

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



**SUSAN G. KOMEN®**  
**New England**

# Table of Contents

<b>Table of Contents.....</b>	<b>2</b>
<b>Acknowledgments .....</b>	<b>4</b>
Introduction to the Community Profile Report .....	6
<b>Executive Summary.....</b>	<b>6</b>
Quantitative Data: Measuring Breast Cancer Impact in Local Communities.....	7
Health Systems and Public Policy Analysis .....	10
Qualitative Data: Ensuring Community Input .....	13
Mission Action Plan .....	21
<b>Introduction .....</b>	<b>28</b>
Affiliate History .....	28
Affiliate Organizational Structure .....	28
Affiliate Service Area .....	29
Purpose of the Community Profile Report.....	30
<b>Quantitative Data: Measuring Breast Cancer Impact in Local Communities .....</b>	<b>31</b>
Quantitative Data Report.....	31
Selection of Target Communities .....	59
<b>Health Systems and Public Policy Analysis.....</b>	<b>65</b>
Health Systems Analysis Data Sources .....	65
Health Systems Overview .....	65
Health Systems Findings.....	66
Public Policy Overview .....	94
Affordable Care Act .....	94
Medicaid Expansion .....	94
Affordable Care Act, Medicaid Expansion and Uninsured Women .....	96
Susan G. Komen Advocacy .....	97
National Breast and Cervical Cancer Early Detection Program .....	98
Qualitative Data Sources and Methodology Overview .....	114
<b>Qualitative Data: Ensuring Community Input .....</b>	<b>114</b>
Connecticut .....	114
Massachusetts .....	127
New Hampshire and Vermont .....	139
Breast Health and Breast Cancer Findings of the Target Communities.....	155

<b>Mission Action Plan.....</b>	<b>155</b>
<b>References.....</b>	<b>156</b>

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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, New England can claim the great misfortune of having multiple states with the highest incidences of this disease in the U.S. Fulfilling the Komen promise here isn't merely an objective, it's an imperative.

Since 1999, Susan G. Komen® 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 \$92 million for breast cancer research in New England. Komen New England is working to better the lives of those facing breast cancer in Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island and Vermont. Komen New England began with Races for the Cure® in Boston and Manchester, VT in 1993 and Hartford in 1994. The Affiliate has invested over \$13 million in Connecticut organizations, over \$3 million in Maine organizations, over \$9 million in Massachusetts organizations, and over \$6.5 million in Vermont and New Hampshire organizations providing breast health services to uninsured and underinsured residents.

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 that leads to breast cancer action 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**

### **Connecticut**

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 Connecticut target areas on which this Community Profile Report focuses (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

<b>Statistically Identified Breast Cancer Priority</b>	<b>Community</b>
<b>High Late-Stage Diagnosis Rate</b>	New London County Litchfield County
<b>High Late-Stage Diagnosis Rate AND High Death Rate</b>	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.

## **Massachusetts**

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

Statistics for this report were obtained from the Massachusetts Cancer Registry and the State of Massachusetts Department of Health. Data for all 351 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 deaths. Age-adjusted incidence and death rates were calculated. Towns with sample size irregularities or fewer than ten total cases of breast cancer were excluded from further inclusion in this report. The Affiliate selected Boston, Springfield and Worcester as the communities of interest. The three communities were reported to have the greatest burden of breast cancer in the state.

<b>Target Community</b>	<b>Incidence of Breast Cancer (Number of Cases)</b>	<b>Late-Stage Diagnosis (Number of Cases)</b>	<b>Death Rates (Age-Adjusted Rate)</b>
<b>Massachusetts</b>	25,434	-	-
<b>Boston</b>	1763	267	22.5
<b>Springfield</b>	528	78	23.1
<b>Worcester</b>	550	66	22.9

Massachusetts is home to immense diversity and with it, immense disparity. Municipalities often had similar rates of breast cancer, sharing more in common with distant towns and cities that were closely matched in terms of education, socioeconomic status 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 more likely to die from breast cancer if diagnosed. Such increased deaths may be related to higher late-stage diagnosis amongst medically underserved populations. 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 substantially 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 led to differential rates of late-stage diagnosis and breast cancer deaths.

## **Vermont-New Hampshire**

### **Breast Health and Breast Cancer Findings of the Target Communities**

Healthy People 2020 (HP 2020) is a national initiative developed by the federal government with specific targets set to improve the health of all Americans by the year 2020 (Komen, 2013).

Many organizations across the country have aligned with the HP2020 objectives to monitor progress related to reducing the burden of disease. The HP2020 target for breast cancer death rates is 20.6 breast cancer related deaths per 100,000 females--a 10.0 percent improvement in comparison to the 2007 rate (Komen, 2013). The target for late-stage incidence is 41.0 cases per 100,000 females (Komen, 2013).

Using the Healthy People 2020 objectives of reducing breast cancers found at a late-stage and decreasing death rates as a guideline, Vermont-New Hampshire has identified target areas within the service area based on how long it is predicted to take each community to reach these HP2020 goals. Women living outside of selected communities will not be excluded from assistance, rather target areas will receive closer review to diminish unmet needs that exist in services or care in jeopardized areas. This will be the focus of in-depth exploration for the duration of the four-year period.

Vermont-New Hampshire has selected five target communities. These areas reflect the greatest need regarding developing and implementing breast cancer programs for the extent of the timeline.

For the duration of the 2015 Community Profile, the selected target communities in Vermont-New Hampshire are:

- Addison County, Vermont
- Bennington County, Vermont
- Belknap County, New Hampshire
- Hillsborough County, New Hampshire
- Strafford County, New Hampshire

Addison County, Vermont and Bennington County, Vermont show remarkable need and therefore fall into the highest priority category. Empirical evidence projects both counties as unlikely to meet either target for HP2020. At the current trend, it is expected to take thirteen years or longer for both of these counties to reach late-stage diagnosis and death rate goals. Again, HP2020 is intended to serve as a measure to evaluate the impact of disease on the nation. In turn, this helps to assess the Affiliate's mission programs to reduce and eventually eliminate female breast cancers.

In the medium-high priority group for meeting HP2020 targets are Strafford, Belknap and Hillsborough Counties of New Hampshire. All three counties are expected to take thirteen years or more to reach the HP2020 late-stage incidence target. Additionally, they are predicted to take between one and five years to reduce death rates and meet HP2020 goals. These particular communities demonstrate highest risk of not obtaining HP2020 goals for decreasing late-stage breast cancer diagnosis.

## **Health Systems and Public Policy Analysis**

### **Connecticut**

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 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.

## **Massachusetts**

### **Health Systems Analysis Data Source**

A statewide inventory of breast cancer services was conducted. Approximately 100 providers in Boston, Springfield and Worcester were found to offer preventative breast cancer care and treatment services. Preventative breast cancer services include early detection education, breast cancer screenings and genetic counseling services. Breast cancer centers located in Boston, Worcester and Springfield provided radiology services and treatment services as well as emotional support. Though the services appeared to meet the standard of care, there were differences in the way the services were delivered across the target areas. For instance, patients had access to navigation services in each target community. However, patient navigation services were provided at different stages of care. In Boston, patients have access to navigation services at the earliest phase of the continuum of care. Navigators were found in a number of Boston-area communities providing outreach education and linking patients to early detection screenings. Boston-area community-based health centers and cancer centers facilitated navigation services with both private and federally funded grants. In Worcester and Springfield, however, navigation services appeared to be only provided to patients after an abnormal finding or a diagnosis of breast cancer.

### **Affiliate Partnerships**

The Community Profile will be utilized to inform health care professionals about the most recent findings of breast cancer and how it relates to women in their communities. The Affiliate has identified health departments and health care providers in the target communities that could benefit from Komen Community Grants to improve or increase breast cancer services. The Affiliate will also seek opportunities to collaborate with Women's Health Network (WHN). WHN services are managed by the Massachusetts Department of Public Health and funded by National Breast and Cervical Early Detection Program.

### **State Cancer Coalition**

Komen New England and the Massachusetts Comprehensive Cancer Prevention and Control Network (MCCPCN) share the goal of reducing the breast cancer burden in Massachusetts. MCCPCN leads efforts with more than 100 public health professionals, survivors, and community-based institutions. The Affiliate supports the MCCPCN by participating in the Secondary Prevention task force that is contributing to the development of the 2017-2021 Massachusetts State Cancer Control Plan as well as other committees led by the group as appropriate.

### **Affordable Care Act**

Recognized nationally for leading the health care reform model in 2006, Massachusetts reports that over 96 percent of the population has health care coverage. The health insurance marketplace managed by the Health Connector utilizes navigators to facilitate enrollment for residents. Insurance was not reported to delay entrance into early detection care. It was reported however that there were limitations for women in need of diagnostic screening services. The small percentage of uninsured residents is responsible for screening costs which may deter women from obtaining routine (annual) screenings. The Women's Health Network aims to inform and educate women about available free and low-cost screenings through their providers.

### **Vermont-New Hampshire**

Vermont-New Hampshire has examined asset maps, provider data and public policy across the continuum of care in each of the five target communities to determine the gaps, needs and limitations in health systems that could delay or prevent access to care. The Affiliate has become aware of various issues affecting the transition through the breast health and breast cancer continuum of care.

The Affiliate concludes that all Vermont-New Hampshire target communities would benefit from increased breast health education and outreach. Hillsborough County offers a greater wealth of resources within a relatively close radius for women living in the county. However, these resources are underutilized by minority women and those experiencing language barriers to screening and treatment. With the exception of Strafford County (32.0 percent rural), the remaining communities are geographically rural. They have limited access to information to make informed choices about health care. Women in these areas may not be aware of the resources and free programs available. They may also face other socioeconomic obstacles in obtaining care even if they have health insurance. Additionally, there are no mobile mammography vans that exist in any of the five target communities. Through discussions with breast cancer professionals, the Affiliate learned that most areas were no longer using mobile mammography due to the concerns with quality of imaging in the past. However, newer digital equipment may be available to reduce these concerns. This could be an avenue for future planning as an alternative means to reach out to the geographically rural and isolated women living in these target communities.

The Affiliate has the potential to develop several new partnerships with medical providers and other nonprofits in the five target communities. Building new relationships to promote breast health education and outreach as well increasing patient navigation providers would be especially helpful in rural areas. Women without knowledge of basic health guidelines would benefit by learning the resources available in their community and how to access them. Based on the results of the Community Profile, the Affiliate will strengthen current partnerships and cultivate new partnerships that will facilitate better health outcomes for women as they make their way through the continuum of care.

Recent changes in health care necessitate that additional education be made available to women. It was discovered that many women who have not had a medical provider and insurance in the past but now have access through the Affordable Care Act, are finding it difficult to enter and navigate the system. It is important for women to know what options are available to them. Breast health education and outreach needs to include information about benefits women have access to, including those provided by the Affordable Care Act, the National Breast and Cervical Cancer Early Detection Program and community resources such as Susan G. Komen. This information must be easily understood, readily obtainable for those living in rural communities, accessible to low-income women, clearly communicated to those who may not speak or understand English, manageable for those with limited education and/or learning disabilities and unbiased for those who may have concerns about being treated unfairly. Additional support may be required to assist these women with completing paperwork and helping with various needs that arise as they enter the health care system.

Vermont-New Hampshire seeks to increase involvement with state specific advocacy and public policy in the future in order to be a resource for legislation that impacts the breast health of local women. Greater advocacy, building new partnerships, and aligning with other agencies will promote better allocation of breast health resources. Ideally, addressing the barriers and gaps in the continuum of care will decrease the number of women being diagnosed at a later stage of breast cancer and reduce the incidence of death. In turn, this will make a lasting impact in the target communities and help meet Healthy People 2020 targets.

### **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 Massachusetts. 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 encountered on the front lines of Massachusetts' battle against breast cancer.

## **Connecticut**

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

<b>Format</b>	<b>Type of Participant</b>	<b># of Participants</b>	<b>Location by County</b>
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.

### **Massachusetts**

Qualitative data were collected through key informant interviews and questionnaires administered to care providers including oncology physicians and nurses, women's health practitioners, health educators, social workers, patient navigators and others. Moreover, to ensure that the report reflects the experiences of those with this disease, focus groups were conducted with 15 breast cancer patients and survivors.

<b>Format</b>	<b>Type of Participant</b>	<b># of Participants</b>
<b>Written Questionnaire</b>	Physicians & Nurses Health Navigators Outreach Workers	21
<b>Key Informant Interview</b>	Health Educators Social Workers Patient Navigators Oncology Specialists Radiology Techs	15
<b>Focus Group</b>	Breast Cancer Patients & Survivors	3 Focus Groups with 15 Participants

All participant responses were professionally analyzed to examine 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 centered 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, services were available to women, within the three target communities. The nationally recognized affordable health care model increased access to health care services to 96.0 percent of the population. Notably, service providers in each target community reported their

patient base to be mostly insured, with a small percentage of self-pay patients. Individuals considered to be self-pay were often referred to local, state and federally funded Breast Cancer Early Detection Programs (Women's Health Network) for screenings.

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 focus groups primarily engaged participants on breast cancer awareness prior to their diagnosis, 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 that they yielded. Financial concerns, primarily those surrounding un- and under-insurance; cost of deductibles; consequences of workplace absences; and competing budgetary expenses 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. Results from focus groups suggested that low-income and medically underserved individuals faced challenges that further delayed their access to care well after symptoms became worrying enough to seek medical attention. Challenges described were related to financial limitations, low health literacy among diverse communities and resources for bilingual and bicultural language interpreters.

### **Vermont-New Hampshire**

Data collection methods for this assessment included key informant interviews with breast cancer survivors, health care providers and those involved in related breast health services. Surveys were utilized and tailored both to health care professionals and breast cancer survivors. A supplemental review of qualitative research was also included. These resources allowed the voice of each community to be heard in order that an appropriate response could be designated by the Affiliate.

### **Addison County, Vermont**

Key questions focused on understanding the increasing rate of breast cancer incidence in Addison County. Factors that may be contributing to the dramatic rise in death rates in this county and possible correlations or causes were considered. Rural geography was a focus in terms of how access, utilization, and quality of care for breast cancer all influence incidence and death rates. Inquiries were made to gain a better understanding of the strengths and weaknesses of the health care system in Addison County in regard to quality performance and accessibility for women along the continuum of care.

**Key Findings:** Addison County offers conventional medical interventions at the local hospital. Those interviewed reported that personalized attention and care was exceptional. Weaknesses reported included longer wait times for routine appointments and therefore reduced convenience compared to larger facilities that provide screening mammography. This may result in delays for women getting screening or the need to travel longer distances outside of the county to obtain care. Additionally, it was reported that oncology treatment such as chemotherapy was not offered on a daily basis in Addison County. Patients may be required to wait for an open chair or choose to travel a distance to a neighboring county for daily care. This

travel can be an hour or more each way and was reported by some key informants as a potential barrier. It was noted that due to the associated discomfort of cancer, including pain, these factors could make travel more difficult, and increasing the possibility of opting out of treatment.

Addison County offers complimentary cancer care such as acupuncture and supportive herbal remedies for breast cancer treatment and symptom management which can be utilized alone or in conjunction with conventional treatment. This is an asset to the community and a well utilized holistic approach to care. There is a well-established telephone support network that is growing in the area, Kindred Connections, for cancer patients of all types. It is becoming more widespread throughout the state of Vermont and a source of social support for those who may not have the access or desire to attend traditional support groups. This group also provides networking to assist with ride sharing to and from appointments. This is particularly beneficial to rural areas and for women with transportation obstacles. However, many women may not be aware of this support in spite of its positive value in the communities of Vermont. Helping women to become aware of the supports and services in their community would be advantageous.

Rural geography was reported as a factor in regard to travel distances to care, obtaining breast cancer risk reduction and early detection messaging, awareness of supplemental funding and programs that help cover screening and treatment costs, and ability to take time off from work to get to appointments. Self-employed women reported financial concerns due to limited or no health insurance. Key informants reported that Ladies First, the Vermont Breast and Cervical Cancer Program provider, delivered a great deal of financial assistance and this was considered an asset. Some key informants reported not having the ability to obtain care without this assistance and expressed sincere gratitude for the program.

Women in Addison County continue to face challenges that arise as a result of living in a rural community and would benefit from additional support and services. Collectively, more organizations, along with Komen Vermont–New Hampshire, have noted issues that may negatively impact these women. In the future, the Affiliate intends to collaborate with the efforts of these organizations to improve the lives of women living in this county and to reach HP2020 goals.

### **Bennington County, Vermont**

Bennington County residents show increased rates of having less than a high school education and living with an income 100-250 percent below poverty. Accordingly, key questions were focused on gaining information regarding financial challenges and obstacles to accessing care. Additionally, the Affiliate took a closer look at the relationship between the increasing age of the female population and the unfavorable trends in this county. A general assessment was made of how education level influences breast cancer risk reduction, awareness messages and seeking services for early detection.

**Key Findings:** In agreement with the Quantitative Data Report, Bennington County was found to be economically depressed. Numerous themes emerged from key informant interviews with health professionals such as limited knowledge of breast cancer guidelines, lack of awareness of financial resources available, and the inability to complete eligibility paperwork for reduced cost programs. The key informants noted that women reported believing that those without a family history of breast cancer would not need mammogram screenings. In addition, they reported that although women from Bennington County in the health care system were regularly presented with information about financial assistance programs for low or reduced cost screenings such as Ladies First, they were sometimes overwhelmed by the paperwork and required assistance in navigating the process. This assistance was provided but limited due to time constraints of professionals providing help.

Health professional key informants explained that many women living in this economically depressed area do not have health insurance or a primary care provider. Women living in Bennington County who have never had a primary care provider report a severe lack of knowledge of preventive health management, lack awareness of free or low-cost preventative health care programs, do not know how to navigate the health care system, or where to seek help. In turn, key informants report that local women often wait until very serious symptoms arise, such as those associated with late-stage breast cancer for example, before seeking care. In turn, the key informants report that their treatment options are more limited and death rates increase.

In addition, males with breast cancer in this county (and all other rural target communities) experience difficulties in obtaining breast cancer education and support. Studies revealed the need for increased sensitivity to address the unique needs of males and early detection.

Another concern for this target community is increasing age and how it impacts the unfavorable status of this area. Age as a factor was assessed through a review of published articles as the key informants were unable to provide sufficient insight relating to the subject. It was found that providers may improve communication with older patients in order to facilitate informed decision making along the continuum of care from screening, diagnosis and treatment to survivorship needs. This research highlights the importance of sensitivity to the individual needs of the patient regardless of age, and the merit of the physician-patient relationship. Furthermore, another vulnerable population that would benefit from additional resources and support is women with intellectual disabilities. Studies demonstrate a growing need for this population and the importance of educating caregivers with key risk reduction and early detection information.

### **Belknap, New Hampshire**

In review, female breast cancers occurred more often in Belknap County than in the Affiliate service area as a whole. There is an increasing trend in the number of new cases in Belknap County, especially in comparison to the Vermont-New Hampshire service area and United States as a whole. The Affiliate has no existing relationships in this community at this time.

The Affiliate would like to gain a better understanding of factors that are contributing to this increasing trend and what resources or partnerships could be cultivated in order to reverse the unfavorable breast cancer incidence and late-stage trends in this county.

**Key Findings:** Key informants from this county reported financial issues hindering access to breast cancer screening as well as overall financial hardships in relation to care. They mentioned that additional effort should be made by health care providers to assess the needs of all family members and to facilitate access to information about low cost, affordable, or free programs for both general and breast health care. They noted the need for more compassion and understanding toward survivors and their unique needs in addition to financial support such as gas and grocery cards throughout treatment. Furthermore, it was noted that more outreach was desired. Word of mouth messaging by providers, other survivors and support groups about programs for risk reduction and survivorship was requested. This county reported a severe shortage of resources in their area and women “going broke” during breast cancer treatment.

The qualitative data collected, although limited, confirms that statistical analysis of this county. Serious financial concerns paired with increased need for outreach and emotional support in Belknap County will be very important to address. With additional resources this area will be more likely to reach HP2020 goals.

### **Hillsborough County, New Hampshire**

Socioeconomic factors such as being foreign-born and linguistically isolated are notable in Hillsborough County in comparison to other counties in the Affiliate service area. Hillsborough County reflects the most diverse population in comparison to the Vermont-New Hampshire service area as a whole. Women in Hillsborough County, New Hampshire confront numerous barriers that influence health outcomes and achievement of the HP2020 targets.

The Affiliate sought to determine the role of linguistic isolation as it relates to the unfavorable trends in this county. The data showed an increased area of diversity which prompted questions such as, “Are women receiving information about services and risk reduction in a language they can understand and that is culturally sensitive?” The Affiliate wanted to understand if disparities are being addressed in order to increase access, utilization and quality of care for the diverse population of women living in this county.

**Key Findings:** Health professional key informants from New Hampshire and Hillsborough County reported that there are a high number of minority women that are in need of risk reduction and early detection education. According to the key informants, many of these women have not sought out health care due to misinformation and myths surrounding breast cancer. Many of these women are reported to be refugees in a Federal program located in Hillsborough County. Some foreign-born women have reported to health professional key informants that they have very different and brutal methods of dealing with breast cancer in their home countries and therefore fear and avoid medical interventions in the United States. The informants reported that foreign born women have limited opportunities in which to seek outreach and education due to the time constraints and nature of their work. In addition to this,

informants noted that these women often have language barriers that interfere with understanding early detection and risk reduction messages, as well as utilizing the health care system in general. On the positive side, it was noted that hospitals offer translation services for all languages in order to make care more accessible.

Given the increased diversity of the population in this target community, more effort needs to be directed toward understanding the needs, and then reaching out, to these women and men. The population requires more sensitivity from health professionals about beliefs that are unique to this diverse community. This has been supported by a key study noting that language barriers, cultural factors and beliefs related to illness, all influence outcomes and the breast cancer continuum of care. Fears, coping styles, and spiritual beliefs were repeated factors throughout the study.

The overreaching concern for Hillsborough County is the increased diversity of the population and the unique concerns, from screening to survivorship, that must be addressed in order to achieve HP2020 goals of reducing late-stage diagnosis and deaths from breast cancer. This is especially imperative in light of the finding that “ethnic minority women are diagnosed with more advanced stage disease and experience greater morbidity (2004).”

### **Strafford County, New Hampshire**

A striking figure of 100 percent of residents live in medically underserved areas in this county. Of the population ages 40-64 living in this county, 13.5 percent has no health insurance. Adding to the vulnerability of this county is an increased level of poverty. Combined, these factors indicate that multiple barriers are interfering with access and utilization of care in this county.

Questions targeted understanding the sparse medical service availability and how that may be a factor in breast cancer outcomes for this county. Qualitative data collection focused on topics of access, utilization and quality of care. Komen New England hopes to play a role in improving outcomes for women in this community by building new partnerships understanding new ways to make a positive impact.

**Key Findings:** Although there were few key informants from Strafford County, the data collected was insightful. The additional responses by key informant health professionals for the State of New Hampshire provided information that will be considered. The limited data once again plays a role in future decision making and supplemental information will be needed.

This target community hosts the fewest number of medical providers of all target areas. However, financial assistance is available through the local hospital and a patient navigator program is in place to lend assistance. Some of the issues specific to this area were related to financial hardships including lack of insurance, being underinsured with high out-of-pocket expenses and not meeting eligibility guidelines for free or reduced-cost programs. Key informants made several suggestions regarding possible ways to reduce the burden for these women and improve their progression through the breast health continuum of care. It was noted that a guaranteed funding program specific for those who are not eligible for other

programs as well as a coordinator that could help link and refer women to the appropriate resources and even help in arranging appointments and/or transportation would be beneficial.

In reference to late-stage diagnosis, health professional key informants agreed that known factors such as lack of health insurance and financial hardships play a role. Others commented that inconsistencies between providers about screening guideline messages exist, leading to a decrease in screenings. This was noted as a problem in identifying breast cancer at its earliest stages and increasing death rates. Efforts will need to focus on addressing additional factors that contribute to late-stage diagnosis. Health professional key informants indicated a belief that residents have more than adequate access to screening and rural geography does not appear to negatively impact this area as noted in other rural communities. However, financial challenges do exist, and the County would benefit greatly from additional support and partnerships in the future.

Limited primary care providers in the area were the greatest concern. Additional support in the form of supplemental funding to assist with financial burdens would be beneficial. Vermont-New Hampshire is not currently partnered with agencies in this community but would like to increase collaboration in the future.

### **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.

### **Breast Health and Breast Cancer Findings of the Target Communities**

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

For the duration of the 2015 Community Profile, the following target areas are:

- Fairfield, New Haven, Hartford, Litchfield, and New London Counties, Connecticut
- Boston, Worcester, and Springfield, Massachusetts
- Vermont
- New Hampshire
- Maine
- Rhode Island

**Table 3.** Mission Action Plan for New England Target Communities

<b>Problem/Needs Statements</b>	
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.
<b>Affiliate Action Plan</b>	
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"> <li>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.</li> <li>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.</li> <li>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.</li> <li>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.</li> <li>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.</li> <li>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.</li> </ol>

	<p>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> <ul style="list-style-type: none"> <li>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.</li> <li>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.</li> <li>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.</li> </ul>
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#### **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"> <li>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.</li> <li>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</li> </ol>

	<p>that ensure breast health services are available to medically underserved communities.</p> <p>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.</p>
<b>Problem/Needs Statement</b>	
<i>Quantitative</i>	Quantitative data reports reveal Boston to have a high breast cancer incidence, number of late-stage diagnosis cases and deaths, with death rates higher than that of Massachusetts as a whole.
<i>Health Systems</i>	Residents reported gaps in health care coverage for diagnostic screening services. Access to breast cancer early detection services was lower among low income and ethnically diverse populations.
<i>Qualitative</i>	Early detection services and treatment services were available but limited for individuals of culturally and ethnically diverse backgrounds in neighborhoods of Boston.
<b>Affiliate Action Plan</b>	
<i>Priority</i>	Increase knowledge and use of breast health and breast cancer navigation programs among low income and culturally/ethnically diverse populations in Boston.
<i>Objectives</i>	<ol style="list-style-type: none"> <li>1. In FY 2016-2019 Develop and issue a request for applications soliciting grants from early detection service providers committed to improving breast health and breast cancer resources for underserved, low income and culturally diverse communities in Boston. Grants will support programs that increase community awareness of services and availability of screenings for uninsured and underinsured patients.</li> <li>2. In FY 2016-2019 Solicit grant applications from organizations seeking opportunities to implement or expand patient navigation programs among low income and culturally/ethnically diverse populations in Boston.</li> <li>3. In FY 2016-2019 Coordinate Affiliate breast cancer wellness events to increase provider knowledge of the Community Profile. Consumers will become informed of breast cancer resources through health events coordinated by the Affiliate in partnership with Komen-funded programs and local breast cancer centers.</li> </ol>
<b>Problem/Needs Statement</b>	
<i>Quantitative</i>	Quantitative data reports reveal Springfield and Worcester to have a high breast cancer incidence and number of late-stage cases and deaths, with death rates higher than that of Massachusetts as a whole.

<i>Health Systems</i>	Health systems seldom promoted early detection breast health and breast cancer services for individuals in low-income communities, medically uninsured and ethnic and cultural diverse populations.
<i>Qualitative</i>	Early detection services and treatment services were available but limited for individuals of culturally and ethnically diverse backgrounds in neighborhoods of Springfield and Worcester.
<b>Affiliate Action Plan</b>	
<i>Priority</i>	Increase breast health and breast cancer knowledge and expand access to and use of breast cancer care and navigation programs among low income and culturally/ethnically diverse populations in Springfield and Worcester.
<i>Objectives</i>	<ol style="list-style-type: none"> <li>1. In FY 2016-2019 Develop and issue a request for applications soliciting grants from early detection service providers committed to eliminating barriers to breast health and breast cancer services for underserved, low income and culturally diverse communities. Grant opportunities will be available for organizations to implement or expand patient navigation programs.</li> <li>2. By December 2016 Explore opportunities with local Women's Health Network providers and cancer centers in Springfield and Worcester to form a breast cancer task force to increase provider and consumer awareness of breast cancer and Affiliate-funded programs.</li> <li>3. By June 2016 Form an educational advisory committee that will be responsible for participating in existing wellness community events. Advisory members will coordinate a series of breast cancer health workshops aimed at educating community leaders from the Springfield and Worcester area. Partner with at least five community leaders in each target area to distribute Komen educational materials and information about local breast cancer resources.</li> </ol>
<b>Problem/Needs Statement</b>	
Women in Addison County continue to face challenges that arise as a result of living in a rural community and would benefit from additional support and services. The Affiliate intends to collaborate with the efforts of similar organizations to improve the lives of women living in this county and to reach HP2020 goals.	
<b>Affiliate Action Plan</b>	
<i>Priority</i>	Increase access to the breast health continuum of care for rural women through developing partnerships in Addison County, Vermont.
<i>Objectives</i>	<ol style="list-style-type: none"> <li>1. In FY 2016, hold at least one grant writing workshop in Addison County, Vermont.</li> <li>2. By FY2017, add at least one medical, public health, or nonprofit professional from Addison County to the Affiliate's Board of Directors to ensure the needs of the county are represented on the Board.</li> </ol>

	<p>3. In FY2018, hold a rural breast cancer summit with providers from Addison County and neighboring counties to discuss possible partnership opportunities with the goal of increasing access to and seamless progression through the breast health continuum of care.</p>
<b>Needs Statement</b>	
<p>Bennington County has a substantially older female population. This county also demonstrates a higher rate of poverty and more residents with less than a high school education. Health professional key informants from this county as well as Vermont State have reported that many women never had health care in the past and have no existing provider. Even with the rollout of the Affordable Care Act, these women do not know who to call, how to access the system, lack general awareness about breast health, and are not aware of free or low-cost screening programs in their area. Additionally, when faced with paperwork for eligibility for these programs they are unable to complete the documents or require assistance to help with this process.</p>	
<b>Affiliate Action Plan</b>	
<i>Priority</i>	Increase the quality of Affiliate funded grants to ensure identified gaps in the continuum of care are addressed in Bennington County.
<i>Objective</i>	<p>1. By the FY2017, a priority of the Community Grants Request for Applications will be increased access to breast health navigation services to assist with education and outreach to uninsured and underinsured women, help complete paperwork, and provide patient advocacy and help with decision making about screening and treatment in Bennington County.</p>
<b>Problem/Needs Statement</b>	
<p>This is the most diverse county in the Affiliate service area resulting in a vulnerable population of women reported as not seeking screening and care due to language barriers and cultural beliefs. Outreach and education is key to increasing access to care.</p>	
<b>Affiliate Action Plan</b>	
<i>Priority</i>	Increase breast health outreach and education to refugees and women of diversity in order to eliminate fears about health care and to facilitate access and utilization of care in Hillsborough County, NH.
<i>Objectives</i>	<p>1. In FY2016, develop at least one new collaborative relationship with community-based organizations that serve refugee and women of diversity in Hillsborough County, NH.</p> <p>2. From FY2016 through FY2019, include in the Vermont-New Hampshire Community Grant RFA, the need for programs addressing the educational needs of refugees and women of diversity in Hillsborough County, New Hampshire.</p>
<b>Problem/Needs Statement</b>	
<p>Compared to the Affiliate service area as a whole, Belknap County possesses higher female breast cancer incidence rates and trends. Incidence rates in Belknap County, New Hampshire (152.4 per 100,000) are greater than the Affiliate service area as a whole (131.8</p>	

per 100,000). It is predicted to take thirteen years or longer to reach the HP2020 late-stage incidence target. The Affiliate has no existing relationships in this community at this time.

