
Appendix I

Communications Materials

Contents: This appendix provides the communications plan for the 131I/NCI Communications Project (I.1), information pertaining to the January 2000 NCI/CDC workshop entitled “I-131 Fallout from NTS: Informing the Public” (I.2–I.5), a description of tools typically utilized for communications planning materials (I.6), and a description of the campaign implementation and evaluation (I.7). Although the campaign is ongoing, these materials are provided for historical reference.

I.1 Outline for I-131 Communications Plan

I.1.1 Situation Analysis

- ◆ In the 1950s and early 1960s, the United States Government conducted almost 100 atmospheric nuclear bomb tests in the Nevada Test Site (NTS), releasing iodine-131 (I-131) and other radionuclides into the atmosphere. In the same period, there were about a dozen underground tests where some atmospheric release of radioactive material was possible. Most of the current scientific information on the subject relates to I-131, which concentrates in the thyroid gland and may be linked to thyroid cancer and other thyroid disorders. Although I-131 released from the NTS has decayed and is no longer present in the environment, at the time of testing, radioactivity was deposited on soil and vegetation throughout the country. Doses of radiation varied widely according to geographic area based on wind and rainfall patterns. Some areas received minimal exposure, while others, sometimes far from the test sites, received higher radiation exposures. After cows and goats consumed the contaminated vegetation, I-131 appeared in the milk produced by those animals.
- ◆ Exposure to I-131 may increase the risk of thyroid cancer and other thyroid disorders. People who drank milk, particularly children, are estimated to have received higher

than average doses of I-131 from the contaminated milk which have been associated with a higher risk for thyroid cancer and other thyroid diseases. Those who were or may have been exposed to I-131 should be informed of their exposure and the potential health effects so that they can consult with a health care provider for monitoring of their thyroid and possible screening. Those who do not have a health care provider should be informed about existing resources that may be able to assist them. Although a diagnosis of thyroid cancer and other non-cancerous conditions must be treated seriously, thyroid cancer is relatively uncommon and is not normally fatal, particularly with early detection and proper treatment.

- ◆ Congress mandated that the National Cancer Institute (NCI) assess the public health impact of the NTS on the American people. Since the publication of NCI's report on estimated exposures and thyroid doses in 1997, an Institute of Medicine committee reviewed and assessed the validity of the report and made recommendations to the government on how to communicate with the public about I-131 exposure from the NTS.
- ◆ NCI has taken the lead role for the Federal Government in the development of a communications plan related to I-131 fallout exposure from NTS. In January 2000, a communications workshop – sponsored by NCI and the Centers for Disease Control (CDC) – was held to gather input from citizens, consumer advocates, physicians, scientists, health department representatives, and other government officials on the best ways to inform the public and health professionals about I-131 exposure. One outcome of the workshop was the formation of a Communications Development Group (CDG), made up of representatives from community groups, health professionals, and concerned citizens, to offer guidance to NCI staff with the development of an NTS I-131 communications plan.
- ◆ Although the current communications plan focuses on I-131 exposure from NTS, there are other sources of I-131 exposures in specific areas around the country. There are four additional nuclear reactor sites in the United States that released I-131 into the atmosphere that may have resulted in multiple I-131 exposures to nearby communities. These sites include the following: Hanford Nuclear Reservation in

Richmond, Washington; Idaho National Engineering and Environmental Laboratory in Idaho Falls, Idaho; Oak Ridge National Laboratory in Oak Ridge, Tennessee; and Savannah River Site in Aiken, South Carolina. There is a level of uncertainty associated with the health effects from multiple exposures to I-131, although it is likely that the health impact of multiple exposures may be more significant than a single dose exposure. In order to address this issue, the current plan will include messages that individuals who lived in and around the aforementioned areas may have received exposure to I-131 from NTS as well as from other sources, and that these multiple I-131 exposures may pose resultant health risks.

- ◆ The feasibility of collecting scientific information about the health effects from global fallout and the levels of exposure from other radionuclides is currently being assessed. If there is agreement on public health outreach concerning multiple I-131 exposures and the levels of exposure from other radionuclides, this communications planning process may be used as a blueprint for future communications efforts.

I.1.2 Challenges and Opportunities

Challenges

- ◆ The credibility of the Federal Government, as a whole, has been compromised on the radiation issue. Therefore, the Federal Government should work with third parties in providing informational messages. In addition, credibility issues vary across government agencies and according to individuals' experiences with particular agencies on issues related to radiation. The general public is largely unaware of radiation exposure that occurred nearly 50 years ago and may experience a variety of emotions when they learn about potential exposure risks. Some people may be justifiably concerned about their exposure and the risks that result from it; others may be unnecessarily frightened; some may question why the government conducted the tests, exposing the public to I-131, while others may not have any interest in the issue. For those who have suffered from thyroid illness or have loved ones who have suffered, the new information may also create a sense of closure and provide some answers. Balancing the need to inform people while creating an appropriate level of

concern with the possibility of creating a significant level of unwarranted anxiety will be an ethical and communications challenge.

- ◆ The I-131 issue is competing with many other health issues that may be perceived to be more current and pressing among health care providers and members of the general public.
- ◆ I-131 exposure and the potential health implications are complex issues marked by scientific and medical uncertainties, and are difficult to communicate to the public in non-scientific terms. Communications about this issue must include honest descriptions of the uncertainties about exposure and potential doses, and honest descriptions of uncertainties related to assessing past exposure and potential doses received. Such communication can help build trust or may exacerbate a lack of trust if it appears to “waffle” on the uncertainties. In addition, because these exposures were *involuntary* and not fully disclosed for many years, reactions to related information will likely be more negative. Therefore, risk communication principles should be employed throughout the program.
- ◆ Communications efforts involving American Indian audiences will have to be sensitive to a heightened distrust of governmental messages and must be coordinated with other government agencies based on the unique government-to-government relationship with American Indian tribes.

Opportunities

- ◆ There are strong citizen networks and health professional organizations in the communities that may support implementation of specific strategies in a comprehensive communications plan. These networks include advocacy groups, public health networks, and Internet communications networks.
- ◆ CDG involvement will ensure that the communications plan is thorough and directed to the most appropriate audiences. The CDG can also help brainstorm possible organizational structures through which the messages can be disseminated.

- ◆ NCI has received a positive response to its efforts to involve the advocacy and the health professional communities at the earliest possible stages in the development of communications surrounding I-131.
- ◆ Other agencies and organizations are involved in addressing I-131 exposure issues. For example, ACERER (Advisory Committee for Energy-Related Epidemiological Research) held a meeting to hear public input on the need for thyroid screening for those exposed to I-131 from the NTS in June 2000.
- ◆ The research group led by Annette O'Connor has expressed an interest in developing a screening decision aid that may be one tool in the implementation of this communications plan. One activity of the plan, therefore, could be to work with this group to create and review such a tool. The feasibility will be explored for developing a decision tree that could help those without health insurance find existing programs that might assist them.

I.1.3 Communication Goals

- ◆ Individuals who may have been exposed to I-131 radiation from the NTS will seek the appropriate guidance of health care providers about the potential health effects of exposure and what can be done to address these effects.
- ◆ Healthcare providers will understand the risk of I-131 exposure and the potential health effects and will be able to advise patients regarding their individual health status, potential risks, and options.

I.1.4 Communication Objectives

- ◆ To communicate to the intended audiences understandable information about the release of I-131 from the NTS, the potential health effects of exposure, and what exposed individuals can do about those effects.
- ◆ To engage intended audiences in the issue and encourage individuals who are concerned about I-131 exposure to consult with a health care provider or other sources of health services.

- ◆ To inform health care professionals about the possible health effects of I-131 exposure and to provide information to assist them in working with patients who are concerned about exposure.

I.1.5 Intended Audiences

The Public

- ◆ Individuals aged 40 and older, particularly those who lived in areas of highest exposure and consumed milk, with special emphasis on underserved populations, including minority groups and those with limited access to the health care delivery system.

Health Care Providers

- ◆ Primary care providers
- ◆ Thyroidologists
- ◆ Obstetricians and gynecologists
- ◆ Managed care organizations
- ◆ Nurses and nurse practitioners
- ◆ Providers in community health centers, migrant health clinics, and the Indian Health Service
- ◆ Psychologists and psychiatrists

Others

- ◆ Social workers
- ◆ Advocacy and support groups
- ◆ Community-based networks
- ◆ Schools of Public Health

I.1.6 Channels

Members of the public, including those who may be at higher risk, may be reached through a variety of channels, including:

- ◆ Intermediary organizations such as environmental advocacy groups and downwinders
- ◆ Community groups (especially in high-risk locations)
- ◆ Health care providers (especially in high-risk locations)
- ◆ State and local health departments, sliding scale clinics, community health centers, and migrant health clinics
- ◆ Bureau of Primary Care, Health Resources and Services Administration (HRSA)
- ◆ Internet (NCI Web site and primary Internet health portals)
- ◆ NCI's Cancer Information Service (CIS)
- ◆ Health-related federal agencies, e.g., Public Health Service, Indian Health Service, CDC, Veterans Administration
- ◆ American Indian Tribal Governments through collaboration and support of the Indian Health Service and other federal agencies
- ◆ Churches and other religious organizations

How Health Care Providers May be Reached

- ◆ Intermediary groups such as professional associations and their media (newsletters, journals, etc.)
- ◆ Professional meetings and continuing education
- ◆ Internet
- ◆ Health-related federal agencies, e.g., Public Health Service, Indian Health Service, CDC, Veterans Administration, Health Care Financing Administration

I.1.7 Core Messages

The Public

- ◆ Brief explanation that everyone in the United States during the time of the tests was exposed to some level of I-131 and depending on individual risk factors, is at varying health risk; description of potential health effects and their symptoms; and how to determine exposure. Messages should also acknowledge that multiple I-131 exposures and exposure from other radionuclides were possible, although less is understood about these other exposures.
- ◆ Recommendation to consult with a health care provider to determine if any steps should be taken to monitor and protect their health. (Information will be available to guide people without health insurance to existing programs that may assist them.)

Healthcare Providers and Others

- ◆ Brief explanation that everyone in the United States during the time of the tests was exposed to some level of I-131 and depending on individual risk factors, is at varying health risk; description of health effects and their symptoms; and how to determine exposure.
- ◆ Suggestions for counseling patients with concerns about the health effects associated with I-131 exposure.
- ◆ Suggestions for assessing appropriate health precautions/monitoring.
- ◆ Resources and references.

I.1.8 Message Tone

- ◆ Compelling, motivating; not frightening
- ◆ Empowering audiences to address their concerns
- ◆ Credible, truthful, engaging
- ◆ Not paternalistic
- ◆ Compassionate

I.1.9 Message Development Process

Message concepts were developed and tested with members of the intended audiences to determine *how* to deliver the messages in the most useful way (after it is determined *what* to say). Concept testing* is the type of research recommended in communications planning after exploratory focus groups and before material pretesting. A creative team then analyzed the responses to determine how messages would be crafted so that audiences would understand and act upon them.

Once materials were created, they were pretested with appropriate audiences, including underserved individuals without access to health providers.

I.1.10 Strategies and Tactics

Create and activate existing community and grassroots networks, along with state and local health departments, to deliver program messages to identified audiences.

The NCI completed the following:

- ◆ Identified and created a contact list of potential organizations to include as a network for program implementation.
- ◆ Developed informational materials to be used at the local level by organizations already involved with radiation exposure issues and those committed to public health, including local health departments. By creating turnkey materials and kits, messages were controlled and consistent. Community groups were encouraged to refer individuals to the Cancer Information Service (CIS) for additional information, answers to questions, and referrals to health provider services and other community services for assistance. Final materials included:
 - **Get the Facts About Exposure to I-131 Radiation**--This general information brochure provides information about the Nevada tests and identifies individuals at particular risk.

* Message concepts, also called creative concepts, are simple graphics paired with headlines and taglines designed to elicit responses from audience groups and get them talking about the issue in very concrete terms.

- **Making Choices: Screening for Thyroid Disease***--This decision aid workbook/brochure is for individuals concerned about their exposure to I-131 from fallout (This is based on decision support format of the Ottawa Health Decision Center at the University of Ottawa and Ottawa Health Research Institute, Ontario, Canada)
- **Radioactive Iodine (I-131) and Thyroid Cancer***--This flip chart, designed for use in small groups of up to 10 people, addresses concerns specific to Native Americans.
- I-131 Website (www.cancer.gov/i131)
- Tools for partners* (“swiss cheese” press release, promotional brochure, web blurb)

Provided technical assistance in communicating information about I-131 and the potential health effects to public health departments in areas of highest exposure.

Developed materials to enable health professionals to respond to patient concerns about potential I-131 exposure and to address the issue with patients who may have received higher exposure. These materials are noted with a * above.

- ◆ Worked with health professional organizations and their members to provide information to patients who may be concerned about their exposure or who may be unaware, yet subject to health complications from their exposure.

Worked with health care providers through their professional organizations (such as medical societies) to raise their awareness of the issue and inform them about materials available for their use. 1-800 phone numbers and Web addresses were highlighted to help health care providers ask for or obtain materials.

Enable audiences to access materials through multiple channels so that information is presented to them proactively but is also accessible upon demand.

- ◆ Developed an “I-131 web page” on the NCI Web site (www.cancer.gov/i131). The page offers sections for consumers and health professionals. The decision aid and the dose/risk calculator are also on the website.
- ◆ Worked with key health information portals targeting health professionals and consumers so that they can either provide a link to the NCI website or post the I-131 materials on their own site.
- ◆ Provided information and training on the topic to the CIS regional offices, which respond to telephone inquiries from consumers and professionals and conduct community outreach on specific cancer-related issues. (Note: Individuals who do not have easy access to the Internet are directed to the CIS which can provide them with information about the tests at the NTS and the potential exposures and possible subsequent health effects. The CIS is also a resource for referrals to other services, such as counseling, for people who learn that they have cancer or other specified health conditions, such as problems caused by exposure to I-131.)

Collaborate with other federal agencies, components of the government and other organizations to achieve consistent communication about I-131 and the potential health effects and demonstrate the effectiveness of the planning process model.

- ◆ NCI worked with key federal partners, including the Centers for Disease Control and Prevention, the Agency for Toxic Substances and Disease Registry, the Department of Defense, the Veterans Administration, the Department of Energy, the Environmental Protection Agency, the Indian Health Service, Bureau of Primary Health Care, and others. This effort was made to ensure consistent, inter-agency communication and actions on related radiation issues and facilitate more information sharing across agencies. (It is not foreseen that these agencies will help facilitate the specific activities described in this plan.)
- ◆ Coordinated and collaborated with Canadian organizations on the decision aid.

