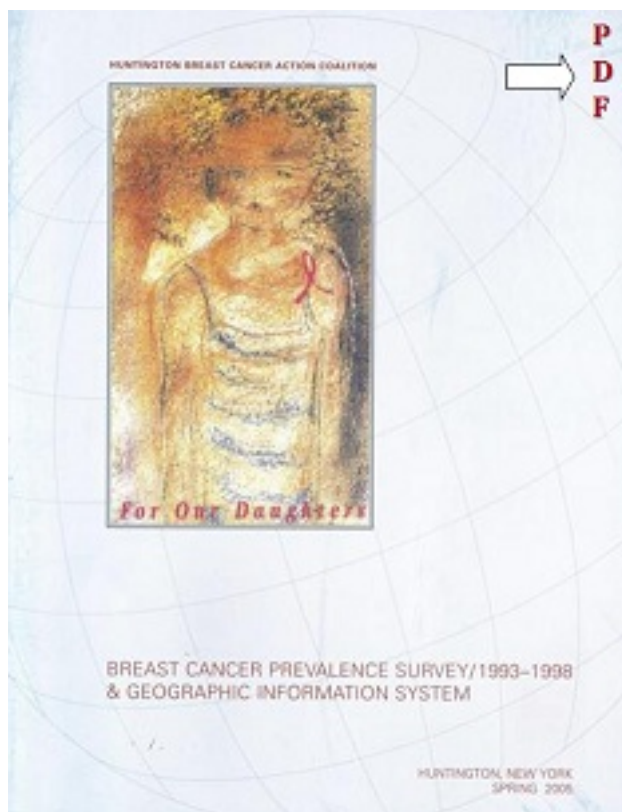


Survey Mapping project. In 1993 HBCAC began to map the incidence of breast cancer in the Township of Huntington. Through a survey questionnaire sent out to over 68,000 households, a Geographic Information System (GIS) was developed to better understand breast cancer patterns. January 2001 with the help of over 300 volunteers this townwide mapping was completed. In Spring 2005, HBCAC published the **BREAST CANCER PREVALENCE & GEOGRAPHIC INFORMATION SURVEY** book based on 1993-1998 breast health survey results.



Community Breast Cancer Mapping Huntington, Long Island

by Dr. Scott Carlin, Southampton College, Long Island University

Abstract

The Huntington Breast Cancer Action Coalition (HBCAC) recently completed a survey of town residents regarding breast cancer. This paper reports on recent efforts to map those surveys using ArcView GIS. Breast cancer cases will be overlaid onto various environmental maps, such as local toxic sites, to look for general patterns among these variables. Basic statistical analyses will also be summarized.

Introduction

Breast cancer now accounts for almost one out of every three cancer diagnoses among women. It is the most common form of cancer for women, excluding non-melanoma skin cancers. Breast cancer is also the leading cause of death for women between the ages of 35 and 54 (1). While many cancer rates have fallen in recent years, breast cancer rates continue to climb (2). Huntington Breast Cancer Action Coalition (HBCAC) was formed in 1993 to educate the residents of Huntington, New York about their breast health. A similar coalition on Long Island, in neighboring West Islip, had formed in 1992, and two years later had developed a "'first of its kind' door-to-door demographic mapping survey (3). Similarly, HBCAC decided to launch a more detailed and comprehensive survey of Huntington women over the age of 25. Following from West Islip's experiences, HBCAC knew from the outset that they wanted to map their survey. Maps were proving to be powerful tools for raising public awareness about the prevalence of breast cancer on Long Island. The Long Island Breast Cancer Maps are powerful examples of community mapping.

Community mapping projects have become an important tool for informing and empowering local citizens. As the Common Ground Community Mapping Project has stated, "Through the process of creating and revising maps, communities are better equipped to proactively address their interests and concerns" (4). Community maps can touch upon a wide range of spatial attributes associated with community life. Through maps, community groups can address environmental, health, economic development, social welfare, historic preservation, land use, demographics, natural hazards and a host of other issues. Using GIS overlays, community mapping projects can be an effective tool for looking at the linkages among different sets of issues. For example, we can use GIS to look at the way breast cancer patterns correlate with demographic or environmental factors. Many of these land features have traditionally been mapped by local planners, academics, or private corporations. If that is true, then what makes community mapping innovative?

