because they were children at the time of testing and may have consumed contaminated milk.

- Despite some initial surprise over seeing the “red spots,” personal concern about developing cancer or non-cancerous thyroid disease was minimal. Most participants said they were not too concerned because:
  - They cannot change the past
  - They need to focus on the future
  - They question the credibility of some of the information in the article
  - They need more information to determine their true risk
  - It would be difficult to prove that any thyroid occurrence is actually caused by I-131 exposure
  - They have other more immediate health concerns such as heart disease, high blood pressure, prostate cancer, and breast cancer
  - They have other (non-health) concerns such as neighborhood violence
  - Thyroid problems have not surfaced thus far after routine checkups
  - The chances of getting thyroid cancer are small

As one participant explained, “I’m sure we probably read about these nuclear tests at one time but then forgot about them. It’s not the ‘here and now.’ The only reason we are thinking about it now is because you are making us think about it.”

- The issue of whether or not their children or spouses could be affected resonated more with participants than their own personal risk. A few asked questions about whether or not the effects of the exposure could be “passed down.” Another said, “If we were affected, that means someone in our family could be affected. How are offspring affected?” One person was worried that the exposure could have caused “a flaw in the [genetic] system that will keep getting passed down.” Another participant, still misunderstanding the time period of exposure, said she was glad her children don’t drink milk.
- A couple of participants said they would worry more about getting other types of cancers from the tests as opposed to developing thyroid problems. One participant asked, “Why does all this focus on the thyroid?” Another participant said he thought skin and bone cancer might be more likely problems based on what happened to the people who were bombed in Japan.

#### Actions Needed

- Throughout the discussions, participants raised more questions than personal concerns about the tests. Questions that have not already been mentioned include:
  - Were all the tests underground?
  - How long does the I-131 fallout last? What is the half-life?

- Can radiation sink into the ground? If so, can it rise back above the surface of the ground?
  - Was the information on the fact sheet compiled during the time of the testing or now?
  - Weren't the tests conducted in the desert so they wouldn't harm any people, plants or animals?
- The majority of participants agreed that a public information campaign would be appropriate. One participant said, "The more people know, the better." However, a couple individuals in the groups noted that it would be important to conduct the campaign carefully so people don't panic needlessly.
  - The majority of participants were not supportive of the IOM recommendation against screening. Most thought people should have the option to decide whether or not they needed to be screened. As one participant put it, "If they think it is relevant for them and they want to have it done, this should override the recommendation."
  - Several participants requested more information about how to get tested for thyroid disease, including where to go and what the test involves. One respondent suggested providing information about how to check one's own thyroid gland for lumps or problems.
  - A couple of participants were concerned that mandatory screening might cause a panic. This prompted one participant to suggest a campaign to inform doctors, so doctors could then decide whether or not a patient needed screening. A few others agreed with this recommendation.
  - A few participants focused on compensation issues related to screening. One thought the government needed to pay for the screening, particularly for people with no insurance, since it was the government that caused the problem. Another participant questioned the motive behind the IOM recommendation, saying insurance companies and medical doctors were probably trying to get out of paying for the screening. One participant said those who were hurt should get "a big check" from the government and then laughed.
  - A few participants thought that additional research was needed to develop a less-invasive screening test for thyroid cancer so more people can get screened without being harmed. Several also wanted more conclusive evidence showing that I-131 does cause health problems.

#### Educational Effort: Who Should Conduct It?

- Participants had few suggestions about who should conduct an educational effort. When probed, a few said the federal government should head the effort since it was responsible for the exposure; several specifically said the Public

Health Service and Centers for Disease Control and Prevention. In addition, a few participants indicated that their local governments should be responsible. Another participant said that “public health organizations that do things like vaccines” would be appropriate. Other organizations mentioned were Blue Cross, EPA, and the American Cancer Society.

- A few participants thought that people would be best educated by their own personal doctor. One participant suggested using an article in a medical society journal to educate physicians.
- When asked if the federal government needed to stay out of the effort, only a few participants commented. One said yes because “they lied once and they’ll do it again.” Another participant thought it was okay for the government to conduct the effort “because the people in government today are not the same people as 40 years ago.” Some participants felt that local government would be better, explaining that local government is more personal and less likely to withhold information.

#### Ethical Considerations:

- Ethical issues related to the Cold War were brought up at two different points during the focus groups -- at the very beginning when participants were asked for their concerns about consequences from the Nevada tests and then again after reading the article. A few participants said testing needed to be conducted for the U.S. to maintain the “balance of power.”
- Only a couple of individuals commented when asked why it was or why it was not important to educate the public about what happened. One participant said it was important because people were “exposed without their knowledge.” Another participant was unsure whether an educational effort was justified because “there was no real thyroid cancer outbreak.”

### **C. Primary Care Physicians**

#### Awareness, Knowledge & Concern **Before** Reading Article and Fact Sheet

- In general, physicians had vague memories but little actual knowledge about nuclear weapons tests conducted in the United States. A couple of participants said they had heard something about the issue in the last few years, but could not provide specifics. One participant said he remembered hearing that the government admitted to exposing people to radiation from some tests that were conducted in the 1950s and 1960s. Another said the government also admitted that workers at a test site in the 1950s were exposed to radiation. In addition, one participant recalled that soldiers were affected by tests conducted “when the atomic bombs were developed.” Another physician recounted his father

warning him as a child to refrain from eating snow, though he did not understand why. Only one participant in Vermont knew specific details about the Nevada testing, recalling that fallout resulted from tests conducted around 1946-1955, that one type of fallout was strontium 90, and that weather patterns carried fallout across the US.

