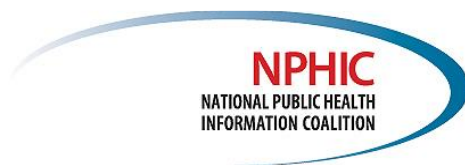


Cancer Clusters: A Toolkit for Communicators



A Collaboration of
The Centers for Disease Control and Prevention and
The National Public Health Information Coalition



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Message from the Co-Chairs of the Cancer Cluster Communications Workgroup

Each year, more than 1,000 suspected disease clusters are reported to state health departments; the majority of them are cancer clusters. As public knowledge of environmental toxins grows, and as technology allows people to draw connections between pollution and disease, we suspect that concerns about cancer clusters will grow. State health departments must be prepared for this reality.

Because of the limits of epidemiology and statistics, cancer cluster investigations to determine possible causation often remain unresolved. Health departments share the common challenge of explaining the limitations of cancer cluster studies to their concerned communities.

To address this problem, a group of state and federal health communicators worked closely with epidemiologists and communities to determine the most essential communication needs surrounding cancer clusters and the most effective ways to address them. In this package you will find

- Sample cancer cluster scenarios based on real-life case studies around the country
- Suggested outreach techniques for various audiences
- Answers to the most commonly asked questions about cancer clusters
- Literature resources about cancer clusters
- Glossary of cancer cluster terms with fact-sheet friendly definitions
- Guide to educating about cancer clusters using social media
- Case studies

The items in this tool kit have been tested with focus groups to verify that the language is appropriate and effective to use with communities that are concerned about their risk of disease. All items are grounded in health communication and risk communication theory.

We deeply respect the public health work you do each day and hope these materials will be helpful. For more information, see our Web site www.nphic.org.

Cancer Cluster Communications Workgroup Co-Chairs:

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SECTION 1:

Cancer Cluster Scenario Flow Chart

The following flow chart is designed to help communicators understand the stages of a cancer cluster investigation and how communicators can insert actions that will help the investigation run more smoothly.

- The stages of the investigation, listed in the left column, are based on the 2013 Cancer Cluster Guidelines. These guidelines were developed collaboratively with CDC and the Council for State and Territorial Epidemiologists, with input from the National Public Health Information Coalition, a creator of this toolkit.
- The communication guidance in the right column corresponds with the four stages of investigating cancer clusters. However, every situation has unique elements, and communicators must use their best judgment as to if or when to apply these principles and actions.

Cancer Cluster Guidelines and Advice for Handling Related Communication Activities

STEP 1: Gather Information

1. Call comes into organization.
2. Gather identifying information, initial data on potential cluster, and information about risk factors.



- ✓ **Involve** someone who has experience in **risk communication** and dealing with cancer cluster inquiries.
- ✓ **Listen. Ask** questions.
- ✓ **Offer** existing educational resources.
- ✓ **Meet** with your team and prepare answers before calling back (if initial judgment is unsure).

TIPS Respond quickly. Show empathy. Monitor response.

RESOURCES FAQ, Glossary

STEP 2: Assess

1. Analyze relevant data to confirm whether an excess of cancer cases exists.
2. Consider case definition, study population, comparison rates, and statistical methods.
3. Identify local environmental concerns.



- ✓ **Meet with key staff** to discuss public health significance, community concerns, and escalation potential.
- ✓ **Develop a communication plan** outlining anticipated audiences, communication channels, and steps or protocol of a potential investigation. Expand or revise plan as necessary.
- ✓ **Stay involved** in decision-making.
- ✓ **Be proactive** in communicating, especially if media or community concern exists.
- ✓ **Prepare audience-appropriate spokesperson(s)** to discuss decisions.
- ✓ **Manage expectations** at every stage by answering questions; sharing timeline, protocol, and possibilities; and sharing the limitations of scientific investigations about cancer clusters.
- ✓ **Continue to listen** to concerns.

TIPS Be proactive in communications.
Manage expectations.

RESOURCES Audience Outreach Guideline,
Social Media

STEP 3: Determine Feasibility of Study

1. Identify goals and purpose of an epidemiologic study.
2. Consider costs and parameters.
3. If warranted, recommend a study design.
4. Involve partners.
5. Consider additional public health actions.



- ✓ **Create** appropriate materials designed for your particular audience (e.g. fact sheets, Web site).
- ✓ **Prepare** subject matter experts to interpret data. Share details of timeline.
- ✓ **Help** your audience understand how the department makes decisions.

TIPS Stay accurate and consistent.

RESOURCES Glossary

Step 4: Conduct Investigation

1. Start the study to determine if exposure to a specific contaminant in the environment is associated with a common cancer in the community.
2. Investigate larger scientific issues of the relationship between the particular cancer and the contaminant.
3. Distinguish association from causation.



- ☑ **Keep your audience informed** at every step of the project with audience-appropriate, clear materials.
- ☑ **Consider** community panels and public meetings if warranted.
- ☑ **Be available** as a resource.
- ☑ **Help** people feel closure once the investigation is over; be clear and consistent about what was done.

TIPS Use clear language

RESOURCES Audience Outreach Guideline, FAQ

NOTE: Assessments may **NOT** go through all four steps. See “insert title” for guidance about whether or not to close the investigation or proceed to the next step.

SECTION 2:

Audience Outreach Guidelines and Recommendations

This section offers tips for communicating with communities and individuals most affected by cancer cluster investigations:

- **Community members, who are worried that they or their loved ones will get cancer;**
- **Media, that have found a compelling story;**
- **Elected officials, who react to constituents' needs;**
- **Physicians, who are often the first line of communication during a cancer cluster;**
- **Community groups, who are concerned about a potential cancer cluster; and**
- **Real estate agents, who work closely in communities and can have an unintentional impact on community morale.**

Community Members

Action Steps for State/Local Health Department

- Listen to and comprehend the feelings and expectations of the community.
- Demonstrate empathy with your words and your actions.
- Be aware of the expectations you create.
- Don't promise or commit to anything you can't deliver.
- Be a credible, consistent, transparent source of information.
- Share the limitations of science in cancer cluster investigations (see FAQ); use case studies.
- Raise awareness of other credible sources; do not stand alone.
- Explain why an analysis will be or will not be done.
- When the investigation is over, say so.
- Promote education.
- Address specific community concerns about hazardous exposures

GOAL: Work with the community to set realistic expectations about the likelihood of finding a common cause of the cancer using epidemiology.

- Help the community understand what a cancer cluster is and the true risk of cancer.
- Demonstrate empathy with the community in your words and actions; listen and respond to community concerns.
- Be aware that members of the community may not see government as a reliable source.

The First Contact

- Responders should be trained in risk communication techniques. Show empathy. Listen to the story. Provide information about local cancer rates and about the definition of a cancer cluster.
- Try to learn as much as possible about the concerns, and assess the degree of distress in the affected community.

Beyond the First Contact

- Identify and proactively meet community stakeholders, including residents, key community leaders, and family members.
- Find the leaders who have the trust of the community—the people who are respected in the community.
- Let the community know you are listening.
- Provide plain-language, audience-appropriate materials such as fact sheets, Web pages, and presentations by experts to address each specific type of cancer that the community is concerned about.
 - Address community concerns as specifically as possible.
 - What scientifically sound information is available about this specific cancer?
 - What are the causes and risk factors (if known)?
 - How can it be prevented (if possible)?

Tactics to Share Information with Community

Plan and adapt your communication tactics to the specific needs of your audience.

- If you're dealing with people who use traditional media (e.g., newspapers, radio), don't rely on social media and other technology-based channels.
- Remain open, transparent, and aware of audience feedback.
- If your audience is already distrustful, be very clear. Ambiguous information may validate their distrust.
- Avoid speech or actions that frame the issue in terms of "them (community)" and "us (public servants)."

Web Site: Update your Web site regularly (at least weekly, depending on interest) with baseline community health information and the latest news about the investigation. Share links to other credible sources such as the American Cancer Society (www.cancer.org) and National Cancer Institute (www.cancer.gov). Keep a rumor control page and an FAQ page.

Social Media: Use social media techniques appropriate to your specific audience. See social media guidelines (Section 7) for tips.

Community Panel: If the investigation expands, consider engaging community leaders and stakeholders in a panel that will meet regularly with you to share community concerns and take information about the investigation back to the community. Consider that in communities where trust is already damaged, a panel sponsored by the health department may not be seen as credible or independent. If this is the case in your community, engage existing community groups and community leaders to sponsor it. Suggest regular, structured, two-way communication.

Community Meetings: Consider community meetings as one avenue of getting information to people. Have a skilled facilitator. Spokespeople should be culturally competent. Types of community meetings include the following (more than one type may be combined if appropriate):

Town-Hall Style	Station Style	Small Group
<ul style="list-style-type: none">▶ Public health officials lead this type of large group meeting. Community members can ask questions and make comments.▶ Town-hall meetings can relieve community stress and help community members understand that the health department is listening to their concerns.▶ Keep presentations short and use plain language.▶ Use a strong facilitator who will not allow any one audience member to dominate the conversation.▶ Have resources available at the meeting for people who need stress relief (e.g., mental health services).	<ul style="list-style-type: none">▶ This type of meeting, more like a health fair, consists of different tables hosted by groups such as the health department or environmental protection agency, where one-on-one conversations can happen.▶ Sometimes this type of meeting is preferred because it is usually more equitable—no one person or group can dominate conversation.▶ If you choose this type of meeting, invite various stakeholders to host stations.	<p>This type of meeting can occur around a table or in a home to keep community members informed and allow people to speak freely.</p>

For more information about community meetings and cancer clusters, see McComas KA, Trumbo CW, Besley JC. 2007. [Public meetings about suspected cancer clusters: the impact of voice, interactional justice, and risk perception on attendees' attitudes in six communities](#). Journal of Health Communication 12(6):527-49.

Additional Engagement: In cases where epidemiological investigation is undertaken, consider the Acreage (Florida) model of a community information center described in the case studies (Section 8) in this tool kit. The center included a storefront with brochures, an epidemiologist, and a receptionist. The information center provided the affected community easy, personal access to information.

Media

Action Steps for State/Local Health Department

- Identify media outlets serving affected areas. Create and maintain a media list so that it is available quickly for communication.
- Target media that have demonstrated concern or interest.
- Provide a media education toolkit with information on the type of cancer, findings of the investigation, and cancer education. Include important articles such as “Understanding Cancer Clusters” and the 2013 Cancer Cluster Guidelines.
- Point media to credible health information about toxins (e.g., ATSDR ToxPortal Web site: www.atsdr.cdc.gov/substances/index.asp).
- Update your Web site as a tool to provide timely information.
- Notify media of privacy laws, such as HIPAA, at the beginning of the investigation. Be extremely careful not to disclose personal medical information.

