Is a health study the answer for your community?

A guide for making informed decisions

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Thank you all.

Introduction

"No matter how good a study may be,
someone will have something bad to say about it.
And if it is a flawed study but people are organized,
it could move mountains."

– Dr. David Ozonoff, Boston University School of Public Health

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This *Health Studies Guide* is meant 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 environmental concerns such as drinking water contamination or concerns about a particular exposure that may be related to a health problem, such as the relation between emissions from a power plant and asthma in the community. People may suspect that a certain disease in their community, such as lupus, has an environmental cause or trigger. All of these may be reasons for wanting a health study.

However, a health study may not always be helpful in resolving an environmental problem in the community. The guide begins by helping readers to consider factors that might influence their decision about *whether* to do a health study. Readers are encouraged to define their goals carefully, consider whether a health study will be useful in meeting these goals, and, if so, to choose the appropriate kind of study.

The main chapters of this guide come in pairs.

- The first two chapters are useful early on—as you consider whether a health study will help you achieve your true objectives (Chapter 1), and, if so, what question you want the health study to answer for you (Chapter 2).
- Chapters 3 and 4 will guide you through the process of choosing the type of health study that best suits your needs. You might work back and forth between these two chapters.
- The next two chapters bookend the actual conduct of the study: Chapter 5 explains issues related to research methods that are important to consider during the planning stage, before your study begins, and Chapter 6 explains how to evaluate the strength of your study's results and think about what they mean. These two chapters may be challenging and may not be necessary for everyone who uses this guide, but they are important in producing and understanding study results.
- Finally, Chapter 7 discusses the roles of community members, government agencies, academic researchers, and others in community health studies.

This guide describes a wide menu of health studies and takes you through the process of choosing and designing a study, but it is not a complete how-to guide. For example, it does *not* explain how to do your own epidemiologic study or risk assessment, nor does it describe how to conduct a health survey. If that is your purpose, we list helpful resources in Appendix.

Most of the contributors to this guide are scientists who have worked with community groups for many years to address environmental health problems. We include insights from focus groups and interviews with community members as well as our own experiences with studies that did or did not resolve community problems. Because we know what it is like not to succeed, the authors believe it is worth discussing alternatives to traditional health studies that may help achieve community goals. We hope that this guide will be useful not only for those who are contemplating a study, but also for those who are involved in a study or are the subjects of one. It will help you think about your expectations for the study's findings, costs, and timeframe. Above all, if you decide on a health study you will want to organize and work with your entire community so that it is meaningful to you. A health study can easily end up on a shelf collecting dust.

Chapters 1 through 6 are designed to be used in the order presented but may also be read singly or in any order. Thought questions follow most chapters. A facilitator's manual to accompany the guide is being developed with questions, worksheets, and guidance for anyone leading a discussion as community group members explore their options. The *Health Studies Guide* is available online and in printed form.

As with any specialty, the area of public health and environmental health science has lots of jargon. We have created a glossary of big or jargon words that appear in the Guide. All words included in the glossary also appear in a Key Word text box at the beginning of each chapter, and in bold in the text. Like the other chapters, the glossary is its own file which can be downloaded as a pdf.

Chapter 1: What is a health study and why would you want one?

"We were hoping to find a connection between the path of the smoke and cancer in town. And we thought [the study] was going to reveal the link between the power plant and our high rates of cancer."

– Joe, Resident of Salem, Massachusetts

"It is not the study that is the problem. It is really the results. You don't know what you are going to get for results until you study it."

– Helen, Resident of Marblehead, Massachusetts

In the public health field, "health study" is a specific term for research looking at patterns of health and disease. However, for the purposes of this guide "health study" refers to *any type of study that can potentially provide information useful to community groups concerned with health or health risks related to environmental exposures*.

Key words

epidemiological study
exposure
latency
(health) outcome
probability

Most health studies are meant to answer a question, but this task immediately poses two challenges.

1) The clearer the question, the more likely it is that a study will be able to address it effectively. Joe from Salem wanted a health study to prove that the smoke from a nearby power plant was causing cancer in his community—a clear question. On the other hand, in the process of sharpening one question so that it can be answered, other concerns may get lost. For example, Joe and his neighbors were also concerned about respiratory diseases and heart problems. These concerns would not be addressed in a study focused on cancer.

