

Greater Bay Area Cancer Registry Report

A publication of the Northern California Cancer Center

2007



Cancer Cluster Investigation in the Greater Bay Area

There is considerable public health concern that environmental hazards cause excess cancers in some communities. Annually, more than 1,000 suspected cancer clusters are reported to state health departments each year (1). Over the years, these reports have increased in intensity, in part due to increased environmental awareness, media attention to cancer, and the raw increase in cancer cases in an aging population (2).

Often, the public is unaware of how common cancer is in the United States. Current data show that men have slightly less than a one in two lifetime risk of developing cancer; for women, the risk is little more than one in three (3). In addition, cancer is not just one disease but in fact is many different diseases caused by a wide variety of environmental and non-environmental factors. Consequently, cancer clusters should be expected to occur often and usually by chance alone (see Figure 1).

Cancer cluster investigation has become a controversial topic. Although cancer investigations are mounted in response to community concern, most have failed to find real cancer clusters. In only five to 15% of reported cancer clusters, statistical testing confirms the number of observed cases exceeds the number of expected (1). Investigations that do find an excess of cancer cases usually are unable to identify a specific environmental cause. Questions about the usefulness of such investigation, given their high costs, have grown, even as reported cluster concerns have increased in intensity.

The Greater Bay Area Cancer Registry has a significant role in cancer cluster investigations. The following report explains the registry role. In this publication, the terms are defined, the history of cancer cluster research is reviewed, and some of the relevant issues on this subject are covered. Finally, the cluster investigation experience of the Greater Bay Area Cancer Registry is described. ●

Defining Cancer Clusters

A cancer cluster can be defined in many ways. It can involve groups of persons with cancer who have any of a number of characteristics in common: age, gender, behavior, occupation, family members, time frame, location, type of cancer, etc. However, it has generally come to mean an unexplained excess of people with cancer diagnosed close together in time and geographic area.

A real cancer cluster involves a greater than expected number of cases given the population size, its age and gender distribution, and local cancer incidence. Though investigations of most clusters determine there are not more cases than expected by chance, most health agencies consider it good public health practice to respond to community concerns about every cancer cluster, perceived or real. ●

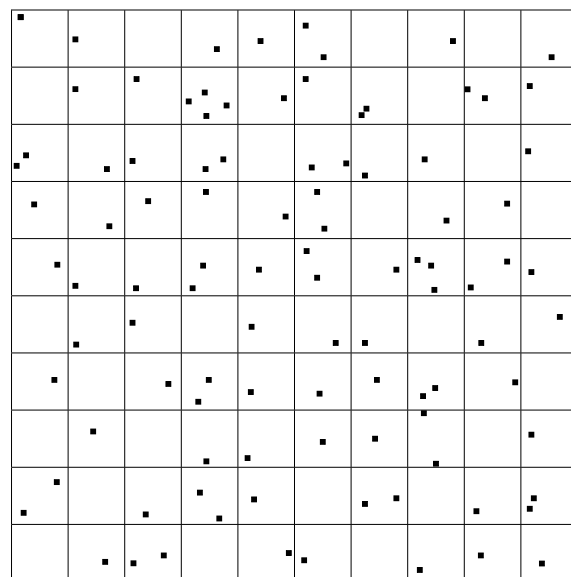


Figure 1. Cancer clusters can and often do occur by chance alone. If a computer randomly assigns 100 dots to a grid with 100 squares - some squares will have several dots and some will have no dots. In the same way, many cancer clusters are groupings of cancer cases in time and geographic area, due to chance alone.

History of Cancer Cluster Investigation

Cancer cluster reports date back to the 18th century. One of the earliest was the discovery of an excess number of scrotal cancers among chimney weeps in 1775. However, it was during the 1960's that we started to see the first of the modern day cancer cluster reports. Over the past 40 years, there have been several national meetings to examine the phenomenon of cancer clusters (4). One of the most prominent of these meetings, convened by the CDC and other groups in 1989, resulted in a clearer articulation of the difficulties surrounding cluster investigations (5). Many of these difficulties are briefly discussed below. ●

Difficulties Associated with Studying Cancer Clusters

- An apparent cluster often includes diverse types of cancer, which reduces the likelihood that it results from a common exposure.
- Many clusters may include so few cases that no reliable conclusions can be drawn about their significance.
- The population in which a cluster arises may not be clearly demarcated, making it difficult to determine the expected number of cases, which is based on the population at risk.
- The definition or boundaries of a particular cluster may be altered over time so as to make the cluster more substantial or inclusive. In this situation the cohesiveness of the cluster is questionable, and the population at risk is difficult to define.
- The numerous statistical and mapping techniques used to establish the significance of the cluster vary in approach and sensitivity. Thus, the conclusions drawn can depend on the methods used and may not be reliable.
- Even if a causal exposure can be specified, it is unlikely to have been sufficiently intense to increase cancer risk enough to produce a cluster.
- A cluster is most likely to represent a chance event, even if an excess of cases is shown to be statistically significant. A statistically significant finding simply means that the likelihood that the event is due to chance is small, not that chance is not responsible for the finding.

