

susan g. komen.  | **COMMUNITY**
PROFILE REPORT 2015



SUSAN G. KOMEN®
SOUTHERN NEW ENGLAND
CONNECTICUT SERVICE AREA

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Acknowledgments

The Community Profile Report could not have been accomplished without the exceptional work, effort, time and commitment from many people involved in the process.

Susan G. Komen® Southern New England would like to extend its deepest gratitude to the Board of Directors and the following individuals who participated on the 2015 Connecticut Community Profile Team:

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A special acknowledgement to the following entities for their assistance with data collection and analyses, as well as providing information included in this report.

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Komen Southern New England and the Community Profile Team are indebted to all the women, social workers and providers who shared their experiences and stories. The knowledge gained allowed the Affiliate to understand the challenges faced by people and families impacted by breast cancer. The recommendations in this report are a result of their story; it is our hope they will have a positive impact on breast education, screening and treatment in Connecticut.

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Executive Summary

Introduction to the Community Profile Report

In 1980, Susan G. Komen died of breast cancer at the age of 36. Before she died, her sister promised she would do everything in her power to end breast cancer forever. In 1982, that promise launched the breast cancer movement that became Susan G. Komen®. Today, Komen is the world's largest grassroots network of breast cancer survivors and activists. Komen has invested more than \$2.8 billion to fulfill the promise, becoming the largest resource of nonprofit funds dedicated to fighting breast cancer in the world.

While even a single case of breast cancer in any woman or man, anywhere, is one too many, Connecticut can claim the great misfortune of having one of the highest incidences of this disease of any state in the U.S. Fulfilling the Komen promise here isn't merely an objective, it's an imperative.

Since 1999, Susan G. Komen® Southern New England has worked tirelessly throughout the entire state of Connecticut to bring an end to this debilitating and sometimes deadly disease. To this end, the Affiliate engages in innovative outreach to underserved and at-risk populations; raises awareness across communities; conducts a competitive grant-making process; and organizes support for those currently and previously afflicted with breast cancer.

Susan G. Komen has awarded more than \$9 million for breast cancer research in Connecticut. Additionally, Susan G. Komen Southern New England has awarded nearly \$12 million to Connecticut organizations that provide breast cancer education, screening, diagnostics, treatment and support services. Excitingly, in recent years, the Affiliate added a second Race for the Cure and a Pink Tie Guy event to its list of fundraising activities, and also supports an annual equine "Ride for the Cure" events. The Affiliate anticipates an increase in funds through these activities to support the local fight against breast cancer.

Through its various educational efforts and grants, the Affiliate has touched the lives of an estimated 72,000 Connecticut women including the screening of approximately 12,000 women who did not otherwise have access to quality breast health services and screenings.

The task put before the Affiliate—providing education and funding screening, treatment and research in order to ultimately end breast cancer death in the state—is clearly a major one. The backbone for these undertakings is the Community Profile, which brings together quantitative and qualitative data from various stakeholders, as well as an analysis of current health systems and relevant policies. The information collected in this process provides insight into the actual breast health needs of women throughout the state, and simultaneously reveals potential new avenues for implementation of the Affiliate's mission. It is through analysis of this information that the Affiliate is able to establish its Mission Action Plan, set future Affiliate objectives and determine funding priorities for the coming years.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Solid, quantitative data is the foundation of the Community Profile. It allows for a meaningful and concise overview of the otherwise complex reality of breast cancer in Connecticut. Such data can aid in measuring the impact of this disease throughout the state, and ultimately provides evidence-based information to identify areas of high priority for Affiliate intervention.

Statistics for this report were obtained from the State of Connecticut Tumor Registry and the State of Connecticut Department of Health. Data for all 169 municipalities in the state were analyzed in terms of early-stage diagnosis, late-stage diagnosis, total incidence, late-stage incidence as a proportion of total incidence and death. Age-adjusted incidence and death rates were calculated. Towns with sample size irregularities or those with fewer than ten total cases of breast cancer were excluded from further inclusion in this report. Based upon the above analyses, five counties were identified as being at medium or medium-high risk of not meeting the Healthy People 2020 goals for reducing the rate of late-stage diagnosis and/or reducing the rate of death. These five counties—Fairfield, Hartford, Litchfield, New Haven and New London—are the focus of this Community Profile Report (Table 1). Within these areas of focus, a further investigation was undertaken in a total of 31 towns and cities in order to better understand the factors underlying the burden of disease.

Table 1. Counties with towns exhibiting high late-stage diagnosis and/or death rates

Statistically Identified Breast Cancer Priority	Community
High Late-Stage Diagnosis Rate	New London County
	Litchfield County
High Late-Stage Diagnosis Rate AND High Death Rate	Fairfield County
	New Haven County
	Hartford County

Connecticut is home to immense diversity and with it, immense disparity. Municipalities that are close in terms of physical location often had very different rates of breast cancer, sharing more in common with those more distant towns and cities which were more closely matched in terms of education, socioeconomics and racial and ethnic composition. Evidence suggests that while White women were far more likely to be diagnosed with breast cancer, Black/African-American women were significantly more likely to die from breast cancer if diagnosed. Such increased death may be related to higher late-stage diagnosis amongst Black/African-American and Hispanic/Latina women. Access to screening and to treatment for these populations may be hindered by such barriers as limited transportation options, the need for translation services, inadequate insurance and lack of breast health education. Socioeconomics and education also factored significantly in the burden of disease. Unsurprisingly, by and large those women in more affluent towns were found to be better educated, engaged in better health habits and had better access to clinical care than their counterparts in less affluent municipalities. This in turn leads to differential rates of late-stage diagnosis and death.

Health Systems and Public Policy Analysis

Early detection and breast cancer treatment is widely available within the Affiliate's service area. At most, when seeking breast cancer screenings and treatment, residents have a number of options of providers within a 20-mile radius. For medically underserved women, typically those with inadequate insurance coverage or those uninsured, various types of funds are available for breast cancer-related medical care. The Affiliate, through grants, has funded a number of providers to ensure that women access early detection screenings in a timely manner. In 2013 the income limit to obtain care through Connecticut Breast and Cervical Cancer Early Detection Program (CBCCEDP) was increased to those that fall under 250 percent of the federal poverty level. Through federal and state funding, the CBCCEDP educates and navigates between 8,500 and 9,000 women through the continuum of breast cancer care. The breast cancer continuum of care refers to how women ideally access early detection services and obtain treatment for breast cancer seamlessly. Breast health providers across the state began efforts in 2013 to improve their delivery of breast cancer care that ensures all women follow through with all services within the continuum of care.

Though services are available across the state, gaps that delay entrance into the continuum of care are present. Gaps noted in this document are related to various barriers faced in specific communities. For example, providers in Hartford, Fairfield and New Haven Counties reported financial barriers may be the root cause for patients declining diagnostic imaging. Among the barriers found to delay entrance into screening were issues such as limited time off of work and travel from rural areas into city centers where screening facilities are located. In Hartford, New London and Bridgeport Counties, individuals with limited English proficiency reported having difficulty communicating directly with screening providers in their native language. While some providers had interpreters, others rely on language interpretative services to communicate with patients with limited English. In Litchfield and New London Counties, mobile mammography units seldom provide services. In 2016, at least one mobile mammography service provider will increase services to these areas. Through grant efforts, funding will be allocated to support education, screening and culturally tailored navigation breast cancer programs. Through partnerships with the CBCCEDP the Affiliate will narrow its focus to support community-based navigation programs. Navigation programs have shown effectiveness in providing guidance through the health care system from diagnosis and into survivorship for breast cancer patients. Plans are also underway to develop and strengthen partnerships with 113 breast cancer providers based within the Affiliate service area. Combined efforts from all breast cancer service providers are necessary to ensure free and low-cost programs are promoted in all communities and accessible to all residents in the state.

Following the implementation of the Affordable Care Act it was believed that most residents would have enrolled into one of many newly available health insurance plans. Through interviews documented in this assessment it was brought to light that many remained uninsured. Though insurance was affordable, some Connecticut residents prioritized covering the cost of basic needs over health insurance. In urban areas like Hartford and Bridgeport, the high cost of living played a role in some residents declining coverage. The issue regarding high out-of-

pocket costs for diagnostic screening concerns the Affiliate. Connecticut was the first state to pass legislation requiring women with dense breast tissue to obtain diagnostic screenings. Women with tissue density greater than 50 percent with basic insurance plans may be required to cover high deductibles. The Affiliate and CBCCEDP, along with other breast cancer providers, can increase education about programs that will eliminate the financial burden and ensure women access all necessary screenings to prevent late-stage diagnoses of breast cancer.

The Affiliate's top advocacy priority is to develop a strategic plan to present pressing breast cancer issues to elected officials. At the top of the list is to address concerns over limitations for women with limited coverage for diagnostic screening needs, as Connecticut remains a restrictive Option 1 state. This prevents women diagnosed with breast cancer at a facility not funded by CBCCEDP from becoming eligible for cancer treatment under Medicaid. It is the Affiliate's goal to work with the legislature to become an Option 3 state. As an Option 3 state, regardless of where an uninsured resident is diagnosed, they would become eligible to have their treatment covered through Medicaid.

Qualitative Data: Ensuring Community Input

In an increasingly data-driven world, hard numbers and measured analyses are crucial in understanding the state of breast health in Connecticut. Yet, despite their accuracy, such data alone do not tell the full story. Qualitative data gives context to the information collected elsewhere in the Community Profile Report, ensures community input and allows for a more nuanced understanding of the topic. Balancing practical considerations with previous experience, the Profile's data collection team determined that focus groups, key informant interviews and written questionnaires would yield both the breadth and depth of insight needed to gain a better understanding of the barriers, needs and successes actually encountered on the front lines of Connecticut's battle against breast cancer.

Table 2 shows the total of 24 key informant interviews, along with 41 questionnaires, that were administered to care providers including oncology physicians and nurses, women's health practitioners, health educators, social workers, patient navigators and others. In addition, to ensure that the report reflects the experiences of those with this disease, six focus groups were conducted including 23 current breast cancer patients and survivors.

Table 2. Qualitative data methods

Format	Type of Participant	# of Participants	Location by County
Written Questionnaire	Physicians & Nurses Health Navigators Outreach Workers	41	Fairfield, Hartford, Litchfield, New Haven, New London
Key Informant Interview	Health Educators Social Workers Patient Navigators Oncology Specialists Radiology Techs	24	Fairfield, Hartford, Litchfield, New Haven, New London
Focus Group	Breast Cancer Patients & Survivors	6 Focus Groups with 23 participants	Fairfield, Hartford, Litchfield, New Haven, New London

All participant responses were professionally analyzed to determine what commonalities exist between them. Although each key informant interview, focus group comment and questionnaire response was unique, several broad themes emerged.

The electronic questionnaires were used to assess the strengths and weaknesses of the larger system of care found in the target communities. Items on these questionnaires center on the types of services offered; mechanisms of the system of care; characteristics of patients; and financial options available to patients. With respect to the strengths of the system of care, a broad array of services, including navigation, may be available to women, depending on their location. Most facilities offer some form of language accommodation, with Spanish translation being available in a majority of organizations. Nearly all service providers offered free or reduced-cost screening services for those in need, and three quarters of those who offered treatment services also provide financial assistance for such treatment.

The key informant interviews focused largely on the types of services available, gaps and barriers related to delivery of services and the process related to receiving services. By contrast, the six focus groups primarily engaged participants on breast cancer knowledge, early detection and barriers to accessing care. Despite differences in the questions posed in these two formats of participant engagement, there was continuity in the responses which they yielded. Financial concerns, primarily those surrounding un- and under-insurance; cost of deductibles; consequences of workplace absences; and competing budgetary imperatives were listed as important barriers to screening and care. Additionally, issues of lack of knowledge and awareness were emphasized in both the key informant interviews and in the focus groups. These include: the scarcity of community-accessible information regarding availability and importance of breast cancer screening, health illiteracy and insufficient emphasis on the need to know family breast cancer history. Results from the focus groups suggest that these factors may be largely rooted in cultural reluctance to openly discuss matters related to breast health even with fellow community members and medical professionals. This culturally-informed reticence may contribute to the false sense amongst some that breast cancer is not an important health issue in their community.

While important, these financial and awareness concerns were far from the only ones identified by the participants. Other noteworthy barriers included language and cultural issues; competing priorities in terms of time; difficulty with transportation to and from clinical services; fear of diagnosis; anxiety regarding interfacing with the medical establishment; and prioritization of other, more immediate health needs.

Mission Action Plan

The Community Profile is conducted to direct where the Affiliate should concentrate its human and financial resources; to determine how it should measure success moving forward; and to monitor change since the issuance of the last Community Profile.

Using methodological and source triangulation, the Affiliate has derived multiple Problem/Needs Statements for each county-level community within its area of service, reflecting the on-the-ground quantitative, qualitative and health systems challenges encountered there. Problem/Needs Statements focus primarily on death and late-stage diagnoses, availability and use of services and barriers to accessing care.

Extrapolated from these statements is a tailor-made, community-wide priority which sets a target towards which Affiliate and grantee efforts must be directed. In turn, specific, measurable, achievable, realistic and time-bound objectives will allow the stated priorities to be successfully pursued (Tables 3 and 4).

Table 3. Mission Action Plan for Fairfield County, Hartford County and New Haven County

Problem/Needs Statements	
Quantitative	Target communities of Fairfield and Hartford Counties were identified as having rising late-stage incidence rates. New Haven County had a higher death rate than the Affiliate service area as a whole.
Health Systems	Existing breast health and breast cancer services within the target communities were not utilized by many women in the target communities.
Qualitative	Financial issues, cultural and language issues, competing medical concerns, health and career responsibilities are obstacles women confront when accessing early detection health and breast cancer services.
Affiliate Action Plan	
Priority:	Reduce barriers to and increase use of existing breast health services in Fairfield, Hartford and New Haven Counties in order to reduce late-stage and death rates throughout cities and towns within these target communities.
Objectives:	<ol style="list-style-type: none"> 1. In FY2016-FY2019, solicit grant applications from organizations that will increase outreach and raise awareness about breast cancer screening services to all women in medically underserved communities in Fairfield, Hartford and New Haven Counties. 2. In FY2016-FY2019, solicit grant applications from organizations experienced in delivering messages about early detection and breast health resources to ethnically diverse women in the target

	<p>communities. Organizations would be required to offer bilingual services and culturally sensitive care to better meet the needs of women with multicultural backgrounds.</p> <ol style="list-style-type: none">3. By March 2016, develop survey and evaluation tools to collect qualitative data and further explore barriers that delay or prevent access to breast health services for women in urban centers of Fairfield County.4. In 2016 and 2018, hold biannual Lunch and Learns for community leaders in each community with the purpose of empowering participants to extend Komen’s breast health messaging and promote available early detection and navigation services in all neighborhoods throughout the target communities.5. By October 2016, host an annual breast health awareness workshop targeting Hispanic/Latina women in all target communities. Recruit Hispanic/Latino business and community leaders as well as grant funded program directors for an advisory committee that will lead efforts to host the event. The overall goal is to address fears and misconceptions about early detection.6. By March 2016, assemble a task force that will advise, plan and implement Affiliate educational activities. The task force will be responsible for organizing educational events and address issues that delay or prevent access to early detection services and/or delay entering the breast cancer continuum following an abnormal finding. Educational activities will be tailored for community and faith-based leaders with strong ties in Black/African-American and Hispanic/Latino communities in Hartford, Fairfield and New Haven Counties.7. In FY2016-FY2019, solicit grant proposals from organizations that seek to streamline existing breast health services and develop strategies to implement a fast-track process to ensure entrance into early detection services and seamless transition into diagnostic care or treatment.8. In FY 2016-FY2019, through grants, increase breast cancer survivorship programs that support women diagnosed with late-stage breast cancer diagnosis, including those with metastatic breast cancer. Grant funding will support navigation projects for patients in need of financial resources, medical supplies and psychosocial support services.9. In FY2016-FY2019, offer grant recipients professional development activities. Grantees will participate in round table discussions that will strengthen their collaborative efforts and open opportunities to share best practices.
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Table 4. Mission Action Plan for Litchfield County and New London County

Problem/Needs Statements:	
Quantitative	Target communities of Litchfield and New London Counties had rising late-stage incidence rates. New London County had a higher late-stage incidence rate than the Affiliate service area as a whole.
Health Systems	Breast cancer resources were limited in the target communities. Many breast health and breast cancer resources were located outside the target communities.
Qualitative	Residents within the target communities reported challenges accessing breast health and breast cancer services in close proximity to their place of residence.
Affiliate Action Plan	
Priority:	Increase availability of breast health resources for women in the target communities of New London County and New Milford (in Litchfield County) in order to reduce late-stage diagnosis in the two target communities.
Objectives:	<ol style="list-style-type: none"> 1. Increase consumer awareness of breast health and breast cancer services by distributing literature to women’s health medical practices located in Litchfield and New London Counties by July 2016. 2. Develop a Request for Proposals for the 2015-2019 grant terms to solicit grant applicants that will increase availability and access to screening and patient navigation services in Litchfield and New London Counties. Grant funds will support evidence-based programs that ensure breast health services are available to medically underserved communities. 3. In FY2016-FY2019 through biannual Lunch and Learn activities for providers in Litchfield and New London Counties, present Community Profile data that specifically targets women in their service area. Providers that demonstrate a capacity to educate, screen or provide breast cancer services will be informed of the availability of Komen Community Grants.

Disclaimer: Comprehensive data for the Executive Summary can be found in the 2015 Susan G. Komen® Southern New England Community Profile Report for Connecticut.

Introduction

Affiliate History

In 1980, Susan G. Komen died of breast cancer at the age of 36. Before she died, her sister promised she would do everything in her power to end breast cancer forever. In 1982, that promise launched the breast cancer movement that became Susan G. Komen®. Today, Komen® is the world's largest grassroots network of breast cancer survivors and activists. Komen has invested more than \$2.6 billion to fulfill that promise, becoming the largest source of nonprofit funds dedicated to fighting breast cancer in the world.

In 1994, the first Komen Race for the Cure® was held in Connecticut, and six years later, on October 4, 1999, Susan G. Komen® Connecticut was established. Today, Komen® Southern New England works throughout Connecticut to fulfill the promise — to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures.

Komen Southern New England's work focuses on educating the community about breast health and breast cancer. Securing funds to make screening and treatment available to all residents of Connecticut is the Affiliate's highest priority. The Affiliate's Board of Directors, staff and volunteers are committed to raising funds that support women in Connecticut and fund breast cancer research. Since its inception, the Affiliate has invested over \$23 million in Connecticut to educate, expand access to screening and treatment and contribute to local and national research.

