

Cancer Registries

Colorado

Using an Internet-Based Query System to Provide Public Access to State and County Cancer Data

Public Health Problem

Each year in Colorado, more than 16,000 cancers are diagnosed, and an estimated 6,000 people die of cancer. In the United States, cancer data are regularly collected, analyzed, reported, and transferred at the state and national levels, but not always at the county level.

Program Example

The Colorado Central Cancer Registry collaborated with the Colorado Health Data Advisory Committee to develop an Internet-based query system called the Colorado Health Information Dataset (CoHID). CoHID's governing board, which includes representatives from both local and state health agencies, sets priorities for new modules and features to CoHID. Health providers and the public can use the system to access cancer incidence and death statistics as well as Behavioral Risk Factor Surveillance System data on health-related and screening behaviors. Tables of cancer counts and rates can be produced by year, county, age, sex, race, cancer site, and stage of disease at diagnosis. To allow easy analysis and customization of data queries, the site has a real-time help screen that allows users to better understand the data, interpret results, and make successful inquiries.

Implications and Impact

Access to population-based health data at the county level is crucial for monitoring health status and planning interventions for prevention and early detection of cancer. CoHID allows users to analyze the stage of cancer at diagnosis. In addition, CoHID complements routine publications of the Colorado Central Cancer Registry and serves a wide variety of data users. This system can be developed and used as a model by other state health departments. In addition, the data can also be used to identify cancer patterns among race, sex, and age-groups and lead to prevention and early detection measures that may save lives.

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Northern New England

Understanding Why Rates of Bladder Cancer and Deaths Are High in Northern New England

Public Health Problem

Rates of bladder cancer deaths have increased among white adults in Maine, Vermont, and New Hampshire over the past three decades. Between 1996 and 2000, Maine men had the highest rate of bladder cancer deaths in the nation (10.7 per 100,000 U.S. standard population versus 7.7 in the nation). Cases of bladder cancer are also on the rise. In 2003, estimated incidence rates of bladder cancer were high among Maine men (45.5 per 100,000 versus 36.6 for men nationwide) and women (12.5 versus 9.6 for women nationwide).

Program Example

With support from the National Program of Cancer Control Registries, the state health departments in Maine, Vermont, and New Hampshire collaborated with the Dartmouth Medical School, the National Institutes of Health, and the U.S. Geological Survey on a case-control study of adults in these three states. Participants included about 1,200 adults aged 30–79 years with histologically confirmed bladder cancer and an equal number without a history of bladder cancer. Because the request for bladder cancer data needed for this study was outside of the standard reporting period for the state cancer registries, the participating health departments asked that the

hospitals and medical facilities review all cases to identify patients with bladder cancer and then report the requested information. A rapid data collection procedure was developed to allow timely personal interviews of residents with a diagnosis of bladder cancer. Residents were asked about their diet, previous residences and occupations, medical history (including family medical history), and medication and tobacco use.

In addition, drinking water and biological specimens were analyzed.

Implications and Impact

Data from this study will be used to estimate the extent to which various lifestyle, occupational, and environmental exposures explain the increased incidence of bladder cancer and related deaths among residents of Maine, Vermont, and New Hampshire. Determining the importance of these potential risk factors will help guide the development of public health interventions and education programs to help residents lower their risk for bladder cancer.



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

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