2) Studies are meant to answer questions, but they do not necessarily give you the answer you are hoping for. When it turned out that the study in Salem was unable to link the power plant to cancer, Joe and many other residents felt frustrated and upset. Some did not trust the Department of Public Health or believe the results of the study. Others realized that the real reason they had wanted a study was to build a case for having stronger emission controls on the power plant. Even if it did not cause cancer, members of the community were certain it was harmful and wanted action. The negative results of the Salem study may have been more harmful than helpful to the group's goals in the long run.

Our goal in writing this guide is to help people who want a health study get the health study that will be useful to them. This chapter will help you recognize whether a health study is what you want or need.

Like Salem, many communities want studies that will help prove their case or provide evidence to strengthen an

argument. However, as we'll see throughout this guide, it is difficult to do a good study. Even when there is a real connection between an environmental problem and the health of the community, a study might fail to document the connection for many reasons—for example, it might be poorly designed, or it might not include enough people. And a study that shows no connection can cause new problems for the community.

> *I think it is really important when these studies are created to say . . . 'How will [the results] be used. . .?' To consider what the public perception is going to be, to look at the big picture . . . to think about, if it came out the way it did, it would be used against us. If I had had a chance to do that with the study . . . I would have said, 'Don't do it!'*
>
> – Erin, Resident of Salem, Massachusetts

Here are lists of some good and bad things that might come out of a health study:

Table 1.1 Possible Impacts of a Health Study

Positive things a health study might do:	Negative things a health study might do:
• Document disease and/or exposure • Demonstrate a relationship between exposure and disease • Educate residents about environmental health concerns • Generate media coverage and motivate the community • Be useful for political leverage in a campaign • Create an opportunity for members of your community to get involved • Be useful in community efforts to protect the health of future generations	• Document no significant relationship between a disease and exposure • Appear to show that there is no problem • Give permission to polluters to continue polluting • Lead to legal issues over confidentiality or lawsuits by polluters • Be used against your campaign or group • Overwhelm your organizing efforts and sap members' energy • Generate statistics that may undermine your efforts • Identify health problems that you are unprepared to deal with • Delay action while waiting for results

Your Reasons for Undertaking a Health Study

To write this guide, we interviewed individuals who had helped to initiate, organize, and conduct health studies. Although they expressed many different reasons for undertaking a study, these reasons fell broadly into two categories. Some people wanted to get information that would help them answer a question or understand a concern about a health issue in their community. Other people expressed a desire to get evidence or proof they could use in a larger campaign, or even just to build awareness and mobilize residents in their communities.

This is an important difference. If the motivation for a study is simply to get information, then the capacity of the study to provide that information will determine whether people's expectations are met. But matters become more complex if the desire for information is combined with goals related to an action plan or strategy to address an environmental concern: for example, forcing the closure of a polluting facility, preventing the siting of such a facility, ensuring enforcement of air or water standards, or forcing the cleanup of a contaminated site. In these instances, the study might be seen as a way to organize the community, educate people, and get them involved. Although studies may serve these purposes, if these are the *primary* reasons for doing a study there may be better ways to do this.

One of the first steps in determining whether a health study may be useful is to identify clearly your reasons for wanting a study. Here are two questions that will help sort out your motives:

Table 1.2 Your Motives for a Health Study

A. *What* do you want to know? That is, what is your *question or concern*?

Sample responses:
- How much soot from the power plant are we breathing?
- Is there too much illness in our community?
- Why are people sick?
- Is the mold in the school making our kids sick?

B. *Why* do you want to know? That is, what is your *goal*?

Sample responses:
- Stop the development
- Prove we were right
- Clean up the site
- Get compensation

If you can answer question A and your response is another question, such as the sample responses, this guide may help you identify a type of study that can answer your question. Studies are designed to answer questions, and a good study is well designed to answer *your* question. Even if you do not like the results, at least your question will have been addressed.

What about question B? *Why* do you want to know? To answer this question you would need to have a clearly defined goal in mind. If you already have a goal you should evaluate whether a health study of some kind can help you achieve it. It may not. Consider that a study may take much time and money and you may get results that put you farther from your goal. When the Salem study, conducted by a state agency, failed to link the power plant emissions with cancer, the power company used the study as evidence that its emissions were safe. According to residents, it was interpreted as permission to continue with "business as usual."

If you already have a goal you should evaluate whether a health study can help you achieve it. It may not.

