Activity Overview

Participants considering a health study review the major concepts in environmental health: exposure and outcome. They analyze their own situation (or a sample) using key health study considerations, and rate the advantages and disadvantages of specific health study types for that situation.

When to Use It

When community members believe that contaminated air, soil, or water (or a combination) is affecting people’s health, and they want a health study to show those effects.

This workshop was created to supplement the publication *Is a Health Study the Answer for Your Community? A Guide for Making Informed Decisions* by Madeleine Kangsen Scammell and Gregory J. Howard, 2013, under a Creative Commons BY-NC-ND 3.0 Unported License. Available at www.busrp.org/hsg

Skills

This workshop will help community members to:

- Describe exposure and outcome as major concept in environmental health.
- Identify pros and cons to doing a health study
- Identify sources for relevant, existing data
- Learn strategies other communities have used to handle similar issues

Smart Moves

- Slow down
- Talk it out
- Seek verification

Time: 75-90 min

Preparation

Read through all the materials and familiarize yourself with all the information. You will need to decide:

- which Health Study Story you will have participants read
- which health study types from Overview of Health Study Types to assign during the workshop. Some may apply to your situation, and some may not.
- This workshop assumes participants are motivated by their own community health situation. If there is no single shared situation, choose a Sample Community Health Scenario to use as an example.
- For a comprehensive overview of the ideas covered in this workshop, read the publication *Is a Health Study the Answer for Your Community? A Guide for Making Informed Decisions* (details on left).

Materials

*Facilitator Instructions* (4 pages, including this page)
*Health Study Stories* (3 pages, choose and print one)
*Health Study Strategies* (1 page, one per participant)
*Overview of Health Study Types* (4 pages, one set per participant)
*Health Study Worksheet* (1 page, one per participant)
*Sample Community Health Scenarios* (1 page)

If applicable, copies of Sample Community Health Scenarios (one per participant)

Pens

Clipboards, if the space does not have tables

Easel (or whiteboard) and three prepared flip charts:

- One labeled “Exposure,” “Outcome,” and “E-O Relationship” (shown next page)
- One with questions for discussion listed in Step 3
- One with headlines from Key Considerations

Optional: *Expert Advice on Health Studies* video on sfa.terc.edu can be used to support the *Overview of Health Study Types* handout. Requires equipment needed to view internet video.

Optional: *Will the Health Study Prove Liability* video on sfa.terc.edu can be used to support the Wayland, MA story in *Health Study Stories*. Requires equipment needed to view internet video.

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Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIEHS, NIH, or NSF.
Step 1: Setting the Stage (5 minutes)

Welcome participants and remind everyone of the group’s main concerns and goals, and how today’s workshop relates to the goals. Tell participants they’re going to learn about different kinds of health studies today, to see if a health study might help the group. This workshop just gives an overview; it won’t cover how to do a health study. The workshop was created with input from public health experts who help communities decide whether or not a health study is right for them. The goals will be to try to answer five questions:

- What is studied in a health study?
- How can a health study help or hurt an environmental campaign?
- What kinds of health studies are there?
- Which health studies might fit with our community situation?
- How could those studies help or hurt our campaign?

Step 2: Exposure and Outcome (10 minutes)

A health study usually studies one of three things – an exposure, an outcome, or a relationship between exposure and outcome. [Refer to labeled flip chart.]

An exposure is a way something harmful can get into a person’s body. Ask: Can anyone think of something people do that could be a harmful exposure? If needed, offer examples like:

- smoking cigarettes
- drinking contaminated well water
- touching, breathing, or eating dust from lead paint.

(Note: cigarette smoke, contaminated well water, and lead paint alone are not exposures. An exposure must include both a toxin and a pathway into the body.)