GOAL: Provide ongoing accurate information and education to the community at large by working with the media.

- Be proactive with the press; reach out to them rather than waiting for their calls.
- Be aware of reporters’ deadlines.

Interviews

As much as possible, hold media interviews in person with local reporters. This will be an opportunity to build rapport.

News Briefings

Conduct news briefings focused on the circumstances of this cluster. Local and state health departments should work together to make sure that efforts are synchronized.

General Tips

- Manage expectations. Clarify the scope and limitations (e.g., authority, financial, scientific) of the investigation. Preview the next steps.
- Explain the difference between correlation and causation (see glossary).
- Be proactive. When possible, reach out to local media by using platforms that best suit your community, such as letters to the editor, op-eds, or editorial boards.
- Always have a backup. Keep another public information officer (PIO) or communication person updated on the status of the investigation so that he or she can step in if you are not available.
- Always be empathetic, even if the results seem to show nothing uncommon is happening. Persons and families being affected will not want to read or hear that nothing is wrong.
- Emphasize what is confirmed and what is possible. For example, although a cancer cluster investigation may not find the cause of the cancer, contaminated water can still be cleaned.

- Keep track of each of your conversations with media and stakeholders (with dates). Also keep a list of all the interested parties so that no one is left out when you have new information to share.
- Refer to agency or 2013 Cancer Cluster Guidelines (<http://www.cdc.gov/mmwr/preview/mmwrhtml/rr6208a1.htm>) when discussing sections of the investigation.
- Consider publishing your protocol online where all stakeholders can find it and can see the steps in this type of investigation. Make sure that you reach consensus with all subject matter experts involved in the investigation before you provide new information or data to a reporter. Be sure that your quotes are in line with the agency position and that you're not breaking protocol by making your statement.

Reporters

- Always keep reporters updated about the status of their request. Establish expectations. If the analysis will take several weeks, check in periodically to let them know that you're still working on their request and to check for additional questions.
- Make sure reporters understand state health agency limitations.
 - Resources are limited, and at any given time the health department may be facing a variety of public health threats. Cancer investigations, like other public health issues, are complex.
 - Health departments should help communities develop a clear understanding of the issues, and the potential effectiveness of proposed solutions, before taking action. Communities and health departments can succeed if they set clear goals and target resource usage efficiently.
- Make sure reporters understand the structure of cancer cluster inquiries. The responsibility for cancer cluster investigations lies with states. The federal government's role is to assist; it does not serve as a source of appeals to overturn state decisions.
- Inform reporters why it would be damaging to the investigation to share any preliminary data or analysis and that public health officers will share information when it is complete.

Dealing with Highly Involved Reporters

- Always take the time to educate reporters on the issue, such as the suspected causes of the type of cancer in question and the progress of the investigation.
- Return calls promptly.
- Be open and proactive. Let them know that your agency is doing all that it can do.
- Be empathetic.
- Have patience. Do not get frustrated on the phone or in a meeting. Impatience can make the reporter think they are close to breaking a story and that you are uncomfortable with it.
- Do not take an aggressive reporter's approach personally. Avoid falling into an "us" vs. "them" type of argument.

Example: "Public health officers are working to check all the information and conclusions to ensure all appropriate steps are being taken. Sharing any information before this process is complete could result in inaccurate information being published, which would not benefit any of the parties involved."

Elected Officials

Action Steps for State/Local Health Department

- Be an ACTIVE RESOURCE for elected officials and appropriate/affected agency heads (e.g., Environment, Public Works).
- Establish two-way communication. Keep them informed from the beginning.
- Be frank and direct; explain investigative steps and available statistics.
- Educate your legislative liaisons. Make sure that they are informed about cancer clusters and have the tools to talk with elected officials when the situation arises. Tell them where to go for answers.
- Share with them the potential outcomes of community outrage.

Example: “The reason we are coming to you is because people are afraid. Property values can be affected. This situation may lead to angry and hurt families who feel they cannot trust anyone. We want to make sure that they feel they can trust you and trust us.”

- Manage expectations. Make sure the elected officials are aware of long-term implications of their actions and statements. Advise them to refrain from making commitments they or the health department may not be able to keep, such as saying, “We will leave no stone unturned.”

GOAL: Elected officials will understand the challenges and opportunities of the situation. With coaching, elected officials will become messengers of accurate information and help manage community expectations. Develop a relationship so they feel free to share information from constituents with the health department.

Physicians

Action Step for State/Local Health Department

- Identify residents who are physicians or public health professionals who may be able to assist in education efforts and serve as credible sources of information. These are the sources that the media and others will seek out, so public health officers want to make sure they have accurate information. Help them understand the health department’s messaging.
- Proactively update oncologists around the state on cancer clusters.
- Consider a physician education package that would include
 - A definition of cancer clusters,
 - Peer reviewed literature, and
 - Suggestions on how to talk to patients and families about cancers potentially caused by environmental exposures.

GOAL: With sound information, area physicians will be credible sources for accurate information about risk.

- They can and will help families work through their feelings.
- Make sure physicians are getting accurate information.
- If you partner with physicians, coach them to provide a consistent, coordinated message.

Community Groups

Action Step for State/Local Health Department

- Create a list of respected community groups or stakeholders with an interest or stake in the issue.
- Include these groups in public outreach efforts. The groups are resources for the community and can provide emotional and educational support.
- Train health department subject matter experts to use empathy, plain language, and cultural competence in presentations and communication with community groups.

GOAL: Build a trusted third party source of information for communities by partnering early with local groups to provide information, education, and perhaps counseling for community members.

- Clear, concise, open dialogue is integral to media relations.
- Community members tend to trust local and nonprofit groups.

Real Estate Agents

Action Steps for State/Local Health Department

- Compile a list of real estate agencies and organizations in the area.
- Provide data and informational materials to ensure that professional associations and real estate agents in the area have accurate information about potential cancer clusters and stages of an investigation.
- Be available to answer questions.

GOAL: Real estate agents or local agent associations will be able to explain the cancer cluster to potential buyers without escalating outrage. Real estate agents will be productive participants in community meetings and able to explain the potential effect on housing prices of a suspected cancer cluster in the community.

Section 3:

Cancer Cluster Glossary

This glossary was created as a resource to assist the public affairs staff in a state health agency.

- **It provides common wording that staff can use when involved with a cancer cluster event in creating communication materials such as fact sheets and Web sites.**
- **This glossary is presented in plain language and is not all inclusive.**

Age-adjusted rate

The rates of almost all causes of disease, injury, and death vary by age. Age adjustment is a technique to reduce the effects of age on crude or raw cancer rates. This allows comparisons across groups of people of different ages. For example, comparing the crude rate of heart disease in Florida with that of California is misleading, because the older population in Florida leads to a higher crude death rate. For such a comparison, age-adjusted rates are better.

Cancer

Cancer refers to a group of diseases in which abnormal cells in the body divide without control and may invade other parts of the body. Some types of cancer include the following:

- [Carcinoma](#): cancer that forms in the skin or lining of organs.
- [Sarcoma](#): cancer that forms in bone, cartilage, fat, muscle, blood vessels, or other connecting or supporting tissues.
- [Leukemia](#): cancer that forms in bone marrow, causing abnormal blood cells to be produced.
- [Lymphoma](#) and [multiple myeloma](#): cancer that forms in the cells of the immune system including lymph nodes.
- Central nervous system cancer: cancer that forms in brain or spinal cord.
- [Mesothelioma](#): A benign (not cancer) or malignant (cancer) tumor affecting the lining of the chest or abdomen. Exposure to asbestos particles in the air increases the risk of developing malignant mesothelioma.
- For additional definitions, please see the National Cancer Institute [Dictionary of Cancer Terms](https://www.cancer.gov/dictionary) at www.cancer.gov/dictionary.

Cancer cluster

The term “cancer cluster” is used in several ways, with slightly different meanings. Cancer clusters may be suspected when people report that several family members, friends, neighbors, or coworkers have been diagnosed with the same or related cancer(s). The official definition used by the Centers for Disease Control and Prevention, National Cancer Institute, and other public health institutions is the following:

“A cancer cluster is a greater than expected number of cancer cases that occurs within a group of people in a geographic area over a defined period of time.”

The terms used in this definition are explained below. To be a cancer cluster, a group of cancer cases **must** meet the following criteria. Until all of these parameters are met, the group of cancer cases is often referred to as a **suspected** cancer cluster.

- **A greater than expected number**
A greater than expected number occurs when the observed number of cases is higher than one would typically observe in a similar setting (e.g., in a group with similar population, age, race, or sex). This may involve comparison with rates for comparable groups of people over a much larger geographic area (e.g., an entire state).
 - Who are the members of our group that have cancer?
 - With whom are we comparing our group?

- ***Of cancer cases***

All of the cases must involve the **same type of cancer**, or types of cancer scientifically proven to have the same cause.

- What kind of cancer do the members of our group have?
- Do we know what causes those kinds of cancers?

- ***That occurs within a group of people***

The greater than expected number of cancers is seen after accounting for the distribution of race, ethnicity, age, and gender in the population for purposes of calculating cancer rates.

- Can we identify all the age, race, and sex of the affected individuals and the population?

- ***In a geographic area***

If the cancer cases are linked together by residence the calculation of the expected number of cases will depend on how we define the geographic area where the cancer cases live. The boundaries must be defined objectively based upon the availability of population-based cancer incidence data rather than by drawing a circle that selectively encompasses the cancer cases. It is possible to “create” or “obscure” a cluster by selection of a geographic area. (See “Sharpshooter Fallacy” in the glossary). Including or excluding cancer cases should be based on the same criteria for eligibility used to calculate expected rates. For example, when cancer incidence rates for geographic areas are based upon residence at the time of diagnosis, the observed number of cancer cases should also be based upon residence at time of diagnosis.

- Have we defined the geographic area?
- What kinds of criteria are we using?

- ***Over a period of time***

The number of cases included in the cluster—and calculation of the expected number of cases—will depend on how we define the time period over which the cases occurred. The selection of a time period may “create” or “obscure” a cancer cluster. Too wide a time period will obscure a cluster. Too narrow a time period will create a cluster. The smaller the population, the wider the time period needed to calculate stable cancer rates.

- Have we defined the time frame over which the cases occurred?
- What kinds of criteria are we using?

In the 1960s, one of the best known cancer clusters emerged, involving many cases of [mesothelioma](#) (a rare cancer of the lining of the chest and abdomen). Researchers traced the development of mesothelioma to exposure to asbestos, a fibrous mineral that was used heavily in shipbuilding during World War II and also in manufacturing industrial and consumer products. Working with asbestos is the major risk factor for mesothelioma.

Confirmation of the existence of a cancer cluster does not mean that an identifiable hazard is causing it or that an identifiable hazard will be found. When no cause is found, it could mean that the cluster is statistically random, or that science is not yet able to determine a cause.

