

# The Strategic Value of Health Studies

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# The Strategic Value of Health Studies

Health Studies and Precaution

Why a health study?

positive & negative things they can do

Types of health studies

Who conducts health studies

Examples of health studies

Heads Up! –things to look out for

# Health Studies

Partners on this project include:

- Center for Health, Environment & Justice
- Toxics Action Center
- Greater Boston Physicians for Social Responsibility

and others...

With funding from the National Institute of Environmental Health Sciences.

# Health Studies

“I have a confession to make:

I have **Erin Brockovich envy**. ...I would love, for once, to work on a project where it was clear who the good guys and the bad guys were, and where I knew for sure that what I was doing would help solve the problem.”

Rachel's #815 - Beyond Erin Brockovich, April 14, 2005

by Sonja Biorn-Hansen

# Health Studies & Precaution

Definition of a public health catastrophe:

“a health effect so powerful, even an epidemiologic study can detect it.”

-David Ozonoff

# Health Studies & Precaution

## Precautionary checklist:

What do we care about?

What are we trying to accomplish?

What choices do we have?

What is the bigger picture?

Do we know enough to act? Do we know so little  
we must act with caution?

Who is responsible?

Chapter 6, Precautionary Tools for Reshaping Environmental Policy  
by Nancy Myers

# Health Studies & Precaution

What do we care about?

**What are we trying to accomplish?**

What choices do we have?

What is the bigger picture?

Do we know enough to act? Do we know so little we must  
act with caution?

Who is responsible?

Why a health study?



# Why a health study?

A. *What* do you want to know?

B. *Why* do you want to know?

What is your question or concern?

What is your goal?

# Why a health study?

*“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.

## Positive things

## Negative things

Document disease and/or exposure

Appear to show there is “no problem”

Demonstrate relationship (“cause”) between disease and exposure

Document no “significant” relationship between a disease and exposure

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

Generate statistics which may undermine your efforts

# Why a health study?

...To answer a question.

Why am I sick?

Why *us*?

# Why a health study?

...To answer a question.

Are people in my community sicker than people who live somewhere else?

Why am I sick?  
Why *us*?

Will the proposed trash incinerator that may be located in our community be safe for our health and the environment?

Are other people in my community sick?

Am I exposed to *chemical X*?

How did we get sick?

What are the major sources of pollution in my community?

# Why a health study?

<b>Exposure</b>	<b>Outcome</b>
PCE in drinking water	Leukemia
Living near a waste site	Rashes
PCBs	Liver damage
Inhalation of diesel exhaust	Asthma
Lead in children's blood	Learning disabilities
Age	Senility

# Types of health studies

Study Type	Time	Cost	Expertise
Registry and Vital Events Data		\$	??
Mapping		\$	?
Community-based survey or interviews		\$	??
Environmental Monitoring		\$ \$	????
Body Burden		\$ \$ \$	???
Case-control		\$ \$ \$ \$	????
Cohort		\$ \$ \$ \$	????
Cross sectional or ecologic		\$ \$ \$	????
Risk & Health Assessments		\$ \$	????
Environmental Impact Statement		\$ \$ \$	????

# Who Conducts Health Studies?

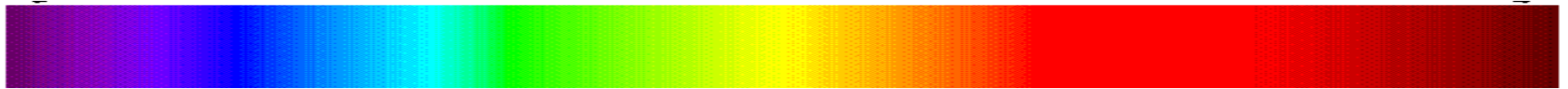
*The group was basically formed to clean up the site, but sitting down one night, one neighbor in particular had mapped out [diseases in] his neighborhood. ... So we just said, “**Why don’t we ask? and Who do we ask?**” We didn’t know who to go to. We didn’t know what to do. ... no matter what feelers 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