- Participants mentioned the western United States, Nevada, Utah and New Mexico when asked about nuclear testing locations.
- Most participants could provide no details about specific types of radiation emitted from the tests or about specific health or non-health related consequences.
- Participants could not recall where they received information about the Nevada nuclear tests. One participant thought there might have been a program about the issue on the Discovery Channel at one time. Another recalled seeing a person on television who recounted watching atomic bomb tests and suffering health effects afterward.
- Participants expressed little concern about their patients having negative health consequences as a result of the Nevada Test Site exposures. One participant said, “I have no day-to-day concerns. It was many years ago.” Another participant thought that any serious consequences “would have shown up by now.”
- Only a few participants recalled having any patients ask them about negative health effects from exposure to nuclear fallout. One physician said that only a few of his patients have expressed concern, and he told them how to “watch for lumps on their thyroid and other symptoms.” Another participant said he had one patient with leukemia ask him if it might be related to the tests, but he couldn’t give the patient an answer. Another mentioned a patient with a brain tumor who once asked about the possible connection to radiation fallout. Other participants said their patients are concerned about and ask questions about cancer, but they don’t tend to relate it to the environment.
- Participants offered some explanations for why their patients are not concerned about radiation from the Nevada Test Site. One participant said patients are more concerned about negative health effects from nuclear power plants or disposal sites. A couple other participants said cellular telephones have recently become a big issue. Another physician noted that a majority of the population of Omaha, Nebraska, moved there from someplace else, thereby diluting the level of concern. Another said, “The testing was so long ago that people have forgotten about it; that’s what the government wants.”

## Awareness, Knowledge & Concern **After** Reading Article and Fact Sheet

- When asked about their initial reaction to the news article and fact sheet, participants responded with questions such as:
  - How did they determine radiation exposure for various areas of the country?
  - How was the data on dosage collected?
  - How can there be areas in the Central US where there was no exposure in between areas in the West and East where there was high exposure?
  - Do thyroid cancer rates map out similar to the radiation dosages displayed on the fact sheet?
  - What type of thyroid cancer might result from exposure to I-131?
  - Is there any scientific evidence that shows a direct link between I-131 exposure and thyroid diseases of any kind?
  - What's happening in Canada?
- Physicians repeatedly expressed a desire for sound scientific data about radiation dosage and links to negative health effects. Some even questioned the validity of the data that currently exists. One participant said he remembered a talk given by a lecturer at the National Cancer Institute who said the NCI exposure data was inaccurate and excluded some people who had higher-exposure because they drank milk from cattle. Another participant said she assumed any exposure information provided by the government would be wrong.
- The majority of participants said they would only be concerned for their patients if they received appropriate risk information indicating that there is a substantial increase in thyroid cancer. One participant said physicians would need to know if there was some type of evidence pointing to a "10% to 15% increase in thyroid cancer." Another asked, "Is this a hypothetical or a *true* risk?"
- The majority of participants agreed that they would not change the way they practice medicine based on the information they had just received and the ensuing discussion. Reasons for not changing their practice were as follows:
  - Thyroid cancer is rare (particularly in Nebraska and Vermont). One participant said she has only seen one case of thyroid cancer in twelve years.
  - Thyroid cancer is very survivable.
  - Most patients have other, more pressing health concerns such as breast cancer.
  - People are already "dying off from something else" by the time they get thyroid cancer.
  - The issue of I-131 has "fallen off the radar screen."

- There is not enough scientific evidence to warrant a high degree of concern.
- They do not want to unnecessarily alarm their patients with information that, to date is scientifically unfounded.
- They already routinely check for cancerous and non-cancerous thyroid problems during regular physical exams.

#### Actions Needed

- When asked what should be done to address I-131 exposure from the Nevada bomb testing, participants mentioned that the environment (air, water, and soil) should be tested and that nuclear testing should be permanently banned.
- Most participants thought an educational campaign targeting the public would be unnecessary and would only serve to cause undue public alarm. One participant said, “Too many things have been done in medicine before all the facts are in; we often put education before science.” Others agreed that nothing should be done until a meaningful increase in actual risk is demonstrated. A couple of participants said a public education campaign would cause “a mess.” Another stated that physicians are sometimes pressured by media coverage to do things just to put their patients’ concerns to rest.
- Nearly all participants agreed that a medical education campaign targeted at physicians would not be beneficial because, again, the information would not change the way they practice medicine. One participant thought some very basic information provided to physicians in higher-exposure areas may be useful just to put them “on alert.”
- All participants agreed with the IOM recommendation that screening at this time is unwarranted. All agreed that thyroid cancer is rare, very survivable and that false positives would result in more harm than good being done to patients. A couple of participants said they were also uncertain about the real benefits associated with early detection of thyroid cancer. One participant stated that checking everyone’s thyroid would be a “logistical public health nightmare.”

#### Educational Effort: Who Should Conduct It?

- If any educational effort were to be conducted, some participants thought the National Cancer Institute or the National Institute of Health would be the most appropriate sponsor because they are science-oriented. Others mentioned medical societies like the American Medical Association or their professional membership organizations such as the American Association of Family Physicians (AAFP).
- A couple of participants expressed concerns about sponsorship by advocacy organizations because they are not research-based and could be motivated by

self-interests. Some participants said the American Cancer Society should not be involved for this reason. When the Vermont participants were asked about the Society of Physicians for Responsible Medicine, all of them laughed and immediately discredited the group as being too politically extreme.

#### Ethical Considerations

- Ethical issues regarding why the nuclear tests were conducted and about individuals' right to know triggered little interest among physician participants.
- Most physicians thought it would be unethical to launch any type of educational effort before there is scientific data to support the necessity of such an effort. One participant said, "It would not be a public service announcement, it would be a public disservice announcement."

## **I-5 ATTACHMENTS**

**I-5-A. Participant Screening Questionnaires**

**I-5-B. Moderator's Topic Guides**

**Screener for Health Focus Groups with Public**

**Name:** \_\_\_\_\_

**Street Address:** \_\_\_\_\_

**City:** \_\_\_\_\_ **Zip Code:** \_\_\_\_\_

**Home Phone:** \_\_\_\_\_ **Work Phone:** \_\_\_\_\_

	City	Group	Facility	Date	Time
<input type="checkbox"/>	Philadelphia, PA	Lower risk	Focus Pointe	Dec. 7	6:00 PM
<input type="checkbox"/>	Philadelphia, PA	Lower risk	Focus Pointe	Dec. 7	8:00 PM
<input type="checkbox"/>	Omaha, NE	Higher risk	Midwest Survey	Dec. 13	5:30 PM
<input type="checkbox"/>	Burlington, VT	Higher risk	Action Research	Dec. 14	5:30 PM

**INTRODUCTION**

Hello, my name is \_\_\_\_\_, and I'm calling on behalf of a national, non-profit organization concerned about the health and well-being of Americans. We're talking to people to learn their opinions about some important environmental and health issues. I want to assure you that we're not selling anything and that your responses will be kept confidential.

