Is a health study the answer for your community?

A guide for making informed decisions

For decades, environmental health scientists at Boston University School of Public Health have worked with community groups to address environmental health problems. We wrote the Health Studies Guide to assist community groups and individuals who think that some form of environmental health investigation or health study may be useful or necessary in their community. Readers of this guide may have concerns about drinking water contamination, or the relationship between emissions from a power plant and asthma in their community. People may suspect that a certain disease in their community, such as lupus, has an environmental cause or trigger. All of these are reasons for wanting a health study. Hopefully this Guide will help readers think this through.

Chapter 7: Who Conducts Health Studies?

Prior chapters (1-4) can be found on our website at

http://www.bu.edu/sph/health-studies-guide/

***Is a Health Study the Answer for Your Community? A Guide for Making Informed Decisions*,**
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Chapter 7: Who Conducts Health Studies?

Sitting down one night, a neighbor had mapped out [diseases in] his neighborhood. …We didn't know who to go to [with the map]. We didn't know what to do. …No matter what feelers we put out, we weren't able to make the right connections. We basically made an appeal to [State Department of Public Health], and two years later they finally contacted us, "Oh, we are about to start your health study."

— Sarah, Wayland, Massachusetts

Key words

community-based participatory research

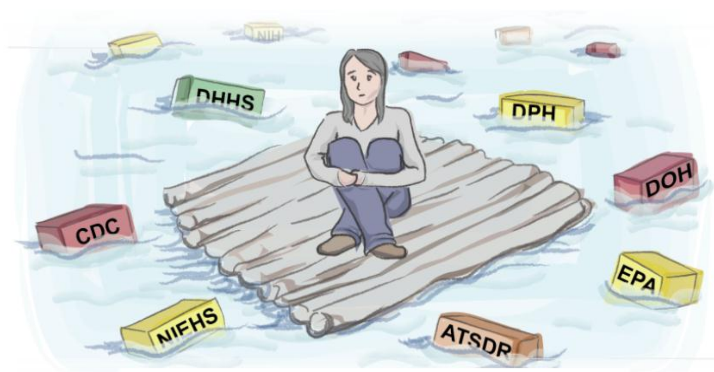
qualitative

quantitative

surveillance

In his book, Contaminated Communities: Coping with Residential Toxic Exposure (2004), Michael Edelstein calls contaminated communities the residential areas with known exposures to pollution. It is exactly these residents who are often the first to identify an environmental health problem where they live. The process may begin with a suspicion of too much disease in a particular geographic area such as childhood leukemia in a neighborhood of Woburn, Massachusetts (Brown & Mikkelsen, 1990), or birth defects and miscarriages as in Love Canal, New York (Gibbs, 1998; Levine, 1982). Residents of "contaminated communities" may also experience an exposure to an agent of unknown but worrisome consequence, like the contamination of cow feed with polybrominated biphenyls (Reich, 1991), the radiation leak at Three Mile Island (Erikson, 1994), or the siting of a waste incinerator as in East Los Angeles (Bullard, 2005). These stories and others (Coburn, 2005; Edelstein, 2004; Lerner, 2005; Sze, 2007), describe how non-scientist residents of communities around the US identify and wrestle with environmental health problems, and the accompanying personal, emotional, social and political turbulence in their homes and communities. Common to all of the stories is the experience of navigating a sea of government agencies, scientists, doctors, lawyers, and technical experts conducting health studies, making measurements, and estimating risks.

As Sarah is quoted above, when a community group thinks they have a problem on their hands, where they should go for assistance isn't always clear. Sometimes groups wait several years for a response from agencies. The purpose of this chapter is to help readers understand some resources, primarily government agencies and public institutions, that may be a source of expertise or may otherwise be involved in responding to community-identified environmental health concerns (even when not invited…). Individuals, governmental agencies or universities each bring a set of political and logistical issues along with their expertise. Thinking through the repercussions of collaboration is an important step. Toward the end of this



"How do I navigate this sea of acronyms?"

chapter we address the role of community groups and non-scientist/residents in conducting studies, even taking the lead!

The Role of Government Agencies

The US government prides itself for being on the cutting edge of scientific and technological innovation. Science is, in many respects, a competitive enterprise and the US has a leading advantage globally. Consequently, the funding of science is often influenced by politics. Figure 7.1 illustrates that the research agencies largely responsible for environmental health are headed by presidential appointees. Although we don't often hear about the Surgeon General (except perhaps on cigarette packages), the US Department of Health and Human Services (DHHS), and the US Environmental Protection Agency (EPA) are the largest sources of funding for state governments and university researchers to conduct environmental health studies. EPA and agencies under DHHS are also responsible for the protection of our nation's public health. This includes funding and supporting research and prevention or intervention programs.

With each new US President and administration, we see a new leader of each of these agencies who will often declare their priorities, commitments and new directions. In addition to the US President who appointed them, agency leaders are accountable to members of the US Congress who write and approve the budget with line items for their agencies (and in some cases, line items for specific research programs within the agencies). Although most US Congressmen and women are not scientists, they do make decisions about which scientific programs will be funded, and which agencies will have their budgets cut or expanded. Under the DHHS are the National Institutes of Health (NIH) and the US Centers for Disease Control and Prevention (CDC).

- ### National Institutes of Health (NIH)

  The National Institutes of Health (NIH) include 27 Institutes and Centers that are the primary source of research funding for scientists working in academia/universities, and for scientists working for non-profit organizations, or independent research institutes. Of all NIH institutes, the National Institute of Environmental Health Sciences (NIEHS) is the agency that funds most of the research on environmental causes of disease.

  NIEHS also publishes a scientific journal, *Environmental Health Perspectives*, to which many environmental health scientists around the world subscribe for information on the latest science and news. Much of it is available free and on-line: http://ehp.niehs.nih.gov/ . For more information on EHP and other data sources, consult *Appendix: Accessing environmental health information.*

  That being said, the annual budget of NIEHS (roughly $740 million in FY2014) is around 2.5% of the entire NIH budget (roughly $30.1 billion in FY2014) (National Institutes of Health, 2016). Most NIH institutes are located in Washington, DC. However, NIEHS headquarters are in Research Triangle Park, North Carolina.