An outcome is a health effect. Ask: Can anyone think of a negative health effect? If needed, offer examples like:

- lung cancer
- asthma
- learning disabilities
Step 2 (continued)

Other health studies study the *relationship between an exposure and an outcome*. Ask: *Can anyone can think of a well-known relationship between an exposure and a negative health effect?* If needed, offer examples like:

- Children exposed to lead have an increased risk of lower IQs and learning disabilities
- Cigarette smoking increases the risk of lung cancer
- A diet high in salt and fatty foods increases the risk of heart disease

Proving a relationship between an exposure and an outcome is very hard to do. Well-known relationships like these are not discovered by just one study, but by *many* studies over many years. Fortunately, that past work makes other health studies less complicated. For example, if a study finds lead contamination in your drinking water, you *don’t* need to prove it is harming you, because we already know that lead in drinking water is harmful.

Step 3: Lessons from Other Communities (15 minutes)

Choose one story (or more, if time allows) from the resource *Health Study Stories*. Before the story, ask participants to consider the three questions below (also written on flip chart).

- What did the community expect to find out about exposures and outcomes?
- What did the study actually find?
- How did the study affect their campaign?

Ask a participant to read the story aloud. After the story, revisit the three questions.

After discussion, give participants the *Health Study Strategies* handout. Briefly review the points. Don't have a discussion about them now, but invite the group to keep these considerations in mind as you review health study types. When possible, connect them to observations participants just shared about the story from *Health Study Stories*.

- Set clear goals for your campaign
- Craft the right question for the study
- Be sure the study can answer your question
- Prepare for different possible results
- Choose your collaborators wisely
- Be part of the study process
Step 4: Reviewing Possible Health Studies (25 minutes)

[Optional: show Expert Advice on Health Studies at sfa.terc.edu/materials/video.html to see a public health expert describing these studies.]

Give participants the Overview of Health Study Types handout (4 pages).

There are many different types of health studies out there. Some take hours to conduct, others take years. Some can be done by anyone for free, some need a team of professionals with a big budget. Some are more easily discredited or attacked than others. The audience for the results of the study is also important: Does the evidence need to be strong enough to prove something in a court of law, or just enough to convince the public?

Have participants divide into pairs or small groups. Assign each group (or have each group volunteer for) one type of health study to review. If there are health study types that clearly do not apply to your situation, do not assign them.

While the groups are reading, hand out one Health Studies Worksheet to each group. Ask each group to fill out the worksheet applying their health study type to the community situation.

Step 5: Debrief (20 minutes)

Start with a lightning round: Give each group up to two minutes to report back about their study type, and why they think it would (or would not) be a good fit.

After the lightning round, ask if any of the study types seem promising. Allow for a longer discussion for that study type, guided by the Worksheet questions and Health Study Strategies.

Finally, take stock. Is there consensus in the group to pursue a health study?

Step 6: Next Steps (as needed)

Health study: If participants make the decision to continue pursuing a health study:

• Document the goals the group identified.
• What steps are needed to follow up on the group’s choices?
• Who will take on different tasks?
• What is a reasonable timeline for each step?

During or after the meeting, you can make a note of any other Statistics for Action activities you think might be relevant or helpful for the group. Suggest these activities to the participants or the group leaders as possibilities for future meetings.

No health study: If participants have determined it is not a good idea to move forward with a full-blown health study, individuals may feel deflated. Be ready to divert the disappointment. Redirect the energy by suggesting a special meeting to work on a media campaign. You could profile people who are sick or create an oral history of the community’s health. Channel the energy in a way that will move their campaign forward.
Health Study Stories


Wayland, MA

Linda Segal in Wayland, MA had heard anecdotal evidence making her believe that cancer rates in her area were higher than normal. She believed it was related to a nearby Dow Chemical research laboratory site. The Dow lab had operated for many years, but was now closed and the site potentially needed a cleanup. Linda and a local group requested a health study, to find out if the Dow site was responsible for the cancer. After two years of silence, the state Dept. of Public Health (DPH) contacted them saying, “We’re about to start your study.”