Use a phased approach to build momentum around the message and an opportunity for on-going evaluation.

The campaign implementation and evaluation is outlined on Page I-124.

Addendum A

Cancer Information Service's Role in I-131 Communication Plan

Materials Distribution

- ◆ The I-131 materials are available from the Publication Ordering Service and on the Publications Locator on the Web.
- ◆ Callers to the CIS are offered appropriate materials.

Information Calls to 1-800-4-CANCER

- ◆ CIS is now using information prepared by NCI to answer inquiries from the public.
- ◆ CIS makes referrals to health care professionals according to its current referral policy. (Note: CIS does not make referrals to individual physicians, only to NCI sponsored programs.)
- ◆ CIS does not use any of the modeling techniques to perform risk assessments for callers.

Referrals to Other Services

- ◆ CIS has referral information for cancer screening, treatment, pain, and indigent care. CIS refers to other community/national organizations for support services; CIS does not maintain referrals for support groups or other local counseling services. If other specific referrals are necessary for this project, they would need to be provided to CIS.

Outreach

- ◆ The CIS Partnership Program distributes I-131 materials to the state, regional, and community/local organizations it routinely works with.

Addendum B

Other Suggestions from the CDG

This document includes issues that cannot be addressed within the scope of the NTS I-131 Communications Plan, but will be shared with other governmental agencies.

- ◆ Develop a pilot project for addressing multiple exposures to I-131 as well as exposure to other radionuclides. This communications plan focuses on exposure to I-131 from NTS, but may be used as a model for future efforts, if deemed scientifically feasible and appropriate.
- ◆ Provide cost reimbursement for screening and/or medical costs associated with exposure to I-131 from the NTS, exposure to other radionuclides from NTS, and exposures to I-131 and other radionuclides from multiple sources, including “global” nuclear testing and radiation releases from United States nuclear facilities.
- ◆ Develop an Information Resource Center similar to the Hanford Health Information Center with a 1-800 number, Health Information Network, and On-line Exposure Health Database. This would enable people to get information, get connected, and get help accessing ancillary services, such as support and counseling.
- ◆ Develop an NTS Fallout Health Effects Subcommittee and an NTS Fallout Health Information Network originally proposed in Utah House Concurrent Resolution 10.
- ◆ Provide training or “train the trainer” sessions on exposure and screening to enhance community-based efforts.
- ◆ Provide counseling/support services (or cost reimbursement) for people who learn that their health has been affected by I-131 from NTS.
- ◆ Incorporate new ACERER recommendations into the plan once they are formally recommended and approved by the Department of Health and Human Services.

I.2 Workshop Agenda

(see next page)



Workshop Agenda

January 19-21, 2000



Wednesday, January 19 – Briefing Day

9:00 a.m. – 9:30 a.m. Arrival and Check-In

Session A

9:30 a.m. – 10:00 a.m. Opening Session
Welcome and Charge to Group Alan Rabson, M.D.
Mike Sage, M.P.H.
Ground Rules and Introductions Denise Cavanaugh, Facilitator

Session B

10:00 a.m. – 10:45 a.m. Broad Overview and History Mark Epstein, Moderator
Brief NTS History Mark Epstein
A Citizen's Perspective Trisha Pritikin, Esq., M.D., O.T.R.
IOM Report Robert Lawrence, M.D.

10:45 a.m. – 11:00 a.m. Break

Session C

11:00 a.m. – 12:30 p.m. The Science of I-131 Exposure and Health

1. What Can Science Tell Us About the Health Risks of I131? Charles Land, Ph.D.
2. What I-131 Doses Did People Receive From NTS Fallout? Steve Simon, Ph.D.
3. Reflections From and Independent Scientist on the Science of I-131. Owen Hoffman, Ph.D.

12:30 p.m. – 1:45 p.m. Lunch

Session D

1:45 p.m. – 2:15 p.m. Public Health Communications Challenge Elaine Arkin

Session E

2:15 p.m. – 3:00 p.m. Table Discussions Denise Cavanaugh

3:00 p.m. – 3:15 p.m. Break

Wednesday, January 19 – Briefing Day (Continued)

Session F

3:15 p.m. – 5:15 p.m. Communications Challenge: Group Discussions

1. Interest Group Perspectives

Moderator	Seth Tuler
State/Local Advocacy Organization	J. Truman
National Advocacy Organization	Maureen Eldredge
Physician Advocate	Tim Takaro, M.D.
Native American	Robert Holden
Ground Zero	Lincoln Grahlf, Ph.D.
Consumer Organization	Jean Halloran

2. Health Provider: Channels and Gatekeepers

Moderator	Kevin Teale, M.A.
Practitioner	R. Michael Tuttle, M.D.
Sliding Scale Clinic	Delvin Little, M.D.
Medical Specialty Group	Henry Royal, M.D.
Risk Communicator	Jim Flynn, Ph.D.
Medical Ethicist	Kristin Shrader-Frechette, Ph.D.

Session G

5:15 p.m. – 5:45 p.m. Wrap-Up

Denise Cavanaugh

5:45 p.m. – 6:30 p.m. Break

Session H

6:30 p.m. – 9:00 p.m. Networking Reception and Dinner

Thursday, January 20 – Discussion Day

7:30 a.m. – 8:30 a.m. Continental Breakfast

Session I

8:30 a.m. – 8:45 a.m. Summary of Day 1 and Charge for Day 2 Denise Cavanaugh

Session J

8:45 a.m. – 10:15 a.m. Screening/Medical Monitoring Denise Cavanaugh
Mark Epstein
Moderators

1. What Recommendations and Current Programs Exist for Screening and Monitoring? Robert Spengler, Sc.D.
R. Michael Tuttle, M.D.
2. Assessing Individual Risk Keith Baverstock, Ph.D.
Owen Hoffman, Ph.D.
3. A Model for Individual Decisionmaking Valerie Fiset, R.N., M.Sc.N.

10:15 a.m. – 10:30 a.m. Break

Session K

10:30 a.m. – 12:00 noon Table Discussions:
What do we know that we can use to begin developing messages and defining populations?
What do we need to know to develop and effective campaign?
What questions should be forward for April screening forum?

12:00 noon – 1:15 p.m. Lunch

Session L

1:15 p.m. – 3:30 p.m. Developing Model Outreach

1. Strategies for Message Development Peter Sandman, Ph.D.
An approach to identifying Target audiences
Considerations for developing Science-based messages Neil Weinstein, Ph.D.
2. Audiences Research Results Ed Maibach, Ph.D.
Presentation of preworkshop research

3:30 p.m. – 3:45 p.m. Break

Thursday, January 20 – Discussion Day (Continued)

Session M

3:45 p.m. – 5:15 p.m. Developing Model Outreach (Continued)
3. Table Discussions Ed Maibach, Ph.D., Facilitator
What additional audience research is needed?

Session N

5:15 p.m. – 5:45 p.m. Wrap-Up Denise Cavanaugh
Identify agreements and outstanding issues.
Move forward on a communications plan.

Friday, January 21 – Input Day

7:30 a.m. – 8:30 a.m. Continental Breakfast

Session O

8:30 a.m. – 9:00 a.m. Summary of Day 2 and Charge for Day 3 Denise Cavanaugh
Review Operating Principles

Session P

9:00 a.m. – 11:00 Breakout Session
Topic Decided on Thursday Afternoon

10:00 a.m. – 10:15 a.m. Break

Session Q

11:00 a.m. – 12:00 noon Reports From Breakout Session Group
Reporters

12:00 noon – 1:00 p.m. Lunch

Session R

1:00 p.m. – 2:00 p.m. Summary James Mathews/Kellie Marciel
Joan Morrissey
Next Steps Nelvis Castro
Owen Devine

Session T

2:00 p.m. – 2:15 p.m. Closings Comments and Thank You to Alan Rabson, M.D.
Participants

I.3 Workshop Summary

I-131 Fallout from NTS: Informing the Public January 19-21, 2000

Workshop Summary

On January 19-21, 2000, a workshop titled “I-131 Fallout from NTS: Informing the Public” was held in Rockville, Maryland. It was sponsored by the National Cancer Institute (NCI) and the Centers for Disease Control and Prevention (CDC) and planned in consultation with a working group of citizen representatives and state health department staff. This report summarizes the workshop proceedings for the benefit of participants and other interested individuals and organizations.

- ◆ Section I.3.1 - Workshop Proceedings
 - ◆ Section I.3.2 - List of Working Group members and government staff
 - ◆ Section I.3.3 - Workshop Participants
 - ◆ Section I.3.4 - Proposed Campaign Operating Principles
 - ◆ Section I.3.5 - List of Other Resources
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The working group designed the workshop with five outcomes in mind:

1. Obtain input for the ongoing process of campaign development and implementation, including the structure for continued public participation in the process.
2. Get input on target audiences and a process for developing messages.
3. Get suggestions for additional audience research.
4. List the scientific questions that still need to be addressed, including suggestions for an April workshop on screening to be hosted by the Advisory Committee for Energy-

Related Epidemiologic Research (ACERER), which advises the Department of Health and Human Services (DHHS) on radiation research¹.

5. Identify ways to leverage this model process to benefit subsequent efforts on the full range of health effects from radionuclides released from the Nevada Test Site (NTS).

The workshop brought together affected citizens, consumer advocates, physicians, scientists, health department representatives, risk communicators, and government officials. Some had a long history with radiation fallout issues; others were new to the field but experienced in communications or reaching specific at-risk populations.

By the end of the three-day workshop, participants agreed on a set of campaign goals, provided organized feedback on four areas of campaign development, and developed a “wish list” of outcomes they would like to see in the near and distant future.

¹ At the time of the workshop, it was anticipated that the ACERER meeting to address screening issues would be held in April 2000. The meeting has since been scheduled for June, 2000.

I.3.1 Workshop Proceedings

I.3.1.1 Day One

Opening and Introductions

The workshop was opened by Alan Rabson, M.D., Deputy Director of the NCI, and Mike Sage, M.P.H., Acting Deputy Director of the National Center for Environmental Health at the CDC. They charged the group with providing input to NCI and CDC in the development of a communications program that will 1) inform the public, and more particularly, the members of the public who are at high risk for health problems because of their exposure to radioactive iodine-131, and 2) educate health providers so they can provide appropriate care. The challenge will be to figure out how best to communicate the history, the science, and the possible health risks from exposure to radioactive iodine-131 from the Nevada Test Site. Dr. Rabson noted the active interest of the Department of Health and Human Services (DHHS), acknowledging the presence of Dr. William Raub, representing DHHS Secretary Donna Shalala.

Denise Cavanaugh, the workshop facilitator, reviewed the ground rules and desired outcomes for the workshop. She reiterated the desire to identify some common ground, to provide scientific background, history on the issue, and to discuss the communications challenges and strategies that might be employed in the campaign. Ms. Cavanaugh encouraged participants to use the listserv set up by NCI to interact and give additional feedback after the workshop. A handout was provided with directions on how to subscribe to the listserv. Ms. Cavanaugh also pointed out the Operating Principles drafted by the working group.

Overview and History

Mark Epstein of Porter Novelli, Washington, D.C., gave a brief overview of the history of the Nevada Test Site, referring participants to the Institute of Medicine (IOM) Report² and working group member Trisha Pritikin's document³ for further details.

Robert Lawrence, MD, of Johns Hopkins University, and chair of the IOM Committee that reviewed NCI's report⁴ on I-131 dose estimates, offered a brief presentation of the IOM Report. He focused on the factors that contribute to individual dose estimates and the problems in making estimates due to geographic variation, dietary patterns, and individual susceptibility. He agreed that excess cases of thyroid disease were caused by radioactive fallout, but he asked whether trying to identify individuals who are at greatest risk and screening them would lead to greater harm than good. And so, the IOM committee took the approach "first, do no harm," in recommending against mass screening for thyroid cancer. He encouraged the group to work toward a communications program that focuses on shared decision-making between individuals and their health care providers.

Trisha Pritikin, a member of the working group, brought the perspective of a citizen exposed to NTS fallout and environmental ionizing radiation emissions, including I-131, from the Hanford nuclear weapons facility. She noted that radioiodine is only one of a host of biologically significant radionuclides released during the NTS nuclear bomb tests. She asked that this I-131-focused campaign be followed by similar campaigns on other NTS radionuclides. She called for an appropriate government response to these involuntary environmental exposures. She also encouraged a discussion of government-sponsored screening for those at highest risk from their childhood exposures, as is anticipated to occur at an upcoming ACERER meeting.

Ms. Pritikin detailed the impact of radioactive fallout on her family, describing her illness and the death of both of her parents. She grew up in Richland, Washington, adjacent to the

² *Exposure of the American People to Iodine-131 from Nevada Nuclear Bomb Tests: Review of the National Cancer Institute Report and Public Health Implications*. 1999. National Academy Press: Washington, DC

³ Ms. Pritikin was a Working Group member who prepared a document, "NTS History," which was included in the packet of materials for workshop participants.

Hanford nuclear weapons facility. She called for estimates of cumulative exposures and risk, based on multiple radioactive exposures such as NTS, Hanford, and global fallout. She also called for discussion of all potential health outcomes, including thyroid cancer, autoimmune thyroiditis, hypothyroidism, hyperthyroidism, hyperparathyroidism, and other related diseases. She noted that screening for non-cancer outcomes involves a simple blood test, which has a different benefit/risk ratio than thyroid cancer screening.

At the completion of her presentation, Ms. Pritikin read from the written and oral transcripts of the Hearing before the Senate Permanent Subcommittee on Investigations of the Committee on Governmental affairs, citing Senator Tom Harkin's support for medical screening for those at highest risk from NTS I-131 exposures, and citing his disagreement with the recommendations against screening made by the IOM committee that reviewed the NCI I-131 report. Dr. Lawrence, chair of the IOM committee, responded by stating that he had spoken with senior members of Senator Harkin's staff regarding these IOM recommendations, and that those staff members then indicated that they understood why the IOM made the recommendations it did.

The Science of I-131 Exposure and Health

Charles Land, Ph.D., of NCI's Division of Cancer Epidemiology and Genetics, explained how NCI developed its estimates of exposure and explained why children were at higher risk than adults: children are more sensitive to radiation; their thyroid glands receive higher doses from ingested or inhaled I-131. They have a higher intake of milk (the main pathway of ingestion), and higher metabolism.

