

THE NEWHALL HEALTH STUDY: COMMUNITY-BASED PARTICIPATORY  
RESEARCH IN ENVIRONMENTAL HEALTH

By

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## *Preface*

This thesis is the result of a project conducted with another joint degree student at the School of Forestry and Environmental Studies, Sarah Vogel. We both had shared and differentiated responsibilities, which ultimately made it a better project than if I had continued to run it alone. Similarly, the joint construction of the thesis resulted in a stronger document as we had different but complimentary interpretations of data and experiences. The bodies of our theses are identical, save for the preface.

The project began when, through my involvement in New Haven area environmental issues, an email request to perform a health study for Newhall residents landed in my inbox. I was immediately interested in being involved in the study for a number of reasons. First, I have an interest in Environmental Justice issues as windows into how environmental problems are inseparable from their social contexts. Second, I wanted the effort and work required to complete a thesis to go toward directly helping people. Third, I wanted to further my involvement in my community since I find that the more I become involved, the more I enjoy being in New Haven. Fourth, I am interested in locally driven sustainability efforts as a promising strategy to create a better world and in the decentralization of knowledge as a necessary component. Fifth, the early stage of this project presented a rare opportunity to hit the ground running since the community was already organized and had strong leadership. Finally, the project was an unusual opportunity to apply and refine a broad range of skills that I acquired at both the Department of Epidemiology and Public Health and the School of Forestry and Environmental Studies that would be useful regardless of my vocation.

In my enthusiasm I ignored the experienced professionals who warned that the project would be more in line with a dissertation, suggesting that I would be unable to do it alone. They were right. A few months into the project, I called Sarah Vogel a number of times for advice on survey instrument development. Through those conversations, we agreed that she would be an excellent addition to the project.

The skills that I brought to the project were knowledge of the history of the Newhall situation, epidemiological training, knowledge of environmental justice theory and literature, statistical analysis of both qualitative and quantitative data, experience in working with communities on environmental issues, communication of scientific concepts to laypeople, Geographic Information Systems skills, and experience in dealing with media.

My responsibilities included

- researching the boundaries of the landfill and the data on contaminants found in the soil;
- developing an address list for the study population;
- establishing a hotline for questions about the survey and responding to those phone calls;
- developing maps of the study area;
- creating, maintaining, and analyzing the follow-up database;
- conducting interviews of non-responders and study group members

Our shared responsibilities included

- facilitation of meetings;
- writing up of meeting minutes;
- door-to-door and phone follow-up;
- developing materials for volunteers (scripts, issue primers, lessons on bias);
- drafting press statements;
- attending and participating in press conference with Newhall Coalition; and
- cleaning and initiating analysis of data in SAS and Microsoft Excel.

In terms of the thesis, we also had shared and distinct responsibilities. Though one person originally authored different sections, revisions by the other author were sufficiently thorough to render an assignment of exclusive authorship impractical.

Nevertheless, the sections I originally wrote are

- Environmental Justice theory
- Methods section except the parts on Health Symptoms and Exposure Assessment
- Discussion section

We jointly authored the Introduction, Results, and Conclusion sections.

I am grateful for the opportunity to work with Sarah on this project. Her involvement did not simply allow the study to continue; she enhanced it greatly. She brought energy, intellect, a strong work ethic and a critical eye in addition to the skills she lists in the Preface of her copy of this thesis. I learned from her as I did from the community, which provided an experience densely packed with lessons.

## **Abstract**

In the early 1900s an area of wetlands in southern Hamden Connecticut was filled in with industrial and private waste. Today, the Newhall neighborhood and the Hamden Middle School sit atop this old landfill and former wetland. In 2000, the Hamden Middle School conducted routine soil testing for a planned expansion and found high levels of lead, arsenic and polycyclic aromatic hydrocarbons (PAHs). The health survey on which this thesis is based was a community-based participatory research (CBPR) project conducted in collaboration with the residents.

The survey was a self-administered questionnaire of the health of all residents living on or near the landfill. The response rate for the survey was low (123 surveys returned; 19.6%). This paper is a *descriptive* analysis of the participatory research approach as an alternative to traditional research. Preliminary summary statistics indicate that responders were representative of the demographics of the area; 74% of the individuals filling out the survey were Black-American with an average of 2.7 individuals in the household. The age distribution was very broad within households and the average age of the individual responding for the household was 55 years of age (median 57). The majority of responders reported that they were concerned about pollution in their neighborhood (83%). Forty three percent of respondents (n=83) indicated they eat from Newhall gardens. The discussion describes the challenges and obstacles encountered throughout the research project. In doing so, this paper provides guidance for CBPR.

## **Acknowledgments**

In a participatory project like this, many thanks are in order. First, we thank Jo Frasier and Elizabeth Hayes of the Newhall Coalition for their trust, hard work, and dedication. We are honored to work with them. Secondly, we thank the members of the study group who faithfully contributed: Oscar Torres, Donna and Crystal Johnson, and Scot X Esdaile. Bob Edwards and James Rawlings also contributed. Faculty support from Dr. Loretta DiPietro was emotionally, intellectually, and logistically crucial. Colleen Murphy-Dunning and Dr. William Burch of the Hixon Center for Urban Ecology at the School of Forestry and Environmental Studies provided invaluable financial and intellectual assistance as well. Dr. Tongzhang Zheng reminded us of the unique and important opportunity this project offered us. He also generously provided us with data entry support. We would like to thank community members who attended meetings, filled out the survey, talked to neighbors, and trusted us with their personal information. Finally, we thank the following people for their contributions.

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## ***I. Introduction***

In late 2000, soil testing performed as part of routine geotechnical and environmental analysis revealed abnormally and consistently high concentrations of lead, arsenic, and polycyclic aromatic hydrocarbons (PAHs) at the Hamden Middle School in Hamden, Connecticut (*1*) (see Appendix 4 for selected soil data). These findings were widely suspected to be the result of contamination from a landfill from the early 1900s in the area on which the school and surrounding fields were built in the mid 1950s. Parents and teachers initially brought the contamination issue to the media, and thus, to popular attention. Over the next few months, government agencies became involved in defining the boundaries of the landfill and identifying the chemicals in the soil around the school. The residents of the surrounding neighborhood, the majority of whom were African-American, began to ask whether their land was also contaminated. In an effort to gain a community voice in discussions and investigations into the contamination of the area, long time resident Jo Frasier initiated a citizen's action group called the Newhall Coalition (NC).

The Newhall Coalition held community meetings and worked with the media to shift public attention to concerns of the residents of the affected area. Residents told stories of “black ooze” seeping from under their driveway and of soda bottles from the turn of the century being unearthed in their yards after heavy rains or powerful winds (*2, 3*). The NC invoked an environmental justice framework, drawing on the assistance of the Greater New Haven Branch of the National Association for the Advancement of Colored

People (NAACP). Local, state, and even federal agencies responded in many ways, one of which was an attempt by the Quinnipiack Valley Health District (QVHD) to verify anecdotal reports of elevated levels of pancreatic cancer in the neighborhood. The small study found no statistically elevated levels, but received a low participation rate of 60%, (4) which is suboptimal for an epidemiological study. Nonetheless, the study was viewed as being “imposed” upon the residents since the community had no say in its conduct. Thus, it further solidified mounting community resentment towards the government investigations of the landfill.

In response to building frustration with the governmental agencies, the NC and the NAACP sought to develop their own health survey with academic assistance. In January of 2002, one of the researchers [Edgerton] met with Frasier at a community meeting in Newhall where this project was born.

Initially, the study was designed to follow a more traditional epidemiological approach to research, wherein the subjects would not participate in designing the study but would help execute it after training. The idea was to teach participants basic science, tap into the knowledge of the neighborhood and gain project legitimacy, and labor assistance. However, an early review of the community-based participatory research (CBPR) literature made it clear that *partial* participation would not be sufficient to achieve these goals. Therefore, in July of 2002, weekly meetings with the NC and the NAACP began and continued until the last day of follow-up in late November.

### *Land Use History*

The area beneath the school and the surrounding Newhall neighborhood was once a wetland with both subsurface and surface water flow (5). In the early 1900s, domestic and industrial waste was used to fill in the low-lying areas, as a means for eradicating malaria. Dumping on the area near the current Hamden Middle School was conducted throughout the early part of the 1900s. One of the parties using the landfills was the Winchester Repeating Arms Company who had a large factory just south of the New Haven/Hamden town line. A partial list of potential contamination sources known to exist on site includes “ash and coal waste, batteries, and empty ammunition shells” (6).

The Connecticut Department of Environmental Protection (DEP) has identified four parties responsible for dumping in this area: the Olin Corporation, formerly the Winchester Repeating Arms; the South Central Connecticut Regional Water Authority (RWA), formerly the New Haven Water Company; the Connecticut State Board of Education who bought the land from the New Haven Water Company hoping to build a vocational high school on site; and the Town of Hamden. The DEP developed a Consent Agreement in March of 2003 that divides responsibilities for remediation of the area, and which was passed by the Town Council in April 2003 (after this study was conducted) (7). The agreement evolved out of the DEP’s investigation into the landfill conducted in three phases. Phase I identifies all areas where contaminants may have been released in the past. This involves a search of old records and speaking to people that know the area or the pollution source (such as former employees).<sup>1</sup> Phase II, seeks to verify the

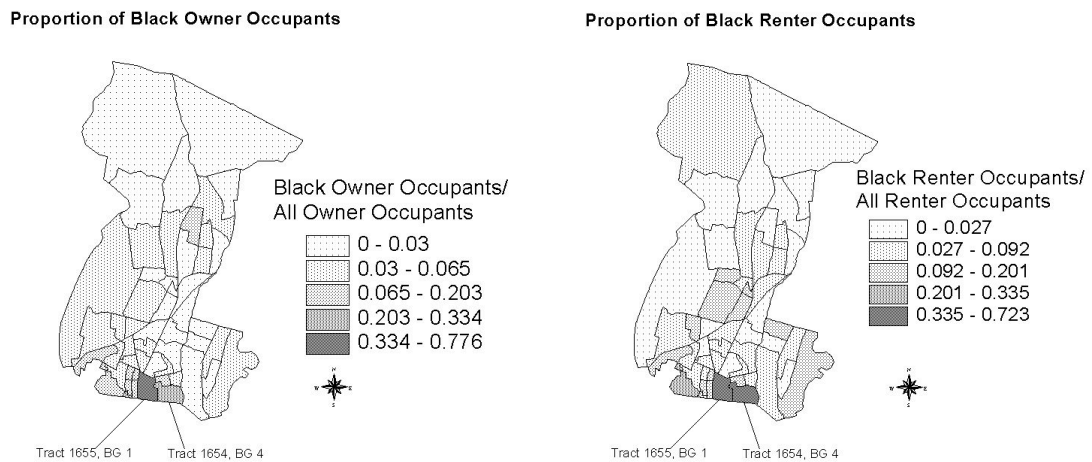
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<sup>1</sup> The historical background on the landfill in this report as noted in the citation and references draws from this Phase I site assessment report.

contamination of the sites identified in Phase I. This often involves testing the air, water or soil. Finally, Phase III, collects data to determine how and where clean-up should occur.<sup>2</sup>

### *The conflict*

The Hamden Middle School sits in the midst of the only African American neighborhood in the Town of Hamden (see Figures 1 and 2). Aside from one magnet middle school, it is the only middle school to serve all residents of the town (which in contrast to the Newhall area is mostly white). This racial disparity may be an underlying source of tension between the government agencies and the neighborhood community.