If it is easier to name your goals than to identify what you want to know, a study may not be the best investment of time and resources.

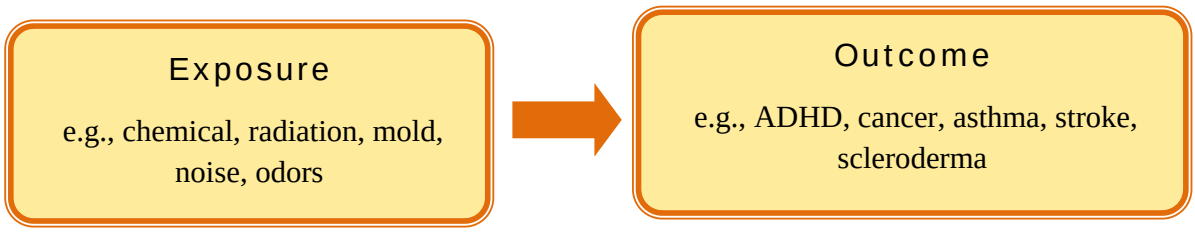
As we will see in Chapters 3 and 4, some studies are more complex than others. Studies that may be most appealing to a community—like the Salem study, which the residents hoped would connect cancer rates to the power plant—are often the most difficult to perform and interpret. On the other hand, some types of studies—like mapping disease occurrence—can be undertaken entirely by the community and provide important evidence that may further your goals. And, very often, a community needs only a relatively limited amount of information to be able to proceed, as described in a question like, *Are we being exposed to soot coming from the power plant?* The following chapters will describe a variety of ways to answer Type A questions.

The Basic Elements of a Research Question

If you are able to answer question A—What do you want to know?—you are on your way to framing a true research question, one that a study can be designed to answer. Chapter 2 will take you through the process of defining a research question. Here we'll introduce the vocabulary researchers use when they talk about research questions.

- ### Pollution and Disease—Also Known as Exposures and Outcomes

  Community members often express their concerns about *pollution* and *disease;* too much pollution, too much disease, or a suspicion that disease is caused by pollution. Often, community health studies try to answer a question about the relationship between something in the environment and a disease or other health effect. However, scientists talk more abstractly about *exposures* and *health outcomes* (often shortened to *outcomes*). To scientists, the term *health outcome* is more neutral than *health effect*, which suggests that a cause has already been established.



  Scientists use the term **exposure** to refer to any chemical pollutant or other stressor (for example, radiation or mold spores) that people may encounter. For the most part, researchers are concerned with exposures that people contact in their environments (*environmental exposures*) and that pose a threat to human health.

  Most health **outcomes** are conditions that we would identify as diseases (not to be confused with the result of a study, sometimes also called the outcome). Sometimes outcomes studied are more subtle than a disease. For example, a decreased level of a hormone in the body is an outcome, as is a slightly delayed reaction time that we wouldn't notice unless we measured it. In some cases these outcomes are too minor to be

diagnosed as a disease in an individual, but they are still of concern, especially when widespread in a population.

- Connecting Exposures to Outcomes

Some health studies are limited to measuring environmental pollution or to measuring the occurrence of diseases. More sophisticated and labor-intensive studies—which we call **epidemiologic studies**, and which will be discussed at length in later chapters—try to measure the *relationship* between a specific exposure and a health outcome. Based on accumulating scientific evidence from health studies, we now know of many relationships between specific exposures and health outcomes. Here are some well-known examples of exposures and associated outcomes: Remember, the exposure is what we think might cause the outcome.

Figure 1.1 Examples of Exposure-Disease Relationships

Exposure	→	Outcome
Lead (as measured in children's blood)	→	Lower IQ and learning disabilities
Poor air quality	→	Asthma and cardiovascular disease
Certain types of pesticides	→	Nervous system disorders
Diet high in salt and fatty foods	→	Heart disease
Cigarette smoking	→	Lung cancer

Epidemiologic studies try to measure the relationship between a specific exposure and a health outcome.

The exposures in this table range from things that are easy to measure (level of lead in the blood) to others that are more difficult to assess (contact with pesticides). The passage of time can also make it more difficult to link exposure to outcome: for example, it is often difficult to link cancer to past exposures because of cancer's long **latency**—the delay between the exposure that begins the process of cancer and the diagnosis of the disease.