<i>Priority</i>	Increase the health care system's capacity to provide quality breast health care in Belknap County, New Hampshire.
<i>Objective</i>	<ol style="list-style-type: none"> <li>1. In FY2016, hold at least two collaborative meetings aimed at hospitals, primary care providers, health clinics and community-based organizations to discuss improving continuity of care between referral, screening, diagnosis, treatment, and support services within Belknap County, New Hampshire.</li> </ol>
<i>Priority</i>	Establish new partnerships with community-based health organizations to effectively implement breast health education and services in Belknap County, New Hampshire.
<i>Objective</i>	<ol style="list-style-type: none"> <li>1. By FY 2019, partner with community-based health organizations to arrange at least two small group education classes on breast health, including risk reduction and early detection.</li> </ol>

#### **Needs Statement**

An increased number of women in Strafford County live in poverty and are more likely to be uninsured or underinsured. It was reported that 25.1 percent of residents age 40-64 were living at 250 percent below the poverty level. Health professional key informants from New Hampshire have indicated that women cannot afford out-of-pocket costs including co-pays, high deductibles, and transportation costs which are financial barriers to early detection.

<i>Priority</i>	Increase access to services for women who do not meet eligibility guidelines for free or low-cost breast health programs to eliminate barriers and increase access.
<i>Objective</i>	<ol style="list-style-type: none"> <li>1. From FY2016 through FY2019, the Vermont-New Hampshire Community Grant RFA will include patient navigator programs aimed specifically at working with uninsured and underinsured women in Strafford County, New Hampshire as a funding priority.</li> </ol>

#### **Problem/Needs Statement**

Target communities in Maine and Rhode Island with rising late-stage incidence rates.

<i>Priority</i>	Increase availability of breast health resources for women Maine and Rhode Island in order to reduce late-stage diagnosis in the two target communities.
<i>Objective</i>	<ol style="list-style-type: none"> <li>1. Increase understanding of breast health needs through discussions with service providers in key areas throughout Maine and Rhode Island.</li> <li>2. Increase the number of grant applications from Maine and Rhode Island. Grant funds will support evidence-based programs that ensure breast health services are available to medically underserved communities.</li> </ol>

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

# Introduction

## Affiliate History

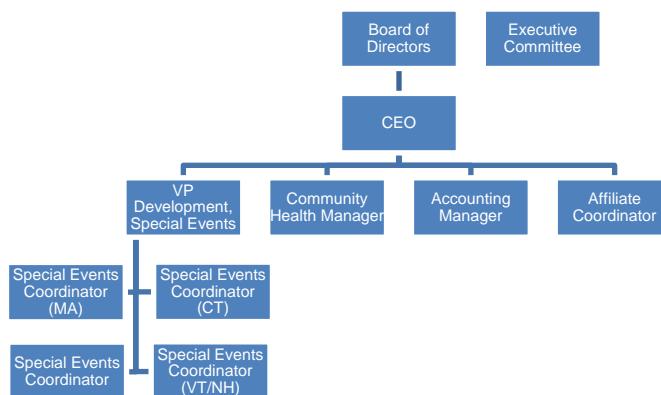
In 1980, Susan G. Komen died of breast cancer at the age of 36. Before she died, her sister promised she would do everything in her power to end breast cancer forever. In 1982, that promise launched the breast cancer movement that became Susan G. Komen®. Today, Komen® is the world's largest grassroots 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.

Susan G. Komen New England began with Races for the Cure® in Boston and Manchester, VT in 1993 and Hartford in 1994. The Affiliate has invested over \$13 million in Connecticut organizations, over \$3 million in Maine organizations, over \$9 million in Massachusetts organizations, and over \$6.5 million in Vermont and New Hampshire organizations providing breast health services to uninsured and underinsured residents. The Affiliate has also contributed more than \$9.5 million to support breast cancer research.

Komen New England's work focuses on improving breast cancer outcomes throughout our area through patient navigation, reducing barriers to care, and providing education that leads to breast health action. Securing funds to make screening and treatment available to all residents of New England is the Affiliate's highest priority. The Affiliate's Board of Directors, staff and volunteers are committed to raising funds that support women in New England and fund breast cancer research.

## Affiliate Organizational Structure

Komen New England has offices in Farmington, CT, Newton, MA and Manchester, VT. The organizational components of the Affiliate are the Board of Directors, the Executive Committee, and staff. A 12-member Board of Directors works with Komen New England staff to fulfill the Komen promise locally: to save lives and end breast cancer forever. Figure 1.1 depicts the Affiliate's organizational structure.



**Figure 1.1.** Komen New England organizational chart

### **Affiliate Service Area**

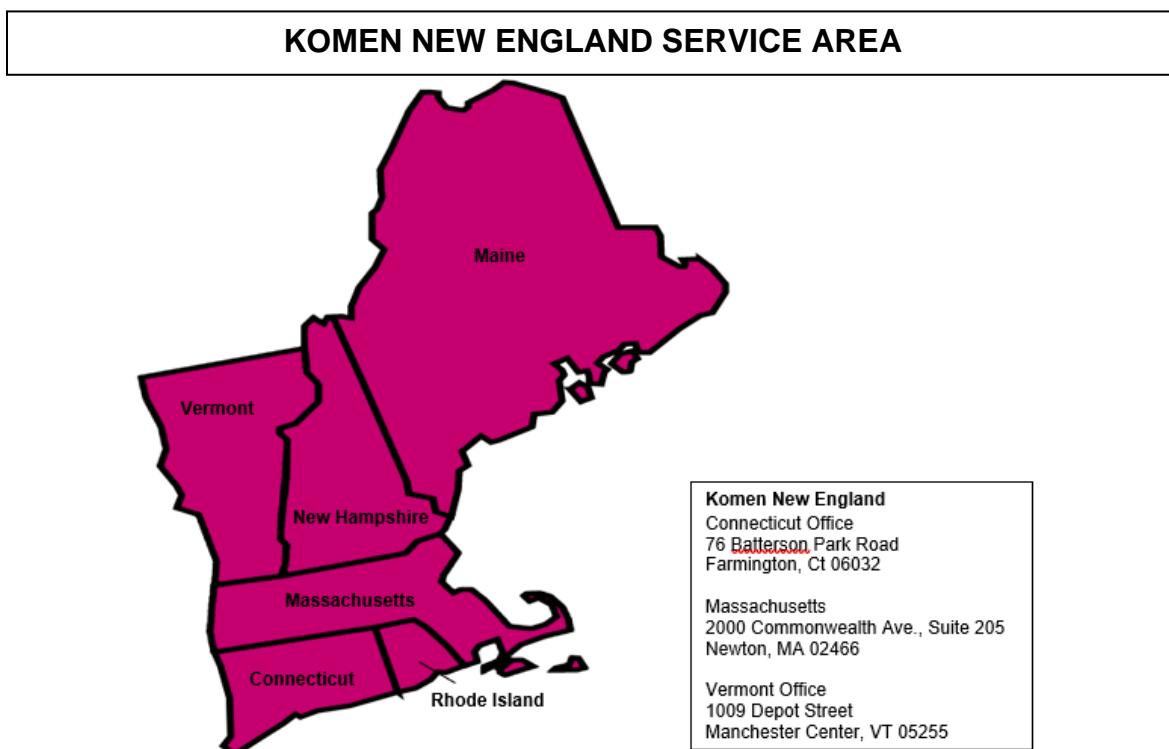
Nationally, New England has the highest rates of breast cancer incidence, led by New Hampshire (144 per 100,000 cases) and Connecticut (142 per 100,000 cases), and followed closely by Massachusetts (138 per 100,000 cases). There are approximately 14 million people residing in New England according to the 2017 U.S. Census estimate. Across New England, there are huge poverty and wealth disparities. Table 1.1 presents a demographic profile of the New England states.

**Table 1.1. Demographic profile of New England**

	CT	MA	ME	NH	RI	VT
Population	3,588,184	6,859,819	1,335,907	1,342,795	1,059,639	626,657
Median Household Income	\$69,461	\$70,954	\$50,826	68,485	\$58,387	\$56,104
Individuals living below the federal poverty line	10.20%	10.40%	12.50%	7.30%	12.80%	11.90%
Percent of population 65 years or older	16.80%	16.20%	19.90%	17.60%	16.80%	18.70%
Ethnic Breakdown of the State Population						
White	80.30%	72.20%	93.30%	90.50%	72.50%	94.50%
Black/African-American	11.90%	8.80%	1.60%	1.60%	8.20%	1.40%
Asian	4.80%	6.90%	1.20%	2.80%	3.70%	1.80%
American Indian	0.50%	0.50%	0.70%	0.30%	1.00%	0.40%
Hispanic/Latino	16.10%	11.90%	1.60%	3.70%	15.50%	1.90%

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

Figure 1.2 depicts the Affiliate service area.



**Figure 1.2. Susan G. Komen New England service area**

### **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 quantitative data report for Komen 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 New England's Quantitative Data Report for Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island and Vermont. 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

		Incidence Rates and Trends			Death Rates and Trends			Late-stage Rates and Trends		
Population Group	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*	-
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	SN	16	28.1	-1.4%
Non-Hispanic/ Latina	1,597,328	2,799	137.7	0.9%	492	22.1	-2.5%	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%
Maine	677,964	1,108	126.5	-1.4%	193	20.9	-2.5%	354	41.6	-1.9%
White	656,644	1,094	126.8	-1.3%	191	20.9	-2.5%	350	41.8	-2.0%
Black/African-American	8,133	SN	SN	SN	SN	SN	SN	SN	SN	SN
American Indian/Alaska Native (AIAN)	5,114	3	88.0	-14.0%	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	8,074	6	81.0	-22.1%	SN	SN	SN	SN	SN	SN
Non-Hispanic/ Latina	669,861	1,105	127.0	-1.4%	191	20.7	-2.3%	353	41.8	-2.0%
Hispanic/ Latina	8,103	SN	SN	SN	SN	SN	SN	SN	SN	SN
Androscoggin County – ME	55,064	74	112.5	0.3%	15	22.0	-1.9%	22	34.1	3.6%
Aroostook County– ME	36,778	54	105.4	-6.7%	12	22.3	-2.2%	17	36.0	-10.6%
Cumberland County – ME	143,930	235	132.4	-0.2%	37	19.4	-2.5%	73	41.9	1.2%
Franklin County – ME	15,655	24	119.7	-0.9%	3	15.3	-2.8%	7	35.7	20.7%

		Incidence Rates and Trends			Death Rates and Trends			Late-stage Rates and Trends		
Population Group	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)
Hancock County – ME	27,698	53	133.9	-4.8%	9	22.1	-1.3%	16	42.0	-7.0%
Kennebec County – ME	62,574	110	137.0	1.5%	20	24.4	-2.5%	36	45.8	1.9%
Knox County – ME	20,305	37	128.4	-3.5%	9	26.8	-1.4%	13	50.5	8.9%
Lincoln County – ME	17,709	33	116.6	-1.5%	4	14.3	-4.2%	10	36.1	-16.0%
Oxford County – ME	29,229	49	128.3	-10.0%	11	25.1	-2.3%	17	47.0	-7.5%
Penobscot County – ME	77,622	118	126.5	1.9%	19	19.6	-2.5%	38	42.4	-3.5%
Piscataquis County – ME	8,892	18	134.7	0.9%	SN	SN	SN	6	44.7	26.2%
Sagadahoc County – ME	18,348	28	121.4	-9.1%	5	21.3	NA	8	38.8	-12.4%
Somerset County – ME	26,417	39	111.8	-2.5%	7	18.4	-2.5%	14	39.2	-3.0%
Waldo County – ME	19,758	35	133.9	1.9%	6	22.2	-1.1%	10	40.8	-3.8%
Washington County – ME	16,836	27	116.0	7.6%	6	22.9	-2.3%	10	43.3	8.0%
York County – ME	101,150	172	132.0	-2.2%	27	20.0	-2.5%	56	43.6	-5.8%
Massachusetts	3,344,752	5,249	134.2	-1.0%	895	21.3	-3.2%	1,586	41.4	-2.6%
White	2,874,871	4,877	137.9	-1.1%	833	21.5	-3.2%	1,449	42.2	-2.3%
Black/African-American	267,969	217	97.7	0.7%	50	23.2	-3.0%	83	36.7	-3.2%
American Indian/Alaska Native (AIAN)	16,022	5	43.0	2.9%	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	185,890	120	79.5	2.6%	12	9.3	-2.2%	42	27.3	-5.2%
Non-Hispanic/ Latina	NA	NA	NA	NA	876	21.6	-3.2%	NA	NA	NA
Hispanic/Latina	NA	NA	NA	NA	19	10.0	-2.0%	NA	NA	NA
Barnstable County - MA	113,950	295	155.9	0.1%	48	23.4	-2.0%	74	42.4	1.5%
Berkshire County - MA	68,233	117	123.5	-8.0%	24	23.3	-3.4%	34	37.3	-12.2%
Bristol County - MA	281,948	402	119.9	-3.0%	72	20.0	-3.0%	133	40.3	-1.8%
Dukes County - MA	8,172	15	136.7	0.4%	3	26.5	-0.9%	SN	SN	SN
Essex County - MA	382,402	618	133.4	0.5%	108	21.6	-3.1%	185	41.0	-2.2%
Franklin County - MA	36,627	67	140.3	-6.8%	10	20.5	0.1%	19	41.3	-6.7%
Hampden County - MA	240,210	366	129.5	-3.2%	64	20.7	-3.6%	106	39.2	-3.8%
Hampshire County - MA	83,701	123	134.8	-3.1%	22	21.9	-3.2%	35	38.5	-6.4%
Middlesex County - MA	760,088	1,228	140.4	-1.7%	190	20.2	-3.5%	359	41.8	-3.8%
Nantucket County - MA	4,891	10	176.7	13.7%	SN	SN	SN	4	72.9	12.3%
Norfolk County - MA	345,127	584	139.2	1.0%	99	21.8	0.5%	179	43.9	-2.0%
Plymouth County - MA	251,923	418	138.3	-0.2%	66	21.0	-3.5%	127	42.4	-0.4%
Suffolk County - MA	365,127	430	125.3	-1.1%	80	22.4	-2.7%	138	40.5	-3.2%

		Incidence Rates and Trends			Death Rates and Trends			Late-stage Rates and Trends		
Population Group	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)
Worcester County - MA	402,352	578	126.1	0.9%	107	21.5	-3.1%	191	41.9	-0.4%
New Hampshire	665,676	1,046	132.0	-0.7%	174	21.3	-3.1%	326	41.6	1.1%
White	639,408	1,027	132.5	-0.6%	172	21.4	-3.1%	320	41.8	0.9%
Black/African-American	8,529	5	107.3	-10.0%	SN	SN	SN	SN	SN	SN
American Indian/Alaska Native (AIAN)	2,215	SN	SN	SN	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	15,524	8	63.2	1.8%	SN	SN	SN	SN	SN	SN
Non-Hispanic/ Latina	648,353	1,036	132.5	-0.8%	173	21.5	-2.2%	323	41.8	1.0%
Hispanic/ Latina	17,323	10	90.9	15.5%	SN	SN	SN	3	29.1	10.6%
Belknap County – NH	30,620	62	152.4	3.7%	9	21.7	-3.0%	20	52.2	2.8%
Carroll County – NH	24,126	42	114.4	-3.2%	10	25.6	-2.2%	15	43.6	-6.4%
Cheshire County – NH	39,692	57	122.6	-4.6%	11	21.3	-3.1%	18	40.7	-11.4%
Coos County – NH	16,567	29	121.4	-2.6%	5	16.5	-3.8%	10	44.1	0.7%
Grafton County – NH	44,649	71	125.2	-3.0%	13	22.8	-3.4%	20	36.7	-3.0%
Hillsborough County – NH	201,881	296	130.6	2.3%	53	23.1	-2.6%	95	42.0	2.6%
Merrimack County – NH	74,470	127	139.6	-0.6%	17	17.5	-3.4%	34	38.3	10.2%
Rockingham County – NH	148,967	239	136.1	-1.5%	37	21.1	-3.8%	73	41.8	2.6%
Strafford County – NH	62,649	89	134.0	-2.1%	14	20.9	-2.9%	30	43.8	1.3%
Sullivan County – NH	22,055	34	114.5	-4.8%	6	18.4	-5.5%	11	37.0	-7.1%
Rhode Island	546,285	853	131.0	-3.2%	149	20.8	-3.3%	272	42.6	-4.8%
White	482,101	811	134.3	-3.0%	142	21.2	-3.2%	256	43.4	-4.1%
Black/African-American	41,148	31	104.0	-10.4%	6	19.7	-5.3%	13	41.8	-16.0%
American Indian/Alaska Native (AIAN)	5,025	SN	SN	SN	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	18,010	7	54.8	17.7%	SN	SN	SN	SN	SN	SN
Non-Hispanic/ Latina	483,479	821	134.3	-3.1%	145	21.2	-3.3%	262	44.0	-4.7%
Hispanic/ Latina	62,805	26	67.2	-5.8%	4	9.9	NA	9	21.9	-12.7%
Bristol County – RI	26,220	45	128.0	-3.1%	9	22.9	-3.4%	13	38.4	5.0%
Kent County– RI	86,848	156	137.6	-2.4%	24	19.6	-3.0%	51	44.9	-4.3%
Newport County– RI	42,663	74	132.3	-4.4%	11	17.0	-3.5%	24	46.1	-8.3%
Providence County– RI	325,294	463	126.1	-4.5%	86	21.4	-3.4%	149	41.3	-8.1%
Washington County– RI	65,260	114	143.5	0.3%	18	21.9	-3.2%	35	44.9	3.1%

		Incidence Rates and Trends			Death Rates and Trends			Late-stage Rates and Trends		
Population Group	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)
Vermont	316,866	514	131.4	-1.2%	84	20.4	-2.7%	148	38.5	1.9%
White	307,213	510	132.5	-1.2%	84	20.7	-2.6%	147	39.0	2.0%
Black/African-American	3,513	SN	SN	SN	SN	SN	SN	SN	SN	SN
American Indian/Alaska Native (AIAN)	1,515	SN	SN	SN	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	4,624	SN	SN	SN	SN	SN	SN	SN	SN	SN
Non-Hispanic/ Latina	312,457	513	132.2	-1.3%	83	20.5	-2.6%	148	38.8	1.9%
Hispanic/ Latina	4,408	SN	SN	SN	SN	SN	SN	SN	SN	SN
Addison County - VT	18,459	29	130.1	6.6%	6	24.8	24.1%	9	39.5	15.3%
Bennington County - VT	19,197	32	120.6	2.0%	7	23.6	-0.9%	11	40.8	4.1%
Caledonia County - VT	15,728	28	143.5	-8.6%	4	19.1	-1.3%	7	38.0	9.2%
Chittenden County - VT	79,302	122	144.3	-0.4%	16	18.4	-3.1%	33	39.1	0.4%
Essex and Orleans Counties - VT	16,778	23	97.3	-1.8%	NA	NA	NA	6	25.8	19.2%
Essex County - VT	3,144	NA	NA	NA	SN	SN	SN	NA	NA	NA
Orleans County - VT	13,634	NA	NA	NA	4	18.7	-3.1%	NA	NA	NA
Franklin and Grand Isle Counties - VT	27,515	39	128.1	2.4%	NA	NA	NA	10	34.0	0.9%
Franklin County - VT	23,953	NA	NA	NA	5	17.6	-3.7%	NA	NA	NA
Grand Isle County - VT	3,562	NA	NA	NA	SN	SN	SN	NA	NA	NA
Lamoille County - VT	12,017	19	141.9	-1.3%	SN	SN	SN	SN	SN	SN
Orange County - VT	14,512	24	127.8	-7.8%	4	22.7	-4.3%	7	37.8	-9.5%
Rutland County - VT	31,619	53	125.9	-0.4%	9	20.6	-3.1%	18	42.9	-9.4%
Washington County - VT	30,060	50	133.1	1.6%	8	21.3	-2.9%	13	35.9	1.7%
Windham County - VT	22,661	41	135.3	-2.3%	6	18.7	-2.8%	16	51.6	15.7%
Windsor County - VT	29,018	52	128.2	-6.9%	10	24.9	-1.6%	14	34.5	-9.3%

\*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 in Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island and Vermont were higher than that observed in the U.S. as a whole. The breast cancer incidence trends were also higher in Connecticut and Maine than that observed in the U.S. as a whole. The breast cancer trends were lower in Massachusetts, New Hampshire, Rhode Island and Vermont than 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.

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 rates and trends in Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island and Vermont were 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.

### ***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. The breast cancer late-stage incidence rate in Maine, New Hampshire and Rhode Island was lower than that observed in the U.S. as a whole, and the breast cancer late-stage incidence trend was lower in Maine and Rhode Island than in the U.S. as a whole. The late-stage incidence trend was higher in New Hampshire than the U.S. as a whole. The breast cancer late-stage incidence rate in the State of Massachusetts was significantly lower than that observed in the US as a whole and the late-stage incidence trend was lower than the US as a whole. The breast cancer late-stage incidence rate in the State of Vermont was significantly lower than that observed in the US as a whole and the late-stage incidence trend was higher than the US 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.

## 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
Informed decision-making with a health care provider at age 40  Mammography every year starting at age 45  Mammography every other year beginning at age 55	Mammography every year starting at age 40	Informed decision-making with a health care provider ages 40-49  Mammography every 2 years ages 50-74

\*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%
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%
Maine	3,789	3,078	82.1%	80.6%-83.6%
White	3,697	3,012	82.3%	80.7%-83.7%
Black/African-American	SN	SN	SN	SN
AIAN	34	24	73.6%	52.4%-87.6%
API	17	13	69.4%	39.9%-88.6%
Hispanic/ Latina	22	18	84.7%	57.5% -95.8%
Non-Hispanic/ Latina	3,740	3,042	82.2%	80.6%-83.6%
Androscoggin County – ME	246	201	82.3%	75.9%-87.3%
Aroostook County – ME	230	198	85.3%	79.2%- 89.8%
Cumberland County – ME	615	504	83.1%	79.3%-86.3%
Franklin County – ME	130	104	81.4%	71.7%-88.3%
Hancock County – ME	163	133	82.9%	74.8%-88.9%
Kennebec County – ME	281	236	82.9%	76.9%- 87.7%
Knox County – ME	211	170	78.4%	71.0%-84.3%
Lincoln County – ME	206	161	78.9%	71.5%-84.8%
Oxford County – ME	151	122	81.1%	72.7%-87.3%
Penobscot County – ME	327	268	85.4%	80.3%-89.4%
Piscataquis County – ME	87	73	84.8%	74.6%-91.3%
Sagadahoc County – ME	151	123	84.9%	76.6%-90.6%

<b>Population Group</b>	<b># of Women Interviewed (Sample Size)</b>	<b># w/ Self-Reported Mammogram</b>	<b>Proportion Screened (Weighted Average)</b>	<b>Confidence Interval of Proportion Screened</b>
Somerset County – ME	126	101	82.8%	73.8%- 89.1%
Waldo County – ME	183	140	71.7%	63.2%-78.8%
Washington County – ME	157	117	70.0%	61.2%- 77.6%
York County – ME	454	372	82.0%	77.4% -85.8%
Massachusetts	7,709	6,635	87.1%	86.2%-88.0%
White	6,744	5,778	86.7%	85.7%-87.7%
Black/African-American	409	361	88.1%	83.4%-91.6%
AIAN	53	45	93.8%	81.2%-98.2%
API	41	36	89.3%	71.9%- 96.5%
Hispanic/ Latina	444	411	90.7%	86.0%- 93.9%
Non-Hispanic/ Latina	7,209	6,178	87.0%	86.0% -87.9%
Barnstable County – MA	243	212	89.9%	84.9%-93.4%
Berkshire County – MA	158	128	83.4%	75.3% -89.2%
Bristol County – MA	982	851	89.1%	86.2%-91.5%
Dukes County – MA	27	20	70.6%	50.4%-85.1%
Essex County – MA	927	787	86.3%	83.3%-88.8%
Franklin County – MA	79	67	89.8%	80.0%-95.1%
Hampden County – MA	705	612	87.0%	83.4%-89.9%
Hampshire County – MA	136	117	85.7%	77.2%-91.3%
Middlesex County – MA	1,313	1,125	85.9%	83.5%-88.1%
Nantucket County – MA	SN	SN	SN	SN
Norfolk County – MA	580	493	87.3%	83.6%-90.2%
Plymouth County – MA	633	539	88.1%	84.6%-90.8%
Suffolk County – MA	747	656	90.2%	86.9%-92.7%
Worcester County – MA	879	769	86.4%	83.2% -89.1%
New Hampshire	2,923	2,363	82.8%	81.0%-84.5%
White	2,833	2,295	82.8%	81.0%-84.5%
Black/African-American	SN	SN	SN	SN
AIAN	17	12	76.0%	48.3%-91.5%
API	SN	SN	SN	SN
Hispanic/ Latina	27	23	92.8%	69.6%-98.6%
Non-Hispanic/ Latina	2,881	2,330	82.8%	80.9%-84.5%

<b>Population Group</b>	<b># of Women Interviewed (Sample Size)</b>	<b># w/ Self-Reported Mammogram</b>	<b>Proportion Screened (Weighted Average)</b>	<b>Confidence Interval of Proportion Screened</b>
Belknap County – NH	229	181	81.4%	74.2%-86.9%
Carroll County– NH	221	169	77.3%	70.2%-83.1%
Cheshire County– NH	214	168	78.1%	70.3%-84.3%
Coos County– NH	205	159	81.3%	73.6%-87.1%
Grafton County– NH	213	175	82.7%	75.6%-88.1%
Hillsborough County– NH	657	538	82.2%	78.3%- 85.5%
Merrimack County– NH	263	220	83.7%	77.0%-88.7%
Rockingham County– NH	381	328	87.2%	82.4%-90.9%
Strafford County– NH	238	195	83.9%	76.7%- 89.2%
Sullivan County– NH	179	138	77.0%	68.9%-83.4%
Rhode Island	2,037	1,705	83.5%	81.4%-85.4%
White	1,865	1,575	84.5%	82.4%-86.4%
Black/African-American	49	38	76.2%	58.6%-87.9%
AIAN	17	11	68.2%	36.1%-89.1%
API	11	8	65.6%	20.5%-93.4%
Hispanic/ Latina	95	75	72.0%	59.0%-82.1%
Non-Hispanic/ Latina	1,933	1,623	84.3%	82.2%-86.2%
Bristol County – RI	85	79	95.6%	86.5%-98.7%
Kent County – RI	293	240	81.1%	74.9%-86.0%
Newport County – RI	163	136	83.3%	75.5%-89.0%
Providence County – RI	1,182	985	83.1%	80.2%-85.6%
Washington County – RI	256	214	83.8%	77.6%-88.6%
Vermont	2,349	1,850	79.5%	77.4%-81.5%
White	2,294	1,812	79.8%	77.7%-81.8%
Black/African-American	SN	SN	SN	SN
AIAN	15	9	55.7%	25.1%-82.4%
API	SN	SN	SN	SN
Hispanic/ Latina	13	12	96.4%	65.6%-99.7%
Non-Hispanic/ Latina	2,327	1,832	79.5%	77.4% -81.4%

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
Addison County – VT	156	120	76.9%	67.8%-84.0%
Bennington County – VT	187	145	77.4%	69.5%-83.7%
Caledonia County – VT	159	127	77.1%	67.4% -84.6%
Chittenden County – VT	310	246	78.3%	72.3%-83.4%
Essex County – VT	SN	SN	SN	SN
Franklin County – VT	141	110	77.8%	68.6%-84.9%
Grand Isle County – VT	SN	SN	SN	SN
Lamoille County – VT	112	76	69.1%	58.2% -78.2%
Orange County – VT	133	111	85.6%	76.4%-91.6%
Orleans County – VT	147	122	86.0%	77.4%- 91.7%
Rutland County – VT	254	194	73.9%	67.0%-79.8%
Washington County – VT	191	162	86.8%	79.8%-91.6%
Windham County – VT	173	135	80.5%	72.5%- 86.6%
Windsor County – VT	202	166	87.4%	80.8%-91.9%

Data are for 2012.

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

### **Breast cancer screening proportions summary**

The breast cancer screening proportions in Connecticut, Maine, Massachusetts, New Hampshire and Rhode Island were significantly higher than that observed in the U.S. as a whole. The breast cancer screening proportion in Vermont was not significantly different than that observed in the US 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.