Why Should Cancer Clusters Be Studied?

It is good public health practice to answer community requests for explanation of, and aid for, health problems. Since concerned citizens often inquire about unhealthy exposures in the environment and unusual clusters of cancer, public health officials must be responsive to such inquiries. If a cancer cluster does exist, citizens can take appropriate action. If a cancer cluster does not exist, often citizens' concerns can be alleviated.

While cancer cluster investigations rarely uncover new scien-

tific knowledge about the causes or prevention of cancer, the reporting of cancer clusters represents people's real and valid fear of this disease. This provides an important opportunity for the clinician or public health official to educate people and promote cancer prevention strategies such as early detection and screening (4). To learn more about cancer prevention, diagnosis, and treatment, contact the Cancer Information Service, a program of the National Cancer Institute at 1-800-4-CANCER or www.cancer.gov/. ●

Examples of Informative Cancer Cluster Investigations

Over the years there have been a number of important cancer cluster investigations that have led to the new discovery of previously unknown human carcinogens. Herbst et al. investigated a cluster of adenocarcinoma of the vagina in young women. They found that the cluster was caused by in utero exposure to DES (diethylstilbestrol, a drug used to prevent miscarriage) (5). Creech and Johnson found that a cluster of angiosarcomas of the liver was caused by exposure to vinyl chloride monomer in an occupational setting (5). The research of Baris et al. found that the fibrous mineral erionite caused mesotheliomas among residents of a small town in Turkey (5).

When cancers are rare, such as the examples above, even a small number of cases represent a dramatic increase in the incidence rate. However, when a cancer cluster concern involves a common cancer (such as breast or prostate) it is much harder to determine if the clustering is a true cancer cluster or an imposter, since increases are mitigated by the background variation that occurs (6). ●

The Investigation Process

Since cancer clusters are rare and are usually due to chance, it is important to balance community concerns with agency resources when deciding to investigate reports. The agency's response is tiered (Figure 2). At each stage of the cancer cluster investigation, the need for more extensive and costly research must be carefully evaluated.

Typically, protocols for cancer cluster investigations include:

- 1) talking with those reporting the cluster, asking and answering questions;
- 2) reviewing and analyzing the reported cases and any exposure data;
- 3) determining if a cluster actually exists and the need for and feasibility of a more extensive study; and
- 4) if appropriate, conducting a full-fledged study to evaluate the relationship between the cancer and the suspected cause(s).

Using a protocol such as this, 75-95% of cluster concerns reported to state health departments are resolved at step one. Approximately one to three percent of these concerns result in a more time-consuming and costly full-fledged analytic study (7).

To review the CDC's proposed Guidelines for Investigating Clusters of Health Events, visit:

www.cdc.gov/mmwr/preview/mmwrhtml/00001797.htm. ●

Overview of the Investigation Procedure

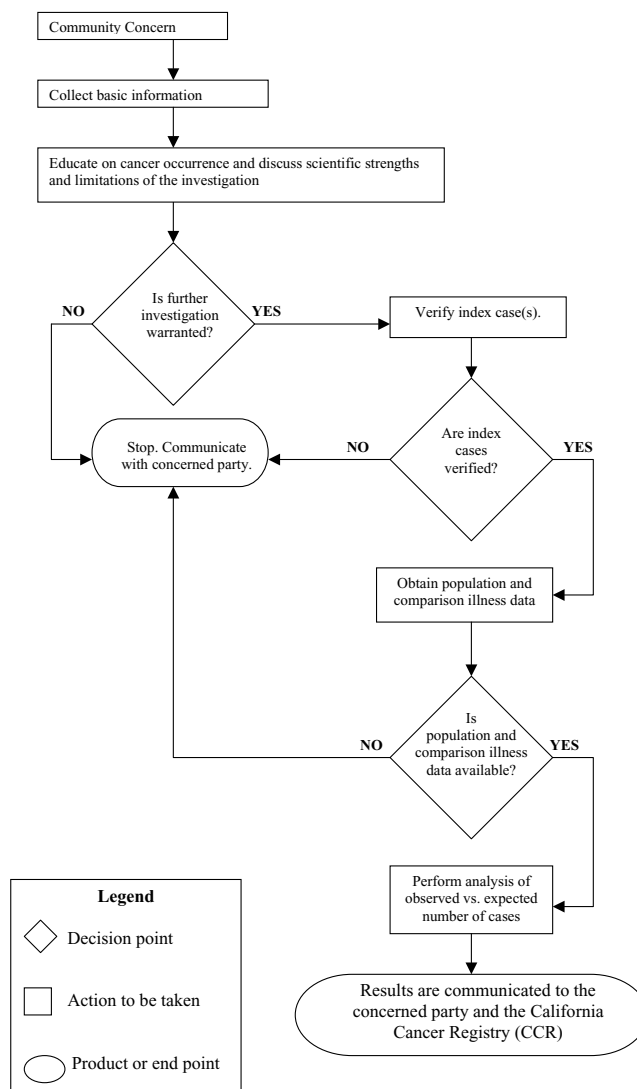


Figure 2. Overview of the Northern California Cancer Center's cancer cluster investigation process.