From 2006 to 2010, Connecticut had the highest breast cancer incidence rate in the nation of all the states. Responding to needs presented in the 2011 Community Profile, the Affiliate enabled 70 breast cancer providers to enhance services, including outreach and education, patient navigation and screening. As a result, over 60,000 women are well acquainted with Komen breast self-awareness practices and follow age-appropriate breast cancer screening practices. Community grant award recipients took an additional step by screening nearly 12,000 women who did not otherwise have access to quality breast health and screenings.

Affiliate Organizational Structure

Komen Southern New England's Connecticut office is in Farmington, Connecticut. The organizational components of the Affiliate are the Board of Directors, the Executive Committee, and staff. An 11-member Board of Directors, works with a Connecticut-based seven-person staff, five full time and two part time, to fulfill the Komen promise locally: to save lives and end breast cancer forever. Figure 1.1 depicts the Affiliate's Connecticut-based organizational structure.

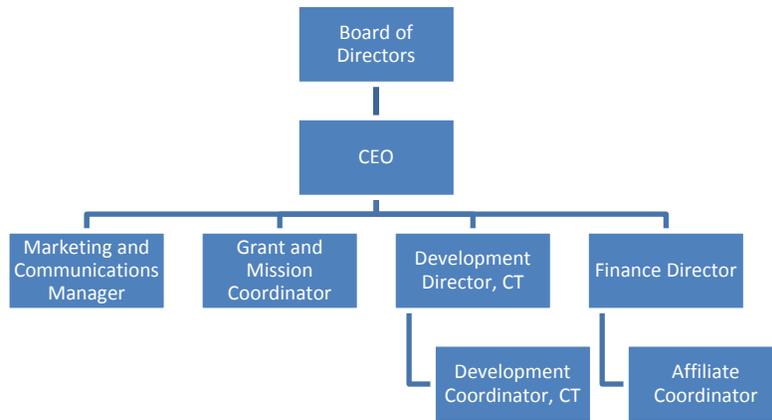


Figure 1.1. Komen Southern New England Connecticut office organizational chart

Affiliate Service Area

Nationwide, Connecticut is the third-smallest state and encompasses a spectrum from extreme wealth to poverty; it has the second largest disparity between poverty and wealth of all fifty states. There are approximately 3.5 million people residing in Connecticut according to the 2013 U.S. Census estimate. Table 1.1 presents a demographic profile of the state.

Table 1.1. Demographic profile of Connecticut

Demographic Description	Measure	
Total Population	3,596,80	
Median Household Income	\$69,461	
Individuals living below the federal poverty line	10.2%	
Percent of population 65 years or older	15.2%	
Ethnic Breakdown of the State Population	White	81.6%
	Black/African-American	11.3%
	Asian	4.3%
	American Indian	0.5%
	Hispanic/Latino	14.7%

State and County Quick Facts, 2013 U.S. Census Bureau

The Affiliate serves the entire state of Connecticut, from Greenwich in the southwest, Salisbury in the northwest, Thompson in the northeast and Stonington in the southeast. Connecticut is bordered by New York to the West, Massachusetts to the North, Rhode Island to the East and the Long Island Sound to the South. Figure 1.2 depicts the Affiliate service area.

KOMEN SOUTHERN NEW ENGLAND SERVICE AREA IN CONNECTICUT

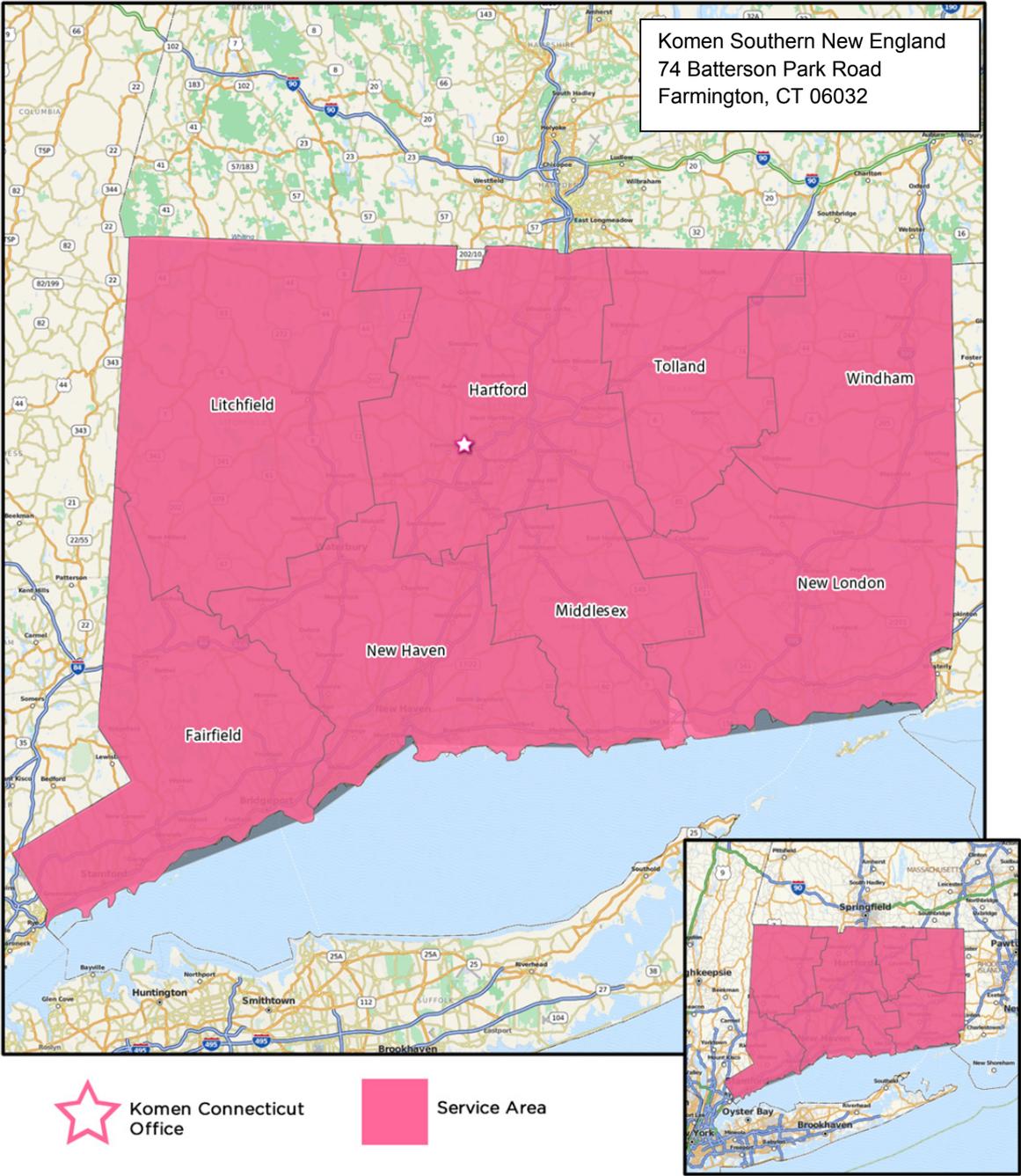


Figure 1.2. Susan G. Komen Southern New England service area in Connecticut

Purpose of the Community Profile Report

The Community Profile will align community outreach, grant-making and public policy activities. The Affiliate relies on information obtained through the Community Profile process to establish priorities and guide its work in Connecticut. This report intends to describe the varied breast health needs in the state as well as potential areas where the Affiliate's programs and funding advance the network's promise of ending breast cancer. Promising opportunities and areas of interest have been drawn from the analyses of breast cancer statistics, policies and programs in the state that may impact breast health and exploratory, primary data collection among providers and breast cancer survivors in the state. After synthesizing data from various sources, this report presents data-driven priority areas from which the Affiliate intends to develop funding decisions for the fiscal years 201-2019.

The Community Profile enables the Affiliate to:

- Include a broad range of people and stakeholders in the Affiliate's work and become more diverse.
- Fund, educate and build awareness in the areas of greatest need.
- Make data-driven decisions about how to use resources in the best way, making the greatest impact.
- Strengthen relationships with sponsors by clearly communicating the breast health and breast cancer needs of the communities.
- Provide information to public policymakers to better understand the true need for their support.
- Strategize direction of marketing and outreach programs toward areas of greatest need.
- Create synergy between Mission-related strategic plans and operational activities.

The Affiliate Board of Directors, staff and volunteers will distribute the 2015 Community Profile in the communities of interest to providers of women's health services and legislators across the state. The Affiliate will mobilize current and formerly-funded grantees to expand distribution within the communities they serve. An electronic version of the document will remain on the Affiliate website through 2019.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Quantitative Data Report

Introduction

The purpose of the Connecticut quantitative data report for Komen Southern New England is to combine evidence from many credible sources and use the data to identify the highest priority areas for evidence-based breast cancer programs.

The data provided in the report are used to identify priorities within the Affiliate's service area based on estimates of how long it would take an area to achieve Healthy People 2020 objectives for breast cancer late-stage diagnosis and death rates (<http://www.healthypeople.gov/2020/default.aspx>).

The following is a summary of Komen Southern New England's Quantitative Data Report for Connecticut. For a full report please contact the Affiliate.

Breast Cancer Statistics

Incidence rates

The breast cancer incidence rate shows the frequency of new cases of breast cancer among women living in an area during a certain time period (Table 2.1). Incidence rates may be calculated for all women or for specific groups of women (e.g. for Asian/Pacific Islander women living in the area).

The female breast cancer incidence rate is calculated as the number of females in an area who were diagnosed with breast cancer divided by the total number of females living in that area. Incidence rates are usually expressed in terms of 100,000 people. For example, suppose there are 50,000 females living in an area and 60 of them are diagnosed with breast cancer during a certain time period. Sixty out of 50,000 is the same as 120 out of 100,000. So the female breast cancer incidence rate would be reported as 120 per 100,000 for that time period.

When comparing breast cancer rates for an area where many older people live to rates for an area where younger people live, it's hard to know whether the differences are due to age or whether other factors might also be involved. To account for age, breast cancer rates are usually adjusted to a common standard age distribution. Using age-adjusted rates makes it possible to spot differences in breast cancer rates caused by factors other than differences in age between groups of women.

To show trends (changes over time) in cancer incidence, data for the annual percent change in the incidence rate over a five-year period were included in the report. The annual percent change is the average year-to-year change of the incidence rate. It may be either a positive or negative number.

- A negative value means that the rates are getting lower.

- A positive value means that the rates are getting higher.
- A positive value (rates getting higher) may seem undesirable—and it generally is. However, it's important to remember that an increase in breast cancer incidence could also mean that more breast cancers are being found because more women are getting mammograms. So higher rates don't necessarily mean that there has been an increase in the occurrence of breast cancer.

Death rates

The breast cancer death rate shows the frequency of death from breast cancer among women living in a given area during a certain time period (Table 2.1). Like incidence rates, death rates may be calculated for all women or for specific groups of women (e.g. Black/African-American women).

The death rate is calculated as the number of women from a particular geographic area who died from breast cancer divided by the total number of women living in that area. Death rates are shown in terms of 100,000 women and adjusted for age.

Data are included for the annual percent change in the death rate over a five-year period.

The meanings of these data are the same as for incidence rates, with one exception. Changes in screening don't affect death rates in the way that they affect incidence rates. So a negative value, which means that death rates are getting lower, is always desirable. A positive value, which means that death rates are getting higher, is always undesirable.

Late-stage incidence rates

For this report, late-stage breast cancer is defined as regional or distant stage using the Surveillance, Epidemiology and End Results (SEER) Summary Stage definitions (<http://seer.cancer.gov/tools/ssm/>). State and national reporting usually uses the SEER Summary Stage. It provides a consistent set of definitions of stages for historical comparisons.

The late-stage breast cancer incidence rate is calculated as the number of women with regional or distant breast cancer in a particular geographic area divided by the number of women living in that area (Table 2.1). Late-stage incidence rates are shown in terms of 100,000 women and adjusted for age.

Table 2.1. Female breast cancer incidence rates and trends, death rates and trends, and late-stage rates and trends

Population Group	Incidence Rates and Trends				Death Rates and Trends			Late-stage Rates and Trends		
	Female Population (Annual Average)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of Deaths (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)
US	154,540,194	182,234	122.1	-0.2%	40,736	22.6	-1.9%	64,590	43.8	-1.2%
HP2020	-	-	-	-	-	20.6*	-	-	41.0*	-
Komen Southern New England Service Area in Connecticut (State of Connecticut)	1,820,737	2,972	136.3	0.6%	507	21.6	-2.3%	958	44.6	0.0%
White	1,529,071	2,688	138.9	0.7%	455	21.3	-2.3%	845	44.5	0.6%
Black/African-American	210,313	202	110.9	-0.3%	46	27.0	-2.0%	81	42.8	-7.0%
American Indian/Alaska Native (AIAN)	9,202	4	54.5	20.8%	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	72,152	39	73.1	3.5%	5	10.1	NA	16	28.1	-1.4%
Non-Hispanic/ Latina	1,597,328	2,799	137.7	0.9%	492	22.1	NA	892	44.7	0.4%
Hispanic/ Latina	223,409	173	119.6	-2.5%	15	11.9	-0.9%	66	42.2	-2.8%
Fairfield County - CT	465,677	780	143.0	3.8%	123	20.9	-2.4%	250	46.2	0.6%
Hartford County - CT	459,018	741	132.6	1.7%	130	21.4	-2.6%	232	42.1	0.2%
Litchfield County - CT	96,621	163	128.0	-2.8%	29	21.5	-1.6%	54	43.6	1.5%
Middlesex County - CT	84,296	155	144.3	-1.4%	22	20.4	-1.2%	49	46.4	1.7%
New Haven County - CT	444,271	715	135.3	-1.0%	137	23.6	-2.1%	235	45.5	-1.8%
New London County - CT	136,638	226	137.0	0.0%	36	20.7	-2.5%	77	47.9	3.5%
Tolland County - CT	74,859	108	130.9	-5.7%	17	20.8	-3.3%	32	38.6	-4.1%
Windham County - CT	59,356	84	123.4	-2.8%	12	17.2	-1.7%	29	42.0	-3.4%

*Target as of the writing of this report.

NA – data not available

SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period).

Data are for years 2006-2010.

Rates are in cases or deaths per 100,000.

Age-adjusted rates are adjusted to the 2000 U.S. standard population.

Source of incidence and late-stage data: North American Association of Central Cancer Registries (NAACCR) – Cancer in North America (CINA) Deluxe Analytic File.

Source of death rate data: Centers for Disease Control and Prevention (CDC) – National Center for Health Statistics (NCHS) death data in SEER*Stat.

Source of death trend data: National Cancer Institute (NCI)/CDC State Cancer Profiles.

Incidence rates and trends summary

Overall, the breast cancer incidence rates and trends in Connecticut were higher than that observed in the U.S. as a whole.

For the United States, breast cancer incidence in Blacks/African-Americans is lower than in Whites overall. The most recent estimated breast cancer incidence rates for Asian/Pacific Islanders (APIs) and American Indian and Alaska Natives (AIANs) were lower than for Non-Hispanic Whites and Blacks/African-Americans. The most recent estimated incidence rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the incidence rate was lower among Blacks/African-Americans than Whites, lower among APIs than Whites, and lower among AIANs than Whites. The incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas. None of the counties in the Affiliate service area had substantially different incidence rates than the Affiliate service area as a whole.

It's important to remember that an increase in breast cancer incidence could also mean that more breast cancers are being found because more women are getting mammograms.

Death rates and trends summary

Overall, the breast cancer death rate and trend in Connecticut were slightly lower than that observed in the U.S. as a whole.

For the United States, breast cancer death rates in Blacks/African-Americans are substantially higher than in Whites overall. The most recent estimated breast cancer death rates for APIs and AIANs were lower than for Non-Hispanic Whites and Blacks/African-Americans. The most recent estimated death rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the death rate was higher among Blacks/African-Americans than Whites and lower among APIs than Whites. There were not enough data available within the Affiliate service area to report on AIANs so comparisons cannot be made for this racial group. The death rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

None of the counties in the Affiliate service area had substantially different death rates than the Affiliate service area as a whole.

Late-stage incidence rates and trends summary

Overall, the breast cancer late-stage incidence rate in Connecticut was similar to that observed in the U.S. as a whole and the late-stage incidence trend was higher than the U.S. as a whole. For the United States, late-stage incidence rates in Blacks/African-Americans are higher than among Whites. Hispanics/Latinas tend to be diagnosed with late-stage breast cancers more often than Whites. For the Affiliate service area as a whole, the late-stage incidence rate was slightly lower among Blacks/African-Americans than Whites and lower among APIs than Whites.

There were not enough data available within the Affiliate service area to report on AIANs so comparisons cannot be made for this racial group. The late-stage incidence rate among Hispanics/Latinas was slightly lower than among Non-Hispanics/Latinas.

None of the counties in the Affiliate service area had substantially different late-stage incidence rates than the Affiliate service area as a whole.

Mammography Screening

Getting regular screening mammograms (and treatment if diagnosed) lowers the risk of dying from breast cancer. Screening mammography can find breast cancer early, when the chances of survival are highest. Table 2.2 shows some screening recommendations among major organizations for women at average risk.

Table 2.2. Breast cancer screening recommendations for women at average risk*

American Cancer Society	National Comprehensive Cancer Network	US Preventive Services Task Force
<p>Informed decision-making with a health care provider at age 40</p> <p>Mammography every year starting at age 45</p> <p>Mammography every other year beginning at age 55</p>	<p>Mammography every year starting at age 40</p>	<p>Informed decision-making with a health care provider ages 40-49</p> <p>Mammography every 2 years ages 50-74</p>

*As of October 2015

Because having regular mammograms lowers the chances of dying from breast cancer, it's important to know whether women are having mammograms when they should. This information can be used to identify groups of women who should be screened or who need help in meeting the current recommendations for screening mammography. The Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factors Surveillance System (BRFSS) collected the data on mammograms that are used in this report. The data come from interviews with women aged 50 to 74 from across the United States. During the interviews, each woman was asked how long it has been since she has had a mammogram. The proportions in Table 2.3 are based on the number of women aged 50 to 74 who reported in 2012 having had a mammogram in the last two years.

The data have been weighted to account for differences between the women who were interviewed and all the women in the area. For example, if 20.0 percent of the women interviewed are Hispanic/Latina, but only 10.0 percent of the total women in the area are Hispanic/Latina, weighting is used to account for this difference.

