Is a Health Study the Answer for Your Community?

A Guide for Making Informed Decisions

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Outline

Why did we write this *Guide*?

Overview of the *Guide*

Closer look at content from Chapters

Background

BU Superfund Research Program

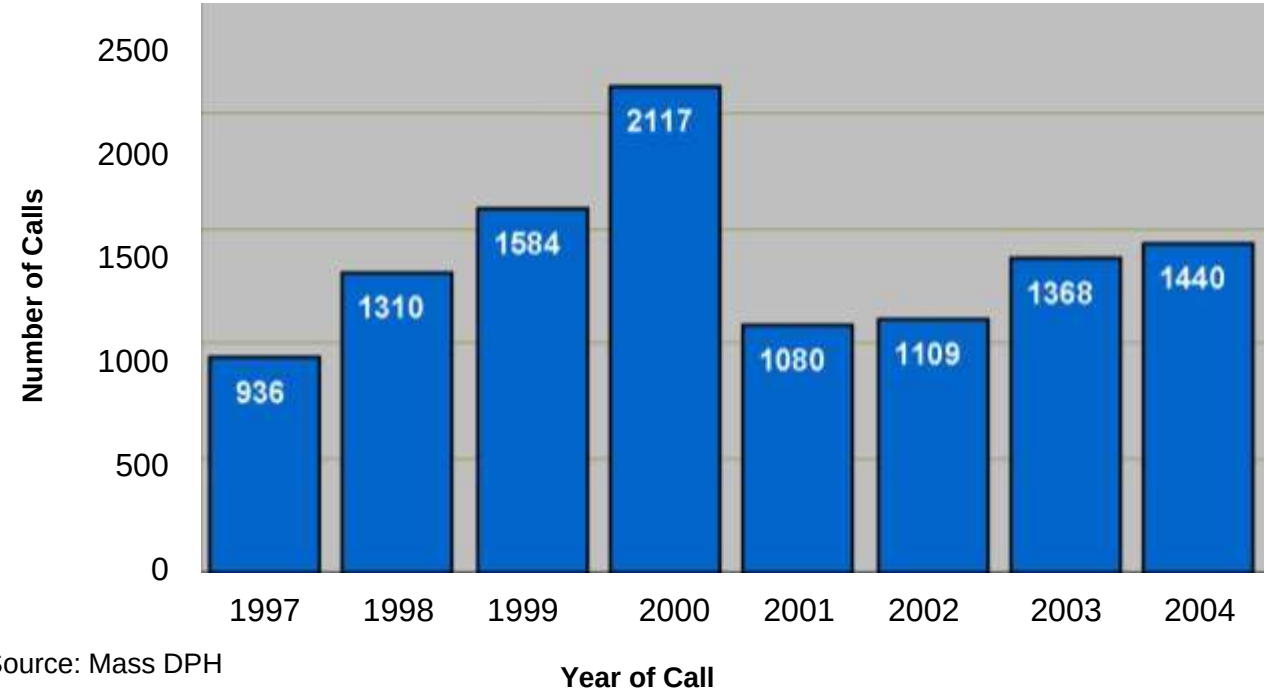
Community Engagement Core

e.g., community air pollution monitoring

National Institute of Environmental Health Sciences (NIEHS/NIH)

Demand for Studies... in Massachusetts

Annual Calls Taken Regarding
Perceived Environment and Disease Clusters



Source: Mass DPH

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

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A guide for making informed decisions

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Funding provided by

National Institute of Environmental Health Sciences, NIEHS, NIH grant numbers 5 R25 ES12084 and 5 P42 ES007381

Health Study Guide Chapters 1 and 2

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Overview of Chapters 1 and 2

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First Three Steps for a Community Health Study

Step 1: Consider possible outcomes, including the possibility that a health study may do more harm than good

Step 2: Help the community identify its goals

Step 3: If a community decides to do a health study, help frame the question

What is a health study?

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

An epidemiologic study (connecting exposure to outcome) is only one of the available types of community health studies.

“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, BU SPH

Salem, MA Story

"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

"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 a chance to do that with the study…I would have said, 'Don't do it!'"

-Erin, Resident of Salem, Massachusetts

Step 1: Consider Possible Outcomes

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

Step 2: Identify Goals

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Important to distinguish organizing goals from study questions

Motives for a Health Study

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Table 1.2 Your Motives for a Health Study

A. *What* do you want to know? That is, what is your *question or concern*?	**B. *Why* do you want to know?** That is, what is your *goal*?
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?	Sample responses: – Stop the development – Prove we were right – Clean up the site – Get compensation

Bottom Line: Carefully consider whether a health study may do more harm than good

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The Boston Globe

CANCER ALERT SOUNDED: STATE STUDY TIES ASHLAND WASTE SITE TO AN ELEVATED RISK
April 26, 2006
By Beth Daley. Michael Levenson of the Globe staff contributed to this report.