The DPH said that it would be very hard to prove that cancer rates were higher in Wayland than in nearby towns. The data about incidence of specific cancers were incomplete; at the time the lab was operating, insurance companies weren’t required to report all cancers to the Centers for Disease Control. Also, people had moved in and out of the community over many years, so it was difficult to identify people who were only affected by local pollution. In the data that were available, there was no cancer cluster among long-term residents that was significant enough to warrant a more detailed study.1

Most of the presumed exposure from the Dow plant had been from air contamination. Since the plant was closed, this was difficult to measure. Residents wondered about looking for evidence of historic air pollution in the soil and trees, but other polluters had been operating in the area at the same time. Proving the contamination came from Dow would be very difficult. Eventually, significant contamination was found on the site, and it was cleaned up. But the purpose of the cleanup was to avoid future exposures, not because a health study had linked contamination to existing health problems.

Cape Cod, MA

A statewide study of cancer prevalence in Massachusetts showed that Cape Cod had unusually high cancer rates. A community group wondered if the cancer was related to chemicals used in cranberry bogs, which are common there. A case-control health study was done in 1990. It looked at data about people who were diagnosed between 1983-1986 with at least one of eight types of cancer, to see if they had more exposure to cranberry bogs than people who did not have cancer. The study found that people who had lived within a half-mile of a bog were more than twice as likely to develop brain cancer. There was no association between bogs and other cancers. Initial results of the study were available in 1991, but it wasn’t formally published until 1996.2

Critics of the study called it “junk science” and claimed that it was “actually a survey” and not a study, that the number of people sampled was small, that it did not account for other risk factors, and that it included people who had only lived in the area for a few years.3

Health Study Stories


North Shore, MA

Mass DPH Study: In 1997 the Massachusetts Cancer Registry released a report on cancer incidence statewide. Residents of Marblehead and Swampscott learned their towns had high incidences of some cancer types. They suspected the nearby coal-fired power plant in Salem was the cause. They asked their State Representative and Board of Health to request a study from the state Department of Public Health.

The 1999 study looked at breast cancer, leukemia, and melanoma incidence in these two towns, to see if there was a geographic pattern to those diseases. The study found no obvious geographic pattern of disease in either town, including the areas most impacted by the power plant. It attributed the cancers to other risk factors.

The study took a long time, and residents were disappointed with the results. Proponents of the power plant used the inconclusive results to claim that the study had shown the plant was not a public health problem.

Harvard Study: Shortly afterward, the Clean Air Task Force commissioned a study of the health effects from the same power plant. The study was conducted by the Harvard University School of Public Health. The study used a computer model to estimate the concentrations of the three biggest air pollutants from the Salem Harbor power plant: sulfur dioxide (SO$_2$), nitrogen dioxide (NO$_2$) and particulate matter (PM$_{10}$). The study then estimated the health effects of those emissions from the plant, looking at respiratory and cardiovascular outcomes instead of cancer.

The study found that the air concentration of PM$_{10}$ and SO$_2$ was greatest within 5 miles of the plant, as were the health impacts. Estimated impacts per year from the power plant included: 53 premature deaths; 570 ER visits; 14,400 asthma attacks; and 99,000 daily incidents of upper respiratory symptoms.

The community group felt validated by the results, and staged a protest, planting 53 crosses near the plant to symbolize the estimated dead. Critics claimed that the results were fabricated by a computer model, and not based on any real data.