The report uses the mammography screening proportion to show whether the women in an area are getting screening mammograms when they should. Mammography screening proportion is calculated from two pieces of information:

- The number of women living in an area whom the BRFSS determines should have mammograms (i.e. women aged 50 to 74).
- The number of these women who actually had a mammogram during the past two years.

The number of women who had a mammogram is divided by the number who should have had one. For example, if there are 500 women in an area who should have had mammograms and 250 of those women actually had a mammogram in the past two years, the mammography screening proportion is 50.0 percent.

Because the screening proportions come from samples of women in an area and are not exact, Table 2.3 includes confidence intervals. A confidence interval is a range of values that gives an idea of how uncertain a value may be. It's shown as two numbers—a lower value and a higher one. It is very unlikely that the true rate is less than the lower value or more than the higher value.

For example, if screening proportion was reported as 50.0 percent, with a confidence interval of 35.0 to 65.0 percent, the real rate might not be exactly 50.0 percent, but it's very unlikely that it's less than 35.0 or more than 65.0 percent.

In general, screening proportions at the county level have fairly wide confidence intervals. The confidence interval should always be considered before concluding that the screening proportion in one county is higher or lower than that in another county.

Table 2.3. Proportion of women aged 50 to74 with screening mammography in the last two years, self-report

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
US	174,796	133,399	77.5%	77.2%-77.7%
Komen Southern New England Service Area in Connecticut (State of Connecticut)	3,147	2,575	81.5%	79.8%-83.1%
White	2,785	2,274	81.3%	79.5%-83.0%
Black/African-American	212	181	84.1%	76.8%-89.4%
AIAN	20	15	71.5%	40.9%-90.1%
API	19	17	87.8%	63.3%-96.8%
Hispanic/ Latina	125	102	79.9%	69.3%-87.4%
Non-Hispanic/ Latina	3,008	2,463	81.7%	79.9%-83.2%
Fairfield County - CT	693	558	77.8%	73.9%-81.2%
Hartford County - CT	670	561	84.5%	80.9%-87.6%
Litchfield County - CT	250	197	84.5%	78.6%-89.0%
Middlesex County - CT	120	100	82.6%	73.0%-89.2%
New Haven County - CT	703	563	80.9%	77.0%-84.3%
New London County - CT	368	310	82.0%	76.8%-86.2%
Tolland County - CT	118	96	81.4%	71.5%-88.4%
Windham County - CT	80	66	83.1%	70.8%-90.9%

Data are for 2012.

Source: CDC – Behavioral Risk Factor Surveillance System (BRFSS).

Breast cancer screening proportions summary

The breast cancer screening proportion in Connecticut was significantly higher than that observed in the U.S. as a whole.

For the United States, breast cancer screening proportions among Blacks/African-Americans are similar to those among Whites overall. APIs have somewhat lower screening proportions than Whites and Blacks/African-Americans. Although data are limited, screening proportions among AIANs are similar to those among Whites. Screening proportions among Hispanics/Latinas are similar to those among Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the screening proportion was not significantly different among Blacks/African-Americans than Whites, not significantly different among APIs than Whites, and not significantly different among AIANs than Whites. The screening proportion among Hispanics/Latinas was not significantly different than among Non-Hispanics/Latinas.

None of the counties in the Affiliate service area had substantially different screening proportions than the Affiliate service area as a whole.

Population Characteristics

The report includes basic information about the women in each area (demographic measures) and about factors like education, income, and unemployment (socioeconomic measures) in the areas where they live (Tables 2.4 and 2.5). Demographic and socioeconomic data can be used to identify which groups of women are most in need of help and to figure out the best ways to help them.

It is important to note that the report uses the race and ethnicity categories used by the U.S. Census Bureau, and that race and ethnicity are separate and independent categories. This means that everyone is classified as both a member of one of the four race groups as well as either Hispanic/Latina or Non-Hispanic/Latina.

The demographic and socioeconomic data in this report are the most recent data available for U.S. counties. All the data are shown as percentages. However, the percentages weren't all calculated in the same way.

- The race, ethnicity, and age data are based on the total female population in the area (e.g. the percent of females over the age of 40).
- The socioeconomic data are based on all the people in the area, not just women.
- Income, education and unemployment data don't include children. They're based on people aged 15 and older for income and unemployment and aged 25 and older for education.
- The data on the use of English, called "linguistic isolation", are based on the total number of households in the area. The Census Bureau defines a linguistically isolated household as one in which all the adults have difficulty with English.

Table 2.4. Population characteristics – demographics

Population Group	White	Black /African-American	AIAN	API	Non-Hispanic /Latina	Hispanic /Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
US	78.8 %	14.1 %	1.4 %	5.8 %	83.8 %	16.2 %	48.3 %	34.5 %	14.8 %
Komen Southern New England Service Area in Connecticut (State of Connecticut)	83.1 %	12.0 %	0.6 %	4.3 %	86.6 %	13.4 %	52.4 %	37.2 %	16.2 %
Fairfield County - CT	81.3 %	12.9 %	0.5 %	5.3 %	83.4 %	16.6 %	51.6 %	35.6 %	15.4 %
Hartford County - CT	79.2 %	15.5 %	0.5 %	4.7 %	84.4 %	15.6 %	52.3 %	37.6 %	16.7 %
Litchfield County - CT	95.8 %	1.9 %	0.3 %	2.0 %	95.4 %	4.6 %	59.0 %	42.8 %	18.1 %
Middlesex County - CT	91.1 %	5.6 %	0.2 %	3.0 %	95.2 %	4.8 %	56.8 %	41.0 %	17.5 %
New Haven County - CT	80.6 %	14.8 %	0.5 %	4.0 %	85.0 %	15.0 %	51.4 %	37.0 %	16.4 %
New London County - CT	86.7 %	7.1 %	1.3 %	4.9 %	91.5 %	8.5 %	53.3 %	38.2 %	16.4 %
Tolland County - CT	92.5 %	3.3 %	0.3 %	3.9 %	95.8 %	4.2 %	49.5 %	34.6 %	13.4 %
Windham County - CT	94.7 %	3.0 %	0.7 %	1.6 %	90.5 %	9.5 %	51.3 %	36.4 %	14.8 %

Data are for 2011.

Data are in the percentage of women in the population.

Source: U.S. Census Bureau – Population Estimates

Table 2.5. Population characteristics – socioeconomics

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistic-ally Isolated	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age: 40-64)
US	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
Komen Southern New England Service Area in Connecticut (State of Connecticut)	11.4 %	9.5 %	22.0 %	8.5 %	13.3 %	5.2 %	12.0 %	6.4 %	9.7 %
Fairfield County - CT	11.6 %	8.3 %	18.9 %	8.5 %	20.1 %	7.2 %	4.6 %	5.9 %	11.1 %
Hartford County - CT	12.7 %	11.0 %	24.5 %	9.0 %	14.4 %	6.4 %	5.4 %	6.1 %	9.8 %
Litchfield County - CT	8.7 %	6.1 %	19.6 %	7.1 %	6.3 %	2.0 %	41.4 %	0.0 %	8.6 %
Middlesex County - CT	7.0 %	5.9 %	17.4 %	6.3 %	7.6 %	1.5 %	24.5 %	0.9 %	7.6 %
New Haven County - CT	12.2 %	11.4 %	24.9 %	9.3 %	11.6 %	5.1 %	3.6 %	11.4 %	9.9 %
New London County - CT	9.9 %	7.7 %	21.9 %	6.9 %	8.5 %	3.2 %	25.8 %	7.7 %	8.6 %
Tolland County - CT	7.6 %	6.7 %	14.7 %	6.2 %	6.7 %	0.9 %	38.2 %	0.0 %	6.6 %
Windham County - CT	14.5 %	10.9 %	27.2 %	10.3 %	4.6 %	4.1 %	49.8 %	0.0 %	9.7 %

Data are in the percentage of people (men and women) in the population.

Source of health insurance data: U.S. Census Bureau – Small Area Health Insurance Estimates (SAHIE) for 2011.

Source of rural population data: U.S. Census Bureau – Census 2010.

Source of medically underserved data: Health Resources and Services Administration (HRSA) for 2013.

Source of other data: U.S. Census Bureau – American Community Survey (ACS) for 2007-2011.

Population characteristics summary

Proportionately, Connecticut has a slightly larger White female population than the U.S. as a whole, a slightly smaller Black/African-American female population, a slightly smaller Asian and Pacific Islander (API) female population, a slightly smaller American Indian and Alaska Native (AIAN) female population, and a slightly smaller Hispanic/Latina female population. The Affiliate’s female population is slightly older than that of the U.S. as a whole. The Affiliate’s education level is slightly higher than and income level is slightly higher than those of the U.S. as a whole. There are a slightly smaller percentage of people who are unemployed in the Affiliate service area. The Affiliate service area has a slightly larger percentage of people who are foreign born and a slightly larger percentage of people who are linguistically isolated. There are a substantially smaller percentage of people living in rural areas, a substantially smaller percentage of people without health insurance, and a substantially smaller percentage of people living in medically underserved areas.

None of the counties in the Affiliate service area have substantially different population characteristics than the Affiliate service area as a whole.

Priority Areas

Healthy People 2020 forecasts

Healthy People 2020 (HP2020) is a major federal government initiative that provides specific health objectives for communities and for the country as a whole. Many national health organizations use HP2020 targets to monitor progress in reducing the burden of disease and improve the health of the nation. Likewise, Komen believes it is important to refer to HP2020 to see how areas across the country are progressing towards reducing the burden of breast cancer.

HP2020 has several cancer-related objectives, including:

- Reducing women's death rate from breast cancer (Target as of the writing of this report: 20.6 cases per 100,000 women).
- Reducing the number of breast cancers that are found at a late-stage (Target as of the writing of this report: 41.0 cases per 100,000 women).

To see how well counties in the Affiliate service area are progressing toward these targets, the report uses the following information:

- County breast cancer death rate and late-stage diagnosis data for years 2006 to 2010.
- Estimates for the trend (annual percent change) in county breast cancer death rates and late-stage diagnoses for years 2006 to 2010.
- Both the data and the HP2020 target are age-adjusted.

These data are used to estimate how many years it will take for each county to meet the HP2020 objectives. Because the target date for meeting the objective is 2020, and 2008 (the middle of the 2006-2010 period) was used as a starting point, a county has 12 years to meet the target.

Death rate and late-stage diagnosis data and trends are used to calculate whether an area will meet the HP2020 target, assuming that the trend seen in years 2006 to 2010 continues for 2011 and beyond.

Identification of priority areas

The purpose of this report is to combine evidence from many credible sources and use the data to identify the highest priority areas for breast cancer programs (i.e. the areas of greatest need). Classification of priority areas are based on the time needed to achieve HP2020 targets in each area. These time projections depend on both the starting point and the trends in death rates and late-stage incidence.

Late-stage incidence reflects both the overall breast cancer incidence rate in the population and the mammography screening coverage. The breast cancer death rate reflects the access to care and the quality of care in the health care delivery area, as well as cancer stage at diagnosis.

There has not been any indication that either one of the two HP2020 targets is more important than the other. Therefore, the report considers them equally important.

Counties are classified as follows (Table 2.6):

- Counties that are not likely to achieve either of the HP2020 targets are considered to have the highest needs.
- Counties that have already achieved both targets are considered to have the lowest needs.
- Other counties are classified based on the number of years needed to achieve the two targets.

Table 2.6. Needs/priority classification based on the projected time to achieve HP2020 breast cancer targets

		Time to Achieve Late-stage Incidence Reduction Target				
		13 years or longer	7-12 yrs.	0 – 6 yrs.	Currently meets target	Unknown
Time to Achieve Death Rate Reduction Target	13 years or longer	Highest	High	Medium High	Medium	Highest
	7-12 yrs.	High	Medium High	Medium	Medium Low	Medium High
	0 – 6 yrs.	Medium High	Medium	Medium Low	Low	Medium Low
	Currently meets target	Medium	Medium Low	Low	Lowest	Lowest
	Unknown	Highest	Medium High	Medium Low	Lowest	Unknown

If the time to achieve a target cannot be calculated for one of the HP2020 indicators, then the county is classified based on the other indicator. If both indicators are missing, then the county is not classified. This doesn't mean that the county may not have high needs; it only means that sufficient data are not available to classify the county.

Affiliate Service Area Healthy People 2020 Forecasts and Priority Areas

The results presented in Table 2.7 help identify which counties have the greatest needs when it comes to meeting the HP2020 breast cancer targets.

- For counties in the “13 years or longer” category, current trends would need to change to achieve the target.
- Some counties may currently meet the target but their rates are increasing and they could fail to meet the target if the trend is not reversed.

Trends can change for a number of reasons, including:

- Improved screening programs could lead to breast cancers being diagnosed earlier, resulting in a decrease in both late-stage incidence rates and death rates.
- Improved socioeconomic conditions, such as reductions in poverty and linguistic isolation could lead to more timely treatment of breast cancer, causing a decrease in death rates.

The data in this table should be considered together with other information on factors that affect breast cancer death rates such as screening percentages and key breast cancer death determinants such as poverty and linguistic isolation.

Table 2.7. Intervention priorities for Komen Southern New England service area in Connecticut with predicted time to achieve the HP2020 breast cancer targets and key population characteristics

County	Priority	Predicted Time to Achieve Death Rate Target	Predicted Time to Achieve Late-stage Incidence Target	Key Population Characteristics
Fairfield County - CT	Medium High	1 year	13 years or longer	Foreign
Hartford County - CT	Medium High	2 years	13 years or longer	
Litchfield County - CT	Medium High	3 years	13 years or longer	Rural
New London County - CT	Medium High	1 year	13 years or longer	Rural
Middlesex County - CT	Medium	Currently meets target	13 years or longer	Rural
New Haven County - CT	Medium	7 years	6 years	
Tolland County - CT	Low	1 year	Currently meets target	Rural
Windham County - CT	Low	Currently meets target	1 year	Rural

Map of Intervention Priority Areas

Figure 2.1 shows a map of the intervention priorities for the counties in the Affiliate service area.

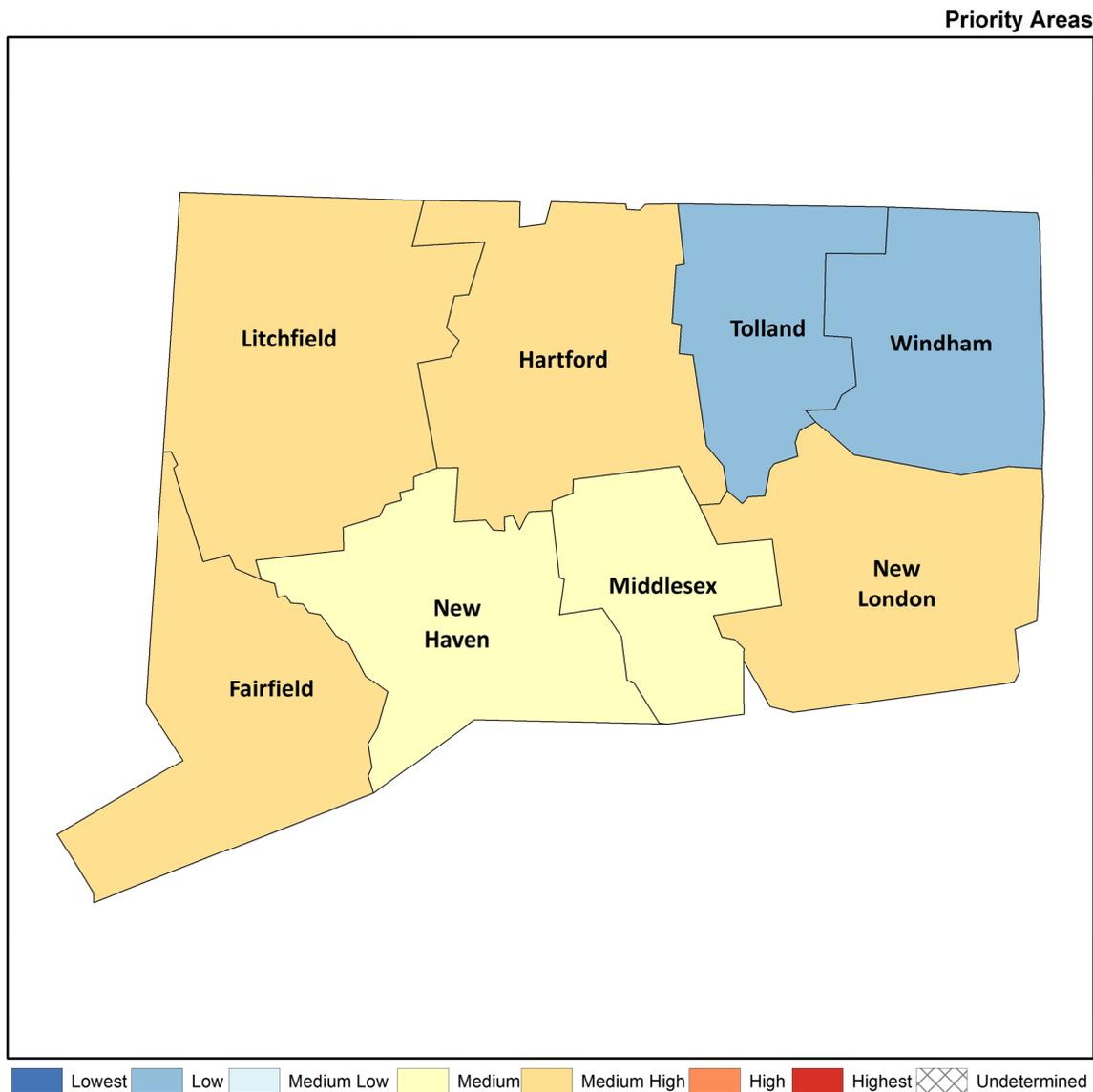


Figure 2.1. Intervention priorities

Data Limitations

The following data limitations need to be considered when utilizing the data of the Quantitative Data Report:

- The most recent data available were used but, for cancer incidence and deaths, these data are still several years behind.
- For some areas, data might not be available or might be of varying quality.
- Areas with small populations might not have enough breast cancer cases or breast cancer deaths each year to support the generation of reliable statistics.