Role of the Northern California Cancer Center (NCCC)

Here at the Northern California Cancer Center, we play a significant role in cancer cluster investigations. Currently, in the state of California, the California Cancer Registry (CCR) handles requests for cancer cluster investigations. The CCR consists of a central registry and eight regional registries. One of these eight registries is the Greater Bay Area Region (GBACR) and is managed by NCCC. The GBACR comprises nine counties: Alameda, Contra Costa, Marin, Monterey, San Benito, San Francisco, San Mateo, Santa Clara, and Santa Cruz.

For more information about the California Cancer Registry and answers to frequently asked questions about cancer, visit: www.ccrca.org/questions.html#data%20available

Unfortunately, it can take people many calls to various agencies before they are referred to NCCC. Once we receive a call or e-mail from an individual or group, we gather as much information about the cancer concern as possible and attempt to provide the caller with general information about cancer occurrence and reassure him or her that their concern is being taken seriously.

After thoughtful evaluation of the concern, if no further investigation is possible or warranted, we communicate our findings to the informant. We may not be able to address all cancer concerns due to data limitations, however we strive to answer all the questions we can. If further investigation seems warranted and is possible, we begin our assessment. ●

Assessment Procedure

Our first step is to define the geographic area and time period to be assessed. For neighborhood cancer cluster concerns, the geographic area is usually a census tract. The assessment consists of comparing the observed cancer cases in the specified neighborhood and time period with the number that would be expected to occur, on average, if the residents of the neighborhood had the same cancer rates as the Greater Bay Area as a whole. We divide the observed by the expected number and determine through statistical analysis if there is an excess of cancer cases in the neighborhood of concern.

In occupational or workplace concerns, the analysis is more difficult, but not impossible. In this situation the comparison is between the number of cases observed during a specific time period and the number expected for the person-years-at-risk for that time period. The expected number is estimated by applying cancer rates for the appropriate time period, specific for sex, race/ethnicity, and age to the corresponding number of the person-years-at-risk. Problems arise when not all the reported observed number of cancer cases can be verified and employee records do not contain the required variables, such as race, age and length of employment. ●

Experience of the Greater Bay Area Cancer Registry at NCCC

For the years 2002 to 2006, the Northern California Cancer Center assessed 24 suspected cancer cluster reports (Figure 3). Only 1 of these reports proved to have a significant excess of cancer cases. It was an occupational clustering of thyroid cancer. The exact reason for the excess was unable to be determined, however, enhanced medical surveillance was suspected to be a likely explanation, in the absence of any environmental exposures of concern. ●

Figure 3. Types of Cancer Clusters reported to the Greater Bay Area Cancer Registry, 2002-2006.

Site	No. of Reports
Mixed, adult	4
Pancreas	2
Non-Hodgkin lymphoma	1
Leukemia, adult	2
Thyroid	2
Breast	3
Oropharynx	1
Brain	1
Kidney	1
Mixed, childhood	2
Leukemia, childhood	5

References

1. Thun MJ, Sinks T. "Understanding Cancer Clusters". CA: A Cancer Journal for Clinicians, 54: 273-280. 2004.
2. Trumbo CW. "Public Requests for Cancer Cluster Investigations: A Survey of State Health Departments". American Journal of Public Health, 90 (8): 1300-1302. 2000.
3. American Cancer Society (ACS). Cancer Facts and Figures: 2007. <http://www.cancer.org/downloads/STT/CAFF2007PWSecured.pdf>
4. Aldrich T, Sinks T. "Things to Know and Do About Cancer Clusters". Cancer Investigation, 20: 810-816. 2002.
5. Rothman KJ. "A Sobering Start for the Cluster Buster's Conference". American Journal of Epidemiology, 132 Supl. 1:S43-S47. 1990.
6. Gawande A. "The Cancer-Cluster Myth". The New Yorker, 34-37. February 8, 1998.
7. Greenberg M, Wartenberg D. "Communicating to an Alarmed Community About Cancer Clusters: A Fifty State Survey". Journal of Community Health, 16:2, 71-82. 1991.



The Northern California Cancer Center (NCCC) is dedicated to preventing cancer through population-based research and community education. An independent organization, NCCC is an established, nationally recognized leader in understanding who gets cancer and why, and how to improve the quality of life for individuals living with cancer.

The Greater Bay Area Cancer Registry Report is published periodically by the

Northern California Cancer Center to discuss cancer registry-related issues and to present cancer incidence information for Alameda, Contra Costa, Marin, Monterey, San Benito, San Francisco, San Mateo, Santa Clara, and Santa Cruz counties.

For more information on the Northern California Cancer Center or the Greater Bay Area Cancer Registry, visit www.nccc.org

Northern California Cancer Center. Finding answers. Making a difference.



**2201 Walnut Ave., Suite 300
Fremont, CA 94538**

Nonprofit Org.
U.S. Postage
PAID
Fremont, CA
Permit No. 297