Steve Simon, Ph.D., of the National Research Council's Radiation Effects Research Board, described dose estimates. He explained how dose is calculated and described how uncertainty is factored in. He also showed a number of maps that showed the high exposure areas, or "hot spots," by birth year.

⁴ *Estimated Exposures and Thyroid Doses Received by the American People from Iodine-131 in Fallout Following Nevada Atmospheric Nuclear Bomb Tests*. 1997. U.S. Department of Health and Human Services, National Institutes of Health, National Cancer Institute.

Both speakers described the complexity of estimating exposure and doses and the limitations of the sources of I-131 exposure information from the 1950s and 1960s, based on the time of year, weather patterns, cow grazing patterns, dairy management practices, etc. Dr. Simon explained the difficulties in coming to individual dose estimates, which rely on the accuracy of the person's memory of where they were and what they were doing during the testing. County-specific estimates already carry a high degree of uncertainty. Individual estimates are more uncertain, still.

F. Owen Hoffman, Ph.D., from SENES Oak Ridge, Inc., shared his perspective. He stated that, although the risk from exposure to iodine-131 is uncertain, it does not prevent us from estimating risk. The uncertainty can be quantified, allowing an estimated range of 8,000 to 208,000 excess cases of thyroid cancer due to NTS fallout. He suggested that most of the excess cases would occur in females who were children at the time of the testing and who resided in the eastern United States because that was where the population was most dense and where the most milk was produced.

Age, gender, and diet are more important determinants of risk than is location, said Dr. Hoffman. He also noted the need to bring together dose reconstructions from various sources of fallout to estimate cumulative doses. He also called for work to extend discussion beyond iodine-131 to other radionuclides in both NTS and global fallout.

Dr. Hoffman argued that health risk evaluations with regard to fallout should include more health effects than thyroid cancer, such as benign nodules and autoimmune thyroiditis. He also urged that other I-131 exposure sources and time periods beyond 1962 be investigated, including the underground testing era.

Dr. Hoffman also reported that there is now a more sophisticated method of calculating the uncertainty associated with dose estimates than what was used in the NCI online dose calculator. Calculations using the "Monte Carlo" method take into account the adding of uncertainties from disparate time periods, and result in smaller uncertainty ranges.

Public Health Communications Challenge

Elaine Bratic Arkin, a health communications consultant, defined health communications and social marketing, using a CDC definition: “the crafting and delivery of messages and strategies based on consumer research to promote the health of individuals and communities.” Communications can prompt people to take simple actions, like call a toll-free number or make an appointment with a doctor. It can correct misconceptions, and it can coalesce relationships. She said that the campaign’s challenges include the public’s complacency (since these exposures happened decades ago), a media environment cluttered with health messages, and a very complex topic to convey to the public.

To be successful, the communications campaign needs to be planned, budgeted and supported over time, Ms. Arkin stated. It needs to be tracked and evaluated in case adjustments are needed. It may need to be part of a multifaceted program, coupled with provision of services and physician education, for example. She also described the components of a communications plan.

Table Discussions

Small group discussions following Ms. Arkin’s presentation focused on two questions: what is the issue, and what one change might advance the effort? Some of the issues and actions discussed:

- ◆ Lack of trust in the government
- ◆ The government must accept accountability for past events and future actions.
- ◆ The program should be comprehensive instead of separating nuclear fallout from mining, milling, production, waste, and weapons use. In other words, the public wants to know about isotopes beyond I-131 and exposures beyond Nevada Test Site.
- ◆ There are two public health issues here: the actual physical impact of exposure and the psychological stress induced in people by the exposure.
- ◆ How will we help people who are mobile and speak a language other than English understand the risk?
- ◆ We’ve got to make clear there was an impact, even if we are uncertain about the magnitude.

- ◆ There is a need to educate physicians so they will take patients' complaints and concerns seriously. If a doctor is honest and up-front, the patient will have less fear and uncertainty.
- ◆ Physicians must be contacted before a public campaign is launched. We need to get the attention of primary care physicians and get health care providers, such as HMOs, on board.
- ◆ It may be difficult to identify a credible source for the information, due to issues of mistrust.
- ◆ There are two components: a notification piece, to educate and reduce fear, and a call to action so that high-risk individuals will seek medical advice, which would include educating physicians to be prepared to respond. There also may need to be some kind of direct help for the affected citizens from the government.
- ◆ Give people a full view of their risk from a combination of sources.
- ◆ Give people the information they need about risk factors so they can determine their own risk level and then give them information on obtaining follow-up consultation or care, if needed.

Panel 1: Interest Group Perspectives

Working group member Seth Tuler, Ph.D., of the Childhood Cancer Research Institute and Clark University, moderated the workshop's first panel discussion. Dennis Nelson, Ph.D., of Support and Education for Radiation Victims (SERV), described the lifestyle of the downwinder population near the Nevada Test Site to give a sense of the downwinder's exposure. He argued against focusing exclusively on I-131 and cancer and called for a national plan to notify people throughout the country so that they could look into their own exposures and seek early detection.

Maureen Eldredge of the Alliance for Nuclear Accountability described her organization's relationship with the government on nuclear weapons issues as a pattern of deceptions and cover-ups. She stated that the government has an obligation to tell the public that they were involuntarily and unknowingly exposed, regardless of how low the exposure or how

minimal the health risk. She suggested also looking at all thyroid disease, not just cancer, and helping people figure out their cumulative doses so they have the full picture of their exposures. It is not up to the government to decide what information people should or shouldn't have because they might make a bad decision with all the information. People should make their own decisions about their health care. Lastly, she said that we should be aware of the impact of money. She said the government might be fearful of providing information out, as people who were exposed may sue the government, whether or not they suffered any ill consequences of exposure. She said the government should pay for the communications, the training and education of health providers, and perhaps even for treatment.

Tim Takaro, MD, of the University of Washington, represented Physicians for Social Responsibility. In his experience with Hanford, the people in the Northwest want to know about their families' illnesses. They want to know if they are at risk, whether they should be tested, and whether their children may be affected. He noted the importance of cumulative doses and called for looking at exposure from mining through weapons disposal. At the same time, physicians don't need to get an accurate dose on a patient to address concerns about risk for certain diseases based on their exposure from Hanford, NTS, and others. He noted that screening large populations with no restrictions is not cost effective, but that screening should not be denied a person who is concerned about his health and the impact of radiation exposure. Physicians will need to address patient anxiety, which in itself is a psychological and physiologic burden.

Robert Holden, of the National Congress of American Indians, discussed the history of the relationship between the federal government and native peoples, stating that the government has a responsibility, based on treaties, to provide for Indian health and welfare. Many Native Americans had multiple exposures. For example, uranium was mined on Navajo land and a national laboratory sits on Pueblo land. He noted that there are certain protocols to communicate with tribal officials. He stated that he hopes that the Native American community can continue a relationship with those planning this campaign to help them better understand Native Americans. He suggested a Native American caucus to work on these issues.

F. Lincoln Grahlfs, Ph.D., is an atomic veteran representing the National Association of Radiation Survivors. He described his experience educating Congress that nuclear radiation is hazardous and getting the word out about the NCI report. His group's media work got tremendous response in areas like St. Louis, Missouri, and Idaho Falls, two "hot spot" areas identified in the report. He warned that special interest groups might try to sabotage efforts to educate the public on issues of radiation exposure and health risks.

Mike Hansen, Ph.D. represented Jean Halloran from Consumer's Union. From his background working on advocacy issues on pesticides and genetically engineered foods, he stated that the government will have to do a few things to gain credibility: 1) take a comprehensive view, broader than I-131 and all potential health effects, 2) provide as much information as possible, and 3) admit the government was wrong. Even if the risk is small, the public will get upset at risks that were involuntary, that they had no control over, and that were done to them without their knowledge. The government will need to be upfront about what happened and how much they don't know. They'll need to work with grassroots organizations and those advocacy organizations that are critical of the government in order to make the campaign successful. The process will be difficult, but important. He suggested working with *Consumer Reports* magazine to write an article on this topic. Dissemination would be widespread, with a readership of 4.8 million subscribers in their 50s and 60s.

Seth Tuler ended the panel by discussing the findings of the ACERER's subcommittee for community affairs. 1) Federal efforts to address the public health consequences of NTS fallout are still inadequate. 2) Difficulty identifying specific fallout injuries does not absolve the federal government of its responsibility to shape a meaningful public health response. 3) Research is not a public health response and is not a substitute for the assistance that many exposed people believe that the government has a responsibility to provide. 4) Delays in sharing important public health information about fallout exposures have reinforced public cynicism toward federal officials.

He then reviewed the ACERER's recommendations: 1) Fulfill the legislative intent of Public Law 97-414, which mandated NCI's study of I-131 NTS fallout; 2) Complete a

comprehensive dose reconstruction project for NTS fallout, with an oversight committee created to keep things on track; 3) Notify Americans of the factors that might help them determine if they received significant radiation doses from NTS fallout, targeting high-risk groups; 4) Create a public and health care provider information service; 5) Support an archival project to document the experiences of exposed people; 6) Further evaluate screening opportunities for thyroid disease.

He finished by summarizing the common themes heard during the panel discussion.

- ◆ The legacy of mistrust
- ◆ Identifying who is at high risk and providing more to them than mere notification
- ◆ Empowering people to make informed decisions about their health care
- ◆ Addressing fears versus creating fears
- ◆ Covering multiple exposures and contaminants
- ◆ Overcoming political resistance to implementing programs

Panel 2: Health Provider Channels and Gatekeepers

The final panel on the first day of the workshop included health professionals and gatekeepers. Kevin Teale, of the Iowa State Health Department, moderated. He began by pointing out the challenge the group faces in trying to get a message about this complex topic out to the broadcast media, which relies on four-second sound bites. He also raised the issue of getting the public to pay attention to the risk, when they already don't pay attention to some of the big health risks like smoking or weight control.

R. Michael Tuttle, M.D., from Memorial Sloan-Kettering Cancer Center, is a practicing thyroid specialist. He treats patients with thyroid disease, many of whom already ask him about radiation exposure and their disease. He sees a big challenge in translating excess relative risk, radiation dosage, and other relevant technical jargon into something meaningful to tell a patient. The program will have to help physicians define who is high-risk and help them discuss risk in a way that makes sense to their patients, which may vary

by geographic location and cultural background. It must give physicians a strong scientific rationale for determining whether a patient is at risk or not.

Henry Royal, M.D., of the Washington University School of Medicine, was a member of the committee that wrote the IOM Report. He contrasted the public health perspective, which shows that thyroid cancer accounts for just 3% of all cancer deaths, with the personal, devastating perspective of a family member dying of thyroid cancer. He advocated allocating limited health care resources where they can have the greatest impact to reduce premature deaths. He acknowledged the difficulty in taking this view when individuals are dying of thyroid cancer, but shifting public health resources to a program that would have a small public health impact would cause others to needlessly suffer the tragedy of premature death.

Delvin Littell, M.D., of the Morgan County Medical Center, adjacent to Oak Ridge, Tennessee, encouraged the group to work with the organizations of community health centers, clinics that reach low-income individuals. In particular, he noted that the migrant labor movement might offer a resource of particular use with people who don't trust "the system." He also advised that communicators keep in mind how they would like to be treated when developing messages and strategies to reach the public.

James Flynn, Ph.D. Decision Research, talked about risk communications, explaining that the messages developed for this campaign will be going to people who will receive them within the context of suspicion of nuclear technology as well as their personal experiences and preformed judgments. These factors will affect the way they receive and respond to the messages.

Kristin Shrader-Frechette, Ph.D., of the University of Notre Dame, provided a medical ethicist's perspective. Two things she says have gone wrong with risk communication about radiological hazards are: the tendency to present scientific opinion as if it were fact and the tendency to make covert ethical judgments as if they were scientific judgments. She used the example of the IOM report recommending against mass screening because of the benefit to harm ratio. That's a value judgment that takes away individual rights. In a democracy, people have the right to know, the right to compensation, to due process, and to self-

determination. People have the right to make mistakes for themselves. Lastly, she stated that, to communicate in a credible way, the government will have to state that this will not be repeated. People are willing to forget the past if we can assure them that what they went through in the past is not going to happen again. Deciding about screening is not just a scientific issue, it is an ethical issue and several members of the public should be involved in the decision-making. She recommended using the 1996 National Research Council report, *Understanding Risk: Informing Decisions in a Democratic Society*, as a way to improve risk communication and involve the public in a meaningful way. She also argued that the government is obligated to take responsibility and spend health care dollars on this issue, even if it involves diseases with small public impact because the government is accountable for the radiation fallout and its impact.

I.3.1.2 Day Two

Screening/Medical Monitoring

Day Two began with a session on Screening and Medical Monitoring. Robert Spengler, Sc.D., of the Agency for Toxic Substances and Disease Registry, and R. Michael Tuttle, M.D., reviewed existing recommendations and programs for screening and monitoring. They provided a handout that described the recommendations of various interested organizations and studies. Dr. Spengler also presented the proposed Hanford Medical Monitoring Program, which is not yet funded. He discussed recent revisions to the proposed program that address and reduce the potential harms of thyroid cancer screening expressed in the IOM report. In addition, he submitted documents on the proposal and revisions to NCI as handouts for the participants.

Keith Baverstock, Ph.D., of the World Health Organization, Helsinki, Finland, and Owen Hoffman, Ph.D., talked about assessing individual risk. Dr. Baverstock discussed the value of estimating individual risk, and the limitations of such estimates. He presented the NAS/IOM scheme for describing individuals' risk as falling into three non-numerical categories. Individuals born after the cessation of testing are not at risk; individuals over 18 at the time of testing are at very low risk. For other age categories, the NAS/IOM recommends that DHHS develop a method for calculating an individual "score"—for purposes of categorizing only, not as a numerical expression of risk—that takes into account location, milk consumption, milk source, and gender differences. The resulting scores would then be linked to recommendations for appropriate actions for individuals in each category.

Dr. Hoffman discussed the identification of high-risk sub-groups. He suggested the following criteria be used to determine high-risk status: those in childhood at the time of atmospheric testing, goat's milk drinkers, those with a family history of thyroid cancer or other thyroid abnormalities, and those with estimated doses above a given decision level. Dr. Hoffman emphasized that for the case of goat's milk drinkers who were children during the testing period, enough is known already to classify them as high-risk, without further

dose refinement. He highlighted the inherent uncertainty of individual dose estimates and proposed that decisions be based on either the upper or lower bound of confidence on the dose estimates, and suggested a detailed framework for doing this.

