



ENVIRONMENTAL HAZARDS & HEALTH EFFECTS

Cancer Clusters

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CDC RESPONSE TO CANCER CLUSTERS

Response to Cancer Clusters with Suspected Environmental Etiology: State and Federal Capacity Building Workshops (March 11-12, 2003)

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Introduction/Background

The National Center for Environmental Health (NCEH) of the Centers for Disease Control and Prevention (CDC) sponsored two one-day workshops to provide a forum for dialogue among CDC and representatives from state health agencies. The workshops provided CDC with information to assist the states in cancer cluster inquiry response and investigation, and to assess capacity at the state and federal level. Representatives from ten state health departments (California, Massachusetts, South Carolina, New York, Missouri, Texas, Georgia, Florida, Washington, Minnesota) reviewed and discussed current protocols and practices for the investigation of reported cancer clusters with suspected environmental etiology.

Workshop goals included the assessment of the states' needs to respond effectively to citizen inquiries about cancer clusters, the coordination of federal response to states' efforts, and the enhancement of the scientific process underlying cluster investigations. During the workshops, recommendations for further research and collaboration with state partners were discussed.

The same agenda and format were used for both workshops; each workshop was one day in length. Two workshops, each with participants from 4-6 states, allowed the attendees greater opportunity to speak and interact with each other and with CDC representatives. Each workshop began with a brief introduction by Dr. Carol Rubin, Chief, NCEH/Health Studies Branch, followed by a review of the agenda and objectives for the workshop. State attendees gave presentations describing their method of responding to citizen's inquiries about potential cancer clusters. The representatives also discussed the strengths and weaknesses of their states' responses, as well as the barriers to effective response. In addition, the representatives described prior experiences that were significant in shaping their current approach, and they discussed issues specific to their state.

The workshop participants discussed the current methods of responding to cancer cluster inquiries, the environment in which inquiries take place, the states' needs, and the potential roles for CDC involvement. Participants reviewed differences and commonalities between the approaches described during the state presentations, as well as the needed resources, collaborations, and ways in which CDC could help the states implement their respective investigation protocols. This report represents a summary of discussions from both workshops.

Current Procedures

Representatives from state health departments and health agencies presented information about their responses to cancer cluster inquiries. Despite differences in experience, policy, resources, and other issues noted by workshop participants, states have a great deal in common in the ways they respond to citizens concerned about suspected cancer clusters. For instance, the majority of states apply a systematic approach in responding to reports of cancer clusters, and most states make an effort to triage incoming calls to the appropriate people. In addition, states have developed and shaped their responses based on their own past experience and the experiences of other states with whom they share information. All the state representatives expressed interest in improving the science relevant to cancer cluster report and inquiry.

The state representatives reported that upon receiving an inquiry from a concerned citizen about a possible cancer cluster, states try to educate the caller about the issues involved in the study of cancer clusters with suspected environmental etiology and with the complexities of the issues. Participants noted that very few inquiries proceed past this initial telephone contact. Most state representatives said that their states generally follow the procedures specified in CDC's "Guidelines for Investigating Clusters of Health Events," accessible on the Internet at <http://www.cdc.gov/mmwr/preview/mmwrhtml/00001797.htm>.

Workshop participants first noted a number of strengths in their response to citizens' inquiries. These strengths included state health department Web sites, which provide information about cancer and suspected environmental causes of cancer. Some states have strong relationships with the public, press, governmental and non-governmental agencies.

During their presentations, state representatives also described potential weaknesses in their response protocols. Limitations in current scientific methods, lack of appropriate or insufficient staff, poor data quality, lack of educational materials, and difficulties in establishing appropriate comparison populations were cited as potential weaknesses. Several state participants noted the difficulty of having sufficient sample size for epidemiological investigations. Other state representatives described methodological problems due to high rates of migration and seasonal residence, as well as the inherent complexities (e.g., latency, residency, small numbers) of cancer cluster investigations.

A problem cited by several state representatives is the lack of trust by the public that state health departments adequately investigate reports of cancer clusters. Constituents may view state departments of health as "government" and may be suspicious of state personnel if no cluster is acknowledged and no environmental link is found. In addition, the public has increasing access to media reports and films sensationalizing instances in which environmental causes have been suggested. As a result, state representatives noted that some of their constituents may believe the government has something to hide, although the constituents have received all available information.

State representatives also mentioned the public's lack of knowledge about cancer and cancer etiology. Workshop participants noted that the public, press, other state agencies, and politicians would benefit from education about cancer and epidemiological methods of investigating cancer clusters. Some participants reported pressure by politicians and media to continue studying a reported cancer cluster when the scientific evidence did not support continuing the investigation. State representatives noted the difficulty in adhering to decision criteria for cancer cluster investigations based on scientific rationale when the impetus for investigation was based primarily on meeting public demand.

Participants discussed past experiences that had had an impact on the development of their states' protocol for responding to citizen inquiries. These experiences included prior investigations, interactions with media or state politicians, identification of novel methods for investigation, and public responses following resolution of reported clusters. In addition, states noted that they often were faced with issues or situations that were unique or specific to their state, including agriculture and industry, data quality, demands for specific uses of data, varying levels of public interest and awareness about cancer and the environment, state-specific historical experiences, transience of state residents, and population demographics.