# Who Conducts Health Studies?

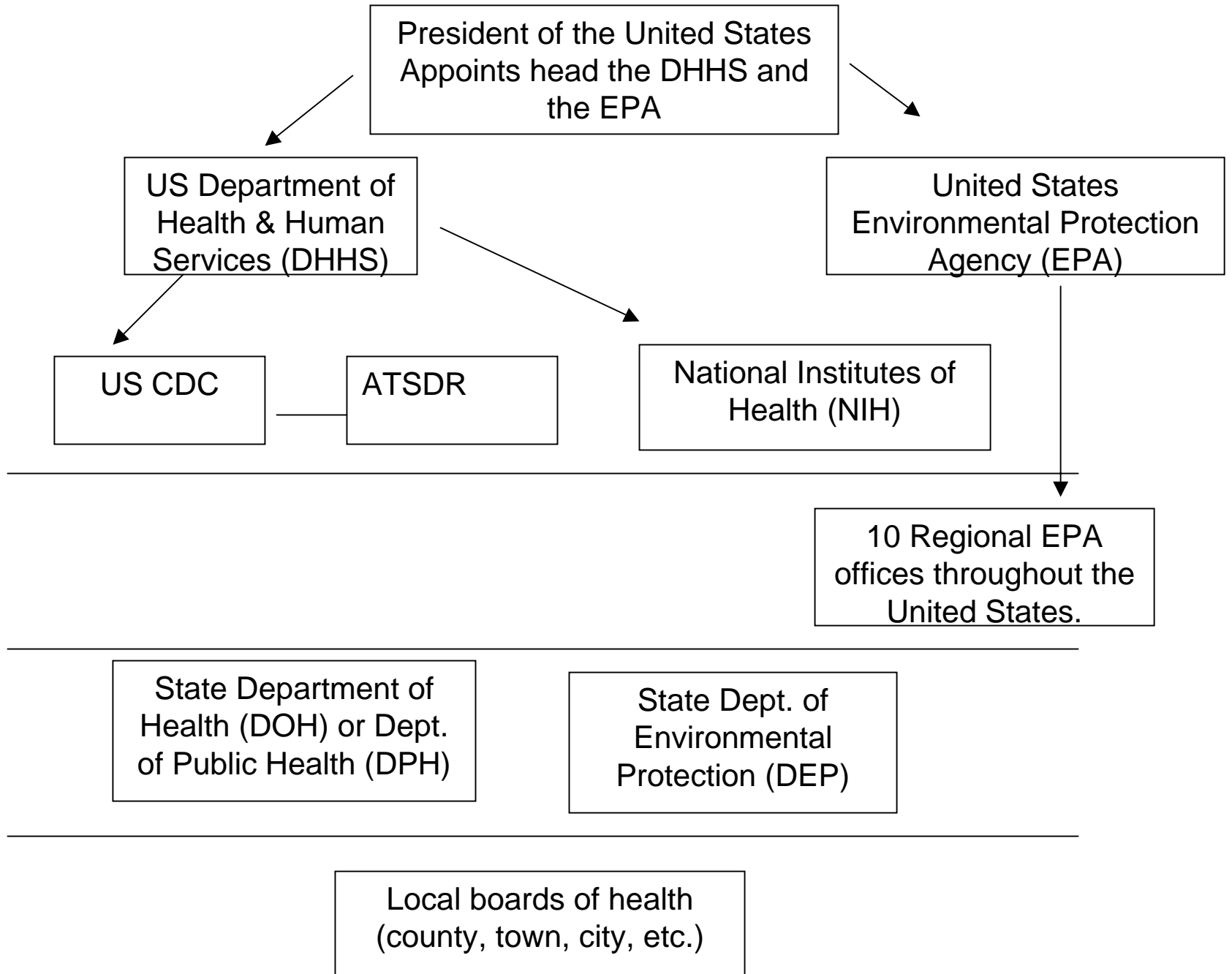
Spectrum of community participation:













**Community-driven** and controlled. Very little outside involvement. Maybe external consultants to assist with technical questions.

**Partnership**  
between professional researchers and community members.  
Equally shared power, decision-making authority, and ownership.  
(CBPR)

**Expert-driven** and controlled. Very little community involvement. Maybe occasional briefings or presentations to community members.