Cancer cluster investigation

A cancer cluster investigation is a review or analysis of a suspected cancer cluster, conducted to determine whether it meets all the elements of the cancer cluster definition. Once a cancer cluster is

confirmed, an investigation may look for possible risk factors or causes of the increased number of cancer cases.

Cancer prevention

Cancer prevention refers to a set of methods designed to prevent cancer, including:

- Eating a healthy diet and getting enough physical activity,
- Abstaining from smoking (and other tobacco use) or quitting smoking,
- Avoiding too much sun exposure,
- Limiting exposure to hazardous agents in medical or work settings, and
- Having regular screenings for cancers that you can prevent (e.g., cervical and colorectal).

Cancer registry

A cancer registry is a system for determining new cases of cancer in a particular group of people or geographic area, such as the residents of a state. Some activities of cancer registries include:

- Tracking and reporting on cancer rates in a population or in a geographic area;
- Supplying information that can be used to investigate cancer and its causes; and
- Supplying information for public health agencies and officials so that they can plan and test cancer prevention and control programs.

For more information, please visit the Centers for Disease Control and Prevention's (CDC) [National Program for Cancer Registries](http://www.cdc.gov/cancer/npcr/) (NPCR) at <http://www.cdc.gov/cancer/npcr/>.

Carcinogen

A carcinogen is a substance known to cause cancer. In its 12th Report on Carcinogens, published in 2011, the National Toxicology Program, U.S. Department of Health and Human Services, identified 54 substances "[known to be human carcinogens.](#)" The report also lists substances that are "reasonably anticipated to be human carcinogens." Appearing on a list does not necessarily mean the chemical will cause cancer in people. Whether it will cause cancer depends on the

- Way the person was exposed (Did a person breathe it, touch it, drink it, or eat it?),
- Amount of exposure (How much of the substance was breathed, touched, drunk or eaten?),
- Sensitivity of the person to that specific substance (How will the person's body react uniquely to this substance?), and
- Duration of exposure (How long was the person exposed?).

For more information regarding carcinogens in occupational settings, visit the U. S. Department of Labor (DOL) Occupational Safety & Health Administration (OSHA) Web [page on the topic](http://www.osha.gov/SLTC/carcinogens/index.html) at <http://www.osha.gov/SLTC/carcinogens/index.html>.

Case control study

A case control study compares persons who have a specific disease ("cases") with a group of persons without the disease ("controls"). Both groups are drawn from the population where the cancer cluster occurred, in an effort to identify what might have caused the illness. In studying a cancer cluster, the primary goal is to identify what might have caused the illness in the cases. A second goal is to identify,

more broadly, risk factors or hazardous agents that might increase the likelihood of getting a specific disease (e.g., a particular type of cancer).

Case group

In a case-control study, the case group is the group of subjects *with* a certain disease or medical problem.

Causation and association

- **Causation:** The action of directly causing or producing an event.
- **Association:** A connection between events that may or may not be causally linked.

A single study might find an association between exposure to a certain substance and a specific kind of cancer. For example, everyone who has breast cancer in a town **also** drank the town's water, which contained a high concentration of fluoride. That does not mean the fluoride **caused** the cancer.

The factors that may need to be considered in establishing whether the agent or risk factor might have caused the illness include the following, identified in 1965 by Sir Bradford Hill, one of the founders of medical statistics. See <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1898525/pdf/procrsmed00196-0010.pdf> for Hill's lecture on the subject.

- **Strength:** How strong is the statistical association between the risk factor and the illness?
- **Consistency:** How many studies have found the same relationship between a specific agent or risk factor and a specific illness?
- **Specificity:** Is the risk factor only related to this disease? If so, the probability of a causal relationship is high.
- **Temporality:** Did the illness occur *after* exposure to the hazardous agent or risk factor?
- **Biological gradient:** Are *higher* levels of exposure to the agent a risk factor associated with *greater* risk of developing the illness?
- **Plausibility:** Is there a known biological mechanism by which the agent or risk factor could be causing the illness? For example, does the chemical affect a certain type of cell that is a player in the type of cancer in question?
- **Coherence:** Does the statistical association found in the epidemiologic study agree with evidence produced through laboratory findings?
- **Experiment:** Is it possible and ethically appropriate to conduct experiments that may provide support for the association identified by the epidemiologic study? Have these experiments produced support for a causal relationship?
- **Analogy:** Have similar agents or risk factors been shown to have disease-causing effects similar to those implied by the epidemiologic study?

Census data

Census data include economic, population, and housing data for the entire United States, collected and provided by the U.S. Census Bureau. Census data are used in cancer investigations to help the epidemiologist determine the number of persons in the population living within a given area during a specified time period. The census population numbers are used to calculate cancer rates.

Census tract

A census tract is a small, relatively stable, statistical section of a county.

Chemical exposure

To have a chemical exposure is to come into contact with a substance by eating, drinking, breathing, or touching. Exposure may be short-term (acute exposure) or long-term (chronic exposure). See definition for “exposure” in glossary.

Cohort study

A type of epidemiologic study in which researchers follow a group of people who do not have a certain disease at the start of the study. The same group is followed over a certain period of time in order to measure the occurrence of that disease.

Confidence interval

A confidence interval is a measure of how precise a number is in a statistical study. Statistics help people guess actual numbers. In a statistical study, usually confidence intervals are set at 95%. For example, suppose investigators find an age-adjusted breast cancer rate in a town of 10 cases per 1,000 women, with a confidence interval of plus or minus 5. This means that the number of cases could range from 5 (i.e., 10 minus 5) to 15 (i.e., 10 plus 5). That indicates a 95% chance that the rate is between 5 and 15 and a 5% chance that the rate is below 5 or above 15. The confidence interval reminds us that although we can get close, we can never be sure that findings are not due to chance. The larger the number of people in the sample, the closer we can get to the actual number.

Control group

A control group is the group of people that serves as a standard of comparison in a case-control study. In a cancer cluster study, the control group is a group of people without the type of cancer under study, but who are very similar—for example in age, occupation, or race—to the group of people who have cancer.

Crude data

Also known as raw or primary data, usually crude data have been collected from a source and have not been analyzed.

Disease cluster

A disease cluster is the occurrence of a greater than expected number of cases of a particular disease within a group of people, a geographic area, or a period of time. Clusters of diseases have concerned scientists for centuries. Recent disease clusters include

- The initial cases of a rare type of [pneumonia](#) among homosexual men in the early 1980s that led to the identification of the [human immunodeficiency virus](#) (HIV) and [acquired immunodeficiency syndrome](#) (AIDS);
- The outbreak in 2003 of a respiratory illness, later identified as severe acute respiratory syndrome (SARS), caused by a previously unrecognized [virus](#); and
- Periodic outbreaks of food poisoning caused by eating food contaminated with [bacteria](#).

While many disease clusters can be traced back to a source or a cause, a cancer cluster is an exception. Very few clusters of cancer cases have been traced to any known cause (see “Cancer Cluster”). For more

information about disease clusters visit the National Cancer Institute Web page on this topic at <http://www.cancer.gov/cancertopics/factsheet/Risk/clusters>.

Environment

The environment includes air, water, and soil, and also substances and conditions in the home and workplace. The environment also includes [diet](#); the use of [tobacco](#), alcohol, or [drugs](#); exposure to chemicals; and exposure to sunlight and other forms of [radiation](#). People are exposed to a variety of environmental factors for varying lengths of time, and these factors interact in ways that are still not fully understood. Also, people have varying levels of susceptibility to these factors.

Hazardous substances are often found in higher levels in the workplace than in the general environment. For this reason, some workers may have greater and longer exposures to such substances than will the general population. Findings of higher than expected numbers of cancer cases among workers in particular occupations or industries provide important leads regarding causes of cancer among the public. In fact, studies of specific groups of workers (occupational studies) have identified many specific cancer-causing substances and motivated research to find ways to reduce or eliminate exposures in the workplace and elsewhere. For more information, visit the National Cancer Institute Web page on this topic at <http://www.cancer.gov/cancertopics/factsheet/Risk/clusters>.

Environmental exposure

Human exposure to pollutants in the environment—usually through contact with water, air, food, or soil—are referred to as environmental exposures.

Environmental hazard

An environmental hazard is a situation or event that poses a threat to the nearby environment. For example, toxic substances, such as chemicals that have been released into the air or water and may pose a health risk.

Environmental sampling

Environmental sampling refers to the process of collecting a sample of air, water, food, or soil for study.

Environmental toxicology

Environmental toxicology is the scientific study of biological, physical, and chemical elements in the environment.

Epidemiologic study

An epidemiologic study looks for the patterns and potential causes of human health effects in a group of people ("population").

The following is a type of epidemiological study that may be used to investigate a cancer cluster:

- A **"case control" study**, which compares individual persons who have a specific disease ("cases") with a group of individuals without the disease ("controls"). Both groups are drawn from the population where the cancer cluster occurred, in an effort to identify what might have caused the illness. In studying a cancer cluster, the primary goal is to identify what might have caused the illness in the specific group of persons who are part of the cancer cluster. A second goal is to

identify, more broadly, risk factors or hazardous agents that might increase the likelihood of getting a specific disease (e.g., a particular type of cancer).

Epidemiologist

An epidemiologist is a scientist who studies the frequency, distribution, causes, and control of diseases in a population.

Expected rate (*background rate*)

The expected or background rate is the rate at which some event normally occurs, at a particular time or in a particular place in a particular group.

Exposure

Exposure is contact with a substance by swallowing, breathing, or touching the skin or eyes. Exposure may be short-term (acute exposure), of intermediate duration, or long-term (chronic exposure).

- **Acute exposure:** Contact with a substance that occurs once or for only a short time (up to 14 days).
- **Chronic exposure:** Contact with a substance that occurs over a long time (more than 1 year).

Familial (family related) cancer cluster

A familial cancer cluster refers to cancer occurring in a certain family more often than would be expected by chance. Familial cancer clusters have been reported for many types of cancer. Because cancer is a common disease, it is not unusual for several cases to occur within a family. Familial cancer clusters are sometimes linked to inherited susceptibility, but environmental factors and chance may also be involved. See [www.cancer.gov/dictionary?expand=f#familial cancer](http://www.cancer.gov/dictionary?expand=f#familial%20cancer).

Gene-environment interaction

The gene-environment interaction is a complex interaction between a person's genetic make-up and environmental agents.

Genetic mutation

A genetic mutation is a permanent change in the DNA sequence that makes up a gene.

Health screening

It is a test or exam of members within the population group where the cluster is suspected, in order to get a more complete picture of the health issues faced by that group. Visit the National Institutes for Health Web page on health screening (<http://www.nlm.nih.gov/medlineplus/healthscreening.html>) for more information.