Valerie Fiset, R.N., M.Sc.N., of the Sisters of Charity Ottawa Health Service, Ontario, Canada, presented a model for helping people make difficult health-related decisions. Decision aids walk patients, with their health care provider, through steps that help them look at options available, the potential outcomes of those options, then help the patient consider their values in relation to those options. Decision aids are used when the outcomes of the options are not very well known and the patient needs to judge the value of the benefits and risks. They are also useful when there is practice variation around a screening or treatment option. Her group has developed decision aids around chemotherapy for advanced lung cancer, hormone replacement therapy, and lumpectomy versus mastectomy for breast cancer treatment.

At this point, participant discussion began. Audience members were looking for clarification of the scope and goals of the campaign. Some expressed frustration with the government's past record on radiation issues and skepticism that things would change. Denise Cavanaugh, the workshop facilitator, asked the group to make recommendations and to develop a "wish list" of outcomes for the campaign. They are listed below.

General Recommendations

- ◆ Move forward with a campaign. Do not wait until all of the science is in. Talk about what you know and explain that more information on dose and associated risks will be provided when feasible.
- ◆ Educate the "publics" about the basics of radiation fallout, exposure (from individual facilities, and globally), and health impacts, while giving a sense of the complexity of the information.
- ◆ Keep public representatives involved as partners.

- ◆ The participants agreed on a framework to discuss I-131 first and then additional radionuclides, as information becomes available. That framework was called: “Public Health Legacy of Nuclear Production, Research, and Testing.”

“Wish List” of Activities

Near Future (3 months)

- ◆ A communications plan with financial support.
- ◆ A decision about access to federally sponsored screening for uninsured and underinsured populations.
- ◆ Inclusion of state health departments in campaign development and implementation.
- ◆ Partnership with Native American tribal governments in developing the campaign.
- ◆ Use of the listserv as an interactive communications tool for discussion and review of draft planning documents.
- ◆ Consideration of a resource center with a toll-free number, i.e., an entity responsible for delivery of information.
- ◆ Development of an archive (or expansion of existing archives around the country) of documents and resources pertaining to the NTS and resulting exposures, in keeping with the ACERER recommendation.
- ◆ Continuation of relationships built at the January 2000 Workshop.
- ◆ Government acknowledgment of the legacy of nuclear production, research, and testing and commitment to prevention in the future.
- ◆ A clear set of recommended actions for the public to take with regard to exposure.
- ◆ Study of the ongoing health effects of existing nuclear action.

Distant Future (36 months)

- ◆ Outreach to communities.
- ◆ Outreach to federal agencies.
- ◆ Physician education implementation.

- ◆ Evaluation of campaign implementation.
- ◆ Benchmarks for physician education, etc.
- ◆ Development of cultural- and language-appropriate messages/materials for special populations.
- ◆ Addressing additional radionuclides.
- ◆ American public understanding fallout and health legacy.

Developing Model Outreach

Peter Sandman, Ph.D., a risk communications consultant, explained the difference between hazard (how dangerous something is) and outrage (how much it upsets people) and the fact that they are often poorly correlated. He suggested a two-pronged campaign. One audience is people who are significantly endangered by NTS fallout and deserve a warning. The second audience is the larger public whose hazard is low. He offered five options for messages to them, ranging from doing what you can to keep them from becoming outraged to getting them outraged to organize them politically. He suggested that the diverse interests in the room could work together on a campaign to reach those who are high risk, but would probably need to work separately to communicate to the larger public, since their goals would likely vary.

Regardless of how hazardous the fallout is to the public's health, Dr. Sandman noted that public outrage over nuclear fallout should be expected and is justified based on a list of twelve factors, including the involuntary nature of the exposure and the government's unresponsiveness to public concern. He said that in order to be credible, the government must acknowledge the outrage and admit that it is justified. He ended by saying that the government should apologize a lot; overestimate, rather than underestimate the risk; show concern, feeling and humanity; and acknowledge the moral relevance of the situation.

Neil Weinstein, Ph.D., of Rutgers University, discussed the challenges involved in communicating about risk, based on his experience with radon and other programs. He talked about the public's difficulty in understanding numbers and probabilities and the likelihood that people will be apathetic to the message that a health risk has occurred. He

also warned against providing too much information in an effort to enable people to make their own informed decisions. He advocated giving recommendations for action with sufficient background information, without flooding people with all the details on dosing, probabilities, and the science of I-131 exposure.

Ed Maibach, Ph.D., of Porter Novelli, presented the results of six focus groups held with consumers and physicians to begin getting a sense of their knowledge and attitudes about radiation fallout and health risks, to understand their perceived risk, their degree of concern, and to understand their needs for information on these issues. The participants were drawn from two cities with a high exposure to I-131 and one with a lower exposure. The preliminary report was provided at the meeting.

- ◆ The consumers in both areas showed little concern about radiation fallout, had little interest in something that occurred in the past, and were more concerned by health issues they face today. But there was great passion for securing assurances that the tests never happen again. People wanted to know the big picture about the consequences of NTS testing rather than just about I-131.
- ◆ The physicians knew very little about nuclear testing and its health impacts. They called for a permanent ban on nuclear testing. They asked that a public education campaign not be mounted because it would create a mess without helping the public. They said a physician campaign might be a good idea, though they weren't convinced it would change their clinical practice at all.

Dr. Maibach ended by reminding the workshop participants that this was just the beginning of the audience research needed to develop a campaign. During the question and answer period following the presentation, workshop participants noted the likelihood that focus group responses were tied to the source and format of the information stimulus they received. It was pointed out that this should be taken into account in locating appropriate “messengers” for delivering exposure information to the public. Later in the workshop, the participants spent time discussing additional audience research needs.

Campaign Goals

Following the audience research presentation, workshop participants developed four goals for the communication campaign, which received wide support:

1. Acknowledge/explain what happened as a result of nuclear weapons production, research, and testing and what is happening now. Engage or encourage the public in a policy discussion on this issue.
2. Educate the public on the potential health consequences of I-131 and other radiation exposures so they can make good decisions. Provide mechanisms for follow-up (e.g. toll-free number) for people without a health care provider.
3. Educate health care providers about the health consequences of I-131 fallout and other radiation exposures as well as the pros and cons of thyroid evaluation so they can help their patients make good decisions.
4. Facilitate diagnosis, screening, and if necessary, treatment, for those with cancer and non-cancer radiation-related illnesses.

A number of organization representatives committed to working on specific campaign goals:

- ◆ Physicians for Social Responsibility, Alliance for Nuclear Accountability, and the National Indian Council on Aging expressed interest in working on goal #1 and bringing the topic to their organizations' meetings in May (PSR and ANA), and August (National Indian Council on Aging).
- ◆ Physicians for Social Responsibility, Alliance for Nuclear Accountability, National Association for the Advancement of Colored People (NAACP), and the National Association of Radiation Survivors offered to work with the federal government on goal #2.

I.3.1.3 Day Three

Organized Feedback

In small working groups, participants gave feedback regarding:

- ◆ Design of an ongoing campaign development workgroup.⁵
- ◆ Recommendations for issues to be addressed at the April 2000 ACERER workshop on screening.
- ◆ Additional audience research needs.
- ◆ Preparation for audience messaging: What key information needs to be communicated?

Each small group's recommendations and comments are presented below.

1. Campaign Development Workgroup

The workgroup that worked with NCI and CDC to plan the January workshop included individuals familiar with the following perspectives, groups, or organizations:

- ◆ Hanford downwinders
- ◆ Alliance for Nuclear Accountability
- ◆ ACERER Subcommittee for Community Affairs
- ◆ Hanford Health Information Network
- ◆ NAACP
- ◆ Physicians for Social Responsibility
- ◆ A Physician
- ◆ State Public Health Department (Radiological Health Section)
- ◆ NCI/CDC/ATSDR staff

⁵ During the Workshop, this group was frequently referred to as the "Campaign Development Group" or "CDG." Since then, NCI staff have elected instead to call the group a "Communications Development Group" to be more encompassing of all the efforts involved in communications planning.

Workshop participants in the small group that discussed this topic proposed that the new “Campaign Development Group” include the following types of representation (this is a list of perspectives to be represented—not specific organizations):

- ◆ Activists (2)
- ◆ Downwinders (2)
- ◆ African American
- ◆ Health educator
- ◆ Health professional organization
- ◆ Hispanic from community and migrant health center
- ◆ Native American
- ◆ Physician
- ◆ State Public Health Department: health education and radiation control (2)
- ◆ Local health department
- ◆ Thyroid Foundation

Criteria for inclusion in workgroup:

- ◆ Long-term view
- ◆ A view broader than I-131 and thyroid cancer
- ◆ Ability and willingness to make necessary time commitment
- ◆ Ability to do outreach to their communities
- ◆ Work toward geographic diversity

It was also agreed that workgroup members need to be reimbursed equitably for the work they do on this project, and that the federal agencies involved must commit adequate staffing to this effort.

2. Recommendations for topics to be addressed at the ACERER meeting to address screening issues

- ◆ Feasibility of identifying higher- and lower-risk groups
- ◆ Basis for decisions regarding policies on screening—scientific analyses alone, versus incorporation of social justice considerations
- ◆ Risks and benefits of screening for cancer and non-cancer thyroid illness
- ◆ Incidence of false positives from most recent Hanford Thyroid Disease Study thyroid cancer medical evaluation
- ◆ Review of science regarding noncancer thyroid outcomes of I-131 exposure
- ◆ Cumulative effects: how do multiple exposures change a person’s risk classification?
- ◆ Progress report on research into other radionuclides
- ◆ Examination of other screening programs around the world
- ◆ Potential funding mechanisms for screening programs; comparison of other screening programs
- ◆ Case study of affected citizens
- ◆ Operating principles

A workgroup will help plan the ACERER workshop. Individuals working on this list offered to participate. They were: John Bagby, Trisha Pritikin, Henry Royal, Robert Spengler, Oscar Tarrago, J.B. Hill, David Becker, and Steve Simon. Tim Takaro, Keith Baverstock, Owen Hoffman, and Kristin Shrader-Frechette also expressed interest in participating in the planning process.

3. Recommendations for Additional Audience Research

Who are we trying to reach? This must be determined before audience research begins. Once this is determined, the research would address:

- ◆ Demographic research on language, culture, education, and literacy levels.
- ◆ Preferred sources of information.

- ◆ Psychographic data -- beliefs/attitudes, epidemiologic data, role of the media.
- ◆ Message and strategy testing -- look at research and campaigns that have already been done. Do a meta-analysis to transform and digest that data to determine audience needs.
- ◆ Process evaluation: Was the campaign done on time, within budget?
- ◆ Outcome evaluation: What were the campaign's effects? What was the reach, frequency, and duration of communications? How many were exposed over a period of time? What were the effects on knowledge, attitudes, and behaviors? What were the long-term effects on behaviors?

4. Preparation for Audience Messaging: What key information needs to be communicated?

- ◆ The general United States population should receive information to improve their awareness.
 - Give historical context, discuss research, production, and testing. Discuss I-131 and other radionuclides. Discuss local testing, global fallout, associated social and ethical issues, and general risk factors (e.g., milk, and gender) so that people can self-identify. Give history of government action and where there is still work to be done. Describe the work that continues on outstanding issues to ensure that exposures from testing won't happen again.
- ◆ "Hot spot" audiences should receive:
 - All the information that the general United States population is receiving (see above).
 - Information on general risk factors plus multiple exposures so they can self-identify.
 - Assurance that health care providers and other agencies (e.g., managers at DOE/contractor facilities) are being told about this.
- ◆ Self-identified as at-risk or other concerned people should receive:
 - Information that the above audiences receive.

- Information on what to do if you don't have a health care provider.
- Details on the ongoing work regarding outstanding issues (screening, compensation, etc.)
- A fact sheet from an official organization to bring to a clinic or physician's office.
- ◆ Health care providers should receive:
 - Everything the above two audiences receive and additionally, resources on screening for all thyroid disease.
- ◆ Payers of Healthcare (HMOs, government programs) and insurance commissioners should receive:
 - Clinical practice guidelines or Standards of Care.
- ◆ Workers (research, production, mining, etc.) should receive:
 - All information that "hot spot" and self-identified at-risk people receive.
- ◆ State Health Departments should receive:
 - All information that health care providers receive so they know they will also be disseminators, and must be kept informed as campaign progresses.
- ◆ State Regulators should receive:
 - All the same information that health care providers and state health departments receive.

We still need to determine the right organizations to communicate messages to various target audiences.

Summary Comments

Anne Lubenow, Acting Co-chief of the Health Promotion Branch in the Office of Cancer Communications, NCI, thanked all of the participants and expressed NCI's appreciation for everyone sharing their views. She encouraged participants to contact the NCI staff as needed. She also stressed that although we don't yet have all of the answers, we are on the

road to developing a campaign, and have identified some common ground, as well as areas that need further discussion.

Joan Morrissey, Health Communicator with the Radiation Studies Branch, CDC, followed by thanking the workgroup for the tremendous amount of work they put in to planning this successful workshop. She specifically noted her desire to put together a Native American caucus, as suggested by Robert Holden. She reiterated the agencies' commitment to developing and implementing this program and doing it right.

A sampling of participants' closing remarks

“It’s been really heartening for me as a person from a significantly impacted community to feel that all these people actually care about people like me, finally, because there are a whole lot of times when I don’t feel that way. And I want to thank the agencies involved for never telling us that we couldn’t discuss something. We were able to put all the issues on the table and discuss everything that I think people wanted to talk about. I feel very good about this process.”

“I see an incredible variety of talent, knowledge, and goodwill in this room, and I see a huge opportunity to make a truly positive impact on all of society.”

“A grave concern in all of this is that these issues have the ability to divide people in this country rather than unite them. If the same spirit of bringing different people together here could be the spirit of whatever moves out of it, I think we can go very far.”

Next Steps

Nelvis Castro, Acting Associate Director for Cancer Communications at the NCI, thanked the participants for their candor and their dedication to this effort. She stated that the summary of the meeting would be posted on the listserv for a 2-week comment period, then finalized and distributed to interested parties. Dr. William Raub has committed to bringing the report to Secretary Shalala’s attention. A Campaign Development Group will be formed and will review the draft communications plan and help with future activities. She estimated that the plan will take about six months to draft. The plan will be refined and modified as necessary based on feedback received from this group. She also hopes to learn about the

communications channels that participants use to reach their constituents to expand the reach of the messages that are developed for this campaign.

Owen Devine, Ph.D., chief of the Risk Assessment and Communication Section, Radiation Studies Branch, CDC, talked about future plans to study other radionuclides and global fallout. A feasibility assessment will be presented to ACERER in June 2000 and to Congress in July 2000. It will be an assessment of the scientific feasibility of estimating dose and risk to the United States population from global fallout, including NTS. There will be a large discussion of communications in the report as well. He thanked all of the participants.