First, community maps raise community participation rates by engaging a broad cross-section of

the community in mapping projects, most of whom have little or no prior background in mapping. In Huntington, HBCAC had no internal mapping resources. HBCAC knew, however, that they wanted to map breast cancer, and they sought out volunteers and paid interns who could help make that goal a reality.

Second, community maps are important educational tools. Maps allow many residents to better understand local issues in a more concrete fashion. Although the residents of Huntington knew breast cancer was an important issue, the maps helped the community to understand the widespread prevalence of this disease.

Third, community maps are a valuable tool for critical thinking. They are not simply learning about their communities by reading maps; they are also asking questions of the maps and manipulating the maps to provide those answers. Through that process, citizens begin to see their community in a new light. Through its maps and other campaigns, HBCAC wants local residents to question whether pest-free lawns are worth the risks of potentially higher breast cancer rates, or if residents really should ignore the broad-based usage of toxic substances in their community.

Fourth, community mapping projects are distinctive because local citizens, often working through non-profit organizations, control the mapping process. They control what is to be mapped, how maps are to be distributed, and how they are going to be publicized. This shift can lead to mapping innovations, like breast cancer maps. Citizens often bring new perspectives to mapping, highlighting previously ignored issues and helping to change local public agendas. Maps can strongly influence community perceptions. In Huntington, HBCAC knew they wanted to use maps to explore the relationship between environmental contamination and breast cancer. They wanted to use their maps to heighten public awareness of the usage of toxic substances in Huntington and to explore whether those substances were affecting local breast cancer rates.

Local control of the mapping process is particularly important because many community mapping projects focus on politically sensitive issues. For that and other reasons, relying upon government agencies for these maps can often lead to frustration. Despite that tension, much of the information that community mapping projects draw upon come from governmental data sources and often require the cooperation of government officials.

Breast cancer maps provide a good illustration of these tensions. Debates about privacy and

data confidentiality have been a frequent source of conflict between government officials and grassroots breast cancer organizations. From the perspective of government, releasing detailed data about breast cancer (or any cancers) can be an invasion of privacy. People's lives can be seriously disrupted by the public release of data describing their health histories. There's a fear that local citizens will be stigmatized or that individuals may lose their jobs. From the perspective of community health advocates it is essential that the public understand the extent of disease within their community. Detailed community maps provide a powerful visual tool for exposing the ubiquity of breast cancer on Long Island.

Fifth, community mapping projects can reveal in powerful ways how much the community's goals differ from their government's goals. Community mapping efforts often begin in a fairly naive way with local citizens believing that by creating maps and mixing new and old sources of data in compelling ways they can open a space in public discourse for considering new alternatives. What community groups frequently learn is that the pace of change in government is often much slower than they anticipated or that key elements of their government are hostile to their plans. Today, a wide chasm has opened up in the environmental health field. On the one side are government officials and academics, who feel that mapping exercises should continue to focus on research. These individuals argue that we do not understand the causes of breast cancer, but improved research, particularly genetic research, and to a much lesser extent mapping research, should proceed and hopefully begin providing the answers we seek.

On the other side are the environmental health advocates and some environmental scientists. They believe cancers, like breast cancer, are a direct product of industrial era chemicals. In particular, much attention is now focusing upon groups of chemicals that affect the body's hormonal system. In *Our Stolen Future*, Dr. Theo Colburn and others argue that synthetic chemicals mimic natural hormones and trigger hormone-related cancers, like breast cancer (5).

Therefore in the area of breast cancer, maps have become deeply politicized. At one level community-based breast cancer maps are about raising public education and awareness. But, at another level, these maps are about changing our understanding of environmental health. In her path breaking book, *Silent Spring*, Rachel Carson begins by noting how intimately we live with modern chemicals - how we eat, drink, and breathe pesticides into our bodies without pausing to consider the devastation that these chemicals cause. Dr. Sandra Steingrabber, author of *Living Downstream*, also emphasized these issues of intimacy. For example, she discussed how mothers pass along PCBs and other chemicals to their newborn children through their breast milk (6).

While community-based maps do not create a two dimensional portrait of these intimate health

relationships, they do paint a powerful picture of communities suffering silently, block after block, through devastating illness. Breast cancer maps are a powerful tool for breaking that silence and forcing the public to confront its secrets.

