

ENVIRONMENTAL HAZARDS & HEALTH EFFECTS

Cancer Clusters

Historical Document

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For current information about cancer clusters, please visit

<http://www.cdc.gov/nceh/clusters/>

CDC CANCER CLUSTER ACTIVITIES STATUS

The Status of Cancer Cluster Activities at CDC (As of January 2006)

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Introduction/Background

More than a decade ago, the Centers for Disease Control and Prevention (CDC) recognized the need to develop operating procedures that would respond to public concern about disease clusters. The National Conference on Clustering of Health Events was held and the proceedings published (Neutra, 1990). At about the same time, CDC released "Guidelines for Investigating Clusters of Health Events" (CDC, 1990) in which a four-stage process was presented, involving (1) an initial response to gather source information, (2) an assessment of the occurrence of the health event, (3) a feasibility study, and (4) an epidemiologic investigation. Many state health departments adopted and modified these guidelines for their specific situations and available resources. The approaches varied among states and also by the nature of the cluster, and the availability of case data and comparison population. The orientation of each state-based inquiry response and investigation plan was also shaped by the state's philosophy and experience with previously reported clusters.

Initial response to public concern is usually handled at the state level, using cancer registry information that allows for comparison between incidence rates at various geographical levels. However, CDC becomes involved when state health departments ask for assistance or when individuals contact the CDC directly. CDC's National Center for Environmental Health (NCEH) has frequently been involved with these inquiries, due to the perception that environmental exposures are directly responsible for cancer.

Since 2000, NCEH has initiated six major cancer cluster activities:

1. Design and implementation of a uniform CDC system for cluster inquiries
2. Review of state protocols on cluster investigation
3. Review of media coverage on cancer cluster reports
4. Site visits to 3 states with recent cluster investigation experience
5. Two workshops on state protocols on cluster investigation
6. Establishment of a cancer cluster listserv.

These initiatives are described below in greater detail and with related links:

Activity 1

In 2000, it became apparent that there was a need to centralize the CDC response to cluster inquiries. CDC's Division of Cancer Prevention and Control (DCPC) and NCEH, CDC's National Institute for Occupational Safety and Health (NIOSH), and the Agency for

Toxic Substances and Disease Registry (ATSDR), met, and NCEH was designated the primary responsibility for cluster inquiries and assistance.

In May 2002, NCEH began running a centralized inquiry system for disease clusters, the CDC/ATSDR Cancer Cluster Public Information Triage System (CCPITS); details may be found at <http://www.cdc.gov/nceh/clusters>. CCPITS provides a system for accurate, consistent and timely responses to cancer cluster inquiries. Primary partners are DCPC, NIOSH, ATSDR, and state level contacts. NCEH receives and coordinates the response to cancer cluster inquiries, which range from direct response to individuals to case-control investigations that are conducted at the invitation of a state health department or recommendation of an expert panel. The recent investigation in Churchill County, Nevada is an example of unusually intense NCEH involvement in cluster investigations (<http://www.cdc.gov/nceh/clusters/Fallon/default.htm>). NCEH has processed 405 inquiries about perceived cancer clusters from May 2002 through January 2004.

Activity 2

The second major activity consisted of surveying state protocols for cancer cluster inquiry and investigation. In an effort to better define existing state-based activities with suspected cancer cluster investigations, identify gaps in current investigation methods, and identify opportunities for increasing the efficiency and utility of state and federal efforts, NCEH developed a survey instrument which was distributed to 56 states and territories (50 states plus the District of Columbia, Guam, American Samoa, Puerto Rico, the Federated States of Micronesia, and the U.S. Virgin Islands).

The survey instrument was designed to provide a mechanism to summarize the content and level of detail presented in each protocol. The instrument lists numerous categories of topics that a cluster investigation protocol might address. The categories of the instrument are based on the 1990 CDC Guidelines in terms of organization and content and consisted of six sections: General, Operating Procedures, Agency Organization/Support, Locus of Responsibility/Control, Communication/Liaison Plans, and Other Items. Across these six sections, 292 individual items were organized by 41 topic areas. Protocols were assessed for level of detail, education provided to callers, responsibility placed on the caller to gather information, structure of decision trees for proceeding to next steps, sequence of activities, available data resources, and official responsibilities. The protocols and accompanying materials were subject to a three stage review process, consisting of primary and secondary reviews, and any discrepancies between the two reviews were adjudicated by a third reviewer.

