

California Breast Cancer Mapping Project Frequently Asked Questions

PROJECT BACKGROUND

What is the California Breast Cancer Mapping Project (CBCMP)?

The CBCMP was funded by the California Breast Cancer Research Program of the University of California to evaluate the utility of sub-county breast cancer mapping and articulate guidelines for its implementation by public health agencies. Staff from the California Environmental Health Tracking Program of the Public Health Institute and an advisory group (AG) representing breast cancer advocates, clinicians, and public health agencies met periodically during a two-year period.

The AG was tasked with addressing the following questions:

- Would making maps of breast cancer surveillance data that go beyond county-by-county rate reporting be useful? In what ways?
- How should these maps be made?
- How should the results be communicated?

What did the CBCMP Advisory Group determine?

In brief, the AG determined that small-area mapping of breast cancer data is extremely useful under specific circumstances. The circumstances include the use of statistical protocols that are scientifically rigorous and protect patient confidentiality, as well as the provision of demographic and clinical information describing any areas that are found to have elevated breast cancer rates.

The AG went on to elucidate their priorities into a comprehensive protocol for the staff to carry out; this protocol was applied to invasive breast cancer surveillance data for California covering 2000-2008. The AG further concluded that the mapping protocol and results should be made publicly available in a report entitled *California Breast Cancer Mapping Project: Identifying Areas of Concern in California*, which is available at www.californiabreastcancermapping.org.

How is the information in the project report different from other reports?

Traditionally, reporting of breast cancer incidence rates is confined to the county level. This report identifies areas that may be smaller than counties or extend across county boundaries for which breast cancer rates are 10-20% higher than the state average.

What is an Area of Concern, and how is it different from a cancer cluster?

For the purpose of this project, an Area of Concern is a collection of census tracts that together have elevated rates of invasive breast cancer that cannot be attributed to population growth, data limitations, or random chance. Although the term cancer cluster is sometimes used to refer to areas such as these, we find that it carries additional implications, such as the idea that the excess numbers of cancer cases are traceable to specific environmental causes. The AG found that the existence of the Areas of Concern constitutes important information in and of itself, even though information regarding their causes—environmental or otherwise—is lacking.

While the AG considers the conversation about whether local increases in cancer rates could have environmental causes to be an important one, it is separate from the question of how cancer surveillance data can and should be communicated to the public. For this reason, the term "cluster" is avoided as much as possible in discussions of the CBCMP and its findings.

BREAST CANCER SURVEILLANCE AND MAPS

What is breast cancer surveillance?

Breast cancer surveillance is the continuous collection, analysis, interpretation, and dissemination of breast cancer data to improve public health and health services. Breast cancer surveillance enables detection of changes in disease patterns over time.

Which agencies conduct breast cancer surveillance?

At the federal level, programs such as the National Cancer Institute Surveillance Epidemiology and End Results (SEER) and the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System (BRFSS) provide information about screening, incidence, prevalence, and mortality for the nation. SEER information is based on data generated by cancer registries such as the California Cancer Registry (CCR); because agencies such as CCR follow rigorous protocols for case identification and data collection, the quality of their data is considered to be exceptionally high. Local Public Health Departments and the California Environmental Health Tracking Program (CEHTP) commonly rely on CCR data for their work. Finally, surveys such as the California Health Information Survey (CHIS) and the California Women's Health Survey (CWHS) provide vital additional information regarding breast cancer screening and individual risk factors, although CWHS has been discontinued due to lack of funding.

Can public agencies provide information on cancer rates for small geographic areas like census tracts or neighborhoods?

Certain issues limit the ability of public agencies to provide sub-county breast cancer data on request. Public agencies are concerned with providing the most reliable breast cancer data and protecting patient confidentiality. In order to meet both these criteria, agencies need large numbers of cases and large geographic areas to conduct their analyses. Another issue is that public agencies may not have the staff or organizational capacity to use different statistical methods that can detect elevations in smaller geographic areas, while still maintaining scientific rigor and patient confidentiality. However, under certain circumstances,

public agencies can provide data for smaller geographic areas. Individuals seeking sub-county data should make a specific request to their local or state agency, as these requests are treated on a case-by-case basis.

How might public agencies use the CBCMP mapping protocol?

Public agencies can supplement their ongoing surveillance activities by using the CBCMP protocol to produce data for smaller geographic areas than counties in order to gain new understanding of specific communities. The CBCMP protocol maintains widely accepted standards of scientific rigor and protects patient confidentiality. The mapping protocol can help answer questions about how breast cancer is or is not impacting specific areas and may provide public assurance that breast cancer surveillance is being conducted with the highest possible geographic resolution while excluding findings that are due to random chance.

Could this mapping protocol be applied to other cancers?

There are several factors involved that make this question a complex one to answer. First, it is important to consider that concerns about breast cancer are, in many cases, different from concerns about cancers of the lung, brain, or immune system. For cancers that differ from breast cancer with regard to screening opportunities and environmental concerns, considerations should be made about the utility and interpretation of maps created using this protocol. It is also important to note that the number of invasive breast cancer cases diagnosed each year in California is quite high relative to other cancers, so methods like the Scan Statistic may be more or less appropriate depending on the number of cases for a specific cancer. We do feel that the consideration of using this mapping protocol for other cancers is a relevant question, however, and should be explored further.