### **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 %
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 %
Maine	96.6 %	1.4 %	0.8 %	1.3 %	98.7 %	1.3 %	55.8 %	41.3 %	17.8 %
Androscoggin County – ME	94.6 %	3.9 %	0.5 %	1.0 %	98.4 %	1.6 %	51.5 %	36.9 %	15.9 %
Aroostook County – ME	96.5 %	0.8 %	2.1 %	0.6 %	99.1 %	0.9 %	58.7 %	45.0 %	21.4 %
Cumberland County – ME	94.6 %	2.5 %	0.4 %	2.5 %	98.2 %	1.8 %	54.1 %	39.0 %	16.5 %
Franklin County – ME	98.4 %	0.4 %	0.6 %	0.7 %	98.8 %	1.2 %	55.3 %	41.4 %	17.7 %
Hancock County – ME	97.8 %	0.6 %	0.5 %	1.1 %	98.8 %	1.2 %	60.7 %	46.5 %	20.3 %
Kennebec County – ME	97.6 %	0.7 %	0.7 %	1.0 %	98.7 %	1.3 %	55.5 %	40.9 %	17.2 %
Knox County – ME	98.4 %	0.5 %	0.4 %	0.7 %	99.0 %	1.0 %	61.1 %	47.7 %	21.6 %
Lincoln County – ME	98.4 %	0.5 %	0.4 %	0.8 %	99.1 %	0.9 %	63.5 %	50.2 %	23.8 %
Oxford County – ME	98.3 %	0.5 %	0.5 %	0.7 %	98.9 %	1.1 %	57.7 %	43.1 %	18.5 %

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
Penobscot County – ME	96.7 %	0.9 %	1.3 %	1.1 %	98.9 %	1.1 %	52.2 %	38.2 %	16.2 %
Piscataquis County – ME	98.1 %	0.5 %	0.6 %	0.9 %	99.1 %	0.9 %	62.4 %	48.3 %	21.8 %
Sagadahoc County – ME	97.4 %	1.2 %	0.5 %	0.9 %	98.8 %	1.2 %	58.1 %	43.1 %	18.3 %
Somerset County – ME	98.0 %	0.6 %	0.7 %	0.7 %	99.2 %	0.8 %	56.7 %	41.8 %	18.0 %
Waldo County – ME	98.2 %	0.6 %	0.6 %	0.6 %	99.0 %	1.0 %	56.9 %	43.4 %	17.5 %
Washington County – ME	93.3 %	0.7 %	5.4 %	0.6 %	98.5 %	1.5 %	59.3 %	46.1 %	21.5 %
York County – ME	97.5 %	0.7 %	0.4 %	1.4 %	98.7 %	1.3 %	56.0 %	41.1 %	17.2 %
Massachusetts	85.1 %	8.4 %	0.5 %	6.0 %	90.3 %	9.7 %	50.8 %	36.2 %	15.7 %
Barnstable County – MA	95.4 %	2.5 %	0.7 %	1.4 %	97.8 %	2.2 %	66.3 %	53.2 %	27.5 %
Berkshire County – MA	94.8 %	3.3 %	0.3 %	1.7 %	96.6 %	3.4 %	58.2 %	44.5 %	21.0 %
Bristol County – MA	92.5 %	4.5 %	0.6 %	2.3 %	93.9 %	6.1 %	52.0 %	36.9 %	16.4 %
Dukes County – MA	92.6 %	4.5 %	1.4 %	1.5 %	97.7 %	2.3 %	59.6 %	44.9 %	18.3 %
Essex County – MA	89.3 %	6.1 %	0.8 %	3.7 %	83.3 %	16.7 %	53.0 %	37.7 %	16.2 %
Franklin County – MA	96.3 %	1.6 %	0.5 %	1.7 %	96.9 %	3.1 %	58.1 %	43.7 %	17.3 %
Hampden County – MA	85.2 %	11.5 %	0.9 %	2.4 %	78.4 %	21.6 %	50.4 %	36.5 %	16.2 %
Hampshire County – MA	90.8 %	3.4 %	0.3 %	5.5 %	95.1 %	4.9 %	47.2 %	34.6 %	14.1 %
Middlesex County – MA	84.0 %	5.5 %	0.3 %	10.2 %	93.4 %	6.6 %	50.0 %	35.0 %	15.0 %
Nantucket County – MA	90.9 %	7.6 %	0.1 %	1.4 %	91.5 %	8.5 %	51.8 %	36.2 %	14.3 %
Norfolk County – MA	83.8 %	6.5 %	0.2 %	9.4 %	96.6 %	3.4 %	52.9 %	37.6 %	16.5 %
Plymouth County – MA	88.4 %	9.5 %	0.4 %	1.8 %	96.8 %	3.2 %	54.2 %	38.2 %	15.9 %
Suffolk County – MA	63.4 %	26.6 %	0.9 %	9.2 %	80.1 %	19.9 %	39.4 %	27.6 %	12.1 %
Worcester County – MA	90.1 %	5.0 %	0.4 %	4.5 %	90.5 %	9.5 %	50.8 %	35.2 %	14.7 %
New Hampshire	95.7 %	1.4 %	0.3 %	2.5 %	97.1 %	2.9 %	53.6 %	38.1 %	15.3 %
Belknap County – NH	97.6 %	0.7 %	0.3 %	1.4 %	98.7 %	1.3 %	57.8 %	43.3 %	18.1 %
Carroll County – NH	98.3 %	0.5 %	0.4 %	0.8 %	98.9 %	1.1 %	64.0 %	49.3 %	22.0 %
Cheshire County – NH	97.4 %	0.8 %	0.4 %	1.4 %	98.5 %	1.5 %	52.6 %	39.0 %	16.3 %
Coos County – NH	98.2 %	0.5 %	0.5 %	0.8 %	98.9 %	1.1 %	61.3 %	47.2 %	22.1 %
Grafton County – NH	94.8 %	1.4 %	0.5 %	3.3 %	98.1 %	1.9 %	53.6 %	40.3 %	17.1 %
Hillsborough County – NH	93.4 %	2.5 %	0.4 %	3.7 %	94.7 %	5.3 %	50.9 %	35.0 %	13.7 %
Merrimack County – NH	96.6 %	1.2 %	0.4 %	1.8 %	98.3 %	1.7 %	54.4 %	39.1 %	15.7 %
Rockingham County – NH	96.8 %	0.9 %	0.2 %	2.1 %	97.8 %	2.2 %	55.6 %	38.3 %	14.5 %
Strafford County – NH	95.6 %	1.2 %	0.3 %	2.9 %	98.1 %	1.9 %	47.4 %	33.2 %	13.4 %
Sullivan County – NH	98.1 %	0.7 %	0.4 %	0.8 %	98.8 %	1.2 %	57.6 %	43.0 %	18.5 %

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
Rhode Island	87.6 %	7.9 %	1.0 %	3.5 %	87.5 %	12.5 %	51.6 %	37.3 %	16.6 %
Bristol County – RI	96.9 %	1.2 %	0.2 %	1.8 %	97.8 %	2.2 %	55.9 %	41.0 %	18.7 %
Kent County – RI	95.4 %	1.9 %	0.4 %	2.3 %	96.6 %	3.4 %	56.9 %	41.4 %	18.3 %
Newport County – RI	92.9 %	4.5 %	0.6 %	2.0 %	95.8 %	4.2 %	57.0 %	42.6 %	19.2 %
Providence County – RI	82.6 %	11.7 %	1.3 %	4.4 %	81.1 %	18.9 %	48.5 %	34.7 %	15.6 %
Washington County – RI	95.2 %	1.7 %	1.1 %	2.0 %	97.5 %	2.5 %	54.8 %	40.3 %	16.9 %
Vermont	96.7 %	1.3 %	0.5 %	1.6 %	98.5 %	1.5 %	54.0 %	39.7 %	16.4 %
Addison County – VT	96.9 %	1.0 %	0.3 %	1.8 %	98.4 %	1.6 %	53.9 %	39.3 %	15.5 %
Bennington County – VT	97.8 %	1.1 %	0.3 %	0.9 %	98.4 %	1.6 %	58.7 %	44.6 %	21.1 %
Caledonia County – VT	97.7 %	0.8 %	0.6 %	0.9 %	98.8 %	1.2 %	54.8 %	41.8 %	16.9 %
Chittenden County – VT	93.8 %	2.4 %	0.4 %	3.4 %	98.1 %	1.9 %	47.4 %	33.5 %	13.3 %
Essex County – VT	98.2 %	0.6 %	0.6 %	0.6 %	99.1 %	0.9 %	61.7 %	46.6 %	20.3 %
Franklin County – VT	97.3 %	0.7 %	1.3 %	0.7 %	98.8 %	1.2 %	50.9 %	34.9 %	13.3 %
Grand Isle County – VT	97.2 %	0.9 %	1.2 %	0.7 %	98.8 %	1.2 %	58.9 %	43.2 %	14.8 %
Lamoille County – VT	97.9 %	1.0 %	0.5 %	0.6 %	98.7 %	1.3 %	50.7 %	36.2 %	14.5 %
Orange County – VT	98.2 %	0.7 %	0.4 %	0.7 %	98.8 %	1.2 %	57.0 %	42.5 %	16.5 %
Orleans County – VT	98.0 %	0.8 %	0.6 %	0.6 %	99.0 %	1.0 %	57.0 %	43.8 %	19.8 %
Rutland County – VT	98.2 %	0.7 %	0.3 %	0.8 %	98.8 %	1.2 %	57.8 %	43.8 %	19.1 %
Washington County – VT	97.6 %	0.9 %	0.4 %	1.1 %	98.3 %	1.7 %	55.9 %	41.0 %	16.6 %
Windham County – VT	96.8 %	1.4 %	0.4 %	1.4 %	98.1 %	1.9 %	58.5 %	44.0 %	17.9 %
Windsor County – VT	97.6 %	0.8 %	0.4 %	1.2 %	98.6 %	1.4 %	59.5 %	45.4 %	19.7 %

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 Underserved 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 %
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 %

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistically Isolated	In Rural Areas	In Medically Underserved Areas	No Health Insurance (Age: 40-64)
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 %
Maine	9.8 %	12.8 %	33.5 %	7.1 %	3.3 %	1.1 %	61.3 %	12.0 %	13.3 %
Androscoggin County – ME	13.0 %	14.2 %	35.1 %	8.8 %	3.3 %	2.2 %	43.4 %	23.1 %	12.4 %
Aroostook County – ME	15.8 %	15.7 %	41.9 %	6.7 %	4.9 %	2.8 %	80.3 %	16.2 %	15.0 %
Cumberland County – ME	6.4 %	10.7 %	26.1 %	5.5 %	5.5 %	1.7 %	36.1 %	2.1 %	11.0 %
Franklin County – ME	11.3 %	16.8 %	38.8 %	8.7 %	1.7 %	0.6 %	83.0 %	10.1 %	14.4 %
Hancock County – ME	8.3 %	12.4 %	34.0 %	7.4 %	2.5 %	0.2 %	90.1 %	14.1 %	15.7 %
Kennebec County – ME	9.1 %	12.2 %	33.9 %	7.8 %	2.4 %	0.8 %	62.8 %	5.8 %	12.9 %
Knox County – ME	9.7 %	11.4 %	35.1 %	4.9 %	2.2 %	0.3 %	67.9 %	9.3 %	14.0 %
Lincoln County – ME	7.7 %	9.8 %	34.6 %	6.3 %	2.0 %	0.3 %	100.0 %	15.2 %	15.1 %
Oxford County – ME	11.8 %	13.4 %	42.4 %	10.8 %	1.6 %	0.5 %	83.1 %	11.7 %	15.4 %
Penobscot County – ME	10.1 %	16.3 %	36.0 %	7.1 %	2.6 %	0.5 %	57.7 %	1.3 %	13.9 %
Piscataquis County – ME	12.1 %	16.9 %	46.0 %	7.1 %	1.6 %	0.4 %	100.0 %	47.8 %	16.4 %
Sagadahoc County – ME	7.7 %	9.4 %	28.2 %	5.2 %	2.6 %	0.5 %	61.7 %	9.7 %	11.5 %
Somerset County – ME	13.3 %	18.5 %	44.2 %	8.9 %	1.9 %	0.5 %	80.5 %	21.3 %	16.0 %
Waldo County – ME	10.0 %	14.5 %	39.2 %	8.7 %	1.5 %	0.2 %	91.3 %	100.0 %	15.1 %
Washington County – ME	14.1 %	20.4 %	47.3 %	10.9 %	3.6 %	0.3 %	92.4 %	51.1 %	20.2 %
York County – ME	9.1 %	8.7 %	27.7 %	6.9 %	3.2 %	1.3 %	56.8 %	1.2 %	12.3 %
Massachusetts	11.1 %	10.7 %	24.0 %	8.1 %	14.7 %	5.7 %	8.0 %	15.7 %	4.4 %
Barnstable County – MA	5.1 %	8.4 %	23.6 %	7.0 %	6.5 %	1.5 %	7.5 %	14.8 %	5.5 %
Berkshire County – MA	9.3 %	11.8 %	31.4 %	8.4 %	4.6 %	1.2 %	31.6 %	100.0 %	4.5 %
Bristol County – MA	19.4 %	11.3 %	27.7 %	9.7 %	12.1 %	5.8 %	9.8 %	10.6 %	5.0 %
Dukes County – MA	7.3 %	10.2 %	26.3 %	5.0 %	7.5 %	1.3 %	39.0 %	0.0 %	6.8 %
Essex County – MA	11.6 %	10.6 %	24.3 %	7.7 %	14.7 %	6.9 %	4.2 %	19.3 %	4.7 %
Franklin County – MA	8.8 %	11.9 %	29.0 %	7.8 %	4.1 %	1.1 %	54.4 %	16.7 %	4.7 %
Hampden County – MA	16.5 %	16.6 %	32.9 %	10.1 %	8.6 %	7.1 %	8.6 %	16.4 %	5.3 %
Hampshire County – MA	7.7 %	11.8 %	22.0 %	7.6 %	8.1 %	1.9 %	27.4 %	5.5 %	4.1 %
Middlesex County – MA	8.2 %	7.7 %	18.6 %	6.6 %	18.7 %	5.6 %	3.0 %	3.9 %	3.9 %
Nantucket County – MA	6.9 %	8.8 %	20.7 %	2.8 %	14.0 %	1.7 %	18.9 %	0.0 %	6.3 %

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistically Isolated	In Rural Areas	In Medically Underserved Areas	No Health Insurance (Age: 40-64)
Norfolk County – MA	6.5 %	6.3 %	15.6 %	6.9 %	15.0 %	3.5 %	1.2 %	1.3 %	3.1 %
Plymouth County – MA	8.1 %	7.2 %	20.4 %	8.8 %	8.0 %	2.1 %	10.3 %	6.0 %	4.2 %
Suffolk County – MA	16.9 %	20.8 %	39.0 %	10.1 %	27.8 %	12.3 %	0.1 %	54.1 %	5.4 %
Worcester County – MA	11.3 %	9.9 %	23.7 %	8.2 %	10.9 %	5.6 %	18.4 %	9.6 %	4.2 %
New Hampshire	8.8 %	8.0 %	22.3 %	6.3 %	5.2 %	1.4 %	39.7 %	16.9 %	12.6 %
Belknap County – NH	10.2 %	8.5 %	27.8 %	5.7 %	3.0 %	0.4 %	66.3 %	0.0 %	14.6 %
Carroll County – NH	8.9 %	10.3 %	31.2 %	5.8 %	2.6 %	0.0 %	90.2 %	100.0 %	18.3 %
Cheshire County – NH	10.0 %	9.9 %	26.6 %	8.8 %	3.1 %	0.5 %	65.0 %	0.0 %	13.6 %
Coos County – NH	15.5 %	13.0 %	37.4 %	7.6 %	3.1 %	1.5 %	66.2 %	0.0 %	16.8 %
Grafton County – NH	9.0 %	9.9 %	26.8 %	4.8 %	5.5 %	0.8 %	68.7 %	0.0 %	14.9 %
Hillsborough County – NH	9.5 %	7.5 %	19.9 %	6.6 %	8.2 %	3.0 %	21.2 %	4.4 %	11.4 %
Merrimack County – NH	8.2 %	8.3 %	22.0 %	5.8 %	3.6 %	0.9 %	54.6 %	0.0 %	12.5 %
Rockingham County – NH	6.1 %	4.9 %	16.9 %	5.9 %	4.5 %	0.8 %	24.9 %	11.4 %	10.7 %
Strafford County – NH	9.7 %	10.8 %	25.1 %	6.4 %	4.2 %	1.4 %	32.4 %	100.0 %	13.5 %
Sullivan County – NH	9.9 %	10.4 %	29.1 %	5.6 %	2.6 %	0.3 %	64.2 %	0.0 %	14.4 %
Rhode Island	15.7 %	12.8 %	27.6 %	8.9 %	12.9 %	5.7 %	9.3 %	15.9 %	12.1 %
Bristol County – RI	12.7 %	7.1 %	17.0 %	7.1 %	8.6 %	2.8 %	1.1 %	0.0 %	8.4 %
Kent County – RI	10.3 %	8.3 %	21.4 %	8.6 %	5.4 %	1.7 %	8.0 %	3.5 %	9.4 %
Newport County – RI	8.2 %	7.7 %	19.8 %	5.8 %	6.3 %	1.2 %	12.1 %	9.3 %	8.9 %
Providence County – RI	20.3 %	16.2 %	33.8 %	10.1 %	17.8 %	8.6 %	5.5 %	24.6 %	14.6 %
Washington County – RI	7.5 %	7.5 %	18.5 %	6.5 %	4.1 %	1.4 %	30.8 %	0.0 %	8.4 %
Vermont	9.0 %	11.3 %	28.4 %	6.3 %	3.9 %	0.8 %	61.1 %	14.5 %	7.6 %
Addison County – VT	9.2 %	10.7 %	26.7 %	6.2 %	4.1 %	0.9 %	78.4 %	7.5 %	7.9 %
Bennington County – VT	10.2 %	12.3 %	32.5 %	6.7 %	3.1 %	0.4 %	64.5 %	0.0 %	8.4 %
Caledonia County – VT	11.3 %	13.5 %	36.4 %	6.6 %	2.3 %	0.3 %	74.4 %	21.4 %	8.3 %
Chittenden County – VT	6.5 %	10.9 %	20.3 %	5.4 %	6.7 %	1.8 %	26.0 %	18.1 %	6.2 %
Essex County – VT	17.0 %	16.2 %	44.8 %	9.3 %	4.3 %	2.8 %	100.0 %	22.5 %	11.7 %
Franklin County – VT	11.7 %	10.2 %	29.2 %	6.7 %	3.0 %	0.7 %	71.7 %	40.8 %	8.3 %
Grand Isle County – VT	7.2 %	9.0 %	24.5 %	6.8 %	3.2 %	0.3 %	100.0 %	100.0 %	8.3 %
Lamoille County – VT	8.3 %	12.7 %	31.4 %	4.9 %	3.3 %	0.1 %	100.0 %	5.1 %	8.9 %
Orange County – VT	9.7 %	10.6 %	30.3 %	6.3 %	1.6 %	0.4 %	97.2 %	4.1 %	8.2 %
Orleans County – VT	15.1 %	16.0 %	40.5 %	7.6 %	4.2 %	1.0 %	85.3 %	27.5 %	10.0 %
Rutland County – VT	11.1 %	12.4 %	31.9 %	8.5 %	2.1 %	0.5 %	61.0 %	0.0 %	7.6 %

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistically Isolated	In Rural Areas	In Medically Underserved Areas	No Health Insurance (Age: 40-64)
Washington County – VT	7.0 %	9.3 %	26.5 %	5.2 %	2.9 %	0.3 %	52.8 %	5.7 %	6.6 %
Windham County – VT	8.4 %	10.7 %	32.5 %	7.1 %	3.6 %	0.2 %	68.2 %	15.2 %	8.0 %
Windsor County – VT	7.6 %	10.3 %	28.0 %	6.4 %	3.0 %	0.6 %	75.6 %	8.8 %	7.5 %

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***

#### *Connecticut*

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.

#### *Maine*

Proportionately, the State of Maine has a substantially larger White female population than the US as a whole, a substantially smaller Black/African-American female population, a substantially smaller Asian and Pacific Islander (API) female population, a slightly smaller American Indian and Alaska Native (AIAN) female population, and a substantially smaller Hispanic/Latina female population. The state's female population is slightly older than that of the US as a whole. The state's education level is slightly higher than and income level is about the same as those of the US as a whole. The state's unemployment level is slightly smaller than that of the US as a whole. The state has a substantially smaller percentage of people who are foreign born and a substantially smaller percentage of people who are linguistically isolated. There are a substantially larger percentage of people living in rural areas, a slightly smaller percentage of people without health insurance, and a substantially smaller percentage of people living in medically underserved areas.

The following county has a substantially larger AIAN female population percentage than that of the state as a whole:

- Washington County

The following county has a substantially older female population than that of the state as a whole:

- Lincoln County

The following county has a substantially lower education level than that of the state as a whole:

- Aroostook County

The following counties have substantially lower income levels than that of the state as a whole:

- Somerset County
- Washington County

The following counties have substantially lower employment levels than that of the state as a whole:

- Oxford County
- Washington County

The following county has a substantially larger percentage of adults without health insurance than does the state as a whole:

- Washington County

### *Massachusetts*

Proportionately, the State of Massachusetts has a substantially larger White female population than the US as a whole, a substantially smaller Black/African-American female population, a slightly larger Asian and Pacific Islander (API) female population, a slightly smaller American Indian and Alaska Native (AIAN) female population, and a substantially smaller Hispanic/Latina female population. The state's female population is slightly older than that of the US as a whole. The state's education level is slightly higher than and income level is slightly higher than those of the US as a whole. The state's unemployment level is slightly smaller than that of the US as a whole. The state 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.

The following county has a substantially larger Black/African-American female population percentage than that of the state as a whole:

- Suffolk County

The following counties have substantially larger API female population percentages than that of the state as a whole:

- Middlesex County
- Norfolk County
- Suffolk County

The following counties have substantially larger Hispanic/Latina female population percentages than that of the state as a whole:

- Essex County
- Hampden County
- Suffolk County

The following counties have substantially older female populations than that of the state as a whole:

- Barnstable County
- Berkshire County

The following counties have substantially lower education levels than that of the state as a whole:

- Bristol County
- Hampden County
- Suffolk County

The following counties have substantially lower income levels than that of the state as a whole:

- Hampden County
- Suffolk County

The county with substantial foreign born and linguistically isolated populations is:

- Suffolk County

#### *New Hampshire*

Proportionately, the State of New Hampshire has a substantially larger White female population than the US as a whole, a substantially smaller Black/African-American female population, a substantially smaller Asian and Pacific Islander (API) female population, a slightly smaller American Indian and Alaska Native (AIAN) female population, and a substantially smaller Hispanic/Latina female population. The state's female population is slightly older than that of the US as a whole. The state's education level is substantially higher than and income level is substantially higher than those of the US as a whole. The state's unemployment level is slightly smaller than that of the US as a whole. The state has a substantially smaller percentage of people who are foreign born and a substantially smaller percentage of people who are linguistically isolated. There are a substantially larger percentage of people living in rural areas,

a slightly smaller percentage of people without health insurance, and a substantially smaller percentage of people living in medically underserved areas.

The following counties have substantially older female populations than that of the state as a whole:

- Carroll County
- Coos County

The following county has a substantially lower education level than that of the state as a whole:

- Coos County

The following county has a substantially larger percentage of adults without health insurance than does the state as a whole:

- Carroll County

#### *Rhode Island*

Proportionately, the State of Rhode Island has a substantially larger White female population than the US as a whole, a substantially 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 state's female population is slightly older than that of the US as a whole. The state's education level is slightly lower than and income level is slightly higher than those of the US as a whole. The state's unemployment level is slightly larger than that of the US as a whole. The state 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 slightly smaller percentage of people without health insurance, and a substantially smaller percentage of people living in medically underserved areas.

The following county has a substantially larger Hispanic/Latina female population percentage than that of the state as a whole:

- Providence County

#### *Vermont*

Proportionately, the State of Vermont has a substantially larger White female population than the US as a whole, a substantially smaller Black/African-American female population, a substantially smaller Asian and Pacific Islander (API) female population, a slightly smaller American Indian and Alaska Native (AIAN) female population, and a substantially smaller Hispanic/Latina female population. The state's female population is slightly older than that of the US as a whole. The state's education level is substantially higher than and income level is slightly higher than those of the US as a whole. The state's unemployment level is slightly smaller than that of the US as a whole. The state has a substantially smaller percentage of people who are foreign born and a substantially smaller percentage of people who are linguistically isolated. There are a substantially larger 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.

The following counties have substantially lower education levels than that of the state as a whole:

- Essex County
- Orleans County

The following county has a substantially lower employment level than that of the state as a whole:

- Essex County

## **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				
Time to Achieve Death Rate Reduction Target		13 years or longer	7-12 yrs.	0 – 6 yrs.	Currently meets target	Unknown
	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 New England 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
Knox County – ME	Highest	13 years or longer	13 years or longer	Rural
Piscataquis County – ME	Highest	SN	13 years or longer	Rural, medically underserved
Kennebec County – ME	High	7 years	13 years or longer	
Androscoggin County – ME	Medium High	4 years	13 years or longer	Medically underserved
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
Washington County – ME	Medium High	5 years	13 years or longer	%AIAN, poverty, employment, rural, insurance, medically underserved

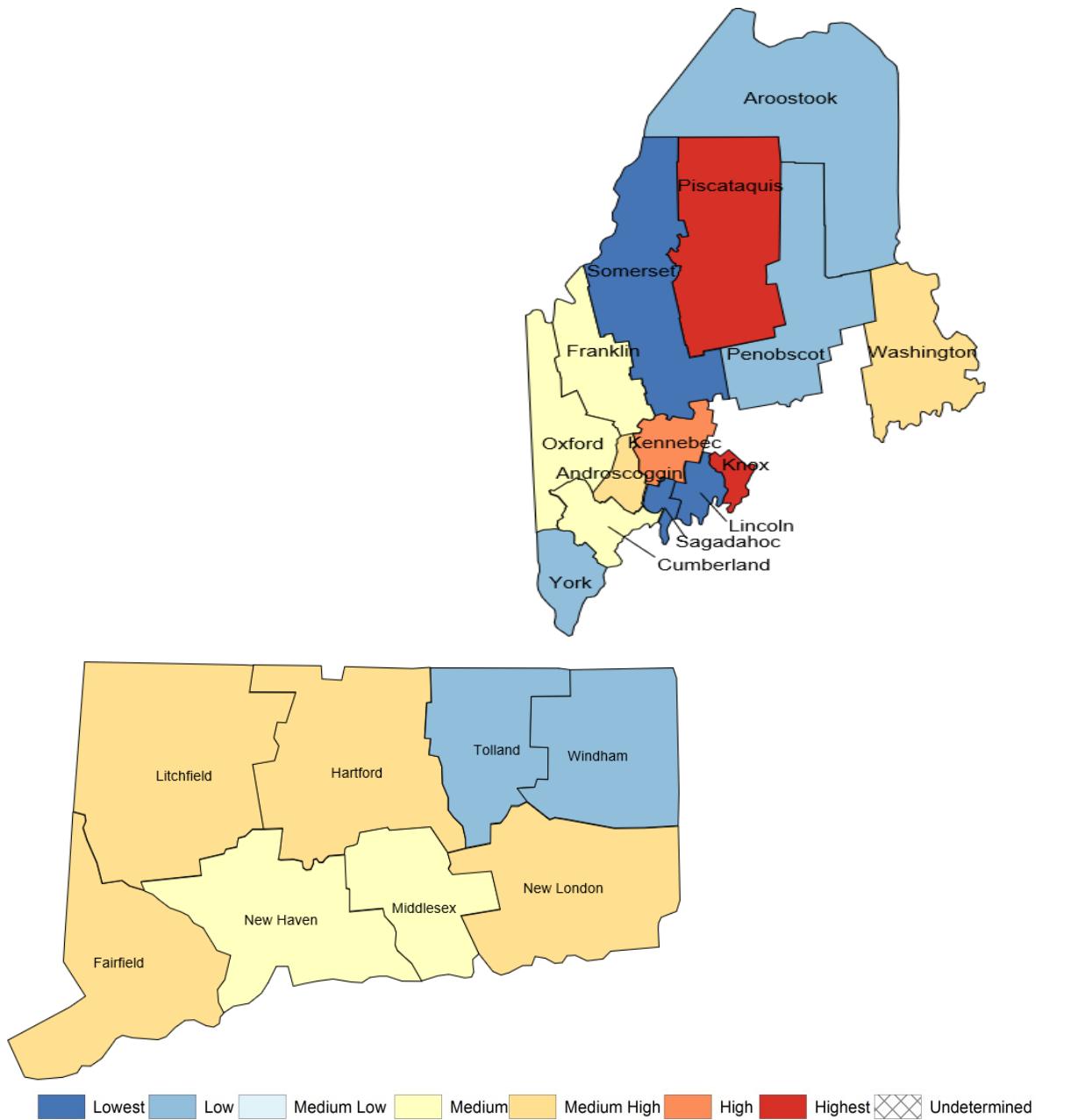
<b>County</b>	<b>Priority</b>	<b>Predicted Time to Achieve Death Rate Target</b>	<b>Predicted Time to Achieve Late-stage Incidence Target</b>	<b>Key Population Characteristics</b>
Cumberland County – ME	Medium	Currently meets target	13 years or longer	
Franklin County – ME	Medium	Currently meets target	13 years or longer	Rural
Middlesex County - CT	Medium	Currently meets target	13 years or longer	Rural
Oxford County – ME	Medium	9 years	2 years	Employment, rural
New Haven County - CT	Medium	7 years	6 years	
Aroostook County – ME	Low	4 years	Currently meets target	Education, rural
Tolland County - CT	Low	1 year	Currently meets target	Rural
Penobscot County – ME	Low	Currently meets target	1 year	
Windham County - CT	Low	Currently meets target	1 year	Rural
York County – ME	Low	Currently meets target	1 year	
Lincoln County – ME	Lowest	Currently meets target	Currently meets target	Older, rural
Sagadahoc County – ME	Lowest	NA	Currently meets target	
Somerset County – ME	Lowest	Currently meets target	Currently meets target	Poverty, rural, medically underserved

### **Map of Intervention Priority Areas**

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

Komen New England

Priority Areas



**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**

### ***Highest priority areas***

Two counties in the Affiliate service area is in the highest priority category. Knox County is not likely to meet the death rate target. Knox County and Piscataquis County are not likely to meet the late-stage incidence target.

### ***High priority areas***

There is one county in the Affiliate service area in the high priority category. Kennebec County is not likely to meet the late-stage incidence target.

### ***Medium high priority areas***

Six counties in the Affiliate service area are in the medium high priority category. All of the six, Androscoggin County, Fairfield County, Hartford County, Litchfield County, New London County and Washington 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. Washington County is a rural and medically underserved community with a relatively large AIAN population, and this county has concerns related to poverty, employment, and health insurance.

### ***Medium priority areas***

Five counties in the Affiliate service area are in the medium priority category. Three of the five, Cumberland County, Franklin County and Middlesex County are not likely to meet the late-stage

incidence rate HP2020 target. It will take seven years for New Haven County to reach the death rate HP2020 target and nine years for Oxford County to reach the target.

In Franklin County, Middlesex County and Oxford County, a relatively large proportion of their populations are living in rural areas. The population in Oxford County also has concerns related to employment.

### **Selection of Target Communities**

The Affiliate utilized the statistical data shown in the Quantitative Data Report and in Tables 2.1 through 2.5 to select areas of interest in New England. The focus was aimed at understanding breast cancer burden throughout New England, specifically: Hartford, Fairfield, New Haven, New London and Litchfield counties in Connecticut, Boston, Worcester, and Springfield, Massachusetts, Maine, New Hampshire, Rhode Island and Vermont.

#### **Connecticut**

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.

#### **Massachusetts**

Statistical data presented in Tables 2.8, 2.9, 2.10 and 2.11 were used to produce a composite map identifying 33 towns and cities with high breast cancer incidence, late-stage diagnosis and deaths (Figure 2.2). Tables 2.8, 2.9, 2.10 and 2.11 identify Boston, Springfield and Worcester as the top communities with the greatest number of cases, in addition to mortality rates exceeding state levels. These three communities were selected and further examined to complete this report.