Dr. Alan Rabson closed the meeting by repeating the apology for NCI's delay in finishing the Nevada Test Site Fallout report. Processes have been put in place at the Institute so that such an "unconscionable delay" will never happen again. He called the workshop an "historic meeting" that has given NCI a new understanding and commitment to working with community representatives. He assured participants that NCI intends to follow through.

I.3.2 List of Working Group Members and Government Staff

I.3.2.1 Community Representatives

H. Jack Geiger, M.D. - (Departed group 11/99)

James B. Hill, Jr. - President, NAACP, Oak Ridge Branch

Yvette Joseph-Fox - National Indian Health Board (Departed group 10/99)

Bea Kelleigh - Executive Director, Hanford Health Information Network Resource Center

Stan Marshall - Radiological Health Section, Nevada State Health Division

Robert Musil - Executive Director, Physicians for Social Responsibility

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Kelli Marciel - Presidential Management Intern, Health Promotion Branch

Jim Mathews - Senior Science Writer, Health Promotion Branch

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I.3.4 Proposed Campaign Operating Principles

- ◆ Honesty, openness to differing points of view, and a willingness to answer questions will characterize the ongoing planning, operation, and evaluation of the campaign.
- ◆ Trust and credibility will be earned and maintained by providing accurate and comprehensive information.
- ◆ The campaign will be respectful of human rights and the dignity of affected people.
- ◆ Persons who may have been exposed to radiation released from the Nevada Test Site will be involved in the development, implementation, and guidance of the campaign.
- ◆ Campaign information will be accurate, scientifically sound, and will explain the uncertainties of current knowledge.
- ◆ Information will be supportive, reflecting compassion and an understanding of scientific, medical, psychological, and ethical issues involved.
- ◆ The campaign will consider the needs of underserved populations and will strive for social equity.
- ◆ Efforts will be outcome-oriented.

I.3.5 List of Other Resources

- ◆ The NCI Fallout Report and all Campaign materials, including an individual dose/risk calculator can be found online at www.cancer.gov/I-131.
- ◆ The IOM's review of the NCI report can be viewed online as well. Visit www.nap.edu and enter 'Exposure of the American*' in the "search all titles" field.
- ◆ The National Research Council report referenced by Kristin Shrader-Frechette in her remarks, *Understanding Risk: Informing Decisions in a Democratic Society*, is also available at www.nap.edu using the title search feature.

- ◆ The Agency for Toxic Substances and Disease Registry Continuing Education Course for health care professionals, *Case Studies in Environmental Medicine: Radiation Exposure from Iodine-131*, is available on the ATSDR website.

Other valuable websites:

- ◆ CDC's National Center for Environmental Health, Radiation Studies Branch homepage (includes links to Hanford Thyroid Disease Study):
www.cdc.gov/nceh/programs/radiation
- ◆ [Hanford Community Health Project](#), an outreach and education initiative sponsored by ATSDR, provides educational information and materials about potential health risks to individuals who were exposed as young children to past releases of radioactive iodine (I-131) between 1944 and 1951 from the Hanford Nuclear reservation, in Washington State: <http://www.atsdr.cdc.gov/hanford/>

The NCI publication *Making Health Communication Programs Work: A Planner's Guide, a resource for health communicators*, first published in 1989 and widely known as the "Pink Book." The 2002 updated version reflects recent advances in knowledge and technology, such as the Internet, that can affect the communications process. This handbook presents key principles and steps in developing and evaluating health communications program for the public, patients, and health professionals. It can be viewed online at www.cancer.gov/pinkbook. Print or CD-ROM copies can be ordered by calling 1-800-4-CANCER (1-800-422-6237) or online at <http://cancer.gov/publications>.

I.4 Report of Key Findings: In-depth Interviews with Experts About I-131 Exposure from the Nevada Test Site

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January 2000

I. INTRODUCTION AND METHOD

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, NCI conducted 19 in-depth interviews with individuals who have expertise in areas related to the issue of nuclear fallout. The main objectives of this research were to measure awareness level, concern, familiarity with, and evaluation of the NCI Report and IOM recommendations about I-131 from the Nevada Test Site, and to obtain recommendations about how to conduct a communication campaign.

A working group consisting of NCI staff, CDC staff, and a panel of community representatives generated a list of potential interviewees. Individuals were suggested in a number of categories, including state and local public health officials, community advocates (including environmental, health, and pro-nuclear groups), scientific experts (e.g., radiation scientists), health-oriented professional organizations, veterans, health care providers (e.g., thyroid specialists), and health educators.

The selection of interviewees was based on the following criteria: 1) level of expertise; 2) an effort to obtain representation from all the categories listed above; and 3) geographic diversity. The original interviewee list was comprised of 29 contact names collectively agreed upon by working group members. Interviews were completed with 19 interviewees. When an effort to contact a particular interviewee was not successful, an alternate name was generally provided by working group members. Alternates were selected from the same type of background as the originally proposed interviewee.

In order to report the interview results in a way that incorporates the contextual background of individuals, interviewees were separated into three major reporting categories:

Public Health Officials: Six government officials were interviewed in this category. Participants included those employed in public health departments in states with varying degrees of I-131 exposure from the Nevada Test Site and other representatives involved in radiation issues at the state level.

Advocacy Groups: Seven individuals were interviewed in this category. Participants held a variety of positions in organizations dedicated to different issues associated with nuclear or radiation issues. Organizations were selected to represent a broad range of opinion. Included in this category were representatives of groups dedicated to radiation-exposed populations, the environment, and the advancement of nuclear science.

Scientific Experts: Six individuals were interviewed in this category. Participants included both radiation and thyroid experts associated with a variety of institutions.

Interview questions were designed to measure awareness, concern and opinions about what constitutes an appropriate outreach response (See Attachment H-4-A for a copy of the interview instrument). It should be noted that the interview guide was not followed verbatim, and language was altered in some cases to be sensitive to the background and expertise level of each respondent. Each interview lasted approximately 30 minutes.

It should also be noted that in-depth interviewing is a qualitative research technique. Although the findings from this research can provide useful detailed insights into the perceptions and views of different organizations and experts involved with the I-131 fallout issue, they cannot represent the views of all such groups or persons.

II. KEY FINDINGS

This section outlines the key/preliminary findings from the interviews. Differences in responses between reporting groups are outlined separately.

A. Awareness and Concern

- **For public health officials, the NCI report frames the boundaries of awareness.**

When asked what they knew about the potential health effects of the Nevada Test Site, the majority of public health officials cited the NCI study as their primary reference point. All agreed that thyroid cancer or “the thyroid problem” was the main potential health outcome to be concerned about. Although two officials mentioned other possible conditions, like autoimmune illnesses and damage to other organs, they qualified these statements indicating that the data and science were only available on the thyroid cancer link. Only one official could name other radioactive substances released from the site in addition to I-131.

On a scale of one to ten, with one indicating “not at all severe” and ten indicating “very severe,” most officials gave the potential health effects from the Nevada Test Site a fairly low severity rating of two or three. Only one official gave it a relatively high rating of six.

None of the officials said their organization had a formal position on I-131 exposure from the Nevada Test Site. One official, in a state with some highly exposed counties, said they were “struggling” to determine whether or not the potential risks justify a public outreach effort.

- **Advocacy groups have a far broader scope of concern.**

Fewer advocacy group participants mentioned the NCI report when asked about their knowledge of the potential health effects of the Nevada Test Site. Although most mentioned thyroid cancer and other non-cancerous thyroid abnormalities as possible outcomes, a few participants also mentioned leukemia. One representative said genetic mutations and birth defects were also a possibility.

In addition to being concerned about more health effects, advocacy group representatives were also more aware of other radioactive materials emitted from the tests. The most frequently cited substances after I-131 were cesium, strontium, and plutonium. When asked which substances they worried about the most, advocates said that all the substances posed significant reasons for concern, but for different reasons. Some pointed out the varying half-lives of the substances; several, for example, talked about plutonium's ability to persist in the environment for long periods of time. One representative took the opportunity to say that the NCI report was "too narrowly and conveniently" focused on thyroid cancer instead of on other more lethal cancers like leukemia, breast and bone cancer that may be caused by other materials like strontium and cesium.

Advocates rated the severity of the health effects from the Nevada Test Site much higher than did the public health officials. Most gave a rating somewhere in the range of eight to ten. Only one respondent thought differently. This participant, who refused to use the rating scale, characterized the potential health effects from Nevada Test Site exposure as 100 times more severe than an accident like Three Mile Island or waste disposal sites, but much less severe than radiation received from medical diagnostic tests.

All but two representatives said their organization had a position on exposure from the Nevada Test Site. One representative said there needed to be more education and research on the association between exposure and non-thyroid disorders, particularly parathyroid disorders. Another said the government needed to be more "forthright" and "conscientious" in its efforts to inform the public. Others called for health care provider education efforts and clinical screening and monitoring. Although two representatives said their organization did not have a formal or official position, they did say their organization generally supports the cause of research and educational efforts conducted for the benefit of exposed populations.

- **Concerns of scientific experts are defined by their evaluation of "the evidence."**

Scientific experts chose to focus primarily on the thyroid-cancer link when asked what they knew about the health consequences of the Nevada Test Site. Most made evaluative comments about the findings. The level of detail provided about the relationship between I-131 and thyroid cancer varied by the type of expert. Radiation experts provided much more detailed information and critiques of the NCI data. One such expert said, "I am aware that 10,000 to 75,000 new thyroid cancers will result from these tests." Another radiation expert characterized the findings as "statistically suggestive rather than significant." Strontium, cesium, and plutonium were most frequently mentioned by radiation experts as some of the other key radionuclides that were emitted from the tests. One expert said I-131 should be paid the most attention because it was the "main fallout product."

Thyroid experts had less detailed knowledge and seemed to retain only the facts they felt were relevant to their concerns and practice areas. These specialists were primarily concerned about the relationship between I-131 and thyroid disorders and less interested in other health effects. They were aware of the Nevada Test Site solely because of its relationship to I-131 (an issue thyroid specialists are quite knowledgeable about), since the

site presents another potential avenue of iodine exposure. These specialists expressed limited concern, stating that exposure was found to be minimal for the most part and that thyroid cancer is highly treatable.

Expert ratings of the severity of potential health effects were more mixed than the other two interviewee groups. One radiation expert rated the severity of the health effects as a one or a two, while another rated it as an eight or nine. Many had difficulty providing unqualified responses, probably due to their high knowledge levels. For example, one radiation expert said the severity rating is dependent on geography, giving a one for a person living in New York City and a four for a person living in Utah. Thyroid specialists shared more commonality in their ratings with most giving it a low rating of a one or two. One specialist said the rating is dependent on age of exposure, giving it a rating of five for a child and only a rating of one for an adult.

B. Familiarity and Evaluation of NCI Report and IOM Action Recommendations

- **Public health officials are in agreement with findings and recommendations.**

All public health officials were quite familiar with the reports, and most had a good working knowledge of risk factors and other specifics. Officials in states with heavily exposed populations were more informed than officials from states with less exposure. One official of a state with areas of high exposure reported using the NCI data to conduct their own state-level investigation. Two officials in less exposed states had a more general level of knowledge about the NCI findings.

Overall, public health officials found the reports useful. Two officials said the most useful information was the county-level exposure information. Two others said the reports serve as good background pieces about the relationship between I-131 and thyroid cancer and will be a useful framework for thinking about other exposure sites throughout the country. There were few suggestions for additional information. One official said more definitive information on the risk associated with I-131 exposure was needed to determine what the exposures really mean from a health perspective. Another official thought information on the relationship between I-131 exposure and non-cancerous thyroid disorders would be important to have since there was a lot of “talk” about this issue.

All officials agreed with the IOM position that screening would cause more harm than good, due to the number of false positives. One individual said screening was also not advisable because the exposure findings were uncertain, and individuals would be better served if their own doctor decided whether or not screening was appropriate for them.

Most public health officials thought the proposed strategy of educating the general public and providing physicians with information to respond to inquiries would be very effective. Some said this was important because health care providers lack knowledge about the association between iodine and thyroid disease. One individual said it would be effective because people listen to and trust their doctors. Another official thought that the strategy

made sense but that the nature of the information would be difficult for the public to understand.

- **Advocacy groups disagree more with findings and recommendations.**

Approximately two-thirds of the advocates said they were very familiar with the NCI and IOM reports. The remaining one-third recalled major pieces of information but without specifics. Advocacy group opinion about the information in the reports was considerably more divided than among public health officials. One representative said that some of the exposure information was inaccurate and that there were more areas listed as low-exposure areas than should be. Another representative held the opposite view, saying that there were more high-exposure areas than should be. A couple of representatives said the reports were useful in the sense that there was an “admittance” of responsibility, and some information was at least “out there.” And another representative took credit for pushing Congress to get the report “done in the first place.”

Advocacy representatives were far less supportive of the IOM screening recommendations than public health officials. Half thought screening for thyroid cancer was necessary, and half agreed that it was not a beneficial course of action. One individual supported the notion that screening for thyroid cancer would result in too many false positives, but felt screening for other disorders like hypothyroidism and hyperparathyroidism should be conducted.

When asked how effective the IOM strategy of educating physicians and the public would be, most advocates characterized the strategy as one that would be “helpful.” Two participants focused on the need to educate physicians so patients will be “taken seriously” and will not have to “educate their physicians.” Only one participant felt the action would be unnecessary and expressed doubt about the ability to educate physicians who are “essentially lay people when it comes to nuclear and radiation issues and lack technical knowledge and background.”

- **Thyroid experts are in agreement, while radiation experts are more divided.**

While the radiation experts were very familiar with the NCI and IOM reports and had examined them in detail, the thyroid specialists were only vaguely familiar with the actual reports. Despite their uncertainty about having read the reports, however, the thyroid specialists felt certain that they understood the overall findings from other sources like professional journals, newspapers, and presentations. In general, they recalled that the exposure did not pose a very significant health threat.

Those radiation experts who had read the reports found some information useful and some not. While one expert said the reports were “most inclusive and helpful,” another said they were “inconclusive” because the findings were “extrapolated from only 100 sites.” Another expert felt the information was useful, but needed to be translated in a way that would make it possible for the lay public to understand. The lack of “risk information” was “curiously avoided,” according to another expert.