Surveying Women in Huntington (7)

In the early 1990's the Town of Huntington had a population of 200,000 (90% white). HBCAC decided to survey the entire town with the goal of mapping and studying breast cancer and reaching a 50% response rate. The survey was written by Roger Grimson, PhD, biostatistician at the Department of Preventive Medicine at the University Medical Center at Stony Brook, along with physicians at Huntington Hospital and local breast health activists. The survey was mailed out to over 68,000 households in September 1993, all known households in the town. The survey was sponsored by Huntington Hospital and supported by Huntington Town officials and community volunteers. The survey was written in both English and Spanish and publicized in community newspapers, radio and television stations, local Parent Teacher Associations (PTAs), and through other civic and religious groups. In response, over 15,500 surveys were filled out and returned.

In June 1994, the Junior League of Long Island and Suffolk County Health Partnership sponsored a second mailing, targeting non-respondent households. HBCAC collected another 9,000 surveys.

HBCAC volunteers entered the surveys into a computer. Each survey was reviewed, assigned a record number, and supplied with a 9-digit zip code if not provided (Nine-digit zip code was obtained manually from US Postal Zip Code books). The surveys were batched in groups of 25. It took 1 to 1½ hours to enter a batch into the computer database. The initial data entry program was written in 1993 by volunteers in DOS and later revised for Windows.

A Town Hall Meeting was held on the evening of March 25, 1995, where HBCAC presented preliminary statistics for the 18,955 Breast Health Surveys they had tabulated. Greenman-Pedersen Inc. geocoded and mapped the survey data. Of the respondents, 5,421 indicated that someone in their family had breast cancer (29%); 939 respondents indicated they themselves had breast cancer at some time (5%).

In July 1996 HBCAC completed a third mailing, bringing in another 5,000 surveys. Also, HBCAC utilized the Huntington Hospital, Town Hall, local libraries, doctor offices, and beauty parlors to distribute and collect additional surveys. Lastly, volunteers visited specific addresses to urge non-responders to fill out the survey in a "Neighbor-to-Neighbor Campaign." As a result, another 1,300 surveys were collected, bringing the gross total number of surveys up to 30,800.

Errors did occur in the data entry process. Upgrading the data from DOS to Windows proved particularly problematic. The date-of-birth field was lost on thousands of surveys and had to be re-entered. Again, volunteers spent countless hours making the necessary corrections.

The database was also checked for duplicates, which were removed. A more careful verification of the survey was initiated by epidemiologist Erin O'Leary, PhD, and initially consisted of a random selection of 10% of the records, which were compared to the original hard copy of the surveys. When these analyses were complete, 23,777 surveys were deemed acceptable for analysis. The difference between the gross and final count was primarily due to duplicate surveys. In the fall of 2000, after seven years of work, the survey was completed.

In the Spring of 1999, HBCAC, with assistance from Long Island University, was awarded a Conservation Technology Support Grant (CTSP), which provided the organization with sufficient resources to do its own breast cancer mapping. Again with the assistance of Greenman-Pedersen, Inc. the final surveys were geocoded with data provided by Geographic Data Technology (GDT), Inc. In January, 2001, HBCAC presented their preliminary findings from the completed survey.

Initial Survey Results

HBCAC asked Dr. Erin O'Leary to analyze the completed survey. Below are some highlights from her findings (8):

Total number of Responses	23,777
Number of women in Huntington, over age 25	63,965
Response Rate	37%

Number of women diagnosed with breast cancer, over age 25	218
Breast Cancer Prevalence Rate	5.7%
Average age of respondents	51 years
Average age of women ever diagnosed with breast cancer	61 years
Average years in residence	17 years
Average years in residence of women over 25 with breast cancer	23 years
Average age at breast cancer diagnosis	58 years

Mapping Breast Cancer in Huntington

Breast cancer mapping in Huntington is still in an early phase of development. The mapping process is envisioned as a three stage process. The first stage is now complete. Cancer cases have been geocoded and mapped using ESRI's ArcView software. The zip+4 geocoded centroids provided by GDT enabled HBCAC to successfully geocode over 99% of the survey. Greenman Pedersen, Inc. printed these maps on a large format printer. The maps are now on display in local libraries.