State health officials urged Ashland residents yesterday to consult a doctor about possible cancer risks if they swam or waded in polluted water and wetlands near a hazardous waste site before 1985.

The warning is based on a seven-year study released yesterday showing that people who grew up in Ashland 20 to 40 years ago and who came into contact with certain ponds and brooks contaminated by the former Nyanza Inc. chemical and dye factory had a risk of developing cancer that was two to three times greater than those who did not have contact with the water. The increased risk of cancer from contact with the water was even higher for those with a family history of cancer.

The state launched the study at the prodding of Ashland residents, concerned about rare cancers diagnosed in five young men in the 1980s and '90s. Two died of the disease. The study involved extensive interviews with 1,387 current and former Ashland residents who were children between 1965 and 1985, and 73 participants reported having been diagnosed with some type of cancer.

The Boston Globe

ASHLAND CANCER RISK IS DISPUTED

May 9, 2006
By Beth Daley

Boston, MA-State health officials' warning last month was clear: Residents who grew up in Ashland and swam or waded in certain polluted waters near a former dye factory more than two decades ago could have a twofold to nearly fourfold increased risk of developing cancer. They were urged to see their doctors.

But the inch-thick study that the warning was based on contains far murkier results.

A Globe analysis of the study shows that contrary to what state officials said, there is a statistically significant cancer risk only for people with a family history of cancer, which includes a sibling or parent. Even then, the risk is limited to those who swam or waded in two areas on or near the site of the former Nyanza Inc. plant.

Step 3: Define Research Question

Three common areas of study:

- Exposures
- Health outcomes
- Connecting exposures to outcomes

Examples of concerns to be addressed in a study

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My concern is…	My study will address…
particulates emitted by a power plant in town	An **exposure**: Have we been exposed to something harmful?
too much breast cancer	An **outcome**: Are there more cases here than one would expect?
possible link between children's poor school performance and our town's old lead water pipes	An **exposure-outcome** relationship: Is a harmful exposure affecting our health and well-being?

Framing Your Question

Three questions researchers answer:

What is the concern we will address in our study?

Whom do we want to study?

Where and when do we want to do our study?

Sample concerns and research question

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My concern is…	My study will address…	My research question is…
particulates emitted by a power plant in town	An **exposure**: Have we been exposed to something harmful?	Over the past 5 years, have people on the east side of town been exposed to high concentrations of airborne particulates emitted by the power plant?
too much breast cancer	An **outcome**: Are there more cases here than one would expect?	Over the past 10 years, does our town have a higher rate of breast cancer in women than other, similar communities do?
possible link between children's poor school performance and our town's old lead water pipes	An **exposure-outcome** relationship: Is a harmful exposure affecting our health and well-being?	Is lead in our drinking water responsible for the current poor performance of local children in school?

See Chapter 2 Worksheet: Developing a Research Question

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Chapter 2 Worksheet: Developing a Research Question

Check the boxes and fill in the blanks using the sample responses as examples.

1. Identifying your concern(s) (**What**):

Are you concerned only about an exposure? __ yes ___no

If yes, what exposure? _____

Are you concerned only about a health outcome? __ yes ___no

If yes, what outcome? _____

Are you concerned about a possible link between an exposure and a health outcome? __ yes ___no

If yes, what exposure? _____

And what outcome? _____

2. **Who** is the focus of concern?

What groups (for example, children ages 5-12, women under age 30, atomic energy workers)?

_____

_____

About how many people do you think are affected? A rough estimate is fine: Fewer than 100?

Chapter 3: A Menu of Health Studies

Figure 3.1 Summary of Study Types

Study Type ---------->	Results
(1) Mapping	
Exposure mapping	Map(s) of exposure
Outcome mapping	Map(s) of disease distribution
(2) Studies of Exposure	
Environmental monitoring	Concentrations in environmental media
Personal monitoring	Concentrations in immediate and personal surroundings
Body burden (biomonitoring) study	Concentrations in bodily tissue or fluid
Environmental impact statement	Description of environmental changes
(3) Studies of Outcome	
Community survey	Survey responses; may be qualitative
Analysis of registry data	Comparison of community disease or mortality rate with standard rate
(4) Studies of Exposure-Outcome Relationship	

Chapter 3: A Menu of Health Studies

(2) Studies of Exposure (p.45)

Are there toxic substances in the environment?