Duxbury, MA

“Jill” (not her real name), an activist in Duxbury, MA, spent years pressuring the state to do a health study to see if local childhood leukemia was caused by a nearby nuclear power plant. They finally agreed, and began a study, but Jill suddenly reversed course. She saw the study design, and knew the study did not have enough study power – it didn’t include enough cases of childhood leukemia to detect a statistical relationship, and so the study was doomed to find nothing. Jill had no doubt the leukemia was linked to the power plant. However, she also knew that if the study was allowed to continue, it would be unable to find a relationship, and that would be wrongly interpreted as proof the power plant did not cause leukemia. She and other members of the community realized that a poorly-designed study would hurt them, so they reversed course, and stopped the same study they fought so hard to get started.
Health Study Stories

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Woburn, MA

In the late 1970s, residents in Woburn, Massachusetts, raised concerns over environmental contaminants (particularly solvents in the water supply) and health. They suspected higher than normal cancer rates, especially in children. A couple of residents went door-to-door to identify cases. They then mapped the cases using pins on a wall map, and by visual inspection it appeared that the cases were clustered in the eastern part of town. In response to these concerns, the Massachusetts Department of Public Health, with help from the CDC, investigated cancer incidence for childhood leukemia, liver cancer, and kidney cancer between 1969 and 1978. Analysis showed that childhood leukemia rates were elevated, specifically on the eastern side of town. Kidney cancer incidence was also higher than expected compared to national rates. However, the study reported that it could not link any particular environmental exposure to the elevated cancer. In 1979, two municipal water wells were closed after tests showed they were contaminated by industrial chemicals.

In 1980, a group of residents then initiated their own further study with researchers at Harvard School of Public Health to investigate whether use of tap water from public wells, which was contaminated with solvents (trichlorethylene and perchloroethylene), was related to the cancers. The research, released in 1984, found an association between risk of childhood leukemia and maternal consumption of drinking water from two specific contaminated wells. It also linked certain birth defects and fetal and infant death with consumption of this water. Throughout the process, other people in the community opposed and threatened the group pursuing the study, because of worries about the property value of their homes, and about losing jobs.

A lawsuit was brought in 1982, and finally settled in 1986. The settlement was smaller than had been hoped, and only one of the two potentially responsible companies was found liable. The companies admitted that contamination was present and had caused illness, but there was no proof the contaminants had come from their properties. The trial gained national attention, and was made into a book and movie, both entitled *A Civil Action*. Seeking funding for cleanup, the U.S. Environmental Protection Agency sued and received a bigger settlement in 1991, from four companies.

In 1997, the Massachusetts Department of Public Health published the results of a case-control study, which confirmed the results of the community study. Children whose mothers drank contaminated well water while pregnant had an eight-fold risk of cancer compared to children of mothers who had not been exposed. The community’s suspicions were validated, but that confirmation came almost 20 years after the first suspicions, and long after the legal cases had been settled.

8. Woburn Trial Chronology, Science Education Resource Center at Carleton College. serc.carleton.edu/woburn/issues/woburn_trial_cronology
Health Study Strategies

Set Clear Goals

Clarify your goals, and how a study may – or may not – support them. Examine each goal. Do you need information from a health study to reach that goal? What audience do you want to convince, and what proof do they need? If you don’t need that information, and if your audience doesn’t require rigorous scientific proof, use other methods to reach your goals.

Craft the Right Question

“What do you want to know?” or “What does the group need to know?” Then refine your question further. Decide if you are focused on an outcome or exposure. The process of refining your question will lead to a better study design and from that will come more useful study results.

Be Sure the Study Answers Your Question

There are many study types out there. Can any of these studies answer your question and help you meet your goals, on a timeline and budget you can afford?

Prepare for the Results

Sometimes health study results can help you reach your goal. Other times they will block progress. Think through the positive and negative things a study might do before pursuing one. If a study is already underway, what will you say about various kinds of results? What might your opponents say?

Choose your collaborators wisely

Health studies can be conducted by government agencies, private companies, not-for-profit organizations, research institutions, or community members. Before starting, research the organization’s history, commitment to the community, and funding sources.

Be Part of the Process

No matter who administers your study, set expectations for communication and decision-making early in the process. Being clear will keep the community’s interests and priorities at the center.
## Overview of Health Study Types

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<th>Study Type</th>
<th>Result</th>
<th>Time</th>
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* Epidemiologic studies. † Sites or behavioral studies

= weeks or a few months.