The second stage of the analysis is to examine the data for possible cancer clusters. This analysis will begin this summer and will hopefully be completed by the end of the year. HBCAC has been working with two software packages: Dr. Martin Kulldorff's SatScan Software and Dr. Gerry Rushton's spatial filtering software.

The third phase of the research is to correlate breast cancer patterns with known environmental hazards in the region. HBCAC has been collecting environmental data sets and done some very preliminary analysis with those datasets.

Stage One: Geocoding and Mapping Breast Cancer in Huntington



Huntington is located in Suffolk County, New York. Breast cancer cases were mapped in two ways.

First, we overlaid respondents who ever had breast cancer onto respondents who never had breast cancer. Of the 23,777 respondents, 5% had breast cancer in their life. Second, we mapped the percent of respondents who ever had breast cancer at each zip+4. Many of these percentages were 100%, reflecting the fact that the only respondent from that zip+4 had been diagnosed with breast cancer. Those zip+4 with no breast cancer cases (0%) were not mapped, to focus upon positive cases.

MAP 2: PERCENTAGE EVER HAVING BREAST CANCER, BY ZIP+4

Breast Cancer Prevalence Study, 1993-1998
Huntington, Long Island, NY



% of Respondents Ever Having BC per ZIP+4

- 0%
- 1-20%
- 21-25%
- 26-50%
- 51-100%

Highways

- ▤ Limited Access Highway
- ▤ Primary Road
- ▤ Secondary Road
- ▤ Long Island Railroad

Parks

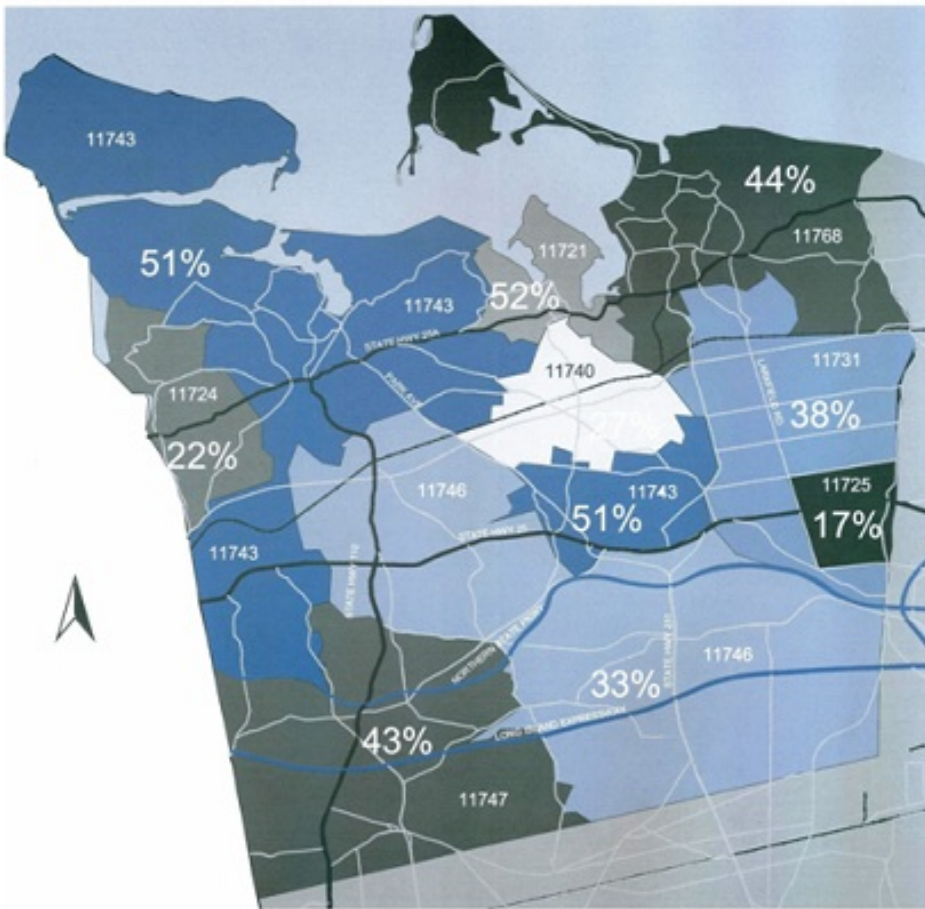
- ▤ Streams
- ▤ Long Island Sound
- ▤ Lakes
- ▤ Town of Huntington
- ▤ Suffolk County