**Table 2.8.** Incidence

Target Town	Cases	Percentage of all cases
<b>Massachusetts</b>	25,434	-
<b>Boston</b>	1,763	6.9
<b>Worcester</b>	550	2.2
<b>Springfield</b>	528	2.1
<b>Newton</b>	474	1.9
<b>Quincy</b>	365	1.4
<b>New Bedford</b>	320	1.3
<b>Brockton</b>	292	1.2
<b>Cambridge</b>	291	1.1
<b>Fall River</b>	281	1.1
<b>Lowell</b>	278	1.1
<b>Framingham</b>	278	1.1
<b>Lynn</b>	273	1.1
<b>Plymouth</b>	273	1.1
<b>Medford</b>	262	1.0
<b>Barnstable</b>	257	1.0
<b>Brookline</b>	246	1.0
<b>Peabody</b>	244	1.0
<b>Waltham</b>	242	1.0
<b>Chicopee</b>	242	1.0
<b>Weymouth</b>	239	0.9

*Top quartile of total breast cancer incidences in Massachusetts from 2006 to 2010. Overall incidence 25,434.*

### Late-Stage Diagnosis

The MCR data included total number of cases and age-adjusted rates for late-stage breast cancer diagnosis. For this analysis, the Affiliate requested the data classified with the numerical stage as used by the American Joint Committee on Cancer (AJCC). AJCC stages breast cancer from Stage 0 to Stage IV. The early stages of breast cancer (Stage 0 to Stage II) are considered treatable and have a high rate of survival. The tumors found at a later stage (Stage III and Stage IV) have a relatively lower survival rate. Breast cancer diagnosed at Stage III has a five-year relative survival rate of 72.0 percent. A diagnosis made at Stage IV has a low five-year relative survival rate of 22.0 percent.

MCR provided data for all towns and cities in Massachusetts with all stages of breast cancer. For the purpose of this assessment and to understand which areas were most impacted by late-stage diagnosis (Stages III and Stage IV), it was necessary to give context to the data. To do this, data were sorted by towns and cities with high rates of late-stage cancers and then by total number of cases. The data indicated that some municipalities with high rates may have accounted for only a small number of cases. As this methodology skewed the data, this analysis identified towns and cities with high late-stage diagnosis rates and more than 30 cases of breast cancer diagnosed at late-stage. For example, the town of Nantucket, MA had a late-stage diagnosis proportion of 31.0 percent. However, this is a result of 13 out of 42 cases. The City of Boston reported a low late-stage proportion of 15.9 percent but included 267 cases of late-stage breast cancer. Table 2.9 depicts the 25 towns that were reported to have the highest rate of

late-stage diagnosis and greater than 30 cases diagnosed at late-stage. The Affiliate will focus its assessment on the 25 towns identified in Table 2.9.

**Table 2.9.** Late-stage diagnosis (2005-2009)

Target Town	Total Cases	Late-Stage Proportion (%)
Boston	267	15.9
Worcester	78	14.9
Springfield	66	12.8
Quincy	62	17.8
Newton	53	11.6
Fall River	52	19.1
New Bedford	52	17.1
Lynn	51	18.9
Brockton	51	18.4
Lowell	47	17.3
Plymouth	46	17.4
Lawrence	44	24.6
Medford	41	16.5
Somerville	38	19.3
Barnstable	36	14.9
Cambridge	36	12.9
Chelmsford	34	17.7
Pittsfield	34	16.1
Haverhill	33	16.6
Chicopee	33	14.4
Peabody	33	13.5
Framingham	33	12.1
Malden	32	16.7
Revere	32	15.5
Weymouth	32	13.9

*Late-stage breast cancer data were sorted by the total number of cases (from highest to lowest).*

### Breast Cancer Deaths

Breast cancer deaths were assessed by a review of both death counts and age-adjusted death rates from the data provided by the MCR. The analysis focused on the municipalities that were in the top 25 percent of deaths related to breast cancer (Table 2.10).

**Table 2.10.** Deaths occurring between 2006 and 2010 in Massachusetts by town

Target Town	Deaths (counts)	Age-Adjusted Death Rate Per 100,000	Proportion of Total Deaths (%)
Boston	329	22.5	7.4
Worcester	127	23.1	2.9
Springfield	99	22.9	2.2
Quincy	71	21.6	1.6
New Bedford	65	18.6	1.5
Brockton	65	24.1	1.5
Newton	58	18.4	1.3
Fall River	57	18.5	1.3
Peabody	56	26.7	1.3
Lynn	55	22.0	1.2
Cambridge	48	20.2	1.1
Barnstable	47	25.6	1.1
Medford	46	24.9	1.1

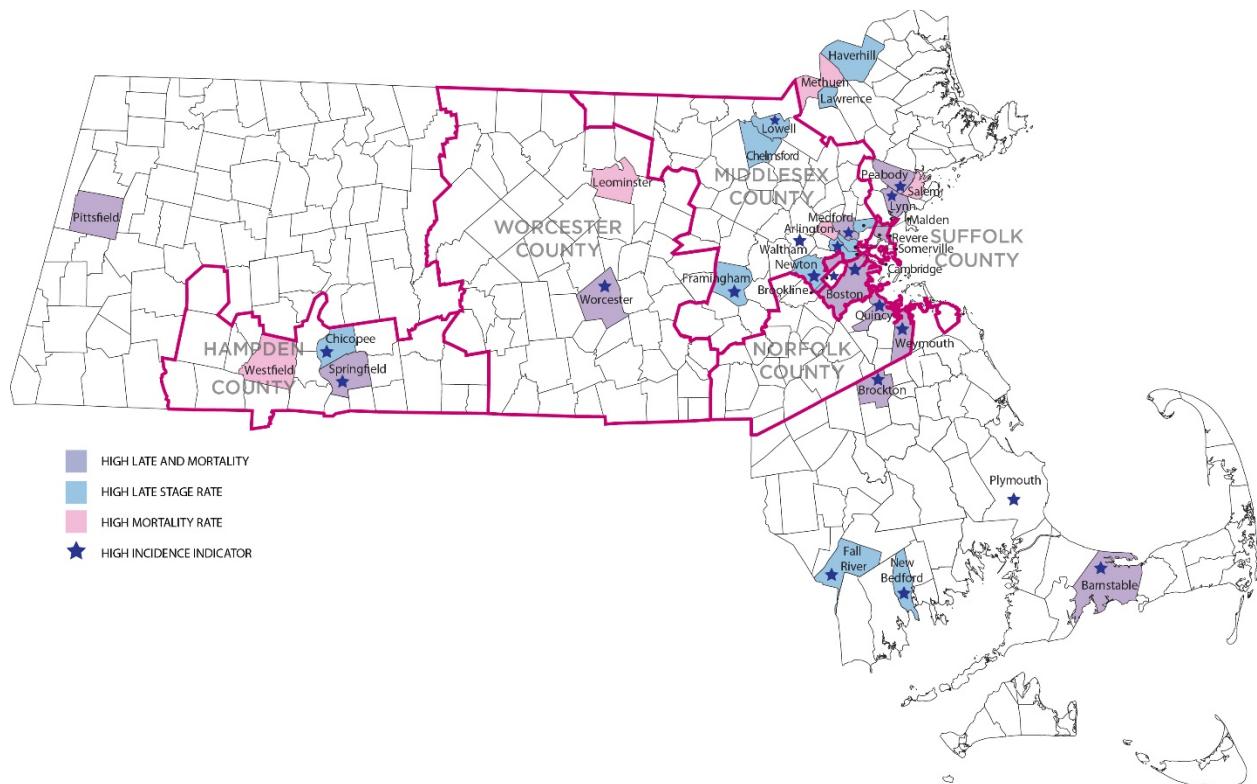
In addition to assessing quantity of deaths, age-adjusted death rates across Massachusetts were analyzed. Death rates ranged from 0 to 83.8 deaths per 100,000 people; however, the age-adjusted rates may not be indicative of deaths related to breast cancer due to skewed outlier data. As an example, the municipality reporting the highest age-adjusted death rate was Peru, Massachusetts at 83.8 deaths per 100,000. To put this value into perspective, Peru only has a population of 847 residents. It reported two deaths over the four years according to the Massachusetts Tumor Registry (2006 – 2010). As a comparison, Boston, Massachusetts the most populous municipality, had 329 deaths over the same four-year period and produced an age-adjusted death rate of 22.5.

The age-adjusted death rate for the entire state of Massachusetts was 21.1 deaths per 100,000 residents. The Affiliate then identified municipalities reporting death rates higher than the state average and a population greater than 40,000 residents (Table 2.11).

**Table 2.11.** Age-adjusted deaths (cases and rates)

Target Town	Population	Deaths (counts)	Age-Adjusted Death Rate Per 100,000
Boston	617,594	329	22.5
Worcester	181,045	127	23.1
Springfield	153,060	99	22.9
Brockton	93,810	65	24.1
Quincy	92,271	71	21.6
Lynn	90,329	55	22.0
Medford	56,173	46	24.9
Weymouth	53,743	42	22.8
Revere	51,755	35	22.2
Peabody	51,251	56	26.7
Methuen	47,255	42	25.7
Barnstable	45,193	47	25.6
Pittsfield	44,737	45	26.2
Arlington	42,844	33	20.3
Salem	41,340	32	23.2
Westfield	41,094	31	23.9
Leominster	40,759	39	30.6

Rates greater than 21.1 and populations over 40,000 residents have been listed



**Figure 2.2.** Massachusetts composite map

Boston was examined as neighborhoods have great variance in socioeconomic status and health disparities, and these issues could be related to late-stage incidence and mortality. Springfield and Worcester were also observed in this assessment and identified with high numbers of new cases of late-stage breast cancer. These municipalities had similar and evident factors that attributed to these results. The federal poverty level (FPL) in Springfield was well below the state average. A total of 28.7 percent of residents in Springfield live below the FPL (US Census Bureau, 2012).

The City of Worcester had income levels, educational attainment and FPL that were fairly comparable to the state average. The Affiliate examined health access in this community as well to gain a better perspective on the burden of breast cancer in Worcester.

#### **Vermont, New Hampshire, Rhode Island, Maine**

For the remainder of the 2015 Community Profile, the Affiliate has determined to consider the states of Connecticut, Massachusetts, Vermont, New Hampshire, Maine and Rhode Island as target communities, without identifying specific cities or towns within those states.

#### **Looking Ahead**

The implementation of the Affordable Health Care Act (ACA) drastically changed the health care system. Komen 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 and Public Policy 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.

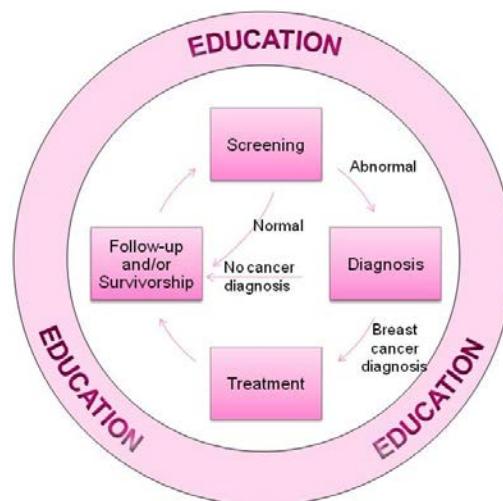
## Health Systems Overview

### **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) 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



**Figure 3.1. Breast Cancer Continuum of Care (CoC)**

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.

## **Health Systems Findings**

### **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

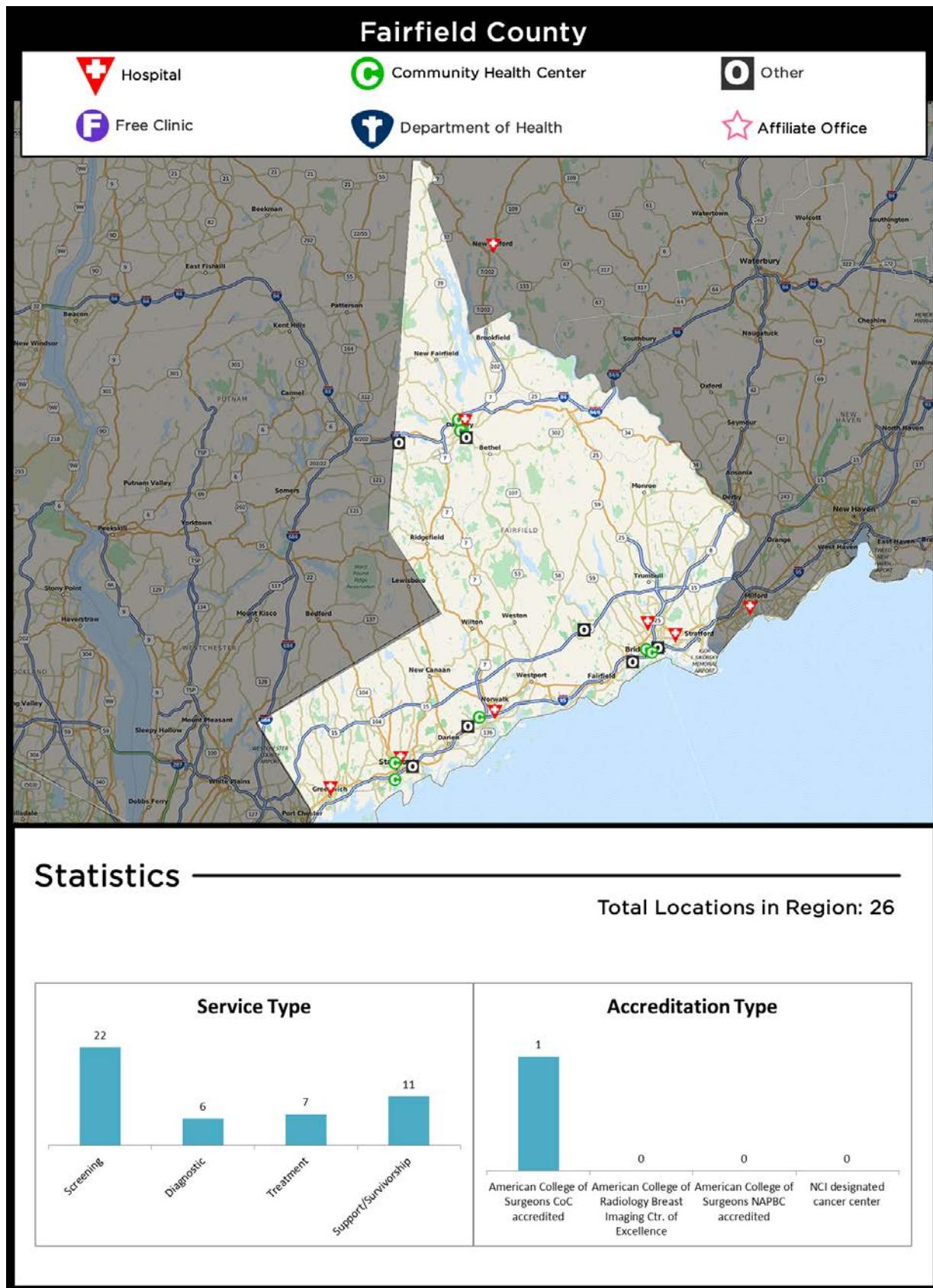
dramatically reduce the time it takes a woman to receive a screening. Women have access to breast cancer screenings in unconventional locations such as churches, shopping plazas, work sites, unemployment centers and CBOs. Mobile mammography managers reported having contracts with large corporations that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

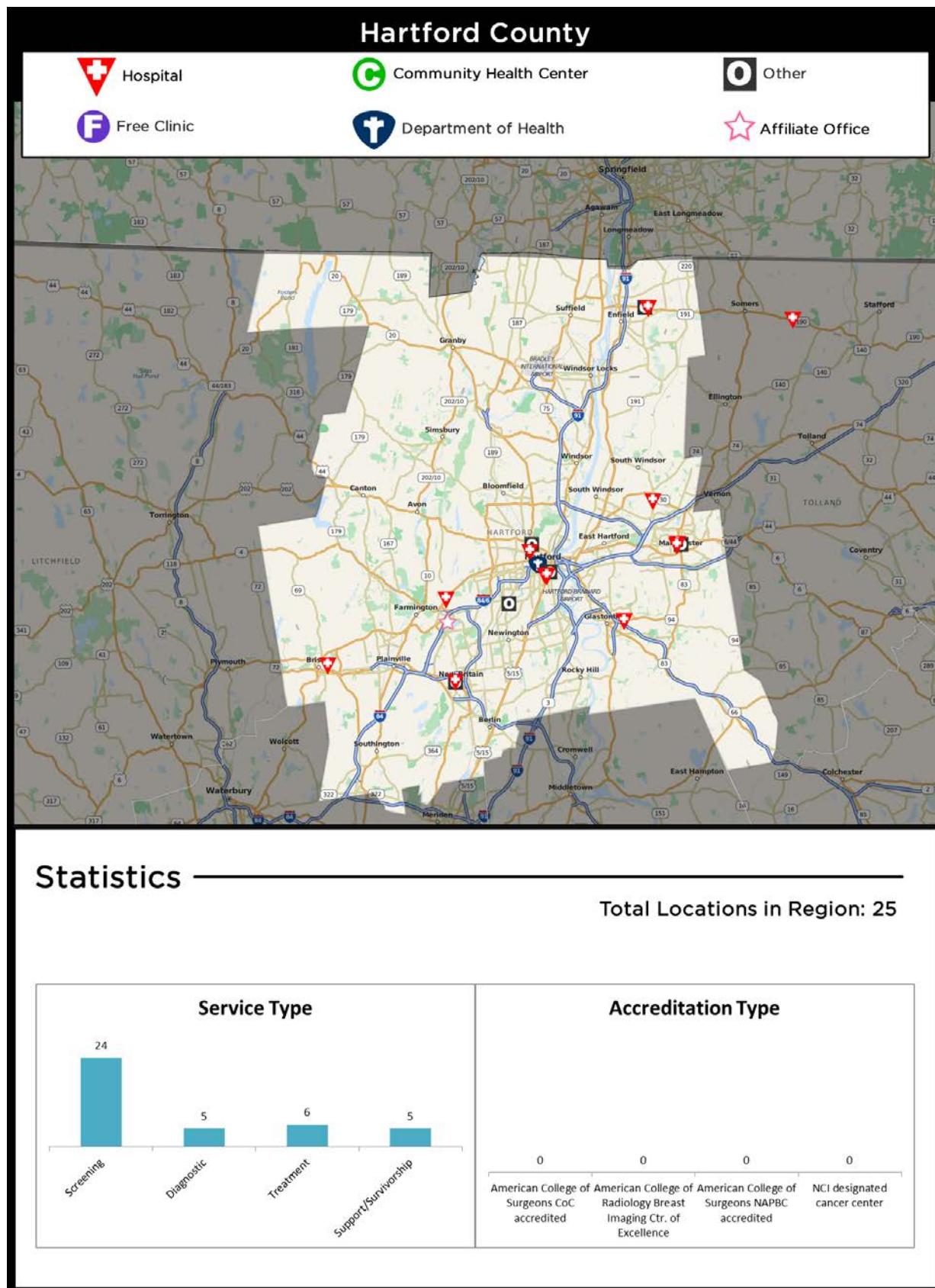
### **Partnerships and Collaborations**

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.

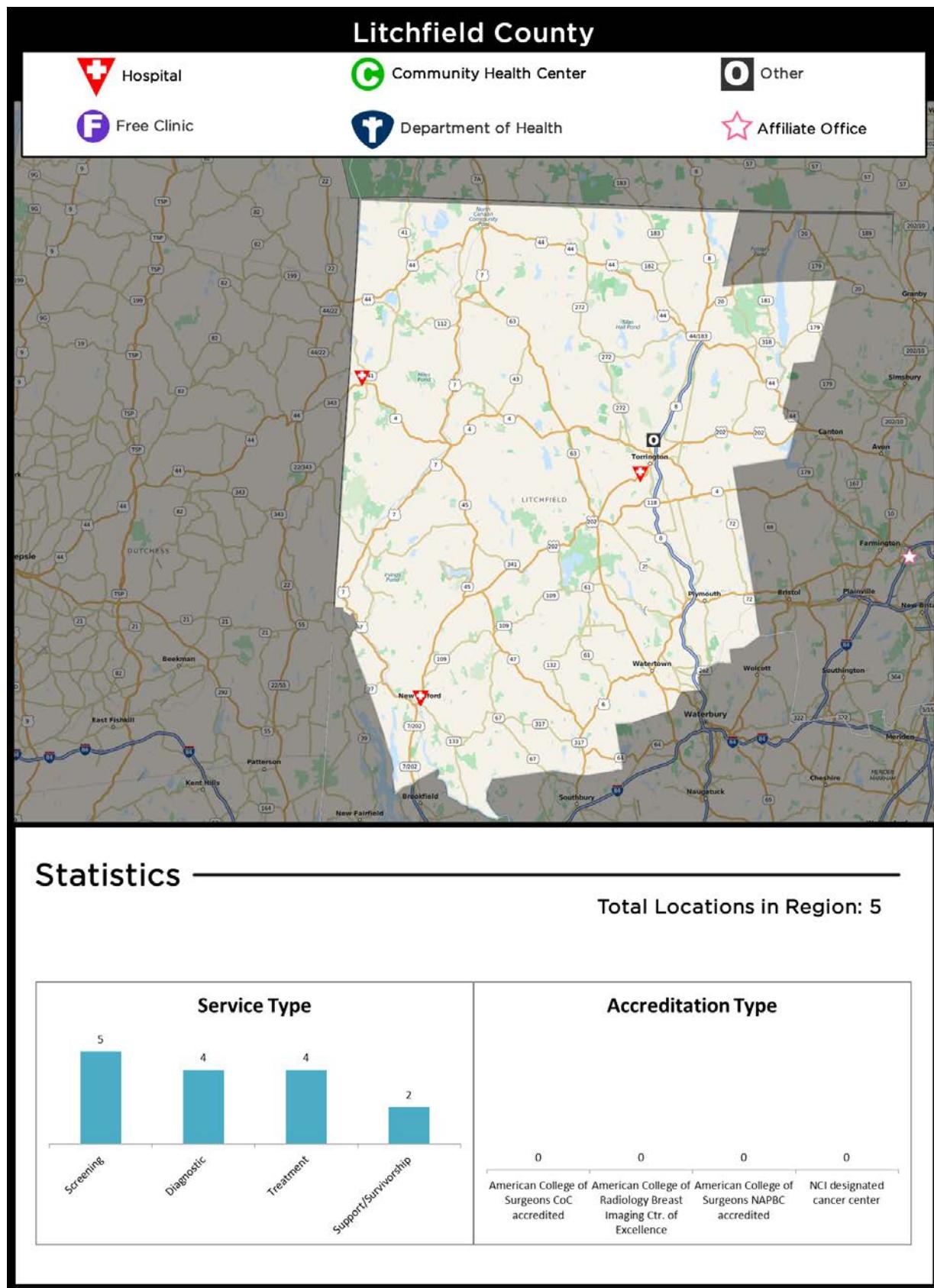
Komen New England has an active Education Committee in Connecticut. This committee assisted in the creation of Faith in Pink, a missions-based initiative to educate women in faith-based organizations. Committee members represent six breast cancer centers in Litchfield, Fairfield and New Haven Counties. 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.



**Figure 3.2.** Breast cancer services available in Fairfield County



**Figure 3.3.** Breast cancer services available in Hartford County



**Figure 3.4.** Breast cancer services available in Litchfield County

## New Haven County



Hospital



Community Health Center



Other



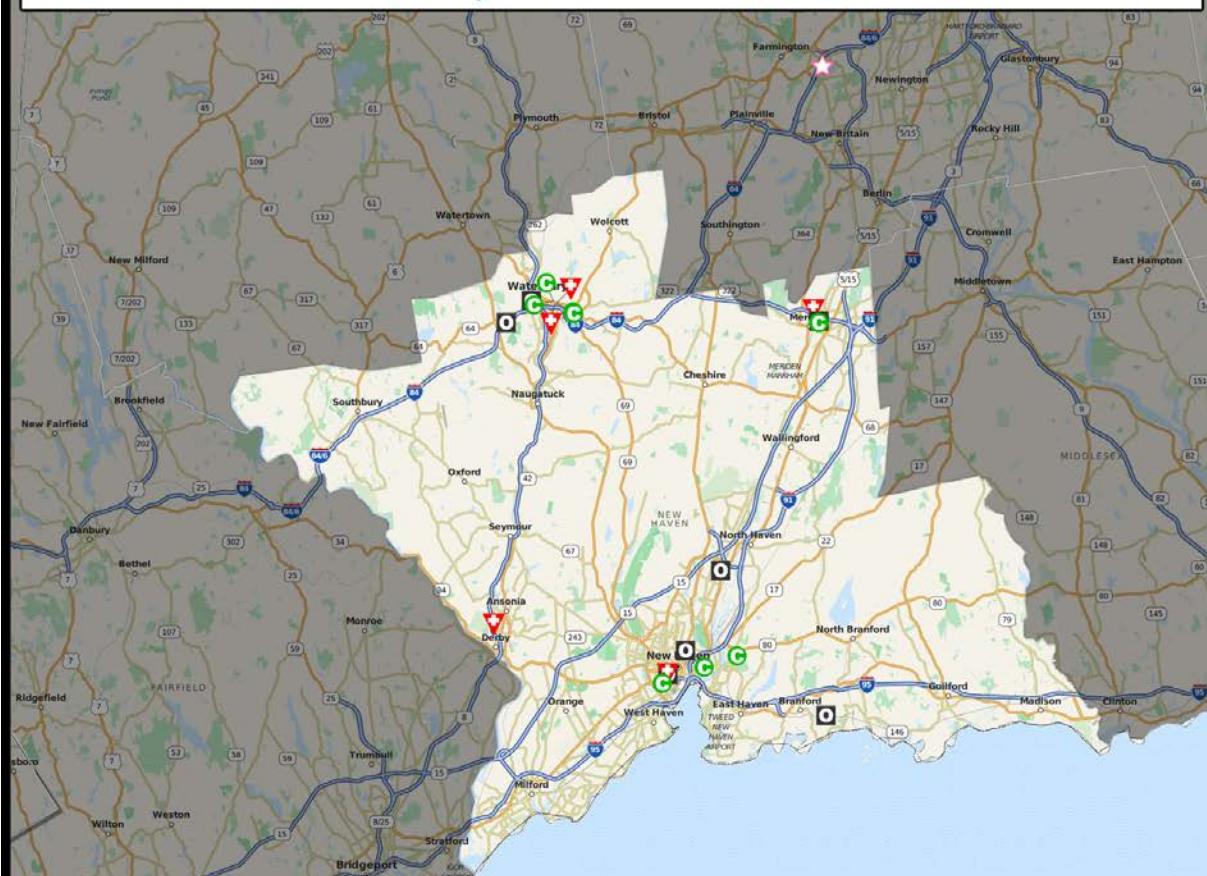
Free Clinic



Department of Health

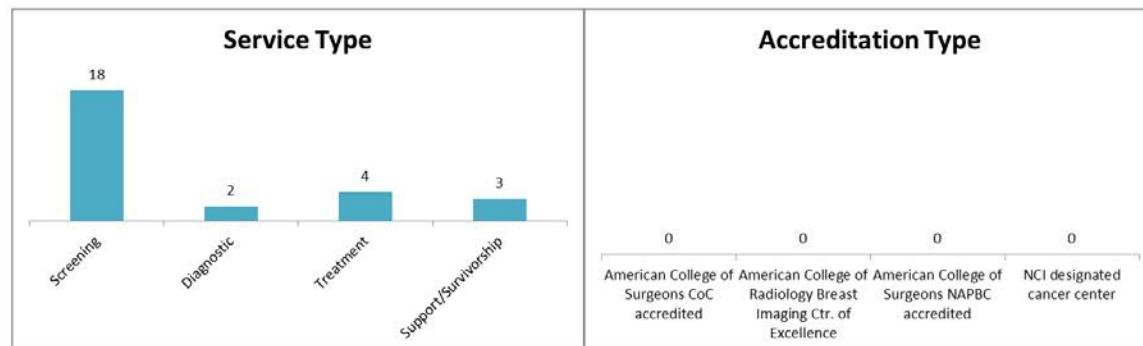


Affiliate Office

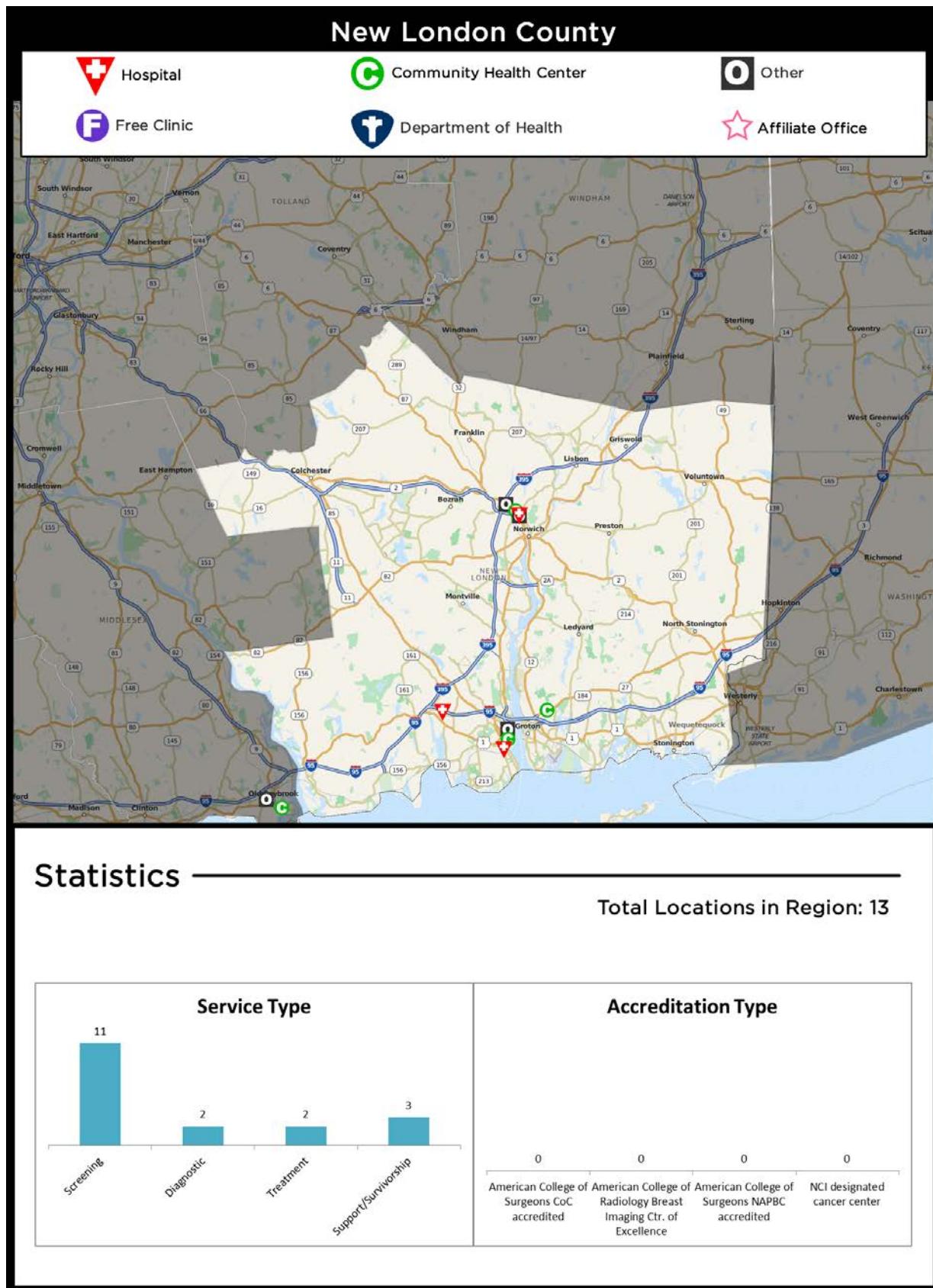


### Statistics

Total Locations in Region: 22



**Figure 3.5.** Breast cancer services available in New Haven County



**Figure 3.6.** Breast cancer services available in New London County

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.

