



Responding to Citizens' Concerns: Cluster Busting on a Shoestring

Public Health Problem

The Oregon State Cancer Registry (OSCaR) receives more than 200 requests for information each year. Many of the requests are from citizens concerned that cancer rates are high in their neighborhoods. Historically, several different state agencies and programs have responded to citizens' requests about possible cancer clusters, creating not only duplication of work but variability in the methods, responsiveness, and public health messages used to respond to citizens' concerns. Even though cancer data for Oregon have been available since 1996, agencies outside of the cancer registry have been unable to use the data because of concerns about analyses that have such small numbers of cases involved in cancer cluster reports.

Program Example

OSCaR developed a protocol to respond to cancer cluster concerns that focused on reducing overlap and inconsistencies in response, establishing clear guidelines, and addressing citizens' concerns by using local data. OSCaR's protocol follows reporting guidelines that call for responsibility, timeliness, and a specific methodology for addressing reports of cancer clusters within a community. A cross-agency Cluster Buster e-mail group was created to pass along citizens' concerns about cancer to researchers from the Oregon Department of Environmental Quality, the Drinking Water Program, and the Department of Environmental and Occupational Epidemiology. Telephone talking points were developed to enable general registry staff to answer broad questions about cancer concerns over the telephone. Citizen fact sheets and a template for an in-depth response letter were written to help citizens understand the burden and risk factors associated with specific cancers, recognize potential cancer clusters, and understand the difficulties of identifying a common cause for individual cancer cases. Templates were developed that allow staff to produce calculations of the observed versus expected number of cancer cases by county, city, or ZIP code and thus determine if the number of cancer cases is unusually high. Finally, a database was created to track all citizen requests for recurring areas of concern.

Implications and Impact

By developing and using this protocol to address people's concerns about cancer clusters, the state has reduced duplication of effort among state agencies as well as the number of cancer cluster requests that ultimately need investigation or follow-up. These tools give Oregon citizens a main point of contact when they have concerns about cancer rates in their neighborhood. They also ensure that results are communicated to citizens in a consistent, timely manner, ultimately reducing the number of potential clusters that the department must investigate.

Contact Information

Oregon Department of Human Services • Oregon State Cancer Registry
800 Northeast Oregon Street, Suite 730 • Portland, Oregon 97232-2162
Phone: (503) 731-4858 • Fax: (503) 731-4848 • Web site: <http://www.healthoregon.org/oscar>