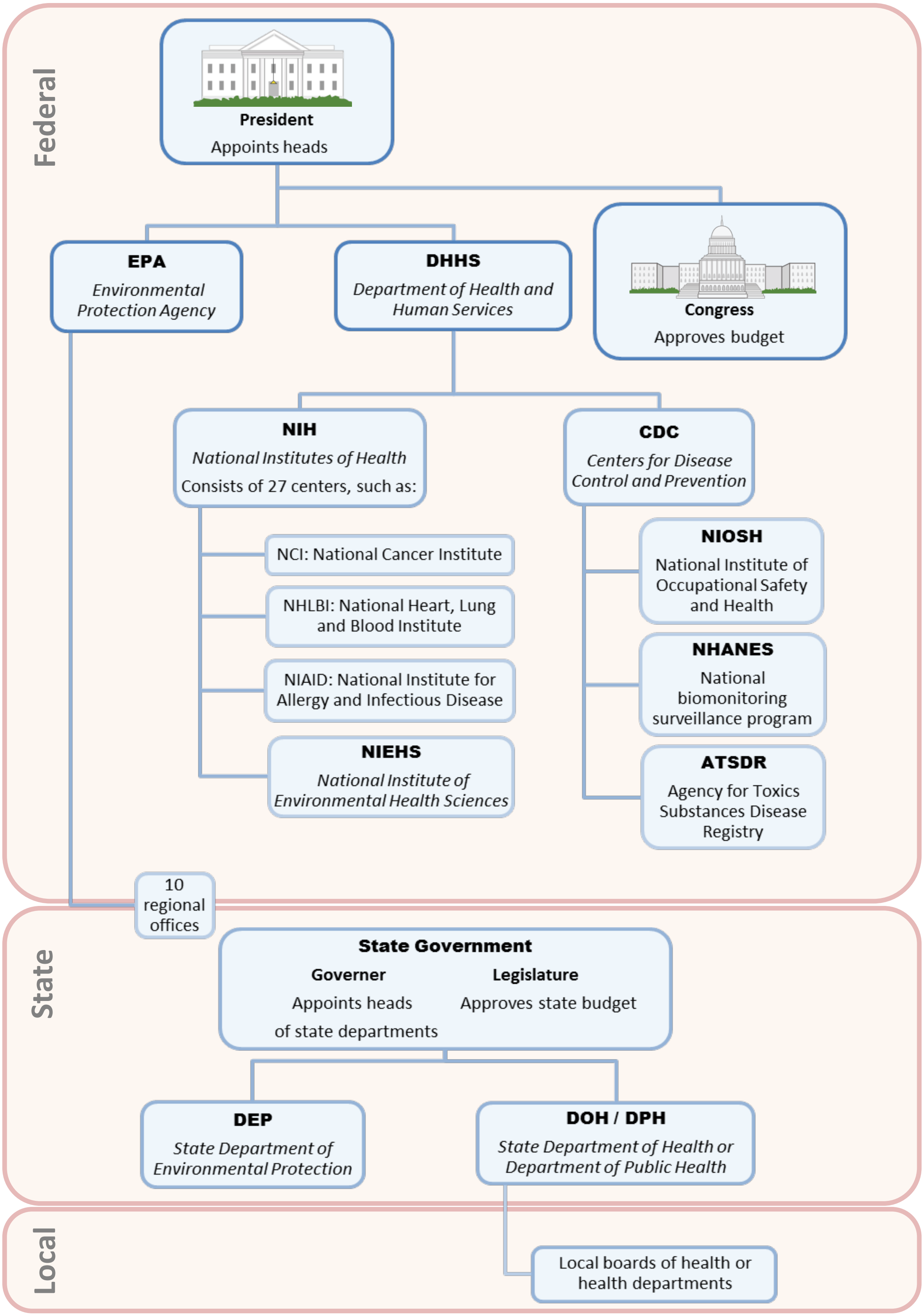


Figure 7.1. Governmental Public Health Organizations

- **Centers for Disease Control and Prevention (CDC)**

  The US Centers for Disease Control and Prevention (CDC), with headquarters in Atlanta, Georgia, also funds research. However, CDC also has the mandate to protect public health, and many of its research programs are oriented toward the prevention of disease. Five programs within CDC have special relevance in the area of environmental health: The National Institute for Occupational Safety and Health (NIOSH), the National Health and Nutrition Examination Survey (NHANES), the Agency for Toxic Substances & Disease Registry (ATSDR), the National Program on Cancer Registries (NPCR), and the National Environmental Public Health Tracking Network (EPHT). The budget for CDC in FY2014 was about $5.8 billion. (CDC, 2015).

1. **NIOSH:** Despite being an "Institute" NIOSH is not one of the NIH institutes. NIOSH was established by the Occupational Safety and Health Act of 1970 with the mandate to assure "every man and woman in the Nation safe and healthful working conditions and to preserve our human resources." NIOSH has more than 1,300 employees from a diverse set of fields including epidemiology, medicine, nursing, industrial hygiene, safety, psychology, chemistry, statistics, economics, and many branches of engineering. NIOSH works closely with the Occupational Safety and Health Administration (OSHA) and the Mine Safety and Health Administration in the U.S. Department of Labor to protect American workers and miners. However, unlike OSHA that regulates workplace conditions, NIOSH is primarily responsible for generating the science that supports the creation of workplace standards. NIOSH has offices in multiple places in the US including Cincinnati, Ohio. Its annual budget was $330 million in FY2014 (CDC, 2015).

2. **NHANES**: CDC coordinates and funds the only US national biomonitoring surveillance program. Every year, the National Health and Nutrition Examination Survey (NHANES) surveys a sample of people living in the US, asking questions about their health and nutritional status, and conducting complete physical examinations. During this examination NHANES collects blood and urine samples which are tested for nearly 400 chemicals from lead and mercury to flame retardants and plastic components. These samples are analyzed at CDC laboratories. NHANES is designed to get information on what the average US resident might be exposed to and the information is made publically available. Its annual budget was $480 million in FY2014 (CDC, 2015).

   The *National Report on Human Exposure to Environmental Chemicals* is published approximately every two years and has information on human exposure to different chemicals according to participants' age, sex, and ethnicity. The most recent report included results for nearly 300 chemicals. Results are reported for the nation, not by state, and no testing is done on children under age six, except for lead. These data have been useful for community groups wanting to compare the results of biomonitoring studies with a nationally representative sample of the population.

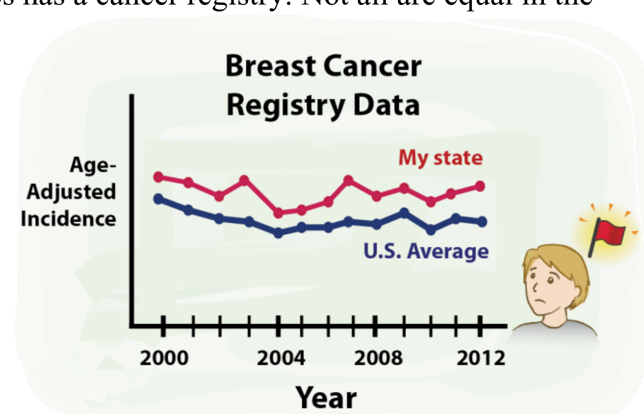
3. **ATSDR**: The Agency for Toxic Substances & Disease Registry (ATSDR) is responsible for " preventing or reducing the harmful effects of exposure to hazardous substances on human health and quality of life" and "for determining, as best as possible, whether people have harmful health effects from their exposure to hazardous substances" (CDC, 2002).

In the history of contaminated communities, ATSDR is well known (for better or for worse). The agency was created in 1980 by a law that also established the Superfund Trust. The Superfund, as it is known, was a tax on corporations that went to a fund which could be used by the EPA to clean up the nation's worst, often abandoned, hazardous waste sites. ATSDR was to evaluate and address the health problems of residents in nearby communities. According to some, the agency did very little on this front until 1986, when Congress passed several amendments to the Superfund law. These included specific deadlines by which ATSDR was to complete public health assessments at Superfund sites (Lester, 1994). With an annual budget of $75 million, it received about 1.3% of CDC's annual budget in FY2014 (CDC, 2015).