Figures 1 and 2. Black homeowner and renter occupancy in Hamden, CT (Source: 2000 Census)

### *The project*

There are two goals of this project. The first is to ascertain a general picture of the state of health of the community. The second is to provide community research participants with a set of scientific comprehension skills and experiences developed throughout the

<sup>2</sup> At the time of this report, Phase II was being completed.



research project. *We propose that this experience will provide the community organization with greater scientific literacy, and thus, the ability to critically understand the voluminous data and other information being presented to them.*

## ***II. Theoretical frameworks***

### *Defining community-based participatory research*

Participatory research or community-based participatory research at first glance may appear to some as ambiguous terms, leading to questions such as, ‘what constitutes participatory,’ ‘who defines participation or community,’ etc. To others it might be considered an obvious practice of collaborating in partnerships and sharing of knowledge. To many it may also represent an erosion of the very central foundations of science. To begin to understand the theoretical underpinnings of this alternative research framework with only this short review several distinctions must first be made, which together with explicit definitions should expose and clarify the framework.

First, a distinction in terminology between participatory research and community-based participatory research needs to be made. Multiple variations of participatory research exist in the literature including, action research, participatory research, mutual inquiry, feminist participatory research and community-based participatory research (8). Each of these theoretical constructs contain different goals and means to reach these goals, but all share similar principles. These principles shape community-based participatory research

in health. This study borrows from Barbara Israel and her colleagues (9), in defining and providing guidelines for CBPR:

- It promotes participation and collaboration at *all stages* of research.
- It fosters *co-learning* between the community participants and the academic researchers.
- Researcher and community participants are engaged in a *joint process* wherein both contribute equally.
- It is an *empowering process* that allows participants to gain increased control over their lives.
- It creates a balance *between* research and action –in other words between science and advocacy.

Community-based participatory research (CBPR) in health, specifically focuses on ending health disparities that often fall along racial, gender, income and ethnic lines (8, 10, 11). In the field of environmental health, this often means issues of environmental injustice or racism, discussed in detail in the next section

Second, a distinction must be made on what community-based participatory research *is not*. It does not seek to establish a new methodology of research nor does it attempt to undermine the material constructs behind these methodologies; rather, it represents a shift in “orientations to research” (8). A critical aspect of this shift includes the emphasis on partnership and collaboration between researchers and “study subjects” with conscious efforts made towards eroding, rather than maintaining, the line between the two (12). In

other words, research shifts from a top-down approach, where researchers take information from the study subjects with little interaction during or after the project, to a bottom-up approach, wherein co-learning occurs between the partners, facilitated by an equitable and balanced relationship. In CBPR, all partners have an immediate vested interest in the project. In the context of this project, graduate students had a thesis to complete and the community participants wanted to know the health of their community. Further, the collaboration must be built on larger shared principles—namely the moral commitment to social change and the recognition that traditional research methods can often miss critical understandings of a community, which can, in turn, result in ineffective policy-making decisions (13).

All derivatives of the participatory approach, including CBPR, recognize a fundamental inequity within the power structure whether locally, nationally, or internationally, and present an alternative framework to research that seeks to privilege knowledge at the margins of the “center of knowledge creation” (14). Participatory research theory often argues that the traditional framework of research privileges the core of power by legitimizing knowledge creation in the institutions of this core (such as universities and development agencies in wealthy nations, like the United States Agency for International Development and the World Bank). This privileging of knowledge de-legitimizes knowledge-making in the communities on the periphery of this core. This dynamic, the argument for CBPR further contends, results in a deepening of the divide between the powerful and the powerless (14). Conversely, the alternative framework of participatory

research deliberately attends to the democratizing of research through the collaborative processes of knowledge-making.

Collaborative processes shift the focus in research from the implementation of knowledge (produced in the core) to produce a *product* (i.e. data), to the *process* of research wherein knowledge is made and shared between individuals and organizations in the core and margins. Knowledge within this framework is no longer a fixed entity to which the researcher alone holds access, but rather it becomes a dynamic process between collaborators. In this framework, information, thoughts and understandings move in both directions recognizing the need for *reciprocity* in research. This becomes critical in working with communities with considerable skepticism of the “experts” because of past abuse and/or neglect, as was the case in Newhall.

<b><i>Traditional epidemiological research</i></b>	<b><i>CBPR</i></b>
Knowledge is fixed product.	Knowledge-making is a dynamic process.
Research privileges knowledge from the core (academia, international development institutions, etc.)	Research privileges the process of knowledge making between core institutions and individuals and marginalized people, communities and organizations.
Researcher has little contact with the study “subjects”.	Researcher(s) are in an equal partnership with the researched.
Knowledge produced is disseminated in academic journals.	Knowledge-making as a process is continuously created and shared by all participants, and the produced results are similarly shared with all participants and disseminated into the community.
Research for the sake of research and expanding scientific knowledge.	Research leads to action (policy reform, empowerment, etc).

Table 1. Traditional research vs. CBPR

The participatory approach in public health is gaining momentum, specifically as a means for addressing health disparities, a national goal of Healthy People 2010 (15). In response

to the setting of this goal, multiple federal health agencies including the National Institutes for Environmental Health Sciences (NIEHS) and the Centers for Disease Control and Prevention (CDC) have developed community-based health initiatives derived from the central tenants of participatory research. NIEHS defines CBPR as “a methodology that promotes active community involvement in the processes that shape research and intervention strategies, as well as in the conduct of research studies”(16).

Many institutional obstacles challenge the practice of CBPR. First, because trust and mutual respect represent critical components of any CBPR project, time spent discussing, arguing, and resolving issues can become a limiting factor. In the context of this study, many meetings with community partners went on for four or more hours discussing issues such as what constitutes bias. At the same time, having the time to work through these issues is essential in maintaining the research partnership. Second, in academia where publication holds the means for advancement and tenure, collaborative work is often discouraged (14), particularly work with non-academics. And third, traditional science contends that developing relationships with research subjects creates bias that alters the conclusions of a study. Participatory research, on the other hand, holds that knowledge formation occurs in the dialogue and discourse between researchers and the researched that better informs findings. Moreover, CBPR addresses the hostility and resentment that can surface in study “subjects” as a result of the lack of communication or sharing of information generated from studies. CBPR effectively challenges researchers to reconsider the way research is conducted, practiced and communicated.

*Defining environmental justice*

The disproportionate burden of environmental hazards in communities of color has provided the framework for understanding environmental health problems in terms of equity and justice based on race—that is environmental racism. Movements to change environmental inequities based on race is popularly known as environmental justice. The Environmental Protection Agency (EPA) defines it as the following:

“Environmental Justice is the fair treatment and meaningful involvement of all people regardless of race, color, national origin, or income with respect to the development, implementation, and enforcement of environmental laws, regulations, and policies. *Fair treatment* means that no group of people, including a racial, ethnic, or a socioeconomic group, should bear a disproportionate share of the negative environmental consequences resulting from industrial, municipal, and commercial operations or the execution of federal, state, local, and tribal programs and policies. *Meaningful involvement* means that: (1) potentially affected community residents have an appropriate opportunity to participate in decisions about a proposed activity that will affect their environment and/or health; (2) the public's contribution can influence the regulatory agency's decision; (3) the concerns of all participants involved will be considered in the decision making process; and (4) the decision makers seek out and facilitate the involvement of those potentially affected” (17).

There is a distinction, therefore, between environmental racism and environmental justice, which informs the framework for understanding the landfill issue in Newhall. Bunyan Bryant, who has worked extensively on environmental justice and racism, defines environmental racism.

“Whereas the term environmental racism focuses on the disproportionate impact of environmental hazards on communities of color, environmental justice is focused on ameliorating potentially life threatening conditions or on improving the overall quality of life for the poor people and/or people of color” (18).

Rather than employing environmental justice or racism, this study draws from the term ‘environmental inequality’ as an appropriate framework to understand the Newhall

landfill situation. David Pellow developed this term, which “addresses more structural questions that focus on social inequality (the unequal distribution of power and resources in society) and environmental burdens” (18). He argues that the focus has largely been on environmental racism as a way of achieving environmental justice, an approach that oversimplifies the problem to the point of being counterproductive (18). In other words, environmental justice issues are typically couched in the “perpetrator-victim scenario” in which a landfill, for example, is sited in a neighborhood of color. However, this is not always the case. Undesirable land uses can often precede the occupation of the nearby community by people of color (19)—as in the case of the Newhall landfill. Defining environmental justice based on whether the hazardous waste coincided with the people of color moving into an area, Pellow argues, is a chicken and egg question, which diverts attention away from the current injustice. Further, arguments for environmental racism that suggest people of color and poor people live in environmentally hazardous area because of the low property values, also risks oversimplifying the situation (18). Pellow argues:

[the need for a] model that emphasizes the linkages among three major points which are (a) the need to redefine environmental inequality as a sociohistorical process rather than simply viewing it as a discrete event (like the siting of a hazardous waste facility), (b) the need to understand that environmental inequality involves multiple stakeholder groups with contradictory and shifting interests and allegiances rather than simply viewing environmental inequality as the result of perpetrator-victim scenarios, and (c) viewing the ecology of hazardous production and consumption through a life-cycle analysis rather than focusing only on one location or site of conflict (18).

