

## OREGON PUBLIC HEALTH DIVISION • OREGON HEALTH AUTHORITY

### PUBLIC HEALTH RESPONSE TO COMMUNITY CANCER CLUSTERS

The Centers for Disease Control and Prevention and the Council of State and Territorial Epidemiologists have updated guidelines for investigating suspected cancer clusters and responding to community concerns.<sup>1</sup> This week's *CD Summary* reviews the national experience with cancer cluster investigations and describes the updated Public Health Division (PHD) process for responding to community cancer cluster inquiries.

#### CANCER CLUSTERS IN THE U.S.

We define a community cancer cluster as an unusual number of the same type of cancer occurring over a given time period among people who live in the same geographic area.\* During the past 40 years health departments and federal partners have responded to inquiries about thousands of perceived cancer clusters.<sup>2,3</sup> In the majority (85%–95%) of these, there was no increase in the number of cancer cases above expected (i.e., no cancer cluster). For the remainder, epidemiologic investigations almost never uncovered an etiologic association; the most likely explanation was chance clustering of cases. The few notable exceptions have involved cancer clusters in occupational or medical settings (e.g., mesothelioma and asbestos exposure; vaginal adenocarcinoma and in utero DES exposure).

Community cancer cluster investigations rarely identify an etiologic agent. In a review of 428 health department investigations conducted during 1990–2011, cancer incidence was thought to be elevated in 72 (13%) instances, but an etiologic agent (asbestos) was identified only once.<sup>2</sup> In contrast to occupational and medical settings where there may be verifiable and sustained high level exposures to potential carcinogens, in community settings individual-level exposures are generally poorly defined, and difficult to confirm or quantify.

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#### SO WHY INVESTIGATE?

The Public Health Division (PHD) has a responsibility to provide a cogent response to a person or community who has concerns that environmental toxins might be the cause of the cluster. This response takes the form of a "health hazard evaluation" in which PHD may conduct analyses of cancer reports and attempt to identify an unrecognized source of a known cause of cancer. PHD may partner with other agencies, such as the Oregon Department of Environmental Quality or the U.S. Environmental Protection Agency, to identify environmental contaminants known to be carcinogenic.

Another reason to investigate is to discover new etiologies for a particular type of cancer. Studies of cancer etiology are generally conducted by academic institutions and, to achieve adequate sample size and power, involve multiple study sites with cases from around the U.S. To facilitate etiologic investigations, the Oregon State Cancer Registry (OSCaR) has a process for making its data available to outside researchers doing etiologic studies.

#### OREGON INQUIRIES

During 2012–2013 OSCaR received 12 inquiries about perceived cancer clusters, which is average for the nation. A 2010 state survey found that 63% reported 1–10 annual requests for cancer cluster investigations, 19% reported 11–25 requests, and 6% reported >25 requests (4% reported no inquiries).<sup>4</sup> Most inquiries come from concerned citizens, but they also come from the media, community groups, policy makers, physicians, and local health departments.

#### OREGON'S RESPONSE

**Listening, Explaining, and Data Collection.** Step 1 is a phone interview with the person reporting a cancer cluster. We listen carefully and show empathy, knowing that many are personally affected by the cancer(s) being reported. Some important points we cover include:

- Cancer is more common than most people realize.
- Risk of developing cancer increases with age.
- Cancer is not one disease.
- Cancers have many different causes.
- Many cancers are related to lifestyle choices (e.g., tobacco use).
- Cancers diagnosed today are usually related to events that happened years previously.
- Cancer clusters can occur by chance; we expect the unexpected.

During the interview we collect: reason for contacting the health department; caller contact information and affiliation; number of persons affected, age, sex, and type(s) of cancer; time period; geographic distribution of cases; and exposures of concern, if any. We explain the evaluation process and timeline. All information is kept confidential.

#### Case Definition and Case Finding.

Step 2 uses information collected during the initial phone interview to create a case definition (i.e., cancer type + geographic area + time period). OSCaR is now a mature surveillance system with high levels of case completeness and data accuracy; it can be used routinely for case finding and verification.<sup>†</sup> Cancer type is standardized in OSCaR and based on the International Classification of Diseases for Oncology.

The geographic area of analysis is usually the county or contiguous census tracts that cover the area of concern identified by the caller, or a region that corresponds to a specified environmental contaminant. The default time period evaluated is the most recent 5-year period with complete OSCaR data.