METHODS AND DATA

Where did the data used in the report come from?

The CBCMP conducted its analysis using data from the California Cancer Registry describing the numbers of cases of invasive breast cancer among women by age, year of diagnosis, and census tract of residence at the time of diagnosis for the years 2000–2008. Population data (or denominators) and information about the populations in the Areas of Concern were taken from the 2000 and 2010 U.S. Census.

Why aren't more recent data available?

At the time of analysis, the most recent year of complete cancer data from CCR was 2008. Because CCR standards for data accuracy and completeness are high, the data themselves only become available two years or more after the year they describe. For example, data from 2008 are not available until 2010.

What is the Scan Statistic?

The Scan Statistic is a method developed during the mid-1990s by Martin Kulldorff and colleagues; it is one of the most reviewed and analyzed statistical methods for depicting cancer geography. It was chosen as the cornerstone of the mapping protocol by the AG because of its ability to find true cancer elevations and exclude

results due to random chance. The CBCMP protocol describes specific ways to implement the Scan Statistic, along with additional steps for screening out unreliable findings.

How did this report make population estimates for non-Census years?

Breast cancer mapping requires two sources of data —the number of breast cancer cases (the numerator) and the total number of women (the denominator) living in a specific time and place. The U.S. Census provides counts of women by age and census tract only once every ten years, so the denominators are only known precisely in Census years like 2000 and 2010. It can be difficult to estimate the population denominator for the in-between years (2001-2009), especially in states like California where population and housing availability have changed dramatically over short periods of time. Under the CBCMP protocol, we used a relatively simple process—called linear interpolation—to estimate between-census populations, followed by additional steps to screen out findings that may have originated from sudden population shifts that may have occurred around the state.

PROJECT FINDINGS

What information do the CBCMP maps provide, and how can it be used?

The CBCMP identifies areas of the state with elevated rates of invasive breast cancer that are missed by the traditional county-by-county method. The CBCMP maps offer information on breast cancer rates for areas that may be either *within* or *across* county boundaries, providing useful information for targeting services and informing local level breast cancer prevention efforts.

The CBCMP maps need not be used as a replacement to other modes of presenting breast cancer surveillance data, but rather as a supplement to them. County level data are still very important, as many funding and interventions are often conceived as county-level initiatives.

Additionally, the maps cannot be used to determine links between rates of breast cancer and the environment. Although scientists are concerned about the possibility that exposure to environmental pollutants could play a role in breast cancer, many believe that the cancer does not develop until decades after these exposures take place. Although the CBCMP maps are based on where women live at the time that they are diagnosed this is likely to have little bearing on where they lived previously or what pollutants they may have been exposed to.

What new information is provided in the report?

The report contains new information on Areas of Concern that may be smaller than counties or cross county boundaries, ultimately providing a more comprehensive picture of breast cancer risk in California than the consideration of counties alone. The report identifies four Areas of Concern:

- An area that includes portions of Ventura and Los Angeles counties had a consistently elevated rate of invasive breast cancer; previous analyses examining these two counties separately had not yielded this information.
- The southern portion of Orange County and a small portion of western Riverside County showed higher breast cancer rates than the state average. However, Orange County as a whole had

previously shown only slight elevations with intermittent statistical significance; Riverside County had shown a significantly lower breast cancer rate than the state average.

- As was previously known, specific areas of Marin County had a higher breast cancer risk; findings in the report suggest communities elsewhere in the northern San Francisco Bay Area may be similarly affected.
- In the southern San Francisco Bay Area, communities in San Mateo County, northern Santa Clara, and southern Alameda counties had a consistently elevated risk of invasive breast cancer.

Do the findings include women who are living with breast cancer, but may have been diagnosed before the period of analysis?

No, the findings are for new cases of invasive breast cancer (i.e. breast cancer incidence) diagnosed during the time period of 2000-2008. The findings do not include all women with breast cancer, many of whom may have developed their illness earlier or later than the specific period of data collection.

What demographic factors were analyzed to describe the women in the Areas of Concern?

The report describes each Area of Concern by calculating its demographic composition, the proportion of women who were diagnosed after their cancer was in a later stage, and the proportion of women who receive government-assisted insurance or who were uninsured at the time of diagnosis. Demographic composition included factors such as age, race/ethnicity, and housing tenure (e.g., renting versus owning).

What do the findings say about breast cancer rates among women of specific racial and ethnic groups living in the Areas of Concern?

Invasive breast cancer is more common among some racial and ethnic groups than it is among others, and it is possible that the Areas of Concern described in the report could be accounted for by these differences. This raises an important question: "Among women in specific racial and ethnic groups, is their invasive breast cancer rate higher than we would expect within the Areas of Concern (or anywhere in California)?" Unfortunately, due to differences in data coding between CCR and the U.S. Bureau of the Census, this question is beyond our ability to answer.