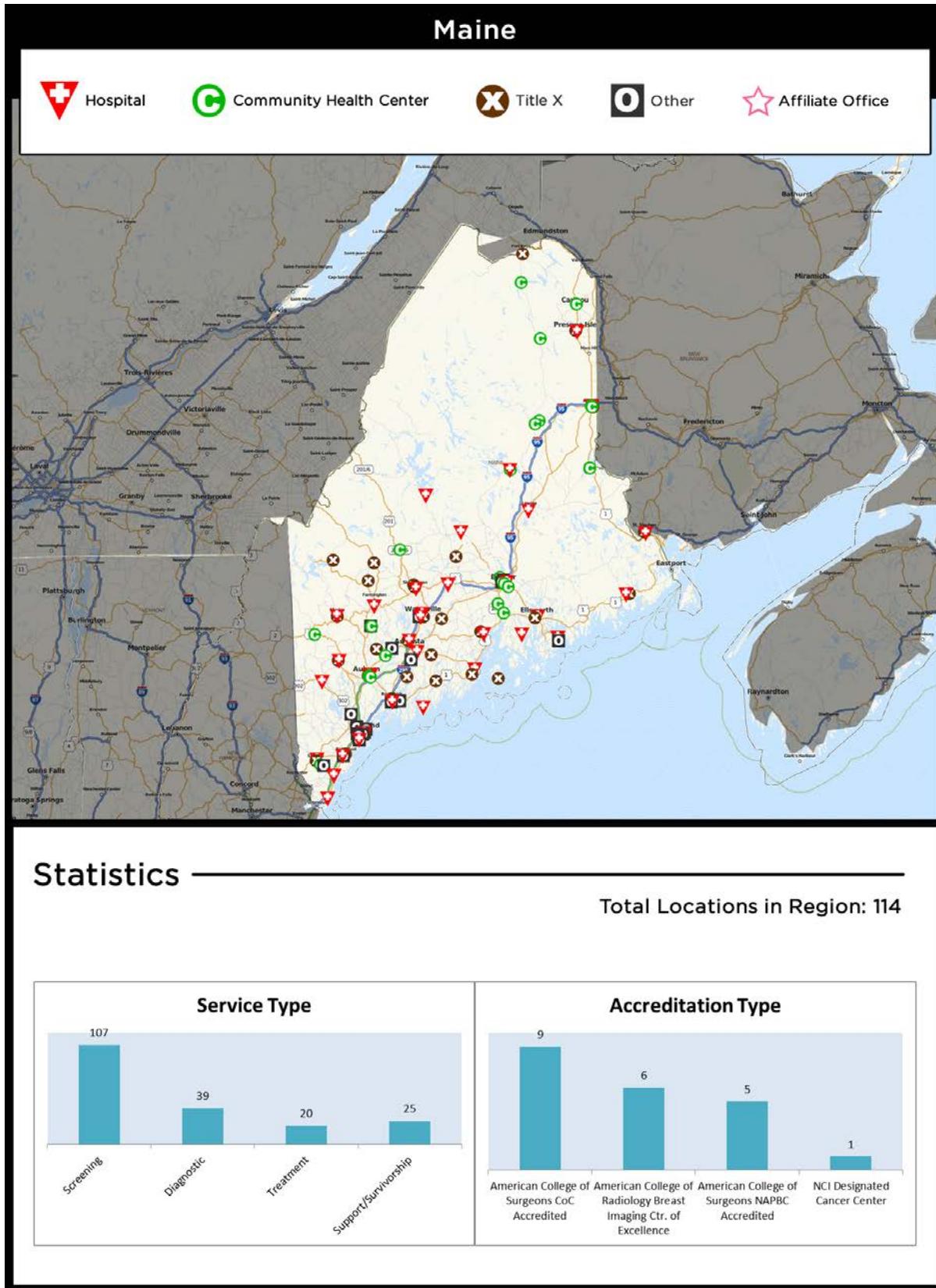
Screening services were available in the five target counties listed in the Quantitative Data section of this report. The majority of the locations that provided free or low-cost screening were in Bridgeport, Hartford, Stamford and New Haven. West Hartford, Guilford, East Lyme, and Darien were among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

### **Maine**

In the State of Maine there were 114 locations found to provide breast cancer services varying between screening, diagnostic, treatment, and survivorship (Figure 3.2). There were 107 locations that provided screening services, 39 locations in the state that provide diagnostic services and 20 locations providing treatment services. In the state there were 25 locations that provided survivorship services or care. Identified facilities that provide mammography services were all accredited by the Federal Drug Administration. There are nine locations that were accredited by the American College of Surgeons Commission on Cancer, six locations accredited by the American College of Radiology as a Breast Imaging Center of Excellence and five locations accredited as an American College of Surgeons NAPBC program. There was one location designated as a NCI Cancer Center.

The following counties are designated as a Medically Underserved Area/Population and/or a Health Professional Shortage Area for primary care: Androscoggin, Aroostook, Cumberland, Franklin, Hancock, Kennebec, Knox, Lincoln, Oxford, Penobscot, Piscataquis, Sagadahoc, Somerset, Waldo, Washington and York.



**Figure 3.2.** Breast cancer services available in Maine

## **Massachusetts**

The State of Massachusetts is a leader in providing residents with universal health care. Massachusetts implemented health care reform in 2006. Health care reform increased the number of residents with health insurance to 96.9 percent (Mass Health 2012). Residents enroll through their employers. Others may enroll between November and February through the Massachusetts Health Connector, the state insurance marketplace.

Women who were considered to be insured had access to early detection services and breast cancer treatment. Early detection services were obtained at primary care, gynecologic and radiology centers in the target communities. Federally Qualified Health Centers were among the providers found to provide early detection services including breast cancer education and clinical breast exams (CBE).

### **Gaps in Breast Cancer Services**

Compared to other states, the number of uninsured residents was fairly low (four percent). Still, uninsured women do not have access to timely breast health or breast cancer services. Women in the target communities of Springfield, Worcester and Boston may access early detection services through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). In Massachusetts, the NBCCEDP is most commonly known as Women's Health Network (WHN). WHN promotes a toll-free number that is widely used in the Springfield, Worcester and Boston areas. Callers are linked directly to a nearby health center that will provide the appropriate breast cancer screening. The WHN contracted sites in Springfield, Worcester and Boston employ community health workers who navigate women with abnormal findings to additional care.

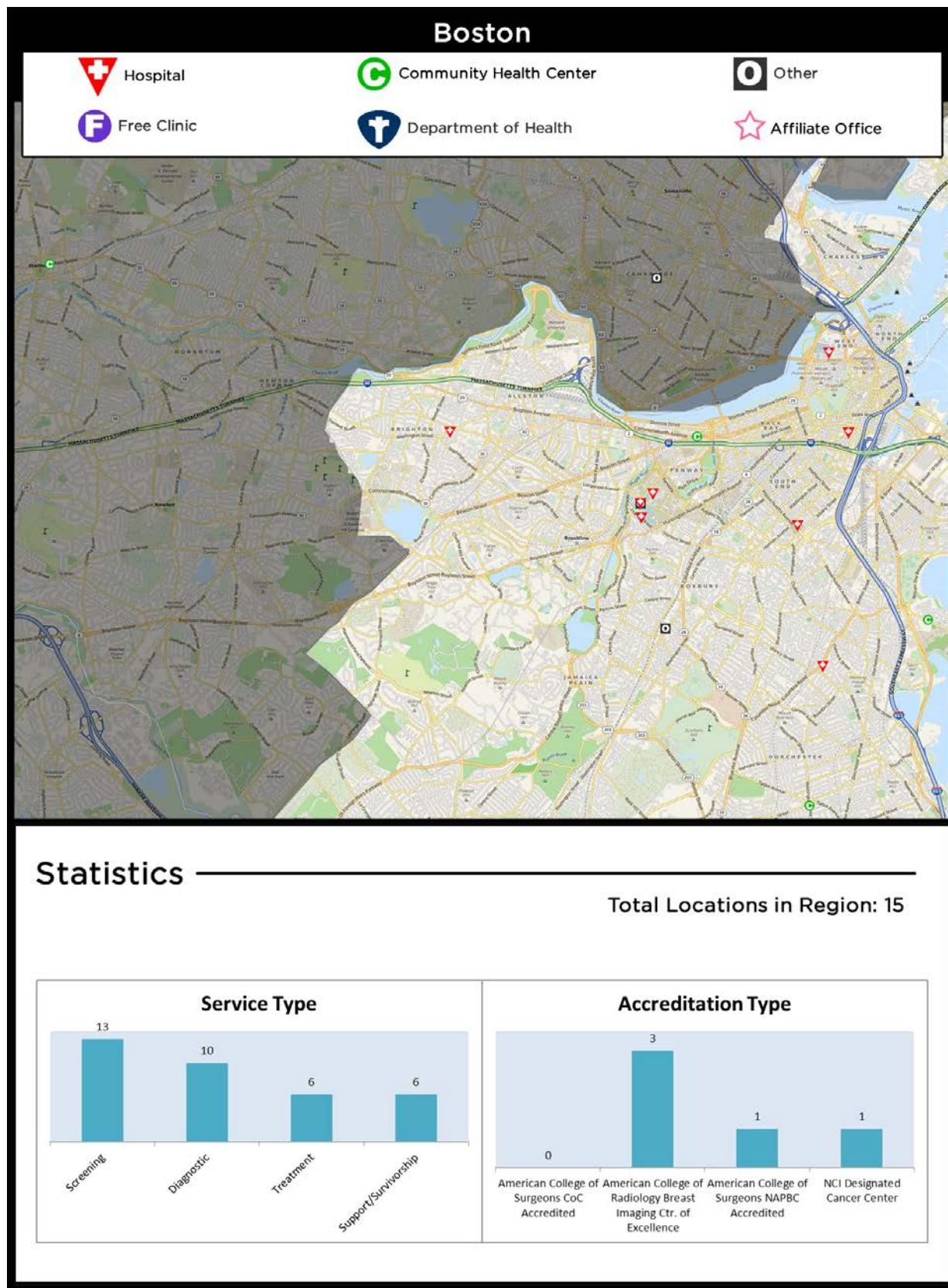
In some cases, uninsured women who do not access WHN, or may not be eligible for WHN services, may apply for financial assistance to cover the cost of screenings. Radiology centers in the target communities have payment plan options for screenings (Figures 3.2, 3.3. and 3.4). The cost of a mammogram in Springfield averages \$320. In Worcester, the same screening ranged from \$300 to \$490. In Boston the screening may cost a patient anywhere from \$300 to \$600. Additional imaging costs for diagnostic screenings were not available. On average, radiology facilities in the target communities were able to schedule routine mammography screenings within a three-week period. Results were given to both the patient and a primary care physician within one to three days. Some facilities provided breast cancer education to women. All facilities provided translation services in at least one other language.

Mobile mammography services were found in the Boston area. Breast cancer screenings on the van are made available to low income, medically underserved women. The van is serviced by the Dana-Farber Cancer Institute and has partnerships with neighborhood and community-based organizations in Boston. These partnerships are in place to ensure continuum of care services for patients that utilize the mobile service.

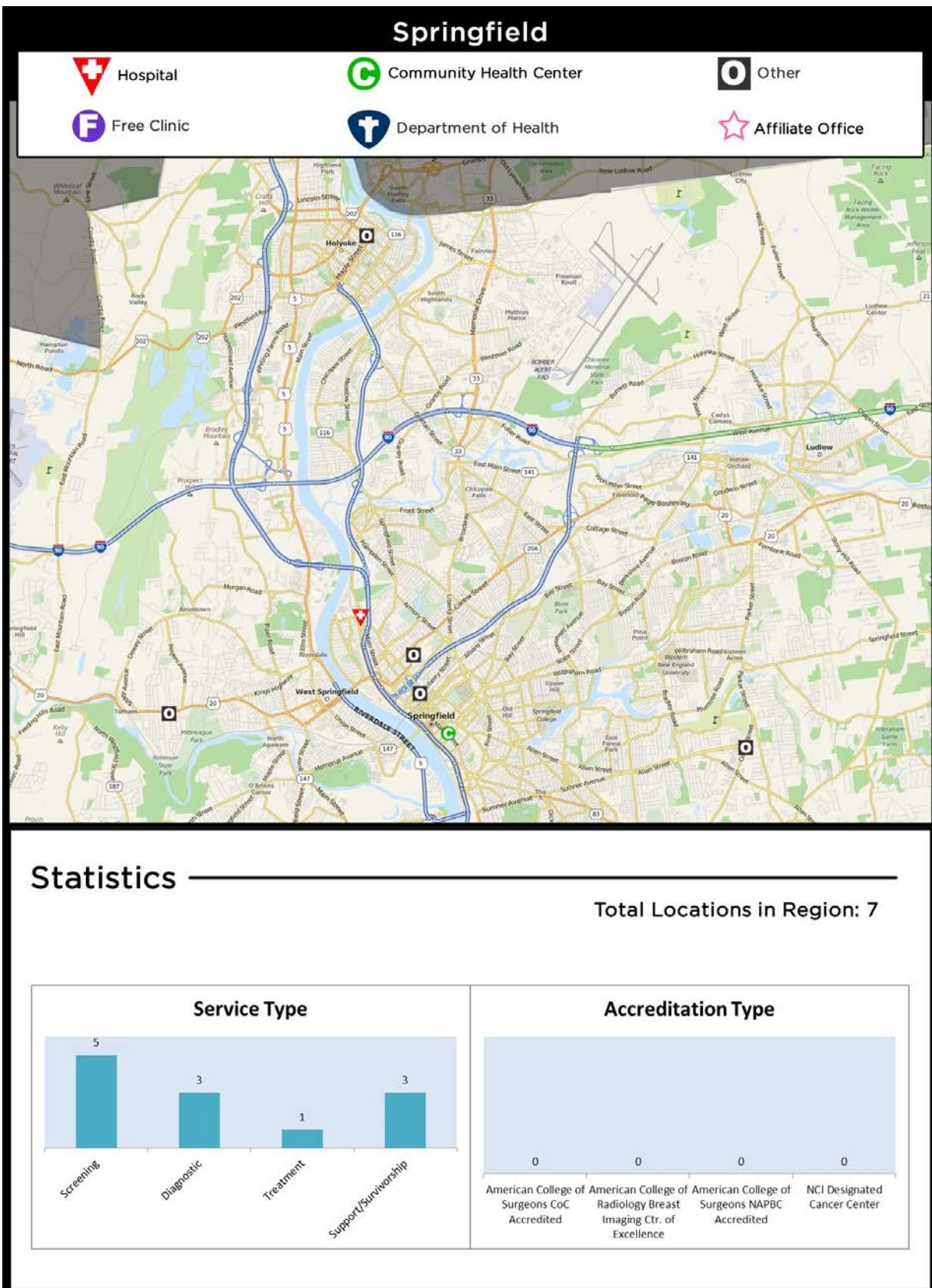
Residents in each target community had various options to consider when accessing breast cancer treatment. Cancer centers strive to deliver quality, comprehensive cancer treatment to all

patients. Though the Affordable Care Act offers options to obtain health care coverage for most, some are still left with the burden of covering copayments and high deductibles for services. In each target community, at least one health system extended financial assistance to patients in need.

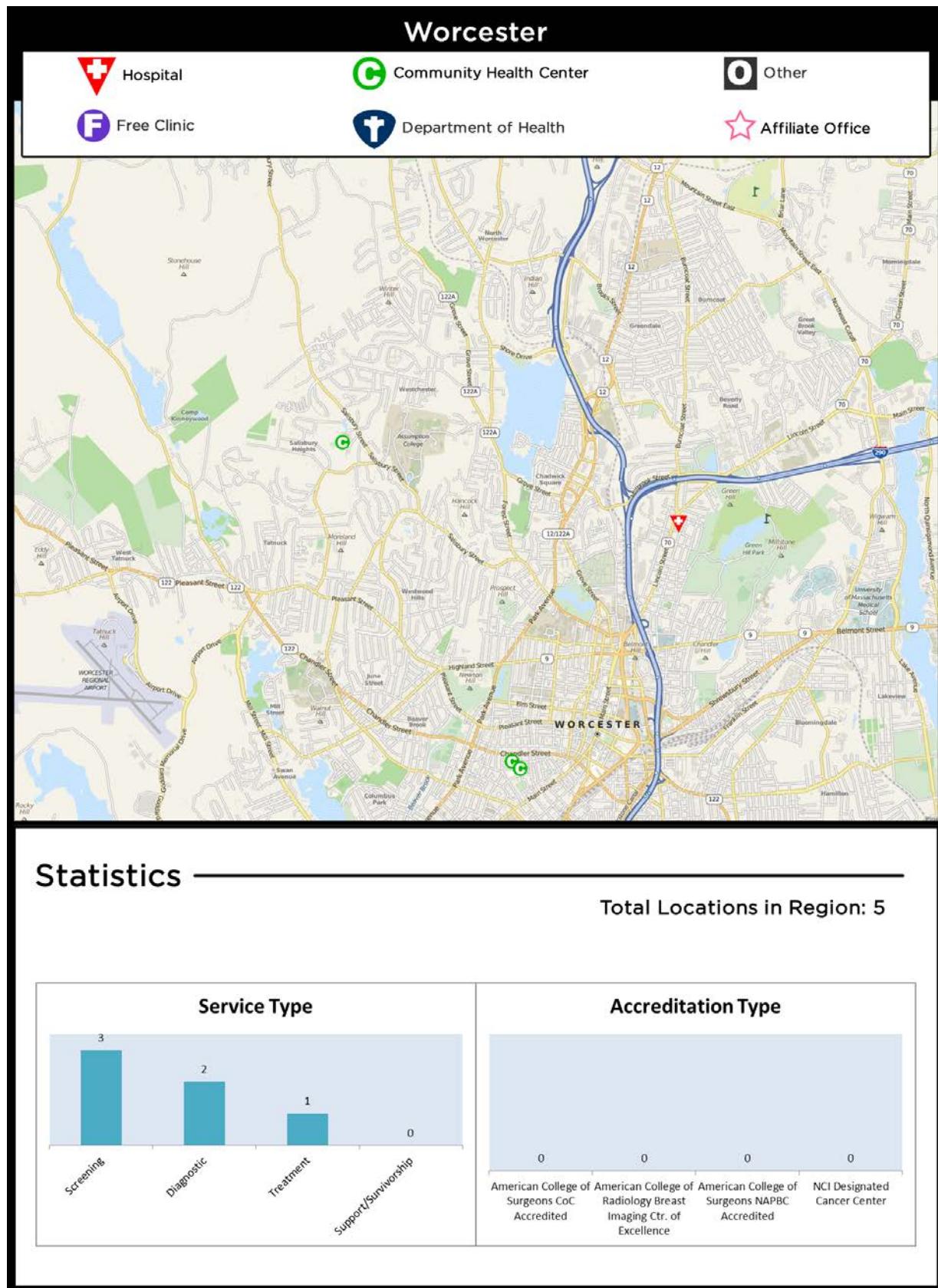
In 2014 the Breast Density Law was signed making changes to early detection and diagnostic screenings. This law requires providers to perform diagnostic screening for women with dense breasts. An issue that providers face is educating women in need of the diagnostic services about their coverage as this may result in meeting an insurance deductible upwards of \$1,000.00. For many, this is a high medical cost that may deter them from following through with the screening.



**Figure 3.2.** Breast cancer services available in Boston



**Figure 3.3.** Breast cancer services available in Springfield



**Figure 3.4.** Breast cancer services available in Worcester

## **Partnerships**

The Affiliate has a long history of collaborating with grant funded programs to increase breast cancer awareness and education statewide. Partnerships with seven grant funded programs, and a grant made possible by Yoplait, brought about a Latina Breast Cancer Symposium in 2012. This event attracted over 250 Latina breast cancer patients and survivors to Boston to learn about cutting edge treatment and programs for breast cancer patients. The Community Profile has opened many other opportunities for partnerships with stakeholders in major cancer centers based in Springfield, Worcester and Boston. The Affiliate plans to collaborate with Boston-based health systems such as Dana-Farber, Boston Medical Center and Massachusetts General Hospital. The Affiliate will pursue future collaborations with UMASS Memorial Cancer Center in Worcester and in Springfield, Bay State Health Systems and Mercy Medical Center.

The Affiliate serves on the Early Detection Steering Committee led by the Massachusetts Comprehensive Prevention and Cancer Control Network. As a member, there will be opportunities to present findings from the Community Profile at key network meetings reaching other committee members who represent cancer programs and cancer centers based in Springfield, Worcester and Boston.

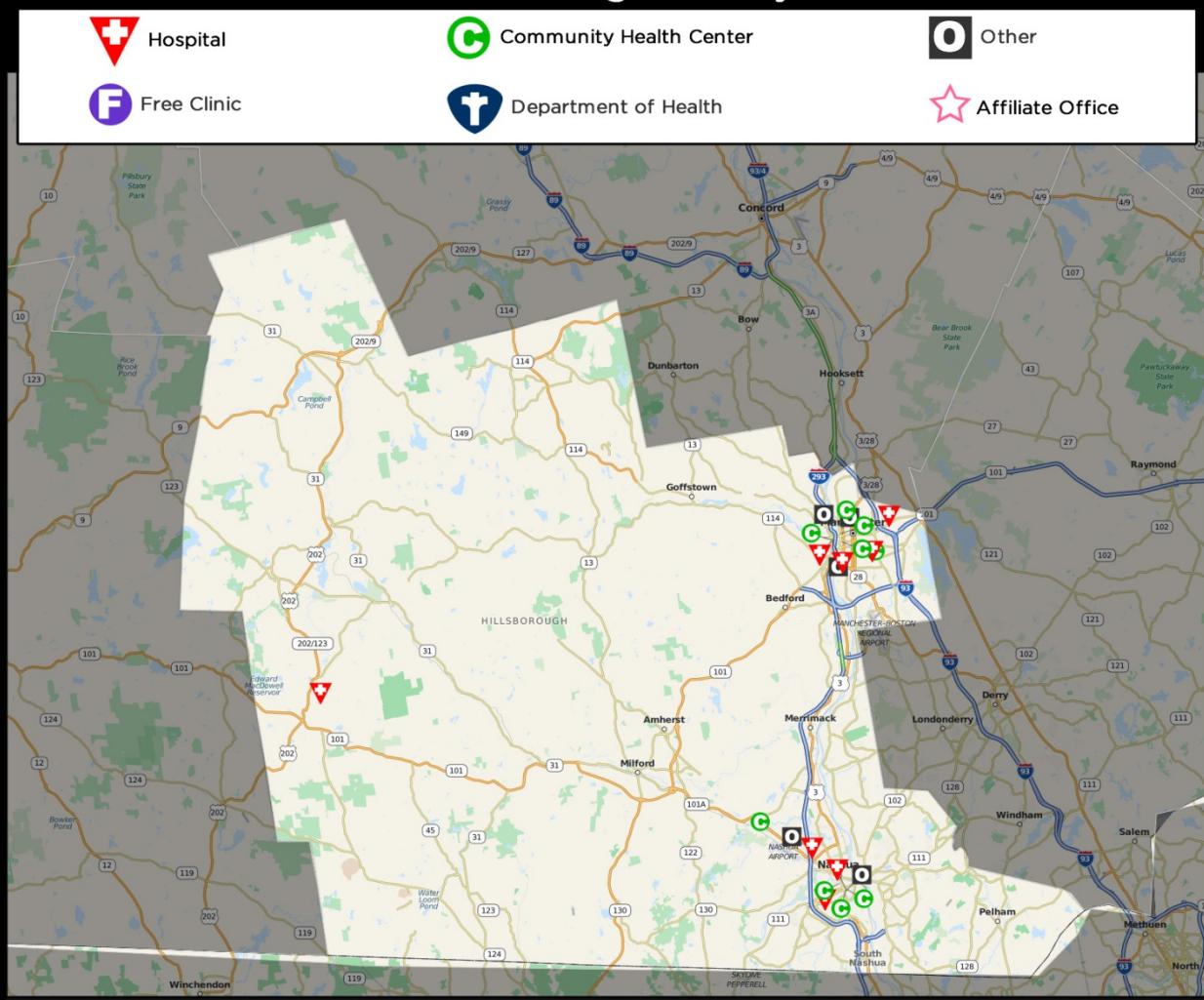
## **New Hampshire and Vermont**

### **Hillsborough County, New Hampshire**

This county has 20 facilities that provide screening services such as clinical breast exams and screening mammography (Figure 3.2). A total number of six facilities provide comprehensive services that include screening, diagnostics, treatment and patient support. Compared to other target communities in the Affiliate service area, Hillsborough County offers the greatest number of facilities providing for the breast health needs of women. This is a demonstrated strength in the continuum of care for women living in this area. Hillsborough appears to offer many choices in care in addition to quality facilities. However, this county is also the largest of the target communities selected and the population of eligible women seeking screening and treatment may be greater than the established facilities can handle. Barriers women may experience could be as simple as securing timely appointments and receiving individualized attention to their unique needs.

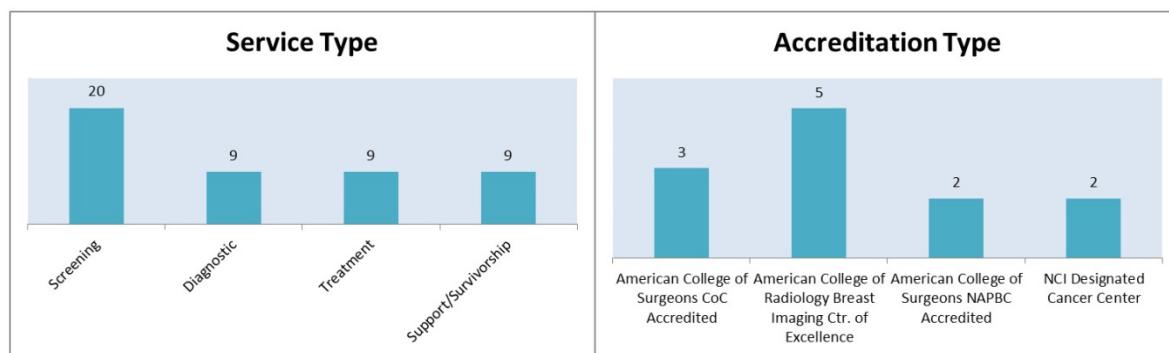
Being the most diverse of the target communities, it is essential to identify and overcome disparities specific to minority women. In order to improve health outcomes in this county, attention and sensitivity to diversity is necessary. At this time, the Affiliate has an existing relationship with Planned Parenthood of Northern New England located in Manchester, New Hampshire. Increasing the Affiliate's involvement with organizations in this community by enriching the resources and breast health outreach for women will serve to positively impact this area.

## Hillsborough County



### Statistics

Total Locations in Region: 22



**Figure 3.2.** Breast cancer services available in Hillsborough County, NH

### **Belknap County, New Hampshire**

This county has four facilities that provide screening services such as clinical breast exams, and screening mammography (Figure 3.3). Only one facility, Lakes Region General Hospital in Laconia, provides a complete spectrum of services from screening to patient support.

Compared to the Affiliate's service area, Belknap County, New Hampshire is more rural, more residents are less educated, and a higher percentage of the population is living 250 percent below the poverty level. The increasing trend in the number of new breast cancer cases in this target community requires exploration. It is uncertain whether the increased incidence is a result of more women being screened and diagnosed, or if there are more women developing breast cancer.

Lake Region General Hospital stands out as a community asset and provides accessible, comprehensive cancer care center for women residing in this county. It is located in Laconia and offers screening, diagnosis, treatment and support. There is a patient navigator available to assist with issues that may arise along the continuum of care. This hospital offers several financial assistance programs to help cover the cost of care. Notably, the Lake Region HealthLink program offers several options to provide discounts and financial aid to those in need.

Lakes Region General Hospital also offers a Mammography Bridge program for uninsured or underinsured women that may have high deductibles. This is another avenue of preventing financial obstacles that could limit access to screening. This program is funded by the National Breast Cancer Foundation and designated to help women who do not meet the requirements for the Breast and Cervical Cancer Program or HealthLink but present unmet needs.

Laconia Clinic and Laconia Women's Health Center offer mammography screening and will refer women for further services if necessary. Caring for Women is a program that provides screening, diagnosis, treatment and support. The Affiliate currently has no existing relationships in this community. Increasing the Affiliate's involvement with organizations in this community will serve to positively impact this area. Further exploration will determine how resources could be used to reverse the unfavorable breast cancer incidence and late-stage trends in this county.