May I speak to an adult in the household? (ONCE SPEAKING TO ADULT, REPEAT INTRODUCTION IF NECESSARY AND ASK:) Would you be willing to answer a few questions?

- Yes (CONTINUE)
- No (THANK AND TERMINATE)

1. What is your exact age? (RECORD EXACT RESPONSE AND CODE IN APPROPRIATE AGE SUBGROUP.)

**Age:** \_\_\_\_\_

- Younger than 39 (THANK AND TERMINATE)
- 39-47 (RECRUIT 4)
- 48-56 (RECRUIT 4)
- 57-64 (RECRUIT 4)
- 65 or older (THANK AND TERMINATE)

2. I'm going to read you a list of statements. For each one, please tell me whether you agree, neither agree nor disagree, or disagree with that statement. (READ.)

	<b>Agree</b>	<b>Neither Agree nor Disagree</b>	<b>Disagree</b>	<b>Don't Know/ Refused</b>
To protect the environment, people need to make big changes in the way they live.	1 (CONTINUE)	2 (CONTINUE)	3 (CONTINUE)	9 (CONTINUE)
I am concerned about the environment because of the potential harm to myself and my family.	1 (CONTINUE)	2 (CONTINUE)	3 (CONTINUE)	9 (CONTINUE)

3. Different areas of the country are more or less concerned about environmental issues. Thus, where we have lived can affect our opinions about the environment.

- a. I'm going to read you a list of states, and please tell me if you lived in any of these states between the time you were born and age 15. (READ STATES IN COLUMN "a" AND CHECK ANY STATES WHERE RESPONDENT LIVED BETWEEN THE AGES OF 0-15. MULTIPLE RESPONSES ACCEPTED.)

IF NO CHECKS ARE MADE IN COLUMN "a," CLASSIFY AS "LOWER RISK" AND SKIP TO Q3.

IF ONE OR MORE STATES ARE CHECKED, ASK Q2b FOR EACH STATE MENTIONED.)

- b. Did you live in [STATE] for at least 5 years? (USE COLUMN "b" TO CHECK ANY STATE(S) WHERE RESPONDENT LIVED AT LEAST 5 YEARS.)

CLASSIFY AS "HIGHER RISK" ANY RESPONDENT WHO HAS LIVED IN AT LEAST ONE OF THE LISTED STATES FOR AT LEAST 5 YEARS BETWEEN THE AGES OF 0-15.)

	<b>a. Lived in state from age 0-15</b>	<b>b. At least 5 years (ASK HIGHER RISK ONLY)</b>
(1) Arkansas	<input type="checkbox"/>	<input type="checkbox"/>
(2) Colorado	<input type="checkbox"/>	<input type="checkbox"/>
(3) Idaho	<input type="checkbox"/>	<input type="checkbox"/>
(4) Illinois	<input type="checkbox"/>	<input type="checkbox"/>
(5) Iowa	<input type="checkbox"/>	<input type="checkbox"/>
(6) Kansas	<input type="checkbox"/>	<input type="checkbox"/>

(7) Minnesota	<input type="checkbox"/>	<input type="checkbox"/>
(8) Missouri	<input type="checkbox"/>	<input type="checkbox"/>
(9) Montana	<input type="checkbox"/>	<input type="checkbox"/>
(10) Nebraska	<input type="checkbox"/>	<input type="checkbox"/>
(11) Nevada	<input type="checkbox"/>	<input type="checkbox"/>
(12) North Dakota	<input type="checkbox"/>	<input type="checkbox"/>
(13) Oklahoma	<input type="checkbox"/>	<input type="checkbox"/>
(14) South Dakota	<input type="checkbox"/>	<input type="checkbox"/>
(15) Utah	<input type="checkbox"/>	<input type="checkbox"/>
(16) Vermont	<input type="checkbox"/>	<input type="checkbox"/>
(17) Wisconsin	<input type="checkbox"/>	<input type="checkbox"/>
(18) Wyoming	<input type="checkbox"/>	<input type="checkbox"/>

4. Currently there are many issues about the environment under public debate, and different people are more or less familiar with them. I'm going to read you a list of specific environmental issues. For each one, please tell me whether you are "familiar," "neither familiar nor unfamiliar," or "not at all familiar" with that issue.

	<b>Familiar</b>	<b>Neither Familiar Nor Unfamiliar</b>	<b>Not at All Familiar</b>	<b>Don't Know/Refused</b>
Liquid waste from chemical plants.	1 (CONTINUE)	2 (CONTINUE)	3 (CONTINUE)	9 (CONTINUE)
Residual pesticides in the water supply.	1 (CONTINUE)	2 (CONTINUE)	3 (CONTINUE)	9 (CONTINUE)
Radioactive fallout from nuclear testing.	1 (THANK AND TERMINATE)	2 (CONTINUE)	3 (CONTINUE)	9 (CONTINUE)
Toxic air emissions from coal plants used to generate electricity.	1 (CONTINUE)	2 (CONTINUE)	3 (CONTINUE)	9 (CONTINUE)

5. Since this study is also about health, I'm going to ask you some health related questions. Have you ever been diagnosed with any of the following diseases ... (READ. DO NOT RECRUIT PARTICIPANTS WHO HAVE HAD THYROID DISEASE OR CANCER.)

- Respiratory disease (CONTINUE)
- Heart disease (CONTINUE)
- Thyroid disease (THANK AND TERMINATE)
- Cancer of any kind (THANK AND TERMINATE)

6. Have any of your immediate family members, that is, your parents, brothers or sisters, partner, or children, ever been diagnosed with any of the following diseases ... (READ. DO NOT RECRUIT PARTICIPANTS WHO HAVE HAD IMMEDIATE FAMILY MEMBER DIAGNOSED WITH THYROID DISEASE.)