Incidence

Incidence is the number of new cases of a disease that occurs over a specific period of time. Incidence is usually expressed as the number of cases per 100,000 persons during that period of time.

Mitigate

To mitigate is to make less harsh or hostile; to make less severe or painful.

Morbidity

Morbidity means sickness or illness.

Morbidity rate

The morbidity rate can refer to either the number of persons who become sick during a certain time period (incidence rate) or the number of persons who already are sick during a certain time period (prevalence rate). **Morbidity rate is usually expressed as the number of cases per 100,000 persons during that period of time.**

Mortality

A synonym of death.

Mortality rate

Mortality rate is the estimate of the part of a population that died during a specified period (death rate). Mortality may be reported for people who have a certain disease, live in one area of the country, or who are of a certain sex, age, or ethnic group. Mortality rate is usually expressed as the number of deaths per 100,000 persons during that period of time.

Observed rate

In health investigations, observed rate refers to the rate of *actual cases* of a disease (in contrast to expected rate): the rate at which some event is generally found to occur.

Occupational cancer cluster

An occupational cancer cluster is a cancer cluster in which the common factor is that the people with cancer work or have worked in the same place. In these cases, often it is easier to track **how long** someone was exposed to an agent, and **at what level** someone was exposed, than in community settings. Only a few studies have clearly identified an underlying environmental cause for a cancer cluster. All of these were occupational or medical exposures—not community exposures. Some examples of occupational clusters with proven environmental links include:

- 1775 scrotal cancer in chimney sweeps exposed to soot from coal,
- 1929 [osteosarcoma](#) in watch dial painters exposed to radium,
- 1965 [mesothelioma](#) and lung cancer in asbestos workers, and
- 1974 [angiosarcoma](#) of the liver in chemical workers exposed to vinyl chloride monomer.

Occupational setting

An occupational setting is the setting in which one performs work. **Nonoccupational** is not related to work.

Odds ratio

An odds ratio is a mathematical formula that calculates the ratio of two odds. In epidemiology, the odds ratio typically refers to the odds of exposure among cases divided by the odds of exposure among noncases. For example, the odds of being exposed to a certain pollutant among those who have a specific type of cancer compared to the odds of being exposed to the same pollutant among those who do not have that type of cancer.

Peer review process

The peer review process is the process by which original articles and grants written by researchers are evaluated for technical and scientific quality and correctness by other experts in the same field. For more information, please visit the National Cancer Institute [Web page on this topic](http://www.cancer.gov/dictionary?CdrID=561727) at <http://www.cancer.gov/dictionary?CdrID=561727>.

Pediatric

Pediatric refers to the branch of medicine relating to, or dealing with children.

Person-time

The sum of time each person contributed while in the study, a measure of the time-contributions from the population that is being studied, or both.

Pollutant

A pollutant is any substance—such as a chemical or waste product—that turns the air, soil, water, or other natural resources harmful or unusable based on factors such as dose, length of exposure, and physical characteristics of affected persons.

Predispose

To predispose is to put at higher risk. For example, certain genes inherited from parents, or lifestyle choices such as smoking or drinking alcohol, may predispose a person—or put a person at higher risk—for getting cancer.

Prevalence

Prevalence refers to the percentage of a population that has a disease at a given time. Prevalence measures existing cases of a disease at a certain point in time or over a period of time. Prevalence is usually expressed as the number of cases per 100,000 persons during that same period of time.

Population-at-risk

A group of people or a cohort who have characteristics that put them at risk of having a certain disease.

Population study

A population study is a study of a group of persons taken from the general population who share a common characteristic, such as age, sex, or health condition. This group may be studied for different reasons, such as their response to a drug or risk of getting a disease.

Protocol

A protocol is the detailed plan of a scientific or medical experiment, treatment, or procedure.

Investigation protocol refers to a formal set of predefined procedures and guidelines for evaluating a specific event (e.g., the 2013 Cancer Cluster Guidelines at <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr6208a1.htm>). In epidemiologic studies, the protocol states what the study will do, how it will be done, and why it is being done. It explains how many persons will be in the study, who is eligible to take part, what drugs or other interventions will be given, what tests will be done and how often, and what information will be collected.

Public health assessment (PHA)

A public health assessment is a process used by a branch of the U.S. Department of Health and Human Services (Agency for Toxic Substance Disease and Registry) that examines hazardous substances, health outcomes, and community concerns at a hazardous waste site to determine whether people could be harmed from coming into contact with those substances. The PHA also lists actions that need to be taken to protect public health. For more info on PHAs, please visit

www.atsdr.cdc.gov/com/pha.html/#2

Qualitative data

The term qualitative data is used to describe in words and explains why people behave or feel the way they do and can be divided into categories that can be described (e.g., hair color or sex).

Quantitative data

This term is used to describe data measured with numbers and shows how often something occurs or to what degree a phenomenon exists (e.g., 125 cases or 34% of a sample survey).

Risk

Risk is the probability that an individual or group will experience an event (e.g., the probability that an individual will become ill or die within a stated period of time).

Relative risk: The likelihood that one group of people will experience an event (e.g., injury, illness or death) over a specific time period compared with the likelihood of the same event occurring in another group of people is called relative risk (e.g., people in one group might be twice as likely to develop lung cancer as people in another group).

Risk factors: A risk factor is something that is known to increase risk for a certain health condition, such as an aspect of personal lifestyle, an environmental exposure, or an inherited characteristic. Examples of risk factors for cancer include smoking, certain genes, or exposure to a cancer causing agent, such as radiation. For more information, you can visit the National Cancer Institute [Web page on this topic](http://www.cancer.gov/dictionary?Cdrid=45873) at <http://www.cancer.gov/dictionary?Cdrid=45873>.

Sharpshooter fallacy

The “sharpshooter fallacy” refers to a way of analyzing data that finds a pattern in random occurrences.

The “sharpshooter” approach is like firing a number of rounds into the side of a barn, and then drawing the “bull’s eye” around the area where most bullets happened to hit. Sometimes people apply this reasoning to disease clusters.

To calculate disease rates scientifically, we divide the number of people who are ill by the number of people in a population, for example, the number of residents in a geographic area. But if we use the sharpshooter fallacy, we tightly draw our “circle” around the smallest area to include all of the affected persons. We then divide the number of ill people by the relatively small number of people in this circle. This makes our circle “neighborhood” appear to be suffering an unusually high rate of disease. But if we

include the rest of the population, we get a lower rate of disease, more representative of the reality of that community.

For example, if 100 persons live in a geographic area and 20 of them are ill, the disease prevalence is 20%. Using the sharpshooter fallacy, we draw a tight boundary that includes all 20 ill people but only 50 people in all, instead of 100. In this case, the disease prevalence appears to be 40%—or twice as high as the real disease rate.

Standardized incidence ratio (SIR)

Usually expressed as a percentage, the SIR is the calculated ratio of the number of observed cases to the number of expected cases of a given disease. An SIR result of 1.0 is defined as no increase in risk.

Anything over 1.0 is an increase, and anything below 1.0 means no increase in risk.

Statistical analysis

Statistical analysis refers to a group of methods used to analyze data and report trends.

Statistically significant*

Statistical significance refers to the likelihood that an event has not occurred solely by random chance. In common practice, a statistically significant finding means that the probability that the observed number of cases could have happened by chance alone is 5% or less. For instance, if one examines the number of cancer cases in 100 neighborhoods, and cancer cases are occurring by chance alone, one should expect to find about five neighborhoods with a statistically significant elevation in the number of cancer cases. In other words, some amount of clustering within the same family or neighborhood may occur simply by chance. For more information, visit the National Cancer Institute's page on this topic at www.cancer.gov/cancertopics/factsheet/Risk/clusters.

**The concept of "statistical significance" in no way implies any sort of judgment about the importance or significance of the issue that is being studied.*

Statistics

Statistics is a branch of mathematics dealing with the collection, analysis, interpretation, and presentation of numerical data: a collection of quantitative data.

Study eligibility criteria

Requirements that a person must meet to be included in a study are referred to as study eligibility criteria. These requirements help make sure that people in the study are similar to each other in terms of factors such as age, type and stage of cancer, general health, and previous treatment. Researchers have greater confidence that results of the study are caused by the intervention being tested and not by other factors when all participants meet the same eligibility criteria (definition from National Cancer Institute).

Superfund site

A Superfund site is a piece of land in the United States that has been contaminated by hazardous waste

and identified by the Environmental Protection Agency (EPA) as a candidate for cleanup because it poses a risk to human health or the environment.

Suspected cancer cluster

A cancer cluster is a group of cancer cases that meets the exact criteria of a cancer cluster in the official definition (see Cancer Cluster). Before these criteria are met, a “suspected” cancer cluster is a situation where there appears to be “a lot of cancer” or “an unusual number of cancer cases” in a community, neighborhood, workplace, school, or some other specific setting, based on informal, subjective observation.

Section 4:

Cancer Cluster FAQ

This section is a compilation of some of the most challenging questions that health departments have received from community and media when addressing cancer clusters, and suggested answers from experienced health department communicators.

- **This material is intended as a resource for health communicators from which they can draw inspiration, or adapt and personalize any of its parts to their specific needs.**
- **Specific answers will depend on the legal framework, structure, purpose, and specific activities of your state's cancer programs.**

What exactly is a cancer cluster?

Cancer clusters may be suspected when people report that several family members, friends, neighbors, or coworkers have been diagnosed with the same or related cancer(s). The term “cancer cluster” is used in several ways, to mean slightly different things. The National Cancer Institute, the Centers for Disease Control and Prevention, and other public health agencies use the following definition:

“A cancer cluster is a greater than expected number of cancer cases that occurs within a group of people or a geographic area over a defined period of time.”

To better understand this definition (page 15), a detailed breakdown of the CDC definition is presented below.

▪ **A greater than expected number**

The number is greater than expected if the observed number of cases is higher than one would typically observe in a similar setting (in a group with similar population, age, race, or sex). This may involve comparison with rates for comparable groups of people over a much larger geographic area (e.g., an entire state).

- Who are the members of our group that have cancer?
- What are we comparing our group against?

▪ **Of cancer cases**

All of the cases involve the **same type of cancer**, or types of cancer scientifically proven to have the same cause.

- What kind of cancer do the members of our group have?
- Do we know what causes those kinds of cancers?

▪ **That occurs within a group of people**

The population in which the cancers are occurring is carefully defined by factors such as race, ethnicity, age, and sex, for purposes of calculating cancer rates (expressed as the number of cases per 100,000 person over a specific period of time). It is possible to “create” or “obscure” a cluster by selection of a specific area. (See definition for “sharpshooter fallacy” in Cancer Cluster Glossary)

- Can we identify all the affected persons?

▪ **In a geographic area**

Both the number of cancer cases included in the cluster and calculation of the expected number of cases can depend on how we define the geographic area where the cluster occurred. The boundaries must be defined carefully. It is possible to “create” or “obscure” a cluster by selection of a specific area.

