

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.

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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

Trisha Pritikin, Esq., M.Ed., O.T.R. - Downwinder

Robert Tiller - Physicians for Social Responsibility (Departed group 12/99)

Seth Tuler, Ph.D. - Childhood Cancer Research Institute and Clark University

I.3.2.2 Government Staff

National Cancer Institute

Nelvis Castro - Acting Associate Director for Cancer Communications

Betsy Duane - Communications Coordinator, Division of Cancer Epidemiology and Genetics

Mark Epstein - Porter Novelli (Consultant)

Anne Lubenow - Acting Chief, Health Promotion Branch

Kelli Marciel - Presidential Management Intern, Health Promotion Branch

Jim Mathews - Senior Science Writer, Health Promotion Branch

Alan Rabson, M.D. - Deputy Director, National Cancer Institute

Paul Van Nevel - Van Nevel Communications, (Consultant - then Associate Director for Cancer Communications - retired as of 12/31/99)

Cori Vanchieri - Vanchieri Communications (Consultant)

Centers for Disease Control, National Center for Environmental Health

Owen Devine, Ph.D. - Chief, Risk Assessment and Communication Section, Radiation Studies Branch (moved to another division 2/1/00)

Christie Ehemann - Epidemiologist

Joan Morrissey - Health Communicator, Radiation Studies Branch

Judith Qualters, Ph.D. - Acting Chief, Risk Analysis and Communication Section, Radiation Studies Branch

Agency for Toxic Substances and Disease Registry

Oscar Tarrago, M.D., M.P.H. - Fellow, Office of the Director, Division of Health Education and Promotion

I.3.3 Workshop Participants

(In alphabetical order by last name)

Elaine Bratic Arkin, Health Communication Consultant

John Bagby, Ph.D., Chairman, Advisory Committee for Energy Related Epidemiologic Research

Wayne Ball, Ph.D., Toxicologist, Utah Department of Health, Bureau of Epidemiology

Keith Frederick Baverstock, Ph.D., Regional Advisor, Public Health and Environmental Radiation, World Health Organization

David V. Becker, M.A., M.D., Professor of Radiology, Professor of Medicine, New York Presbyterian Hospital, Weill Medical College of Cornell University

Marco Beltran, M.P.H., Program Specialist, Migrant Head Start Quality Improvement Center

Joni Berardino, M.S., National Center for Farmworker Health

Luis Buen Abad, M.Ed., Environmental Specialist, Hanford Health Information Network

John Burklow, Deputy Director for Communications, Office of Communications and Public Liaison, NIH

Leticia Camacho, J.D., M.A., Director of Policy and Advocacy, Migrant Clinicians Network

Nelvis Castro, Acting Associate Director, Office of Cancer Communications, National Cancer Institute

David Cooper, M.D., Director, Division of Endocrinology, Sinai Hospital of Baltimore

Sharon Cowdrey, R.N., President, Miamisburg Environmental Safety and Health

Owen Devine, Ph.D., Chief, Risk Assessment and Communication Section, Radiation Studies Branch, CDC

Betsy Duane, Communications Coordinator, Division of Cancer Epidemiology and Genetics, National Cancer Institute

Christie Ehemann, Ph.D., Epidemiologist, Centers for Disease Control and Prevention

Maureen Eldredge, Program Director, Alliance for Nuclear Accountability

Mark Epstein, Communications Consultant, Porter Novelli

Valerie Fiset, R.N., M.Sc.N., Clinical Nurse Specialist, Palliative Care, Sisters of Charity of Ottawa Health Service

James Flynn, Ph.D., Senior Research Associate, Decision Research

Patricia George, Community Research Coordinator, Nuclear Risk Management for Native Communities Project

Thomas M. Gerusky, Certified Public Health Physicist, Retired Director, Pennsylvania Bureau of Radiation Protection, Conference of Radiation Control Program Directors

Hossein Gharib, M.D., Professor of Medicine, Mayo Medical School, Mayo Clinic

F. Lincoln Grahlfs, Ph.D., M.A., President, National Association of Radiation Survivors

Michael Hansen, representing Jean Halloran, Director, Consumer Policy Institute, Consumers Union

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

Felicia Hodge, Dr.P.H., Director, Center for American Indian Research and Education

F. Owen Hoffman, Ph.D., President, SENES Oak Ridge, Inc.

Robert Holden, Director, Nuclear Waste Program, National Congress of American Indians

Bea Kelleigh, M.P.A., Executive Director, Hanford Health Information Network Resource Center

Gary Kodaseet, Vice Chairman, National Indian Council on Aging

Susan Koppi, Director, Public Affairs, The Endocrine Society

Gary L. Kreps, Ph.D., Chief, Health Communication and Informatics Research Branch, National Cancer Institute