- Respiratory disease (CONTINUE)
- Heart disease (CONTINUE)
- Thyroid disease of any kind, including thyroid cancer (THANK AND TERMINATE)
- Cancer of any other kind (CONTINUE)

7. I have a few more questions to ask for classification purposes. Which of the following best describes your race? (READ. RECRUIT 8 WHITE AND 4 NON-WHITE. NEBRASKA FACILITY MUST RECRUIT AT LEAST 2 AMERICAN INDIAN/ALASKA NATIVE.)

- White
- Black or African American
- Hispanic or Latino
- Asian
- Native Hawaiian/Other Pacific Islander
- American Indian /Alaska Native

8. Which of the following best describes your highest level of education? (READ.)

- Less than high school degree (THANK AND TERMINATE)
- High school degree (RECRUIT AT LEAST 3)
- Some college/technical school/associates degree (RECRUIT AT LEAST 3)
- 4-year college degree (RECRUIT NO MORE THAN 3)
- Some graduate school or more (THANK AND TERMINATE)

9. (NOTE GENDER:)

- Male (RECRUIT 6)
- Female (RECRUIT 6)

10. Have you ever been employed in any of the following settings?

	Yes	No	Don't Know/Refused
Medical or health setting	(THANK AND TERMINATE)	(CONTINUE)	(THANK AND TERMINATE)
Advertising or market research setting	(THANK AND TERMINATE)	(CONTINUE)	(THANK AND TERMINATE)

11. Have you ever participated in a focus group discussion or been paid to be part of a discussion group?

- Yes (CONTINUE)
- No (SKIP TO INVITATION)

12. How recently did you participate in the focus group?

- 6 months ago or less (THANK AND TERMINATE)
- More than 6 months ago (CONTINUE)

13. What did you talk about during the groups? (RECORD VERBATIM. DO NOT RECRUIT IF TOPICS WERE ABOUT THE ENVIRONMENT, ATOMIC BOMBS, NUCLEAR RADIATION, THYROID DISEASE, OR CANCER.)

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### INVITATION

Thank you for answering our questions. We'd like to invite you to take part in a focus group discussion of 8-10 people. We're talking to adults across the U.S. so that we can better plan for a national program focusing on the environment and the health of Americans. Your participation is very important to us. The focus group will take place [FACILITY, DATE, TIME] and will last about 2 hours. Participants will be paid \$\_\_\_\_\_ in cash for their time to take part. We'll also serve refreshments. Will you take part?

- Yes (CONTINUE)
- No (THANK AND TERMINATE)

Thanks for accepting our invitation. For contact purposes, may I get your name, address, and daytime and evening phone numbers? (RECORD INFORMATION ON FIRST PAGE)

We will send you a packet with a confirmation letter three to five days before the focus group is held. It will include directions to the location where the discussion will take place. It is very important that you arrive on time. If you need glasses for reading, please bring them to the discussion. If you have any questions or find out that you cannot attend the focus group, please call \_\_\_\_\_ at \_\_\_\_\_ so that we can find someone to take your place. Thank you for agreeing to take part in our study. We look forward to meeting you. Goodbye.

(NOTE TO RECRUITER: If respondents have any questions or concerns about the focus group topic, please contact Memi Miscally at Porter Novelli at 202-973-5845. Do NOT give her name to respondents.)

**Recruited by:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Confirmed by:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Screener for Health Focus Groups with Physicians**

**Name:** \_\_\_\_\_

**Street Address:** \_\_\_\_\_

**City:** \_\_\_\_\_ **Zip Code:** \_\_\_\_\_

**Home Phone:** \_\_\_\_\_ **Work Phone:** \_\_\_\_\_

	<b>City</b>	<b>Group</b>	<b>Facility</b>	<b>Date</b>	<b>Time</b>
<input type="checkbox"/>	Omaha, NE	Physicians	Midwest Survey	Dec. 13	7:30 PM
<input type="checkbox"/>	Burlington, VT	Physicians	Action Research	Dec. 14	7:30 PM

**INTRODUCTION**

Hello, my name is \_\_\_\_\_, and I'm calling on behalf of a national, non-profit organization concerned about the health and well-being of Americans. We're talking to physicians to learn their opinions about some important health issues. I want to assure you that we're not selling anything and that your responses will be kept confidential. May I speak to a physician? (ONCE SPEAKING TO PHYSICIAN, REPEAT INTRODUCTION IF NECESSARY AND ASK:) Would you be willing to answer a few questions?

- Yes (CONTINUE)
- No (THANK AND TERMINATE)

1 Which of the following best describes the kind of medicine you practice? (READ.)

- a. General practice (CONTINUE)
- b. Family practice (CONTINUE)
- c. General internist (CONTINUE)
- d. Other (THANK AND TERMINATE)

2. Are you a practicing physician—that is, do you see patients on a regular basis?

- a. Yes (CONTINUE)
- b. No (THANK AND TERMINATE)

3. Which of the following best describes how old the majority of your patients are? Are they ... (READ.)
- a. Younger than 18 (THANK AND TERMINATE)
  - b. 18-64 (CONTINUE)
  - c. 65 or older (THANK AND TERMINATE)
4. Do you see approximately equal numbers of males and females?
- a. Yes (CONTINUE)
  - b. No (THANK AND TERMINATE)
5. How many years have you been practicing medicine?
- a. Less than 5 years (THANK AND TERMINATE)
  - b. 5 years or more (CONTINUE)
6. How long have you been practicing in the state of Nebraska/Vermont?
- a. Less than 3 years (THANK AND TERMINATE)
  - b. 3 years or more (CONTINUE)
7. Are you employed full-time by a managed care company such as Kaiser Permanente or Aetna?
- a. Yes (RECRUIT NO MORE THAN 2)
  - b. No (CONTINUE)
8. Have you ever been employed in an advertising or market research setting?
- a. Yes (THANK AND TERMINATE)
  - b. No (CONTINUE)
9. Have you ever participated in a focus group discussion or been paid to be part of a discussion group?
- Yes (CONTINUE)
  - No (SKIP TO INVITATION)
10. How recently did you participate in the focus group?
- 6 months ago or less (THANK AND TERMINATE)
  - More than 6 months ago (CONTINUE)

11. What did you talk about during the groups? (RECORD VERBATIM. DO NOT RECRUIT IF TOPICS WERE ABOUT THE ENVIRONMENT, ATOMIC BOMBS, NUCLEAR RADIATION, THYROID DISEASE, OR CANCER.)