- Have we defined the geographic area?
- What kind of criteria are we using?

▪ **Over a period of time**

The number of cases included in the cluster—and calculation of the expected number of cases—will depend on how we define the time period over which the cases occurred.

- Have we defined the time frame over which the cases occurred?
- What kind of criteria are we using?

Confirmation of the existence of a cancer cluster does not mean that an identifiable hazard is causing it or that an identifiable hazard will be found. When no cause is found, it could mean that the cluster is statistically random or that science is as yet unable to determine a cause. Scientists are still trying to understand the causes of most cancers. It is important to address the fact that “cancer cluster” does not mean the cancer is contagious. It does not necessarily mean you are more at risk for cancer if you live in a certain area.

How do you decide what is the “expected” number?

[State cancer registries](#) may be able to look at factors such as age, race, and sex in your community and compare the cancer rates with similar communities. The more factors that are considered, the more accurate the estimate on whether the level of cancer is higher than expected. An analysis by the state cancer registry is one step in figuring out if the number of cancers in your community is believed to be higher than expected.

We’ve seen [number] cases of cancer in [name of community or neighborhood] over the last [time frame]. Is it unusual to see this much cancer in such a small group of people?

Even though scientists have made progress in understanding and treating cancer in our lifetimes, cancer is still a very scary illness because we still have not conquered it, and it is associated with so much suffering. More than a thousand potential cancer clusters are reported to public health agencies every year in communities all across the United States. Of those numbers, according to a [2004 study](#), *Understanding Cancer Clusters* (Thun 2004), most reported situations do not fit the scientific definition of a cancer cluster.

In 5% to 15% of situations, formal testing confirms that the number of cancer cases of a specific cancer in a community exceeds the expected number, given the age, sex, and size of the population. Even in these situations, in the majority of the cases, science is unable to identify the specific hazards causing the cancer.

Here are some important points to remember regarding “average or higher than average rate” of cancer:

- The “average” cancer rate is typically calculated for some large population group—an entire state, for example.
- “Higher than average” really just means higher than the average for that larger group. For example, a town with a lot of retirees may have a higher-than-state-average rate of prostate cancer, because this cancer occurs more frequently in older men. A town with mostly college students and fewer older adults may have a lower-than-state-average rate of prostate cancer. Each community is made up of a unique group of people with a unique set of circumstances and cancer risk factors.
- Changes in the number of people in the underlying population can change the “average rate.” For example, migration in and out of the community can change the characteristics and the size of the population.

- Few, if any, groups or communities will have exactly the same rate that has been reported statewide; most will be either higher or lower.
- Having higher than expected cancer rates doesn't necessarily mean that science can identify something in your group or community that is *causing* the cancer.
- Having lower than expected rates doesn't necessarily mean that science can establish that something in that group or community is *protecting* its members from cancer.

Why am I seeing high rates around me?

Reasons why the cancer rate may be, or may *appear* to be, “higher than expected” in a particular community include the following.

- **Some cancer rates (e.g., breast cancer) may be higher due to better medical care or screening in certain areas.**
- **Cancer rates in each group or community tend to change over time because the community changes.**
 - The rate may be “above average” today and “below average” tomorrow.
- **Cancer is a common disease.**
 - Although some forms of cancer are relatively rare, men in the U.S. have a 1 in 2 chance of developing cancer and women have a 1 in 3 chance of developing any cancer in their lifetime (American Cancer Society, www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspsc-031941.pdf).
 - It may not be that unusual to see what looks like “a lot of cancer” in a particular community.
- **Cancer is at least partly a disease of aging.**
 - Cancer is more common as people get older.
- **Cancer is not one disease, but many.**
 - Science has identified more than a hundred different kinds of cancer, many of which have different—and most of the time, unknown—causes.
 - Some cancer-causing agents, such as tobacco, cause more than one kind of cancer. But if people in your group or community have many different kinds of cancer, it's less likely that they were caused by the same thing.
- **Cancer can take a long time to develop.**
 - Although childhood cancers are an obvious exception, people may develop cancer a long time after being exposed to a cancer-causing agent. This “latency period” can be years or even decades.
 - That means that identifying when a person might have been exposed to a particular carcinogen is extremely difficult. The cancer may have been caused by something that happened somewhere else, a long time ago.
 - For adult cancers, unless people have remained in the same geographic area or type of work for many, many years, cancers caused by something in the place where they now live and work are unlikely.

We've always heard that most cancers are caused by something in the environment. Isn't that the most likely explanation?

- Perceptions about the role of the environment in causing cancer may depend on what you mean by "the environment." Scientists tend to use the term differently from the rest of us.
- When scientists say that most cancers are "environmentally caused," they simply mean "caused by something other than heredity."
- By that definition, "environmental" causes of cancer can include things like:
 - Smoking;
 - Poor nutrition, obesity, and lack of physical activity; or
 - On-the-job exposure to hazardous agents.
- "Environment" could also refer to cancer-causing chemicals in the air, water, or soil.
- In short, people can't simply assume that a cancer cluster is caused by "environmental contamination" (as most understand the term). If public health officials and community members determine that environmental contamination is a concern, they must work together to set realistic expectations about what steps can be taken (see 2013 Cancer Cluster Guidelines at <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr6208a1.htm>).

Still—can you totally rule out the possibility that something in the environment is causing these cancers?

- No, we can't ever conclusively rule out a possible link between a diagnosis of cancer in a person and something in the environment—although we certainly wish we could. Scientists all over the world are looking for answers to the same questions. Tremendous progress has been made in recent years, but we have not been able to conquer cancer yet.
- Science can't "prove a negative." We can't "prove" that some particular hazard is *not* causing a particular health problem.
- What science can do, through well-designed studies, is test the idea that a particular hazard is associated with a particular health issue.

What about carcinogens or substances that are known to cause cancer?

- A carcinogen is a substance or agent known to cause cancer. In its 12th Report on Carcinogens, published in 2011, the National Toxicology Program, U.S. Department of Health and Human Services, identified 54 substances "[known to be human carcinogens](#)." The report also lists substances that are "reasonably anticipated to be human carcinogens."
- Whether a carcinogen will cause cancer depends on the following:
 - The type of exposure: Did a person breathe it, touch it, drink it, or eat it? Each substance causes cancer in a different way.
 - The sensitivity to exposure: How sensitive is the person who was exposed to that particular substance? Each person's body is different and will react differently.
 - The amount of exposure: How much of the substance was eaten?
 - Duration of exposure: How long was the person exposed?

Because you can't rule out the possibility of an environmental cause, wouldn't it make sense to do some kind of study?

- See 2013 Cancer Cluster Guidelines for more protocol information about when health departments conduct a study. In general, scientists conduct studies in cases where they determine, based on the information available, that a study would provide answers for people.
- When health departments choose not to do a study of this type, it is usually because limiting factors of science would prevent the study from providing answers.
- Before a study begins, communities and public health officials must work together to set realistic expectations about what steps can be taken.
- Some of the key questions to be addressed are:
 - What are we trying to find out?
 - Are we likely to find those answers through a study?
- When there is an environmental hazard in the community, action can be taken to reduce or remove the hazard without necessarily conducting a cancer cluster investigation.

What have cancer cluster investigations found in the past?

- Some reports of suspected cancer clusters have resulted in in-depth investigations.
- The results of these well-designed, exhaustive studies about cancer clusters have been published in the scientific literature.
- To date, from thousands of reported and suspected clusters, only a few investigations have clearly identified an underlying environmental cause.
 - All of the exposures were occupational or medical exposures: none were community exposures.
 - The cancers were very rare.
 - The exposures involved intense and sustained exposure to an unusual chemical, occupation, infection, or drug.
 - 1775 scrotal cancer in chimney sweeps exposed to soot from coal.
 - 1929 [osteosarcoma](#) in watch dial painters exposed to radium.
 - 1965 [mesothelioma](#) and lung cancer in [asbestos](#) workers.
 - 1974 [angiosarcoma](#) of the liver in chemical workers exposed to [vinyl chloride](#) monomer.
 - 1971 vaginal clear cell [carcinoma](#) in daughters exposed in utero to [diethylstilbestrol](#).
 - 1981 [Kaposi sarcoma](#) in homosexual men with AIDS exposed to human herpes virus B.

Why can't studies of community clusters tell us what's causing the cancer?

- Science does not know the causes of most types of cancer. A population study would never be able to tell why any one person got cancer because for each person, cancer is thought to be caused by a combination of many factors, genetic and environmental.

- Science is limited in this area. Cancer cluster studies tend *not* to provide all answers that people want:
 - No link with anything in the environment has been scientifically proven.
 - Sometimes, researchers might be able to confirm an environmental exposure and confirm cases of cancer, but science might be unable to determine whether the exposure caused the cancer because answers to the following remain unknown:
 - **Who** was actually exposed to a potential cancer-causing agent?
 - What **specific agents** they might have been exposed to?
 - What was the **level** of exposure to these agents?
 - **How long** were they exposed?
 - Often the number of people diagnosed with cancer in a community is in the tens or dozens. Researchers need larger numbers of persons in order to have a more accurate and representative picture of the reality of a community. Even if an environmental contaminant were causing health effects, the study would not be able to identify it because cancer is believed to be the result of a combination of factors, and the environment is just one of them. Studies of environmental contaminants are more useful and produce better results when they are looking at thousands of people, rather than a smaller group.
 - When exposure levels are very, very high, fewer people are needed to show an effect. However, even when exposure levels are high, if the number of cases is small, science is not always effective. An experience to consider is Love Canal, New York. Here, a community was exposed to an extremely large amount of toxic waste in the 1970s. Even in this community with a proven exposure (approximately 21,000 tons of toxic waste), studies could not conclusively prove exposures caused increased cancer rates; the numbers of people with specific cancers were still too low.
 - Cancers can take years, or even decades to develop following exposure to a cancer-causing agent.
 - The cancers that are occurring in a particular group or community right now may have been caused by something that happened somewhere else a long time ago.
 - Unless the people involved in a cancer cluster have been in the same place for a long time, the cause may not be something they're being exposed to right now.

Would it be helpful to do some testing—to find out if in fact dangerous cancer-causing or other hazardous agents are in the environment?

- Before you begin to do environmental testing, communities and public health officials should work together to set realistic expectations about what steps can be taken, to assertively address unrealistic expectations, and to determine steps to take. (See 2013 Cancer Cluster Guidelines at <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr6208a1.htm>).
 - The underlying question is “What are we looking for, and why?”
 - Finding contaminants in the environment won't necessarily give researchers the answers to questions about whether people are being exposed—or tell if the contaminants found played any role in creating the cancer cluster. Community members and public health officials must be aware of that possibility before any testing effort begins—and when the results become available.