Charles Land, Ph.D., Division of Cancer Epidemiology and Genetics, National Cancer Institute

Robert Lawrence, M.D., Associate Dean for Professional Education and Programs, School of Hygiene and Public Health, Johns Hopkins University

Lisa Ledwidge, M.P.A., M.S.E.S., Outreach Coordinator and Editor, SDA, Institute for Energy and Environmental Research

Delvin Littell, M.D., Medical Director, Morgan County Medical Center

Paul A. Locke, M.P.H., Dr.P.H., Deputy Director, Pew Environmental Health Commission

Anne Lubenow, M.P.H., Acting Chief, Health Promotion Branch, National Cancer Institute

Roger Macklin, M.S., Health Physicist, Tennessee Department of Environment and Conservation, Director of Radiological Health

Kelli Marciel, M.P.A., Presidential Management Intern, Health Promotion Branch, National Cancer Institute

Stan Marshall, Radiological Health Section, Nevada State Health Division

James Mathews, Senior Science Writer, Office of Cancer Communications, National Cancer Institute

Normie C. Morin, Ph.D., M.P.H., Project Director, Rocky Flats Health Studies, Disease Control and Environmental Epidemiology Division

Joan Morrissey, Health Communicator, Radiation Studies Branch, Centers for Disease Control and Prevention

Robert Musil, Executive Director, Physicians for Social Responsibility

Dennis Nelson, Ph.D., Director of Research, Support and Education for Radiation Victims

Nancy Nelson, Mass Media Branch, Office of Cancer Communications, National Cancer Institute

Claudia Parvanta, Ph.D., Director, Division of Health Communication, Office of Cancer Communications, Centers for Disease Control and Prevention

Judy Patt, Cancer Information Service, National Cancer Institute

Devon Payne-Sturges, M.P.H., Assistant Commissioner for Environmental Health, Baltimore City Health Department

Stacye Poer, Program Analyst, Office of Legislation and Congressional Activities, National Cancer Institute

Trisha T. Pritikin, Esq., M.Ed., O.T.R., Downwinder/Community Representative

Idaho J. Purce, Project Director, HIV/AIDS Education, NAACP; INEEL Health Effects

Judith R. Qualters, Ph.D., Acting Chief, Risk Analysis and Communication Section, NCEH, Centers for Disease Control and Prevention

Alan S. Rabson, M.D., Deputy Director, National Cancer Institute

William Raub, Deputy Assistant Secretary for Science Policy, Department of Health and Human Services

Karim Rimawi, Ph.D., Director, Bureau of Environmental Radiation Protection, New York State Department of Health

Jacob Robbins, M.D., Scientist Emeritus, National Institute of Diabetes and Digestive and Kidney Diseases

Henry D. Royal, M.D., Professor of Radiology, Division of Nuclear Medicine, Mallinckrodt Institute of Radiology, Washington University School of Medicine

Michael Sage, Acting Deputy Director, National Center for Environmental Health, Centers for Disease Control and Prevention

Peter Sandman, Ph.D., Risk Communication Consultant

Elke Shaw-Tulloch, Manager, Environmental Health Education Program, Idaho Division of Health

Kristin Shrader-Frechette, Ph.D., Medical Ethicist, Department of Philosophy and Department of Biological Sciences

Steven L. Simon, Ph.D., Senior Staff Officer, National Academy of Sciences, Board on Radiation Effects Research

Robert F. Spengler, Sc.D., Associate Administrator for Science, Agency for Toxic Substances and Disease Registry

Patrice Sutton, M.P.H., Western States Legal Foundation

Diana Swindel, Associate Director, Communications Office, National Center for Environmental Health

Tim K. Takaro, M.D., M.P.H., M.S., Acting Assistant Professor, University of Washington School of Medicine

Oscar Tarragó, M.D., M.P.H., Fellow, Office of the Director, Agency for Toxic Substances and Disease Registry, Division of Health Education and Promotion

Kevin Teale, M.A., Communications Director, Iowa Department of Public Health

Stephen Thomas, Ph.D., Associate Professor, Director, Institute of Minority Health Research, Rollins School of Public Health, Emory University

Tim L. Tinker, Dr.P.H., M.P.H., Chief, Communications and Research, Agency for Toxic Substances and Disease Registry

Seth Tuler, Ph.D., Childhood Cancer Research Institute and Clark University

R. Michael Tuttle, M.D., Assistant Attending, Memorial Sloan-Kettering Cancer Center

J. Paul Van Nevel, Van Nevel Communications, Consultant to the National Cancer Institute

Cori Vanchieri, Vanchieri Communications, Consultant to the National Cancer Institute

Neil Weinstein, Ph.D., Professor, Department of Human Ecology, Rutgers University

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>.