<sup>†</sup> There is an 18 month lag period before data are considered complete.

\* Adapted from reference 1.



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**Analysis and Interpretation.** Step 3 is to determine whether there is a possible increase in the number of incident cancer cases by estimating the number of expected cases using OSCaR data and a suitable reference population (e.g., the rest of Oregon), and comparing it with the observed number of cases in the area under investigation during the 5-year period. An observed number of cases that greatly exceeds the expected number provides evidence for clustering but needs to be evaluated in terms of what is known about etiology and community exposures.

#### **BIOLOGICAL PLAUSIBILITY**

Biological plausibility is assessed at each point in the evaluation process. For example, often during the initial interview we learn that the caller is concerned about an increase in all types of cancers or an increase in multiple types of common cancers. Different types of cancer have different causes, and the type(s) of cancer reported often have no known biological link to contaminants in the environment or to other types of cancer being reported; no health hazard evaluation is pursued in these circumstances. For reports of an increase in a single type of cancer, we review the scientific literature about known etiologies, and then assess potential exposures in the community.

#### **ENVIRONMENTAL EXPOSURES**

Callers sometimes report concerns about specific environmental contaminants as the likely cause of cancer. In these situations PHD and other partner agencies will evaluate the evidence of an existing or historical public health hazard and, if confirmed, will make recommendations for remediation or

avoidance, as appropriate. This health hazard evaluation is not limited to concerns about carcinogenic potential.

#### **WHAT PROVIDERS CAN DO**

Health care providers play an important role in responding to patient concerns about cancer clusters. As respected sources of information, you can help deliver the key points in the bulleted list above. Additionally, you can provide individualized cancer prevention messages for patients based on medical history and behaviors which increase risk of developing cancer.†

#### **WHAT PUBLIC HEALTH CAN DO**

We try to be responsibly responsive. We listen to stakeholders and take concerns seriously. We use OSCaR to look for community cancer clusters and thoughtfully evaluate the findings. We partner with other agencies to look for health hazards, past and present; if we find one, we work with those agencies on abatement. We deliver authoritative messages to promote healthy lifestyles and appropriate cancer screening.

#### **WHAT WE CANNOT DO**

For the 5%–15% of investigations where we have some evidence of an increase in cancer cases above expected, but no biologically plausible hazard has been identified, our options are limited. In the majority of cases, the observed increase will be due to chance; we can monitor cancer trends over time to determine if subsequent fluctuations are consistent with the variability associated with a chance event. That can take years and may not meet community expectations. The public health investigation

† For a clinician's point of view, read Atul Gawande's "Medical dispatch: the cancer-cluster myth" in *The New Yorker*, February 8, 1999, pgs 34–37.

looks for etiologic agents when those agents are known or strongly suspected; we cannot routinely do research to discover new causes of cancer. If that's required, we can share our data with qualified researchers who can design and seek the necessary resources to conduct an etiologic study that is reviewed by peers for scientific merit and compliance with ethical standards.

#### **RESOURCE**

- National Public Health Information Coalition. Cancer clusters: a toolkit for communicators. September 2013. Available at <http://cancercluster.nphic.org>.

#### **FOR MORE INFORMATION**

- Oregon State Cancer Registry: visit <http://public.health.oregon.gov/DiseasesConditions/ChronicDisease/Cancer/oscar/Pages/index.aspx> or call 971-673-0986.
- Environmental Public Health Section: visit <http://public.health.oregon.gov/HealthyEnvironments/Pages/index.aspx> or call 971-673-0977.

#### **REFERENCES**

1. Centers for Disease Prevention and Control. Investigating suspected cancer clusters and responding to community concerns: Guidelines from CDC and the Council of State and Territorial Epidemiologists. *MMWR* 2013;62(No. RR-8);1–24. Available at [www.cdc.gov/mmwr/pdf/rr/rr6208.pdf](http://www.cdc.gov/mmwr/pdf/rr/rr6208.pdf).
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4. Council of State and Territorial Epidemiologists. A synopsis of the 2010 national assessment of state cancer cluster investigations and protocols. July 2012. Available at [www.cste2.org/webpdfs/ASynopsisofthe2010NationalAssessmentofStateCancerClusterInvestigationsandProtocols.pdf](http://www.cste2.org/webpdfs/ASynopsisofthe2010NationalAssessmentofStateCancerClusterInvestigationsandProtocols.pdf).