In the case of Newhall, environmental inequity provides a more appropriate framework for trying to determine why this neighborhood, a community of color, (see Figures 1 and 2), is bearing an environmental burden.

Though the actual siting of the landfill preceded the African American population in the neighborhood by several decades, racial inequities continue to define this contamination problem. The recent decision to close the Middle School and potentially consolidate contaminated soil from the neighborhood at the school (7) reinforces racial disparities and inequities in environmental quality. Feeling disenfranchised from the process at every turn, the Newhall Coalition has fought an up-hill battle against institutions and individuals in power who were often skilled with technical knowledge spanning disciplines from engineering to the law. They have been included in a decision-making process that gives them extensive input without any decision-making authority. “We don’t want all 32 teeth, we just want a few” says Dr. Hamid, a Newhall resident about participation in decision making about the future of the community (20). Moreover, the individuals representing these institutions of power were disproportionately white.

Framing the landfill problem as an environmental injustice or inequity issue fits well with a national NAACP campaign to assist communities fighting similar battles. As a result, the NAACP provided funding and media expertise for this project. The invocation of the civil rights combined with the environmental injustice was compelling, easy to understand quickly, and morally repugnant enough to engage residents more than they might have otherwise been.

Understanding the roots of environmental justice or inequity in this community raises important questions. If the demographic transition was not due entirely to depressed land values, why did this happen? Why is the neighborhood African-American? Why is the



landfill on that spot? What are the reasons for the confluence of African-Americans and the landfill? Although a full answer is outside the scope of this thesis, several clues and further questions are listed below.

1. Winchester Repeating Arms: Winchester was not only the source of much of the contamination in Newhall soils but was also directly responsible for much of the area's original housing boom. Between the time that Winchester bought Eli Whitney's gun manufacturing business in 1888 (21) and its peak during World War II, Winchester ballooned to employ 13,667 workers (22) which drove the housing demand that ultimately resulted in Newhallville. Along with guns and ammunition, Winchester produced roller skates, batteries, and lipstick cases. It had its own foundries, its own powder farm (now known as the Pine Swamp directly north of the study area and a State Superfund site), and its own railroad siding. An ex-employee recalled, "The neighborhood itself was existing solely because of Winchester" (23). By the 1980's a combination of "anti-gun sentiment, foreign competition, and on-going labor strikes" caused the number of employees to decrease to 800 (22). It is likely that property values dropped severely as a result, attracting a disadvantaged population. While a number of other industries in the area experienced a relatively concurrent rise and fall (such as carriage, rubber, clock, and corset manufacturing) the proximity of Newhallville (and the nearby Newhall neighborhood in Hamden) to Winchester caused it to be the most directly affected.

2. Changing Demographics: The early white settlers to the New Haven area were Puritans. In the early 1900s a wave of Irish and German immigrants moved into the area and provided cheap labor for builders of the Farmington Canal and the railroads (23). Italians and Eastern Europeans were attracted to plentiful manufacturing jobs at around the same time (24). African-Americans and Hispanics started to emigrate after World War II when “restrictive anti-immigration laws drastically cut down the flow of arrivals from Europe” (24).  
What attracted these particular ethnic groups? Were property values already low because of the smaller influx of Europeans? How much of the current residence of African-Americans in the Newhall area can be attributed to its history as a blue-collar area, which can be traced all the way back to Eli Whitney and his introduction of mechanized gun manufacturing processes?
3. Land Use: As previously mentioned, the Newhall neighborhood is built on a domestic and industrial waste heap that fills a former wetland area, which used to contain flowing water and was filled for malaria abatement. Was a plentiful water source an attraction for Winchester as it has been for so many other industries that choose their site based on proximity to water bodies, which provide power and transportation?
4. Housing Sale Policy: Disclosure of soil contamination data to individuals purchasing a home is not legally required. Indeed, this is what caught many Newhall residents by surprise even though testing dating back to the 1980’s

showed soil contamination in the immediate area. Could this lack of full disclosure have facilitated the occupation of the area by disadvantaged populations?

Understanding the complexities of racism that entangle this project extends beyond the scope of this paper. However, the framework of environmental justice and inequity not only provides political traction for the community, it brings to light a serious problem embedded within environmental health.

### ***III. Methods: Developing the study***

#### *Study area*

The study population included members of the households (including those that spend more than 30 hours a week in a household) who were currently living in 627 residences in the area suspected to be on or near the old landfill sites. The boundaries of the old landfill sites as defined by the Connecticut Department of Environmental Protection (DEP) were used as a guideline for establishing the study boundary (see Figures 3, 4, and 5). The boundaries for this study were extended from the DEP's to include homes residing on or near former watercourses, which were suspected to be filled with waste, or were located in close proximity to the known landfill sites (see Figure 5). No homes in the City of New Haven, many of which are located less than a city block from known landfill sites, were surveyed due to political obstacles as well as a lack of data for areas south of the Hamden/New Haven line.

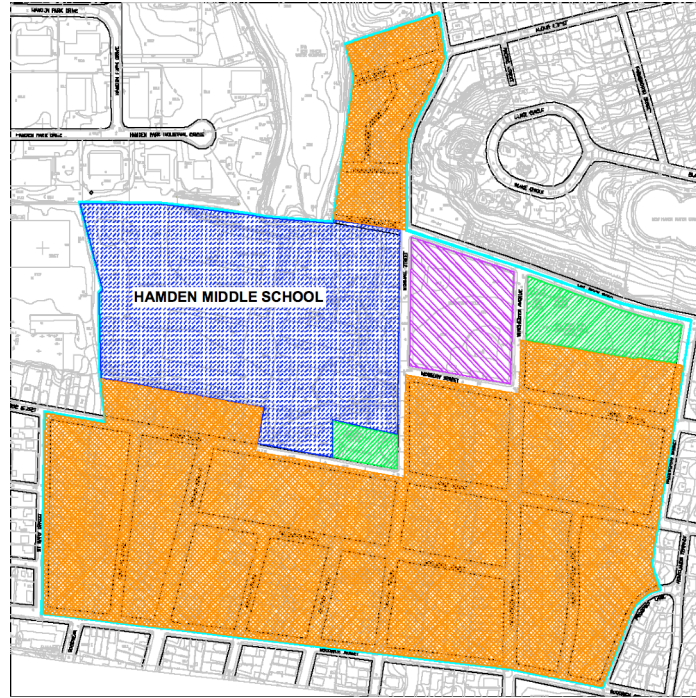


Figure 3: DEP study area boundaries. Residences are south and north of the school. Other areas are public or open spaces (25)



Figure 4. Newhall Health Study Boundaries



Figure 5: 1934 Aerial Photo of study area. Thick vegetation marks former wetlands.

Soil testing of the Hamden Middle School and homes in the community conducted by the Department of Health and Olin Corporation detected the presence of arsenic, lead and several polyaromatic hydrocarbons (PAHS) including benzo-a-pyrene (see Appendix 4). All homes receive water from the municipality.

#### *Survey instrument*

Based on the preliminary soil data, a literature review was conducted to develop a list of potential health effects related to *chronic* and *acute* exposure to arsenic, lead and PAHs, (specifically benzo-a-pyrene, because of its high toxicity and human carcinogenicity).

Both *chronic* and *acute* exposures were assumed to be possible, as the distribution of the landfill is largely undefined and the concentration of lead in some pockets was as high as 39,400 ppm, 35 times higher than the EPA's lead standard of 1100 ppm, 79 times higher

than the Connecticut Department of Public Health's standard of 500 ppm, and 98 times higher than the Quinnipiack Valley Health District's standard of 400 ppm. The route of exposure was assumed to be dermal, ingestion or inhalation of contaminants in the soil, as no evidence of exposure from drinking water had been identified.

### *Health Symptoms*

An extensive literature review was conducted using Medline and Toxline, and included toxicological and epidemiological studies on both developing and adult animals and humans, as the study surveyed all members of the community from the young to old. A review of landfill studies identified an association between several non-specific symptoms, such as headaches, difficulty with balance, dizziness, irritations of the eyes, nose, and throat and living near former dumps (26-28). From this review, we included a list of 21 non-specific symptoms known to be associated with living on or near a landfill. From review of the carcinogenic properties of benzo-a-pyrene (29, 30), lead (31, 32), and arsenic (33, 34), we developed a short list of 11 organ-specific cancers plus an 'other' category. The broad categories of cancer were chosen because of the self-administered style of the survey (prostate, breast, pancreatic and lung, for example).

Exposure related effects on other systems in the body including neurological, cardiovascular and reproductive were also identified in reviews. The effects of lead on neurological development provided the evidence to ask about behavior problems, particularly in children (35-41). Reproductive effects of lead (42-46) arsenic (47, 48) and

PAHs (49) provided evidence to ask questions of pregnancy outcomes, miscarriages, and fertility (low sperm count, infertility). To consider the possible cardiovascular effects of arsenic (30) and lead (32) broad, non-specific questions about cardiovascular disease were asked. For example, questions of heart attack, stroke and high cholesterol were included. Other potential endpoints identified in review include diabetes (50) and renal problems (hypertension) (51) (see Table 2 for summary of health effects).

Chemical	Reproductive Outcome	Neurological Outcome	Carcinogen	Cardiovascular	Other
<i>arsenic</i>	adverse pregnancy outcomes (stillbirths, low birthweight, preterm births) (34, 47, 48)	changes in peripheral nerve function (34)	human carcinogen (lung, skin, bladder, kidney, prostate, liver) (33)	ischemic heart disease; hypertension; cardiovascular disease (33, 34)	corns, warts on hands and feet (34)  diabetes (50)
<i>lead</i>	miscarriage; decreased sperm count and mobility(32, 42-45)	learning disabilities in children; decreased mental abilities (35-37, 39, 40, 52, 53)	reasonably anticipated to be a carcinogen(31)	increased blood pressure (32)	
<i>PAHs</i>	Difficulty reproducing and adverse pregnancy outcomes (30)		some classes probable and potential human carcinogens (29, 30)		

Table 2: Summary of health effects for lead, arsenic and PAHs

### *Exposure Assessment*

To begin to assess the possible *duration* and *route* of exposure, questions were asked about the duration of residence at the current home and in the Newhall neighborhood. Additional questions were asked about activities that may put an individual at high risk of exposure to the soil, including gardening and renovation work as well as the direct participation in these activities.

To control for major confounding factors, questions about age, race, body weight and height (to create a body mass index), smoking status, alcohol consumption, job description of longest held and current occupation, as well as known hazardous materials handled in these jobs were asked.