Environmental monitoring looks for and measures concentrations of chemicals or other toxicants in the environment. Depending on the availability of equipment and laboratories, samples of air, water, soil, or food can all be examined for evidence of contamination. For example:

- *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?*

Have we been exposed to pollutants? Are there toxic chemicals in my body?

A **body burden study** measures chemicals that are in a person's body. By taking samples of body tissue (blood, urine, saliva, hair, nails, or breast milk) some specific contaminants can be measured. These studies answer questions such as:

- *Is there lead in my blood? How much?*
- *Is there mercury in my hair? How much?*
- *Have I been exposed to PCBs? Is there evidence of them in my body?*

Chapter 4: “More About Each Type of Health Study”

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Mapping

Studies of Exposure

- Environmental or Personal Exposure Monitoring Study
- Body Burdens and Biomonitoring
- Environmental Impact Statement

Studies of Health Outcomes

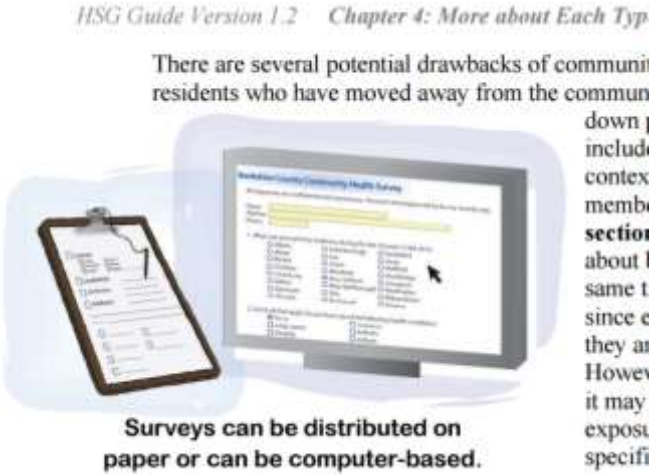
- Community Survey
- Analysis of Disease Registry Data or Vital Events Data

Studies of the Exposure-Outcome Relationship

- Ecologic Study
- Cohort Study
- Case-Control Study

Studies of Contaminated Sites

- Risk Assessments
- Public Health Assessments



Still to Come

Chapter 5: Key Considerations in Planning a Good Health Study

- The Meaning of “Proof”
- Basic concerns for any study
- Ethical concerns of involving people, or information about people, in your study
- Special considerations for the design of epidemiologic studies

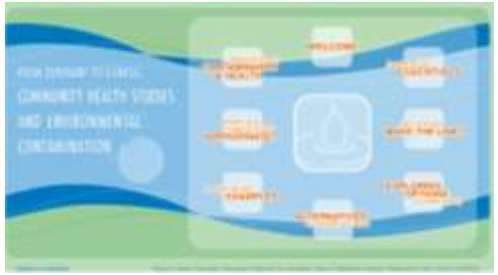
Chapter 6: How to Evaluate the Results of a Health Study

- Reading and interpreting study results
- Evaluating the role of chance
- Do our results make sense?
- Epidemiologic studies: Evaluating confounding and interaction
- “More research is needed”

Chapter 7: “Who Conducts Health Studies?”

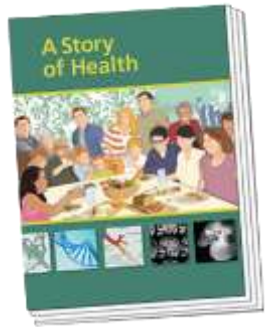
Chapter 7: “Who Conducts Health Studies?”

Complementary Resources



- Cancer Downstream: A Citizen's Guide to Investigating Pollution/Health Connections, Steve Dickens, River Network
- CommunityHealthStudies.org - An interactive website introducing users to environmental health issues and study designs using case studies. *California DPH EHIB*

- Statistics for Action, website with videos, activities and exercises on environmental sampling, understanding test results and data.
- Community Environmental Health Assessment Workbook – Environmental Law Institute
- A Community Guide to Environmental Health, A 600+ page illustrated manual for community members, health educators and everyone in between. *Hesperian*.



- The Story of Health: Interactive ebook that includes cases of asthma, leukemia, learning disabilities and environmental risk factors.

Acknowledgements

Gregory J. Howard, DSc, MPH

Dick Clapp, David Ozonoff, Stephen Lester, Jennifer Ames, Nancy Irwin Maxwell, Nancy Myers, Gregory Patts, Susan Santos, Alyssa Schuren, Meredith Small, Heather Simpson, Leslie J. Somos, May Woo

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Funding provided by **National Institute of Environmental Health Sciences, NIH**

Thank you!

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