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**INVITATION**

Thank you for answering our questions. We'd like to invite you to take part in a focus group discussion of 8-10 people. We're talking to physicians across the U.S. so that we can better plan for a national program focusing on the health of Americans. Your participation is very important to us. The focus group will take place [FACILITY, DATE, TIME] and will last about 2 hours. Participants will be paid \$\_\_\_\_\_ in cash for their time to take part. We'll also serve refreshments. Will you take part?

- Yes (CONTINUE)
- No (THANK AND TERMINATE)

Thanks for accepting our invitation. For contact purposes, may I get your name, address, and daytime and evening phone numbers? (RECORD INFORMATION ON FIRST PAGE)

We will send you a packet with a confirmation letter three to five days before the focus group is held. It will include directions to the location where the discussion will take place. It is very important that you arrive on time. If you need glasses for reading, please bring them to the discussion. If you have any questions or find out that you cannot attend the focus group, please call \_\_\_\_\_ at \_\_\_\_\_ so that we can find someone to take your place. Thank you for agreeing to take part in our study. We look forward to meeting you. Goodbye.

(NOTE TO RECRUITER: If respondents have any questions or concerns about the focus group topic, please contact Memi Miscally at Porter Novelli at 202-973-5845. Do NOT give her name to respondents.)

**Recruited by:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Confirmed by:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Moderator's Guide for I-131 Focus Groups with the General Public**

**I. EXPLANATION AND INTRODUCTIONS (10 minutes)**

1. **Thanks** for coming today. Your participation is very important to us; your insights will help us develop a national public health program.
2. My name is \_\_\_\_\_ and I work for \_\_\_\_\_, an independent research company. I do not work with the sponsor of these groups, so please feel that you can give me your **honest** opinions—**positive and negative**.
3. What we're doing today is called a focus group. You may have guessed that all of you **live in the Philadelphia/Omaha/Burlington area**, and for the next 2 hours, we're going to talk about the **environment and your health**.
4. I'm interested in all of your ideas, comments, and suggestions. There are **no right or wrong answers**. It's important that I hear what everyone thinks, so please speak up, especially if your view is different from something someone else says.
5. We'll **audio-tape** and **video-tape** this discussion. In addition, program planners sitting behind this mirror will **observe**. We're taking these steps because everything you say is important to us, and we want to make sure we don't miss any comments.
6. Please **talk one at a time** and in a voice at least as **loud** as mine so that the recording equipment can pick up everything that is said.
7. Later, we'll go through all of your comments and use them to write a report. Remember that all of your comments are **confidential**. Your name will not be used in the report.
8. If you need to use the bathroom, please go **one at a time**.
9. Please turn off any **beepers, pagers, or cell phones** that you may have.
10. Before we begin the discussion, please **introduce** yourself. Please tell us your:
  - First name
  - Number of years you've been living in the Philadelphia/Omaha/Burlington area

**II. GENERAL AWARENESS, KNOWLEDGE, AND CONCERN (25 minutes)**

1. What are some of the environmental issues that you've heard about, if any at all? Where does nuclear radiation fit into the list of issues? (SPEND ONLY A MINUTE AND THEN MOVE ON)
2. What words, images, or feelings come to mind when I say the word nuclear radiation?
3. What, if anything, have you heard about nuclear weapons tests conducted in the United States? (TRY TO OBTAIN PLACES AND DATES OF ATOMIC BOMB TESTING AND TYPES OF NUCLEAR RADIATION RELEASED)

About 100 atomic bomb tests were conducted in the state of Nevada during the 1950s and 1960s. These tests released different types of radioactive material into the atmosphere. The rest of this discussion will pertain to these tests and the nuclear radiation fallout.

4. Have you heard anything about these tests? IF YES: What have you heard about these tests?

PROBE: Types of radiation released?

IF AWARE OF MORE THAN ONE MATERIAL: Are you concerned about some of the radioactive substances more than others? What makes you more concerned?

5. What, if any, questions do you have about these tests and the nuclear radiation released?

PROBE: How about health related consequences?

How about any non-health related consequences?

6. What, if any, concerns do you have about these tests and the nuclear radiation released?

PROBE: How about health-related consequences?

How about any non-health-related consequences?

7. From what sources have you gotten any information you might have? IF MEDIA: From what sources did the media get their information? For example, do you remember any specific individuals, experts or organizations that the media quoted or mentioned? (PROBE FOR AWARENESS OF NCI AND IOM REPORTS)

### III. REACTIONS AFTER SEEING ARTICLE (30 minutes)

Now, I'm going to give you a newspaper article (or fact sheet) to read about the Nevada nuclear bomb tests. Some of this information you may already know. Please read all the information carefully as we will be discussing this material in detail next.

*I'd like to mention one other thing. The newspaper article mentions that people were most likely to be exposed to I-131 radiation if they lived around Nevada, specifically in the states of Montana, Idaho, Utah, South Dakota, and Colorado. FOR NEBRASKA GROUPS: Please note that Nebraska is near this region and was also a highly exposed state. FOR VERMONT GROUPS: Please note that Vermont was another highly exposed state, because weather patterns carried the radiation north and east of Nevada.*

1. What are your initial reactions to this article and the additional information I've given you? (LEAVE OPEN DISCUSSION AROUND EMOTIONS/FEELINGS OR THE INFORMATION ITSELF)
2. When might people living in the U.S. have been affected by I-131? During the 1950s and 1960s when the tests were conducted? Now, in the 1990s? In the future, when it's 2000 and beyond?