For some chemicals, federal or state government standards have been set to limit people's exposures. Often these standards are maximum allowable concentrations in water or air. We can sometimes compare exposures in a community to these standards. Of course, standards are not perfect, and many standards allow exposure to pollutants at levels that some scientists think are unhealthy. Even more important, there are thousands of chemicals in commerce, and for most of them, no standards have been established.

Just as some exposures are more difficult to measure than others, some outcomes are more difficult to measure or define. For example, people may have asthma or a learning disability without having a diagnosis from a doctor. It is difficult to study an outcome in a population if

some cases are not identified. In contrast, death is a clear outcome, as is a diagnosis of lung cancer. In these instances, we can use death certificates or other data collected by the government (such as a state cancer registry as we'll explain in Chapter 4) to count outcomes, giving us solid information.

Most important, in any particular situation, the link from exposure to outcome is not a certainty—even if a disease is known to be related to an environmental exposure. For example, even though the relationship between cigarette smoking and lung cancer is well known, some people who smoke cigarettes all their lives will never get lung cancer. And smoking is not the only cause of lung cancer: some people who never smoked a cigarette will get this disease. What health studies have been able to demonstrate, though, is that on balance, smoking increases the **probability** that a person will get lung cancer. Most epidemiologic studies are designed to detect that increased probability, or risk, of a health outcome in a population.

A Health Study Is Not the Last Word

In public health investigations, there is a pattern of reassuring findings that do not lead to change. Cleaning up toxins in the environment costs money for business; treatment of cancer makes money for business. This political climate is simply not friendly to prevention.

— Terry, resident of Tuscon, Arizona[1]

Five well-established relationships between exposure and outcome are listed in Figure 1.1. These relationships are considered well established because they have been documented repeatedly in research studies over many years. A single study rarely provides enough evidence to change scientific understanding. Science works on accumulated evidence, and since any single study could be wrong, scientists (and policy makers) are generally reluctant to draw conclusions from one study. Thus you should not expect your health study to establish a definitive relationship between an exposure and an outcome.

In fact, even a mountain of scientific evidence is not always enough to provoke action. For example, it was first discovered that lead in children's blood was associated with learning problems decades ago, yet many, many studies were conducted before legislation was written in the United States to protect children from lead poisoning. This legislation was passed only because scientists and community members pressured politicians and executives in the lead industry to act on the scientific evidence. Science does not usually speak for itself. Only with organized community pressure and persistence will study findings be put to use.

Science, on its own, does nothing without the engine of community and political organization.

Neither agencies that conduct health studies nor academic researchers have the power, on their own, to change or enforce environmental health regulations. In fact, sometimes researchers who try actively to change policies or regulations are accused of being "junk scientists" or "activists," often by interests that are perfectly willing to hire different scientists to present different conclusions. Whether this is fair or not, it can harm a scientist's career as well as the community's cause. Scientists can provide crucial information about exposure and disease, but it is best left to legislators, educators, attorneys, advocates,

corporations, and communities to translate that information into changes that will improve public health. Science, on its own, does nothing without the engine of community and political organization.

Summing Up

Now that you've read this chapter, answer the questions below to help you think about your own situation. If you find that a health study is not the best strategy to meet your goals, or that your goals will best be met by organizing in your community or pressuring government or industry, don't be discouraged! You can make a persuasive argument even without health study findings to back you up. (See the Appendix on organizing resources.)

On the other hand, you may be more convinced than ever that your community needs a health study of some sort—anything from a relatively simple measurement of pollution at a facility to a complex epidemiologic study that will potentially identify causes of disease in the community. The next chapters will help you develop your research question and pick a study design that is most appropriate for your needs.

Key Points from Chapter 1

– The term "health study" may be used differently by scientists and community leaders.
– A good study is one that answers your question.
– Study results may be used against you.
– Studies can examine exposures, outcomes, or both.
– Science builds on evidence; one study is rarely enough to convince the scientific community.
– Science does not speak for itself.

Questions to Think About

– What do you want to know? What exposures or outcomes concern you most?

- What are your organizational/community goals?
- Will a health study help you achieve these goals?
- Look at the examples of positive and negative things that a study can do. In your case, what positive and negative outcomes could you expect from study results in your community?

Further Reading

– Rosner D., & Markowitz G. (2002) *Deceit and Denial: The Deadly Politics of Industrial Pollution*. Berkeley: University of California Press.

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