In total, the survey included 55 questions about the health of all current residents in the household, and did not include deceased members of the home. Responses to questions were categorical (yes, no, don't know or not applicable) or continuous (age, years of residency, year of diagnosis) with two open ended questions at the end (addressing medication use and other medical conditions). The survey instrument and its accoutrements are included as Appendix 1.

### *Data Collection*

Self-administered questionnaires were mailed to 627 addresses in the study population with a return, addressed and stamped envelope enclosed. An information sheet introduced the study and listed several risks and benefits to participating in the survey, in compliance with the Human Investigations Committee requirements. The decision to conduct self-administered questionnaires was based on discussions with community participants. Furthermore, limited financial resources and time combined with the lack of a large volunteer base were critical factors in choosing to conduct self-administered surveys.



The instructions for the survey asked one member of the household to fill out the survey for all individuals in the home. Each survey included space to answer for five individuals or “Persons” with an additional copy of the survey included for households with more than 10 individuals. The answers for each Person (1-5) were to remain consistent throughout the survey (i.e. Person 1 answers questions in the space for Person 1 throughout the survey). The individual filling out the survey for the household was instructed to answer for Person 1.

Questionnaires were mailed to residents in fluorescent green envelopes in order to distinguish the survey in the mail. This visual recognition cue was repeatedly used throughout the duration of the study, mentioned in the press and in community meetings, and used for the color of flyers.

To protect the confidentiality of the information provided on the surveys, names and addresses were excluded from the survey. Each questionnaire was assigned a code generated randomly in Microsoft Excel and only the Yale investigators (Edgerton and Vogel) were given access to this list. Communication with the community about issues of confidentiality was a major priority throughout the duration of the study and was a central issue in several meetings held during preparation of the press materials. All procedures were approved by the Human Investigation Committee at Yale University School of Medicine.

*Launching the study: meetings and the media*

In the weeks preceding the release of the study, volunteers placed flyers throughout the study area (on bright green sheets of paper) announcing the study, and the Newhall Coalition held a community meeting. The meeting was held ten days before the survey was mailed to discuss issues of confidentiality and the process of filling out the survey, as well as to address any further concerns or questions. Two days prior to the study launch, a press release was sent to the major newspaper, television and radio stations announcing the study. The use of the media was heavily discussed among all participants. The collective decision held that the media was an effective tool for reaching a broader audience. Additionally, because of the high profile nature of the issue, the media were likely to cover the study. Therefore, the study group felt the best approach was to present information on the study directly to the press, in order to protect individual confidentiality and to avoid potential information bias.

A press conference was held four days before the surveys were placed in the mail. Several media channels reported the story including Channel 8 (an ABC affiliate, broadcast on the 10 and 11 o'clock news), the New Haven Register (a front page article) (see Appendix 2), and local radio stations including Connecticut NPR. One additional means for communicating with the public was the establishment of an information hotline phone number, which was provided in all communication about the study (meetings, flyers, press, and the study information sheet). The hotline provided a resource for support in filling out the questionnaire, or for further information on the study or confidentiality.

### *Follow-up*

Three rounds of follow-up were conducted to improve the response rate (as permitted by the HIC protocol). The first round took place ten days after the surveys were mailed.

Residents were contacted by phone and homes were visited. All partners in the research project found going door-to-door to be a more effective means of communication and as a result, a decision was made to focus accordingly in the next two rounds. The second round occurred one week after the first and the third round occurred the following week.

All three rounds of follow-up were conducted on Saturday mornings. This time was chosen for three reasons: 1) this was a time when volunteers were most available; 2) because the study was conducted in the fall, it became dark by five, excluding the possibility of having volunteers go out after work (despite the general safety of the neighborhood, all participants decided that no one should go out at night); 3) it was agreed that many residents would be home on Saturday, as opposed to Sunday, as there are many Christian churches in the area.

Data collected during follow-up included the response of the residents in the household:

1) did someone answer the door; 2) was a flyer left; 3) did the household receive the survey; 4) did the household need another survey; and 5) if the household did not want to participate was there a reason provided.

### **III. Methods: Facilitating the participatory process**

#### *Study Group*

Participatory research, as discussed in detail above, adds several new dimensions to the traditional practice of epidemiology and public health. This section will outline the process as it developed in the Newhall Health Study by describing the activities of the meetings. Specifically, it will describe the meeting participants (henceforth called the “study group”), the settings, and the issues discussed.

The study group consisted of members of the community (some of which were affiliated with the Newhall Coalition), Vic Edgerton and Sarah Vogel, and Scot X Esdaile of the NAACP. Each participant brought unique skills and points of view to the discussions to the project. Others played a role in the group but their attendance was sporadic or they dropped out for a variety of reasons. A brief description of the main participants follows. Jo Frasier is an African-American resident of Newhall, former Fire Commissioner for Hamden and has occupied a host of other local political posts. As the founder of the Newhall Coalition, he brings local political savvy, eloquence, resolve and legitimacy to the group. Elizabeth Hayes is an African-American Newhall resident, and along with Jo Frasier is the major driving force of the Coalition and the project. She brings a business sense, real estate knowledge, a strong work ethic, and an increasingly sharp ability to advocate for her community. Oscar Torres is a Hispanic-American Newhall resident who brings years of experience in community organizing around different issues. Further, he provides honest and accurate appraisals of goals and is one of the most dependable

members of the study group. Donna Johnson is an African-American Newhall resident who contributed valuable ideas and criticisms despite a demanding work and personal life. She brought an intimate knowledge of the community and the people in it, and was able to predict with astonishing accuracy some of the biggest obstacles to successful completion of the study. Scot X Esdaile grew up near the study area and is now the President of the Greater New Haven Branch of the NAACP. He brought media and public relations savvy, funding and political strength. Vic Edgerton is a Master's student at the School of Forestry and Environmental Studies and the School of Epidemiology and Public Health at Yale. He brings scientific, environmental, and political expertise and experience in public relations and media. Sarah Vogel is a Master's student at the School of Forestry and Environmental Studies and the School of Epidemiology and Public Health at Yale. She brings scientific, environmental, and social expertise as well as experience in funding the environmental movement. Other contributors included Bob Edwards (Newhall resident), James Rawlings (VP of the New Haven NAACP), and Kim DeFeo (CT Toxics Action Center).

While individual meetings and conversations between Newhall Coalition members and Vic Edgerton began in January 2002, the participatory process did not start until July 2002. By that time, enough groundwork had been laid to call in the community members for the planning process. Most meetings were held on Saturday mornings at the Three Brothers Diner on Dixwell Avenue, just outside the border of the study area. The time and location was chosen in an effort to maximize community participation. As the

survey release day neared, meetings were moved to rooms on campus to ensure quiet, privacy, and the ability practice presentations.

There were eight official planning meetings between July and November with a few extended phone calls and scattered meetings attended by some members of the group.

The official meetings lasted between 1.5 and 4.5 hours. Meetings ceased after the third round of follow-up as the wait for data entry began (see Appendix 5 for meeting minutes).

During the meetings a number of issues and questions were addressed, some repeatedly, and were recorded in meeting minutes and meeting primers. A summary of the most important issues is provided here, followed by a list of the remaining topics covered. One of the most important issues was how the decision-making process would be organized. By the end of the second meeting, it was decided that when the three sub-groups (community members, NAACP and Yale students) disagreed, all three sides would make their case but the community members would have the final say. That said HIC and the thesis advisor (LDP) had the last word on any issues that encompassed scientific integrity, potential Yale liability or ethics violations. Only once did a disagreement arise in which the representatives of the community organization made the final decision. The question was whether to include questions about health outcomes on the survey that were personal and might be considered too invasive. This risk was balanced against the increase in sensitivity of the survey, which the community representatives felt was necessary.

A number of meetings were dedicated solely to preparing the publicity materials. Within those meetings, most of the time was spent wordsmithing the press release, the Public Service Announcement, the media advisory (to precede the press release), and the fliers. The primary difficulty was in making a statement compelling residents to participate in the survey without introducing bias.

Funding became an important issue particularly in the final stages when all of the necessary monies were needed (mailing, copying and supplies). An overly optimistic budget and a changing protocol resulted in a frantic search for funding that was successful only at the last minute. Considerable meeting time was spent trying to be creative about bringing in the needed \$5600. The funding ultimately came from small grants and in-kind services.

The format for information collection was one of the parameters that changed several times during the course of the study planning period. The initial vision was for community members to interview residents face-to-face. The plan then changed to consider the option of having volunteer health care workers perform the interviews. Realizing the financial limitations to this option, the plan changed to handing out a self-administered questionnaire. Finally, the goal moved to mailing a self-administered questionnaire. Each change was made in an effort to minimize costs but compensate for the lack of available labor.

A considerable focus was also devoted to existing data sources. Much of Vic Edgerton's time over the summer was spent trying to identify a way to assess exposure. Soil testing data were "available" but were difficult to access due to location (at a library with limited hours or at Hartford DEP), copying costs (\$0.25 per copy at DEP with boxes of data), or unusable formats (incompatible Geographic Information Systems formats). Accordingly, meeting time was spent trying to think of ways to get the information without having to fundraise specifically for it.

Meeting the requirements established by Human Investigation Committee occupied conversation during many of the meetings as well. This was especially true when the HIC's original requests for the content of the Information Sheet became clear for the first time. One version contained the claim that, if illnesses were found, an employer could illegally discriminate against the community member in providing health insurance. The HIC also suggested that if a lawyer subpoenaed the data, researchers would be forced to hand over the data, thus potentially compromising confidentiality. The community members felt these statements would scare study subjects and greatly diminish the participation rate. Several meetings were spent trying to find a middle ground.

The topic of bias—what is it and how it can affect a study—was the focus of many conversations over the course of the study. Since community members and NAACP members would likely be interviewed on camera, it had to be clear why and how bias had to be controlled. This entailed detailed explanations of methodology and study design, which took up almost two full meetings. Furthermore, this process had to be done twice in



order to get an additional member up to speed since absenteeism precluded a full understanding.