You may or may not have a thorough understanding of thyroid cancer. To ensure that all of us have the information we need to get through tonight's discussion, I'd like to give you some information about thyroid cancer. (SHOW BOARD)

#### **Thyroid Cancer**

*This type accounts for 1% of all cancers.*

##### **Symptoms:**

Lump in the neck (most common) \_\_\_\_\_

Tight or full feeling in the neck \_\_\_\_\_

Difficulty breathing or swallowing \_\_\_\_\_ (less common)

Hoarseness \_\_\_\_\_

Swollen lymph nodes \_\_\_\_\_

3. Based on the information provided, who do you think is at risk for thyroid cancer from the Nevada tests? What are the major factors that make someone more at risk?

PROBE: Different geographical areas  
Age  
Milk consumption

4. How concerned are you personally about your risk for developing thyroid cancer as a result of these tests and exposure to the fallout? What makes you particularly concerned?

At the present time, there is no scientific evidence that the amount of I-131 exposure that people received from the Nevada Site is related to any other types of thyroid disease besides thyroid cancer. Research is being conducted to find out if the amount of I-131 exposure people received could be related to other thyroid disorders. Here are descriptions of SOME of the symptoms of two disorders that some people have claimed could be related to the I-131 exposure from the Nevada Test Site. (SHOW BOARD)

### **Hypothyroidism**

A condition in which the thyroid gland becomes underactive. The thyroid gland is located in the neck and affects heart rate, blood pressure, body temperature, metabolism, and childhood growth and development.

Symptoms:

Lack of Energy, Tiredness  
Depression  
Feeling Cold  
Dry, Coarse, Itchy Skin  
Dry, Coarse, Thinning Hair  
Muscle Cramps  
Constipation  
Weight Gain

### **Hyperparathyroidism**

A condition in which the parathyroid glands become overactive. The parathyroid glands are located next to the thyroid and affect the body's supply of calcium.

Symptoms:

Calcium Deposits  
Osteoporosis or Loss of Bone Density  
Muscular Weakness  
Nervousness  
Irritability  
Racing Heart  
Increased Perspiration  
Thinning of Skin  
Fine, Brittle Hair  
Frequent Bowel Movements  
Weight Loss

5. How concerned are you personally about your risk of developing any of the non-cancerous thyroid diseases I mentioned as a result of the Nevada tests? What makes you concerned?
6. In comparison to other types of health risks like heart disease or stroke, how concerned are you about getting thyroid cancer? How about non-cancerous thyroid diseases?
7. Is the information I provided you with confusing or clear? What would need to be done to make it easier to understand?
8. Would you like more information to determine how important a health issue the I-131 fallout from the Nevada tests is for you? Why or why not? What information?

#### **IV. EDUCATIONAL CAMPAIGN (40 minutes)**

1. What, if anything, do you think should be done about I-131 and any potential health risks?

PROBE:       Public Education  
                  Screening  
                  Compensation for Medical Expenses

2. Who should be responsible? (IF GOVERNMENT: PROBE FOR LOCAL, STATE OR FEDERAL, IF FEDERAL PROBE FOR AGENCIES) What about these entities makes them responsible?
3. What are your opinions about this recommendation?

*In 1999, the Institute of Medicine (IOM), a panel of experts from the National Academy of Scientists congressionally mandated to advise the federal government on medical issues, released medical screening recommendations for people who may have been exposed to I-131 released from the Nevada Tests. The panel concluded that the available science does NOT warrant medical screening tests within the general population or within any subgroups of the population.*

*The reasoning behind this recommendation is that very few people get thyroid cancer and those that do are very likely to be cured. In addition, the current method of thyroid cancer screening can produce false positives, meaning that people may be inaccurately diagnosed with thyroid cancer and consequently subjected to unnecessary fear, medication and surgery.*

*For these reasons, the IOM felt that the evidence suggests that more harm to the public than good would be done with screening.*

*Do you think there is a need for a public information campaign to educate people about their possible exposure to I-131 and the potential risks associated with that exposure?*

4. In your opinion, who needs to be informed about the possible risks associated with the I-131 emitted from the nuclear tests? Should everyone in the U.S. be the focus, or should information be targeted to those who may have been more exposed? Why?
5. IF GENERAL PUBLIC: What information do you think the general public needs to get? IF THOSE MORE EXPOSED: What information do you think people who were heavily exposed need to get?
6. What information do you think you personally need about the I-131 emitted from the Nevada tests and its possible health effects?
7. What do you think would be the most effective ways to get this information to people?

PROBE:        Television/radio  
                  Newspapers/magazines  
                  Conferences/meetings  
                  Interpersonal communication  
                  Brochures  
                  Internet

8. What health care professionals, if any, do you think should be involved in reaching out to people? What about these people makes them important?
9. If an educational effort is to be launched, some organization or organizations need to be responsible for implementing the effort. Are there any organizations or types of organizations that you particularly trust to implement these efforts? What about those organizations makes you trust them?

(PROBE: Government agencies, non-profit organizations or advocacy groups?)

10. Are there any organizations or types of organizations that should NOT be involved in implementing these efforts? What makes them untrustworthy?
11. Do you think people will trust a public education campaign that is conducted by the federal government? Would it matter what specific federal agencies are involved? Why?

**V.     ADDITIONAL CONSIDERATIONS (10 minutes)**

1.     In your opinion, what are the **main** reasons why the public should be informed about the Nevada Test Site, I-131 exposure, and any potential health problems?

IF NECESSARY, PROBE: Some people think the government has an obligation to let people know about the exposure from the Nevada Test Site primarily because some people could have been harmed by the fallout. Other people think that regardless of the level of harm people experienced, the government has an obligation to inform the public because the public has a right to know about its government's actions. Which of these best represents your views? Why?

2. Based on everything you know now, what if anything, would justify the Nevada atomic bomb testing?

IF NECESSARY, PROBE: People were exposed to radioactive material while nuclear weapons were being tested for the purpose of defending our country. What do you think about this?

3. Do you think the government would have intentionally exposed people to radioactive material or do you think the government probably didn't know about the negative health effects that may be associated with the exposures until after the tests were already conducted?
4. What else do you think needs to be done to address the issue of I-131 fallout from the Nevada Test Site that we have not talked about?
5. How do these ethical considerations impact your trust in the government as a whole and different government agencies?
6. Is there anything else that you think needs to be done to address the issue of I-131 fallout from the Nevada Test Site that we have not talked about?

