
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 Although the campaign is ongoing, these materials are provided for historical reference.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.