Since then, ATSDR has become the primary federal agency that responds to requests from communities about health problems, and do so in the following ways:

- They conduct "health studies" either in the form of a health assessment, health consultation, disease cluster investigation, or an epidemiological study. In performing public health assessments, the ATSDR will often work with city, state and federal agencies to collect the necessary data on exposures and health in the population of concern, and they will summarize the health effects for a particular chemical. In doing these assessments, ATSDR relies entirely on existing data. They do no environmental monitoring, no exposure assessment or biomonitoring, and so work closely with the EPA and other state and local health agencies that may actually collect this type of primary data in a community. ATSDR then makes recommendations to these agencies based on the findings of its health assessments.
- They gather information and concerns from the communities surrounding contaminated sites and communicating the results of their evaluations to the community. In the cases of contaminated sites such as Toms River and Camp Lejeune, ATSDR has also conducted health studies in the surrounding communities which are separate from public health assessments.
- Also due to the congressional mandate, ATSDR is required to publish fact sheets about the toxicity and human health risk of the chemical substances found at these hazardous waste sites. Again, to summarize these health effects they will review other, existing data sources (including EPA). These toxicological profiles, or ToxProfiles, are also available free via their website and are a valuable source of information for researchers and community groups alike (See Appendix for more on ToxProfiles and other resources).

4. **NPCR:** Every state in the 50 United States has a cancer registry. Not all are equal in the quality of their data (how well new cases are document, the geographic location of the case, the specificity of the cancer type, etc.) However, in addition to providing support to states for their registries, the CDC gathers and makes data from the registries available for national analyses of cancer trends, including incidence (new cases) and mortality over time: http://www.cdc.gov/cancer/npcr/. The



idea is these data help to answer questions such as, "What is causing cancers in some populations more than others?" and "What populations are getting what kinds of cancers? Is this changing over time?"

5. **EPHT:** The CDC's National Environmental Public Health Tracking Network (EPHT) began several years ago in recognition of the lack of environmental health surveillance programs nationally, and the uncoordinated efforts of several state agencies. Health **surveillance** is the systematic, ongoing collection, analysis, and interpretation of health data (for example, cancer registry data). Analysis of trends in surveillance data allows people to look for "red flags" indicating possible elevations of disease and their relation to pollutant sources/levels. Thus, these "red flags" often lead to epidemiological studies. Environmental Public Health Tracking is the ongoing collection, integration, analysis, interpretation, and dissemination of data from environmental hazard monitoring, and from human exposure and health effects surveillance. CDC provides funds to 26 state and local health departments to develop local tracking networks. These networks feed into the National Tracking Network, a system of integrated health, exposure, and hazard information and data from a variety of national, state, and city sources. On the Tracking Network, you can view maps, tables, and charts with data about chemicals in the environment, and some chronic diseases and conditions at a smaller geographic scale than Nation or State.

- ## Environmental Protection Agency (EPA)

The US EPA consists of federal EPA headquarters in Washington DC and ten regional EPA offices throughout the country. The EPA was established in 1970 by President Richard Nixon. The EPA's general goal is the protection of the environment and human health. In FY2014, its annual budget was approximately $8.2 billion (EPA, 2015).

Functions:

1. **Drafting Regulations and Setting Federal Standards:**

   Since its establishment, it has been responsible for drafting regulations that enact the laws created by Congress, researching and setting standards for national programs related to the environment, and placing sanctions or assisting states not in compliance with federal law (i.e., enforcement).

   - For example, the EPA has oversight of the Superfund law, enforcement of air pollution laws under the Clean Air Act, and water quality standards under the Clean Water Act and the Safe Drinking Water Act.
   - Standards set by EPA are based on periodic analyses of scientific data, and are expressed as Reference Dose and Reference Concentration (see Chapter 4 for more information). These standards, along with the summaries of the scientific data, are published on EPA's website in a database known as IRIS (Integrated Risk Information System). Unfortunately, of approximately 80,000 chemicals in commerce, fewer than 400 chemicals have toxicity values (or standards). Additionally, although these values are intended to be based on the best science available, it is difficult for EPA (and all agencies) to keep up with research. Many standards are outdated, while you will find that others are being revised. (See Appendix for more information on IRIS).

2. **Funding Research:**

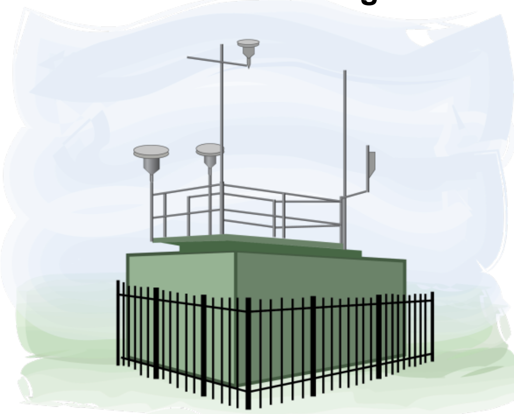
Consequently, EPA also funds research. The EPA's Office of Research and Development provides grants and funding to universities and students conducting research. EPA is also responsible for financially assisting state environmental programs (usually in the form of grants), providing environmental education resources, and making information regarding its research and activities available to the public. EPA also offers funding specifically to community groups through its Community Action for a Renewed Environment (CARE) and Environmental Justice grants program.

3. **Risk Assessments:**

While EPA fund health studies, EPA staff and scientists most often conduct risk assessments that contribute to the setting of standards and regulations and to our understanding of environmental exposures:

- Much of EPA's work goes into risk assessments that attempt to predict how an individual, community or population would respond to exposure to a partiuclar pollutant in the enviornemnt. The EPA also works with state and local groups, or regional EPA offices, on community-based risk assessments. For example, EPA will conduct a site risk assessment when there is concern about the effects of chemical exposures due to living near a Superfund site (discussed in Chapter 4). However, EPA does not conduct health studies and does not collect information about the actual health of community members.

EPA Air Monitoring Site



- EPA also works on community-based air toxics projects, also a type of risk assessment. EPA mainly provides financial and technical support, while the community is primarily responsible for the projects and how the data is used to make change in their communities (see http://www.epa.gov/air/toxicair/community/index.html).

- In addition to community-based air toxics monitoring, the EPA has a number of national and regional programs to monitor a great number of environmental exposures (such as radiation and regulated air pollutants) as part of their obligation to enforce standards. Much of the data from these programs is publically available via the Internet, and may be used by others. EPA is a valuable source of data for ATSDR and independent researchers who want to conduct their own risk assessments.