- There are often several sources of cancer statistics for a given population and geographic area; therefore, other sources of cancer data may result in minor differences in the values even in the same time period.
- Data on cancer rates for specific racial and ethnic subgroups such as Somali, Hmong, or Ethiopian are not generally available.
- The various types of breast cancer data in this report are inter-dependent.
- There are many factors that impact breast cancer risk and survival for which quantitative data are not available. Some examples include family history, genetic markers like HER2 and BRCA, other medical conditions that can complicate treatment, and the level of family and community support available to the patient.
- The calculation of the years needed to meet the HP2020 objectives assume that the current trends will continue until 2020. However, the trends can change for a number of reasons.
- Not all breast cancer cases have a stage indication.

Quantitative Data Report Conclusions

Medium high priority areas

Four counties in the Affiliate service area are in the medium high priority category. All of the four, Fairfield County, Hartford County, Litchfield County and New London County, are not likely to meet the late-stage incidence rate HP2020 target.

Fairfield County has a relatively large foreign-born population. In Litchfield County and New London County a relatively large proportion of the population is living in rural areas.

Medium priority areas

Two counties in the Affiliate service area are in the medium priority category. One of the two, Middlesex County is not likely to meet the late-stage incidence rate HP2020 target. The other, New Haven County is expected to take seven years to reach the death rate HP2020 target.

The incidence rates in Middlesex County (144.3 per 100,000) appear to be higher than the Affiliate service area as a whole (136.3 per 100,000) although not significantly. The death rates in New Haven County (23.6 per 100,000) appear to be higher than the Affiliate service area as a whole (21.6 per 100,000) although not significantly. The late-stage incidence trends in Middlesex County (1.7 percent per year) indicate that late-stage incidence rates may be increasing.

In Middlesex County a relatively large proportion of the population is living in rural areas.

Additional Quantitative Data Exploration

Komen Southern New England has utilized data reports provided by the Connecticut Department of Public Health Tumor Registry to complete the quantitative section of this report.

In accordance with Healthy People 2020 (HP2020), the Affiliate has selected five Medium to Medium-High Risk areas of interest. Litchfield, Fairfield, Hartford, and New London counties are at Medium-High risk of not meeting the HP2020 goals of reducing high rates of late-stage incidence of breast cancer. New Haven County is a Medium priority county based on the HP2020 targets for reducing breast cancer deaths and late-stage incidence. The areas chosen to be highlighted in this community profile were done so through analysis of data obtained from the Connecticut Vital Statistics Section for the years of 2006 through 2010 in conjunction with data obtained from the State of Connecticut Tumor Registry from 2007 through 2011. Data were then analyzed to pinpoint areas where breast cancer presents the greatest burden to society.

Connecticut is comprised of eight counties, consisting of 169 municipalities and 77 local health departments or local health districts. Items assessed in the data analysis included: late-stage tumor incidence (categorized as initial diagnosis at stage III or stage IV), early-stage tumor incidence (categorized as initial diagnosis at stage I or stage II), total incidence, late-stage incidence as a proportion of total incidence, and death data. Municipalities reporting 10 total incidences or less were suppressed from these analyses.

Further analysis was conducted because incidence rates for late-stage diagnosis reported by municipality were skewed due to fewer cases being reported in less populous municipalities (Tables 2.8, 2.9 and 2.10). As an example, the town of Chaplin, CT had a late-stage incidence proportion of 26.7 percent, which is the fourth highest incidence rate in the state; however, this proportion comes as a result of four out of 15 total cases reported as late-stage, in a town with a population of 2,298. At the other extreme, Bridgeport, CT, the most populous municipality in the state only reported a late-stage incidence proportion of 18.5 percent, with 74 cases out of 401 total cases being classified as late-stage, in a city population of 145,638 residents. Population estimates were obtained using data reported by the State of Connecticut's Department of Health's 2011 data.

Table 2.8. Incidence rates (2006-2010)

Town	County	Number of New Cases	Age-Adjusted Rates
Stamford	Fairfield	501	145.8
Bridgeport	Fairfield	434	119.5
New Haven	New Haven	393	135.5
Waterbury	New Haven	380	121.9
Greenwich	Fairfield	347	168.3
West Hartford	Hartford	346	154.4
Hartford	Hartford	317	109.4
Norwalk	Fairfield	315	120.0
Fairfield	Fairfield	300	176.4
Bristol	Hartford	271	139.9

Note: Listed are towns with the highest number of diagnosed breast cancer cases.

Table 2.9. Incidence rates above state average (2006-2010)

Town	County	Number of New Cases	Age-Adjusted Rates
Branford	New Haven	178	181.9
Canton	Hartford	59	193.4
Darien	Fairfield	97	183.3
Groton	New London	197	183.9
Marlborough	Hartford	33	295.7
Middlefield	Middlesex	28	264.6
New Canaan	Fairfield	111	189.8
Orange	New Haven	87	186.0
Westport	Fairfield	181	221.7
Woodbridge	New Haven	69	222.1

Note: The towns listed have statistically significant higher age-adjusted incidence rates than the state average of 136.3.

Table 2.10. Late-stage rates (2007-2011)

Town	County	Percentage of Late-Stage Rates
Norwich	New London	27.8
New Milford	Litchfield	25.5
Hartford	Hartford	21.9
West Haven	New Haven	20.0
East Hartford	Hartford	19.7
Waterbury	New Haven	19.4
Danbury	Fairfield	18.6
Bridgeport	Fairfield	18.4
East Lyme	New London	18.4
Hamden	New Haven	18.4
Stratford	Fairfield	18.4
Meriden	New Haven	18.3
Groton	New London	18.3
Guilford	New Haven	17.5
West Hartford	Hartford	17.1

Note: Late-stage breast cancer data were sorted by percentage of late-stage cancers (from highest to lowest) and the top 15 towns with 100 or more total breast cancers (all stages)

Death Rates

Death rates for municipalities with 11 or more breast cancer deaths were examined and two cities, Bridgeport and New Haven, experienced age-adjusted death rates that were significantly higher when compared to the state death rate (see Table 2.11). Data have shown that White women are more likely to be diagnosed with breast cancer, but Black/African-American women are more likely to die from breast cancer if diagnosed.

Table 2.11 Death rates (2006-2010)

Town	County	Age-Adjusted Rates
New Haven	New Haven	31.1
East Hartford	Hartford	29.7
Bridgeport	Fairfield	26.9
Hamden	New Haven	24.1
Meriden	New Haven	24.1
Milford	New Haven	23.2
Stratford	Fairfield	22.7
West Haven	New Haven	22.6
Waterbury	New Haven	22.0
Norwalk	Fairfield	21.8
Danbury	Fairfield	21.7
West Hartford	Hartford	21.2
Bristol	Hartford	20.5
New Britain	Hartford	20.0
Stamford	Fairfield	19.9
Greenwich	Fairfield	19.1
Hartford	Hartford	18.6

Note: Death data were sorted by age-adjusted death rate (from highest to lowest) and the top 17 towns with 40 or more total breast cancer deaths

Disparities within Connecticut

Connecticut has unique socioeconomic factors within the selected counties. It is reported that 8.8 percent of Fairfield County lives below the national poverty line. However, a further look into Bridgeport, located in Fairfield County, shows 23.6 percent of the residents live below the poverty line. The poverty level for the city of Hartford which is located in Hartford County is an astounding 33.9 percent.

Ethnic and racial disparities are likely to be a factor in late-stage diagnosis among Black/African-American and Hispanic/Latina women. Compared to the national average, Connecticut has a lower percentage of Hispanic/Latino and Black/African-American populations. When taking a closer look at urban areas within the selected counties, the percentage is increased. For instance, the city of Hartford has a population of approximately 38.7 percent Black/African-Americans and 43.4 percent Hispanic or Latino. The city of Waterbury, located in New Haven County, has a Hispanic/Latino population of 31.2 percent and 20.1 percent Black/African-American. Access to screening and treatment may be limited due to barriers such as the availability of transportation and language interpretation services.

Selection of Target Communities

The Affiliate utilized the statistical data shown in the Quantitative Data Report and in Tables 2.8 through 2.11 to select five counties of interest. The focus was aimed at understanding breast cancer burden in Hartford, Fairfield, New Haven, New London and Litchfield counties. Hartford, Fairfield, New London and Litchfield counties are unlikely to meet the HP2020 late-stage incidence targets. All four counties have rising late-stage incidence trends. New Haven County is likely to take the longest amount of time (seven years) to reach the HP2020 death rate target of any county in the service area. It has the highest breast cancer death rate of any county in the state (23.6 per 100,000 compared to 21.6 per 100,000 for the state). The additional quantitative analysis highlighted a total of 31 towns within the five counties that were directly affected with breast cancer.

Towns with similar breast cancer rates were impacted by education and socioeconomic factors. The towns of West Hartford and Hartford had a 10.1 percent difference in number of new cases (Table 2.8). These towns, while close geographically, have distinctive characteristics related to health disparities. Hartford residents, according to the U.S. Census, had significantly lower socioeconomic and education levels compared to West Hartford. The median income for Hartford residents was estimated just over \$28,000 annually in comparison to \$81,588 in West Hartford. The federal poverty level (FPL) was examined since it is a key factor contributing to health disparities. The town of West Hartford had 6.6 percent of the population below the FPL. In Hartford, 41,255 individuals, or 33.0 percent of the population, live below the FPL (U.S. Census, 2010). Further examination of other towns in Connecticut produced similar results.

Looking Ahead

The implementation of the Affordable Health Care Act (ACA) drastically changed the health care system. Komen Southern New England has been exploring how ACA has changed the health system in relation to breast health and breast cancer services. A full report on changes within the breast cancer systems since the implementation of ACA can be found in the Health Systems Analysis.

Health Systems Analysis Data Sources

In 2011, the Affiliate created a database containing a comprehensive inventory of organizations that provide breast cancer services. This database, which was initially developed to complete the 2011 Community Profile, laid the groundwork for this Health Systems Analysis (HSA). The inventory comprised over 100 breast health and breast cancer providers. To confirm services, the Affiliate placed calls with administrative personnel at each location. In a few cases, service providers did not respond to the Affiliate's request to update the information listed on the database. The Affiliate conducted an additional internet search to confirm services listed on the provider's website. This internet search led to locating other breast health providers in the target communities. Those services were then added to the database. Organizations no longer providing breast cancer services were removed from the database. The Affiliate mapped the geographic locations of the existing breast cancer services using a mapping software program. Services were heavily concentrated in the urban areas such as New Haven and Hartford Counties. Services are inclusive of early detection screenings, diagnostic services, treatment and survivorship care.

Health Systems Overview

Continuum of Care Model

The Breast Cancer Continuum of Care (CoC) is a model (Figure 3.1) that shows how a woman typically moves through the health care system for breast care. A woman would ideally move through the CoC quickly and seamlessly, receiving timely, quality care in order to have the best outcomes. Education can play an important role throughout the entire CoC.

While a woman may enter the continuum at any point; ideally, a woman would enter the CoC by getting screened for breast cancer—with a clinical breast exam or a screening mammogram. If the screening test results are normal, she would loop back into follow-up care, where she would get another screening exam at the recommended interval. Education plays a role in both encouraging women to get screened and reinforcing the need to continue to get screened routinely thereafter.

If a screening exam resulted in abnormal results, diagnostic tests would be needed, possibly several, to determine if the abnormal finding is in fact breast cancer. These tests might include a diagnostic mammogram, breast ultrasound or biopsy. If the tests were negative (or benign)

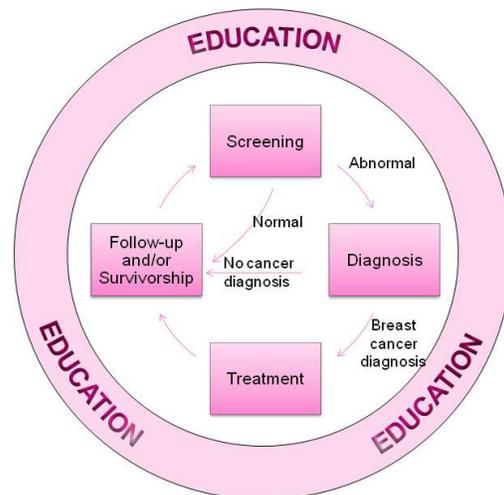


Figure 3.1. Breast Cancer Continuum of Care (CoC)

and breast cancer was not found, she would go into the follow-up loop, and return for screening at the recommended interval. The recommended intervals may range from three to six months for some women to 12 months for most women. Education plays a role in communicating the importance of proactively getting test results, keeping follow-up appointments and understanding what it all means. Education can empower a woman and help manage anxiety and fear.

If breast cancer is diagnosed, she would proceed to treatment. Education can cover topics such as treatment options, how a pathology report determines the best options for treatment, understanding side effects and how to manage them, and helping to formulate questions for providers.

For some breast cancer patients, treatment may last a few months and for others, it may last years. While the CoC model shows that follow up and survivorship come after treatment ends, they actually may occur at the same time. Follow-up and survivorship may include things like navigating insurance issues, locating financial assistance and symptom management such as pain, fatigue, sexual issues, bone health, etc. Education may address topics such as making healthy lifestyle choices, long term effects of treatment, managing side effects, the importance of follow-up appointments and communication with their providers. Most women will return to screening at a recommended interval after treatment ends, or for some, during treatment (such as those taking long-term hormone therapy).

There are often delays in moving from one point of the continuum to another. Delays occurred at the point of receiving an abnormal screening result, starting treatment, and completing treatment. Delays attributed to poorer outcomes. There are also many reasons why a woman does not enter or continue in the breast cancer CoC. These barriers can include lack of transportation, system issues including long waits for appointments and inconvenient clinic hours, language barriers, fear, and lack of information—or the wrong information (myths and misconceptions). Education can address some of these barriers and help a woman progress through the CoC quickly.

Connecticut Breast Cancer Health Services

Breast health and breast cancer services were found in hospitals and community clinics in each of the target communities (Figures 3.2, 3.3, 3.4, 3.5 and 3.6). Comprehensive breast cancer centers accredited by the American College of Surgeons were found in cities within Hartford, Litchfield, New London, New Haven and Fairfield Counties. Comprehensive breast cancer centers are designed to provide patients with a wide variety of services through the CoC. Radiology services, oncology services, infusion centers and psychosocial support services are all provided under one roof. Hospitals in Hartford, New Haven, Fairfield and New London Counties have formed partnerships with nationally renowned cancer centers. Partnerships have been formed with Dana Farber Cancer Institute, Memorial Sloan Kettering and the MD Anderson Network. These partnerships have been formed to improve the delivery of services, meet patient needs and provide quality care.

Patient navigation was among the many services patients had access to within the five target communities. Patient Navigators are typically based in cancer centers to guide patients through the Breast Cancer Continuum of Care. Navigation services may occur at various stages during the treatment. The most common stage in which patients encountered a navigator was immediately after receiving a positive diagnosis of breast cancer. Nurse Navigators guided breast cancer patients to ensure a smooth transition from diagnosis and into treatment. Within the five target communities, navigation services also guided patients to access supportive and financial assistance.

Early Detection Services

Providers in Hartford, New Haven and Fairfield Counties included an outreach education component to their breast cancer services. The outreach education component is one of the most effective tools to reach women in underserved communities with limited access to health services. The goals are to educate women in non-traditional settings with the purpose of promoting available free and low-cost early detection services. Outreach educators promote breast health and refer women into screening. Outreach educators work in settings such as Federally Qualified Health Centers (FQHCs), Community Based Organizations (CBOs) and Hospitals. Partnerships formed with FQHCs, CBOs and mobile mammography vans had successful outcomes screening women who didn't otherwise have access to early detection services. Outreach education programs were available but limited in Litchfield and New London Counties. Outreach education programs were provided based on the availability of private grant funds made available to the breast cancer service providers. Several programs that served vulnerable communities in Fairfield and Hartford Counties fluctuated due to inconsistent funding.

Federally Qualified Health Centers located in Hartford, New Haven, New London and Fairfield Counties offered early detection services for the uninsured and underinsured population based on income eligibility. Early detection services at all FQHCs were available at a reduced cost or free for women who fit the eligibility criteria of the centers. FQHCs confirmed they were subcontracted to offer services using state and federal funds. All FQHCs provided clinical breast exams and referred women to imaging centers if mammograms were needed. Equipment to perform screening or diagnostic mammography services were not found at any FQHC. However, it should be noted that several FQHCs collaborate with larger medical institutions that have mobile mammography units to serve their patients on a monthly or quarterly basis. Mobile mammography services require coordination between the FQHC and the institution providing services to ensure results are communicated to the patient and their primary care provider. Gaps in services were found in the Litchfield County area. In Litchfield County, the town of New Milford did not have an FQHC. However, residents had access to services in nearby Danbury where two FQHCs offer clinical breast exams and referrals to routine and emergency imaging.

Mobile Mammography Units

Mobile mammography vans provide fast and easy access to breast cancer screenings for women. Mobile mammography services are available in Hartford, Fairfield, New Haven and New London Counties. All mobile vans are equipped with the latest digital imaging equipment. At least one van was equipped to provide ultrasounds. Mobile mammography vans can

dramatically reduce the time it takes a woman to receive a screening. Women have access to breast cancer screenings in unconventional locations such as churches, shopping plazas, work sites, unemployment centers and CBOs. Mobile mammography managers reported having contracts with large corporations that extended the convenient service to screen employees during business hours.

To ensure quality care, women must have identified a primary care provider who will receive results of the screening. In most situations, if a screening was abnormal, patients were navigated through the diagnostic care at the hospital. Patient Navigators aboard the mobile van determine eligibility of uninsured patients as they may be eligible for a screening at no cost to them.

Partnerships and Collaborations

The Affiliate maintains strong partnerships with more than 40 current and former grant-funded programs. A referral system exists between the Affiliate and the grant-funded breast cancer programs in each target community. In Hartford and Fairfield Counties, Komen has funded and collaborated with three mobile mammography vans. The mobile mammography van coordinators provide the Affiliate with information about dates open to the general public. The Affiliate Mission Coordinator refers callers to mobile services when appropriate. Since its inception in 1994, the Affiliate has collaborated with all grantees in each target community on numerous community health activities and breast cancer awareness projects. The Affiliate plans to strengthen partnerships in New London and Litchfield Counties as limited breast health and breast cancer services are available in these areas. The Affiliate will identify candidates that are eligible to increase the availability of breast cancer early detection and treatment services.

Komen Southern New England has an active Education Committee in Connecticut. This committee assisted in the creation of Faith in Pink, a missions-based initiative to educate women in faith-based organizations. Committee members represent six breast cancer centers in Litchfield, Fairfield and New Haven Counties. In 2014, the Education Committee planned to extend the Faith in Pink program to New London and Hartford Counties. Mission staff participates in several committees designed to raise awareness and reduce late-stage breast cancer diagnosis in underserved communities.