The radiation experts were also divided on the issue of screening. One agreed with the argument that “screening will do more harm than good.” Another agreed that it made no sense to screen the general population, but did think the issue of screening high-risk populations needed to be addressed. Another expressed agreement with not screening for thyroid cancer, but thought looking into screening for other non-cancerous thyroid disease was essential. The thyroid specialists were less divided, all indicating that wide-scale screening for thyroid cancer would result in too many false positives and could result in harm to the patient in terms of unnecessary surgical procedures.

Most experts thought the action recommended by the IOM would be very effective. Their reasons for thinking this strategy would be effective were similar to those of the other groups. Explanations provided were that physicians lack knowledge and have direct patient contact, while patients for the most part feel comfortable with their doctors. One expert said the strategy would be only “moderately effective” because physicians may not take the time to review the information provided and because not everyone has health insurance and/or is under the care of a physician.

C. Educational Efforts: What’s Needed?

- **Public health officials think risk factors should determine the focus and scope of the campaign.**

When asked if the entire U.S. needs to be the target of an educational effort or if the effort should be confined only to those most heavily exposed, officials answered in accordance with their understanding of the risk factors and exposure patterns. One official thought the campaign could be focused on those who were children at the time and drank milk from a backyard goat or cow since these individuals were most at risk. Another official thought everyone should be given information, but the campaign should be more aggressively focused on those at higher risk. Those who thought a campaign would need to target the whole population grounded their opinions on the premise that it would be difficult to “find” everyone at high risk due to factors like mobility and storm and wind patterns.

By far, the most important information that officials thought needed to be provided to people is a profile of the risk factors. One official thought such a profile, along with an 800 number for those who need more information, would be a good idea since it is so difficult to separate out those who need to be concerned from those who don’t.

- **Advocacy groups say a “right to know” argument prevails.**

A majority of advocates said a national campaign was needed because citizens have “a right to know” about the actions of their government. For example, one advocate said, “Everyone should know that this was done without our knowledge” because “the government has no right to contaminate us.” Another said information should not be “denied to people,” but qualified the response by saying it would be difficult to really get the information to everyone because a “large portion of the public is apathetic,” especially when something seems so “far away.” Some thought a general public information campaign was needed

along with a more targeted and aggressive effort to ensure that high-risk groups are reached. Only one advocacy group representative thought that little needed to be done; this individual expressed the view that something “had to be done” because the issue had become “so political,” but thought that the campaign should be very targeted to those at highest risk.

In addition to providing information on risk factors, advocates often mentioned a need to translate the information into a format that people can understand. One said people need to be provided with a listing of symptoms that may signal a thyroid problem so they can ask their doctor for a blood test or ultrasound. Another said people needed all the information required to calculate their own dose.

- **Scientific experts propose solutions mixed with some worry about invoking “unnecessary” fear.**

Although solutions proposed by scientific experts varied, more participants in this group than others expressed concern about the need to present information in a way that does not provoke anxiety or panic on the part of the public. The thyroid specialists frequently made this argument and expressed a preference for a targeted “talk to your doctor” type approach, especially aimed at those who were children at the time of exposure. One specialist thought it would be important to assure people that the NCI study was a “very carefully run study so they should not be afraid.”

Radiation experts were more divided. One expert thought the “right to know” demanded a national campaign. This individual characterized the notion of a targeted campaign as a scientific impossibility because it would be too difficult to “find” the people most heavily affected. Another felt the information was already “out there” for people who needed to find it. He said that “the advocates do a good job of letting people know who need to know” and any further effort will start a public panic.”

D. Participant Recommendations for How to Conduct a Campaign

- **The majority of participants are in consensus about campaign “how-to’s.”**

Although there was much disagreement about the appropriate scope and focus of a potential educational information campaign, a high degree of consensus emerged on how a campaign would be best implemented.

- Most participants said that such a campaign would need to be conducted at a national level with significant use of mass media. Even many of those who thought more targeted campaigns were appropriate “back-tracked” a little here, realizing that a national effort may be needed in order to “find” everyone.
- Providing information about exposure and risk was seen as important; dose information, as less so. A substantial amount of concern was expressed about the use of risk comparisons because they may tend to trivialize the issue.

- By far, participants across all three groups thought a coalition of different types of organizations (government, advocacy groups, and non-profits) should implement the campaign.
- The belief that a coalition was needed to counteract a lack of public trust in government and lend credibility to the campaign was expressed far more often by advocates than by public health officials and scientific experts.
- State public health officials thought their departments could play valuable coordinating roles at the state and local levels.
- In terms of federal government participation, there was little preference for which agency(ies) should lead the effort. It became apparent throughout many of the interviews, particularly with advocates, that individuals do not make distinctions between various federal agencies -- for example, CDC, NCI, the Department of Energy (DOE), or the Environmental Protection Agency (EPA). Many think of the “government” as an all-encompassing entity. When participants did make agency recommendations, NCI and CDC were the most frequently mentioned.
- Participants thought a variety of materials and resources would be helpful to their organizations: fact sheets, information kits, videos, in-person meetings, conferences and web-based materials. Web-based information was very appealing; videos and in-person meetings, somewhat less so.

INTERVIEW GUIDE FOR IN-DEPTH INTERVIEWS ABOUT I-131 EXPOSURE FROM THE NEVADA TEST SITE

November 1999

I. INTRODUCTION (3 MINUTES)

Hello, my name is _____ from Porter Novelli, and I'm calling on behalf of the National Cancer Institute and the Centers for Disease Control and Prevention. These organizations are currently working to develop educational efforts to address health effects that may be related to nuclear fallout from an atomic weapons testing program conducted in Nevada in the 1950s and 1960s. Do you have approximately 30 minutes so that I can talk with you about health issues related to the Nevada nuclear tests?

[IF YES, CONTINUE. OTHERWISE, TRY TO RESCHEDULE FOR ANOTHER DAY AND TIME.]

If it is alright with you, I would like to audio-record this discussion because everything you say is important. All of your comments will be kept confidential, and your responses will never be connected to your name or organization.

IA. ORGANIZATIONAL DEMOGRAPHICS (4 MINUTES)

First of all, I'd like to understand more about your organization.

1. What is your organization's mission and goals?
2. Who or what does your organization represent?
3. Does your organization have membership? Approximately how many members do you have?
4. Does your organization have any other core audiences or stakeholders?
5. How do you typically communicate with your audiences?

II. AWARENESS AND CONCERN (5-10 MINUTES)

1. What nuclear or radiation issues are you involved with or concerned about?

PROBE for both locations (e.g., Hanford, etc.) as well as different types of radiation.

2. I'd like to talk specifically about the Nevada nuclear bomb tests now. What knowledge do you have about the Nevada tests and their consequences? What about health effects specifically?

PROBE: Potential cancer-related health effects?
Non-cancer-related effects?

3. Overall, on a scale of 1 to 10 (with 1 meaning not severe at all and 10 meaning very severe), how severe do you think the possible health effects of the Nevada nuclear bomb tests are? (INTERVIEWER NOTE: Collect professional/organizational perspective rather than personal.)
4. How would you rate the severity of these effects in relation to other nuclear or radiation issues that you are concerned about on a scale of 1 to 10? (INTERVIEWER NOTE: Collect professional/organizational perspective rather than personal.)
5. About 100 nuclear bomb tests were carried out in Nevada in the 1950s and 1960s. These tests released different types of radioactive material into the atmosphere. Which of these radioactive materials are you aware of?

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

Before proceeding, I'd like to provide you with some additional background. One of the radioactive materials released from the Nevada tests was Iodine 131, commonly referred to as I-131. As you are probably aware, some epidemiological studies have found an association between exposure to I-131 and the risk of thyroid cancer. In addition, I-131 may also be related to other types of thyroid disease, such as hypothyroidism or an underactive thyroid gland, hyperparathyroidism, a condition in which the parathyroid glands located next to the thyroid become overactive, and noncancerous thyroid growths. While everyone in the United States experienced some exposure to the I-131 fallout, those in areas adjacent to the Nevada Test Site, downwind, and in other areas of the country where wind patterns served to increase fallout were most heavily exposed. These risks may be highest for young children who drank milk and lived in high fallout areas during the time of the tests.

[INTERVIEWER NOTE: Read high-exposure state list only if interview asks about the heavily affected region: Some adjacent states with high county exposure rates are

Colorado, Idaho, Kansas, Minnesota, Missouri, Montana, Nebraska, Nevada, South Dakota, Utah.]

In 1997 and 1999, two documents regarding the Nevada tests were released to the public. The National Cancer Institute or NCI released results of a study that assessed U.S. residents' possible exposure to radioactive Iodine-131 fallout during and shortly after the nuclear bomb tests.

In addition, the National Academy of Science's Institute of Medicine or IOM released a review of the NCI's methods and findings. This review also included recommendations on educating the general public about I-131 and advising physicians on how to approach patients who may have questions about I-131.

6. How familiar are you with the NCI and IOM reports, if at all?
7. If FAMILIAR: Do these reports provide your organization with the information you need to communicate with your key audiences about this issue?

IF YES, PROBE: What information is useful?

IF NO, PROBE: Why haven't the reports been useful?

8. Aside from what is provided by the NCI and IOM reports, what else does your organization know about this issue?

PROBE: Where has your organization gotten that information?

How has that information been useful?

9. What additional information do you need to understand the issues involved with I-131?
10. Does your organization have a position on the issues surrounding I-131 exposure from the Nevada Test Site?

IF YES: What is that position?

What specific concerns about I-131 exposure does your organization have?

III. EDUCATIONAL EFFORTS (10-15 minutes)

1. Residents of the U.S. were not uniformly exposed to I-131 fallout. In addition to factors such as geography and residential history, the dose of radiation individuals may have received varies by other factors, like age and dietary patterns.

In your opinion, who needs to be informed about the possible risks of associated with the I-131 emitted by the nuclear tests? Should everyone in the U.S. be the focus, or should information be more targeted to those who may have been more heavily exposed?

[INTERVIEWER NOTE: Read high exposure state list only if interview asks about the heavily affected region: Some adjacent states with high county exposure levels are Colorado, Idaho, Kansas, Minnesota, Missouri, Montana, Nebraska, Nevada, South Dakota, Utah]

2. What information do you think people who were heavily exposed need about I-131?

IF THEY BELIEVE GENERAL PUBLIC SHOULD BE INFORMED: Which of these types of information do you think the general public should know?

3. Now I'm going to read you a list of different types of educational information that could be provided. Please rate how helpful each would be on a scale from 1 to 5 with 1 meaning not helpful at all and 5 meaning very helpful.

- a. Potential exposure levels based on factors like geography and age
- b. Dose information, an estimate of the amount of radiation actually absorbed by the thyroid)
- c. Risk information about potential health effects
- d. Risk comparisons, which quantify risk levels in various contextual ways to aid understanding
- e. Information about scientific uncertainties surrounding the estimates and associations between cause and effect

4. What do you think would be the most effective way to reach these populations?

PROBE: Should education be conducted on a national, regional or local level? Why?

5. The IOM report concludes that the available science does NOT warrant routine clinical screening for thyroid cancer in the general population or within subgroups of the population as an intervention strategy. Do you think that the general population or any groups within the population need to be screened? Why or Why not?

The IOM report suggests that the general public be targeted with educational information about their possible exposure to I-131 from the nuclear bomb test fallout. It also suggests that information be provided to health care providers so they can answer any questions that members of the public may ask them about the fallout and potential health consequences such as thyroid cancer.

6. How effective do you think this approach would be in educating the general public about I-131 fallout from the nuclear tests at the Nevada Test Site? Why?

7. What else, if anything, do you think would need to be done to better educate the general public about the issue of I-131 exposure?
8. Overall, who do you think should implement these efforts? Who should NOT conduct them?

PROBE: Government agencies, non-profit organizations, or advocacy groups?
National, regional, state, or local level?

IF FEDERAL GOVERNMENT AGENCIES: Which government agencies do you think should implement the efforts? (PROBE: CDC, EPA, NCI, DOE)

(INTERVIEWER NOTE: If regional, state, or local organizations are suggested, collect information that would be useful for future contact.)

9. Would your organization want to play a role in efforts to educate the public about possible I-131 exposure from nuclear tests conducted at the Nevada Test Site?

IF YES: Which publics or groups would your organization want to play a role in educating?

What would that role be?

How would that role fit in with your organization's mission, goals, values, and activities?

10. Now, I'm going to read you a list of materials. Please indicate on a scale from 1 to 5 how helpful each would be to your organization (with 1 meaning not helpful at all and 5 meaning very helpful).
 - a. Stand-alone materials such as brochures and fact sheets
 - b. Information kits
 - c. Videos
 - d. In-person meetings
 - e. Conferences/group meetings
 - f. Web-based materials
 - g. Would any other types of materials be helpful?

IV. CLOSING (2 MINUTES)

Thank you very much for speaking with me today. NCI and CDC are working together on this project to provide information on this issue to the public and health care providers. If you have any questions or if you would like to receive materials about the Nevada tests and I-131 fallout, please call Kelli Marciel at the National Cancer Institute at 301-496-6667.

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 15.⁶ 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

⁶ 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.

research with both the higher- and lower-exposure public was done to obtain a 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 with⁷.

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.

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

⁷ 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.)

	Agree	Neither Agree nor Disagree	Disagree	Don't Know/ Refused
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.)

	a. Lived in state from age 0-15	b. At least 5 years (ASK HIGHER RISK ONLY)
(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.

	Familiar	Neither Familiar Nor Unfamiliar	Not at All Familiar	Don't Know/Refused
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.)

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: _____

	City	Group	Facility	Date	Time
<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.)