## Belknap County



Hospital



Community Health Center



Other



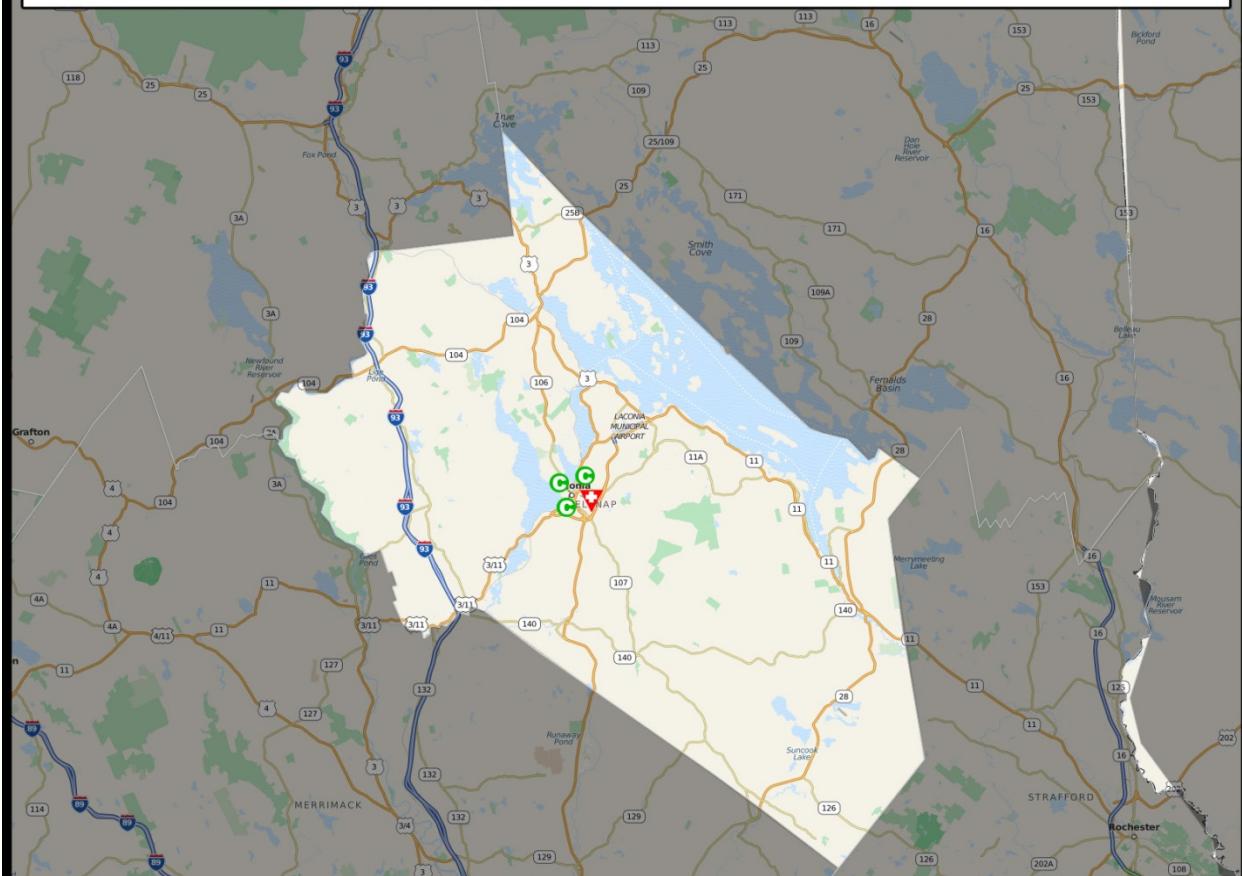
Free Clinic



Department of Health

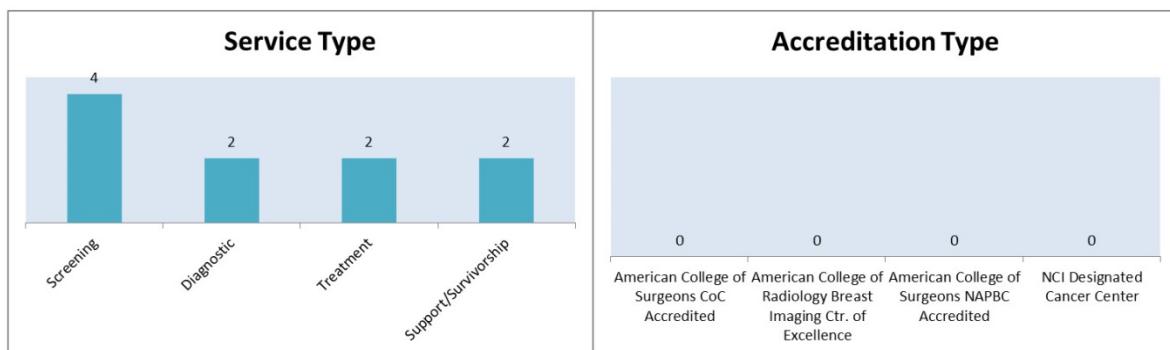


Affiliate Office



### Statistics

Total Locations in Region: 4



**Figure 3.3.** Breast cancer services available in Belknap County, NH

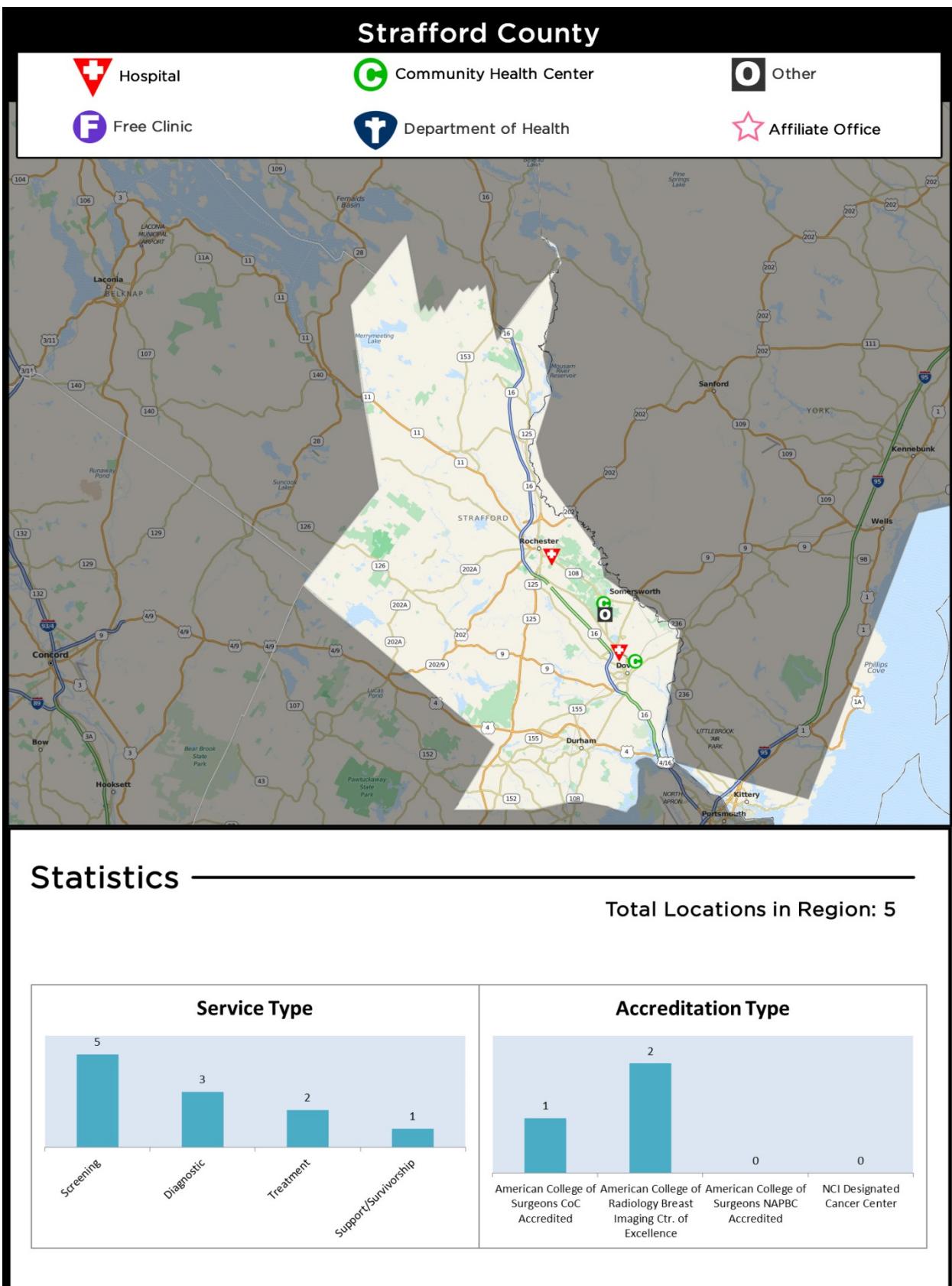
## **Strafford County, New Hampshire**

Strafford County, New Hampshire has been noted as 100 percent medically underserved. This county has five facilities that provide screening services such as clinical breast exams, and screening mammography (Figure 3.4). Only one facility, Wentworth Douglas Hospital-Seacoast Cancer Center, provides a complete spectrum of services that includes screening, diagnostic, treatment, and support services. One can obtain comprehensive care only at a single facility. Offering patient navigation services could reduce the negative implications of being lost in the system when referred from one place to another for services. Patient navigation could have a positive effect on the likelihood of a smooth transition throughout the breast cancer continuum of care and improve health outcomes for women in Strafford County.

In addition, Frisbee Memorial Hospital in Rochester, NH offers Oncology care on site as well as through a clinical affiliation with Lahey Health's Sophia Gordon Cancer Center. This center is not located in Strafford County but in a neighboring county. For breast health including mammography and breast ultrasound, women are referred to the Women's Life Imaging Center located in Somersworth, NH. In spite of these resources, this County is still demonstrating a need for more support in order to reach HP2020 goals.

This county has an increased proportion of women living in poverty. While these women may qualify for benefits that would allow access to screening and treatment, there are additional disparities these women face as a result of their economic status. These women may be particularly challenged to find transportation to and from appointments or have less ability to leave work for medical reasons. Lower-income families may be living with only one vehicle, if any. The price of gas and additional living costs are expenses that may not be covered by state and federal programs.

Women in Strafford County would likely benefit from supplemental support such as patient navigation and breast health education. Additional resources in these areas would increase the likelihood of obtaining a positive health outcome and keeping women moving smoothly through the continuum of care. Currently there are no existing partnerships with the Affiliate in Strafford County, but it is recognized that cultivating relationships would be beneficial for women in this community. The fact that 100 percent of women in this area are medically underserved underscores the need to reduce barriers and improve care for these women. It is clear that the Affiliate could have a positive and long-lasting influence for the women in this community.



**Figure 3.4.** Breast cancer services available in Strafford County, NH

### **Addison County, Vermont**

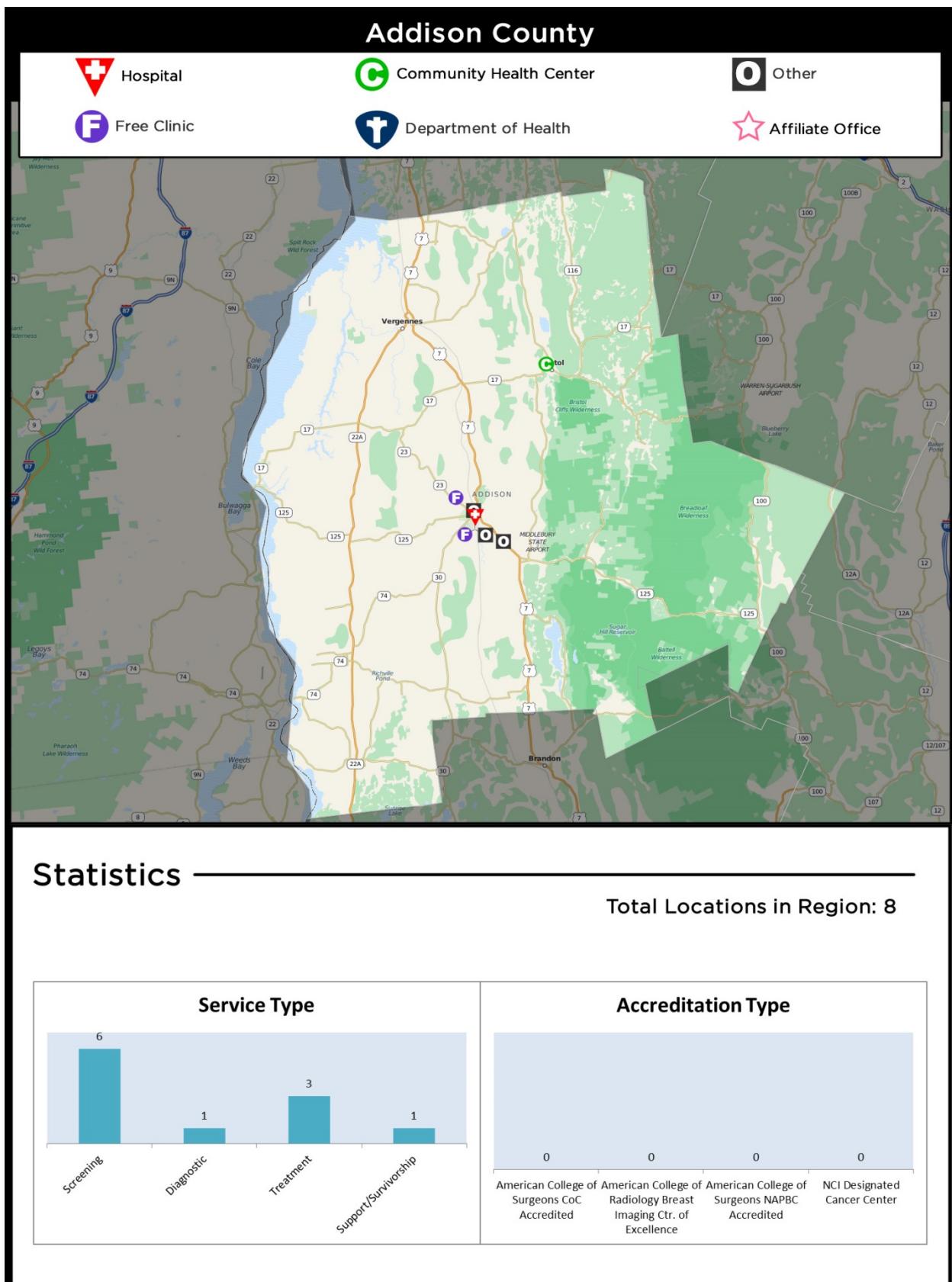
Addison County, Vermont is a geographically rural area that offers limited resources to women for breast health. Convenient access to care is less available than in other counties, creating obstacles in the continuum of care. Of the residents in this county, 78.4 percent live in geographically rural areas. Difficulty reaching service providers could derail diagnosis and treatment for women.

This county has six facilities that provide screening services such as clinical breast exams, and screening mammography (Figure 3.5). Only one facility, Porter Medical Center in Middlebury, provides a complete spectrum of services that includes screening, diagnostic, treatment, and support services. However, it should be noted that all services are not provided on a daily basis. The hospital contracts with another provider to provide cancer treatment two days a week in a building adjacent to the hospital.

This county has demonstrated a dramatic, increasing trend in breast cancer incidence in comparison to other areas of the state. Late-stage diagnosis trends are also increasing which may mean that women in this area are not obtaining early detection screenings. Porter Medical Center in Middlebury provides the greatest resources for this community. They offer screening and diagnosis but refer patients outside of the facility for treatment. Local clinics are available near the hospital. These clinics operate on a limited schedule, presenting a problem for patients who would benefit from comprehensive cancer care services in one location. Women in Addison County require more travel to seek comprehensive medical care.

Although a small-town hospital such as Porter may offer personalized attention to patients, in the case of Addison County, there are few choices in breast health care and many may have to travel out of county for care. Breast cancer patient navigation is critical to the continuum of care and presently, Addison County is without this very important resource. This is an area of need in this community.

A noted strength in this county is the existence of several free or reduced cost clinics within the area. This makes screening more accessible and available to uninsured or underinsured women. There is also an Integrated Medicine clinic that offers complimentary cancer treatments. However, these services may not be covered by insurance. The Affiliate is currently partnered with Planned Parenthood of Northern New England. The office is in Middlebury, Vermont, and is an asset to women living in this community. Increasing involvement with organizations in this community will serve to positively impact this area. Further exploration will determine how resources could be used to reverse the unfavorable trends in this county.



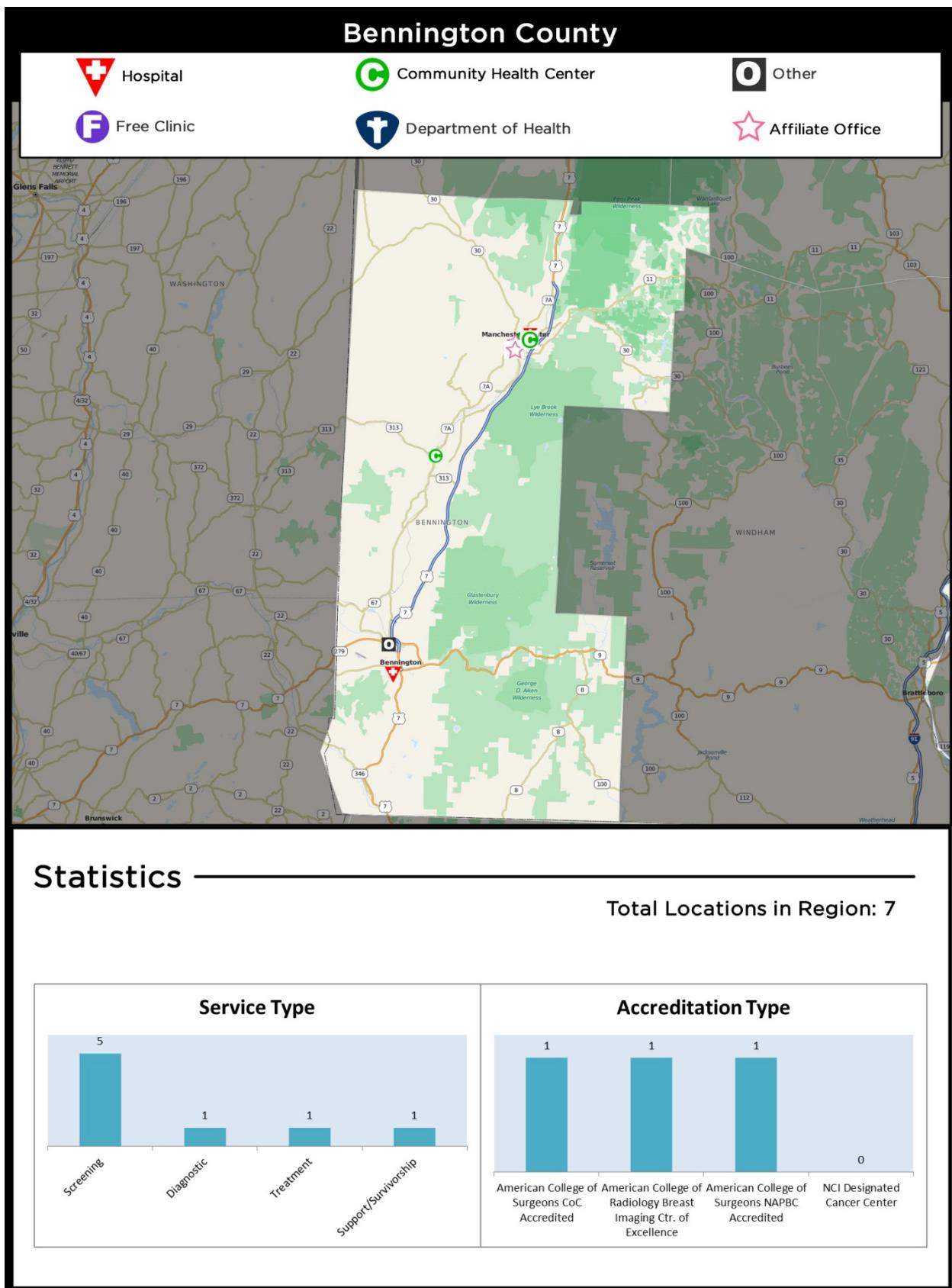
**Figure 3.5.** Breast cancer services available in Addison County, VT

## **Bennington County, Vermont**

This county has three facilities that provide screening services such as clinical breast exams, and screening mammography (Figure 3.6). Only one facility, Southwestern Vermont Medical Center, provides a complete spectrum of services that includes screening, diagnostics, treatment, and support. Bennington County is notable for a larger, older female population compared to other target communities. This area demonstrates a higher level of poverty and a decreased education level. Additionally, this target community shows fewer women self-reporting annual screening mammograms. For these reasons, more information is needed in order to make positive impact in this target community and reduce the unfavorable trends in the breast health continuum of care.

The Affiliate is partnered with Southwestern Vermont Medical Center in Bennington which offers exceptional screening, diagnostic and treatment services at the facility. They provide patient navigation, support services and are accredited by several organizations including The American College of Surgeons CoC and American College of Surgeons NAPBC. This is an asset to the women living in the community.

There is a community health center in the city of Manchester Center that provides mammograms to women and referrals to other resources for additional care if needed. This provides convenient access in order to maintain annual screenings. The Affiliate is partnered with the Northern New England Planned Parenthood in Bennington, Vermont. This is an excellent resource for women living in this county. Despite these resources, Bennington County continues to see increasing rates of breast cancer incidence and late-stage diagnosis as well as an above average trend in death rate from breast cancer. The reasons behind these statistics must be explored and the breakdowns in the continuum of care determined. Again, increasing involvement with organizations in this community will serve to positively impact this area.



**Figure 3.6.** Breast cancer services available in Bennington County, VT

In regard to all five target communities, barriers to good health care for women exist including: limited comprehensive cancer care sites, inadequate number of patient navigators to assist women making their way through the continuum of care, lack of insurance or being underinsured, lack of awareness about free or reduced cost programs, language barriers and drive times due to more rural communities. These barriers were derived by reviewing resources available online. However, further investigation is needed via qualitative data collection to understand the underlying issues leading to the unfavorable trends in the target communities.

The assessment for Vermont and New Hampshire is unique in that it covers two states and includes 26 counties. The target communities of the 2015 Community Profile Report are vastly different than in previous years, largely as a result of using the Healthy People 2020 targets. The Affiliate has developed many solid, long-term partnerships with organizations in the service area, although not necessarily in the target communities identified in this report. Clearly, this will be reevaluated as the Affiliate utilizes the information gathered herein. A need to develop new partnerships exists in the five target communities and plans are to continue growing the connections and building relationships.

All five target communities may benefit from increased breast health education and awareness of risk reduction and early detection. Hillsborough County offers a greater wealth of resources within a relatively close radius for women living in the county. However, it is questionable if these resources are being utilized by minority women and those experiencing language barriers to screening and treatment. With the exception of Strafford County, the remaining communities are geographically rural and have limited access to information to make informed choices about health care. Women in these areas may not even be aware of the resources and free programs available. They may also face other socioeconomic obstacles in obtaining care even if they have health insurance. Additionally, there are no mobile mammography vans that exist in any of the five target communities. Through discussions with breast cancer professionals, the Affiliate learned that most areas were no longer using mobile mammography due to the concerns with quality of imaging in the past. However, newer digital equipment may be available to reduce these concerns. This could be an avenue for future planning as an alternative means to reach out to the geographically rural and isolated women living in these target communities.

Vermont and New Hampshire have the potential to develop several new partnerships with medical providers and other nonprofits in the five target communities. Building new relationships to promote breast health education and outreach as well increasing patient navigation providers may also be especially helpful in rural areas. Women who are not equipped with basic health guidelines would benefit by knowing the resources available in their community and how to access them. The Affiliate will strengthen current partnerships and cultivate new partnerships based on the results of the Community Profile that will facilitate better health outcomes for women as they make their way through the continuum of care.

Recent changes in health care require that additional education be made available to women. It is important for women to know what options are available to them. When women discover they are able to obtain free screenings and may receive financial assistance in the event of a breast cancer diagnosis, they would have a behavioral incentive to take action. Breast health education and outreach needs to include information about benefits women have access to, including those provided by the Affordable Care Act, the NCCEDP and community resources such as Susan G. Komen. Delivery of this information must be easily understandable and available, readily obtainable for those living in rural communities, accessible to low-income women, clearly communicated to those who may not speak or understand English, manageable for those with limited education and/or learning disabilities and unbiased for those who may be treated unfairly.

Addressing the barriers and reasons for gaps in the continuum of care will decrease the number of women being diagnosed at a later stage of breast cancer and reduce the incidence of death, with the goal of enabling these counties to meet Healthy People 2020 targets. Additionally, the Affiliate will determine the need for increased advocacy and public policy in the future. The benefits of this activity to the Affiliate service area and women living in these communities will be determined.

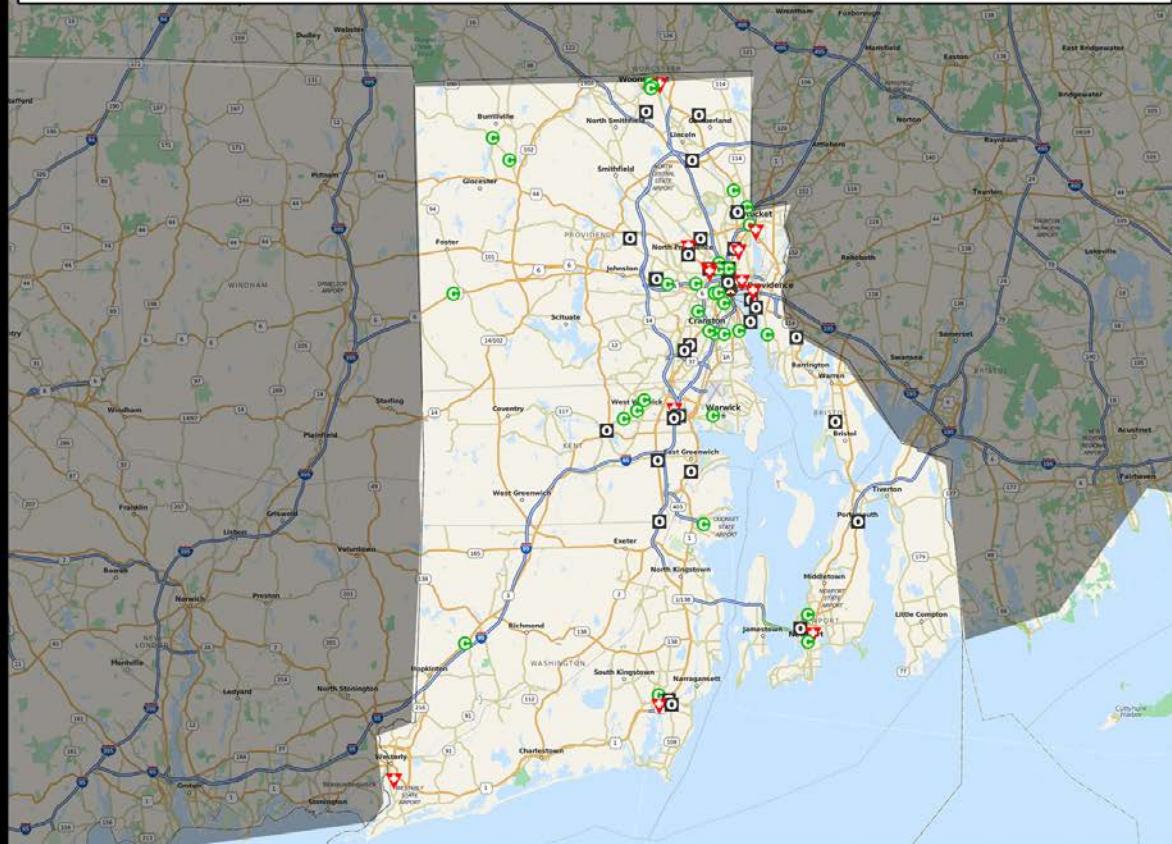
### **Rhode Island**

In the State of Rhode Island there were 76 locations found to provide breast cancer services varying between screening, diagnostic, treatment, and survivorship (Figure 3.2). There were 76 locations that provided screening services, 43 locations in the state that provide diagnostic services and 12 locations providing treatment services. In the state there were 12 locations that provided survivorship services or care. Identified facilities that provide mammography services were all accredited by the Federal Drug Administration. There are 12 locations that are accredited by the American College of Surgeons Commission on Cancer, four locations accredited by the American College of Radiology as a Breast Imaging Center of Excellence and five locations accredited as an American College of Surgeons NAPBC program. There are no locations that are designated as a NCI Cancer Center.

The following counties are designated as a Medically Underserved Area/Population and/or a Health Professional Shortage Area for primary care: Bristol, Kent, Newport, Providence and Washington.

## Rhode Island

Hospital      Community Health Center      Title X      Other      Affiliate Office



### Statistics

Total Locations in Region: 76

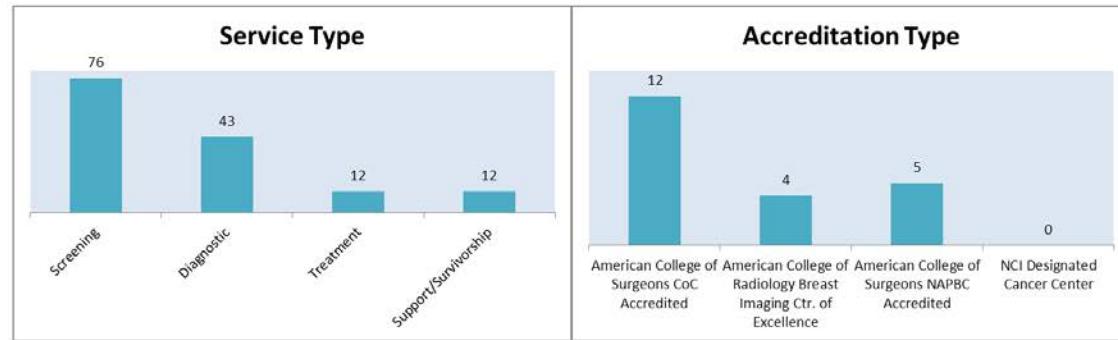


Figure 3.2. Breast cancer services available in Rhode Island

## **Public Policy Overview**

### **Affordable Care Act**

In 2010, Congress passed the Patient Protection and Affordable Care Act (commonly known as Affordable Care Act or ACA) to expand access to care through insurance coverage, enhance the quality of health care, improve health care coverage for those with health insurance and to make health care more affordable (US Department of Health and Human Services, 2015a).

The ACA includes the following mandates to improve health insurance coverage and enhance health care quality (US Department of Health and Human Services, 2015a):

- Prohibit insurers from denying coverage based on pre-existing conditions
- Prohibit insurers from rescinding coverage
- Prohibit annual and lifetime caps on coverage
- Provide coverage of preventive services with no cost-sharing (including screening mammography, well women visits)
- Establish minimum benefits standards, known as the Essential Health Benefits (EHB)

The ACA provides tax subsidies for middle-income individuals to purchase insurance through the health insurance exchanges (commonly called the Marketplace). To be eligible to receive health coverage through the Marketplace, an individual must live in the United States, be a US citizen or national (or lawfully present), cannot be incarcerated, fall into certain income guidelines and cannot be eligible for other insurance coverage (i.e., Medicaid, Medicare and employer sponsored health care coverage) (US Centers for Medicare and Medicaid Services, n.d.).

For more information about the Affordable Care Act or to obtain coverage, please visit the following websites:

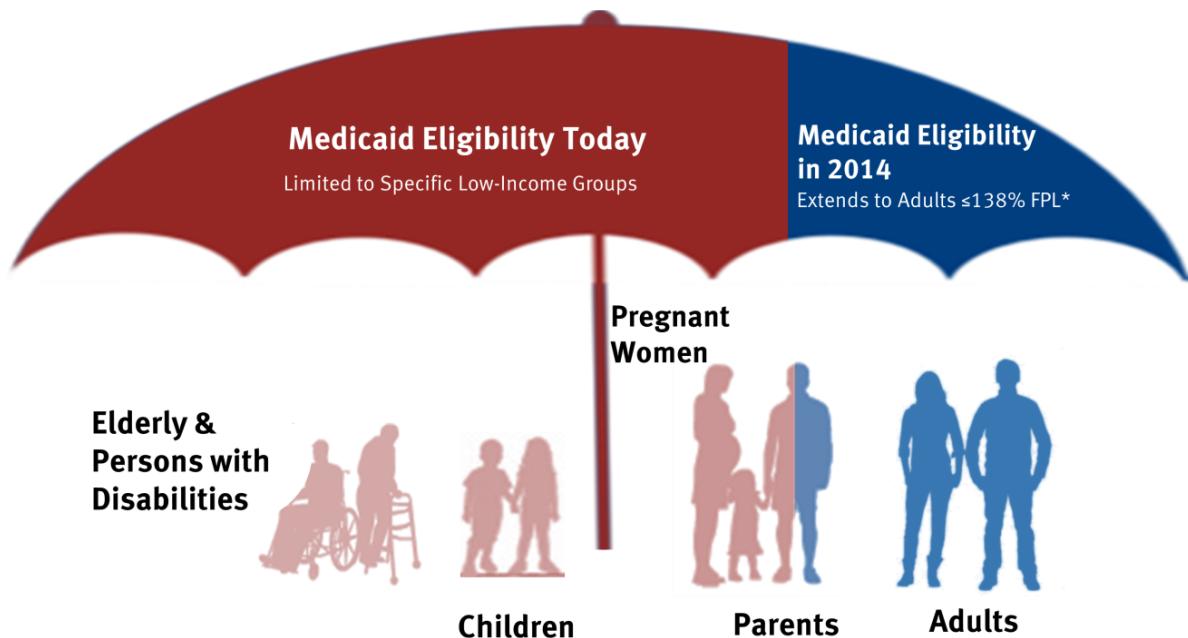
- US Department of Health and Human Services: <http://www.hhs.gov/healthcare>
- Information about health insurance coverage: 1-800-318-2596 or [www.healthcare.gov](http://www.healthcare.gov)
- ACA assistance in the local community: <https://localhelp.healthcare.gov/#intro>

### **Medicaid Expansion**

Traditional Medicaid had gaps in coverage for adults because eligibility was restricted to specific categories of low-income individuals (i.e., children, their parents, pregnant women, the elderly, or individuals with disabilities) (Figure 4.1) (The Henry J. Kaiser Family Foundation, 2014). In most states, non-elderly adults without dependent children were ineligible for Medicaid, regardless of their income.