State Needs

To better understand the challenges faced by the state health departments, CDC invited workshop participants to identify needs that, if addressed, would improve the states' ability to respond to cancer cluster inquiries and to pursue investigations when appropriate. Several participants reported a need for additional funding and full-time staff, particularly for trained epidemiologists. The participants requested CDC-sponsored workshops on and training in specific areas related to cancer cluster methodological issues, scientific developments, and information sharing among states in cancer cluster inquiry response and investigation. The participants were particularly interested in having CDC provide validated questions for cluster inquiry. State representatives also stated a need for recommendations on software for spatial/temporal data analysis, as well as for education on interpreting the results. Several state representatives expressed the need for advice and assistance on particularly difficult investigations.

A few workshop members indicated a need for more definitive decision criteria for proceeding through the phases of investigation. They felt that the decision criteria set forth in the 1990 CDC recommendations were not specific enough, thus allowing for much variance in the way the criteria are interpreted. However, some state representatives were secure with their own protocols and did not feel any need for further CDC-recommended actions. Participants also identified a need for training in risk communication to appropriately convey their messages to citizens, the media, state politicians, and other interested parties.

State representatives were interested in receiving updated information about environmental exposures that are carcinogenic. Several state representatives mentioned the difficulties in trying to stay current on the scientific literature in cancer etiology. In addition, they explained the need for a central point of contact at CDC for cancer cluster-related activities, as well as a central clearinghouse of relevant research, methodology for cancer cluster investigations, and information on chemical carcinogens. They indicated that having a contact person at CDC would help facilitate communication and better address their needs.

Although the participants were aware of the CDC/ATSDR Cancer Cluster Inquiry Response System, they still felt the need for a contact person to discuss scientific matters with and to provide assistance or training when needed. The CDC/ATSDR Cancer Cluster Inquiry Response System (cdcinfo@cdc.gov or 1-800-CDC-INFO) provides a centralized response for cancer cluster inquiries, and in addition, tracks and maintains a database of these inquiries. The purpose of the system is to coordinate the federal government's response to inquiries regarding cancer clusters, with the overall goal of increasing the speed, accuracy, and efficiency of the government's response to concerns about cancer clusters.

Workshop participants stated that CDC support would increase their credibility with the public. A number of state representatives shared anecdotes about citizens and members of the media questioning their qualifications to look into issues of environmentally related cancers. They noted that a "stamp of approval" or endorsement from CDC would improve their constituents' opinions about the methods they use to investigate suspected cancer clusters. Endorsements could come in the form of CDC recommendations on the use of specific software, suggested guidelines or decision criteria for proceeding with investigations, information about the benefits and limitations of cancer cluster studies, educational material geared toward the public, and other resources that might indicate CDC's approval of protocols used at the state level.

CDC Roles

The workshop participants discussed what CDC might do to help them disseminate educational information about suspected cancer clusters or conduct investigations in response to queries. The majority of participants wanted CDC to help enhance state health department credibility by validating existing educational materials and leading a national media campaign. Several participants asked for CDC recommendations for dealing with public, media, or political pressure in conducting an inquiry, as well as for support from the agency when those recommendations were followed. Several state representatives asked if CDC could be involved in a few investigations each year and then share study methodology and results. Direct technical assistance from CDC to assist in difficult investigations would be helpful in achieving greater public approval of the investigation methods, results, and conclusions.

Most participants would like to have CDC lead an effort to pool data to conduct larger, more meaningful studies that might contribute to the science on cancer clusters. They noted that a problem with current investigations is insufficient numbers of cases and lack of robust denominator data. Participants felt that the ability to pool data when appropriate might increase the precision of studies and increase the potential to yield statistically significant results.

The participants also requested additional information and training from CDC. One suggestion was for CDC to provide an evaluation instrument for states to use to evaluate their efforts in responding to cancer cluster reports. All participants supported the identification of a single CDC point-of-contact who could facilitate communication among state health representatives and provide assistance with difficult investigations. They requested that CDC consider providing available updated information on known carcinogens and laboratory analysis methods. In addition, the participants wanted CDC to provide standardized and more definitive decision criteria for proceeding through sequential levels of inquiry in cancer cluster investigations. It was suggested that the criteria be put on the CDC Web site.

Another suggestion was for CDC to sponsor an electronic listserv (this has been implemented) for a network of state health department and other cancer agency representatives who work in the area of cancer cluster investigation. The listserv serves as a mechanism for states to remain informed about what others are doing, as well as to share protocols and data collection instruments.

Some participants noted that CDC might also use this mechanism to provide training on working with the media. The participants felt that media training and scientific information provided by the CDC would increase their credibility with their state constituents. Many state representatives requested additional workshops, and increased funding for cancer cluster activity. Most states were in need of additional full-time employees, particularly epidemiologists, who can assist in implementing cancer cluster protocols.

There were differences in the dynamics and the conclusions reached among the participants during the two workshop days, but on both days the participants reported that the workshop was very useful in increasing their knowledge about how other states respond to cancer cluster reports, and the protocols that the other states follow. The states enhanced their linkages with other state cancer cluster experts, and most felt that the meetings were very valuable. Clearly, some of the participants are much more experienced and comfortable in handling cancer cluster inquiries, and some of the states already have systems, staff, and Web sites in place, whereas other states are still in the process of building capacity and infrastructure. The workshop was also particularly useful for CDC to understand more about cancer cluster inquiry and investigation protocols in different states, and to understand what assistance was needed from CDC. These workshops provided the initial step for an interactive CDC-facilitated state network of cancer cluster activity.