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)

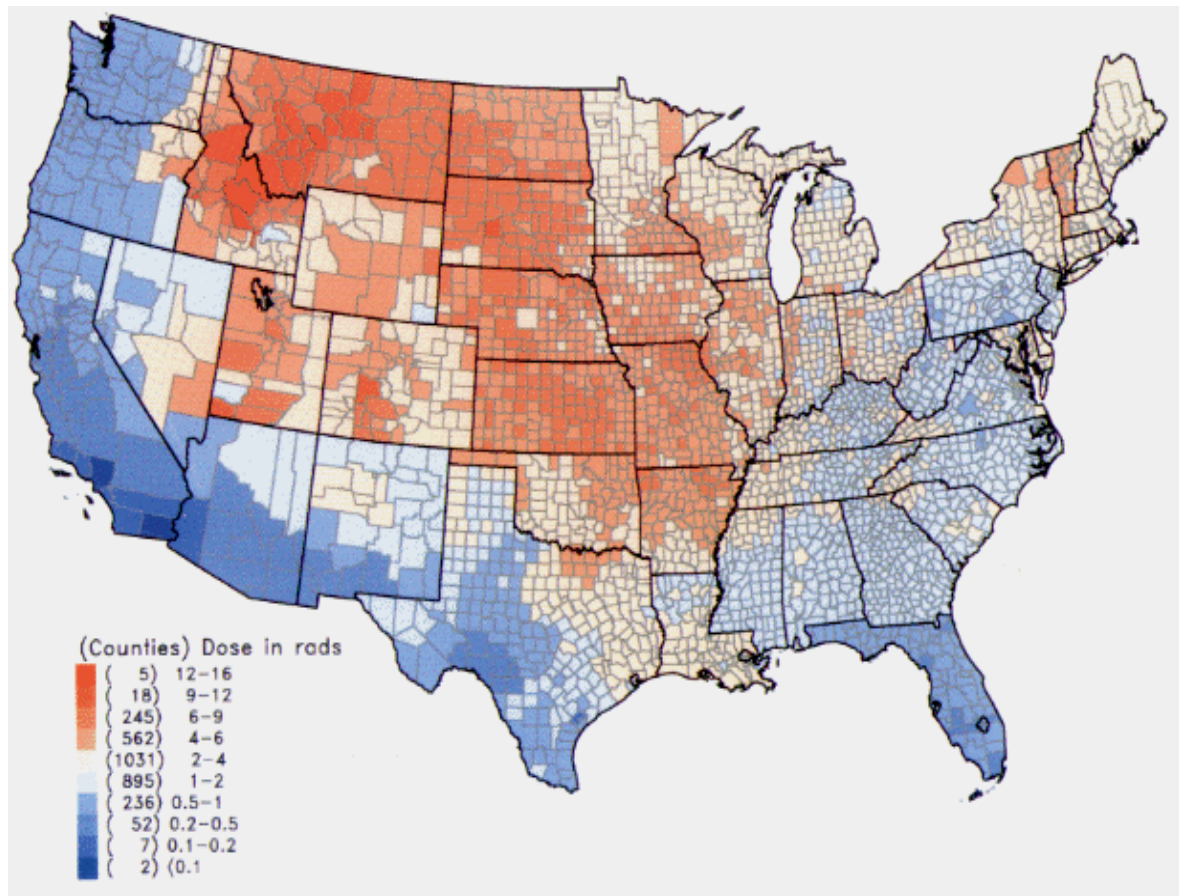
1. CHECK WITH OBSERVERS FOR ADDITIONAL QUESTIONS.
2. Those are all of the questions I have. Do you have any final comments?
3. Thanks for your participation today. I have some bookmarks that can provide you with current information about what we've discussed this evening. Feel free to take one before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



I.6 Tools for Research

(see next page)

1 Table I.6.1 “Tools” typically utilized for communications planning research.

Research Method	Description	Pros	Cons	Common Uses
Surveys/Questionnaires (self-administered)	Questionnaires or survey forms are filled out by the respondents themselves. Clarity in question design and instructions for completion are important.			
By mail	Questionnaires or survey forms are sent to potential subjects for them to complete on their own time and mail back to researcher.	<ul style="list-style-type: none"> • Generalizable results (if sufficiently large, probability sample with high response rate) • Can be anonymous (especially useful for highly sensitive topics) • Respondents can answer questions when most convenient for them • Can collect both program data and personal data (e.g., participant characteristics) • Does not require staff time to interact with target population • Can be used to access difficult-to-reach populations (e.g., the homebound, rural populations) • Can incorporate visual material (e.g., can pre-test prototype materials) 	<ul style="list-style-type: none"> • Not appropriate for respondents who cannot read or write • Low response rate diminishes value of results. May require follow-up by mail or telephone to increase response rate (increases total costs). • Respondents may return incomplete questionnaires • Limited ability to probe answers • Respondents may self-select (potential bias) • May take long time to receive sufficient numbers of responses • Does not yield reliable assessments of attention-getting ability or recall of message • Postage may be very expensive if sample is large 	<ul style="list-style-type: none"> • Obtain baseline data • Acquire self-reported information on behaviors, behavioral intentions, attitudes • Determine message’s reach, attention-getting ability • Test knowledge, comprehension

Research Method	Description	Pros	Cons	Common Uses
By handout	Respondents are asked to complete survey at a location frequented by the target population (e.g., during a conference, in a classroom, after viewing an exhibit at a health fair).	<ul style="list-style-type: none"> • Can more readily improve response rate because there is an opportunity to use face-to-face persuasion tactics • Can collect both program data and personal data (e.g., participant characteristics) 	<ul style="list-style-type: none"> • Not appropriate for respondents who cannot read or write • Must be able to reach respondents in person at a central location or a gathering 	<ul style="list-style-type: none"> • Obtain baseline data • Acquire self-reported information on behaviors, behavioral intentions, attitudes • Test knowledge, comprehension
By Computerized Self-administered Questionnaires (CSAQ)	A questionnaire is programmed and displayed on a computer screen with respondents keying in their answers. Requires that respondents have access to programmed computers and that they be somewhat familiar and comfortable with using computers.	<ul style="list-style-type: none"> • Useful for complex questionnaires because complex “skip patterns” can be preprogrammed • Can control sequencing of questions • Can provide quick summary and/or analysis of results by eliminating the step of data entry from paper questionnaires or interviews 	<ul style="list-style-type: none"> • Not appropriate for audiences who cannot read or those unfamiliar or uncomfortable with computers • Requires expensive technical equipment that may not be readily available or may be cumbersome in many settings 	<ul style="list-style-type: none"> • Test knowledge, comprehension • Acquire self-reported information on behaviors, behavioral intentions, attitudes • Pre-test visual material • Determine if audience attends to, comprehends, and remembers contents of message.
Surveys/Questionnaires (administered by interviewer)	A trained interviewer asks survey questions of respondents. Allows respondent to ask for clarification and allows interviewer to control question sequence.			

Research Method	Description	Pros	Cons	Common Uses
By telephone	Respondents are contacted via telephone by trained interviewer. Respondents may be selected in advance from a list or contacted randomly (increases generalizability of results).	<ul style="list-style-type: none"> • Generalizable results (if sufficiently large, probability sample with high response rate) • Appropriate for those of lower literacy • Interviewer available to clarify questions for respondent and probe answers • Decreased likelihood of incomplete questionnaires 	<ul style="list-style-type: none"> • Requires interviewer training • Low response rate diminishes value of results • Potential respondents who do not have a phone cannot participate • Respondents often hang up if they believe the survey is part of a solicitation call 	<ul style="list-style-type: none"> • Obtain baseline data • Determine message's reach, attention-getting ability • Acquire self-reported information on behaviors, behavioral intentions, attitudes • Test knowledge, comprehension.
By computer-assisted telephone interviewing (CATI) technology	Respondents are contacted via telephone by a trained interviewer who has the questionnaire displayed on a computer terminal. The interviewer enters data directly into the computer.	<ul style="list-style-type: none"> • Generalizable results (if sufficiently large, probability sample with high response rate) • Can program allowable codes for responses which interviewer can use to correct mistakes during interview • Can program help menus to assist interviewer • Computer controls question sequence, allowing complex "skip patterns" • Provides a more efficient means of generating a probability sample 	<ul style="list-style-type: none"> • Considerable development work and lead time are needed before survey implementation • Requires much interviewer training • Not useful for small samples because the workload costs of CATI exceed the benefits 	<ul style="list-style-type: none"> • Obtain baseline data • Test knowledge and comprehension • Obtain self-reported information regarding attitudes and behaviors.

Research Method	Description	Pros	Cons	Common Uses
Face-to-face	One-on-one, in-person interview is used to collect information on knowledge, attitudes, and/or behaviors.	<ul style="list-style-type: none"> • Generalizable results (if sufficiently large, probability sample with high response rate) • Appropriate for those of lower literacy • Useful with difficult-to-reach populations (e.g., homeless, low-literacy) or when target audience cannot be sampled using other data collection methods • Interviewer available to clarify questions for respondent and probe answers • Decreased likelihood of incomplete questionnaires 	<ul style="list-style-type: none"> • Can be more labor intensive than self-administered or telephone data collection • Less appropriate for sensitive or threatening questions (respondents may not answer truthfully in person) 	<ul style="list-style-type: none"> • Obtain baseline data • Determine message's reach, attention-getting ability • Acquire self-reported information on behaviors, behavioral intentions, attitudes • Test knowledge, comprehension

Research Method	Description	Pros	Cons	Common Uses
Central location intercept interviews	Potential respondents are approached in a public area by a trained interviewer and invited to participate in the survey. Usually conducted in a high-traffic area (e.g., mall, student union) or other area frequented by target population. Requires highly structured, pre-determined questions that primarily use multiple-choice or close-ended questions.	<ul style="list-style-type: none"> • Can connect with harder-to-reach respondents in locations convenient and comfortable for them • Can be conducted quickly • Cost-effective means of gathering data in relatively short time • Increased number of respondents within intended population if appropriate location chosen • Larger sample size than focus groups • Eliminates group bias that is possible in focus groups 	<ul style="list-style-type: none"> • Requires interviewer training • Quota sample, not probability sample • Not appropriate for sensitive issues or potentially threatening questions • Cannot easily probe for additional information (too time consuming) 	<ul style="list-style-type: none"> • Test program messages, materials
Written responses to requests for information (e.g., diaries, activity logs, anecdotal accounts)	Information is requested in a specific format from individuals implementing a program or from participants themselves. Information may relate to such issues as quality of program components or how components are used by target population.	<ul style="list-style-type: none"> • Can allow respondents more flexibility in their replies • Can enable researchers to receive reports on behavior over time, rather than a “snapshot” 	<ul style="list-style-type: none"> • Requires considerable effort on respondents’ parts • Incoming data may be voluminous and challenging to code and compare • Not appropriate for respondents who have poor writing 	<ul style="list-style-type: none"> • Track program implementation • Learn what questions program participants had • Learn what technical assistance was needed by program staff

Research Method	Description	Pros	Cons	Common Uses
<p>Review of existing data (e.g., program registration rolls, grocery store receipt tapes, hospital discharge records)</p>	<p>A structured evaluation of information previously collected by local, state, or national agencies is undertaken. Existing sources of health data (statistics, tracking records, treatment patterns) may be available on the World Wide Web or through government agencies, local or university libraries, health departments, clinics or hospitals, police departments, schools, research or nonprofit organizations. Organizations may collect data not originally intended as health data, but useful nonetheless. Examples include grocery store receipts and event attendance records. Analysis of existing data is useful for all forms of evaluation</p>	<ul style="list-style-type: none"> • Use of existing data means less effort in data collection • May be inexpensive if owner of data provides them at little or no cost • Possible sources of data are plentiful 	<ul style="list-style-type: none"> • Diminished ability to control data points and data collection methods 	<ul style="list-style-type: none"> • Conduct needs assessment • Track the number of people engaging in a behavior in a given locale (e.g., accessing free mammography screening services, purchasing sunscreen).

Research Method	Description	Pros	Cons	Common Uses
In-depth personal interviews	Qualitative data collection method involves less rigid question structure and interviewing style than quantitative methods.	<ul style="list-style-type: none"> • Can explore long or complex draft materials • Can be effective with those of lower literacy • Allows considerable opportunity to probe answers • Allows for intensive investigation of individual thought, opinions, and attitudes 	<ul style="list-style-type: none"> • Time consuming • Requires level of trust between interviewer and respondent, especially when dealing with sensitive or threatening material • Interviewer must be highly skilled in active listening, probing, and other interviewing skills • Interviewer must be knowledgeable about and sensitive to a respondent's culture or frame of reference 	<ul style="list-style-type: none"> • Develop concepts or messages • Test long or complex draft materials • Conduct a needs assessment.
Focus groups	This tool is a qualitative method of data collection wherein a skilled moderator facilitates discussion on a selected topic among 6 to 10 respondents, allowing them to respond spontaneously to the issues raised. Lasts for 60 to 90 minutes per session. For focus group research to be most valuable, the moderator must cover the research topics, establish an environment in which all points of view are welcome, and follow up on unexpected but potentially valuable topics that are raised.			

Research Method	Description	Pros	Cons	Common Uses
Face-to-face	When focus groups are conducted in person, participants and the moderator gather, usually around a table. Observers (members of the research team) sit behind a one-way mirror or unobtrusively back from the table and take notes. Groups may also be recorded by audio- or videotape.	<ul style="list-style-type: none"> • Interaction in the group can help elicit in-depth thought and discussion • Considerable opportunity to probe answers • Can yield richer data than surveys about the complexities of audience's thinking and behavior • In-person groups give moderator more opportunity to read nonverbal cues and use nonverbal cues to control the flow of discussion than in telephone focus groups • Rapport can be fostered more easily among in-person groups than telephone groups 	<ul style="list-style-type: none"> • Findings not generalizable • Respondents may be concerned about lack of anonymity • Can be labor intensive and expensive, especially if groups are conducted in multiple locations 	<ul style="list-style-type: none"> • Explore complex topics with target audience prior to program (e.g., what helps/hinders healthy eating) • Learn about feelings, motivators, past experiences related to a health topic • Test concepts, message, materials, and artwork • Can generate and test hypotheses.

Research Method	Description	Pros	Cons	Common Uses
By telephone	When focus groups are conducted by telephone, the moderator and participants speak by conference call with observers listening and taking notes. Telephone groups may be recorded by audiotape. Typically, 6 to 8 people participate.	<ul style="list-style-type: none"> • Interaction in group can help elicit in-depth thought and discussion • Considerable opportunity to probe answers • Can yield richer data than surveys about the complexities of audience's thinking and behavior • Telephone focus groups can be more easily convened than in-person groups when participants' occupations/lifestyles afford little free time (e.g., doctors, mayors); reduce travel burden on research staff; and can allow for broad geographic representation • Allow for project staff and partners to listen from their homes or offices 	<ul style="list-style-type: none"> • Findings not generalizable • Respondents may be concerned about lack of anonymity • Telephone groups tend to work best when participants have tangible materials to which they can respond (e.g., pre-testing materials). • Long distance phone bills for groups can be expensive, especially if many people listen in • Productive sessions by phone cannot usually be sustained more than 1 to 1½ hours 	<ul style="list-style-type: none"> • Explore complex topics with target audience prior to program (e.g., what helps/hinders healthy eating) • Learn about feelings, motivators, past experiences related to a health topic • Test concepts, message, materials, and artwork • Generate and test hypotheses.