Study Type	Time	Cost	Expertise
Registry and Vital Events Data		\$	??
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Community-based survey or interviews		\$	??
Environmental Monitoring		\$\$	????
Body Burden		\$\$\$	???
Case-control		\$\$\$\$	????
Cohort		\$\$\$\$	????
Cross sectional or ecologic		\$\$\$	????
<b>Risk &amp; Health Assessments</b>		\$\$	????
<b>Environmental Impact Statement</b>		\$\$\$	????

# Types of Health Studies

## Community-Based Survey:

- Three examples of recent experiences
  - Housatonic River Initiative, Pittsfield MA
  - Monticello UT mill tailings
  - Lipari Information Network, Mantua NJ

## **PLEASE READ BEFORE STARTING**

### **PITTSFIELD DECEASED RESIDENT QUESTIONNAIRE**

Please fill out a copy of this questionnaire for the deceased individual who lived in your Pittsfield household for at least one year between 1967 and 1984. We realize that you may not be able to answer all of the questions, but please answer as completely as you can.

#### **INSTRUCTIONS:**

- When dates are requested, please complete the year:  
19\_\_\_\_ to 19\_\_\_\_ or: 19\_\_\_\_
- Answer questions carefully, and write clearly.
- All responses will be kept completely confidential, and they will never be used in a way that could identify individual respondents.
- If you have any questions, please call Wendy Phillips at 413.499.6112 or 413.528.3341.
- When you have completed the survey, please mail it back in the pre-paid envelope.

**HOUSATONIC RIVER INITIATIVE/COMMUNITY HEALTH STUDY**

**THANK YOU IN ADVANCE FOR YOUR PARTICIPATION**

## SECTION A: GENERAL

**A1. Sex:**                    1 Male            2 Female

**A3. Year of death:** 19\_\_\_\_

**A2. Age at death:** \_\_\_\_\_

**A4. Cause of death:** \_\_\_\_\_

## SECTION B: MEDICAL HISTORY

*This section asks about health problems that a doctor diagnosed.*

B1. Was the individual found by a doctor to have any of the following problems at the time of their death (or previous to death)?				B2. If yes, list year doctor first diagnosed.
	YES	NO	UNSURE	YEAR
a. Asthma, bronchitis, or emphysema	1	2	3	19____
b. Pneumonia	1	2	3	19____
c. Any other respiratory diseases SPECIFY: _____	1	2	3	19____
d. Eczema, psoriasis, dermatitis, or other skin trouble	1	2	3	19____
e. Arthritis or rheumatism	1	2	3	19____
f. Goiter or other thyroid disease	1	2	3	19____
g. Epilepsy	1	2	3	19____
h. Parkinson's disease	1	2	3	19____
i. Dementia (such as Alzheimer's)	1	2	3	19____
j. Hearing impairment	1	2	3	19____
k. Blindness in one or both eyes	1	2	3	19____

# Medical history, continued..

**B8.**  
Has the individual ever had any of the following types of cancer?

**B9.**  
If yes, list year doctor first told

	<u>YES</u>	<u>NO</u>	<u>UNSURE</u>	<u>YEAR</u>
a. Stomach	1	2	3	19__
b. Colon or rectum	1	2	3	19__
c. Bladder	1	2	3	19__
d. Hodgkin's lymphoma	1	2	3	19__
e. Non-Hodgkin's lymphoma	1	2	3	19__
f. Lung	1	2	3	19__
g. Breast	1	2	3	19__
h. Ovarian	1	2	3	19__
i. Cervical	1	2	3	19__
j. Uterine	1	2	3	19__
k. Prostate	1	2	3	19__
l. Testicular	1	2	3	19__
m. Brain or other nervous system	1	2	3	19__
n. Leukemia	1	2	3	19__
o. OTHER Cancer type. Specify: _____	1	2	3	19__
p. OTHER Cancer type. Specify: _____	1	2	3	19__
q. OTHER Cancer type. Specify:	1	2	3	

## SECTION C: ACTIVITIES

The following questions are about various types of activities they may have participated in.