Other issues and questions tackled at meetings include:

- Defining collective goals for the project (count diseases in the neighborhood, build community capacity by strengthening scientific familiarity).
- What an epidemiological study can and can't identify
- Defining the study area
- Piloting the survey
- Clarifying ownership of data (will go to the community without identifying information)
- Sample size
- Perfecting the publicity plan
- Options for data entry
- Having a longer survey vs. including more health outcomes
- Framing the partnership to the public: Is it a community-led project with Yale and NAACP assistance? A Yale study requested by the community? A three-way equal partnership?
- How to distribute materials from meetings to those without email access?
- Revising timelines as necessary
- Handling the media prior to the release of the study
- Ways to get a high response rate
- What illnesses in the community is there anecdotal evidence?
- How many press conferences to hold?
- Coordination and planning of follow-up
- How are finances controlled as funding comes in? Through NAACP? Should the Newhall Coalition try to get 501c3 tax status (for non-profit organizations)?
- If the group allows the New Haven Green Party to assist with follow-up coordination and execution, will that make it look the study is biased?

While the list is long, it paints only a rough picture of the work done in the study group meetings. Larger, full community meetings were also held to answer questions about the study in conjunction with the survey release to Newhall residents.

### **III. Methods: Data analysis**

All data were entered by a professional firm (DATAPREP) and analyzed with SAS statistical software and Microsoft Excel. Summary descriptive statistics were obtained for age, race, years lived in the area, years lived in Newhall, and number of members in the household, in order to determine the general demographics of the responders. Basic data were also taken for garden eating habits, since the levels appeared to be high enough to potentially pose a health risk. Summary statistics were also obtained on answers to the question of “concern for pollution in the neighborhood” so as to help determine if the respondents were likely to be answering the survey because of concern.

### ***IV. Results***

#### ***Summary Data***

The response rate for the survey was 19.6% (123 households responding out of 627 addresses), which compromised both the internal and external validity of the data. This paper only presents preliminary statistics due to the time still required to prepare the data for analysis and analyze it. The age range of respondents was extremely broad, but evaluating ages per Person responding presents a range in averages from 55 years of age

to 14 years of age (See Table 2). [Note: Person 1 was the individual filling out the survey].

Age (years)	Mean Age (std) (n)	Median Age		Race/Ethnicity	Percentage (n)*
Person 1	55.0 (15.1) (115)	57		Black-American White (non-Hispanic)	68.97 (80) 14.66 (17)
Person 2	44.5 (20.0) (90)	45		Black-American White (non-Hispanic)	77.01 (67) 9.20 (8)
Person 3	21.6 (15.8) (53)	19		Black-American Other	76.92 (40) 9.62 (5)
Person 4	13.9 (6.8) (26)	15		Black-American White (non-Hispanic) Other	80.65 (25) 6.45 (2) 6.45 (2)
Person 5	14.4 (8.10) (9)	13		Black-American	72.73 (8)
<b>Total</b>	<b>40.8 (22.3) (293)</b>	<b>43</b>		<b>Black-American White (non-Hispanic) Hispanic West Indian American Indian Other</b>	<b>74.07 (220) 10.10 (30) 3.70 (11) 3.37 (10) 2.36 (7) 6.40 (19)</b>

Table 3: Age and Race/Ethnicity

The average number of residents in the household was 2.7 (1.33) with 115 households responding (median 2.0).

The number of years spent in the current residence and in the Newhall area corresponded to the age of the Person responding with the oldest individuals in Person 1 spending the most time in residence (See Table 4)

	<b>Mean (std) (n) Years in current residence</b>	<b>Median</b>		<b>Mean (std) (n) Number of years in the Newhall area</b>	<b>Median</b>
Person 1	20.0 (14.0) (115)	19.0		22.3 (14.3) (110)	23.0
Person 2	16.5 (12.9) (85)	14.0		18.5 (13.1) (60)	17.0
Person 3	10.6 (7.8) (47)	9		12.6 (8.5) (35)	10.0
Person 4	8.3 (7.2) (28)	6.0		8.5 (7.2) (22)	6.0
Person 5	.	.		5.8 (5.1) (9)	3
Range	(60, 1)			(60, 1)	
<b>Total</b>	<b>15.8 (12.8) (284)</b>	<b>13</b>		<b>18.0 (13.4) (236)</b>	<b>16</b>

Table 4: Years in Current Residence and Years in Newhall Area

Of the 108 individuals who answered the question “are you concerned about pollution in the community,” 88% of the individual filling out the survey (Person 1) responded “yes”.

For all Persons, a high percentage responded yes, with the number of missing responses increasing with the age of the Person decreasing (See Table 5)

Concerned about pollution in the neighborhood	Percentage who responded ‘Yes’ (n)	Percentage who responded ‘No’ (n)	Number of responses missing
<b>Person 1</b>	<b>88.03 (103)</b>	<b>10.26 (12)</b>	<b>6</b>
Person 2	84.72 (61)	9.72 (7)	51
Person 3	73.81 (31)	19.05 (8)	81
Person 4	71.43 (20)	17.86 (5)	95
Person 5	83.33 (10)	16.67 (2)	111
<b>Total</b>	<b>83.03 (225)</b>	<b>12.55 (34)</b>	<b>1.5 % (4) “Don’t Know” 3.0% (8) “ Not Applicable”</b>

Table 5: Pollution Concern

In response to the question, “If there is a garden (within Newhall), do members of the household eat what is grown in the garden,” 42.3% (n=83) replied affirmatively (see Table 6).

Eating from Newhall gardens	Percentage who responded 'Yes' (n)	Percentage who responded 'No' (n)	Percentage who responded 'Don't know'	Percentage who responded 'Not applicable'
Person 1	42.2 (41)	36.1 (35)	0	21.6 (21)
Person 2	47.9 (23)	33.3 (16)	0	18.8 (9)
Person 3	44.4 (12)	33.3 (9)	0	22.2 (6)
Person 4	33.3 (6)	33.3 (6)	0	33.3 (6)
Person 5	16.7 (1)	50.0 (3)	0	33.3 (2)
<b>Total</b>	<b>42.3 (83)</b>	<b>35.2 (69)</b>	<b>0.0 (0)</b>	<b>22.4 (44)</b>

Table 6.: Eating from Newhall gardens

## *V. Discussion*

### *Interpretation of the descriptive data*

Preliminary analysis of the demographics of the respondents suggests that despite the low participation rate we did receive, at least demographically, a group representative of the surrounding population: 74% African-American, 10% White, 4% Hispanic, 6% other, which matches closely to the data for the two applicable Census Tracts. According to the 2000 Census, the population is approximately 80% African-American and 13% White or Hispanic. Age distribution in the respondents resembled the Census age distribution for the applicable block group with the exception of the underrepresented age categories of “Under 5” and “25 to 29” years (see Figures 6 and 7). A potential explanation is that parents with young children were too busy to fill out the survey.