## **VI. CLOSING (5 minutes)**

1. CHECK WITH OBSERVERS FOR ADDITIONAL QUESTIONS.
2. Those are all of the questions I have. Do you have any final comments?
3. Thanks for your participation today. I have some bookmarks that can provide you with current information about what we've discussed this evening. Feel free to take one before you leave.

Moderator's Guide for I-131 Focus Groups with Physicians

**I. EXPLANATION AND INTRODUCTIONS** (10 minutes)

1. **Thanks** for coming today. Your participation is very important to us; your insights will help us develop a national public health program.
2. My name is \_\_\_\_\_ and I work for \_\_\_\_\_, an independent research company. I do not work with the sponsor of these groups, so please feel that you can give me your **honest** opinions – **positive and negative**.
3. What we're doing today is called a focus group. You may have guessed that all of you are **primary care physicians**, and for the next 2 hours, we're going to talk about the **environment and the health of your patients**.
4. I'm interested in all of your ideas, comments, and suggestions. There are **no right or wrong answers**. It's important that I hear what everyone thinks, so please speak up, especially if your view is different from something someone else says.
5. We'll **audio-tape** and **video-tape** this discussion. In addition, program planners sitting behind this mirror will **observe**. We're taking these steps because everything you say is important to us, and we want to make sure we don't miss any comments.
6. Please **talk one at a time** and in a voice at least as **loud** as mine so that the recording equipment can pick up everything that is said.
7. Later, we'll go through all of your comments and use them to write a report. Remember that all of your comments are **confidential**. Your name will not be used in the report.
8. If you need to use the bathroom, please go **one at a time**.
9. Please turn off any **beepers, pagers, or cell phones** that you may have.
10. Before we begin the discussion, please **introduce** yourself. Please tell us your:
  - First name
  - Number of years you've been practicing in the Omaha/Burlington area

**II GENERAL AWARENESS, KNOWLEDGE, AND CONCERN (25 minutes)**

1. What are some of the environmental issues that you've heard about, if any at all? Where does nuclear radiation fit into the list of issues? (SPEND ONLY A MINUTE AND THEN MOVE ON)
2. What words, images, or feelings come to mind when I say the word nuclear radiation?
3. What, if anything, have you heard about nuclear weapons tests conducted in the United States? (TRY TO OBTAIN PLACES AND DATES OF ATOMIC BOMB TESTING AND TYPES OF NUCLEAR RADIATION RELEASED)

About 100 atomic bomb tests were conducted in the state of Nevada during the 1950s and 1960s. These tests released different types of radioactive material into the atmosphere. The rest of this discussion will pertain to these tests and the nuclear radiation fallout.

4. What, if anything, have you heard about these Nevada bomb tests conducted during the 1950s and 1960s and the resulting nuclear radiation fallout?

PROBE: Types of radiation released?

IF AWARE OF MORE THAN ONE MATERIAL: Are you concerned about some of the radioactive substances more than others? What makes you more concerned?

5. What, if any, questions do you have about these tests and the nuclear radiation released?
6. What, if any, concerns do you have about these tests and the nuclear radiation released?

PROBE: Any concerns about health or non-health related consequences?

7. Have you and your patients discussed the Nevada bomb tests and health problems resulting from the I-131 fallout radiation? If so, how often? What have you talked about? Who typically initiates the conversation—you or your patients?
8. Relative to their other health concerns, how concerned are your patients about experiencing health problems as a result of being exposed to I-131?
9. How concerned about I-131 health effects is your community in general?
10. From what sources have you gotten any information you might have? IF MEDIA: From what sources did the media get their information? For example, do you remember any specific individuals, experts or organizations that the media quoted or mentioned? (PROBE FOR AWARENESS OF NCI AND IOM REPORTS)

**III REACTIONS AFTER SEEING ARTICLE (30 minutes)**

Now, I'm going to give you a newspaper article and fact sheet to read about the Nevada nuclear bomb tests. The article actually appeared in newspapers across the country, perhaps even in your area. Some of this information you may already know. Please read all the information carefully as we will be discussing this material in detail next. (SHOW ARTICLE)

I'd like to mention one other thing. The newspaper article mentions that people were most likely to be exposed to I-131 radiation if they lived around Nevada, specifically the states of Montana, Idaho, Utah, South Dakota, and Colorado. **FOR NEBRASKA GROUPS:** Please note that Nebraska is near this region and was also a highly exposed state. **FOR VERMONT GROUPS:** Please note that Vermont was another highly exposed state, because weather patterns carried the radiation north and east of Nevada.

1. What are your initial reactions to this article and the additional information I've given you? (LEAVE OPEN DISCUSSION AROUND EMOTIONS/FEELINGS OR THE INFORMATION ITSELF)
2. When might people living in the U.S. have been affected by I-131? During the 1950s and 1960s when the tests were conducted? Now, in the 1990s? In the future, when it's 200 and beyond?

You may or may not have a thorough understanding of thyroid cancer. To ensure that all of us have the information we need to get through tonight's discussion, I'd like to give you some information about thyroid cancer. (SHOW BOARD)

**Thyroid Cancer**  
This type accounts for 1% of all cancers.

**Symptoms:**

Lump in the neck (most common)	_____	} (less common)
Tight or full feeling in the neck	_____	
Difficulty breathing or swallowing	_____	
Hoarseness	_____	
Swollen lymph nodes	_____	

PROBE: Different geographical areas  
Age  
Milk consumption

4. Given the identified risk factors, how concerned are you that any of your current patients may be at risk of developing thyroid cancer?

At the present time, there is no scientific evidence that the amount of I-131 exposure that people received from the Nevada Site is related to any other types of thyroid disease besides thyroid cancer. Research is being conducted to find out if the amount of I-131 exposure people received could be related to other thyroid disorders. Here are descriptions of SOME of the symptoms of two disorders that some people have claimed could be related to the I-131 exposure from the Nevada Test Site. (SHOW BOARD)

### **Hypothyroidism**

A condition in which the thyroid gland becomes **underactive**. The thyroid gland is located in the neck and affects heart rate, blood pressure, body temperature, metabolism, and childhood growth and development.