Under the ACA, states were provided the option to expand Medicaid coverage to a greater number of non-elderly adults with incomes at or below 138 percent of poverty (about \$16,242 per year for an individual in 2015); thus, reducing the number of uninsured, low-income adults (The Henry J. Kaiser Family Foundation, n.d.). As of January 2016, 32 states including the District of Columbia have adopted and implemented Medicaid Expansion, three states are still

considering adopting Medicaid Expansion and 16 are not adopting Medicaid Expansion at this time (The Henry J. Kaiser Family Foundation, n.d.).



NOTE: The June 2012 Supreme Court decision in *National Federation of Independent Business v. Sebelius* maintained the Medicaid expansion, but limited the Secretary's authority to enforce it, effectively making the expansion optional for states. 138% FPL = \$15,856 for an individual and \$26,951 for a family of three in 2013.

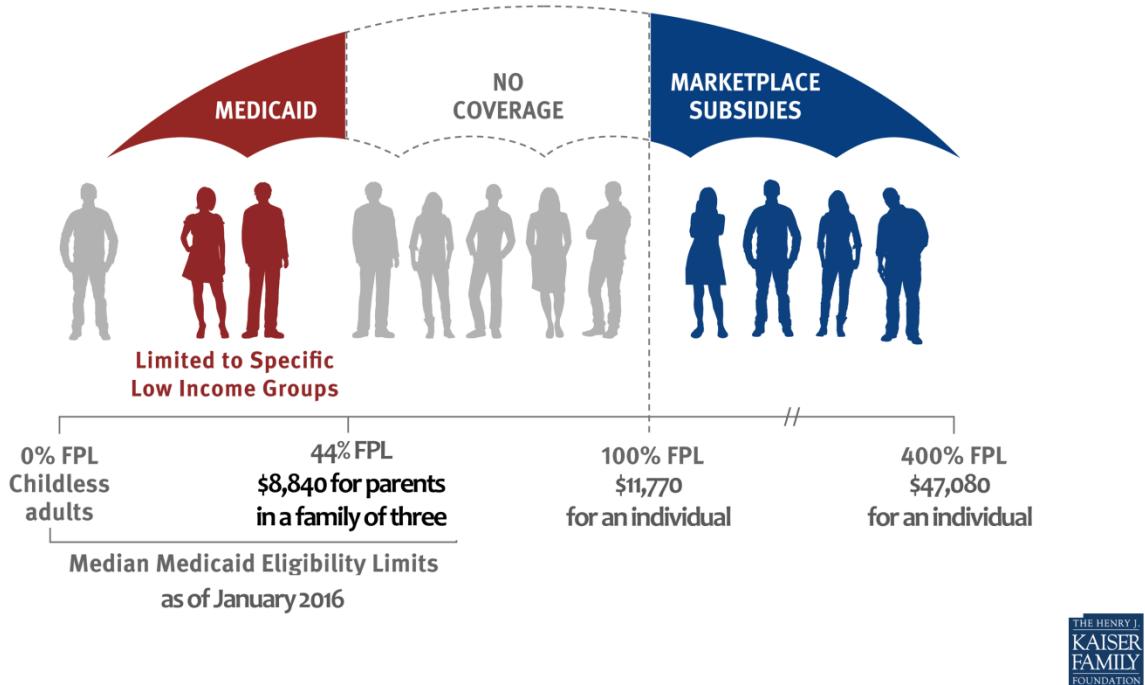
THE HENRY J.  
KAISER  
FAMILY  
FOUNDATION

**Figure 4.1.** The ACA Medicaid Expansion fills current gaps in coverage

Additional information regarding Medicaid Expansion can be found at the following websites:

- The Henry J. Kaiser Family Foundation State Health Facts: <http://kff.org/>
- US Centers for Medicare and Medicaid Services: <https://www.healthcare.gov/medicaid-chip/medicaid-expansion-and-you/>

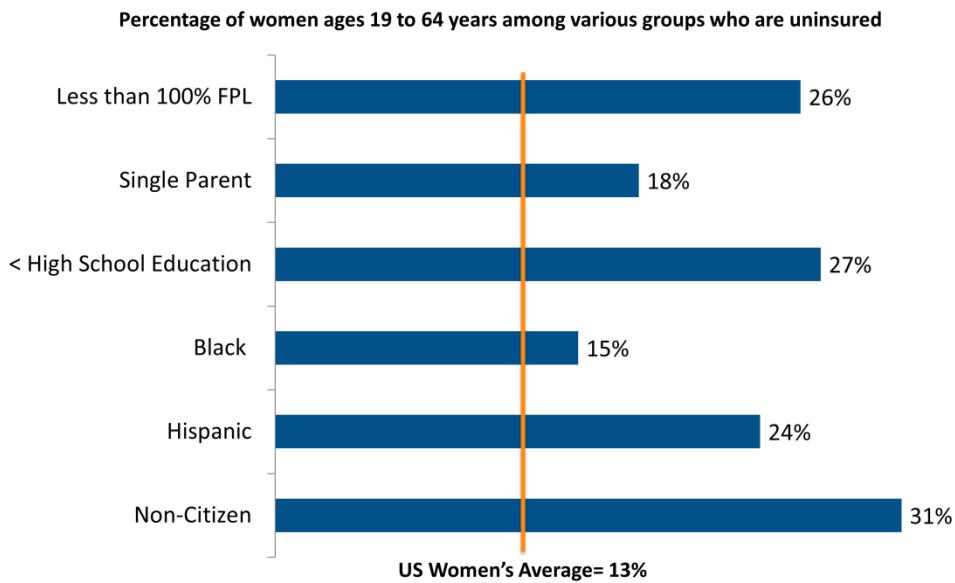
In states that did not adopt Medicaid Expansion, low-income “adults fall into a ‘coverage gap’ of having incomes above Medicaid eligibility limits but below the lower limit for Marketplace premium tax credits (Figure 4.2) (Garfield and Damico, 2016).



**Figure 4.2.** Gap in coverage for adults in states that do not expand Medicaid under ACA

#### **Affordable Care Act, Medicaid Expansion and Uninsured Women**

Even after implementation of the ACA and Medicaid Expansion (in some states), there are approximately 12.8 million women (ages 19 to 64) in the US that remain uninsured (The Henry J. Kaiser Family Foundation, 2016). Uninsured women have been found to have inadequate access to care and receive a lower standard of care within health systems that lead to poorer health outcomes (Kaiser Commission on Medicaid and the Uninsured, 2013). Women that are single parents, have incomes below 100 percent federal poverty level, have less than a high school education, are women of color or immigrants are at greatest risk of being uninsured (Figure 4.3) (The Henry J. Kaiser Family Foundation, 2016).



Note: The Federal Poverty Level (FPL) in 2014 was \$19,790 for a family of three.  
 SOURCE: Kaiser Family Foundation analysis of 2015 Current Population Survey, U.S. Census Bureau.



**Figure 4.3. Women at greatest risk of being uninsured, 2014**

A 2014 survey by The Henry J. Kaiser Family Foundation (2016) found that 47.0 percent of uninsured women indicated that insurance was too expensive, 13.0 percent were unemployed/work does not offer/not eligible through work, 8.0 percent tried to obtain coverage but were told they were ineligible, 7.0 percent were not eligible due to immigration status and 4.0 percent indicated that they did not need coverage. Of the 405,000 women in Maine, 48,600 (12.0 percent) were without health insurance coverage in 2014 (The Henry J. Kaiser Family Foundation, 2016).

### **Susan G. Komen Advocacy**

Susan G. Komen is the voice for the more than three million breast cancer survivors and those who love them, working to ensure that the fight against breast cancer is a priority among policymakers in Washington, D.C., and every Capitol across the country.

Each year, Komen works to identify, through a transparent and broad-based, intensive vetting and selection process, the policy issues that have the greatest potential impact on Komen's mission. This process includes the collection of feedback from Komen Headquarters leadership, policy staff, and subject matter experts; Komen Affiliates from across the country; advisory groups including the Komen Advocacy Advisory Taskforce (KAAT), Advocates in Science (AIS), and Komen Scholars; and other stakeholders with a vested interest in breast cancer-related issues.

The selected issues are the basis for Komen's state and federal advocacy work in the coming year. While the priority issues may change on an annual basis, the general focus for Komen's advocacy work is to ensure high-quality, affordable care for all, though access to services and an increased investment in research to ensure the continued development of the latest

technologies and treatments. For more information on Komen's current Advocacy Priorities, please visit: <http://ww5.komen.org/WhatWeDo/Advocacy/Advocacy.html>.

All of Susan G. Komen's priorities were included in the health reform. This includes the following (Susan G. Komen, 2013):

- mammography as a required benefit
- breast cancer education for young women
- access to clinical trials and patient navigation
- elimination of pre-existing condition exclusions, lifetime
- lifetime out of pocket spending limits

Access to good health care influences health outcomes for women. Research has shown that there is an increased incidence of mammography screenings in women that have Medicaid compared to those who were not able to enroll in Medicaid (Komen, 2013a). The Affordable Care Act should allow more women access to screening, education about risk reduction and increase overall access and affordability of services. The National Breast and Cervical Cancer Early Detection Program will help make these services accessible for women that are have a lower income or are underinsured. However, there will be instances where women will need additional assistance to help cover costs and grant funding will be beneficial to help bridge these gaps.

Future issues may occur in spite of the benefits of the Affordable Care Act. There will still be women that choose not to enroll in Medicaid even though they could qualify, women that are exempt for various reasons, undocumented immigrants, and those who choose to pay the penalty and remain uninsured (Komen, 2013d). Women that encounter these obstacles or make the decision not to obtain insurance will be difficult to reach.

Overall, the Affordable Care Act is intended to increase access to health care and breast health services for women. However, according to the CDC, "even with adequate health insurance, women will still face substantial barriers to obtain screening such as geographic isolation, limited health literacy or self-efficacy, lack of provider recommendations, inconvenient times to access services, and language barriers (CDC, 2010)." Due to the challenges women may face, the NBCCEDP has designed new means of outreach focused on behavioral choices, organizational, community and policy level factors that influence those choices (CDC, 2014).

### **National Breast and Cervical Cancer Early Detection Program**

The United States Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990, which directed the Centers for Disease Control and Prevention (CDC) to create the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) to improve access to screening (CDC, 2015a). NBCCEDP is a federal-state partnership which requires states to satisfy a 1:3 matching obligation (\$1 in state funds or in-kind funds for every \$3 in federal funds provided to that state) (CDC, n.d.). Currently, the NBCCEDP funds all 50 states, the District of

Columbia, five US territories, and 11 American Indian/Alaska Native tribes or tribal organizations, to provide the following services to women (CDC, 2015a; CDC, n.d.):

- Breast and cervical cancer screening for women with priority to low-income women.
- Providing appropriate follow-up and support services (i.e., case management and referrals for medical treatment).
- Developing and disseminating public information and education programs.
- Improving the education, training and skills of health professionals.
- Monitoring screening procedure quality and interpretation.

To be eligible to receive NBCCEDP services, uninsured and underinsured women must be at or below 250 percent of the federal poverty level and between the ages of 40 to 64 for breast cancer screening (CDC, 2015a; CDC, n.d.). Uninsured women between the ages of 50 and 64 who are low-income (up to 250 percent federal poverty level) and who have not been screened in the past year are a priority population for NBCCEDP (CDC, n.d.).

While federal guidelines are provided by the CDC, there are some variations among states, tribal organizations and territories (CDC, 2015b):

- Program funding, clinical costs and additional eligibility guidelines vary by state, tribal organization and territory which influence the number of services that can be provided.
- Flexibility of the program allows each state, tribal organization and territory to adopt an operational model that is appropriate for their respective public health infrastructure and legislative policies.

Since the launch of the program in 1991, NBCCEDP has served more than 4.8 million women providing over 12 million breast and cervical cancer screening services that has resulted in more than 67,900 women being diagnosed with breast cancer (CDC, 2015a).

Congress passed the Breast and Cervical Cancer Prevention and Treatment Act in 2000 to provide states the option to offer Medicaid coverage for breast cancer treatment for women who were diagnosed when receiving services through from the NBCCEDP (CDC, 2015a). To date, all 50 states and the District of Columbia have approved provision of Medicaid coverage for cancer treatment; therefore, providing low-income, uninsured and underinsured women coverage from screening through completion of treatment (CDC, 2015a). Congress expanded this option 2001, with the passage of the Native American Breast and Cervical Cancer Treatment Technical Amendment Act, to include eligible American Indians and Alaska Natives that receive services by the Indian Health Service or by a tribal organization (CDC, 2015a). State Comprehensive Cancer Control Plans (2015c) can be located at the following link:  
[http://www.cdc.gov/cancer/ncccp/ccc\\_plans.htm](http://www.cdc.gov/cancer/ncccp/ccc_plans.htm).

## **Connecticut**

### **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)

<b>Breast and Cervical Cancer Medicaid Treatment Options</b>
Option1: 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 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 Assisters (NIPAs) inform individuals of the various plan options for which they are eligible. NIPAs guided individuals through the entire enrollment process.

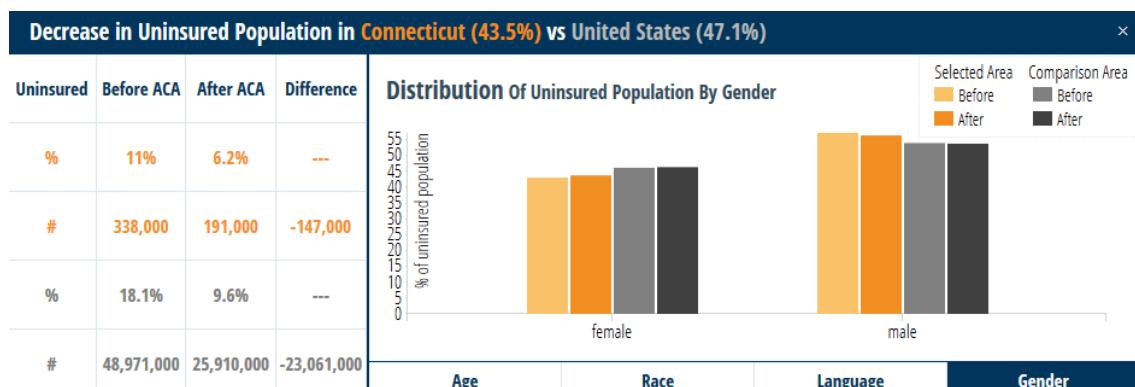
By late spring 2014, noticeable changes had been reported by health care providers. Overall, most providers considered implementation of the ACA to be an improvement to health care. Project directors from many Affiliate-funded screening programs reported an increase in patients with health insurance. 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 they 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
<b>Connecticut</b>	136,151
<b>Fairfield County</b>	26,954
<b>Hartford County</b>	39,925
<b>New Haven County</b>	44,704
<b>New London County</b>	7,872
<b>Litchfield County</b>	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 NCCEDP-funded program. If they were

screened and diagnosed elsewhere (e.g. by a free mammogram provided by a Komen 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.

### **Maine**

In the State of Maine, the NBCCEDP is known as Maine's Breast and Cervical Health Program and is administered by the Maine Center for Disease Control and Prevention, DHHS. From July 2009 to June 2014, Maine's Breast and Cervical Health Program provided 11,315 breast cancer and cervical cancer screening and diagnostic services to women. The program provided 18,155 mammograms that resulted in 1,738 women receiving an abnormal result and 133 women being diagnosed with breast cancer (NBCCEDP Minimum Data Elements, 2015). To find out more information about getting screened and eligibility, contact the Breast and Cervical Health Program (1-800-350-5180).

### **State Comprehensive Cancer Control Plan**

Maine's comprehensive cancer control plan for 2011-2015

([http://www.maineccancerconsortium.org/Cancer+Plan\\_2011-2015\\_Final\\_10.14.10\\_Bookmarked.pdf](http://www.maineccancerconsortium.org/Cancer+Plan_2011-2015_Final_10.14.10_Bookmarked.pdf)) includes the following goals and objectives specific for breast cancer:

Goal:

- Promote, increase, optimize, and support the use of high quality cancer screening tests and follow-up services in Maine for all detectable cancers.
  - Objective 1. Increase to 79.5 percent the proportion of Maine women ages 40-49 who have received a mammogram within the past two years by 2015. (Baseline: 78.6 percent, BRFSS, 2008)
  - Objective 2: Increase to 86.0 percent the proportion of Maine women ages 50 and older who have received a mammogram within the past two years by 2015. (Baseline 85.1 percent, BRFSS, 2008) †
    - Strategy1: Work with healthcare providers and community-based organizations to use the Maine Breast and Cervical Health Program (MBCHP) in order to increase screening mammography rates.
    - Strategy: Collaborate with partners statewide to raise population awareness of breast cancer and the importance of routine screenings.

For more information regarding Maine's comprehensive cancer plan please visit:  
<http://www.maineccancerconsortium.org/cancer-plan/>.

Based on 2015 data, of the estimated 121,000 total number of uninsured in Maine, 15.0 percent are Medicaid eligible, 33.0 percent are eligible for tax subsidies and 32.0 percent are ineligible for financial assistance due to income, employer sponsored insurance offer or citizenship status (Garfield et al., 2015).

Some of the ways that the ACA has affected Maine over the past five years include (US Department of Health and Human Service, 2015b):

- Making health care more affordable and accessible through Health Insurance Marketplaces.
  - In Maine, 74,805 consumers selected or were automatically re-enrolled in health insurance coverage.
- Reducing the number of uninsured.
  - The number of uninsured in Maine decreased to 11.6 percent (2014) from 16.1 percent (2013).
- Removing lifetime limits on health benefits and discrimination for pre-existing conditions resulting in cancer patients not having to worry about going without treatment.
  - In Maine, over 172,000 women no longer have to worry about lifetime limits on coverage.
- Making prescription drug coverage more affordable for those on Medicare.
  - In Maine, Medicare covered individuals have saved nearly \$45,844,329 on prescription drugs.
- Covering preventive services, such as screening mammograms, with no deductible or co-pay.
  - In Maine, over 138,000 women received preventive services without cost-sharing.
- Providing increased funding to support health care delivery improvement projects that offer a broader array of primary care services, extend hours of operations, employ more providers and improve health care facilities.
  - Maine received \$66,454,348 under the health care law.

As of January 2016, Maine has not adopted Medicaid Expansion. In Maine, 24,000 people fall within the "coverage gap". Of those in the "coverage gap", 100 percent are adults without dependent children, 58.0 percent are female and 88.0 percent are part of a working family (the individual, or a family member, is employed but still living below the poverty line) (Note: individuals can be classified in more than one category) (Garfield and Damico, 2016). If Maine would have adopted Medicaid Expansion, an estimated 44,000 uninsured adults (including those in the coverage gap) would have been eligible for Medicaid coverage (Garfield and Damico, 2016).

## **Massachusetts**

### **NBCCEDP Women's Health Network**

The Women's Health Network (WHN) is a public health program located at the Massachusetts Department of Public Health. A major component of the network is the Care Coordination Program, which provides breast and cervical cancer screenings to underserved communities using patient navigation and case management as key strategies (Table 3.1). Women eligible for WHN can access breast cancer screenings and care coordination. Education about WHN is extended to the general public and health professionals. WHN care coordination services are reserved for women ages 40-64 and are considered to be at or below 400 percent of the federal poverty level. Uninsured patients may be fully covered to receive medical services if they fall below 250 percent of the poverty level. Uninsured residents, in most circumstances, become eligible for emergency Medicaid if diagnosed with breast cancer at any facility.

WHN's primary goal is to aid in the delivery of optimum care by educating patients about their options, assisting them with navigation to access all appropriate preventative services and continuing care, including diagnoses and treatment as needed to achieve optimal outcomes.

**Table 3.1.** Women's Health Network Centers

An estimated 12,000 individuals may access services from 25 centers statewide.

<b>Women's Health Network</b>	
Contractors	11
Community Health Centers	9
Hospital Based Programs	2
Community-based Organizations	3

## **State Cancer Coalition**

Plans to reduce cancer burden are directed by the Massachusetts Comprehensive Cancer Prevention and Control Network (MCCPCN). More than 100 public health professionals and survivors from medical and community-based institutions are active members of MCCPCN. MCCPCN committees are involved in reducing breast cancer late-stage diagnosis, ensuring quality of care and increasing services for patients.

Komen New England and the Massachusetts Comprehensive Cancer Prevention and Control Network (MCCPCN) share the goal of reducing the breast cancer burden in Massachusetts. MCCPCN leads efforts with more than 100 public health professionals, survivors, and community-based institutions. The Affiliate supports the MCCPCN by participating in the Secondary Prevention task force proposing recommendations for the 2017-2021 Massachusetts State Cancer Control Plan as well as other committees led by the group as appropriate.

**Table 3.2.** Massachusetts Comprehensive Cancer Control Plan, 2012-2016 Goals to reduce breast cancer burden

<b>Objective 1:</b>	<b>Objective 2:</b>
By 2016, increase the percentage of Massachusetts women ages 50–74 who have	By 2016, decrease the rate of Non-Hispanic White and Non-Hispanic Black/African-

had a mammogram in the past two years to 90 percent.	American women diagnosed with late-stage (regional and distant) breast cancer to 35 per 100,000.
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Source: Massachusetts Comprehensive Cancer Control Plan

### Affordable Care Act

Massachusetts is recognized nationally for leading the health care reform model in 2006. Already having some of the highest number of residents insured, Massachusetts looked to improve health care for residents. The health insurance marketplace approved by the federal government is managed by the Health Connector. Medical insurance available through Mass Health (Medicaid in Massachusetts) was expanded to an estimated 220,000 individuals. Residents at or below 400 percent of the federal poverty level have also been extended options to purchase subsidized health plans. Residents may determine eligibility using the Health Connector website or by accessing a Health Connector facility. Health Connector has trained navigators to assist residents in making informed decisions to obtain health insurance. Estimates provided by Massachusetts Department of Public Health and Health Connector report between 96.2 to 97 percent of residents were insured.

Overall, women had various options to enroll in health insurance plans and access to breast health and breast cancer treatment in Springfield, Worcester and Boston. A further assessment is necessary to understand the reasons why women do not elect to enroll in an insurance plan.

To an extent, free and low-cost early detection services were available to low income residents who were not enrolled in an insurance plan. Breast health resources funded by state and private foundations provided financial support for the uninsured in need of early detection services. Providers and breast cancer survivors made suggestions about how these services should be advertised to uninsured women. The mobile mammography van is in high demand to screen low income and uninsured women in the Boston area. Based on feedback from providers in health systems in the Springfield and Worcester areas, there was interest in mobile mammography vans as they may be beneficial to improving access to care.

### New Hampshire and Vermont

#### National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

More women are able to access treatment in Vermont and New Hampshire because both states have agreed to expand Medicaid programing. This will have a positive impact allowing more women to access treatment in the service area and reduce the burden of breast cancer.

New Hampshire and Vermont are designated as Option Two in reference to the State action on Medicaid expansion. This means that, “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 women’s screening may not have been paid directly from NBCCEDP funds (Komen, 2013c).”

### **New Hampshire**

In conjunction with the Breast and Cervical Cancer Program (BCCP), New Hampshire utilizes the “Let No Woman Be Overlooked” program to provide breast health outreach and education as well as free or low-cost screening for early detection. This is part of the state initiative to reduce the burden of breast cancer (and cervical cancer) for women living in New Hampshire. Participants must meet financial guidelines in order to qualify for the program with the target population being uninsured or underinsured women. These screenings are available at numerous hospitals and health clinics across the state.

Women that receive a cancer diagnosis or require additional diagnostic services will be referred to other sources for financial assistance to pay for services required. Women must meet guidelines set by the federal and state in order to qualify. This is administered through the Let No Woman Be Overlooked program. However, if the criteria are not met, some funding is provided through resources such as grants from organizations, including Vermont-New Hampshire. This helps assist with costs not covered and allows for greater access to care.

Vermont-New Hampshire does not work directly with Let No Woman Be Overlooked program, however the Affiliate does partner with community health centers and hospitals in the service area by providing grant funding to assist with the costs of breast cancer services not covered by the NH BCCP. These partnerships are continually growing in order to provide the greatest amount of assistance for women making their way through the continuum of care, to achieve breast health awareness and improve treatment outcomes. The Affiliate plans to strengthen the relationship with the New Hampshire BCCP program, Let No Woman Be Overlooked, by discovering areas of need and increasing collaboration over the next four years. As these partnerships expand, more women will have access to the care they need and receive information about making better health choices.

### **Vermont**

Ladies First is the Breast and Cervical Cancer Program for Vermont that offers free breast, cervical, cholesterol, blood pressure and diabetes screenings. This program works in conjunction with Green Mountain Care (Medicaid) to help low-income, uninsured, or underinsured women access free or low-cost breast cancer screenings and treatment. Services are available through a woman's own physician in most cases and will cover repeat mammograms, ultrasounds and biopsies (Ladies First, 2014). Additionally, this program will pay for transportation costs as well as interpreter services. Ladies First is federally funded through the National Breast and Cervical Cancer Program and by the State of Vermont Health Department.

In order to access general Medicaid in Vermont, minimum eligibility guidelines determined by the State and Green Mountain Care must be met. In the event that a woman that is not currently receiving or eligible for general Medicaid is diagnosed with breast cancer, she will then be considered for coverage. Under the Medicaid Treatment Act passed in 2010, women who are found to have breast cancer or pre-cancerous conditions may obtain Medicaid coverage to pay for their treatment. Minimum guidelines for this program are breast cancer or pre-cancerous

diagnosis, under age 65, and not eligible for Medicaid (Vermont Department of Health, (2012). *Breast Cancer in Vermont*). This means that even women who do not typically qualify for general Medicaid but receive a breast cancer diagnosis, will obtain financial assistance to help cover the cost of treatment.

In 2015, Vermont-New Hampshire granted funds to Ladies First and has partnered with community health centers and hospitals in the service area by providing additional funding to assist with the costs of breast cancer services not covered by the NCCEDP. Other partnerships are continually growing in order to provide the greatest amount of assistance for women making their way through the continuum of care in order to achieve breast health awareness and improve treatment outcomes.

The Affiliate plans to strengthen the relationship with each state's Breast and Cervical Cancer Program over the next four years by discovering areas of need and increasing collaboration. As these partnerships expand, more women will have access to the care they need and receive the information about making better health choices.

### **State Comprehensive Cancer Control Coalition New Hampshire**

In New Hampshire, the Comprehensive Cancer Collaboration is actively working towards their objective of increasing the number of women getting mammography screening. They acknowledge the importance of early detection and work in collaboration with the NH BCCP, Let No Woman Be Overlooked, to continue to offer free or low-cost screening to women. Specified objectives outlined in the New Hampshire State Comprehensive Cancer Control Plan for 2010-2014 are as follows: Increase the percent of women age 40 and older in the lowest income and education levels who report receiving recommended breast cancer screenings to 68.0 percent and 69.0 percent, respectively. Baseline: 66.4 percent and 66.8 percent (2008 New Hampshire Behavioral Risk Factor Surveillance System). Enhance existing and developing new strategies to advocate for continued funding for the NH BCCP as well as Medicaid treatment options at the state and federal levels (CDC, 2014).

Vermont-New Hampshire has been in contact with the NH CCC, receives regular newsletters and updates from the organization as well as attending meetings when possible. Three common interests are fostering communities and systems that reinforce healthy lifestyles, detecting cancer at its earliest stage, and optimizing quality of life for those affected by cancer. Recognizing the common goals and shared mission of the two groups, the Affiliate aims to increase involvement with the NH CCC in the future.

### **Vermont**

In Vermont, the Comprehensive Cancer Control Plan was federally funded by the Center for Disease Control. This resource is known as Vermonter's Taking Action Against Cancer and is facilitated by the Vermont Department of Health ([www.healthvermont.gov](http://www.healthvermont.gov)). Currently, the objectives for breast cancer are related to risk reduction, early detection, access, quality of life and end of life care, and advocacy for improved treatment and care. Vermont-New Hampshire

has recently become a member of the Vermonter's Taking Action Against Cancer program, recognizing the common goals and shared mission of the two organizations.

The goals for the Vermont Comprehensive Cancer Plan that relate to breast cancer are as follows (healthvt.gov, 2014):

- Increase early detection of breast cancer among Vermont women.
- Increase the percentage of women age 50-74 getting mammograms within the past two years.
- Reduce the rate of breast cancer diagnosed at an advanced stage among women age 50 and over (# per 100,000).
- Reduce the rate of breast cancer diagnosed at an advanced stage among women age 40-49 (# per 100,000).
- Increase the percentage of adults who receive recommended breast cancer screening (Women age 50-74).

#### *Breast Cancer Strategies*

- Promote nationally recognized cancer screening guidelines to the health care provider community and to the public
- Encourage health care providers to utilize evidence-based practices to increase cancer screening percentages such as provider and client reminder and recall systems.
- Educate health care providers and the public about low and no-cost cancer screening resources for low income Vermonter's.
- Conduct provider education and training to increase awareness of the need for appropriate breast cancer screening and increase awareness of the need for risk assessment in discussing breast cancer screening with women age 40-49.

#### **Affordable Care Act (ACA)**

Vermont agreed to Medicaid expansion in order to decrease the number of uninsured residents. Vermont Health Connect is the marketplace for Vermonters to buy health insurance since the implementation of the Affordable Care Act. Vermont opted to create a unique way of implementing the system by creating the Vermont Health Connect program ([info.healthconnectvermont.gov](http://info.healthconnectvermont.gov)).