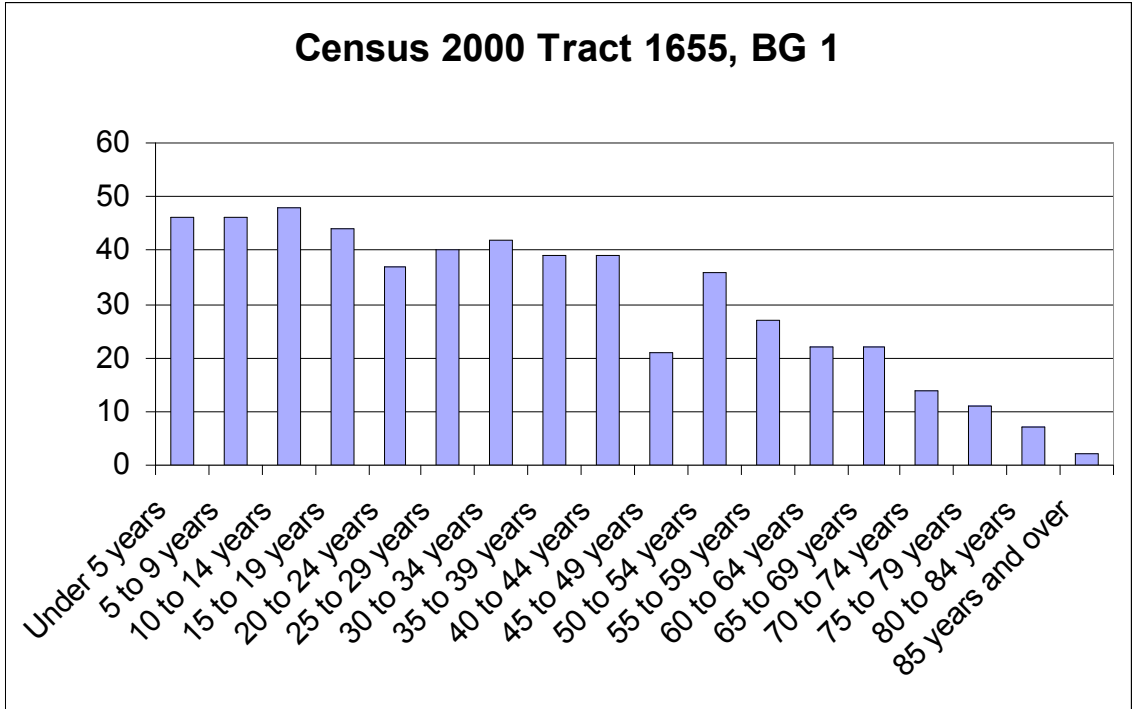


Figure 6: Age Distribution of Census Tract 1655, Block Group 1

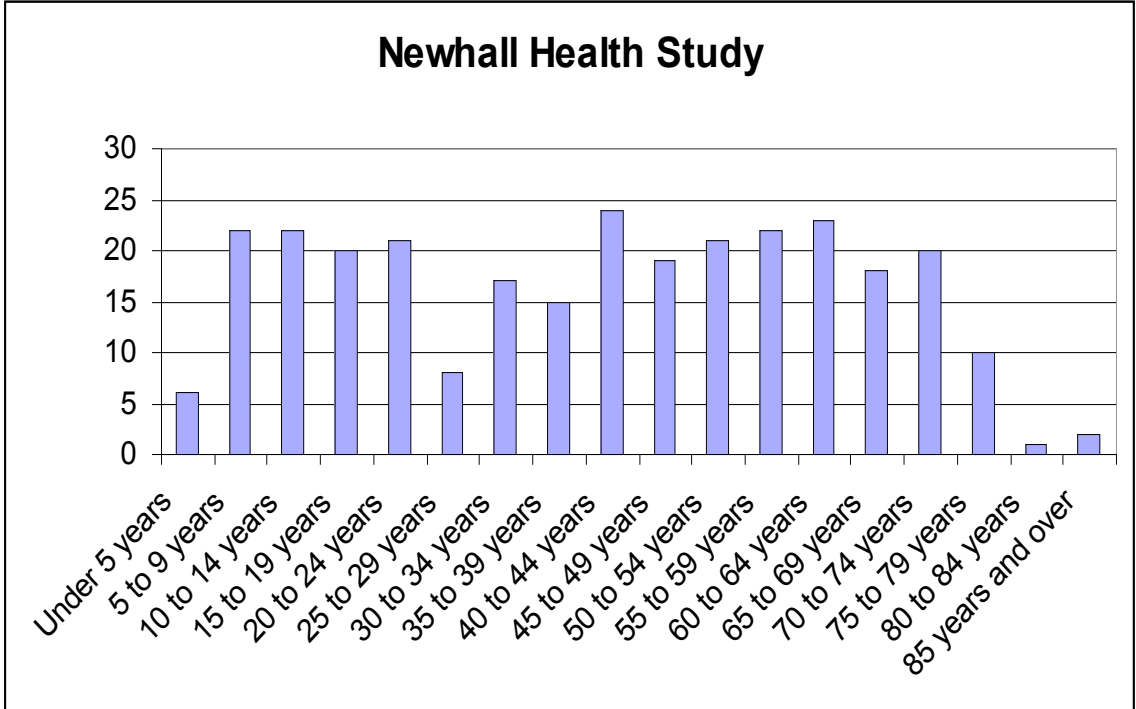


Figure 7: Age Distribution of Newhall Health Study Responders

However, the high percentage of responders who were concerned about the pollution in the community suggests an information bias. This bias is likely non-differential as those

individuals concerned with the pollution may be sicker, but may also be healthier and more likely to participate. The individuals within the neighborhood who came to meetings tended to be relatively healthy, motivated because they were long-time residents, or politically active in the area. In any case, this greater representation by healthy people would only result in attenuating any statistical associations between soil contamination and health.

*The high number of individuals eating from gardens (n=83) is of public health concern as lead, arsenic, and PAHs, all of which are present in the soil in the surrounding area, are capable of transport into vegetables (54). In order to minimize possible exposure through the soil, residents should be informed of the risks involved in growing food in contaminated soil. Representatives of the Newhall Coalition, the DEP, the CT Department of Public Health, and the Quinnipiack Health District were informed of the high number of individuals eating from gardens in the area.*

*Understanding the low response rate: examining qualitative data*

The low rate of participation of 123 households was disappointing. The participatory research approach had held the promise to increase participation, but was clearly presented with several challenges and obstacles that resulted in this low response. This discussion will highlight several of these challenges we believe contributed to the low response rate based on conversations, semi-structured interview, and qualitative analysis of the responses during follow-up. During follow-up, qualitative data were collected on: 1) type of contact with the household (i.e. phone message, conversation, not at home, left

a flier); and 2) response of the participant (needed a new survey, filled out the survey, did not wish to participate and reasons for non-participation). Of the 627 legitimate addresses on the study population list, only 343 were spoken to directly. A random sample (n=10) of the non-responders was contacted in March 2003 for semi-structured interviews, which sought to identify reasons for non-participation. Additionally, four individuals from the study group were interviewed for their interpretations of the reasons for the low response rate.

Below are a list of some of the reasons cited for non-participation based on the semi-structure interviews and analysis of the qualitative data gathered during follow-up.

1. Refusal to participate. The most frequently cited reason from the follow-up data was “Refuses to give a reason for refusing.” Of the twenty-six refusals, sixteen would not give a reason.
2. Too long. At 12 pages (55 questions), the survey was long. One person from the follow-up data and one person interviewed indicated that they began to fill out the survey but never finished it. The latter person kept up to date on the issue and asked for a new survey during follow-up, demonstrating a clear interest in the subject and the study.
3. Too busy/too sick. Three of the ten random interviewees indicated that they were too busy to fill out the survey. One additional interviewee was too sick, and two



follow-up refusals were too busy taking care of someone who was sick to complete it.

4. Information sheet. One study group member faulted a statement on the information sheet that accompanied the survey per HIC requirements (“You are free to decide not to participate in this research”) as a major reason people did not respond. In addition, the information sheet disclosed three risks: 1) the potential risk of filling out the questionnaire involves partial loss of property value if the study found elevated rates of any health problems; 2) neighborhood efforts to get financial support for home relocation and medical expenses could be set back if the study did not find unusual levels of health problems; 3) risk of disclosure of health information in the event of a court subpoena.
  - a. Confidentiality – One of the 26 stated refusal was due to concerns about researchers’ ability to prevent the release of health data. In addition, one member of the study group felt that confidentiality concerns were serious enough to prevent a few residents from responding.
  - b. Property values – Three of the stated refusals were due to concerns over property devaluation. One person was trying to sell their house. Connecticut state law requires the home seller to disclose only whether they have tested the soil for contaminants. If no testing has been done, the seller is only required to say so. It is, therefore, in the seller’s best interest

to avoid testing in case contaminants are found at sufficient levels to warrant expensive clean up. Anecdotally, several residents divulged their fear of property devaluation.

5. Question of effectiveness – There was no evidence indicating whether or not people thought a health survey was an effective way to help them achieve their goals with respect to the contamination issue. However, one study group member felt it was at least part of the problem. One potential respondent indicated a lack of trust in the study group’s intentions, manifesting as a belief that the survey was unscientific: “Headaches? C’mon.” A researcher tried to explain the scientific foundation for the question without introducing bias but the person’s mind was clearly already made up. The potential respondent also did not think their home should have been included in the study area since they were convinced their home was not at all affected.
6. Rumors – Three pieces of evidence indicate that rumors discouraged people from participating. First, one study group member who had done the most door-to-door work felt this was a major factor. Second, a researcher spoke to an elderly woman during follow-up who said that a number of people in the community were telling other residents not fill the survey out because it would make property values go down. The third piece of evidence comes from a study group member who was told by a resident in the study area that the reason for refusing to participate was because this individual had been informed that the survey asked

how many times people had sex.

7. Too personal/invasive – The survey asked about health outcomes with strong negative social stigmas such as sexual dysfunction, weight, and reproductive problems. The decision of whether to include such potentially problematic questions was a point of contention among the study group, but discussions about the need for increased survey sensitivity led to the agreement to keep these more invasive questions on the survey. However, this decision may have contributed to the low response rate. One of the twenty-six follow-up refusals indicated directly that the questions were too invasive. Two of the four study group members suggested it was an issue. One pointed out that there is a population of people, especially older African-Americans, who are quite secretive about personal issues, such as health. In addition, one study group member mentioned that at the beginning of the study, the Newhall Coalition, represented by Frasier and Hayes, may not have had the level of general familiarity and support in the community that they now enjoy (partially as a result of the community work done as a result of this project). Asking people to divulge their personal information to relative strangers, even though they represented the community, might have presented a problem. This may have been exacerbated by the perception of the “outsider” nature of the other two groups within the study group: Yale Graduate Students and the NAACP, the latter of which is negatively perceived as a “rabble-rousing” group among some, especially the older African-American crowd according to

one study group member.

8. Insufficient Pre-survey work – Several reasons for the low response rate were anticipated but could not be avoided. Most importantly, more time was necessary for explaining the study. Had the group been able to spend enough time with residents explaining the study and the issue more thoroughly, residents might have been more likely to participate. The insufficient communication prior to the study's release lead to several critical shortcomings:
  - a. Failure to understand the issue – The soil contamination issue in the Newhall neighborhood is tremendously complicated on a political, scientific, and moral level. It is not surprising, therefore, that a lack of familiarity with the issue was an obstacle to full participation. It is equally difficult to judge residents' knowledge of the subject. Two of the four study participants and two of the ten non-responders interviewed, indicated that the complexity of the issue, and their lack of information were main reasons for their non-response. Confusion about the study is reflected in a conversation with one resident who said he first received a letter in the mail suggesting that he not let his grandchildren play in the yard. If they did, the letter continued, the child's shoes should be washed. A subsequent letter assured him that there was nothing to worry about. When a researcher asked who sent the letters, he replied that he did not

know “who’s who” and he did not know who to listen to.

- b. Failure to know about the study– Despite holding a community meeting, putting up fliers in the neighborhood several times, and receiving media coverage on the evening news, multiple radio stations and the front page of the New Haven Register (see Appendix 2), all of which were constructed to announce the study to residents, many residents did not know it existed. There are several pieces of evidence supporting this claim. First, of the 627 legitimate addresses on the study population list, only 343 were spoken to directly. Second, three of ten non-responder interviewees indicated they did not know anything about the study despite the phone messages and fliers left with both. This response implies that the phone message and fliers are insufficient educational tools when used in isolation, or an information bias due to the time between the follow-up contact and the interview. Third, one non-responding interviewee and one follow-up refusal indicated that some elderly residents defer judgment on the importance of their mail to close friends or relatives, who often live outside of Newhall and are therefore less likely to know about the survey. Fourth, after every round of follow-up there were 47, 58, and 70 requests for new surveys from residents with whom follow-up volunteers had directly spoken in rounds one, two and three, respectively. This could mean that people did not receive the survey, that they were simply trying to get the volunteers to leave them alone, or that they did not hear about

the study but wanted to participate and may have thrown away or misplaced the survey. It is highly unlikely that the post office failed to deliver the high number of surveys resent. Furthermore, researchers checked the addresses with respondents and rarely found an error. It is difficult to distinguish between people who wished to participate and those simply using this answer to make the follow-up volunteer leave.

However, three calls to the hotline out of approximately ten during the follow-up period were from residents indicating that they wanted a survey. If a resident was trying to get volunteers to leave them alone, they would not be expected to call the hotline unless they were doing so to refuse participation and avoid future visits. Therefore, at least a few residents who may have wanted to participate may not have heard about the study.