= At least a few years

= some expert advice, maybe via phone or internet

= consulting firm, university, government professionals

= $100 - $1,000

= more than $100,000
Overview of Health Study Types

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Studies Mapping Exposure and/or Outcomes

**Exposure mapping** helps show sources of pollution and identify patterns of exposure. It can be done either by community groups or by scientists. Some exposures are obvious; others require data from an environmental agency or other source.

- Some drinking water wells have been closed as a result of contamination. Where are these wells, in relation to homes and schools?
- Which neighborhoods are closest to the farms where sludge is sprayed?
- Are there more smoke-spewing industries in our area than in other parts of the state?

**Outcome mapping** helps show patterns of health problems in an area. It can be done either by community groups or by scientists, but it does require that you already have the data, perhaps from a survey or registry.

- Where are the lung cancer cases located in our neighborhood?
- Are there clusters of leukemia in our county, or is it evenly distributed?

**Exposures and outcomes on one map** help show patterns that point towards an exposure-outcome relationship. This can help justify a more detailed study.

- The west side of town has more cases of brain cancer for its population than other neighborhoods. Does it also have more hazardous waste sites?
- Are there more breast cancer cases near the underground plume of contamination compared to areas with no ground water contamination?
- Do cases of cardiovascular disease mortality appear to be higher downwind of the coal-fired power plant?
Overview of Health Study Types

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**Studies of Exposure**

**Environmental monitoring studies** measure levels of chemicals or other toxins in the environment. Samples of air, water, soil, or food can be examined for contamination.

- Is there lead in my garden soil? How much?
- Is there mold in the air I am breathing? How much?
- Are there hazardous chemicals in my drinking water? Which ones and how much?

**Body burden studies** measure chemicals in a person's body. Samples of body tissue or fluids (blood, urine, saliva, hair, nails, or breast milk) can be tested.

- Is there lead in my blood? How much?
- Does my hair show that I’ve been exposed to mercury? How much?
- Am I passing PCBs to my baby through my breast milk?

**Environmental impact statements** try to describe the possible environmental and health impacts of a new development, or a modification of an old one. They are not technically exposure studies, but the results may be useful in thinking about exposure.

- How will building a power plant here affect the air quality in this area?
- How will storm water runoff from the new parking lot affect pollution in the river?
- When they clean up the old factory, will all that contaminated dust go into the air?

**Studies of Contaminated Sites**

**Risk assessments** describe contamination at a site, estimate how people might be exposed, and estimate the probability of health hazards from that exposure.

- What are the chances of getting cancer from the levels of TCE in our drinking water?
- Is the abandoned factory site dangerous for my children, if they don’t go on the site itself?

**Public health assessments** take existing information about contamination levels at a particular site, and look into the details of exposure.

- What are people’s actual exposures to this site?
- Have people’s actual exposures to this site made them sick?
Overview of Health Study Types

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Studies of Outcomes

Community surveys can help you learn about health problems in your area, by going door-to-door or by making phone calls.

- What health problems are residents of our street experiencing?
- What health problems are of concern to my neighborhood?

Analysis of disease registry data or vital events data lets you compare known death rates or the rates of certain diseases (mostly cancer) with rates in other areas. Some data is publicly available online; other data is only accessible to researchers at universities.

- Does our county have a higher rate of lung cancer than the state average?
- Are people dying younger in my city than in other cities?

Studies of Exposure-Outcome Relationships

Ecologic studies ask whether there is an association between a particular exposure and a particular health outcome, across a set of large geographic areas like towns or counties.

- Do cities in this state with high brain cancer rates also have more hazardous waste sites?
- Across the U.S., do counties with a coal-fired power plant have higher rates of asthma?

Cohort studies follow a group of people over time, some of whom were exposed to a hazard and others were not, and compares the health outcomes.