Fairfield County



Hospital



Community Health Center



Other



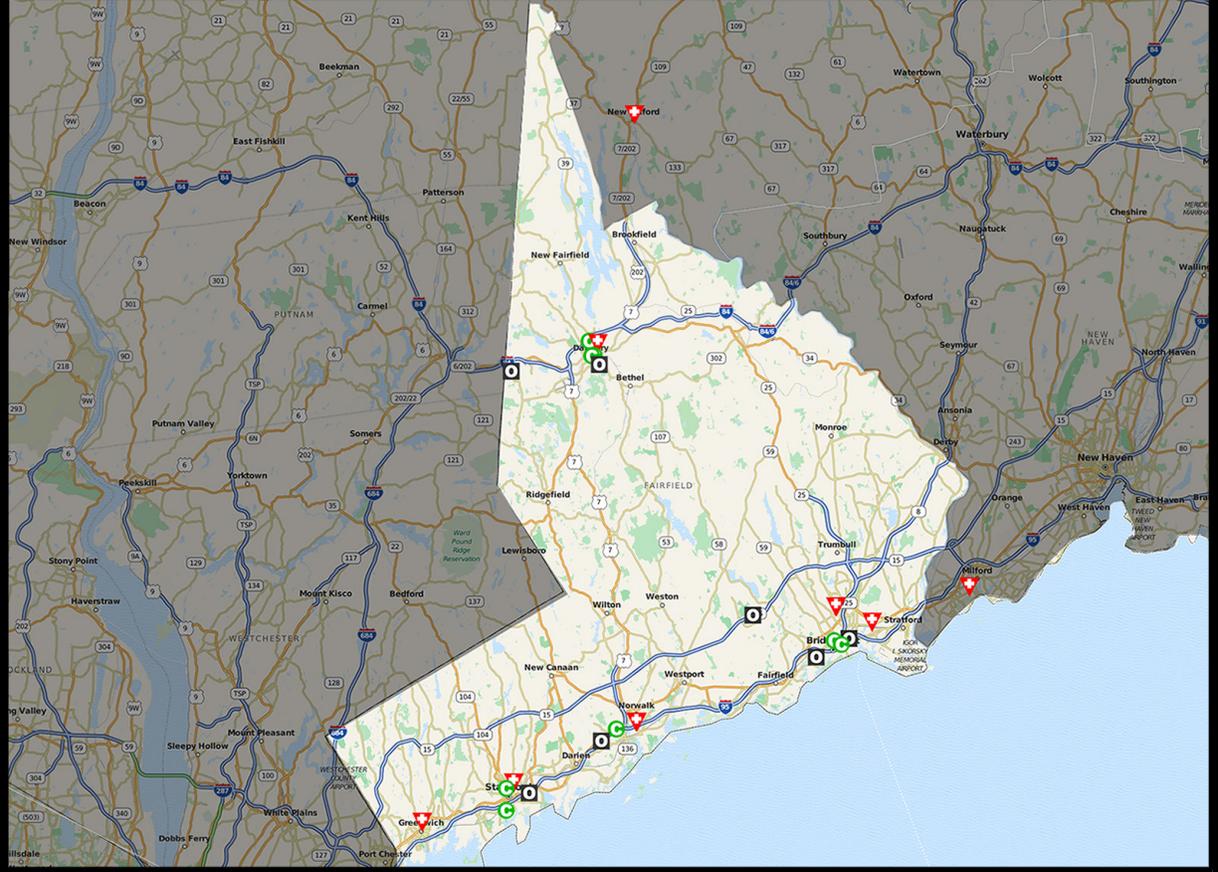
Free Clinic



Department of Health



Affiliate Office



Statistics

Total Locations in Region: 26

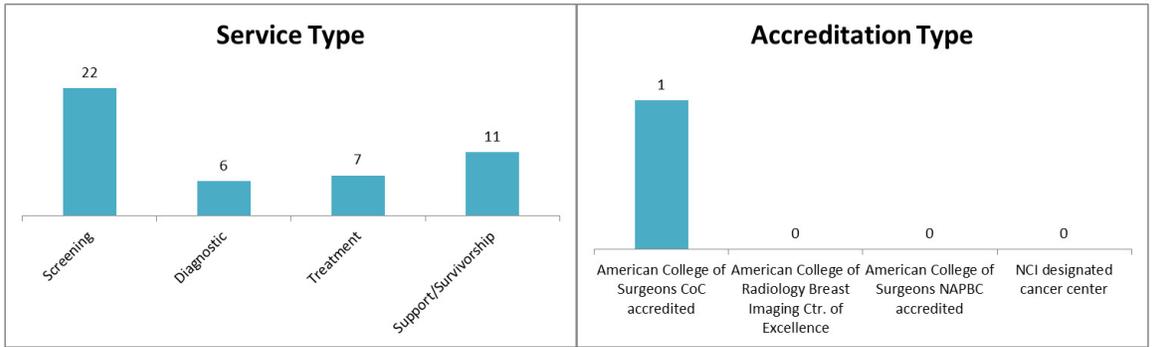


Figure 3.2. Breast cancer services available in Fairfield County

Hartford County



Hospital



Community Health Center



Other



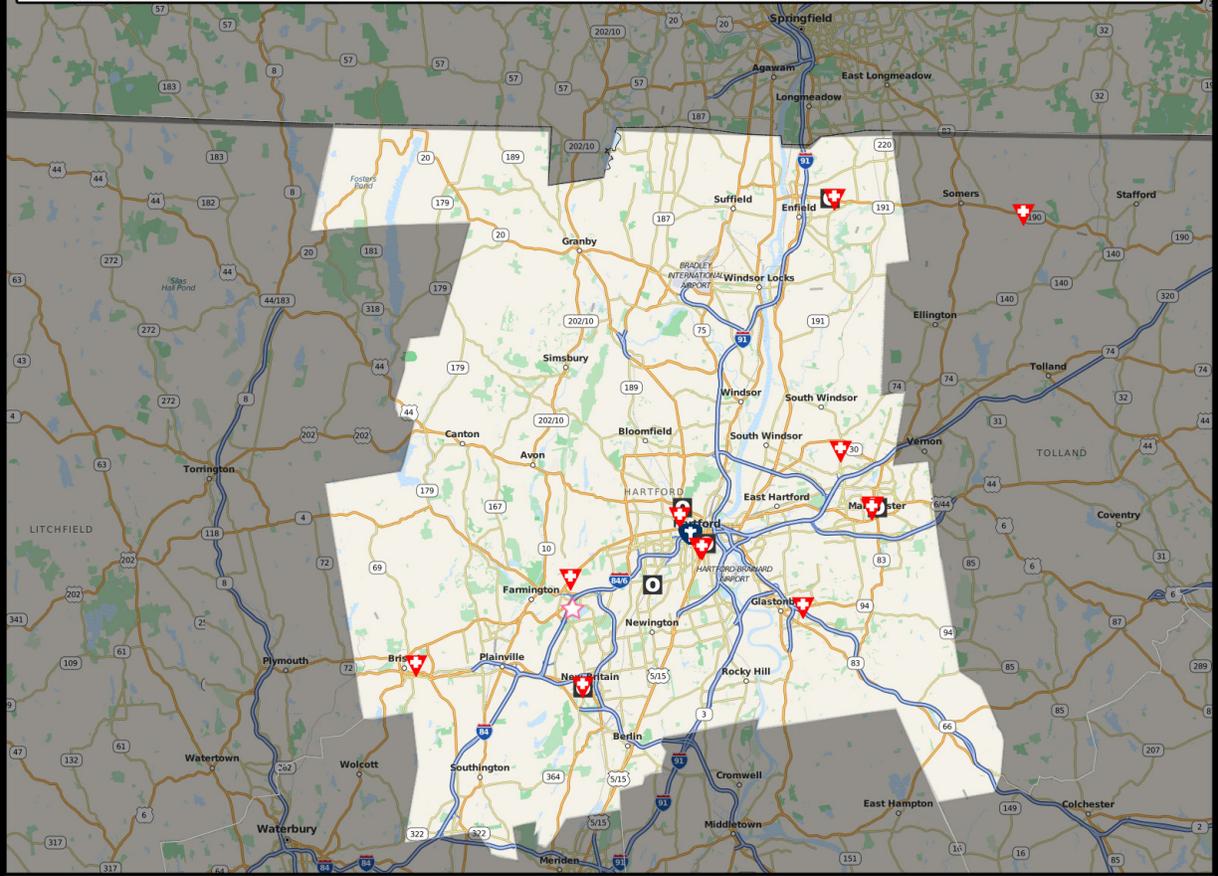
Free Clinic



Department of Health



Affiliate Office



Statistics

Total Locations in Region: 25

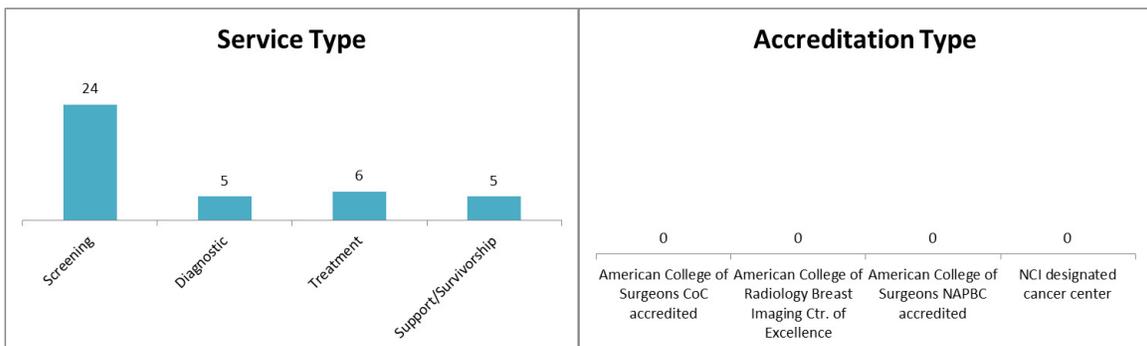


Figure 3.3. Breast cancer services available in Hartford County

Litchfield County



Hospital



Community Health Center



Other



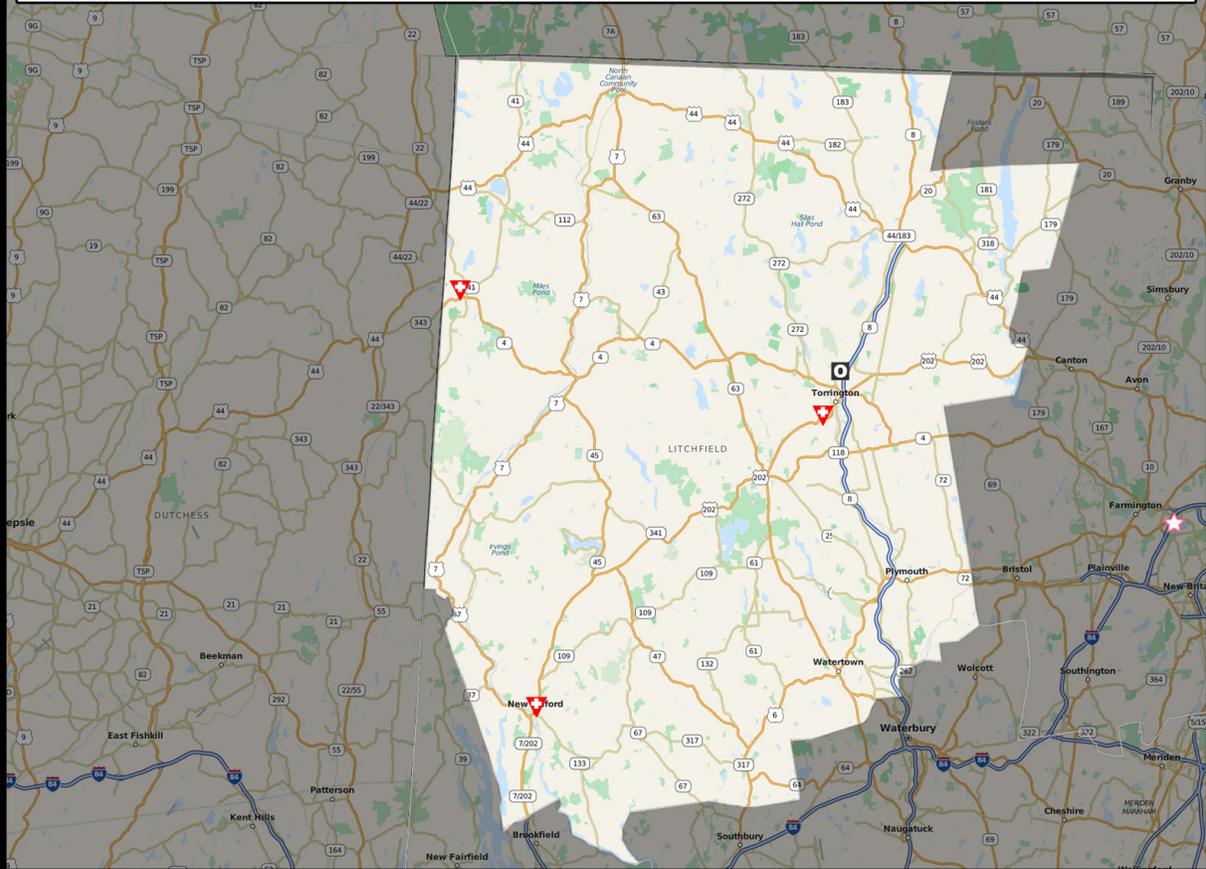
Free Clinic



Department of Health



Affiliate Office



Statistics

Total Locations in Region: 5

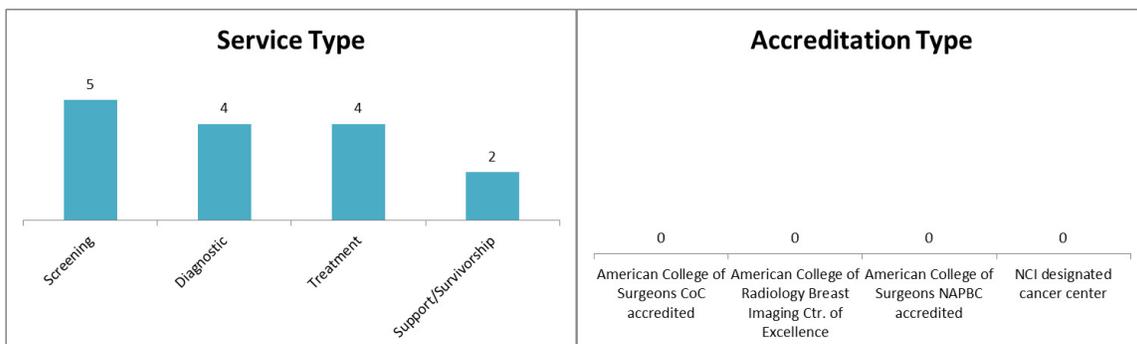


Figure 3.4. Breast cancer services available in Litchfield County

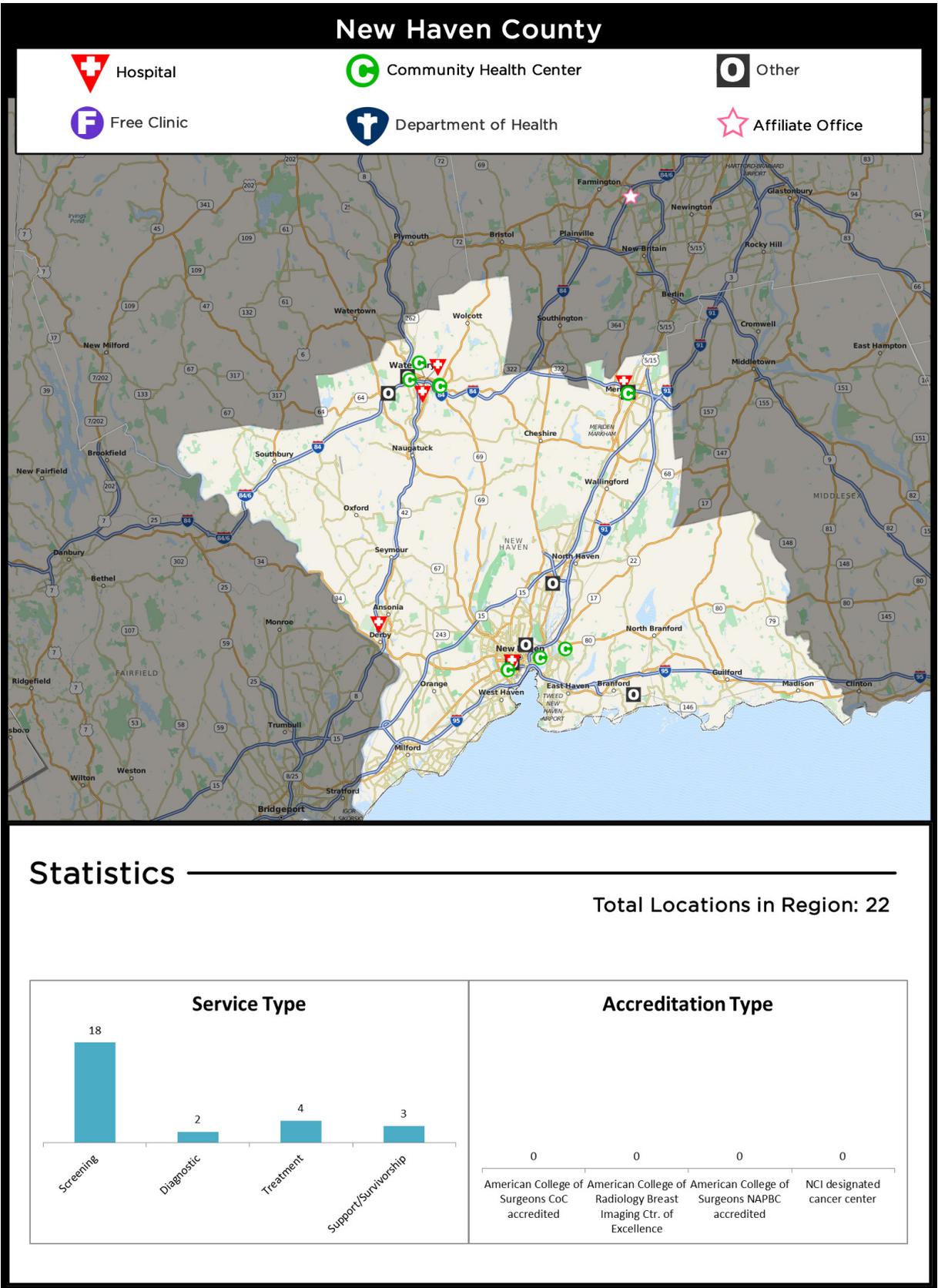


Figure 3.5. Breast cancer services available in New Haven County

New London County



Hospital



Community Health Center



Other



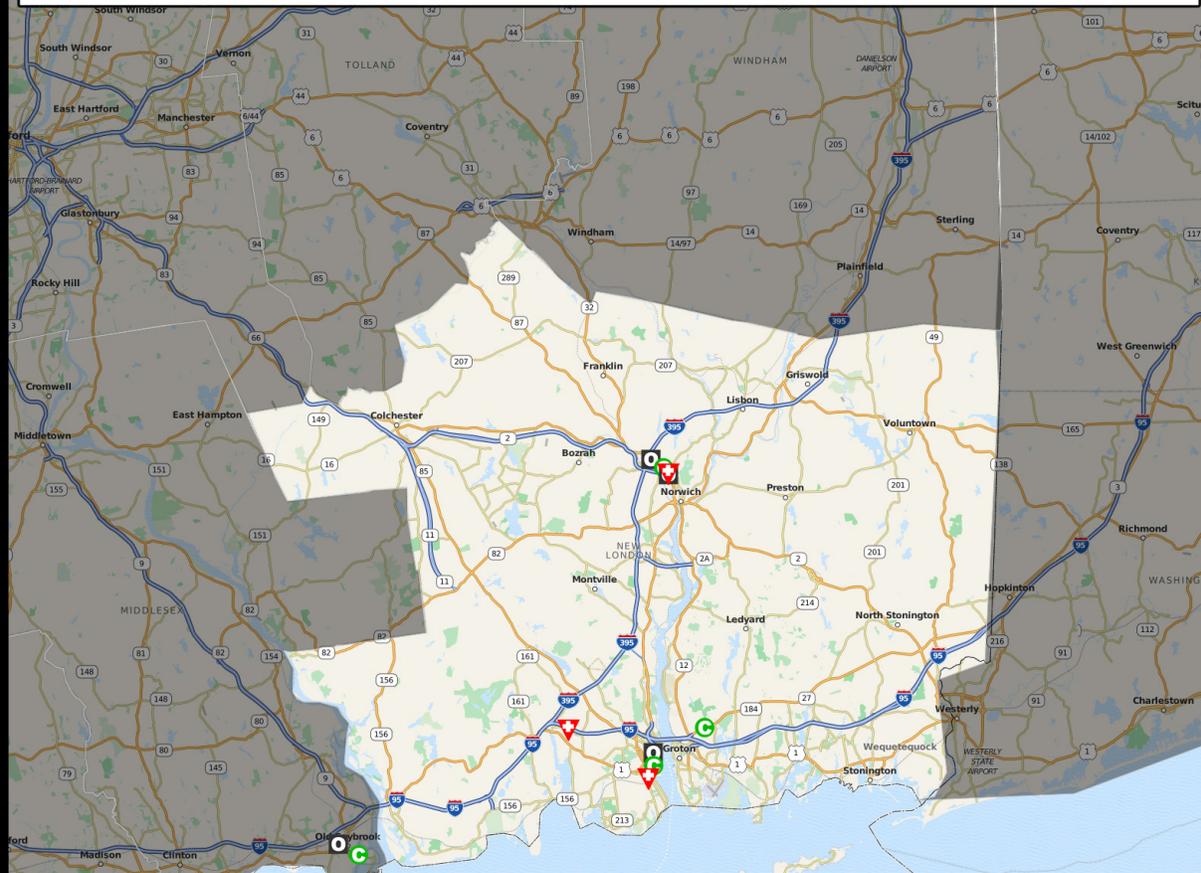
Free Clinic



Department of Health



Affiliate Office



Statistics

Total Locations in Region: 13

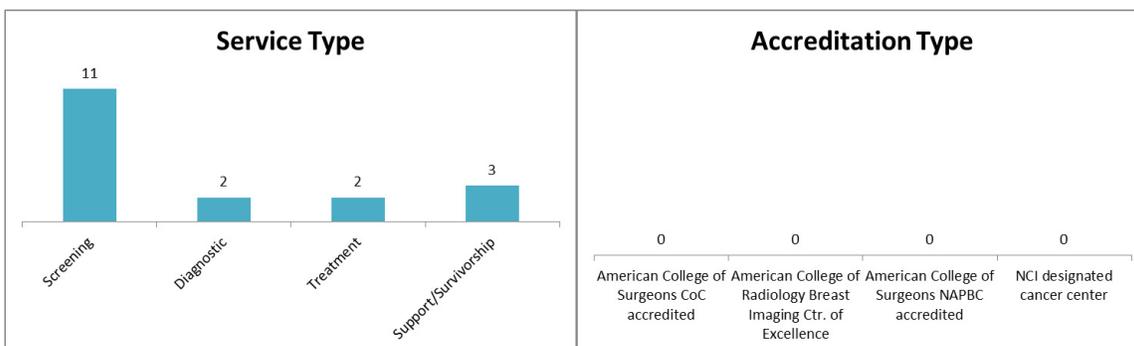


Figure 3.6. Breast cancer services available in New London County

Public Policy Overview

National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

The Connecticut Breast and Cervical Cancer Early Detection Program (CBCCEDP) receives approximately \$1,120,000 in federal funding and \$2,200,000 in state funding annually. The funds are used to provide breast and cervical cancer screening, diagnostic screening, treatment referral, case management, and patient navigation services to between 8,500 and 9,000 low-income, underserved women. These services are delivered via 11 contracted provider sites with nearly 200 subcontractors that include Federally Qualified Health Centers, Planned Parenthood, hospital clinics, and private practice physicians located throughout the state.

Women in Connecticut must receive services funded all, or in part, by federal NBCCEDP funding at one of the 11 contracted provider sites to be presumptively eligible for enrollment into the Breast and Cervical Cancer Medicaid Treatment Act for payment of a diagnosed breast cancer, or precancerous or cancerous cervical lesion. Connecticut was approved to implement all three options of the Breast and Cervical Cancer Medicaid Treatment Act. Due to budgetary reasons, Connecticut has only implemented option one (Table 4.1). The 11 contracted provider sites complete the necessary Medicaid application and forward it to the Connecticut Department of Social Services (DSS) for processing.

Table 3.1. National Breast Cancer Early Detection Treatment Program (Susan G. Komen 2014)

Breast and Cervical Cancer Medicaid Treatment Options
Option 1: A woman is considered “screened under the program” and is therefore eligible for Medicaid services if NBCCEDP funds pay all or part of the costs of her screening services.
Option 2: A woman is eligible if her provider receives NBCCEDP funds and the service was within the scope of a grant, sub-grant or contract under that state program—even if the woman’s screening may not have been paid directly from NBCCEDP.
Option 3: A woman can receive Medicaid services regardless of where she was originally screened, as long as she would otherwise meet the other eligibility requirements.

The CBCCEDP and DSS have developed a good working relationship. Staff assigned to oversee the Breast and Cervical Cancer Medicaid Treatment Act implementation at DSS conducted periodic trainings at CBCCEDP’s quarterly meetings to ensure staff at the contracted provider sites are knowledgeable of the Treatment Act and are familiar with administrative procedures.

The CBCCEDP and the Affiliate have developed a beneficial collaborative relationship. The Cancer Program Director at the Connecticut Department of Public Health (DPH), who oversees CBCCEDP, is the Chair of the Komen Southern New England Grant Development Committee for Connecticut. This committee develops the direction and content of the request for proposals

(RFP) distributed for community programming. In addition, the DPH Cancer Program Director is serving as Co-Lead of the team developing the 2015 Community Profile.

Connecticut Comprehensive Cancer Control Plan

In 1998, the Centers for Disease Control (CDC) implemented and funded cancer control plans to reduce cancer burden in the United States. The 50 states, tribal groups and U.S. territories were to develop programs that would address cancer burden. The Connecticut Cancer Partnership (CCP) was established in 2002, forming a coalition with over 150 local organizations. Members represent local and state health departments, health care providers, cancer survivors and public health professionals. Affiliate staff are active members and support breast cancer related initiatives organized by CCP.

CCP recognizes that Connecticut has among highest incidence rates of breast cancer in the United States. The statistical data used in the 2014-2017 Connecticut Cancer Control Plan indicates the breast cancer incidence rate of 138.5 per 100,000 is significantly higher than the U.S. rate (CCCP 2014-2017).

CCP has recently released the 2014-2017 Cancer Control Plan. Over the next four years, goals directly aimed to reduce breast cancer burden can be found in Table 3.2.

Table 3.2. 2014-2017 Connecticut Cancer Control Plan

2014-2017 Connecticut Cancer Control Plan	
Goal 1	Primary prevention of cancer through healthy living at all levels across the state.
Goal 2	High quality cancer screening and early detection services are available to all people living in Connecticut.
Goal 3	High quality comprehensive cancer treatment and the opportunity to participate in clinical trials are available and accessible to all people living in Connecticut.
Goal 4	High-quality palliative care is available to all people living in Connecticut.
Goal 5	High quality of life and care is available to all Connecticut cancer survivors.
Goal 6	High quality hospice care is available to all people living in Connecticut.

Affordable Care Act

As of April 1, 2014, thousands of Connecticut residents became insured by means of the expansion of the Affordable Care Act (ACA). Connecticut offers insurance through the Access Health Connecticut (AHCT) health exchange. AHCT serves as the federally approved state health insurance exchange. In its first year, AHCT reported extending health insurance coverage to 197,878 residents. Over 65 percent of the newly insured were covered by Medicaid expansion. Individuals ineligible for Medicaid enrolled in other private insurance subsidies. Expanded Medicaid in Connecticut met the new income eligibility guidelines to cover residents whose household income is under 133 percent of the federal poverty line. Four levels of health plans are made available, each with its own limitations on coverage. AHCT Navigators and In-

Person Assistors (NIPAs) inform individuals of the various plan options for which they are eligible. NIPAs guided individuals through the entire enrollment process.

By late spring 2014, noticeable changes had been reported by health care providers. Overall, most providers considered implementation of the ACA to be an improvement to health care. Project directors from many Affiliate-funded screening programs reported an increase in patients with health insurance. Breast cancer screening facilities reported routine mammography screenings were typically covered services with all insurances. Routine screenings include clinical breast exams and screening mammography. This is dependent on a woman’s age and risk factors. As diagnostics such as ultrasounds, diagnostic mammograms and biopsies are not considered to be a preventative service, women pay out of pocket unless the deductible has been met, or are responsible for a copay.

Gaps in Health Care: Uninsured

The Affordable Care Act aimed to improve health care for all Americans by expanding health insurance and ensuring quality health. Despite efforts, a number of individuals remain uninsured (Figure 3.7). It has not yet been determined exactly how many women remain uninsured. Estimated totals of uninsured females can be found in Table 3.3.