BCPS - Breast Cancer Prevalence Study - NCI/ACS

MAP 1: SURVEY RESPONSE RATES, BY 5-DIGIT ZIP CODES

Breast Cancer Prevalence Study, 1993-1998
 Huntington, Long Island, NY



Highways
 Limited Access Highway
 Primary Road

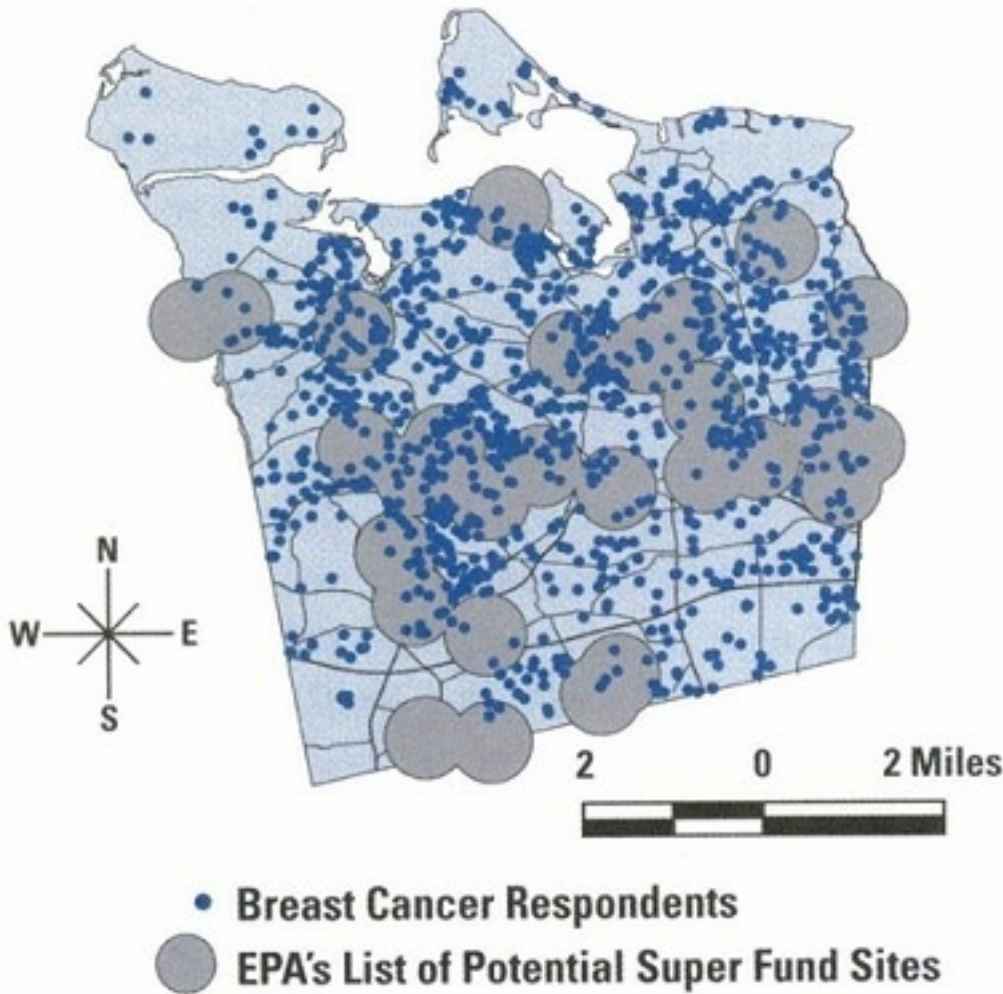
Secondary Road
 Long Island Railroad

Long Island Sound
 Suffolk County



Breast Cancer Prevalence Study - HBCAC • 15

Figure 2 **3/4 Mile Buffer Analysis Around EPA's List of Potential Superfund Sites**



Ever Have Breast Cancer?	Total Number	Area	Density
Inside 0.75 mile buffer	414	33	13/sq. mile
Outside 0.75 mile buffer	802	62	13/sq. mile



www.hhpnet.org/nishecure.org/ www.senate.gov/epw/Sim107/nim#06/ www.legis.wv.gov/