- Are the people who lived near the hazardous waste site 20 years ago more likely to have had cancer than people who lived far from the site?
- In the next five years, what will happen to people who are exposed to this radiation source compared with people who are not exposed to it?

Case-control studies compare people who have had a specific illness or condition with people who do not.

- Were adolescents who have learning disabilities more exposed to lead paint as toddlers, compared with adolescents who do not have learning disabilities?
- What differences in lifestyle, behavior, genetics, or environmental exposures exist between women with breast cancer compared to women who do not have breast cancer?
Health Study Worksheet

1. In this situation, what are...
   ...the *exposures* of concern? (Known, or suspected)
   ...the *outcomes* of concern? (Already evident, or feared)
   ...reasons to think there is a *relationship* between these exposures and outcomes?

2. What *question* about this exposure and outcome do you want a health study to answer?

3. Pick one *health study type* you think might answer your question. Which did you choose?

4. What are your ultimate *campaign goals*?

5. The results of a health study might show the problem you suspect, or show that there is no problem, or results may be inconclusive (showing not enough evidence either way). How might each of these results help or hurt your goals? Include factors like time and expense.

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<td>Shows problem</td>
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<tr>
<td>Shows no problem</td>
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<tr>
<td>Inconclusive (not enough evidence)</td>
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Sample Community Health Scenarios

These scenarios accompany the workshop *A First Look at Health Studies* and can be used when a group does not share a common community health concern. The examples are all from real communities, though some happened many years ago and have since been resolved.

**Lindsay, CA**

Lindsay, California, is a small town with hundreds of acres of orange groves. To make a “perfect”-looking orange, growers use chlorpyrifos to keep insects off the orange trees. The Environmental Protection Agency banned the use of chlorpyrifos in homes and apartments in 2001, because it poses severe health risks to children. But California orange growers still use chlorpyrifos. It is common for people in Lindsay to feel sick when the orange groves are sprayed. People report headaches, blurry vision, weakness, and vomiting after the spray is used. Some residents wanted to know if the insecticide is getting into their bodies, and if so, how much.

**Monticello, UT**

The community is the site of a former uranium mill that operated from 1940 through 1962. Uranium mining waste accumulated in large piles on the mill property, and dust from these piles blew throughout the town for many years. There was considerable contamination of nearby residential property, grazing lands, and streams. In addition, mill tailings were used to make cement sidewalks and the grout used in fireplaces and chimneys of some homes. The town was eventually designated a Superfund site, and widespread environmental testing and mapping were carried out in the early to mid-1990s. A cluster of leukemia was identified in the late 1960s in one small part of town, a short distance from the mill, but the number of cases was small and no conclusions were drawn about exposure to uranium dust or other potential causes. Residents want the town cleaned up, but they think nobody will pay for it unless a health study shows an ongoing health problem.

**Anniston, AL**

Anniston, Alabama, used to be the site of a manufacturing plant. The plant was contaminated with cancer-causing chemicals called PCBs. Residents have not noticed any particular health effects, but they wonder if they are at risk from the contamination.

**Corrales, NM**

For a few years, residents have been having symptoms like fainting, rashes, seizures, and irritations of the nose, throat and lungs. There have been miscarriages and birth defects. Some people blame the Intel plant located 100 yards uphill, but Intel supporters want to ignore residents’ concerns. *The Albuquerque Journal* quoted a state representative who said only a “handful of crazies” had complaints.

**Ashland, MA**

The Nyanza Chemical Waste Dump site operated in Ashland from 1917 to 1978. During that time, local children routinely played on and near the site, coming in contact with both waste lagoons and a small stream (nicknamed “Chemical Brook”) into which partially treated chemical wastes were dumped. Many years later, Ashland residents documented five cases of soft tissue sarcoma (a rare form of cancer) in young men who had played on the site as children from 1965-1985. Residents want to know if the companies who dumped chemicals are responsible for their health problems.

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