- As a result of centuries of industrial activities affecting the water, air, and soil, researchers are likely to find environmental contaminants any time they look for them.
- [Use the following according to relevance and organizational support:]
 - Our department supports efforts to clean up environmental hazards where they exist.
 - The state encourages people to have private well water tested if they are not on public water supplies.
 - The health department supports efforts by environmental agencies to test for environmental hazards where they are plausible and where levels have not been previously tested.

If we do find out that contamination from [name of presumptive source] has made it into the [water/soil/air], is that a potential health threat?

- Yes, depending on levels discovered, hazardous substances in the water, soil, or air can represent a potential health threat that must be addressed. However, the presence of contaminants may not have a connection with a suspected cancer cluster.
- The citizens of our community deserve a healthy environment, to breathe clean air, to drink clean water and to have access to clean playgrounds for our children.
- Even if a study can tell us what chemicals are present in the environment, it won't tell us whether any people have actually been exposed to these substances, or at what levels.
 - Did people actually breathe air that contained these agents?
 - Did they eat or drink contaminated food or water?
 - Was there any way they might have absorbed hazardous chemicals through their skin?
 - What level of contamination were the people exposed to?
 - Over what time period were people exposed?
- Getting good information about what people were exposed to, at what level, and for how long may be very difficult—especially if the exposure took place in the past.
- Researchers will need more than environmental testing alone to determine if cancer or other disease outcomes may be related—or how big the threat might be.
- Without precise information about actual human exposure, it's **[it will be]** difficult to determine how much impact, if any, these contaminants might have had on cancer rates in the community. [Use the following according to relevance and organizational support:]
 - Our department supports efforts to clean up environmental hazards where they exist.
 - The state encourages people to have private well water tested if they are not on public water supplies.
 - The health department supports efforts by environmental agencies to test for environmental hazards where they are plausible and where levels have not been previously tested.

Aren't you concerned about not being able to find out if there is an environmental cause? People in this community are very ill and some are dying!

[Listen to the concerns of your community. Use empathy in all words and actions.]

- Identifying threats to the health of the public and addressing them is a core part of the public health mission. Preventing disease and protecting the health of our residents is our highest priority.
- We (public health officials) wish science could provide us (public health officials and community) with more definitive answers to questions about our health and the specific health challenges we (public health officials and community) face here. We (public health officials) will work with you (community) and provide all the answers we can.
 - Public health officials cannot promise answers that they won't be able to deliver. Public health officials and community members need to take that into consideration before an investigation launches. Otherwise, the research may simply deliver frustration to everyone.
- Communities and public health officials must work together to set realistic expectations about what steps can be taken, assertively address unrealistic expectations and determine those steps that will be taken (2013 Cancer Cluster Guidelines). Public health officials need to focus their efforts where they will do the most good and be realistic about science's ability to resolve the uncertainties that inevitably surround cancer clusters.

How do you track cancer cases in the state, and how is the information used?

- As part of our state cancer registry program, **[specify what division, office, agency]** collects information on all newly diagnosed cancers in the state and enters the information into a statewide database.
- **[Specify division, office, agency]** has been collecting this information since **[date]**.
- This information is used to identify statewide trends in cancer rates—and to some extent, trends for communities in our state. It can be used to identify areas of the state where the incidence of a particular kind of cancer is higher than the rate for the state as a whole. It can also be used to provide context in evaluating situations where people believe they are suffering an unusually large number of cancer cases. For example, it can tell us whether suspected cancer clusters reported by people in a community actually involve a higher-than-expected number of cancer cases, based on the experience of comparable communities or groups of people. *However, it can't tell us, by itself, whether a particular hazard or cancer-causing agent is causing a cancer cluster.*

How can you be sure there aren't more cancer clusters in the state or in neighboring states?

[Modify the following message points as needed to reflect your state's registry program and specific situation.]

- Every year, around a thousand suspected cancer clusters are reported nationwide. **[Name of city]** public health department routinely uses the state's cancer registry to look for trends in cancer rates and possible regional cancer clusters.

- Environmental Public Health Tracking (EPHT) data for many states can supplement cancer registry data. For more information on this subject, please visit the National Environmental Public Health Tracking Network page at <http://ephtracking.cdc.gov/showHome.action>.
- [Specify department, office, division, etc.] also coordinates and shares information with public health agencies in other states.
- Most states *do not* actively look for trends in cancer incidence for geographic units below the county level.
 - Smaller geographic areas—such as neighborhoods or communities—tend to be more subject to random variation in cancer rates.
- [Specify dept., office, division, etc.] also receives reports from citizens concerned about potential cancer events in their communities.

Do you plan to proceed with a study anyway, even though it's unlikely to provide the answers people want? Why?

Public health officials try to base all decisions on science. The 2013 Cancer Cluster Guidelines contain clear steps and procedures to determine whether an investigation should proceed. However, sometimes other factors must be taken into consideration:

- **Mandate:** Ultimately, public health officials work for the people of [name of state] and have a legal and ethical obligation to address people's concerns – whether expressed directly, by individual residents, or through their elected officials.
- **Funding:** As a public health agency, we are supported by taxpayer dollars and must work within our allotted budget.

Many people—including a number of elected officials—have criticized your response to the [name of community] cancer cluster. Are you concerned that you didn't respond more quickly? Should you have devoted more resources to this investigation?

[The following message bullets can be applied to questions reducible to “did you do enough/fast enough.” However, the bullets are **only suggestions**. Please make **additions, deletions and modifications or substitutions** that are appropriate for your circumstances. Specific answers will depend on the legal framework, structure, purpose, and specific activities of your state's cancer registry program.]

- Nothing is more important to our health department than protecting the health of the people in this state.
- Responding to potential health threats and concerns that people may have about their health is always [specify name] highest priority.
- [Specify name] knows people are very concerned about what's happening in this community, and we share that concern.
- [Specify name] knows people want us to respond as quickly as possible, and we always strive to do that.

- **[Specify name]** has responded to this situation as quickly as we could with the resources we have available – and we know that there is always room for improvement.
- At the same time, our resources are limited, and at any given time we may be facing a variety of public health threats.
- Before we (public health officials) take action we must develop a clear understanding of the issues we face and the potential success of proposed solutions.
- We (public health officials) cannot be effective in achieving our mission unless we are able *to set clear goals and target our use of resources in the most productive manner possible*. For example, we can put money towards cancer prevention strategies that we know are effective.

Why aren't you more concerned about the families who are being affected by this? Children are getting sick. Some of them are dying. Why isn't this a higher priority?

- Nothing is more important to our health department than protecting the health of the people in this state, and no part of that is more important than protecting the health of our children. **[List a series of actions you have already conducted or will conduct based on community concerns]**.
- Resolving the kinds of questions raised by the cancer cluster is among our highest priorities. It's part of our core mission.
- To do that we need to develop the clearest possible understanding of what needs to be done, and the best way to go about doing it.
- Our resources are limited; so we need to target our efforts carefully.
- No group or set of concerns or issues is more important than another. We have an obligation to focus our efforts where we believe they will do the most good.

[Name of community] is a relatively upscale community. If it weren't, would people be making such a big deal of this?

- It would be not only illegal but also morally wrong for me and my colleagues to discriminate based on any social or economic issue. We have never discriminated and will never allow it to happen.
- Everyone should have the opportunity to live in a healthy environment free of environmental hazards.
- Our core mission is always the same – protecting the health of all of our state's families and individuals regardless of where they live or their personal circumstances.
- There were clearly serious public concerns about cancer rates in **[name of community]**, and we have been working to address them. **[Repeat from question above if possible: List a series of actions you have already conducted or will conduct based on community concerns]**.

If [name of community] were a wealthier neighborhood, would something like this be allowed to happen?

- Federal agencies recognize that minority and low-income populations experience disproportionate exposure to environmental hazards with negative health effects. We are committed to doing everything in our power to address those environmental challenges.
- Everyone should be able to live in a healthy environment free of environmental hazards.
- Our core mission is always the same—protecting the health of all state residents, regardless of where they live or their personal circumstances.
- We are focusing on the specific public health questions that are being raised about cancer rates in this community.

So if you can't do a study, how exactly can the health department help us?

- When facing the possibility of a cancer cluster case, communities and officials from the health department must work together to set realistic expectations about what steps can be taken, assertively address unrealistic expectations and determine those steps that will be taken (see 2013 Cancer Cluster Guidelines).
- We can help raise attention to public health actions that could be taken by other agencies, such as removal of known environmental hazards.
- For this type of cancer in particular we are/have been: **[list actions health department has taken to learn and educate about specific cancer]**
- The health department works hard to help prevent cancer in this community. Some of the cancer prevention programs we support include: **[list below]**.
- We are providing information to increase communities' knowledge about cancer and encourage participation in cancer screenings and healthy behaviors.
- The health department wants (or is working) to establish better relationships with community members, and to hear from community members about health concerns.
- Unfortunately for all of us, there are conditions and situations for which science doesn't offer answers yet. The only thing it is possible to do is to analyze all the options at our disposal, establish a plan of action, and make sure community members and public health officials take advantage of all the available opportunities.

Section 5:

Cancer Cluster Resources in Scientific and Popular Literature

This section is a compilation of some of the most relevant materials addressing cancer clusters.

References and Additional Cancer Cluster Scientific and Popular Articles

- Aldrich T and Sinks T. 2002. Things to know and do about cancer clusters. *Cancer Invest* 20:5:810–16.
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- Besley J, et al. 2008. Local newspaper coverage of health authority fairness during cancer cluster investigations. *Sci Commun* 29(4) 498–521.
- Gawande A. 1999 Feb 8. The cancer-cluster myth. *The New Yorker*.
- Greenberg M and Wartenberg D. 1991. Communicating to an alarmed community about cancer clusters: A fifty state survey. *J Comm Health* 16(2).
- Morbidity and Mortality Weekly. (in press). Guidelines for investigating cancer clusters.
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- Thun MJ and Sinks T. 2004. Understanding cancer clusters. *CA Cancer J Clin* 54:273–80.
- Trumbo CW. 2000. Public requests for cancer cluster investigations: A survey of state health departments. *Am J Public Health* 90:1300–302.