- c. Overestimation of outreach penetration—The lack of penetration of media and other outreach strategies into Newhall represents another potential explanation for the low response rate. Press coverage only occurred over two days, but eight of the ten random interviewees indicated they did not see either the newscast on Channel 8 news or the front page New Haven Register article (see Appendix 2), indicating that they either did not see or recall the newscast or that it did not create a lasting impression. Two of these interviewees mentioned that they regularly watch the news and read the paper. The community meeting held before the press conference, used to announce the launch of the study, did not reach as many as hoped,

drawing approximately only 40 people. In addition, the group overestimated the number of volunteers that would help with follow-up for the first two rounds. In the first round, there were four study group members and one graduate student volunteer. In the second round, there were four study group volunteers and two non-community member volunteers. For the final round, when members of the New Haven Green Party were allowed to help organize volunteers and the weather was finally amenable, there were four study group members and 25 volunteers, most of which were non-community members. In rounds one, two and three, the percentage of study households for whom contacts were attempted was 55% (mostly over the phone), 46%, and 81%, respectively. Informal outreach was also conducted. For example, supportive community members encouraged their neighbors to fill out the survey. Members of local churches were asked to mention the survey before services, and a leading representative of a local church blessed the community meeting. The effectiveness of such efforts was not monitored and is therefore unknown. The combination of low media penetration and weak follow-up efforts likely contributed to the number of people that did not know about the study.

- d. Issue not important to them– There was evidence that residents were aware of both the issue and the study but simply did not perceive it as a significant issue. Three of the ten non-responder interviewees reported

they did not remember anything about the survey. However, the same three were all spoken to face-to-face during follow-up. Two requested another survey and received a flier in the subsequent round. A resident that filled out the survey but was accidentally contacted for a non-responder interview indicated that he almost did not participate because he did not see himself being at risk: “I’m not going to ingest soil.” In addition, one study group member opined that the primary reason for low response was “apathy, pure and simple.” Another study group member who asked a resident why he didn’t respond was told that he simply kept putting off completing the survey until it was too late. One resident explained that by refusing to participate, she hoped to send a message to the Hamden Mayor that “cleaning the streets” and other neighborhood concerns were more important than the contamination issue. Finally, one of the follow-up refusals was explicitly attributed to the perception that there was no problem.

- e. Uncertainty of intent – Some residents seemed to understand the issue, know about the study, and care about it but did not know or trust the intended use of the data. One study group member felt that this was a major obstacle. Furthermore, the resident who thought the survey was unscientific because it asked about headaches felt that the survey was more of a political tool than a scientific one, and subsequently, did not trust that the data would be used in a way that reflected her priorities. In



addition, at least two refusals were explained by claiming there were no health problems in the household and there was therefore no need to fill out the survey. The implication could be that study organizers were only looking for negative health outcomes.

- f. Poor Communication– Reflecting an underlying obstacle throughout the study was the difficulty in making the case to individual residents (especially renters) that the study would affect them directly without resorting to sensationalism. All four study group members cited this as a major obstacle. One was convinced that if he was able to speak more explicitly about the anecdotal reports of diseases in the neighborhood, he might have convinced more people to participate. In the same breath, he also acknowledged that doing so would have compromised the scientific integrity of the study. A further communication problem may have occurred within the household of the residents. Providing a survey that must be completed by all members of a household assumes that individuals are communicating frequently and effectively with one another. This could explain why interviewees may not remember the survey, but follow-up shows that contact was made with the household. In other words, if the individual opening the survey does not share this information in the household, communication about the study breaks down.

## ***VI. Obstacles and challenges***

### *Conflict of Interest*

Major obstacles were faced throughout the study, some of which were touched on in the description above about the qualitative data. In expanding on these obstacles further, we aim to develop a better understanding the participatory process in the context of this study.

A critical component of community-based participatory research is the identification of a “community.” Communities can exist around both a geographic space and a common interest. In this study, the definition of community was never made explicit. Clearly, there was a community affected by the landfill, but it included those families coming to the Hamden Middle School, as well as the residents around the school. Race and geography were two characteristics defining this community of interest based on place. However, the ambiguous boundaries of the landfill made this geographic distinction nebulous. It should be noted that the boundaries of the study extended to include several blocks of a wealthy, white neighborhood. The study boundaries were designated according to the suspected area of the landfill moving the study area, which possibly extended beyond the imagined boundaries of the community.

Several competing interests stymied the formation of a single, explicit common ground of interest. Understanding of these interests emerged through discussions with community participants and during community meetings. A clear interest was expressed in keeping

the middle school in the Newhall neighborhood, as an essential component to maintaining a viable neighborhood. The closing of the middle school represents a potentially serious blow to the financial value of residents' homes, as well as the general perception of the quality of the neighborhood. There was considerable concern as to what would replace the school, and whether it would degrade the value of the neighborhood. In some respects this led to the impetus to not favor the identification of the landfill as a hazardous site. Although only anecdotal evidence supports this interpretation, several residents in the neighborhood told researchers, and as well wrote on blank returned surveys, that everyone was healthy in their family, that everything was fine. Whether this is related to the concern that the landfill would degrade the value of the community cannot be determined, but it may indicate the desire of some residents for the problem to 'go away'.

The interest in property values conflicted with a second interest in finding out whether the landfill is affecting the health of residents. Clearly, many residents, specifically those who participated in the research project and attended community meetings were concerned with the physical impacts of the landfill.

#### *Developing the partnership*

Reluctance to participate in the study was a known challenge when beginning to develop this study. The collaboration with the community organization was, in part, an effort to overcome this obstacle. The community members seeking research partners did so because amidst all the soil testing, press and parental uproar, they felt nothing had been

initiated in the interest of the neighborhood. They wanted something by and for the neighborhood, which became the original motivation for the partnership.

Whether we, as graduate students of Yale University, were interpreted by the broader community as trustworthy partners remain unknown. It is unclear as to why graduate students from Yale University would be perceived as a trustworthy partner and not, for example, the Connecticut Department of Environmental Protection. We were not representative of the government but we did represent Yale, which arguably does not hold the highest respect and trust among many residents. Whether our race and institutional affiliation were also factors in the low response rate is speculative at best, but presents a serious question to community-based participatory research: how to develop trust and a mutually balanced partnership.

Long meetings of struggles to find consensus, walking together in the cold rain, and early morning breakfasts helped to build trust within the partnership. To develop these individual relationships took time and patience on both sides, which for many researchers is a limiting factor in participatory research.

The lack of a strong community organization base despite the unwavering dedication of several deeply committed individuals was made explicit during the follow up period. The hope for a large and strong base of volunteer support (nursing support as well) was not fulfilled, and as a result, the first two rounds of follow-up were conducted with very little

labor support. In the third round more efforts had been made to reach out to residents in Hamden outside of the neighborhood and a strong base of support was achieved.

This experience in the follow-up period highlighted the critical need for a strong and well-developed community organization in a research project like this one. This is not to imply by any means the lack of hard work and dedication of the Newhall Coalition, but rather, acknowledges that the organization is young. Overwhelmed with taking on an entire research project, combined with the little experience we had in conducting a follow up, unequivocally presented the project with a serious challenge.

#### *Institutional barriers*

The community-based participatory research approach requires partners to communicate effectively as a critical aspect to building the necessary trust discussed in the previous section. The need for constant communication throughout the study calls for a more iterative approach to the research process. As new ideas and information emerge, changes to the research must be made accordingly. This need for an iterative process conflicts with some of the more rigid structures built into the traditional research framework. Specifically, the Human Investigations Committee provides strict guidelines for research in order to protect the confidentiality and rights of study subjects. This committee unequivocally serves an important purpose in the research process. The HIC's primary task emerged, historically, from abusive relationships between the researcher and the researched. However, *theoretically*, the trust and respect inherent to the CBPR approach supersedes the need for a HIC approval process. By no means does this argue against the need for HIC, or to suggest that abusive relationships never occur under the

guise of participatory research. However, it does question the rigidity of several of the guidelines provided by HIC, which may have contributed to the low response rate. The development of communication channels between HIC and community organizations may help address this issue, and thereby, improve the participatory process in the future. This is not to diminish the adverse effect of our lack of experience with HIC, which may have contributed to the difficulty in translating the community member's concerns to HIC. Had we been more experienced, we may have been more successful in working with HIC to re-word the informed consent agreement. This then suggests that participatory research may need seasoned researchers to ensure its success.

Two critical guidelines required by HIC conflicted severely with community participant's ideas for how the study should have been conducted. First, the original request by the researchers for five rounds of follow-up was denied by HIC and reduced to three.

Community participants felt strongly that people within the community would need to be contacted many more times to increase the participation rate due to reluctance, distrust and very busy lives. Furthermore, the paucity of resources led to the decision that five rounds would be necessary. Upon review, HIC insisted on three rounds of follow-up arguing that more would disturb individuals.

The second obstacle experienced during the HIC review was the statement of risks in the information sheet enclosed with each survey. As previously mentioned, HIC insisted that the possible decrease in property values be included on the list of risks associated with participating in the study. Community participants strongly expressed the feeling that

these statements would scare people from filling out a survey. Moreover, the community participants argued that the decrease in property value risk was remote, especially since property values in the community had already been decreasing in recent years (as opposed to the surrounding areas in Hamden where prices had been increasing). Further, the risk of researchers being forced to disclose health information by a court order concerned community participants. Immunity to subpoenas requires a three month long Certificate of Confidentiality (DHHS) application process. Nonetheless, data has been forcibly released in similar situations (55).

The concerns and frustration of community representatives regarding the HIC review became a critical tension in the project. As graduate students, we were placed in the difficult situation of being both the translators of the HIC committee and the research partners with the community organization. Since HIC was the overriding authority on all these decisions, the community participants lost the ultimate say in the direction of the research.

What can be learned from these differing options between HIC and community participants? Should HIC decide what constitutes a risk or should community participants? How should competing and conflicting interests be fairly and properly dealt with? We do not claim to be able to answer these difficult questions, but feel they are necessary issues to explore as the participatory research approach integrates into public health research in the future.

*Methodology: mailings and the survey*

The use of the regular mail presented a serious challenge. The high number of resent surveys reflects some of the problems with using the mail: individuals do not read their mail carefully, many may throw out items that are not a bill or are not personally marked (no names were placed on the envelopes), or items are lost in the mailing process.

In addition, acquisition of a simple mailing list of the area was unexpectedly time consuming and difficult. The Town of Hamden only had addresses and names for landowners but many plots have multiple households. The Direct Marketing Association keeps an annual list of names, addresses and phone numbers but there was a high error rate. Voter registration rolls are also considered public record but are incomplete since considerably less than 100% of the population is registered to vote. Finally, purchasing a list from a company like Advo who specializes in direct mail costs approximately \$250 but is the most complete of all the above options. In order to get the most complete list possible, all four sources were combined into a single database by hand.