Symptoms:

Lack of Energy, Tiredness  
Depression  
Feeling Cold  
Dry, Coarse, Itchy Skin  
Dry, Coarse, Thinning Hair  
Muscle Cramps  
Constipation  
Weight Gain

### **Hyperparathyroidism**

A condition in which the parathyroid glands become **overactive**. The parathyroid glands are located next to the thyroid and affect the body's supply of calcium.

Symptoms:

Calcium Deposits  
Osteoporosis or Loss of Bone Density  
Muscular Weakness  
Nervousness  
Irritability  
Racing Heart  
Increased Perspiration  
Thinning of Skin  
Fine, Brittle Hair  
Frequent Bowel Movements  
Weight Loss

5. Do you believe these concerns about non-cancerous thyroid conditions are warranted by available information on I-131 and its effects on human health? Or are these concerns needlessly raised?

6. Additional research into the non-cancerous thyroid conditions due to I-131 exposure is being conducted. How worthwhile do you think this effort is?
7. How concerned are you about your patients' risk of developing any of the non-cancerous thyroid disease I mentioned as a result of the Nevada tests? What makes you concerned?
8. In comparison to other types of health risks, how concerned are you about your patients' risk for thyroid cancer as a result of I-131 exposure? Non-cancerous thyroid diseases? (DETERMINE WHETHER PARTICIPANTS ARE MORE CONCERNED ABOUT THYROID CANCER OR NON-CANCEROUS THYROID DISEASES)
9. What other information would you need to make a good determination of whether you have patients that are at heightened risk for I-131 related problems?

**IV. EDUCATION CAMPAIGN (45 minutes)**

1. What, if anything, do you think should be done to educate the public about I-131 and potential health risks?

PROBE:           Public education  
                       Screening  
                       Compensation for medical expenses (RESERVE ANY  
                       DISCUSSION AROUND ADDITIONAL TYPES OF  
                       COMPENSATION FOR SECTION V)

2. Who should be responsible for implementing these efforts? (IF GOVERNMENT: PROBE FOR LOCAL, STATE OR FEDERAL, IF FEDERAL PROBE FOR AGENCIES) What about these entities makes them responsible?

*In 1999, the Institute of Medicine (IOM), a panel of experts from the National Academy of Scientists congressionally mandated to advise the federal government on medical issues, released medical screening recommendations for people who may have been exposed to I-131 released from the Nevada Tests. The panel concluded that the available science does NOT warrant medical screening tests within the general population or within any subgroups of the population.*

*The reasoning behind this recommendation is that very few people get thyroid and those that do are very likely to be cured. In addition, the current method of thyroid cancer screening can produce false positives, meaning that people may be inaccurately diagnosed with thyroid cancer and consequently subjected to unnecessary fear, medication and surgery.*

*For these reasons, the IOM felt that the evidence suggests that more harm than good to the public would be done with screening.*

3. What are your opinions about this recommendation? How important is it to educate the public about I-131 and the potential health risks?
4. In your opinion, who needs to be informed about the possible risks associated with the I-131 emitted from the nuclear tests? Should everyone in the U.S. be the focus, or should information be targeted to those who may have been more exposed? Why?
5. IF GENERAL PUBLIC: What information do you think the general public needs to get?

IF THOSE MORE EXPOSED: What information do you think people who were heavily exposed need to get?

6. What role, if any, should physicians play in a campaign to educate the public about I-131 health implications?
7. Based on what you know now, is it important for you to inform your patients? Why or why not?
8. What barriers might you encounter? What support might you need?

PROBE:           Time  
                      Money  
                      Tips on how to talk to patients  
                      Materials (What types?)  
                      Further information

9. What other types of health care professionals should be involved in an educational effort?
10. If an educational effort is to be launched, some organization or organizations need to be responsible for implementing the effort. What organizations or types of organizations would you particularly trust to implement these efforts? What about those organizations makes you trust them?

PROBE:           Government agencies  
                      Non-profit organizations  
                      Advocacy groups  
                      Medical associations

11. What organizations or types of organizations should NOT be involved in implementing these efforts? What makes them untrustworthy?
12. How much do you think people will trust a public education campaign that is conducted by the federal government? What specific federal agencies should be involved? Why?

**V. ADDITIONAL CONSIDERATIONS (5 minutes)**

1. In your opinion, what are the **main** reasons why the public should be informed about the Nevada Test Site, I-131 exposure, and any potential health problems?

IF NECESSARY, PROBE: Some people think the government has an obligation to let people know about the exposure from the Nevada Test Site primarily because some people could have been harmed by the fallout. Other people think that regardless of the level of harm people experienced the government has an obligation to inform the public because the public has a right to know about its government's actions. Which of these best represents your views? Why?

2. Based on everything you know now, what if anything, would justify the Nevada atomic bomb testing?

IF NECESSARY, PROBE: People were exposed to radioactive material while nuclear weapons were being tested for the purpose of defending our country. What do you think about this?

3. Do you think the government would have intentionally exposed people to radioactive material or do you think the government probably didn't know about the negative health effects that may be associated with the exposures until after the tests were already conducted?
4. What else do you think needs to be done to address the issue of I-131 fallout from the Nevada Test Site that we have not talked about?

**VI. CLOSING (5 minutes)**

1. CHECK WITH OBSERVERS FOR ADDITIONAL QUESTIONS.
2. Those are all of the questions I have. Do you have any final comments?
3. Thanks for your participation today. I have some bookmarks that can provide you with current information about what we've discussed this evening. Feel free to take one before you leave.

## Additional Facts

- Thyroid cancer accounts for 1% of all cancers.
- Some areas near the Nevada Test Site were highly exposed to I-131 radiation. Other areas farther from Nevada also were highly exposed because weather patterns carried the radiation north and east of Nevada.

Study Estimating Thyroid Doses of I-131 Received by Americans from Nevada Atmospheric Nuclear Bomb Tests

**Figure 1**  
**Per capita thyroid doses resulting from all exposure routes from all tests**