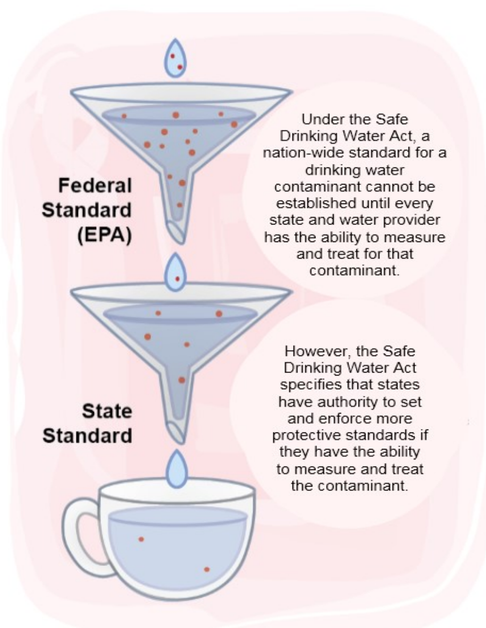
- In addition to monitoring levels of pollutants in the environment, EPA also publishes reports of many different types of emissions: For example, these data also include reports by industry on the release of hazardous chemicals. The same law that required ATSDR to conduct health assessments at Superfund sites also required industries that use hazardous chemicals to report releases to EPA. This law applies to industrial facilities with 10 or more full-time employees, facilities that process more than 25,000 pounds of hazardous chemicals, or more than 10,000 pounds of any single chemical. The reports are published in a Toxics Release Inventory, available on the Internet. These data have been used in studies to examine, for example, the proximity of pregnant mothers to toxic chemical facilities and releases associated with childhood cancers (Choi, et al., 2006).

- ## State Departments of Environmental Protection

Each of the 50 states has a department of environmental protection, usually called the Department of Environmental Protection (DEP) although their names vary. The Illinois DEP, for example, is called the Illinois Environmental Protection Agency (Illinois EPA) despite the fact that they are not affiliates of the federal EPA. In every state the governor appoints the head of the department of environmental protection and the department is intended to carry out the governor's environmental policy according to federal and state law.

Functions:

- In general, state departments of environmental protection are responsible for issuing permits and enforcing national regulations at the state level. The state must, at a minimum, adhere to regulations as required by federal environmental law, but states may in some cases have more protective regulations than mandated by federal law. The state DEP is the agency that develops and enforces the state's own laws and regulations. As with any of these governmental agencies, its actions are affected by the administration in power at both the state and federal level.



- State DEPs are responsible for the oversight of contaminated sites that are not federally designated Superfund sites (sometimes referred to as State Superfund sites) and Brownfields (often abandoned or undeveloped lots in urban neighborhoods where contamination is uncertain).
- In some instances there is justified confusion among residents as to which agency has authority over certain sites, for example, a Superfund site in a town or city may have some oversight by the state DEP and some by the EPA. "Turf" can be a source of tension between agencies, and residents can find themselves getting the "run around" when who has the last word is not established.

How might they be involved in community studies?

Generally, if you are concerned about a specific local pollution source, industry, or instance of environmental contamination, you will want to begin by going to someone at your local or state department of environmental protection. You may also contact your department of public health with specific health concerns. These agencies can be useful resources for collecting information.

- ## State and Local Health Departments

Every state also has a department of health (DOH) or department of public health (DPH), depending on where you live. As with the departments of environmental protection, the heads of state health departments are also political appointees, usually by the governor. Also depending on where you live there are smaller county, parish or city/town boards of health whose members are either elected or appointed by the mayor, city manager, or town selectman. Most states have county/regional health departments, while some may also have a few city health departments. Massachusetts is the only state with a health department in every city and town, although some have combined into regional associates (see www.nashoba.org for example).

Functions:

- State and local health departments operate primarily under state law. The individual laws regarding public health are specific to each state, though the general goal of health departments is the prevention of disease and promotion of health and well-being. However, the extent to which the law mandates primary prevention or even health intervention is mostly weak. For example, while state laws often mandate that health departments oversee surveillance of state and city/town health status (for example, annual reports of cancer incidence), boards are not required to inform communities whose rates are elevated, nor are they required to intervene (Brown, 2003).

How might they be involved in community studies?

Health departments' involvement in community health studies will depend on the state. Some state health departments have large environmental health programs, while others may have only one staff member working on such issues. In addition, most state health departments have very limited budgets and thus are less aggressive in their pursuit of environmental health concerns. Sometimes they will only act on requests for community health investigations if there is a documented environmental exposure of concern. In some areas it is not difficult to see the influence of politics in a public health department, which may color agency perception of environmental health issues and the way in which they deal with community concerns.

It is a strategic decision for a community group as to where to focus attention-getting efforts. Sometimes, to get the attention of a federal agency you need to first get the attention of your local or state agency. In other instances, it might be that the federal EPA or CDC will request information from a state agency about a local situation after a community member has made enough noise.

In Massachusetts, the state Department of Public Health, Bureau of Environmental Health, received 2,117 telephone calls inquiring about environment and disease clusters in the year 2000 (Condon, 2004). The mission of the Bureau is to respond to environmental health concerns and provide communities with epidemiologic studies and health assessments (Massachusetts Department of Public Health, Bureau of Environmental Health, 2011). But with an average 1000 - 2000 calls per year, an investigation cannot be mounted in response to each call (Daley, 2004). At any given time, the Massachusetts Department of Public Health, Center for Environmental Health, has a waiting list of dozens of residents who have requested research assistance from the state (Daley, 2005).

Once a state health agency agrees to conduct a health study, as in Massachusetts, it is usually an epidemiologic study. Due to budget restraints and chronic understaffing of state health departments, they are more likely to do the ecologic studies than the more expensive, time consuming case-control and cohort studies.

Despite their limitations, state health departments are valuable resources and new programs, such as the EPHT Network described above, have been developed that have made more funding available to local and state environmental health research.

The Role of Non-Governmental Organizations

- **Colleges and Universities**

Colleges and universities are a major source of expertise and assistance to community groups. Generally researchers in academia, though not all of them, are freer to conduct research in response to community concerns, especially compared with government agencies. While one might argue that it is the responsibility of agencies to conduct health studies, they may be more limited in resources and by the types of studies they can conduct. For political reasons, or to protect them from liabilities, agency researchers may "stick to the book" using only study designs deemed to be "tried and true." Researchers at academic institutions do not have the same constraints. While they will be concerned with issues of quality, they may be more willing to take the roads less traveled.

However, academic researchers face the challenge of funding. Environmental health scientists and epidemiologists at research universities are funded primarily by research grants for specific projects. They have to meet the obligations of those grants and have little incentive for doing work for free in response to a community group's concerns. However, there are several ways to work around this limitation.

- One is to appeal to a university's mission, which is often to serve surrounding communities. This is particularly true of Land Grant Colleges and Universities which were largely founded for that purpose. Researchers at such institutions should find opportunities to couch their response to community needs as a service obligation. Academic institutions often claim to have a strong interest in serving their local communities, and researchers can make sure that their institutions pay more than just lip service to this notion. Furthermore, it is not uncommon for researchers who work at colleges or universities to have a greater vested interest because they too may live in those same communities where there are environmental health concerns.
- Another way to work with academic researchers is to entertain the possibility of working with them to write a research grant that will fund them, and a community group, to conduct community-based participatory research (see below).
- Even without funding, students, more so than faculty members, may be willing and able to help and can play valuable roles assisting community groups. Students will often work under faculty members for little or no cost. For example, when one university researcher could not secure funding to study the infamous community of Love Canal, which discovered it was situated next to a buried toxic waste dump, she was able to do research with the help of a number of graduate students as part of their educational experience and course work (Brown, 2003). Students often have to do research as part of their degree program, and

undergraduate educational programs may also have a "service learning" component (i.e., the student provides services to a community while learning in the process). Challenges of working with students include the fact that they often have limited time (one semester or so) to complete their research. Furthermore, they will likely have limited resources and perhaps less expertise than other researchers. Students may also promise more than they can deliver.