The results of the survey indicated considerable variation among state protocols; however, every state queried provided some education concerning cancer and/or cancer clusters. Criteria which were common among states for proceeding towards the next step in investigation of a cluster included:

- identification of a single cancer type
- biological plausibility and adequate latency for the reported cancer
- political pressure
- identification of a common cancer in an unusual age group
- identification of a rare cancer
- identification of exposure to a carcinogenic substance

However, there was considerable variation in the structure of the decision trees and/or flow charts, as well as in the state perspective and experience on cancer cluster investigation.

Activity 3

NCEH conducted an extensive literature search to identify and characterize media reports that discussed cancer clusters. Approximately 1,440 reports were identified between 1977 and 2001, for approximately 175 incidents. The reports were characterized according to several variables, including state, date, specific incident reported and perceived environmental exposure. The results of this project will be published in the near future.

Activity 4

To further understand state health departments' experiences during recent cancer cluster investigations, NCEH conducted site visits to New Jersey, Arizona, and Ohio. These were states in which there were high profile investigations of leukemia in circumscribed areas, documented protocols for handling cluster inquiries and investigations, and considerable experience and expertise in disease clusters.

Activity 5

To further the understanding of state protocols and methods in cancer cluster investigation, NCEH sponsored two workshops during which representatives from 10 states met and discussed cancer cluster activity: From these workshops as well as the 3 site visits, NCEH noted the following concerning cancer cluster protocol:

- There was a high importance placed on educational components; all provide education to callers
- Most states had standardized forms to enhance information gathering
- States take a systematic approach
- States triage incoming inquiries
- Response varies greatly depending upon state experience and politics
- States are interested in better science and methodology
- Most states follow 1990 Guidelines to some extent
- Most have websites that address cancer clusters
- States are well aware of inherent complexities in cancer cluster investigations including data quality, small numbers, political issues

- Most state protocols were continuing to evolve.

In conclusion, some of the important messages articulated during the workshops concerning the needs of states, included:

- Desire for validation from federal agency
- Need for additional funding/full-time employees
- Need for training (CDC sponsored workshops on methods and media)
- Desire for CDC-facilitated information sharing/data sharing (e.g. CDC-sponsored listserv)
- Assistance with complex investigations

Details of the workshop proceedings may be found at <http://www.cdc.gov/nceh/clusters/response.htm>.

Activity 6

In 2003, NCEH established an electronic listserv for state and federal health agency staff to communicate about cancer clusters. This mechanism enhances dialogue among the states, and will enable progress in scientific methods and data sharing.

CDC will use the information obtained through these 6 activities, in addition to that obtained through future activities and communications, to identify ways to increase the utility of state and federal cluster investigation efforts.

Cancer clusters continue to concern the public, and the link to environmental exposures, whether perceived or actual, is an important issue that must be addressed. There are many similarities across states in their efforts to respond to cancer cluster inquiries; however, there is a definite need for state and federal coordination. In the future, an important role for NCEH may be to facilitate communication among states, to provide assistance when appropriate, and to foster the development of new approaches to cluster investigation.

Additional information and links are provided below.

Links

- NCEH Cancer Cluster Website
<http://www.cdc.gov/nceh/clusters>
- Cancer Cluster Public Inquiries Triage System
cdcinfo@cdc.gov
- CDC's Churchill County (Fallon), Nevada Exposure Assessment
<http://www.cdc.gov/nceh/clusters/Fallon/default.htm>
- CDC Cancer Cluster Listserv cdc_cancer_cluster@listserv.cdc.gov

References

- Neutra RR. Twenty-two years of cancer cluster investigations at the Centers for Disease Control. *American Journal of Epidemiology*. 1990;132(1):1-202.
- Centers for Disease Control and Prevention. Guidelines for investigating clusters of health events. *MMWR*. July 27 1990;39(RR-11):1-16.