Reasons for opting out of insurance plans varied across Connecticut residents. For most, though the plans offered attractive rates, the cost may still have been too high. Low socioeconomic status forced some residents to make decisions to cover costs of basic needs or add the cost of insurance plans. Nearly 10 percent of Connecticut residents live below the federal poverty level (U.S. Census 2010).

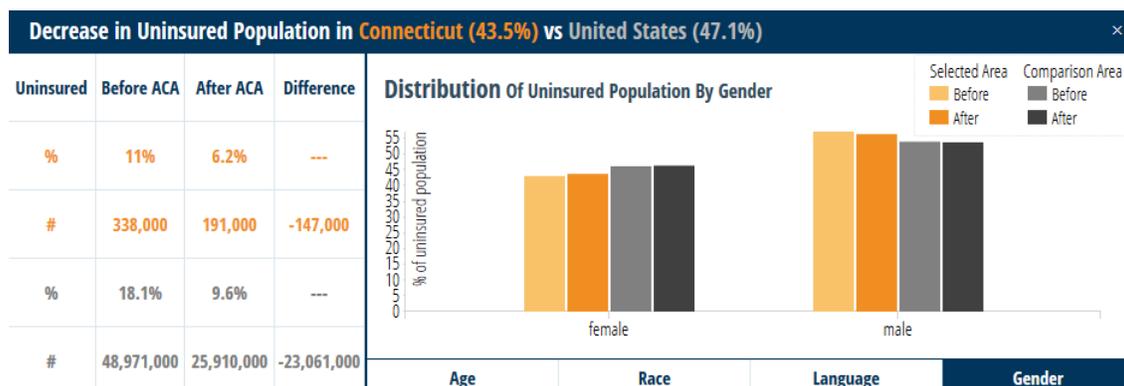


Figure 3.7. Uninsured percentages in Connecticut (Kaiser Family Foundation)

Table 3.3. Connecticut uninsured female population by county (Connecticut DPH)

Target Communities	Estimated Number of Uninsured Females
Connecticut	136,151
Fairfield County	26,954
Hartford County	39,925
New Haven County	44,704
New London County	7,872
Litchfield County	4,077

Note: Listed are the target counties identified in the quantitative data section.

Connecticut is currently an Option 1 state, which is the most restrictive category in terms of how states regard women’s eligibility for emergency Medicaid-covered breast cancer treatment. States that are Option 1 consider women eligible for Medicaid treatment only if their clinical services were paid for all or in part by the state’s NBCCEDP-funded program. If they were screened and diagnosed elsewhere (e.g. by a free mammogram provided by a Komen Southern New England-funded grant), they are not eligible for Medicaid Treatment.

Legislative Issues

In 2013, the Connecticut General Assembly passed a bill that prohibits some insurance companies from imposing copayments of more than \$20 for breast ultrasounds that insurance policies are required to cover. The new law also restricts copayments of no more than \$30 per visit for in-network occupational therapy services. The income limit for the state’s Breast and Cervical Cancer Early Detection and Treatment Referral Program has also been increased from 200 percent to 250 percent of the federal poverty level which expands the program to more women in the state.

Health Systems and Public Policy Analysis Findings

Insurance has lifted some of the burden from women that once did not have access to screenings by allowing them to obtain screenings. Unfortunately, if women are in need of diagnostic screenings, a high cost may be attached. This may attribute to women dropping out of the CoC.

The target communities with the greatest burden of breast cancer were found to benefit from access to a breast cancer screening facility within a 20 mile radius. Transportation was noted to be an issue for women who reside in communities with limited services nearby. Moreover, women with transportation issues were limited to receiving care based on distance to the center and not by their preference.

Screening services were available in the five target counties listed in the Quantitative Data section of this report. The majority of the locations that provided free or low-cost screening were in Bridgeport, Hartford, Stamford and New Haven. West Hartford, Guilford, East Lyme, and

Darien were among the towns that were not found to offer free or low-cost screenings aside from screening offered in those towns by a mobile mammography van. Diagnostic screenings were found to be provided in towns scattered throughout the five target communities. Diagnostic screenings in at least seven towns were covered by Komen or CBCCEDP programs. A small number of radiology groups in New Haven and Fairfield Counties had started foundations to cover the cost of imaging for uninsured or underinsured patients.

The Affiliate provides details of additional findings and explains what the various community needs were in the Qualitative Data section of this report.

Qualitative Data: Ensuring Community Input

Qualitative Data Sources and Methodology Overview

Methodology

Komen Southern New England utilized the Quantitative and Health Systems Data Report to formulate questions to better understand the overarching breast cancer gaps and needs in Connecticut. At a glance, services were prominent in large municipalities within the five target communities identified in the Quantitative Data Report. The questions formed by the Affiliate relate to access to care, quality care and availability of services for all women in the five target communities.

To determine the data collection method, the Affiliate took into account the size of the target community, availability of breast cancer providers in the target area and the timeline in which the data could be collected. When seeking breast cancer services, most women in Connecticut utilize the health centers in Hartford, Fairfield and New Haven Counties. It was determined that Key Informant interviews would provide the Affiliate with data on accessing early detection and cancer care services. The Affiliate planned on collecting data from twelve providers in Hartford, Fairfield and New Haven Counties. The Affiliate also wanted to get a perspective on access to breast cancer services.

Komen Southern New England designated three Community Profile team members to conduct interviews. The interviewers were required to have a Public Health background and experience conducting focus groups. Interviewers utilized the Quantitative and Health Systems Analysis Reports to formulate questions that would be used for Key Informant interviews and focus groups with providers and breast cancer survivors. It was determined by the Affiliate that focus groups should be recorded. Recorded sessions were submitted to the Affiliate and used to transcribe the interview sessions. Transcribed interviews have been filed confidentially by the Affiliate. The Affiliate utilized a spreadsheet to keep track of the total number of key informant interviews and focus groups that were conducted in each target community.

At the beginning of each group, interviewers introduced themselves and provided participants with a detailed history of the Community Profile. Interviewers set a goal to ensure each participant understood the history of the Community Profile and the importance of their participation in the focus groups. The interviewers used a script with details of the Community Profile process. The script included specific details of the target communities. The consent forms were read aloud and provided at the beginning of each focus group session. Once signatures were on every consent form, the group facilitator collected the signatures and began the focus group.

Sampling

Based on the questions and time allotted to collect the data, the Affiliate conducted focus groups with breast cancer survivors and interviewed providers of women's health services. Breast cancer survivors were culturally diverse and had been diagnosed with breast cancer at different stages (Stage 0-Stage IV). Survivors' ages ranged from 37 to 68 years old. It is important to note that women with metastatic breast cancer were included in the focus groups.

Key informants were identified through a breast health service provider database created to complete the Health Systems Analysis Report. The database was used to identify those providers who offer breast cancer education, early detection screening services and breast cancer treatment. The key informants who participated in the interviews included health educators, patient navigators, oncology physicians and radiology personnel.

The sampling strategy used to identify focus group participants was non-probability based, using a snowball sampling technique. The Affiliate determined it was most appropriate to identify women who had been diagnosed with breast cancer within the past two years. Survivors who have most recently utilized early detection and treatment services would be in a better position to attest to the services currently being provided. The sampling technique used to select Key Informants was a simple random method. Twelve providers from each target community were informed and invited to participate in the interviews. Nearly 32 percent of providers agreed to participate in the interviews.

Ethics

Komen Southern New England selected interviewers who possessed the skills required to conduct the focus groups. Interviewers understood the importance of protecting the identity of participants and maintaining document confidentiality. Consent forms and interview notes collected by interviewers were compiled by the Affiliate. Names were excluded from transcriptions and notes taken during the interview. For purposes of identifying responses, the interviewer assigned number codes to each participant (Participant 01, Participant 02, etc.). This method was helpful in identifying the responses when transcribing documents.