Academic researchers usually get their funding to study environmental health from state and federal agencies, but they may also receive funding from industry or corporations (for example, chemical companies or manufacturing associations). This funding raises the issue of conflict of interest for the researcher, since they may conduct or interpret their research in a way that is affected by their desire to maintain funding. Individual academic institutions have policies that address these concerns, and federal research agencies also request information about sponsorship of research from investigators they are funding. If approaching an academic researcher, a community member should feel free to inquire about these concerns.

- **Industry**

Though they are not agencies which can generally help you with a health study, corporations and industries often have staff scientists, hire scientists and commission their own health studies. Industries may also conduct their own studies in response to other studies, or to produce evidence on the safety of their products/actions. Chemical companies in particular (e.g., Dow, DuPont and Monsanto) publish toxicological studies on the effects of chemicals in animals, and these are often a source of data and information for government and academia.

- **Nonprofit Organizations**

Nonprofit organizations also conduct a variety of types of research. Some well-known and recent examples include in 2003, the Environmental Working Group released *Body Burden: The Pollution in People*, a report that described the results of nine people tested for 210 chemicals. Later studies by the same nonprofit science advocacy organization tested breast milk and the blood from newborn babies' umbilical cords. A May 2006 study by the Toxic Free Legacy Coalition in Washington tested the hair, blood, and urine of 10 Washington residents.

The Center for Health, Environment and Justice (CHEJ), formerly the Citizens' Clearinghouse for Hazardous Wastes, is a nonprofit organization in Falls Church, VA that provides technical assistance and makes scientific knowledge available for community groups across the country. Since 1981, the CHEJ has contracted with over 11,000 local groups and communities facing contamination. They offer workshops on various issues from movement building to science and conducting community-based health surveys.

Similar groups work only within their locality, such as West Harlem Environmental Action in New York City, Project South in Atlanta, Georgia, and the JSI Center for Environmental Health Studies in Boston, Massachusetts (Sclove, Scammell, & Holland, 1998).

The Role of Communities

There are many individuals, institutions and agencies involved in environmental health research. In the past 15 years or so, community groups and residents of contaminated communities have come to realize that they have a right to be more than research "subjects", but active collaborators in research. Likewise, professional researchers have begun to realize that residents have a lot to offer that can't be learned without their involvement. "Popular epidemiology" is a term used to describe instances where non-scientists unite with scientists to conduct epidemiologic studies about health and the environment in response to community concerns (Brown, 2003).

- **Community-Based Participatory Research**

> *The community should be in the heat of conducting [a study], and they should be right on the side of [scientists]. It's a partnership, it's a husband and wife, a boyfriend and girlfriend, whatever you want to say. But it should be a partnership. But to have the community this small and the agencies that large, it's not balanced. It's not equitable at all.*
>
> –Ethel, Louisiana

You may have heard the term **community-based participatory research** (CBPR). This is defined as research that directly involves the community it stands to benefit, not just as subjects, but as participants (AHQR 2014). Community-based participatory research (CBPR) is the product of several terms including *community-based research* (research physically located in a community), *action research* (research for change), *and participatory action research*. Each phrase has distinct roots, which have grown and intertwined over time. There is also the term *community-driven* research, which suggests questions originating in a community setting are the driving force behind research. Today, the term CBPR is most often used in the field of environmental health in the context of collaborative, multi- and interdisciplinary endeavors, and partnerships (for example, between grassroots community groups and academic institutions).

Most people describe CBPR by its characteristics or principles (Israel, Schulz, Parker, & Becker, 1998; O'Fallon, Tyson, & Dearry, 2000). These principles include:

- the participation of those affected by the results of research at every step of the process (defining the problem, designing the study, analyzing results);
- the equitable distribution of decision-making power and resources among participants;
- a solution-oriented outcome.

No matter who is involved, it is important that anytime a community group contacts an expert to help with a study, they are clear about the research process and their respective roles in it. Below we present a spectrum of community participation (Figure 7.2). Where do you fit into this spectrum? Do you want to be involved in a process that is driven by community concerns, by expert concerns, in a partnership, or somewhere in between? Consider the pros and cons of working with professionally trained researchers.

Academic researchers are more frequently involved in CBPR, often funded by grants from the CDC and NIEHS. However, private foundations, universities, and state/local agencies have also funded some CBPR (Viswanathan, et al., 2004).

Community researcher-		**Partnership**		**Professionally trained researcher**
driven and controlled. Very little outside involvement. Maybe external consultants to assist with technical questions.	⟷	between professional researchers and community members. Equally shared power, decision-making authority, and ownership.	⟷	driven and controlled. Very little community involvement. Maybe occasional briefings or presentations to community members.

Figure 7.2: Spectrum of community participation in health studies

Communication is key to collaboration:

In theory, CBPR should provide immediate benefits to the community through emphasis on interventions and change in policy (AHRQ 2014). While it should benefit the community, partnering with grassroots community groups provides support and knowledge to researchers as well, thus CBPR involves a mutually beneficial relationship. Unfortunately, the research relationship is rarely entirely equal, and often it is the researchers who command the majority of the resources (Viswanathan, et al., 2004). However, researchers often hire and pay community members for their efforts, which gives them power and a stronger sense that their voice is heard (Srinivasan & Colwell, 2005). Another challenge lies in that community groups and researchers often disagree on how they feel the study should be done, what data should be collected, etc. Trust, respect and communication between researchers and community members are necessary to making CBPR work.

Providing social context:

Another integral part of CBPR is consideration of the social factors which influence the environment and disease in a community. Often, CBPR integrates epidemiological methodology, which is considered **quantitative** (involving measurable, numerical data), with **qualitative** research (observation, interviews and descriptive information that "tells a story"). Thus, researchers get numerical measurements of environmental exposures and health outcomes, but also gain an understanding of the experience of community members through verbal descriptions of the environmental health concern. This qualitative data provides a social and economic context for the health issue. Overall, the combination of these two types of research allow for a more holistic understanding of community environmental health concerns (Brown, 2003; Scammell, 2010).

Sometimes it is more difficult to receive funding for CBPR studies because of unfamiliarity with and skepticism about producing high-quality research in this framework. In addition, researchers say that involving communities in data collection and interpretation can sometimes lead to an unrepresentative sample of the population or potential biases (for example, selection bias; see Chapter 6), though the overwhelming consensus is that community involvement is beneficial. It can lead to increased participation, better follow-up of study participants, and meaningful results (AHRQ, 2014).

Conclusion

There are many agencies involved with environmental health research, but each has a set of potential ethical, political, monetary, and time-related constraints. Sometimes it can be difficult to determine whether these groups are keeping the community's best interests in mind. It might be helpful if your community group reviews research proposals on its own to assess whether studies are going to benefit the community, before allowing any other group or agency to become involved. Finally, always remember that if you are a participant in any type of study, it is the opinion of these authors that you have the right to know the results, including any individual measurements (for example, the results of blood sample tests for a body burden study). Despite the potential problems, there are researchers and institutions with genuine interests in helping communities, and these people can be powerful assets and allies. If you would like to know more about approaching governmental agencies or if you need assistance in organizing your community, there are many non-profit groups that can help you. (See Appendix for more on organizing resources).