*Limitations of 'participation'*

As the launching of the study drew near, the frequency of the meetings increased. During this process we lost the participation of two of the four community participants. This may have been a critical mistake because it happened at just the moment when we needed to build support. The meeting time and place also changed from a diner in the neighborhood to a building at Yale. The reasons for this decision were because we needed more space to work and plan and because a representative of the Toxics Action



Coalition in Hartford, Connecticut, could only provide media assistance on weeknights. Another factor that may have contributed to the attrition in participants was the limitations of time.

All participants had serious time restrictions. As graduate students we were bound to the academic calendar, and community participants all held daytime jobs that limited hours spent on the study. Furthermore, community participants frequently expressed the sense that they were tired of participating with no substantive return on their efforts. With each delay in the process, for example, with the HIC approval, tensions rose. The time delay in obtaining HIC approval delayed the release of the study from the initial goal of the beginning of September to the end of October. As a result, the study in essence had to take place between the end of October and prior to the start of the holidays with Thanksgiving. The community participants strongly felt that the study needed to be completed before the holidays, because individual attention would be diverted to planning for this time, traveling and visiting with family. As the study came within weeks of being launched, the project became a full time job, placing more stress on those community members participating actively. Therefore, the increased frequency of meetings was bound to lose participants. However, what we did fail to facilitate effectively was communication with the other members about what was going on and why the change of venue had occurred.

### *Limitations of the Follow-up*

Going into the follow-up process we did not have a solid coalition of individuals as discussed in the above section on ‘defining community.’ The NAACP had been a financial and community participant from the initiation of the study, but continuously presented multiple problems to the partnership, largely in making false promises. In the first two rounds of follow-up, no members of the organization participated, after promising nurses and community members. The reasons for this failed relationship are uncertain.

One critical mistake made during the follow-up was how the partnership divided up responsibilities. We allocated our time towards preparing materials for a large number of volunteers, which in retrospect, should have been spent securing individual commitments to work on the follow-up. Another significant obstacle was the lack of a space with multiple phone lines for follow-ups by phone. This combined with the negative responses we were receiving with phones (hang-ups and answering machines) led us to concentrate exclusively on door-to-door follow-up for the last round.

The limitation of having to conduct the follow-ups on Saturdays presented two potential biases and challenges. First, by visiting homes on Saturdays we necessarily missed those residents who may work, have appointments, go to church, or do errands routinely on that day of the weekend. Initially, we had established a method to rotate days to avoid this problem, but the unforeseen lack of community volunteers at the time of follow-up forced the research group to change this plan and only go out on Saturdays. The second

uncontrollable challenge was the weather. The first two rounds were cold, rainy days, the second of which brought a strong rainstorm. Clearly, it was just incredible bad luck to have two horrible days of weather for follow-up. Time constraints of the volunteers combined with the need to have the follow ups occur soon after the households in the study area received the survey, placed considerable restrictions on the timing of follow up.

*Further obstacles and problems with data*

Several other noteworthy remarks were made during the research process as potential reasons for the low participation rate, which do not fit into the above discussion, but deserve mentioning. First, the choice of a church as a community meeting venue may have kept those not affiliated with the church away, or may have falsely associated the project with a religious organization. Second, some residents assume that the government will protect them. One community resident called this the “plantation mentality” that suggests individuals believe the “great white hope” will look out for them (20). This tacit consent, of course, is not restricted to Newhall or African-American communities. And finally, the lack of familiarity with the then relatively young Newhall Coalition, whose leadership spearheaded the community involvement in the study, may have kept people from participating or knowing about the study.

An additional obstacle to the completion of the project for the thesis was data processing. Despite the use of a professional data entry company, a tremendous amount of time was required to prepare it for analysis. Due to delays in obtaining the data back from the

company, we were unable to complete the quantitative component of this study in time for the binding of this thesis. A report for the community to be prepared in the summer of 2003 will include more detailed quantitative data analysis.

## ***VII. Conclusion***

### *Lessons learned*

Although, a 20% response rate was disappointing, this does not undermine the achievements of this project. Several practical lessons were gained throughout the course of this project. The first, and probably most important lesson was that a thorough pilot study could be a critical first step in research. At the outset of the project, researchers had no idea of the breadth of reasons people would have for avoiding participation. It was incorrectly assumed that if the community was sufficiently upset and concerned they would be eager to fill out the survey. Had a thorough pilot study been done, it is possible that a more complete view of community attitudes and familiarity with the issues would have been discovered ahead of time.

The second lesson is that when more resources are available, the project has a better chance of success. Human and financial capital are integral to success of any project. Human capital is the most important since, as discussed above, speaking to people face-to-face is by the far the most effective way to get a community on board with the project. Speaking with individuals *prior* to the start of the project is especially important. Trying

to get people on board after the project has been launched is distracting and drains valuable resources at a time when they are needed the most.

A third lesson is the critical importance of effective communication with the public. The study group spent dozens of hours over several meetings shaping the message in a way that would boost response rates while maintaining scientific integrity. The deficiency, in this case, was the failure to develop a statement that both expressed the direct and individualized benefits of participation and would encourage individuals to fill out the survey. This problem was anticipated in the beginning of the project but was not surmounted. Additionally, the informed consent letter poorly communicated risk and contributed to the low response.

Finally, we learned about the limitations of traditional epidemiological survey tools. Surveys can be ineffective tools for several reasons. First, people are incredibly busy and even with good intentions many individuals may not find the time to fill out a survey. Second, people are inundated with information, allowing surveys like ours to slip through the cracks. And third, following up with non-responders has become increasingly difficult as people use answering machines to screen calls and are infrequently home or unwilling to answer their door. Developing means for communicating with people in the fast pace of the information age is challenge for epidemiology at all levels. In the context of this study, it questions the effectiveness of a survey, and calls for creative and innovative means for communicating with the public.

Beyond the lessons gained from this project, an unintended positive outcome was also realized; the strengthening of the community organization. Through efforts at securing funds and communicating with the broader community, the Newhall Coalition was strengthened and solidified. Newhall Coalition began organizing community meetings around the issue of the landfill. But in the course of these meetings, a variety of related issues surfaced and the need for community organizing became apparent. Funding obtained during this study may be available to support the further development of the organization. It should be noted that we are not suggesting that a research study should be employed as a means for strengthening a community organization; rather, it is only to indicate that this was a positive outcome of the work.

Establishing a community organization provides the opportunity for future collaborative work with Yale and with government agencies. This study in effect can be used as a pilot study for further work with the Newhall Coalition. Conducting epidemiological studies with a strong community organization creates opportunity for the community's voice to be heard. This is essential for effective public health research and policy making because residents are frequently the first to recognize health problems in their community (56). Moreover, it is often the community members that understand health behavior and practice. Thus, the strengthening of a community organization provides the potential for future approaches to closing the gap in health disparities and improving community health. If participatory research aims to encourage the development of context-based knowledge, the establishment of this community organization will provide a foundation upon which to begin to construct this knowledge.

This study also provided the opportunity for a collaborative effort between a Hamden/New Haven community and Yale vis à vis the School of Forestry and Environmental Studies and the Department of Epidemiology and Public Health. This builds on the principle in participatory research of reciprocity in research. Our efforts have been directed at establishing a more permanent relationship between the community and Yale as a means for improving not just the community, but the Yale environment and research, as well.

#### *Future Directions in Research*

Much work remains to be done in, for, and with the Newhall community. In an effort to address some of this necessary work, we developed a scientific workbook in the fall of 2002, as part of an independent study. The goal of the project was to provide support for the community in the area of scientific literacy. Extensive soil and water testing conducted by the DEP and Regional Water Authority, respectively, as part of their investigation of the landfill, was being presented to the community in a scientific language often unfamiliar to lay citizens. The workbook provided a background in environmental health sciences, epidemiology and risk assessment so as to guide the community in understanding the strengths and limitations of the studies being conducted in their community. This guide also aimed to serve as a guide to other resources in environmental health, in particular other community groups, as well as governmental and non-governmental websites for further research and information (NIEHS, ATSDR, etc).

The Newhall Coalition is also seeking assistance with interpretation of scientific data, collecting their own environmental testing data, and conducting a spatial analysis of soil contaminant distribution. These projects and a continuation of the relationship with the Newhall Coalition are desired outcomes of this study. As part of the agreement made with the Newhall Coalition, more detailed data analysis will be conducted and presented to the organization in the summer of 2003.

Based on our experience and understanding of the landfill problem, we propose several recommendations for improving the environmental health of the Newhall area. First, no testing of dioxins and furans has been conducted to date. The presence of vinyl chloride in the landfill combined with evidence of burning trash strongly suggests that dioxins and furans may be present. The second recommendation is to continue testing in the city neighborhood that abuts the Newhall area. There is no evidence to suggest that the contamination stops at the city/town boundary, which lies only feet from properties with known soil contamination or subsidence problems. The final recommendation is for the testing of soils in residents' gardens. With 83 individuals reporting that they eat from their garden, potential exposure via soil and food could present a health risk.

Although the participatory approach to research presented many challenges and pitfalls, the rewards were numerous. First and foremost, the process revealed how public health issues can become politically situated. Specifically, the intimate interaction with individuals living in the area of study taught us about the political and social complexities behind understandings of risk, health and exposure. This on-the-ground experience as



epidemiologists in-training showed us how public health goes well beyond the analysis of data to involve critical understanding the political, historical and social variables contributing to the health problem or risk.

Second, the participatory process provided an opportunity for the development of the relationship between Yale University students and the Newhall neighborhood, and as a result, brought an increased awareness of the landfill at the university. Since the initiation of this project, an undergraduate student and a graduate student of the School of Forestry and Environmental Studies have written about the Newhall Coalition and the landfill. The graduate student's work, a popular press article, is currently being submitted for publication.

Third, the participatory process highlights the critical importance of communication in efforts to improve public health. Effective communication involves careful and comprehensive interpretation of scientific information. The structure of the participatory process (including meetings, press releases and frequent informal conversations) provides the opportunity to practice and develop this critical skill.

Finally, the participatory process demonstrated to us how to integrate public health and social change through collaborative knowledge-making. The collaborative process of this research project provided an opportunity for learning and knowledge-making across institutional and social barriers—young and old, black and white, Ivy League and grassroots organizing. Bridging these different communities and individuals presents

obstacles and challenges, as well as institutional resistance. The aim of this community-based participatory research project was to face these challenges by developing the relationships necessary for the sharing of knowledge that can in turn begin to shape social change and improve public health.

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*Appendices*