Qualitative Data Overview

An independent analysis of the data was conducted by an expert in qualitative data techniques and analysis. The data was provided in the form of verbatim transcripts of the Key Informant interviews and summaries of the focus group findings. In order to assess the accuracy of the transcribed recordings, a random sample was chosen for review. Grounded theory was used where, through an iterative process, Key Informant interview transcripts were read thoroughly, major points were highlighted and themes were generated. Transcripts were reviewed again to identify common themes across participants. The focus group summaries underwent a similar process. The end result was a series of themes/categories that were generated and compared and contrasted to the Key Informant interviews and focus groups.

The survey data was provided in summary format through Survey Monkey. The results were compared and contrasted to the Key Informants and focus groups results. Similarities and differences were noted between the types of respondents (e.g. practitioner vs. breast cancer survivor.)

Key Informant Interviews

A total of 24 participants from Hartford, New London, New Haven and Fairfield Counties participated in the Key Informant interviews. The interviews were conducted with a broad

selection of staff types including: a) health educators; b) social workers; c) patient navigators; d) oncology physicians; and e) a radiology technician. The selection of key informants was based on an understanding of clients' experiences prior to entering the Continuum of Care (outreach and engagement), early detection (e.g. screening, biopsy) and referral to treatment (e.g. linkages to treatment and supportive services).

The Key Informant questions addressed the types of services available, gaps and barriers related to service delivery, and the processes related to receiving services (e.g. service flow within organizations). The analyses reflect the aggregate responses of participants with differences noted between communities. For the most part there was synergy with respect to what respondents across these target communities noted regarding types of services and gaps and barriers.

Key Informants Report on Services Offered

The types of services women benefit from in the five target communities for breast health or breast cancer services include:

- Community outreach and engagement
- Breast cancer health education and breast health literacy
- Mobile mammography screening programs
- Connecticut Breast and Cervical Early Detection Program screenings
- Patient navigation services
- Women's health services (including annual gynecological exams)
- Hospital services (e.g. imaging, biopsy and cancer treatment)

In order to raise awareness about breast health and available services, each of the communities engaged in outreach, engagement and health education efforts. The types of activities and strength of engagement with the community varied by location depending upon the relationships built with the community. In Fairfield County, Key Informants reported a strong connection to community-based, faith-based, health and non-profit organizations. Services offered in these entities included outreach to promote breast health and available breast cancer services to target populations.

Women entered the diagnosis phase after receiving an abnormal screening through various entry points. Key Informants in the hospitals reported that most uninsured women were referred by a community health center. Other key informants based at hospital breast centers reported women entered the system through a mobile mammography program. Providers also noted that those with an abnormal screen may also self-refer or go through their primary care provider. In Hartford County the women had access to a community or clinical navigator to access additional diagnostic screening services. In Fairfield County, radiology technicians interviewed reported making calls to some of the patients with abnormal results the same day. In each county, Key Informants based at hospitals in each target community reported patients are tracked (including telephone calls and certified letters) and monitored through the system step-by-step. In New London County, Key Informants reported most women accessed the community health center for early detection screenings. Providers then referred women for imaging at the hospital or

private imaging center. However each of these communities noted that they remain engaged from the point of abnormal screening result all the way through treatment.

The Continuum of Care in each of these communities varied. Key Informants in Hartford County noted that the hospitals had a strong collaboration with community-based and learning institutions. The CoC in Hartford County began with residents receiving breast health information and then entering the breast health system. The CoC model in New London County started in the community health center. Education was provided to women during their routine gynecological visits. Women over 40 and women with abnormal clinical breast exams were then referred to diagnostic care. In Fairfield County, the Community Profile Team found a more streamlined CoC. Women had access to community health centers and mobile mammography programs and experienced an easy transition into treatment services, if needed. In Hartford, Fairfield and New Haven Counties, the Community Profile Team learned that hospitals had strong community partner linkages.

With respect to payment for services, there were several options noted. While some services were free depending on income level, some were offered on a sliding scale and/or with co-payment. All locations had access to bilingual/multi-lingual staff and/or access to telephonic interpreters. All locations were familiar with Komen-funded screening programs, CDC guidelines and Connecticut Breast and Cervical Early Detection Programs.

Key Informants Report on Gaps and Barriers

The types of obstacles that women face when accessing breast health or breast cancer services include:

A. Financial Issues

- Inability to make payment or copayment due to competing financial priorities (e.g. basic household expenses) *“Low income families in treatment struggle to keep a roof overhead while managing illness and work and family. They are often on waiting lists for affordable housing.”*
- Uninsured
- Underinsured with high deductibles for diagnosis and cancer treatment
- Undocumented without sufficient income to support services *“Large undocumented community without link to primary care making it difficult to get into services.”*

B. Employment-Related

- Taking time off work to attend appointments difficult and may require a doctors' note
- Hourly employment and living paycheck-to-paycheck means they can't afford to take the time off

C. Cultural/language

- Women may need approval from spouse (South and Central American women in particular)
- Language barriers (separate from interpretation which is available at all locations)

- While language services may be available they may not be ideal. *“I have experience using the line with patients, it delays the medical visit. In addition if a man is on the other line, women may not feel as comfortable or open to sharing medical information regardless of their ability to speak their language. It is helpful for basic screening but not for diagnosis.” “First should be the option to have a bilingual medical provider, second would be an in-person interpreter, and last should be an interpreter on a phone in a random location.”*

D. Time

- Many women are single parents without time to attend appointments
- Competing concerns taking care of children/relatives
- Providers may not be spending sufficient time with women in order to explain medical facts and support adequately. *“We have 5-20 minutes.”*

E. Transportation

- Difficulty getting to appointments using public transportation that may require long length of travel time
- Inclement weather conditions prohibit women from attending appointments

F. Education

- Women may not know the facts about breast cancer. *“A woman once told me you can get breast cancer from being hit in the breast.”*
- Women need to be educated about available resources to support them financially through cancer treatment
- Low health literacy

G. Stress

- Fear of having and managing cancer treatment *“Some don’t ask enough questions. I don’t think they know how to advocate for themselves.” “When your whole life is altered it presents obstacles to accessing breast cancer treatment.”*

H. Competing health issues

- Other health conditions take priority over breast cancer screenings

Focus Groups

Six focus groups were held across the state (Hartford, Fairfield, Litchfield, New London and New Haven Counties). Participants represented a broad spectrum of cancer survivors with experience in the system of care. The key questions discussed during the focus groups centered around knowledge and awareness of breast cancer, early detection and barriers to accessing services. General themes that emerged from the focus groups included:

A. Knowledge and Awareness (patients and providers)

- Breast screening and cancer are not often talked about by community members, unlike diabetes where it impacts daily life by having to change diet

- Very few women know other women with breast cancer until they get into treatment and support groups
- Although awareness may be there, it needs to reach all women and to start earlier with young girls becoming educated about the importance of breast self-awareness and addressing positive family history
- More information should be provided to women who have dense breast tissue so that they are referred to ultrasounds
- Clarity of terms used needs to be provided, e.g. what does metastatic mean?
- Providers need to pay attention to forms that patients complete, e.g. when someone checks off positive family history there needs to be follow through
- Providers need to do more careful breast examinations during routine physical exams
- Although the pink ribbon is known, there is not enough information provided in doctors' offices or in the community about screening; exception may be the billboards along highways for places to get treatment (not screening focused)
- A lot of information is provided to those who are in treatment—binders of reading materials—but you have to feel well to read through them

B. Financial

- Lack of insurance or being underinsured is a barrier to seeking screening and/or treatment

C. Competing medical concerns

- People may be more concerned about heart conditions, obesity and diabetes but cancer is discussed as well
- Mental health *"I feel like depression and anxiety keep you at an arms distance from taking better care of yourself."*

D. Other competing concerns

- Others come before me *"I have a sick mom that I have to take care of. I didn't take care of myself, and I wound up with stage four breast cancer. I was unemployed and did not have health insurance. I did not know the system of going to the state of Connecticut and saying I'm out of work, I'm uninsured, I need help. I know I would've gotten help if I did. This is something I would want to speak about to other women. I knew I had a lump in my breast. I knew that I was sick. I think I knew when it became breast cancer from a lump. I just had other things that needed to be taken care of. When I realized the lump was bigger, I told my mom, I have to get a job to get insurance to take care of myself."*
- Taking time off from work when you don't get sick time or vacation time
- Too little time to take care of ourselves when we have family to take care of (e.g. making dinner)

E. Cultural Factors

- Stigma and misinformation around cancer is common among Black/African-American women, even among those educated *“At a local health clinic, there is a mobile mammography van. Even with that, people are scared to get exams. They think they are going to die. In the Black community especially, they think ‘we are going to die anyway’. I am an example. I have friends and family that died of cancer. When I got cancer and became bald headed, they became afraid. My sister was afraid. Look at me, I have bounced back. Still I talk about it, they don’t go. Just a few friends have gone for screening. The Black community, they are in fear, they will not show up.”*

Barriers to Screening

Participants presented several factors that prevented them from accessing timely care. Factors were linked to lack of insurance, transportation, lack of health education and busy work schedules. The most common theme among all focus groups was that the lack of insurance prevented many women from accessing routine screenings. Most participants were uninformed about programs that offered free and low cost breast cancer screenings to uninsured and underinsured women. Women reported accessing the free and low cost screening programs well after they noticed a symptom that they interpreted may be cancerous. In the Litchfield County area, women reported having a concern about their breast health and neglecting it due to lack of insurance to access services. In Fairfield County, women shared this experience.

Taking time off from work was a major concern for women when considering when they can obtain health screenings. Women in Fairfield, Litchfield and New London Counties expressed their primary concern was requesting the time off from work. If sick days were available, they were considered best used for when they were sick and not for early detection screening. Getting screened was not perceived as a measure to detect cancer early.

The final focus group question focused on participants sharing what they would like other women to know about their experience and offering suggestions for engaging more women in screening. Here are some of the highlights:

“Susan G. Komen has done such incredible work to educate women about breast cancer. Their messages push women to get screened. But there are still women that are not aware. I know women that flat out won’t go. But many of us especially in the advanced stages feel like that the war has pretty much been won. The next stage is—where is the research?”

“Women need to know their family history.”

“Get screened each year, no matter what happens in your life.”

Some of the suggestions for getting more women engaged in screening included:

- Address the “squash” (perceived pain/discomfort from compression of the breast during a mammogram) —women are afraid of it so letting them know labor is worse might be a way to get through it

- Offering incentives like a card from a local grocery store
- Make it fun—reach out to churches
- Get it into the educational curriculum in schools
- More examples on television *“At night, I watch my famous Latina actors and singers that had breast cancer. We need more women to share and make it public that cancer is almost curable.”*

Surveys

A total of 41 participants reflecting a combination of physicians, nurses, community health navigators, and outreach workers completed the 2014 Community Profile Survey with representation across the state of Connecticut. Of the 27 medical/clinical specialists participating, 33 percent were from gynecology, 19 percent family medicine, 19 percent oncology, 11 percent internal medicine, 11 percent surgery and seven percent radiology. Figure 4.1 presents the results of the types of breast cancer services provided by participating organizations. Outreach and education (70 percent), followed by patient navigation services (70 percent), screening and diagnosis (55 percent) and wellness and health promotion services (50 percent) were the most commonly stated services. With respect to screening and diagnostic services, the most commonly provided services reported included clinical breast examination (68 percent), sonogram/ultrasound (44 percent), provide follow up care (42 percent), biopsy (37 percent) and MRI (37 percent).

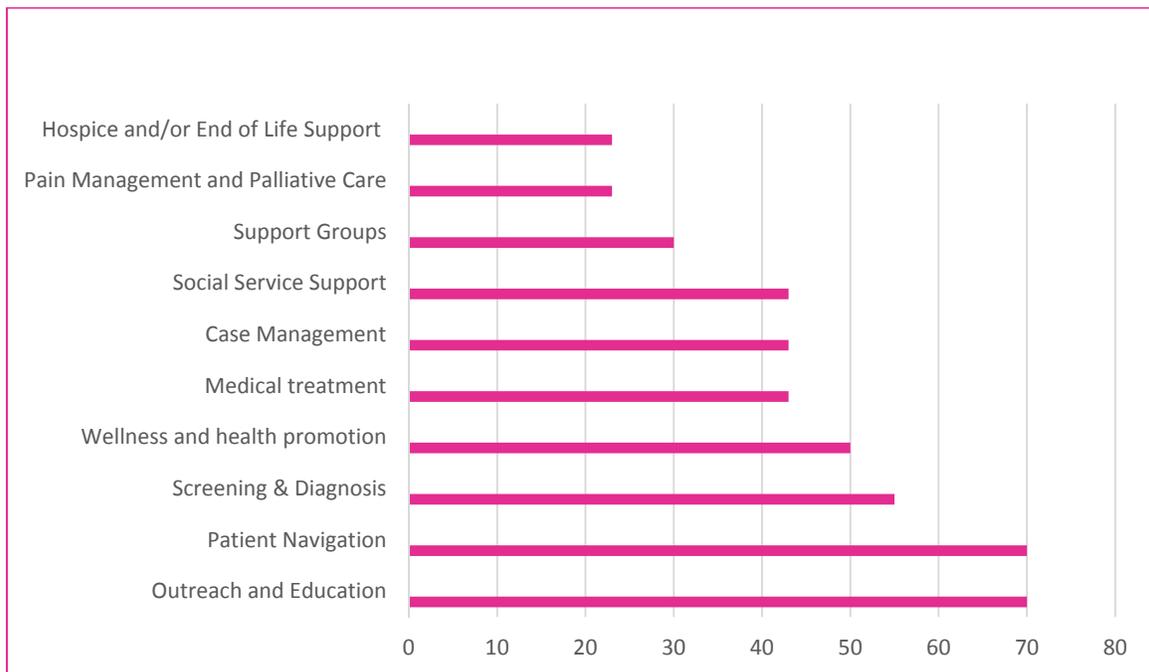


Figure 4.1. Types of breast cancer services provided by participating organizations (%)

With respect to payment for services, 93 percent of the organizations are able to provide free or reduced cost screening services to uninsured and/or underinsured women and 93 percent accept Medicaid and Medicare payments. In addition, providers are able to accommodate

language barriers by having interpretation services provided to patients (83 percent reported Spanish language services) and other languages are also available including Chinese, Arabic, Creole and Polish.

Participants were asked questions regarding the system of care. The first question was regarding how providers communicate with patients who have an abnormal screening. Providers use a variety of methods, including calling the patient with a reminder about follow-up (86 percent) and/or mailing reminders (72 percent). For women who are overdue for their routine mammography, 72 percent call for follow-up and/or send a letter. For women whose breast density is noted as 50 percent or more, providers reported that their next step is typically to order an ultrasound (55 percent), refer to a specialist (41 percent), order screenings (31 percent) and/or ordering breast MRI (24 percent). For women who reported an elevated risk for breast cancer (e.g. family history), 90 percent of providers reported that they take note of this. For those at elevated risk, 86 percent of providers refer to social or educational information. They are referred to the following organizations: American Cancer Society (81 percent), Komen Southern New England (50 percent), Cancer Care (46 percent) and Susan G. Komen National (31 percent).

For women who screen positive, 43 percent of the providers reported that they provide breast cancer treatment to their patients. Of these providers, most (75 percent) provide financial coverage for the treatment. When asked whether they refer their patients to clinical trials for breast cancer, 36 percent reported that they did with the same percent reporting that the trials were being conducted at their facility.

Figure 4.2 presents characteristics of the types of population served by the facilities. The most common characteristics included women who are uninsured or underinsured, Medicaid/Medicare recipients, have low literacy/education or may be obese/physically inactive.

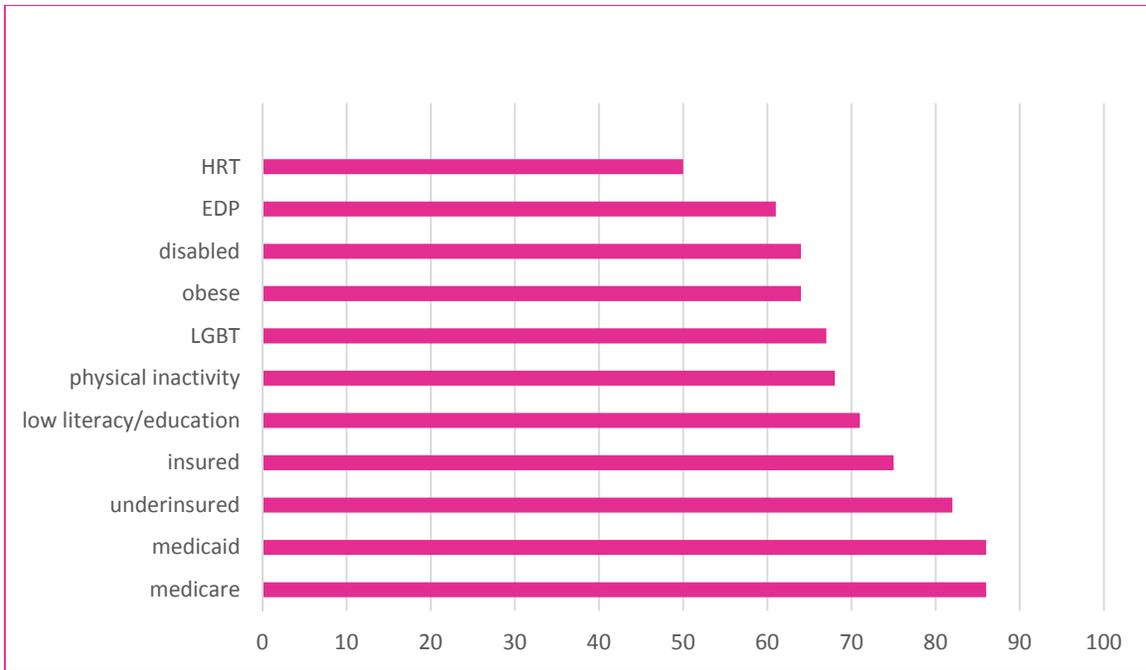


Figure 4.2. Characteristics of the types of population served by the facilities (%)

Figure 4.3 presents factors that providers believe women with late-stage breast cancer have in common. The most commonly reported factors included lack of a medical home, misunderstanding of perceived risk, socioeconomic status, more pressing personal issues and education level.