Indeed, the biggest piece of advice the authors of this guide would like to offer to readers is: **Do not leave the research to the experts! Involve yourselves. And don't let the results of research be a complete surprise that gets you from behind. Anticipate them because you have been involved with the whole process.**

Key Points from Chapter 7

- Be a critical consumer of studies.
- There are many organizations who may have data you want, from federal government, to state or local government, to industry groups or nonprofit organizations.
- Keep in mind that state health departments are more likely to do the ecologic studies than the more expensive, time consuming case-control and cohort studies, if they agree to do a health study at all.
- Community Based Participatory Research, when carefully planned out, is often an ideal approach to conducting a community health study.

Questions for Thought: Chapter 7

- *Who can best help me achieve my goals?*
- *Other options: Do we have any relationship with any of these agencies, organizations? Do we want to request assistance from them?*

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Is a health study the answer for your community?

A guide for making informed decisions

For decades, environmental health scientists at Boston University School of Public Health have worked with community groups to address environmental health problems. We wrote the Health Studies Guide to assist community groups and individuals who think that some form of environmental health investigation or health study may be useful or necessary in their community. Readers of this guide may have concerns about drinking water contamination, or the relationship between emissions from a power plant and asthma in their community. People may suspect that a certain disease in their community, such as lupus, has an environmental cause or trigger. All of these are reasons for wanting a health study. Hopefully this Guide will help readers think this through.

Appendix: Environmental Health Information and Resources

The Guide can be found on our website at
http://www.bu.edu/sph/health-studies-guide/

Appendix: Environmental Health Information and Resources

1. Data on Exposures and Health Outcomes in your Community

- **Toxics Release Inventory – http://www.epa.gov/tri**

  US EPA's **Toxics Release Inventory** reports the quantities of several hundred toxic chemicals released by individual industrial facilities each year; each facility is required to submit detailed information about releases, both intentional and accidental, for a large list of hazards. If you are interested in a particular facility, or in releases of a particular chemical across your region, you are likely to find it here. The 2014 national data is now available as of January 2016.

  - **TOXMAP** combines the TRI data with a very flexible mapping program. You may need to refer back to the TRI Explorer at times. In addition, TOXMAP lists sites on the National Priorities List (that is, Superfund sites), with information about contamination and the status of cleanup. http://toxmap.nlm.nih.gov/
  - The **TRI Explorer** is a good tool for quick and easy access to the TRI database. The on-line tutorial will guide you through the steps taken to access and interpret the TRI data. http://www.epa.gov/triexplorer/

- **Scorecard – http://www.scorecard.org**

  Environmental Defense's **Scorecard** service is a very useful site for examining pollution in on your community, and will help you locate and evaluate TRI data, in addition to much more. This may be a good place to start when auditing a local exposure, as you can see how your own community is ranked with regard to various environmental hazards (at least according to the Environmental Defense scorecard method).

- **National Program of Cancer Registries** - http://www.cdc.gov/cancer/npcr

  CDC's National Program of Cancer Registries compiles data from local cancer registries into one site, with features such as state-level cancer facts and an interactive cancer atlas.

- **EPHT** – http://ephtracking.cdc.gov

  Environmental Public Health Tracking Program is an integrated and interactive CDC database of systematically updated health, exposure, hazard information and population data from variety of national, state, city sources. The extensive database is searchable by environmental medium, chemical or health outcome, and can be made viewable by map or chart view using the embedded "Query Panel". 26 different state and local tracking networks feed into this national program.

- **Envirofacts** – http://www3.epa.gov/enviro

  EPA's **Envirofacts** is an online database that allows users to quickly search for exposure source information by location (Zip code, county, etc.), topic (air, waste, radiation, etc.) or more detailed queries such as facility name for permit compliance or toxic release data. Envirofacts is a comprehensive source that compiles data from many different datasets including aforementioned TRI data.

- **CDC Wonder** – http://wonder.cdc.gov

  This is a single point of access to the vast array of public health data made available by the CDC. Examples of information include statistics on births, mortalities, and cancer incidences by year, location, race, ethnicity, and/or gender.

2. Sources of Information on Specific Chemicals

- **IRIS** – http://www.epa.gov/iris

  The EPA **Integrated Risk Information System** database provides extremely detailed summaries related to toxic chemicals of special interest to the EPA (chemicals which have been the subject of a risk assessment). The IRIS QuickView is the simplest way to access a **reference dose** for a noncancer hazard, or a cancer slope factor for a carcinogen (see sidebar, *About dose-response assessment*, in Chapter 4). The database will also give background information on the sources of toxicity data and the process by which this information was assessed. This information is the primary source for scientific and regulatory information on toxic chemicals. Unfortunately, of approximately 80,000 chemicals in commerce, less than 400 chemicals have toxicity values (or standards). Additionally, although these values are intended to be based on the best science available, it is difficult for EPA (and all agencies) to keep up with research. Many standards are outdated, while you will find that others are being revised.

- **ATSDR Toxic Substances Portal** – http://www.atsdr.cdc.gov/substances/index.asp

  The Agency for Toxic Substances and Disease Registry portal contains profiles for toxic chemicals in extensive detail. While these "ToxProfiles" are very detailed and full of scientific jargon, ATSDR makes available:

  - **ToxFAQs** are summary factsheets of full ATSDR profiles and public health statements and are available for important chemicals. They provide chemical properties and toxicity data in a more comprehensible form and also answer the most frequently asked questions about exposures and effects of these chemicals. Many of the TRI Chemicals have fact sheets listed here. http://www.atsdr.cdc.gov/toxfaq.html

- **TOXNET –** http://toxnet.nlm.nih.gov

  TOXNET is a good starting place for chemical information; it searches and summarizes a number of different databases. From here, knowing the name(s) of your chemical or its Chemical Abstract Service number (CAS, available from the Form R) you can search a number of databases. (The CAS number is a unique identification given to each chemical in commercial production.) The support pages for TOXNET are particularly useful and will guide you through the various data bases linked here as you select each one.

Among the most useful sites via TOXNET are:

- **Hazardous Substances Data Bank**: The HSDB compiles information from the scientific literature to describe a particular chemical's physical property, environmental and biological fate, human and animal toxicity data, and more. However, this information is provided in brief snippets with little context, and can be difficult to interpret.
- **International Toxicity Estimates for Risk** (ITER): The international database on health studies, presented in table format for easy comparison.
- **Toxline**: for finding references to a particular chemical in the toxicology and risk assessment literature.
- **Household Products Data Base**: Because hazardous chemicals are not found only at industrial facilities!

- **Right to Know Hazardous Substances List** – http://web.doh.state.nj.us/rtkhsfs/rtkhsl.aspx

  New Jersey's Right to Know information provides convenient summaries of health impacts of many important toxic chemicals.