What if the information in the project report conflicts with information in other reports?

The CBCMP report utilized the Scan Statistic to identify Areas of Concern; these areas may or may not include counties that have been identified in previous analyses as having significantly elevated rates. This is partly because—for mathematical reasons—Areas of Concern require higher standards for statistical significance than individual counties. Previously documented information about breast cancer rates in individual counties—including those based on more conventional statistical methods—is still valid and should not be considered undermined by the CBCMP results.

What if I live in one of the Areas of Concern identified in the report? What does this mean about my personal breast cancer risk?

A person's risk for developing breast cancer depends on multiple risk factors including genetics, lifestyle, and the environment. Only some of these factors have been discovered by scientists, and there may be additional factors waiting to be discovered. Therefore, it is very difficult to predict any individual's risk for developing breast cancer.

In this report, the risk (or rate) of breast cancer for an Area of Concern represents an *average risk* among all of the women living in that area. For each Area of Concern, the average rate was 10-20% higher than other parts of California during 2000-2008. Because of the risk factors mentioned above, your individual risk may be higher, lower, or the same as the overall risk for the Area of Concern in which you live. See Resources, below, to learn more about risk factors for breast cancer.

What if I don't live in one of the Areas of Concern identified in the report, yet I have reason to believe that women in my community may have an elevated breast cancer risk?

Taken as a group, the women in your county, city, or neighborhood may have a higher or lower breast cancer rate compared to California overall, regardless of whether they are included in the Areas of Concern. The only way to know for sure is to calculate the rate for the group of women in question, which someone with access to the appropriate data (usually a public agency) can do *only if the population is of a sufficient size to permit such a calculation*.

The CBCMP protocol is designed to identify areas with elevated rates of invasive breast cancer *without specifying their location, shape, or size in advance.* For example, these areas may be smaller than counties or they may extend across county boundaries. In order to be detected, these geographic areas must either have a sufficient size or have a sufficient increase in the breast cancer rate. For a group of 50 census tracts, the CBCMP protocol can reliably detect an invasive breast cancer rate if it is 50% above the state overall. The CBCMP protocol can detect a larger area with a smaller increase, and it can only detect a smaller area if the rate increase is higher than 50%.

It is possible that your community has a higher breast cancer risk than the state overall, but that it cannot be identified using either the CBCMP protocol or standard calculation methods. The CBCMP protocol requires a large enough geographic area or a large enough degree of risk elevation in order to detect an area of concern. Standard calculation methods require large enough numbers of breast cancer cases in order to determine risk in a reliable and accurate manner. Concerns about the collective risk for women in your community may still be valid, even if this risk cannot be measured.

RESOURCES

Where can I get more information about breast cancer in my area?

Your local public health department is usually the best place to start. They will likely have county level data, and in some cases sub-county level data. You may be referred to the California Cancer Registry (CCR),

especially in cases where sub-county data are requested. In many cases, you can access the data and information that you need through the CCR website, either through available reports or their online data tool.

Whom can I contact if I have questions about this report?

Staff from the Public Health Institute is available to answer questions about the CBCMP project and report. Contacts include Principal Investigator, Eric Roberts, MD, PhD (<u>eric.roberts@phi.org</u>) and Health Educator, Natalie Collins, MSW (<u>natalie.collins@phi.org</u>). Additionally, more information related to the report and project is located on the project website at <u>www.californiabreastcancermapping.org</u>.

Where can I get more information about breast cancer risk?

Advocacy and research organizations can answer many concerns related to breast cancer risk. Some common organizations and their resources are listed below:

American Cancer Society

Breast Cancer Overview www.cancer.org/Cancer/BreastCancer/OverviewGuide Breast Cancer Facts & Figures www.cancer.org/Research/CancerFactsFigures/BreastCancerFactsFigures Breast Cancer Risk Factors www.cancer.org/cancer/breastcancer/detailedguide/breast-cancer-risk-factors

Breast Cancer Fund

Understanding Environmental Links to Breast Cancer <u>www.breastcancerfund.org/clear-science</u> State of the Evidence 2010 <u>www.breastcancerfund.org/assets/pdfs/publications/state-of-the-evidence-2010.pdf</u> Reduce Your Risk www.breastcancerfund.org/reduce-your-risk

California Breast Cancer Research Program

Position Papers & Reports www.cbcrp.org/publications/papers

Where can I find additional breast cancer data?

Many government programs collect or provide breast cancer data. Additional public resources include the following:

National Cancer Institute Surveillance Epidemiology and End Results (SEER) www.seer.cancer.gov/canques

Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System (BRFSS) <u>https://apps.nccd.cdc.gov/BRFSS-SMART</u>

California Cancer Registry (CCR)

www.cancer-rates.info/ca/index.php

California Environmental Health Tracking Program (CEHTP) www.cehtp.org/p/cancer_query

California Health Information Survey (CHIS)

www.chis.ucla.edu

California Women's Health Survey (CWHS)

www.cdph.ca.gov/data/surveys/Pages/CWHS.aspx

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