Risk Communication Resources

- Sandman P and Johnson B. 1992. Outrage and technical detail: The impact of agency behavior on community risk perception. NJ Dept. of Environmental Protection.
- Sandman P. 2010 Feb. 8. Outrage management via online social media. Available at: <http://www.psandman.com/gst2010.htm#online>.
- Selected resources from Peter Sandman risk communication Web site (www.psandman.com)
 - What Makes an Interaction Responsive?
 - Reducing Outrage: Six Principal Strategies
 - A planning Process for Public Involvement
 - The “Publics” in Public Involvement
 - Goals for Dealing with Activist Groups
 - Guidelines for Dealing with Activist Groups
 - Twelve Principal Outrage Components
 - The Four Traditional Stages of a Risk Controversy
- Selected resources from CDCynergy Emergency Risk Communication Tools (add Web site)
 - Emergency Risk Communication Quick Planning Worksheet

- Emergency Risk Communication Objectives Development Worksheet
- Site History Worksheet

Useful Links

- <http://www.cancer.gov/cancertopics/factsheet/Risk/clusters>
- <http://www.cdc.gov/cancer/npcr/>
- <http://www.osha.gov/SLTC/carcinogens/index.html>
- http://dhss.delaware.gov/dph/dpc/files/cancer_cluster_investigation_protocol.pdf
- <http://www.epa.gov/osw/hazard/>

Section 6:

Social Media

Social media tools are powerful channels to reach target audiences with strategic, effective, and user-centric health interventions, including individuals and groups concerned about cancer clusters.

- **This document provides an introduction to social media and examples of ways to use it in cancer cluster messaging.**
- **It describes what social media are, why they're important, the policies required to use social media responsibly, and technical requirements.**

What are Social Media?

Social media are information-content resources created by people using highly accessible and scalable publishing technologies. They are intended to facilitate communications and to influence interaction between peers and with public audiences. This is typically done via the Internet and mobile communications networks. The term most often refers to activities that integrate technology, telecommunications, and social interaction, and the construction of words, pictures, video and audio. This interaction, and the manner in which information is presented, depends on the varied perspectives and "building" of shared meaning among communities, as people share their stories and experiences. Businesses also refer to social media as user-generated content (UGC) or consumer-generated media (CGM).



Image from <http://communitywealth.com>

Types of Social Media

Social media is a broad term that encompasses a variety of information channels. Below are descriptions of some common types of social media.

Social Networking Services

A social network service focuses on building and reflecting social networks or social relations among people who share interests or activities. A social network service essentially consists of a representation of each user (often a profile), his or her social links, and a variety of additional services. Profiles can be established for individuals as well as groups and organizations. Most social network services are Web-based and provide means for users to interact over the Internet, such as e-mail and instant messaging. Social networking sites allow users to share ideas, information, activities, events, and interests within their individual networks. Popular social networking sites include Facebook and LinkedIn.

Blogs

Blogs, or Web logs, are regularly updated online journals that almost anyone with an Internet connection can create. Some blogs target a small audience, while others boast a readership comparable to national newspapers. They may have only one author or a team of regular authors, but most blogs share a similar format in that the entries are posted in a reverse chronological order and may allow readers to comment on posts.

Microblogging is a form of blogging that allows users to send brief text updates to a Web site that aggregates these messages for viewing by either a friend list or the public. These messages can be submitted by a variety of means, including text messages, mobile Web sites, audio, the Web site hosting the micro-blog, or other sites that are supported by an Application Program Interface (API). Twitter is currently the most popular of these sites.

Content Sharing

The content sharing category of social media includes any Web site that allows users to distribute content they have generated— this may include information, photographs, music, and videos. Web sites in other categories have incorporated elements of content sharing (e.g., Facebook users can share photographs in their profiles). However, some sites are dedicated exclusively to content sharing, including Flickr (photos) and YouTube (videos).

Content Syndication

Web syndication refers to a way in which Web site material is made available to multiple other sites at once, often through “syndication feeds.”



Podcasts

A podcast is a multimedia file distributed over the Internet using syndication feeds, for playback on mobile devices and personal computers.



RSS Feeds

RSS (short for Really Simple Syndication) is a format for delivering regularly updated Web content to multiple sites at once. Many news-related sites, Web blogs and other online publishers syndicate their content as an RSS Feed. When a Web blog “subscribes” to the feed, content from the initial Web site automatically is posted on the blog. This allows subscribers to easily stay informed by automatically retrieving the latest content from the sites they are interested in.

Widgets

A widget is an application that displays featured content directly on Web sites that choose to use it. Widgets allow you to embed content in personalized home pages, blogs, and other sites. Once you've added the widget, there's no technical maintenance. When the creator updates the widget, the widget is effectively updated for everyone who uses it, automatically.

Wikis

A wiki is a collaborative Web site, with an emphasis on **easy access** to, and **modification** of, information. Pages within a wiki are typically interlinked, so that users can move between pages easily. Wikipedia has become the best known and most widely used wiki.

Monitoring Applications

There are a variety of options for monitoring social media. Even if your organization is not currently engaging in the social media exchange, it is important to know what is being said about the situation and about your organization's actions. For more on these applications, go to the “Technical Requirements” section below.

Why Social Media are Important

CDC uses social media to provide users with access to credible, science-based health information when, where, and how they want it. A variety of social media tools are used to reinforce and personalize

messages, reach new audiences, and build a communication infrastructure based on open information exchange.

Social media offer many advantages over more traditional media options. They are inexpensive (often free) and quick (often immediate). They go beyond Web pages to include interactive ways to share or disseminate information using electronic media. And with social media becoming popular among a variety of populations, they can reach more people than do traditional methods alone.

In short, social media are fast, cheap, and popular.

Deciding to Use Social Media

When deciding on how and when to use social media, it is important to consider your audience. According to a study by the National Cancer Institute published in 2009, approximately 69% of U.S. adults reported having access to the Internet in 2007. Among Internet users, 5% participated in an online support group, 7% reported blogging, and 23% used a social networking site. Younger age was the only significant predictor of blogging and social networking site participation; a statistically significant linear relationship was observed, with younger categories reporting more frequent use. Younger age, poorer subjective health, and a personal cancer experience predicted support group participation. In general, social media are penetrating the U.S. population independent of education, race/ethnicity, or health care access.

The authors concluded that recent growth of social media is not uniformly distributed across age groups; therefore, health communication programs utilizing social media must first consider the age of the targeted population to help ensure that messages reach the intended audience.

Carlsbad Cluster Example

You may be wondering what social media related to a cancer cluster might look like. The Carlsbad cluster is a good example; multiple sites and profiles are related to this cluster. This shows that the use of social media is not a matter of *if* or *when*; people *already are* engaging in a social media dialogue regarding suspected clusters. The fact that people are looking to discuss cancer clusters on social media demonstrates the need for accurate, reliable information in the social media world regarding cancer clusters.

- **Twitter posts:**
 - Padres in Escondido, Bad Checks In Vista, Cancer in Carlsbad – KPBS
<http://twitter.com/escondidojobs/statuses/20183293530>
 - Parents Told to Raise Funds for Cancer Cluster Study
http://twitter.com/topix_dos/statuses/19811677322
- **Blog posts:**
 - <http://www.carlsbadistan.com/?p=7576>
- **Web site and associated content:**
 - Facebook profile for Cancer Connection
<http://www.facebook.com/pages/Carlsbad-Cancer-Connection/112871382056432?ref=search>

How to Use Social Media

Different types of social media can overlap in their content and functionality, so the choice of what to use in a particular situation may be a matter of personal judgment and preference. To get you started, here are some examples of how CDC uses social media:



- **Blogs:** Blogs allow their owners to share information and also receive and respond to comments regarding their posts. CDC is home to a number of blogs on topics ranging from occupational health to HIV prevention and control. CDC blogs allow programs to share information in a way that encourages readers to comment and engage with the content. Example:
<http://blogs.cdc.gov/healthprotectionperspectives/>
 - **Buttons and Badges:** CDC uses buttons and badges to share health messages and information about campaigns and causes online. Buttons are graphic elements that usually include an image, a short message, and a link for more information. Buttons are often created to be shared and include HTML code that allows them to be posted on a Web site. Ideally badges should include your organization's logo, an attractive image, and a simple, easy to understand message. Examples:
<http://www.cdc.gov/SocialMedia/Tools/ButtonsGallery.html>
- 
- **Image Sharing:** CDC's photo sharing spaces allow the agency to share information and make public health resources available to the public. See CDC's Flickr photostream for ideas:
http://www.flickr.com/photos/cdc_e-health/
 - **Micro-blogs:** CDC encourages the strategic use of Twitter to effectively and inexpensively reach individuals and partners with timely health and safety information. People can follow updates from CDC on various topics, including emergency information and flu updates. See <http://twitter.com/CDCemergency> for one example.
 - **Online Video:** Users can watch one of CDC's online videos to engage with CDC content in a fun, visual, and interactive way. The CDC Streaming Health channel on YouTube currently hosts almost 60 videos on a variety of health topics, from novel H1N1 flu to HIV/AIDS and many more. See www.youtube.com/CDCstreaminghealth for videos.
 - **Podcasts:** CDC produces podcasts to provide health information in a portable format. Visit <http://www.cdc.gov/podcasts> to check out the most popular CDC podcasts.
 - **RSS:** CDC RSS subscriptions enable people to personalize the health information they receive by selecting the topics of greatest interest to them. Users can select from more than 25 unique [RSS feeds](#) from CDC—including Spanish-language feeds—so that they are notified whenever updates are made to the selected pages.

- **Social Networking Sites:** Users can connect with CDC on multiple social networking profiles, including [Facebook](#), [MySpace](#) and [Daily Strength](#).
- **Widgets:** CDC provides a number of widgets on a variety of topics, including novel H1N1 flu (swine flu), smoking and tobacco use, seasonal flu, everyday health tips (available in English and Spanish), and much more. Users can add a CDC widget to their Web page, social networking profile, or blog, and stay informed with up-to-date, credible health and safety content. This content is then also shared with others who view the widget within the Web site. Visit <http://www.cdc.gov/widgets/> for CDC's available widgets.

What if you can't use social media?

Go to third parties! If you are restricted by current policy and can't use social media directly, you may want to identify groups using social media who have a vested interest in the cluster (e.g., a "mommy bloggers" group). These groups should be informed and well respected. Groups that are thought leaders in the social network talking about the cluster may be able to convey your messages through social media if you can't do so directly.

Let these third parties know you want to be a resource for them. Supplying accurate and useful information to third parties prominent in the social media world is your next best option to using social media directly.

Staffing and Training Requirements

Working in social media can be labor intensive. Because of its unique characteristics, social media requires additional maintenance that is not necessary for more traditional media outreach. Different types of social media will require a variety of staffing roles. These may include a blogger, a podcast recorder, a tweeter, or a Facebooker. One staff member may be able to fill any or all of these roles. Some common tasks may include the following:

- Frequent content development and input
 - This can range anywhere from new tweets and blog posts to video updates and new podcasts, and it may necessitate consultation with subject matter experts (to ensure that content is accurate and up-to-date) or health communication specialists (to check messages for adherence to basic health literacy principles).
- Development and implementation of appropriate policies and best practices (see "Social Media Policy" section)
- Monitoring other sites and responding to misinformation or criticism
- Reviewing and replying to user comments
- On-going evaluation of social media (e.g., which materials garner the most positive response?)