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3. Surveillance, Mapping, and Organizing Tools

- **Mapping exposures or health outcomes:**
  - **Health Landscape** – http://www.healthlandscape.org
    A free tool developed by American Academy of Family Physicians that allows users to quickly import their own data to visualize trends from the zip code to regional level. Alternatively, it also contains a collection of commonly requested health and demographic data for implementation. It is a less expensive and more accessible alternative to complicated mapping software like ArcGIS.
  - **MyEnvironment** – http://www3.epa.gov/enviro/myenviro
    Plug in your address and this tool will compile EPA data such as air emissions sources and levels, toxic water releases, and nearby Superfund or Hazardous waste sites in chart or map form.
  - **EJScreen** – http://www.epa.gov/ejscreen
    An environmental justice mapping and screening tool by EPA that combines national data on environmental and demographic indicators for a user-specified location.
- **Surveys**
  - **Creating Surveys Toolkit** - http://www.datacenter.org/research/creatingsurveys
    A useful guide for determining the usefulness of a survey, the appropriate type of survey to conduct, and other information on executing a community wide survey.

  - **Survey Monkey** – http://www.surveymonkey.com
    Simple and popular online survey platform.

- **Community organizing**
  - **Community Toolbox**: http://ctb.ku.edu/en
    A tool box developed by University of Kansas for community organizing, planning, evaluation, networking, and sharing resources

4. Accessing the Scientific Literature

- **PubMed**: http://www.ncbi.nlm.nih.gov/pubmed/ or http://www.pubmed.gov

  PubMed, a service of the National Library of Medicine, is the single most useful tool for searching the extensive literature on health and environment (and all medical and bioscience topics). Keyword searches for specific exposures or diseases are easy to perform in PubMed. For most papers, PubMed will provide you with a brief **abstract** describing the study and its results; often, this abstract will provide enough detail to get you started.

  Many PubMed searches will return tens of thousands of papers. When starting research on a new topic, you may want to filter your results (on the right side of the screen) to find only the "**Review**" papers, which attempt to sum up the literature to give a detailed overview of a particular topic. Unfortunately, many scientific papers are accessible only by subscription, so you will often find papers in PubMed which you cannot read. It is possible to filter your search results for "Free Full Text" papers, which you're guaranteed access to. If you find key papers which you can't access, consider teaming up with a researcher at a college or university, or asking the university library to provide you with a copy.

- **Google Scholar:** http://scholar.google.com

  Google Scholar harnesses Google's search capabilities to find scientific papers in all fields. Keyword searches are possible, but return very many results. If you are looking for a specific paper, and have the title, it will be most useful to enter the title in double quotes.

  Google Scholar can often find scientific papers in locations throughout the web, not just on the webpages of scientific journals, and is therefore an excellent resource for finding articles you can't access through PubMed.

- **Important journals in the field of Environmental Health:**
  - Environmental Health Perspectives
  - Environmental Health
  - Environmental Science & Technology
  - American Journal of Public Health

The following is an excerpt of the Glossary from *Is a Health Study the Answer for Your Community? A Guide for Making Informed Decisions* by Madeleine Kangsen Scammell and Rye J. Howard, 2013.

GLOSSARY

absorbed dose

the quantity of a toxicant that enters the human body.

adjust

manipulate the crude data to account for the effects of factors such as age, sex, smoking, and other risk factors. This helps a researcher interpret the impact of a specific exposure on disease rates without worrying about the other factors.

ambient pollution

emissions a facility releases into the atmosphere. Regulations limit the amount of ambient pollution that can be released.

average daily dose

amount of a chemical that a person takes in during an average day.

bias

in epidemiology, a systematic error in the way subjects were selected or information was gathered.

biological plausibility

any biological reason to think that the exposure may cause the disease such as a known molecular mechanism, supporting animal evidence, etc.

biomonitoring

the measurement of a biological marker of exposure inside the body on a regular basis.

cancer registries

the systematic collection of data on all diagnosed cancer and tumor cases in a population. Every US state has its own cancer registry and maintains records on patient history, diagnosis, treatment, and status.

case-control study

an observational epidemiologic study in which subjects are selected according to their disease status (for example, lung cancer [cases], no lung cancer [controls]), and then compared on their past exposures to some factor of interest (for example, cigarette smoking).

causality

a relationship between a cause or set of causes (i.e. risk factors) and an effect (i.e. health outcome) in which the effect is a direct consequence of the cause.

choropleth map

a map in which different regions are colored or shaded to represent some information about the region such as disease prevalence or population density.

cohort study

an observational epidemiologic study in which subjects are selected according to exposure status (for example, smoker, nonsmoker) and then compared on disease status (for example, lung cancer, no lung cancer)

community-based participatory research

an approach to environmental health research that features genuine participation by those affected by the research, equitable power sharing between community and researchers, and an emphasis on practical solutions.

community-based survey

health surveys of individuals in a community that are initiated and conducted by community members.

concentration

the abundance of a chemical in a total volume of a mixture (for example, in water, soil, or air).

confidence interval (CI)

a confidence interval consists of an upper limit value and a lower limit value that define a range around the point estimate. The confidence interval is interpreted as the range within which the true value of the point measure is likely to fall.

confounding

in epidemiology, the mixing of effects that occurs when a factor that is associated with the risk factor of interest is itself a risk factor for the health outcome of concern.

controls

in a case-control study, the study subjects who do not have the disease of interest.

cross-sectional study

an observational epidemiologic study in which the subjects are cross-classified on exposure and health outcome; in this study design it may not be clear that exposure preceded outcome.

crude

a statistical finding that is not adjusted for the influence of sex, age, or other risk factors that may differ between the two groups in the comparison.

cumulative risk assessment

a risk assessment that attempts to account for the combined effects of multiple chemicals, types of exposures, and risk factors such as social stressors.

dermal exposure

a major route of exposure to environmental contaminants through the skin.

disease cluster

an unusual number of disease cases located geographically close to each other in a community.

disease registry

database of cases of a disease diagnosed by a physician. Such registries are usually managed by a state or federal agency.

dose

the amount of an exposure that comes into contact with the body.

dose-response relationship

the quantitative relationship between a dose and a toxic effect ("response"), often summarized in a graph.

dot density map

the dots are not exact locations of cases but instead refer to several cases within some geographic area, like a county or a zip code. Useful for visualizing where disease is more common, but difficult to interpret without knowing the population of each area where there is a dot.

dot map

a simple map using dots to locate polluting facilities, or other sources of exposure and the homes of the diagnosed cases to help visualize patterns of pollution in a community.

ecologic bias

a limitation and potential flaw of ecologic studies where the relationship between exposure and disease at the individual level may be wildly different than at the population level. Thus a community-level correlation between an exposure and an outcome cannot be interpreted to mean that the exposure and the outcome are similarly correlated at the individual level, much less that the exposure causes the outcome.

ecologic study

an observational epidemiologic study in which all information on health outcomes, exposures, or other characteristics is at the level of the community rather than at the level of the individual.

effect measure

a measure of comparison of disease frequency; absolute comparisons look at risk or rate differences (subtraction) and relative comparisons look at risk, rate, or odds ratios (division).

effect modification

in epidemiology, a joint effect of two risk factors that is either greater than or less than the sum of their individual effects.

emissions

the amount of pollutant emitted from a power plant, your car's tailpipe, or some other source.

