

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

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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.