Staff will need to be trained in the use of social media sites so that they are comfortable navigating through the sites. More basic health communication training should be incorporated as well. Although social media reaches out to audiences in a very different way than traditional media, it is still important that staff members are trained in basic health literacy. Content should be written at a 6th to 8th grade reading level and should be accessible to the general public.

Social Media Policy in Your Organization

Establish a policy within your organization that dictates when and how social media will be used and maintained. This policy can be tailored to the specific needs and uses of your organization. Some examples of common issues that should be addressed in your policy on social media use are listed below.

- If a comment to your blog is posted as a question, how quickly must the question be answered?
- How often (times per day/week/month) should your organization tweet, update its Facebook profile, or post new blog entries?
- What will the approval policy for posting be?
- Will you require approval of comments before they are posted? If so, what will your “terms of use” policy be?
- How should employees or organization members conduct themselves when engaging in social media outlets outside of work hours (i.e., when not acting as an official representative of your organization)?

For CDC’s guidelines and best practices, see <http://www.cdc.gov/SocialMedia/Tools/guidelines/>.

Technical Requirements

In addition to staffing requirements, the use of social media may present specific technical needs. Before jumping into any particular type of social media, anticipate what your technology needs will be. For example, you may need to purchase equipment or download software that allows you to do any or all of the following:

- Record and manipulate audio and visual data
- Edit photographs
- Edit content in code, such as HTML
- Monitor various channels



TweetDeck allows users to track updates on popular social networking sites including Twitter, Facebook, MySpace, LinkedIn, Google Buzz, and Foursquare. Users can split the program into columns which show different things, such as updates from select Web sites or specific people. (Available at <http://www.tweetdeck.com/>)



CisionPoint offers one such social media monitoring tool. Watch the video at <http://us.cision.com/media-monitoring/social-media-monitoring.asp> for a better understand of how it operates.



“Involver’s amp” is a dashboard that allows users to monitor, publish, schedule, and manage information across social media channels. (Available at <http://www.involver.com/amp.html>)

Some of these types of tools have extensive functionality and can be expensive, while others are simpler and relatively cheap or even free. Remember that there are many options. Try to find the one that works for your organization.

This list is not exhaustive; the important point is that both staffing and technical requirements should be considered when integrating social media into your communication strategy.

Partnership Considerations

Remember that the whole idea behind social media is sharing! Be sure to represent partner organizations where appropriate. That may include linking to their social media sites through your own: become a fan of their Facebook page or add them as a friend on MySpace. You can also choose to embed their content within your site via RSS feeds and widgets. By collaborating with partners through social media, you can increase your reach and strengthen existing partnerships. You can also build credibility with your audience by partnering with organizations that they already know and trust.

More information is better than less. One of the greatest benefits to using social media is that it offers real-time communication with partners, stakeholders, and other concerned parties. You can build credibility by proving to your audience that you are listening and responding.

Remember that social media is not a one-time effort! Using it effectively involves frequent monitoring and updating. But if it is used effectively, social media provides a powerful channel to reach target audiences with strategic, effective, and user-centric health interventions.

Section 7:

Template for Communication Planning

This section provides a sample template for health departments conducting communication planning. It can be adapted for your needs.

Draft communication plan, XX/XX/XXXX
Suspected neighborhood cancer cluster

Background

Give context for the people reading the plan. What are the circumstances that require you to prepare a communication plan? How did the cancer cluster come to your attention, and what has been the community reaction until now?

Communication Objective

In one sentence, describe what you would like the outcome of your communications activities to be. What will have changed as a result of your communications?

Communications Strategy

Broadly describe the health communication or risk communication theory behind your proposed tactics. For example, “Use risk communication techniques of empathy and proactive information-giving to provide targeted information for our audiences.”

Audiences

Be as specific as possible, remembering there is no such thing as the “general public.” Who exactly are you trying to reach with your messages?

Methods

List specific methods, keeping in mind you will use different channels to reach different audiences. Will you use one-on-one meetings, a press conference, or a social media channel?

Key messages and talking points

What is the main thing you need people to understand? Stay within the “lane” of the health department and your area of expertise. Do not make promises you cannot keep. Risk communication research has shown that people will remember three messages in times of distress. Keep your main messages short—about 9 words, with the most important message first. Then you can support each message with 3 points. Keep in mind these messages may change during the investigation, and you may need to tailor messages for different audiences.

Spokesperson

Choose who will be speaking in media interviews and at public meetings. The spokesperson should be well-versed in risk communication techniques and know how to be empathetic and speak in plain language. The person should also be familiar and comfortable with the culture of the audience.

Timeline

Create a table explaining what steps will be taken, who will take them, and deadlines for each. Deadlines can be moving targets if needed. Be as specific and detailed as possible on tasks that must be done.

Section 8:

Case Studies in Cancer Cluster Communication

In this section, you can read about the challenges that several states have faced in communicating about perceived cancer clusters.

Susquehanna University

A cancer cluster investigation was triggered by a March 2007 news story in a central Pennsylvania newspaper that detailed cases of cancer among young alumni from Susquehanna University, many of whom once lived in an off-campus area in Selinsgrove, Pennsylvania, near a contaminated former mill site. A Pennsylvania Department of Health (DOH) investigation found no evidence of a cancer cluster associated with the environment or attending the school.

Related Clips

- http://www.pennlive.com/specialprojects/index.ssf?/news/patriotnews/stories/cancer_a_030507.html
- <http://www.pennlive.com/midstate/index.ssf/2009/01/selinsgrove.html>
- http://www.dailyitem.com/0100_news/local_story_022234837.html/

Communication Challenges

- The reporter first called the Pennsylvania DOH asking general, vague questions. The press officer taking the call was not aware of the reporter's angle. Months later, the reporter ran a front-page story with details from many sources and many inaccuracies. Internally, both the Secretary of Health and the Governor's office were unaware of the news story until it ran.
- Pennsylvania DOH defines a cancer cluster differently from the way the public defines it.
- The story had a tragic origin: a mom lost her child to cancer. It is hard to speak science with such an emotional topic, particularly when it comes to public perception.
- Some details could not be disclosed to the press.
- The community and press had some mistrust of government in general.

Communication Successes

- When the Pennsylvania DOH final report was done, it was presented to the school and local legislators to discuss the findings and talk about the DOH communication strategy.
- The Pennsylvania DOH scheduled a face-to-face with the reporter who originally broke the story to ask him to work with the health department in communicating what we found. Being proactive and giving this reporter an exclusive resulted in a much more balanced story. The other media outlets had been relatively balanced to begin with, so they were not as much of a concern. However, DOH did follow up with them to talk about the report.

Lessons Learned

- Use empathy first, even when talking about science and facts.
- Communication strategy needs to begin in the early stages, not the final stages.

Polycythemia Vera

The U.S. Agency for Toxic Substances and Disease Registry, with assistance from the Pennsylvania Department of Health (DOH), confirmed an elevated number of cases of polycythemia Vera, or PV, in a 20-mile stretch between Hazleton and Tamaqua, Pennsylvania. PV is a rare blood disorder in which the bone marrow overproduces red blood cells. Residents in the affected area were four times as likely to suffer from PV as residents living in outlying areas. The cause of PV is unknown.

Related Clips

- <http://residentresidentsvoice.com/news/blood-cancer-cluster-researchers-to-hold-public-meeting-1.343785>
- <http://www.msnbc.msn.com/id/21423926>
- http://www.usatoday.com/news/health/2008-08-26-toxic-cancer_N.htm?csp=34
- http://www.pennlive.com/midstate/index.ssf/2008/08/feds_confirm_elevated_cancer_1.html

Communication Challenges

- A small number of physicians in the community, as well as some legislators, tried to connect the disease with past environmental concerns even though the cause of the disease is unknown. They created excitement among the community during public meetings. This resulted in combative public forums.
- The Pennsylvania DOH found a problem but could not find a cause, and no cure exists.
- Scientists could not scientifically prove the PV was related to a Superfund site despite the community's belief that the disease was connected to environmental pollution.

Communication Successes

- The Pennsylvania DOH coordinated effectively with ATSDR to update the community frequently during the investigation.
- The Pennsylvania DOH educated the local physician community on PV.

Lessons Learned

- The state health department should invite speakers who will relay messages clearly and consistently. Also, invite a strong mediator to facilitate meetings with multiple speakers.
- State roles in a federally led investigation need to be clearly defined from the beginning.

The Acreage

A cancer study was conducted by the Florida Department of Health (DOH) at the request of a family living in a community known as The Acreage, in northern Palm Beach County. While waiting for treatment in a pediatric oncology center, the family found other families with cancer. Their chance meeting led to a conversation with their oncologists who recommended they reach out to the DOH and ask for a cancer study.

Using 2000 Census data, DOH's initial investigation noted an elevation of pediatric brain cancer in this community of about 35,000 residents. Additional studies with a more current population estimate confirmed an elevation of pediatric brain cancer in females. DOH and partner agencies engaged in a detailed study involving water, radiation, and soil in the community to determine whether a source or cause for this increase could be identified.

The community was outraged and divided into two camps. One group did not believe a cluster existed, and felt that the declaration by DOH lowered their property values for no reason. The other group believed the cancers had an environmental cause and that if DOH looked hard and long enough it would be discovered.

Related Documents

- http://www.pbchd.com/spotlight/acreage/cancer_cluster.html

Communication Challenges

- The media coverage of this cluster was intense and often sensational. The ability for anyone to start a blog, forum, or Web site and post information made it difficult to respond to and eliminate all false information. Legal class-action groups held regular community meetings and posted results of tests that were later retracted due to factual errors.
- At the same time, Nemours Children's Hospital and the University of West Florida published a report in a peer-reviewed journal indicating that all of South Florida was experiencing an increase of pediatric cancers and should be considered a cancer cluster. DOH met with the investigator and concluded that the South Florida cancer cluster may not stand the test of repeatability when other research entities rerun the data.
- DOH investigation and parents of children with brain cancer in The Acreage were featured on a national television program (Dr. Oz). This attention helped to divide the community even more.

Communication Successes

- Several communication channels were up and running early in the process.

- DOH opened a Community Information Center in a popular local shopping center. An epidemiologist was available to answer the questions and concerns of residents on Tuesday through Saturdays from 10 a.m. to 6 p.m.
- DOH brought together a community focus group of residents representing both sides of the issue. This diverse group of residents mirrored the community and acted as an informal focus group for testing outreach material.
- DOH developed a dedicated Web page, with RSS feeds and email notifications for updates, and a rumor control page.

Lessons Learned

- DOH needed a clear presence and voice within the community earlier than occurred.
- Even though leaders had been taught risk and crisis communication, a refresher course would have been helpful in the early stages of this investigation.
- DOH needed a more effective rumor control mechanism. (Due to internal policies, DOH could not comment on blogs and other nonofficial communication channels.)