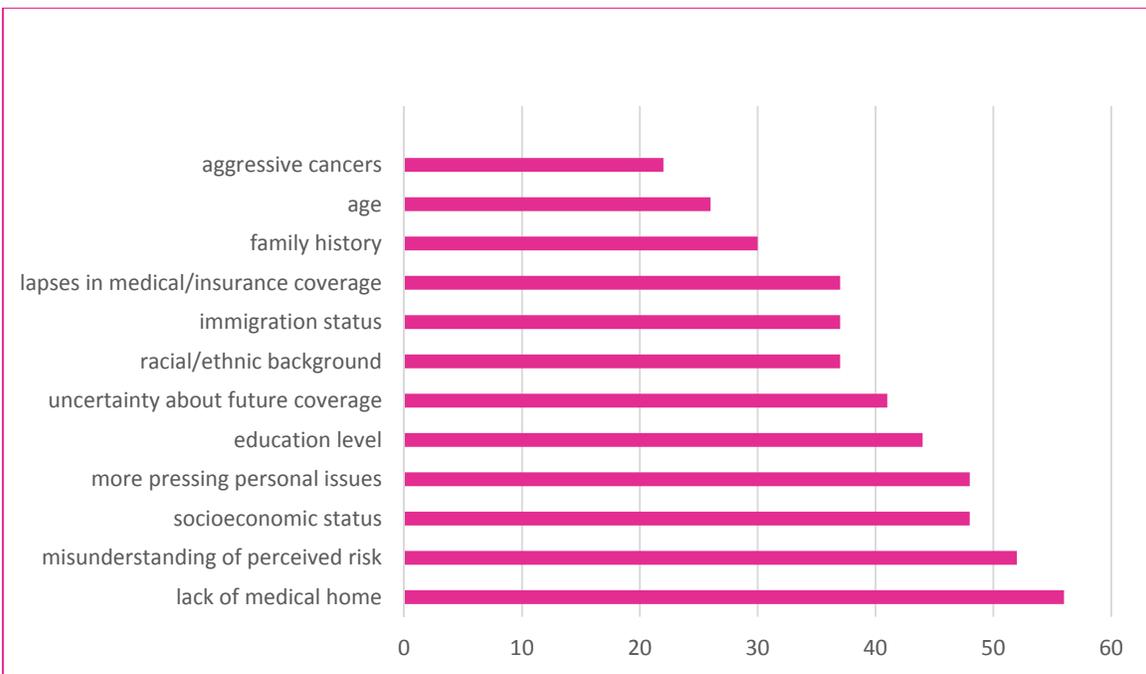


Figure 4.3. Factors that providers believe women with late-stage breast cancer have in common (%)

Providers were asked to comment on any types of services that they believe would be helpful to improve the current service delivery system. Examples of their responses were:

- “Collaborative efforts from community health centers, cancer organizations and cancer centers/cancer wellness centers to provide community education”
- “Education for women in their work environments”
- “Increase our outreach efforts”
- “Access to affordable plastic surgeons for reconstructive options”

Additional issues and concerns raised by providers that they felt affected women in their community from seeking services and treatment include:

- Need access to plastic surgeons who accept Medicaid or offer discounted fees
- Need to address social issues including child care, ability to take time off work
- Addressing misconceptions about the effectiveness of screening, therapeutic radiation, fears about chemotherapy and its side effects
- Ability to afford follow-up diagnostic imaging
- Identify ways to free them from financial stress

Qualitative Data Findings

Qualitative findings confirmed breast cancer needs in the target communities identified in the Quantitative Data Report. The qualitative data collected shed light on communities that lack early detection services due to gaps in health education and access to the health system. The Affiliate has a deeper knowledge of issues related to the recent implementation of Affordable Care Act and its limitation for early detection services.

Limitations

Komen Southern New England anticipated collecting data that would lead to comprehension of the Continuum of Care at various health systems in the target communities. It is clear that the Affiliate’s conclusions can only be as good as the data obtained. Breast cancer survivors were interviewed to comprehend access to early detection and treatment. Furthermore, survivors provided personal experiences that would increase the Affiliate’s knowledge about attitudes and beliefs women have about breast cancer. The methods used to collect the qualitative data by the Affiliate were Key Informant interviews, focus groups and provider surveys. These methods are recognized and widely used among researchers.

The qualitative data collection methods used to complete this report provided answers to questions raised about access and utilization of breast cancer services. Despite strategically planning the interviews and focus groups, participation was lower than was anticipated. Due to the lower numbers of focus groups and interviews, qualitative data may not be representative of the target communities.

The Affiliate determined that interviewing Key Informants in Hartford, Fairfield and New Haven Counties would be most beneficial to this report as breast cancer services were abundant in these areas. Key Informant interviews were scheduled with 12 providers in Hartford, Fairfield

and New Haven Counties. Key Informants had time constraints that prevented many from participating. On average, the Affiliate interviewed four Key Informants who were representative of each target community.

Focus groups in the Litchfield and New London Counties had low participation. The Affiliate was fairly flexible when coordinating the groups as the two counties have more rural towns and few very small cities. Groups were scheduled a month in advance, multiple reminders were sent out and additional time was allotted to conduct the groups. The Affiliate was unsuccessful in reaching survivors to participate in these counties. The participants in Litchfield and New London Counties were hesitant to take part in the groups.

Summary of Qualitative Data Results

Komen Southern New England discovered themes in the delivery and access of breast cancer services for the target communities across the state:

Hartford County

Early detection and treatment services were available and easy to access in the major urban areas. Smaller health facilities in suburban areas provided the services but lacked the resources and/or skills to reach specific populations. Additional outreach, education and navigation through the health systems would benefit patients and providers alike. Patients were aware of the services, but required assistance entering the system. Providers propose implementing more outreach to certain populations. Health systems in this community strive to provide in-person language interpretative services to patients with limited English.

Fairfield County

Strong collaborative efforts were effective at providing education and linking women to care. Women in this community found the use of mobile mammography programs was easiest to access early detection services.

Litchfield County

Focus group participants mentioned many barriers to access early detection and supportive treatment services. The Affiliate discovered that women living in Litchfield County access early detection services in the city of Danbury, located in neighboring Fairfield County. Educational outreach was not present in this community.

New Haven County

Access to breast health services in this county varied. Outreach, education, screening and treatment services were widely available to residents in the City of New Haven. Residents in Meriden and Waterbury, located in New Haven County, reported barriers to accessing services. Free and low cost diagnostic breast cancer screenings were not available to uninsured patients. Transportation and language issues were among the barriers reported by survivors. Having bilingual/bicultural providers would increase the level of trust within the Hispanic/Latino communities in Meriden and Waterbury.

New London County

Community-based health clinics played a key role in the health system in New London County. Community members' attitudes about the services received at the community health clinics were positive. The community health clinic provided referrals to imaging and cancer services if women were diagnosed. Providers and survivors presented concerns about supportive and navigation services post diagnosis.

Common themes emerged from both patients and providers. Focus group participants in all counties echoed that the topic of breast cancer is not often discussed within their communities. Though breast cancer is among the topics that affect women in the five target areas, it was last on the list when these participants ranked their health concerns. Diabetes, cardiovascular and other cancer types were among other health topics community members felt more comfortable discussing. Participants in Hartford and New London Counties reported that when faced with a health concern, it was common to seek medical attention if it impacted their daily life. This statement was reaffirmed by providers in the five target areas. It was acceptable to discuss breast cancer issues during Breast Cancer Awareness month. Advertisements about breast cancer appeared to be aimed at women over the age of 40. Participants were vocal about awareness reaching all women and starting the conversation about the importance of breast self-awareness and family history at a younger age. Additionally, participants commented on the lack of breast cancer literature in physicians' offices. Questions were also raised on the issue of dense breast tissue and screenings. Five out of seven women in a focus group in Fairfield County had dense breast tissue. At the time of the focus group, two still had questions about what dense breast tissue was.

Focus group participants shared similar experiences when describing a routine well visit with a gynecologist or a primary care physician. Participants informed the Community Profile Team about experiences they had while completing health history forms during well visits. Forms inquired about the history of breast cancer in the family. Participants in Fairfield County and Hartford County echoed that if their response was "no history of breast cancer," there was no discussion about screening. Focus group participants recommend physicians revise this section in the health history form. Perhaps women should be educated to the fact that, regardless of family history, all women are at risk of developing breast cancer, and so all women should be screened. Clinical breast exams that are conducted by GYN and PCP were not followed by a discussion about breast cancer.

The participants that attended the Fairfield County focus group were all diagnosed at a late-stage and have metastatic breast cancer. This group was particularly concerned with the education offered to women post-diagnosis.

Conclusions

The results of the Key Informant interviews, focus groups of patients and surveys of providers, when taken together, have provided substantial insight into the strengths, challenges, and barriers of the current system of care for women accessing services, staying in services and/or receiving the care that they need. It is important to note that the triangulation of data (i.e.,

combining the perspectives of key informant interviews, surveys and focus groups) reflects similar experiences and observations where patients echoed the providers. For example, there was substantial overlap between what patients and providers were observing with respect to financial concerns (e.g. uninsured/underinsured, lack of paid time off work, copayments, job loss, costs of breast reconstruction, meeting basic needs), time constraints (e.g. related to work, transportation), competing family concerns (e.g. childcare), psychological factors (e.g. stress, anxiety and fear of cancer and treatment) and educational factors (e.g. lack of knowledge and understanding of terminology, myths and misconceptions.)

With respect to the strengths of the system of care, there is a broad array of services provided to patients reflecting the Continuum of Care from outreach and education, screening, follow-up diagnostic imaging, biopsy and into cancer care. There are multilingual/bilingual services available and for those in treatment. Patients also have access to nurse and/or patient navigators. The challenges noted, however, were insufficient outreach and education services and the lack of ensuring patients do follow-up assessments (for some sites where there wasn't co-location of screening and follow-up imaging for positive tests).

Mission Action Plan

Breast Health and Breast Cancer Findings of the Target Communities

A thorough analysis of quantitative, qualitative and health system data identified issues in five target communities that were perceived to delay entrance into care for breast cancer patients.

Summary of the findings from the Quantitative Data Report

Fairfield County

The late-stage incidence trend in Fairfield County is rising, and therefore the county is unlikely to meet the HP2020 late-stage incidence rates. For this target community, three towns, Greenwich, Stamford and Norwalk, had previously been identified as areas with higher death rates, and three other towns, Bridgeport, Stratford, and Danbury, had been identified as areas of both high death rates and high late-stage diagnosis.

New Haven County

New Haven County has the highest breast cancer death rate of any county in the state. For this target community, two towns, Milford and New Haven, had been identified as areas of higher death rates; one town, Guilford, had been identified as an area with higher late-stage diagnosis; and four towns, Waterbury, Meriden, Hamden and West Haven, had been identified as areas of both high death rates and high late-stage diagnosis.

Hartford County

The late-stage incidence trend in Hartford County is rising, and therefore the county is unlikely to meet the HP2020 late-stage incidence rates. For this target community, two towns, Bristol and New Britain, had previously been identified as areas of high death rates, and three other towns, West Hartford, Hartford, and East Hartford, had been identified as areas of both high death rates and high late-stage diagnosis.

New London County

The late-stage incidence trend in New London County is rising, and therefore the county is unlikely to meet the HP2020 late-stage incidence rates. For this target community, three towns, Norwich, Groton and East Lyme, had previously been identified as areas of high late-stage diagnosis.

Litchfield County

The late-stage incidence trend in Litchfield County is rising, and therefore the county is unlikely to meet the HP2020 late-stage incidence rates. For this target community, one town, New Milford, had previously been identified as an area of high late-stage diagnosis.

Summary of the findings from the Health Systems and Public Policy Analysis

Women in the target communities of Fairfield, Hartford and New Haven had access to numerous breast health and breast cancer resources at hospitals, community health centers and mobile mammography vans within close proximity. Limited resources were available in rural New London and Litchfield Counties. Mobile mammography services had the greatest impact in delivering educational, screening and referrals for women across all communities. Services

were, however, limited to women in New London and Litchfield Counties, as mobile vans were unaffiliated with the local imaging centers and hospitals. Mobile mammography services have considered expanding to these communities once partnerships and/or mergers have been formed with the purpose of providing a Continuum of Care. The Affiliate will continue to promote early detection screening as the key to surviving breast cancer and increase awareness of resources to all target communities. The findings identified areas for improvement with respect to access to the full breast cancer CoC, especially following an irregular finding.

Summary of findings from the Qualitative Data

Providers and breast cancer survivors representative of every target communities contributed to this assessment, providing invaluable information and sharing their personal and professional experiences. Each candidly shared their experiences in providing services and accessing care in the various breast care systems. The results bring attention to areas in which Komen Southern New England may serve as a liaison to support and increase breast cancer programs. Three target communities have been effective at streamlining a CoC to reduce late-stage diagnosis and death of breast cancer. Plans were underway in New London and New Haven Counties to make improvements to services that would reach underserved women and ensure an easy transition into the CoC. Concurrently, the data highlighted health systems in target communities that have room to improve services by incorporating and expanding services to reach underserved communities. Providers presented issues sustaining funds that support early detection programs. Health care workers experienced challenges educating and providing services to women in Black/African-American, Hispanic/Latino and other ethnically diverse communities in urban cities in the target areas. Stigma and misinformation is common, and having bicultural and bilingual personnel was key to conducting outreach.

Across the state, women from diverse socioeconomic and ethnic backgrounds reported that taking time off from work was the most likely reason for delaying early detection screenings. Paid sick time off from an employer was normally used, for example, to care for a child or ill family member or to seek personal medical attention for an existing health concern if it interfered with work. Participants openly shared experiences about routine medical visits. Discussions about breast health or breast cancer with medical providers was considered to be brief or overlooked if women did not report having any family history or were under 40 years of age.

Early detection services were available and being utilized; however, providers perceived women diagnosed did not follow a CoC. Providers seek to improve the delivery of patient navigation services in Fairfield, Hartford and New Haven. Providers reported challenges reaching women in underserved neighborhoods in Fairfield, Hartford and New Haven. Difficulty navigating early detection and treatment services within the health system was reported as a challenge by survivors and patients in urban areas. Although medical insurance coverage has been expanded, women in all communities experienced some degree of challenges to obtain breast care.

Mission Action Plan

Mission Action Plan for Fairfield County, Hartford County and New Haven County

Problem/Needs Statements	
Quantitative	Target communities of Fairfield and Hartford Counties were identified as having rising late-stage incidence rates. New Haven County had a higher death rate than the Affiliate service area as a whole.
Health Systems	Existing breast health and breast cancer services within the target communities were not utilized by many women in the target communities.
Qualitative	Financial issues, cultural and language issues, competing medical concerns, health and career responsibilities are obstacles women confront when accessing early detection health and breast cancer services.
Affiliate Action Plan	
Priority:	Reduce barriers to and increase use of existing breast health services in Fairfield, Hartford and New Haven Counties in order to reduce late-stage and death rates throughout cities and towns within these target communities.
Objectives:	<ol style="list-style-type: none"> 1. In FY2016-FY2019, solicit grant applications from organizations that will increase outreach and raise awareness about breast cancer screening services to all women in medically underserved communities in Fairfield, Hartford and New Haven Counties. 2. In FY2016-FY2019, solicit grant applications from organizations experienced in delivering messages about early detection and breast health resources to ethnically diverse women in the target communities. Organizations would be required to offer bilingual services and culturally sensitive care to better meet the needs of women with multicultural backgrounds. 3. By March 2016, develop survey and evaluation tools to collect qualitative data and further explore barriers that delay or prevent access to breast health services for women in urban centers of Fairfield County. 4. In 2016 and 2018, hold biannual Lunch and Learns for community leaders in each community with the purpose of empowering participants to extend Komen's breast health messaging and promote available early detection and navigation services in all neighborhoods throughout the target communities. 5. By October 2016, host an annual breast health awareness workshop targeting Hispanic/Latina women in all target communities. Recruit Hispanic/Latino business and community leaders as well as grant funded program directors for an advisory committee that will lead efforts to host the event. The overall goal is to address fears and misconceptions about early detection. 6. By March 2016, assemble a task force that will advise, plan and implement Affiliate educational activities. The task force will be responsible for organizing educational events and address issues

	<p>that delay or prevent access to early detection services and/or delay entering the breast cancer continuum following an abnormal finding. Educational activities will be tailored for community and faith-based leaders with strong ties in Black/African-American and Hispanic/Latino communities in Hartford, Fairfield and New Haven Counties.</p> <ol style="list-style-type: none">7. In FY2016-FY2019, solicit grant proposals from organizations that seek to streamline existing breast health services and develop strategies to implement a fast-track process to ensure entrance into early detection services and seamless transition into diagnostic care or treatment.8. In FY 2016-FY2019, through grants, increase breast cancer survivorship programs that support women diagnosed with late-stage breast cancer diagnosis, including those with metastatic breast cancer. Grant funding will support navigation projects for patients in need of financial resources, medical supplies and psychosocial support services.9. In FY2016-FY2019, offer grant recipients professional development activities. Grantees will participate in round table discussions that will strengthen their collaborative efforts and open opportunities to share best practices.
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Mission Action Plan for Litchfield County and New London County

Problem/Needs Statements:	
Quantitative	Target communities of Litchfield and New London Counties had rising late-stage incidence rates. New London County had a higher late-stage incidence rate than the Affiliate service area as a whole.
Health Systems	Breast cancer resources were limited in the target communities. Many breast health and breast cancer resources were located outside the target communities.
Qualitative	Residents within the target communities reported challenges accessing breast health and breast cancer services in close proximity to their place of residence.
Affiliate Action Plan	
Priority:	Increase availability of breast health resources for women in the target communities of New London County and New Milford (in Litchfield County) in order to reduce late-stage diagnosis in the two target communities.
Objectives:	<ol style="list-style-type: none"> 1. Increase consumer awareness of breast health and breast cancer services by distributing literature to women's health medical practices located in Litchfield and New London Counties by July 2016. 2. Develop a Request for Proposals for the 2015-2019 grant terms to solicit grant applicants that will increase availability and access to screening and patient navigation services in Litchfield and New London Counties. Grant funds will support evidence-based programs that ensure breast health services are available to medically underserved communities. 3. In FY2016-FY2019 through biannual Lunch and Learn activities for providers in Litchfield and New London Counties, present Community Profile data that specifically targets women in their service area. Providers that demonstrate a capacity to educate, screen or provide breast cancer services will be informed of the availability of Komen Community Grants.

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