	<u>NEVER</u>	<u>1-29 TIMES</u>	<u>30-100 TIMES</u>	<u>MORE THAN 100 TIMES</u>	<u>UNSURE</u>
C1. How often did they eat vegetables that they grew in their own garden while living in Berkshire County?	1	2	3	4	5
C2. How often did they eat fish caught in the Housatonic River?	1	2	3	4	5
C3. How often did they eat animals (other than fish) hunted near the Housatonic River?	1	2	3	4	5
C4. How often did they go swimming or wading in Goodrich Pond?	1	2	3	4	5
C5. How often did they eat fish caught in Goodrich Pond?	1	2	3	4	5
C6. How often did they participate in other recreational activities (such as walked, played, jogged, or biked) along the Housatonic River?	1	2	3	4	5
C7. How much time did they spend working or playing in their yard?	1	2	3	4	5
C8. Did they ever enter beyond the chain link fences that enclose the GE facility?	1 <u>YES</u> 2 <u>NO</u> 3 <u>UNSURE</u>				
C9. Did they attend any of the following schools?	<u>YES</u> <u>NO</u>		C10. During which years?		
a. Allendale School	1	2	19_____ to 19_____		
b. Pittsfield High School	1	2	19_____ to 19_____		
c. Hibbard School	1	2	19_____ to 19_____		
C11. Did they ever have a private well?	C12. If yes, FIRST time used well: 19_____				
	LAST time used well: 19_____				



## SECTION D: WORK EXPOSURE

This section includes questions about the person's work and hobbies.

### D1.

Did they have any hobbies or things they often did in their spare time that involved contact with any of the following chemical substances?

	<u>YES</u>	<u>NO</u>
a. Paint strippers	1	2
b. Glues	1	2
c. Art materials	1	2
d. Varnishes	1	2
e. Welding materials	1	2

### D2.

Were they ever been employed either full-time or part-time?

- 1 YES      2 NO (IF NO, Skip to Section G, Tobacco, Page 7)

### D3.

What sort of work did they do on their last job, or what was their job title?

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### D4.

What type of business or industry was this in? That is, what product was made or what service is given?

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### D5.

In what year did they start working there?      19\_\_\_\_ - 19\_\_\_\_

### D6.

Were they ever been employed by GE? (If yes, answer D7)

- 1 YES      2 NO

### D7.

In what capacity?



# Health Survey: Negative things they can do...

(Center for Health, Environment & Justice)

- Force you to constantly defend the credibility of the survey
- Identify health problems you are unprepared to deal with
- Generate statistics which undermine your organizing efforts
- Lead to legal complications over confidentiality or lawsuits

# Health Survey: Positive things they can do...

(Center for Health, Environment & Justice)

- Build the credibility of your group
- Create an opportunity for lots of members to help
- Educate your group about a health problem(s) in your community
- Possibly provide evidence which will motivate community involvement, generate media coverage, or fulfill other strategic goals.

# Health Studies ‘Heads Up!’

## Study Power

*“I try to get studies, and stop studies. The childhood leukemia study, which finally got going, had to be stopped. The Department of Public Health was given a very small amount of money by the legislature to do a study that was going to have **no power**. They drew up a design of the study... And then, seeing that study, I depended on... epidemiologists’ help from around the country to look at the study design and say, ‘Isn’t this bullshit?’ Writing to the legislature and then going to the press. The study was stopped.”*

–Jill, Activist in Duxbury, Massachusetts.

# Health Studies 'Heads Up!'

## Study Power

Influenced by:

- 1) Background rates of illness
- 2) Magnitude of difference you want to detect
- 3) Sample size

# Health Studies 'Heads Up!'

## Study Power

example

Detecting Leukemia due to benzene exposure

Background rates of leukemia is  $\sim 1/100,000$  or 0.00001

Can we detect a 16x increase?

Should we start a health survey to find out if there are too many cases of this type of Leukemia?

# Health Studies 'Heads Up!'

## Study Power

### Exercise

Given:

- Background rate of illness is 0.10
- We want to be 80 % likely to be able to able to detect a 3-fold increase, if one exists
- How big must the study population be?



# Health Studies & Precaution

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# Health Studies & Precaution

*“I think it is really important when these studies are created to say... ‘How will [the results] be used...?’ To just kind of consider what the public perception is going to be, to... look at the big picture... [to consider] 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

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

--David Ozonoff (again)