endocrine disruptors

chemicals that interfere in some way with the body's endocrine system (hormone system).

environmental monitoring

measurement of the concentration of a toxicant in air, water, or soil on a regular basis.

environmental standards

concentrations considered safe in a particular environmental medium (e.g., water or air). Should be interpreted according to how people come in contact with that medium. For example, Maximum Contaminant Level (MCL) standards are created by EPA to set the maximum amount of a chemical legally allowable in drinking water.

epidemiologic

of or pertaining to the methodology used to measure the relationship between a specific exposure and a health outcome in a population.

epidemiology

quantitative research methods for the study of the distribution and determinants of health outcomes in human populations.

exposure

any chemical pollutant or other stressor (for example, radiation or mold spores) that people may encounter.

exposure assessment

an applied science comprising methods to measure or estimate human contact with environmental contaminants; in a risk assessment for a chemical or site, an estimation of the exposure of the populations(s) of concern to the chemical(s) of concern.

geographic information system

a computerized system that combines a database of spatially linked information with application software for spatial analyses and mapping.

hand-to-mouth

exposure to a contaminant in soil or dust that is carried to the lips by the hands (for example, in eating or smoking).

in utero

an exposure to toxic chemicals carried by the mother, or to which the mother is exposed, that then lead to exposure of a fetus in the womb, before birth.

ingestion

a major route of exposure to environmental contaminants through eating or drinking.

inhalation

a major route of exposure to environmental contaminants through ordinary continuous breathing.

institutional review board (IRB)

a group of experts from a research institution charged with approving all research protocols to ensure that the rights of the human subjects, or research participants, are being protected throughout the study.

latency

the period between the exposure that initiates the biological changes leading to disease and the recognition of the disease (i.e. cancer).

medium (media, plural)

the environmental container of a contaminant. Generally, air, soil, or water.

micro-environment

the immediate environment of an exposure (for example, a room, yard, or workstation).

multivariate regression

a statistical method used to analyze data for a number of confounders at the same time.

odds

a statistic for describing the likelihood of an event compared to the likelihood of that event not occurring.

odds ratio

a relative comparison between the odds of an exposure among two groups (for example, comparing the odds of exposure in cases versus controls).

(health) outcome

a condition that we would identify as disease or a subtle change in normal function that could lead to disease.

parts per billion (ppb)

a common way of expressing concentration in environmental media. If we say that a sample of soil is contaminated with 200 ppb lead, we mean that for every billion parts of soil, there are 200 parts of lead.

parts per million (ppm)

a common way of expressing concentration in environmental media. If we say that a sample of soil is contaminated with 200 ppm lead, we mean that for every million parts of soil, there are 200 parts of lead.

personal exposure monitoring

measurement of the concentration of a toxicant in an individual's personal environment (for example, air sampling in an individual's breathing zone).

point estimate

the best estimate of a health effect around which there is an uncertainty described by a confidence interval and/or p-value.

prevalence

the proportion of a population that has a disease at a given point in time.

probability

the likelihood of an event occurring. The certainty with which we can predict an outcome.

prospective cohort study

a study design in which participants are grouped on the basis of past or current exposure and are followed into the future in order to observe the outcome of interest.

PubMed

an online searchable database of virtually all scientific literature relating to health and environment that is cataloged by the National Library of Medicine (a branch of the National Institutes of Health). (http://www.ncbi.nlm.nih.gov/pubmed/)

p-value

the probability of obtaining the observed result and more extreme results by chance alone, given that the null hypothesis of no association is true. P-values <0.05 is the generally accepted cutoff for statistical significance but should not be the sole factor used to evaluate the meaning of a finding.

qualitative

research that is unquantifiable such as observations, interviews and descriptive information that "tells a story".

qualitative research methods

research methods that employ open-ended (without predetermined responses) survey questions. This technique is exploratory, and the information these methods yield is descriptive, rather than numerical.

quantitative

research that looks at measurable factors and produces numerical data.

rate

one number divided by another where time is an important part of the denominator (for example, the number of new cases of disease/10,000 people in the population per a year).

ratio

a comparison of two risks or rates where the exposed group is generally the numerator.

recall bias

a type of data misclassification that can occur in an epidemiologic study when different groups remember things differently. For example, people with a disease may be more likely to remember toxic exposures or occupational exposures than healthy controls, because sick people have given much thought to possible causes of disease. This can lead to skewed results.

reference concentration

a concentration expected to have no adverse effects in people who are particularly sensitive to the chemical's effects and who are exposed over a 70-year lifetime; the reference dose has united mg/(kg*day)

reference dose (RfD)

a dose expected to have no adverse effects in people who are particularly sensitive to the chemical's effects and who are exposed over a 70-year lifetime; the reference dose has united mg/(kg*day)

relative risk

a comparison of two risks where the risk in the exposed group is generally the numerator and the risk in the unexposed group is the denominator.

retrospective cohort study

a study design, both the exposures and outcomes have already occurred in the study population before the study begins. There is no investigation of future outcomes.

risk

the probability of harm from some hazard.

risk assessment

an applied science consisting of formal procedures for evaluating and integrating scientific information on exposure and toxicity to estimate real-world public health risk of a hazard.

risk factor

a factor that has been shown to pose a risk of a specific harm.

risk management

actions taken to prevent or mitigate environmental health hazards; the process balances risks, benefits, and costs, and also considers social context.

route of exposure

route by which people contact and absorb environmental contaminants (mainly inhalation, ingestion, and dermal contact)

selection bias

an error in recruitment of subjects for a study that leads to the two groups not being very comparable and can skew the results. Often arises where cases and controls are recruited differently.

source (of an exposure)

the source of a contaminant. For example, the facility that emits air pollution or lead paint that contaminates surrounding soil.

standardized incidence ratio (SIR)

a ratio whose numerator is the *observed* (actual) number of cases of a disease in a population of interest during a given time period, and whose denominator is the number of cases that would be expected in the population if the age-specific rates of some reference population were applied to the local population; often abbreviated as "observed over expected."

standardized rate (SR)

the rate of disease that would occur in a given location if it had the age distribution of some reference population, but its age-specific rates were unchanged.

standardized rate ratio (SRR)

the ratio of two standardized rates, both of which are standardized to the same reference population.

statistical power

The statistical power of a study to detect a genuine association, also called **study power**, is affected not only by study size, but also by the strength of the association between the exposure and disease and the disease risk among the unexposed, and/or the exposure rate among the non-diseased.

statistical significance

of a statistical association; unlikely to be due to chance alone (according to an agreed criterion).

stratified analysis

the process or result of separating a sample into several subsamples according to specified criteria such as age groups, socioeconomic status, etc. The effect of confounding variables may be controlled by stratifying the analysis of the results.

study power

see *statistical power*

surveillance

the tracking of disease or injury rates and the comparison of rates over time or across places of disease.

temporality

in assessing casual relationships, the cause (exposure) must precede the disease.

threshold

(of a dose response curve) the highest dose at which no toxic effect occurs.

toxicologist

scientists who study the effects of toxic chemicals, primarily by running experiments on animal models.

toxicology

the science of the disposition and effects in the body of toxic substances, including man-made chemicals, natural toxins, and physical hazards such as asbestos fibers and radiation.