Research Method	Description	Pros	Cons	Common Uses
Theater testing	Quantitative data is collected from a large group of respondents (generally 60-100 people per session) who respond to audio-visual materials (e.g., commercials, PSAs). Some messages shown are controls and others are being tested, allowing for a more “real life” assessment of message concepts. Respondents answer questionnaires or respond electronically means.	<ul style="list-style-type: none"> • Can gather quantitative data from large group at once • Data available immediately • Showing “actual” audiovisual materials allows more realism than storyboards • Using control messages allows more realism 	<ul style="list-style-type: none"> • Significant production costs associated with making draft materials available to test • Limited ability to ask open-ended questions • Rely on technological equipment that may not be readily accessible 	<ul style="list-style-type: none"> • Test audiovisual materials with many respondents at once
Observational studies	Individuals are observed in a natural setting with minimal observer interaction (e.g., observing shoppers in a grocery store to see if they are reading posted nutritional charts)	<ul style="list-style-type: none"> • Can observe behaviors or program implementation directly 	<ul style="list-style-type: none"> • Can be labor intensive; requires site visits • Many behaviors and program activities not easily observed • Presence of observer can alter behavior of those being observed • Ethics of observing people without their knowledge may be questioned 	<ul style="list-style-type: none"> • Counting people accessing a service • Assessing the consistency with which a service is delivered (e.g., whether registration desk clerks mention a program to all potential participants) • Observing whether skills (e.g., testing blood sugar) have been learned correctly • Useful for observing behavior at baseline, during a program, and after it ends.

Research Method	Description	Pros	Cons	Common Uses
Readability testing	Estimates the educational level required for target population to adequately comprehend written materials (i.e., if a pamphlet’s readability level is sixth grade, readers need to read at about the sixth grade level in order to comprehend the pamphlet.. Readability tests are available on many standard word processing packages or a test can easily be computed by hand.	<ul style="list-style-type: none"> • Inexpensive • Test can be performed very quickly 	<ul style="list-style-type: none"> • “Rule of thumb” only, not predictive of readers’ ability to understand content • Must be interpreted with caution because many additional factors can enhance or diminish comprehension of written material (e.g., the conceptual context of the material, reader’s motivation or interest in the material, layout of concepts in a passage, use of graphics and symbols) 	<ul style="list-style-type: none"> • Increase likelihood that materials will be comprehensible for those with lower literacy levels
Expert review	An analysis of program material or approaches is performed by individuals who are particularly knowledgeable in a content area. Reviewers may check such issues as scientific and technical accuracy or cultural appropriateness. Reviewers may be individuals such as medical research scientists, social workers, law enforcement officials, teachers, or community leaders.	<ul style="list-style-type: none"> • Inexpensive • Can help obtain support or “buy in” for your program 	<ul style="list-style-type: none"> • Risk of experts seeking to take over or radically change program plans • Can be challenging to reconcile differing viewpoints 	<ul style="list-style-type: none"> • Obtain input prior to program design from experts in a health field or who have experience working with your target audience • Ensure that your messages are scientifically accurate • Test program materials (e.g., ensure materials are culturally appropriate).

Research Method	Description	Pros	Cons	Common Uses
Gatekeeper Review	The appropriateness of draft program material for a target audience is assessed by individuals who can facilitate, complicate, or deny access to target population (e.g., those who control distribution channels). Gatekeeper commitment may be necessary to ensure that a program will be implemented as planned.	<ul style="list-style-type: none"> • Inexpensive • Can help obtain support or “buy in” for your program • Can ensure and smooth access to target populations 	<ul style="list-style-type: none"> • Can cause setbacks if major revisions are needed (project staff can plan ahead and use formative research to avoid this) • Obtaining cooperation and getting priority attention can be challenging if gatekeepers are not especially invested in the population 	<ul style="list-style-type: none"> • Ensure that messages will be disseminated and program plans carried out by obtaining gatekeeper approval prior to program dissemination • Obtain “buy in” from influential people who control distribution channels • Ensure that products conform to gatekeeper agency policies and goals (e.g., television station regulations for PSAs)
Media tracking (print, audio, or audiovisual media)	Content communicated by mass media outlets (e.g., television, radio, billboard advertisements) is tracked and analyzed systematically. A professional service typically is hired to do the tracking if the range of media sources extends much beyond the local level.	<ul style="list-style-type: none"> • Allows tracking of media that can be influential for the target audience • Allows health communicators to better understand patterns of media attention given their topic 	<ul style="list-style-type: none"> • Review of data is time consuming • May require training of readers or video viewers if automated tracking is not used • Print and video clipping services are expensive 	<ul style="list-style-type: none"> • Conduct needs assessment • Track changes in media treatment of a topic in response to an event or program • Identify issues addressed by media channels that focus on program’s target audience • Discern whether media outlets are disseminating program messages as hoped or planned
Source: CDCynergy: Your health communication planning and evaluation tool. Version 1.0. Centers for Disease Control and Prevention; Office of Communication. July 1998.				

I.7 NCI's ¹³¹I/NTS Communications Campaign and Process Evaluation Plan

I.7.1 NCI's ¹³¹I/NTS Communications Campaign

The goals of NCI's ¹³¹I/NTS Communications Campaign were:

- To inform health care providers (via health provider organizations) who conduct thyroid screening and education about the availability of NCI's I-131 materials, especially those practicing in significant fallout areas
- To inform consumer organizations that focus on health education needs of people ages 40 and older, with particular emphasis on groups responsible for thyroid education, about the availability of NCI's I-131 materials
- To inform federal agencies about the availability of NCI's I-131 materials for incorporation into their communication channels
- To make information about I-131 materials easily accessible for use by interested consumers, the public at large and advocacy organizations for inclusion in their communication channels

In December 2002, the NCI released communication materials for the Project, developed with extensive input from advocacy groups, community representatives and health officials, as well as extensive focus group testing. Materials included:

- **Get the Facts About Exposure to I-131 Radiation**--This general information brochure provides information about the Nevada tests and identifies individuals at particular risk.
- **Making Choices: Screening for Thyroid Disease**-- This decision aid workbook/brochure is for individuals concerned about their exposure to I-131 from fallout (Based on decision support format of the Ottawa Health Decision Center at the University of Ottawa and Ottawa Health Research Institute, Ontario, Canada)
- **Radioactive Iodine (I-131) and Thyroid Cancer**--This flip chart, designed for use in small groups of up to 10 people, addresses concerns specific to Native Americans.
- **I-131 Web Site** (www.cancer.gov/i131), which includes tools for partners ("swiss cheese" press release, promotional brochure, etc.)

In order to accomplish these goals, by June 2003, NCI had accomplished the following

- Held a national teleconference (Dec 2002), at which NCI staff and invited experts discussed pertinent I-131 issues and plans for public promotion and dissemination of the materials
- Disseminated materials to project partners
- Within key exposure areas⁸, disseminated materials through email and US postal service. Efforts concentrated on reaching key intermediaries-- health provider associations, community health clinics, advocacy and support groups, community-based networks, state health agencies, schools of public health, social workers, and federal agencies (including local clinics of the Indian Health Service.) (Full list follows). These intermediaries were provided tools to reach secondary audiences, which include individual health care providers and the concerned public aged 40 and older, particularly those who lived in areas of highest exposure and who consumed milk during the testing period.
- Conducted follow up calls to key organizations to ascertain interest in additional activities

In sum, the NCI conducted direct outreach with over 1000 local, regional and national organizations (see attached list).

I.7.2 NCI's ¹³¹I/NTS Process Evaluation Plan

In evaluating the promotion and dissemination efforts of the NCI's ¹³¹I/NTS Communications Campaign, the NCI developed the following measurable objectives:

1. By January 31, 2003, NCI will send promotional materials and educational products to all organizations on the original recruitment list.
2. By January 31, 2003, NCI will send promotional materials and educational products to health professional, consumer health, advocacy, and federal organizations identified by key stakeholders⁹.
3. NCI will send promotional materials to 100% of organizations who request information on the educational products.
4. By December 31, 2002, NCI will conduct a teleconference to launch the materials with the media and key stakeholders.

⁸ Twenty states received the highest fallout and include: Montana, Nevada, Utah, Colorado, North Dakota, South Dakota, Nebraska, Kansas, Oklahoma, Missouri, Arkansas, Minnesota, Iowa, Wisconsin, Illinois, Wyoming, Idaho, Indiana, Texas and Vermont. There are 7 states (Massachusetts, Tennessee, New York, Oregon, Ohio, Michigan and Louisiana) in which only a few counties within each state were affected.

⁹ Group of key informants representing health professional, consumer health, advocacy and federal organization who are interested in I-131 issues and who were identified by NCI at the project's inception. Largely consists of members of NCI's I-131 listserv.

5. By February 3, 2003, NCI will send I-131 promotional materials to 100% of specified NIH and NCI-affiliated groups
6. By February 10, 2003, NCI will send I-131 promotional materials and educational products to 100% of specified core thyroid health groups
7. By February 17, 2003, NCI will send I-131 promotional materials and educational products to 100% of specified general medical societies and primary care institutions
8. By February 27, 2003, NCI will send I-131 promotional materials and educational products to 100% of specified consumer health organizations
9. By February 21, 2003, NCI will send I I-131 promotional materials and educational products to 100% of specified Federal agencies (see Appendix B. Promotion Plan).
10. By July 3, 2003, NCI will follow-up with 100% of specified core thyroid health specific groups

A Process Evaluation Template, which includes evaluation questions, indicators, measures, process objectives, data sources, and frequency of data collection was developed. Data is to be analyzed in 2003.

This list represents over 450 national organizations/groups who received I-131 promotional materials disseminated by the Office of Cancer Communications in December 2002 [in addition to 121 Members of Congress].

<p>AARP Agency for Toxic Substances and Disease Registry Alliance for Nuclear Accountability Alliance of Atomic Veterans American College of Preventive Medicine American Thyroid Association (1000) Association of State and Territorial Health Officials ATSDR (1000) Baltimore City Department of Health Center for American Indian Research and Education Center for Global Security & Health, Physicians for Social Responsibility CDC: State Radiation Directors (54) CDC: Division of Health Communication-Childhood Cancer Research Institute and Clark University Colorado Department of Public Health and Environment Conference of Radiation Control Program Directors Consumers Union Council of State and Territorial Epidemiologists Decision Research US Department of Health and Human Services Vanderbilt University-Department of Radiology Dine Care Group Downwinders, Inc. Elder Voices, Inc. Hanford Health Information Network Resource Center HRSA: radiation education grantees (36) HRSA: Bureau of Primary Health Care: Primary and community health centers in high-exposed counties (390) Idaho Division of Health Indigenous Environmental Network Institute for Energy and Environmental Research Institute for Energy and Environmental Research Interpretive Consultations, Inc, Risk Communication and Environmental Education Iowa Dept. of Public Health Johns Hopkins University School of Hygiene and Public Health Mallinckrodt Institute of Radiology-Washington University School of Medicine Mayo Medical School-Mayo Clinic Rochester Memorial Sloan-Kettering Cancer Center Miamisburg Environmental Safety and Health Migrant Clinicians Network</p>	<p>Migrant Head Start Quality Improvement Center Morgan County Medical Center Morgan County Medical Center NAACP-Oak Ridge, TN National Association of County and City Health Officials National Association of Radiation Survivors National Center for Environmental Health National Center for Farmworker Health National Committee for Radiation Victims National Congress of American Indians National Institute of Diabetes and Digestive and Kidney Diseases National Medical Association Natural Resources Defense Council Navaho Uranium Radiation Victims Committee Directors Consumer Liaison Group-National Cancer Institute Nevada State Health Division New England Journal of Medicine New York Presbyterian Hospital- Weill Medical College of Cornell University New York State Department of Health Nuclear Information & Resource Service Oak Ridge Environmental Justice Committee Oregon Department of Human Services Oregon Health Division Environmental and Occupational Epidemiology Pew Environmental Health Commission Physicians for Social Responsibility Porter Novelli Public Interest Research Group- United States Radiation and Public Health Project Radiation Health Effects Archives Radiological Health Section, Nevada State Health Division Redish & Associates, Inc. Rutgers University Scarboro Community Environmental Justice Council SENES Oak Ridge, Inc. Short Cressman & Burgess PLLC Sinai Hospital of Baltimore Sisters of Charity of Ottawa Health Services Snake River Alliance Social and Environmental Research Institute Standing for the Truth About Radiation Support and Education for Radiation Victims Tennessee Department of Environment and Conservation The Endocrine Society</p>
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The National Academies
Thyroid Disease Information Source
Tufts University, Editor in Chief, Medicine and
Global Survival
U.S. Department of Health and Human Services
University of Colorado School of Medicine
University of North Carolina at Chapel Hill School
of Public Health
UPMC News Bureau

Uranium Education Program
Utah Department of Health, Bureau of
Epidemiology
Vanchieri Communications
Western States Legal Foundation
Women's Action for New Directions
World Health Organization-Regional Office for
Europe

This list represents over 200 national organizations/groups and their affiliates or chapters who received I-131 promotional materials disseminated by the Office Education and Special Initiatives in Spring 2003.

Alaska Native Tribal Health Consortium
American Academy of Family Physicians (chapter heads in 20 states)
American Academy of Nurse Practitioners
American Academy of Physician Assistants
American Association of Cancer Education
American Association of Retired Persons (local chapters and clearinghouse)
American Board of Internal Medicine
American Cancer Society (divisional offices)
American College of Obstetricians and Gynecologists
American College of Preventative Medicine
American Indian Institute
American Medical Association
American Nurses Association (state/local chapters in priority regions)
American Public Health Association
Association of American Indian Physicians
Association of Community Cancer Centers
Center for Medicaid and Medicare Services
Centers for Disease Control and Prevention
Chronic Disease Directors (communications committee)
Environmental Protection Agency (American Indian Environmental Office)
Indian Health Service (American Indian Environmental Office)
National Association of Community Health Centers (20 risk states)
National Association of County and City Health Officials
National Association of Social Workers
National Association of State Directors of Migrant Education
National Black Nurses Association
National Center for Farmworker Health
National Council of La Raza
National Hispanic Medical Association
National Hispanic Nurses Association
National Indian Health Board
National Medical Association (local and state societies)
National Rural Health Association
Native American Cancer Initiative
Native American Health Issues
Office of Minority Health (HHS clearinghouse)
Office of Minority Health Affairs
Older Women's League
Oncology Nursing Society – Special interest committees: Cancer Program Development, Management: Patient Education and Prevention, Early Detection Special Interest Groups
Thyroid Cancer Survivors' Association (local chapters)
Veterans Administration