It is difficult to estimate the number of uninsured Vermont and New Hampshire residents following the implementation of the Affordable Care Act. Theoretically, the Affordable Care Act will decrease the utilization of the Vermont and New Hampshire NBCCEDP funds as more women gain insurance coverage. However, there will be a continued need for the NBCCEDP as the Affiliate is aware of the numerous women that will not obtain the health care provided by the ACA. Gaps in the continuum of care will continue to exist and require supplementation from other programs.

The implications of the Affordable Care Act for the Affiliate are difficult to predict at this time. Preliminarily, the Affiliate has had one grant recipient request to alter the way funds are utilized

in their organization as a result of the ACA. A small amount of funding was moved from screening to diagnostics in this instance. The Affiliate predicts these requests will occur more often in order to address the changing needs that are on the horizon. This is a transition period in which the Affiliate will make appropriate adjustments in order to meet the needs of the women in the service area.

The Affordable Care Act has only recently gone into effect and may change over the next four years with the changes in political leadership. Some concerns have been voiced about the potential negative impact these changes could have on women accessing the continuum of care. As more women gain access to care, the health care system may become overwhelmed by the increasing need. During the qualitative assessment of target communities, these variables will be explored. This will help identify the barriers that women may face and to generate dialogue among professionals and Affiliate partners in order to overcome these issues.

Conversely, more women will have insurance coverage and access to care. This will be free from the previous restrictions of exemption due to pre-existing conditions and caps on out of pocket spending. The Affordable Care Act policy has both strengths and limitations that will continue to be exposed as the plan rolls out. Vermont-New Hampshire will continue to play a vital role in awarding grants that will assist breast health programs in bridging barriers that may result from this new policy.

### **Affiliate's Public Policy Activities**

Over the next four years the Affiliate will focus on Susan G. Komen's advocacy priorities including but not limited to:

- Advocate for expanded federal funding for breast cancer research conducted at the National Institutes of Health (NIH), National Cancer Institute (NCI), and Department of Defense (DOD) to discover and deliver the cures.
- Support federal and state funding for the Centers for Disease Control and Prevention's (CDC) National Breast and Cervical Cancer Early Detection Program (NBCCEDP) to ensure all women have access to potentially lifesaving breast cancer screening.
- Advocate for policies to improve insurance coverage of breast cancer treatments and screening, specifically pertaining to increased access to drug therapies and limiting out of pocket costs for diagnostic mammography.
- Evaluate state and federal policies to increase awareness, education and access to clinical trials for all patient populations.

Vermont-New Hampshire has not been active in the public policy at the federal or state level. The Affiliate will explore the possibility of recruiting a public policy intern from one of the local colleges or universities with the intention of increasing public policy outreach in Vermont and New Hampshire, as well as cultivating new partnerships. Over the course of the next four years, further attention will be directed to the target communities in order to amend the identified areas of need.

### **Rhode Island**

In recent years, public policies pertaining to breast cancer have undergone substantial changes that will affect at-risk women across the United States. States have responded differently to the public policy developments concerning access to services within the breast cancer continuum of care (screening, diagnostic, treatment and survivorship care); therefore, women are dependent on their state's agenda and action on health care reform. This section of the state report will focus on the following public policies that affect breast cancer care in the state: National Breast and Cervical Cancer Early Detection Program, State Comprehensive Cancer Control Plan, the Affordable Care Act and Medicaid Expansion.

### **National Breast and Cervical Cancer Early Detection Program (NBCCEDP)**

In the State of Rhode Island, the NBCCEDP is known as Rhode Island's Women's Cancer Screening Program and is administered by the Rhode Island Cancer Control Program, Rhode Island Department of Health. From July 2009 to June 2014, Rhode Island's Women's Cancer Screening Program provided 16,405 cancer and cervical cancer screening and diagnostic services to women. The program provided 13,586 mammograms that resulted in 1,692 women receiving an abnormal result and 92 women being diagnosed with breast cancer (NBCCEDP Minimum Data Elements, 2015). To find out more information about getting screened and eligibility, contact the Women's Cancer Screening Program (1-401-222-4324).

Rhode Island's comprehensive cancer control plan for 2013-2018

(<http://health.ri.gov/publications/strategicplans/2013-2018RhodeIslandCancerPreventionAndControl.pdf>) includes the following goals, objectives and strategies:

#### **Goal:**

- Increase early detection of breast cancer among Rhode Islanders.

#### **Objective:**

- By 2018, increase the percentage of women ages 50 through 74 who have had a mammogram in the past two years to 94.0 percent (Baseline: 88.0 percent, Behavioral Risk Factor Surveillance System 2010).

#### **Strategies:**

- Educate women one-on-one and in group settings about the benefits of mammograms and ways to overcome barriers to screening.
- Use small media, such as videos, letters, brochures, and newsletters, to inform and motivate women to have a mammogram.
- Support and promote community-based events that encourage increases in breast cancer screening.
- Reduce structural barriers to screening by providing transportation, adjusting appointment hours, and providing screening in various settings.
- Support the state's Women's Cancer Screening Program, which provides routine screening and treatment for uninsured and underinsured women.

- Work with Rhode Island-based health insurers to address disparities in health insurance coverage in regard to screening versus diagnostic procedures for all preventive cancer screening services.

For more information regarding Rhode Island's comprehensive cancer plan please visit:

[http://health.ri.gov/programs/detail.php?pgm\\_id=10/](http://health.ri.gov/programs/detail.php?pgm_id=10/)

### Affordable Care Act

Based on 2015 data, of the estimated 55,000 total number of uninsured in Rhode Island, 49.0 percent are Medicaid eligible, 23.0 percent are eligible for tax subsidies and 27.0 percent are ineligible for financial assistance due to income, employer sponsored insurance offer or citizenship status (Garfield et al., 2015).

Some of the ways that the ACA has affected Rhode Island over the past five years include (US Department of Health and Human Service, 2015b):

- Making health care more affordable and accessible through Health Insurance Marketplaces.
  - In Rhode Island, 31,337 consumers selected or were automatically re-enrolled in health insurance coverage.
- Reducing the number of uninsured.
  - The number of uninsured in Rhode Island decreased to 9.4 percent (2014) from 13.3 percent (2013).
- Removing lifetime limits on health benefits and discrimination for pre-existing conditions resulting in cancer patients not having to worry about going without treatment.
  - In Rhode Island, over 147,000 women no longer have to worry about lifetime limits on coverage.
- Making prescription drug coverage more affordable for those on Medicare.
  - In Rhode Island, Medicare covered individuals have saved nearly \$45,245,581 on prescription drugs.
- Covering preventive services, such as screening mammograms, with no deductible or co-pay.
  - In Rhode Island, over 107,000 women received preventive services without cost-sharing.
- Providing increased funding to support health care delivery improvement projects that offer a broader array of primary care services, extend hours of operations, employ more providers and improve health care facilities.
  - Rhode Island received \$49,784,169 under the health care law.

### Medicaid Expansion

Rhode Island adopted Medicaid expansion, effective January 1, 2014. There are currently 55,000 total individuals who are uninsured and 27,000 are Medicaid eligible (The Henry J. Kaiser Family Foundation, 2016). The state Medicaid program is administered by the Rhode Island Executive Office of Health and Human Services and the Department of Human Services. Eligible residents with a yearly income up to 133 percent of the federal poverty level (FPL) may

be eligible to enroll in a Medicaid health plan (Health Source RI, n.d.). Adults (21 and older) may also be eligible to enroll in a health plan called Connect Care Choice ([www.eohhs.ri.gov](http://www.eohhs.ri.gov)). More information about Rhode Island's Medicaid program can be found at the following website: <https://healthyrhode.ri.gov/HIXWebI3/DisplayHomePage>.

# Qualitative Data: Ensuring Community Input

## Qualitative Data Sources and Methodology Overview

### **Connecticut**

#### **Methodology**

Komen 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 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 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.”*

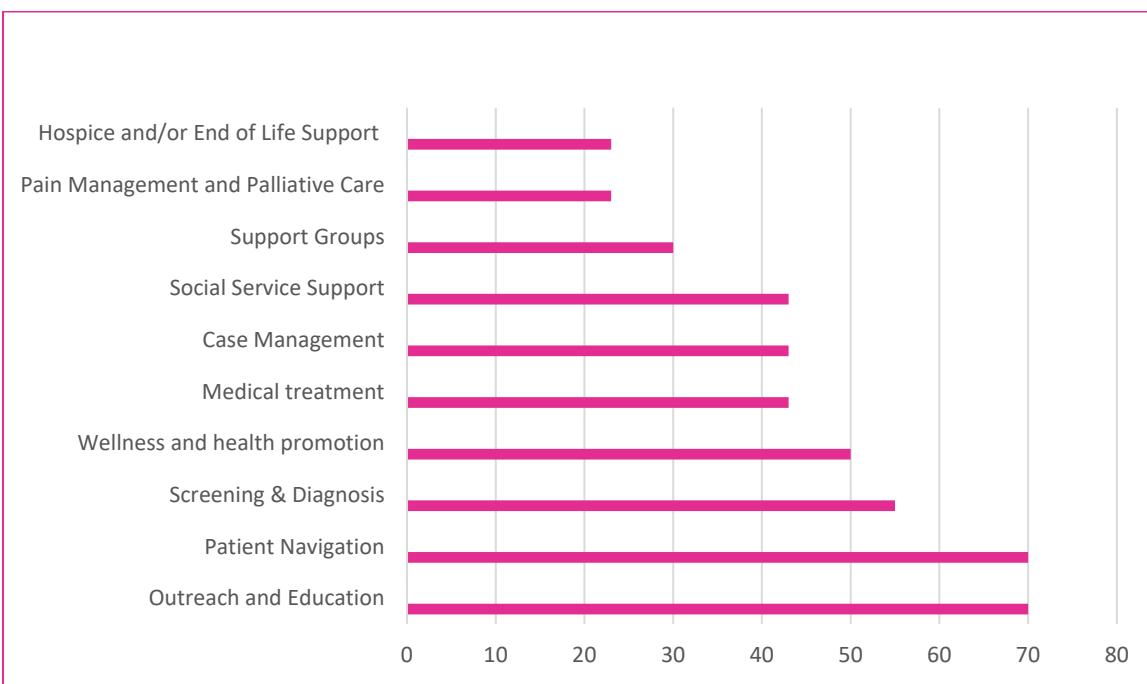
Some of the suggestions for getting more women engaged in screening included:

- 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 (%)

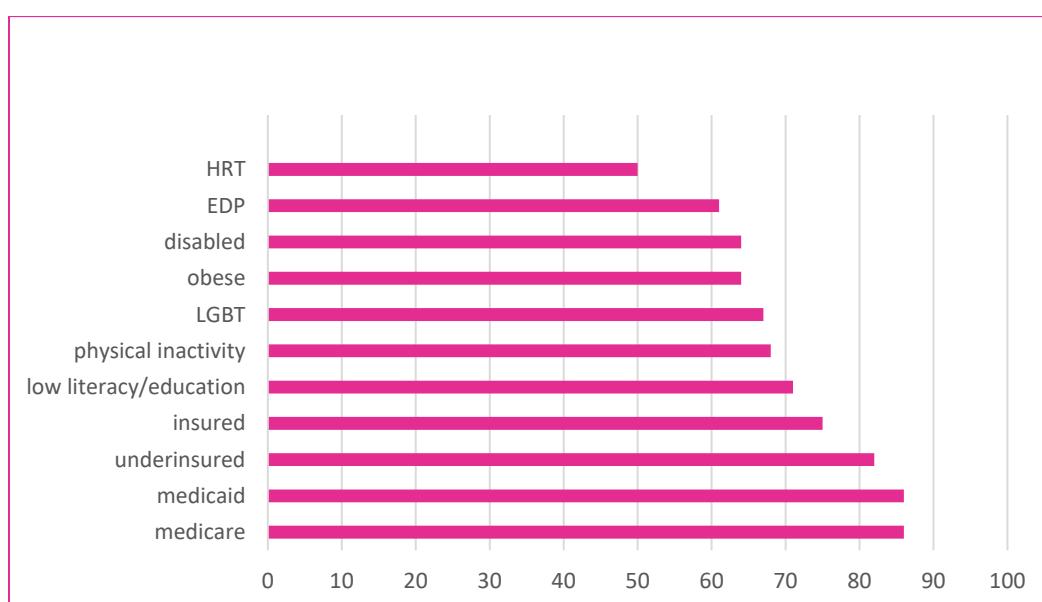
With respect to payment for services, 93 percent of the organizations are able to provide free or reduced cost screening services to uninsured and/or underinsured women and 93 percent accept Medicaid and Medicare payments. In addition, providers are able to accommodate

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 New England (50 percent), Cancer Care (46 percent) and Susan G. Komen National (31 percent).

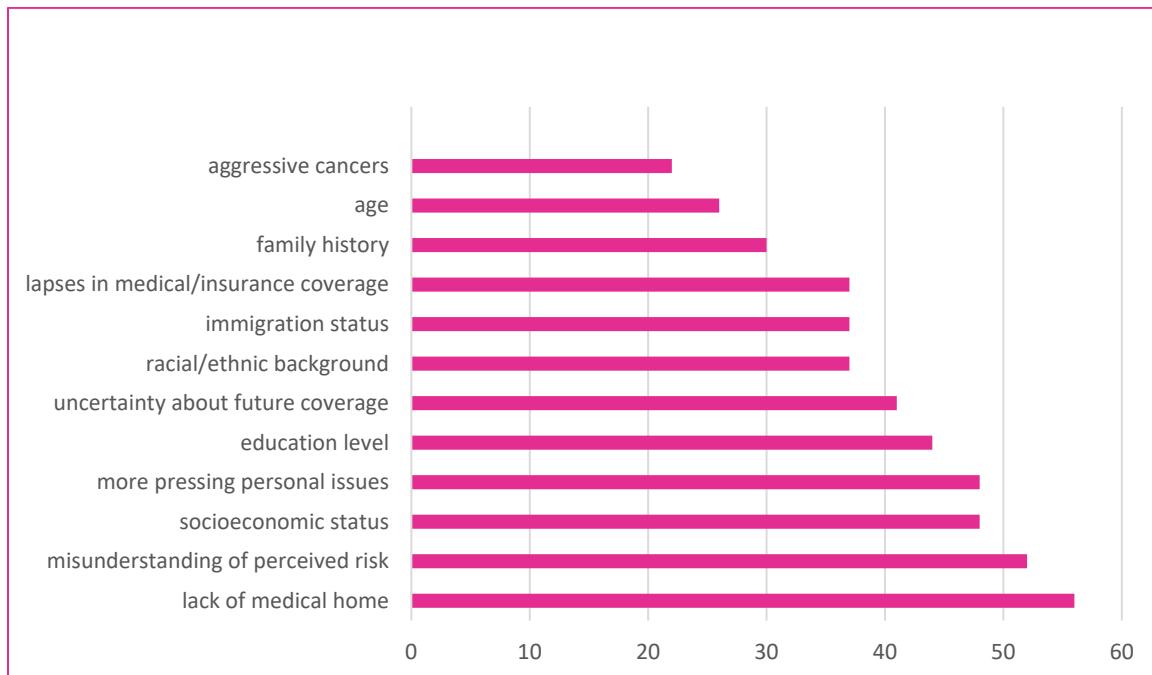
For women who screen positive, 43 percent of the providers reported that they provide breast cancer treatment to their patients. Of these providers, most (75 percent) provide financial coverage for the treatment. When asked whether they refer their patients to clinical trials for breast cancer, 36 percent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

## **Massachusetts**

### **Methodology**

Komen New England utilized the Quantitative and Health Systems Data Report to formulate questions to understand the overarching gaps and needs for early detection and treatment services in Massachusetts. The target communities, considered to be metropolitan areas of Massachusetts, are the home of renowned cancer centers. However, a health systems assessment showed that services varied within the target communities. This qualitative assessment takes a deeper look into the different levels of services available to each target community. Interviewers focused on questions related to equal access to quality preventative care and treatment in each target community.

When determining the data collection techniques that would be used for this assessment, the Affiliate considered several factors. The Affiliate took into consideration availability of staff and volunteers that would commit to collecting and analyzing data. As providers and breast cancer survivors would be the primary individuals recruited for interviews, travel and busy schedules were considered. Based on these factors, it was determined that using electronic surveys, focus groups and key informant interviews would allow the Affiliate to collect sufficient data to better understand needs and gaps in services. Women's health providers and cancer center medical staff from the Boston, Springfield and Worcester areas were recruited for participation in the Key Informant Interviews (KII).

Focus groups and key informant interviews were conducted by Affiliate community health staff. The interview questions were formulated based on gaps presented in the Quantitative and Health Systems Analysis Reports. Interviews were conducted both in person and by telephone. Field notes were taken by the interviewers and have been filed confidentially by the Affiliate. The number of Key Informant Interviews and Focus Groups was tracked and filed confidentially by Affiliate staff and volunteers.

To kick off the focus groups and individual interviews, Komen staff provided participants with the history of Susan G Komen and the Affiliate as well as details of the purpose of the Community Profile. Informing participants about confidentiality was the highest priority for the interviewer. Consent forms were provided to all participants. Those interviewed by phone were given electronic forms to complete and return to the Affiliate. Komen New England followed protocols to collect and file all data confidentially.

### **Sampling**

The Affiliate interviewed breast cancer survivors and providers from women's health practices located in Boston, Springfield and Worcester. Breast cancer survivors responded to recruitment announcements posted at local cancer centers and community-based organizations. In addition, former Komen-funded grant project directors involved in the Key Informant Interviews referred current and former patients. Health providers who served as key informants were identified using the Grants eManagement System used by Komen New England. Several key informants were recruited at random using the Directory of Licensed Mammography Facilities in Massachusetts. Breast cancer survivors were culturally diverse and had been diagnosed with

breast cancer at different stages (Stage 0-Stage IV). Survivors' ages ranged from 41 to 72 years old. Key informants included medical professionals from oncology and radiology departments. Among the oncology staff were patient navigators who, day in and day out, serve as advocates for patients. Key informants had interacted with patients at different points within the continuum of care. The data collected from each informant were vital to understanding breast cancer issues in the three target communities.

The sampling technique used to identify focus group participants was non-probability sampling, specifically snowball sampling. The Affiliate determined it was most appropriate to identify women that had been diagnosed with breast cancer within the past two years. Survivors that have most recently utilized early detection and treatment services would attest to the services being provided today. The technique used to select key informants was simple random sampling. Four providers from each target community were invited to participate in the interviews. Health providers from two major health systems in Springfield participated in the Key Informant Interviews. Participation was low in Worcester; only four health providers from two community health centers participated. In Boston, nine breast cancer health providers participated in the assessment.

### **Ethics**

The Affiliate selected interviewers that possessed the skills required to conduct the focus groups. Interviewers understood the importance of protecting the identity of participants and maintaining all documents confidentially. Consent forms and interview notes collected by interviewers were filed 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 to identify 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 were 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 KIIs and focus groups.

The survey data were provided in summary format through SurveyMonkey. 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. provider vs. breast cancer survivor).

## **Qualitative Data Findings**

### **Key Informant Interviews**

A total of 15 participants from Worcester, Springfield and Boston participated in the Key Informant Interviews. The interviews were conducted with patient navigators, oncology physicians and radiology personnel. Key informants provided the Affiliate with a deeper understanding of the services available to patients at different points in the continuum of care.

Questions addressed by key informants included:

- Their perception of how services were being delivered and whether services were utilized by all community members.
- Specific types of services such as screening programs for insured or uninsured, breast health education initiatives, and navigation services for patients from diagnosis into survivorship.

Listed below are the most common responses shared by providers in each target community.

### ***Target Community: Springfield***

#### *Breast Cancer Services Available*

- Early detection services are available at Federally Qualified Health Centers (FQHCs), primary care and breast wellness centers. *"Whether self-referred or physician-referred, women that require urgent care for a breast health concern are seen within one day at our breast cancer wellness center."*
- Residents have access to two cancer centers nationally accredited by the American College of Surgeons. Both strive to provide quality breast cancer care to all women. Patients have access to oncology, chemotherapy, radiation, survivorship and palliative care.
- Patient navigation was offered to women recently diagnosed with breast cancer at the breast wellness center.
- Supportive breast cancer services are also available to women diagnosed. *"There is one program that offers some case management and support to Latina women."*

#### *Access to Care*

- Community health workers in several community health centers in Springfield have and continue to enroll women into the state Medicaid program providing they meet eligibility criteria. *"Having health insurance is a state mandate, however, there are small pockets of communities that are eligible, but have not yet enrolled".*
- Though the breast health and breast cancer services were readily available, accessing the services posed challenges to Springfield residents. Key informants did not play a role in conducting targeted outreach to women in low income neighborhoods. Providers who had a presence at community health events did not possess the skill to educate women with limited English.
- Providers expressed concerns about patients with a late-stage breast cancer diagnosis.

### **Barriers to Care**

- “Women from the Vietnamese and Russian communities may not have sufficient resources to obtain breast cancer education and care.”
- “Programs that have funded unique needs in our community have not been well funded. Our health care teams offer breast cancer services with assistance from medical interpreters.”

### **Target Community: Worcester**

#### **Access to Care**

- FQHCs provide early detection and care coordination to a large Hispanic/Latino population. New patients being served represent individuals from African and Middle Eastern countries. “Our health team offers health awareness and medical services to new immigrants in our communities. Care coordinators build trust with the families to provide care.”
- “Community members have shared fears of taking the first steps to access early detection services. Through grant funds our navigators conducted outreach and offered guidance into early detection services, helping women better understand screenings and abnormal findings. Grant funds to sustain those programs are hard to come by.”

#### **Barriers to Care**

- Collaborative efforts between cancer centers and community-based health centers can be strengthened. “Coordinators and navigators find challenges reaching out to minority communities. Worcester is home to many immigrant families; we are learning new strategies to educate these individuals. Breast cancer health is one among many other health concerns we educate them on.”
- Outreach educators and navigators are not specific to breast health.

### **Target Community: Boston**

#### **Breast Cancer Services**

- This community is home to well-known breast cancer medical centers. Women diagnosed with breast cancer have access to two nationally recognized medical centers that provide high quality treatment. “Women who receive a breast cancer diagnosis, especially at a late-stage, often consider seeking second opinions from renowned cancer teams here in Boston.”
- Mobile Mammography Services are offered to women in various neighborhoods throughout Boston. “We have the only mobile mammography unit in the state. Our focus is to fill the gap in care and provide underserved women with quality breast cancer services.”

#### **Access to Care**

- Services are available to women throughout Boston. Health care providers are cognizant of the gaps to accessing care in lower income communities. “Our health providers make all attempts to be present at community health events (health fairs) to educate our residents about the availability of services.”

- Women's Health Network (WHN) offers care coordination to women insured, underinsured and the few uninsured. Community members and providers alike may need to be educated on how women access services provided by WHN.

#### *Barriers to Care*

- Concerns about access to care for Black/African-American women were echoed by four health care providers. Examples of barriers faced by some Black/African-American women in Boston were the inability to afford basic health insurance, limited early detection education and fear of diagnosis.
- Providers generally were not informed of outreach health efforts that were taking place in the community. *"Implementation of evidence-based programs that have strong outreach components is crucial to deliver services to African-American women in all Boston neighborhoods."* One provider disclosed, *"Outreach needs to extend beyond the local community center, it needs to extend into the schools in which their children attend and into the workplace."* Few providers based in area hospitals collaborate with local health centers to reach women in medically underserved areas.
- Accessing treatment after a breast cancer diagnosis posed unique challenges to Black/African-American and Latina women. Black/African-American women experienced some delays as they had challenges navigating their way into the cancer care system. Similarly, Latina women experienced language barriers that prevented them from understanding the cancer care system.
- Patients with limited English-speaking skills often do not have the opportunity to effectively discuss cancer-related concerns with their cancer care provider team. Providers preferred to have in-person interviewers over use of language lines. The providers believed that most health care systems in Boston had sufficient interpreters at the cancer centers.
- All women with lower income before diagnosis struggle to make ends meet and obtain care. In many cases, women of lower socioeconomic status prioritized working in order to save money before entering the cancer care system.
- Black/African-American and Latina women presented struggles with special diets while in treatment.

#### **Summary of Access to Breast Health Services**

Breast health and breast cancer services were made available to all residents in the target communities. Barriers were found within each community, delaying or preventing access to women of lower socioeconomic status, uninsured and underinsured women, and Black/African-American, Latina and women of other ethnic minority groups with a limited comprehension of the English language. Furthermore, challenges accessing care were also found in women who were uninsured and women with basic insurance coverage. Uninsured women did not access breast health services unless a concern led them to seek urgent care services. Underinsured women accounted for those that had basic insurance coverage for routine exams, excluding any diagnostic care. Uninsured adults, ages 18-64, accounted for 6.3 percent of the population in Boston, 6.2 percent in Springfield and 6.8 percent in Worcester (Table 4.1) (American Community Survey 2013).

**Table 4.1.** Rates of uninsured population, 18-64 years of age, in the target communities identified by Komen Mass as having high incidence, late-stage diagnosis and deaths due to breast cancer.

Target Community	Total population age 18-64	Estimated number of uninsured	Percentage of uninsured
Boston	460,896	29,261	6.3%
Springfield	152,634	9,494	6.2%
Worcester	120,114	8,215	6.8%

Health Insurance Coverage, 2011-2013 American Community Survey (ACS)

Women who were enrolled in a health insurance plan with limited or no interruptions were most likely to seek routine screenings. Improving the access to care was a common topic of discussion among the key informants. Informants advocated for increasing awareness of early detection services, breast cancer and navigation programs. Health providers believed improved outreach within each target community would encourage more screening, leading to early stage diagnosis of breast cancer. Providers also commented on the effectiveness and benefits of navigation for patients through the entire continuum of care. Community health organizations and cancer centers located in Springfield reported success with navigation services in place for recently diagnosed patients. It is important to note that these reports came from providers that served patients with private insurance and patients with limited barriers to accessing cancer services. Provider reports revealed challenges promoting and providing navigation services to low income patients and patients with limited English proficiency. These challenges, reported by a Springfield based provider, were worrying, as disadvantaged patients often did not remain on a steady path through the continuum of care and into survivorship. Though navigation services were available in Boston and Worcester, gaps were still present. Participants living in metro areas of Boston and Worcester reported navigating the health systems “*was at times frustrating and at times, intimidating*”. Navigators often had caseloads of 200-300 patients. While some medical centers had the capacity to provide navigation to all recently diagnosed patients, others struggled with limited funding for personnel. In most cases the navigation services in hospitals in each target community were found to offer services to male and female patients with various cancer types. Limited cancer centers offered navigation services that met the unique needs of breast cancer patients. One Boston-based provider noted that implementation of a culturally tailored navigation program would be crucial to supporting their diverse population. However, at the time, this medical center simply did not have the capacity to develop plans and financially support such a program. This medical center, among many others, continues to seek alternative solutions to serving patients with limited trained navigators.

Providing navigation is the most effective way to ensure that a patient follows through with treatment and stays in the continuum of care. Navigators are also a valuable resource for patients in need of supportive and financial assistance during their treatment. Removing some of the psychosocial and financial burdens can increase the patient’s ability to follow through with

care. However, changing health systems and limited funding streams pose challenges for hospitals to sustain this service. Navigation is becoming recognized as a highly effective service in cancer centers and community-based organizations alike. Health systems are actively developing plans to secure funding and determine a standard of care model that will benefit patients in their communities. The Affiliate is committed to supporting these efforts through grants and partnerships with organizations that are aligned with Komen's mission and priorities.

Through data collection, Komen New England has located the following types of breast health and breast cancer services in Massachusetts:

- Breast Cancer Health Education and Breast Health Literacy
- State and federally funded early detection breast cancer services (Women's Health Network)
- Care coordination services
- Patient navigation services
- Hospital services (e.g. imaging, biopsy and cancer treatment)

### **Focus Groups**

Four focus groups were held in Boston, Springfield and Worcester. Participants represented a broad spectrum of cancer survivors. Women with early-stage breast cancer diagnoses, late-stage and metastatic breast cancer were present in each focus group. It was important to the Affiliate that women with different cultural backgrounds and socioeconomic status were represented.

Represented in the focus groups were:

- White, Black/African-American, Hispanic/Latina, Asian/Pacific Islanders
- Patients unemployed without insurance coverage at time of diagnosis, women who became eligible for insurance post diagnosis and women who were undocumented and ineligible for financial assistance

The key questions discussed during the focus groups centered around awareness, access to care and barriers to care. General themes that emerged from the focus groups conducted in the target communities included:

### ***Target Community: Springfield***

#### *Breast Cancer Awareness*

- Female physicians took additional time to discuss breast cancer issues if patients were open about breast cancer family history.
- Literature on breast cancer early detection was disseminated by community health centers at annual health fair events. Though informative, staff who represent health centers did not provide referrals or make appointments for women in attendance at health fairs. Appointments were not made at the time women received the education. Participants were not informed of when health fairs were taking place, “we stumble into them if they are held on a weekend.”

- Awareness campaigns are helpful reminders for women to get screened. In this community, the campaigns are not often translated to communities of Hispanic/Latina, Vietnamese or Russian populations.

#### *Access to Care*

- The state mandates that all residents must obtain health insurance. Residents have ample services within the community and online that provide guidance on how to enroll. The high costs of premiums deterred low income residents from enrolling in even the most basic insurance plans.
- Having health insurance did not necessarily mean all women accessed early detection services. For some, if an abnormal routine screening required additional imaging, they were responsible for paying out of pocket for the diagnostic imaging.
- Participants were promptly seen by radiologists if they had any abnormal findings.

#### *Barriers to Care*

- Women with limited English reported confiding in an immediate family member if they struggled with understanding medical terms. Women reported using available interpreters or language lines for general breast health screenings. *"I had an interpreter at the hospital. It always took a long time for them to arrive, so I began bringing my daughter to the appointments. I felt I took up all of the doctor's time when we had to wait for the interpreter."* Participants perceive the use of language lines as a last resort.
- Public transportation is available for residents in Springfield. Participants used public transportation for annual medical visits. Women requiring weekly or daily breast cancer treatment did not find public transportation reliable.
- For the most part, participants were satisfied with their breast cancer treatment. Some participants questioned whether a second opinion at a larger cancer research and treatment institution would have provided an alternative to treatment and surgery. Reliable transportation would have influenced their decision to access hospitals in Boston that are recognized for providing innovative treatment options.
- Participants found comfort in accessing care at their community health center as a more diverse and often bilingual medical staff was readily available. Though cancer centers provided quality treatment for breast cancer patients, programs culturally tailored to meet the needs of ethnically diverse patients were not found.
- Community health centers required women to be patients of the center before receiving care. A few participants expressed frustration about health centers that did not have urgent care available. Others reported that as walk-in patients, they received immediate care for their breast health concern.
- Breast cancer services included a nutritional component. Patients had access to a nutritionist during treatment. Participants reported diet plans were not tailored to individuals who consumed ethnic foods.

## **Target Community: Worcester**

### *Breast Cancer Awareness*

- Health fairs provide educational materials. Community health workers provided women with details of the process to obtain the services. Appointments were not made at the time women received the education.
- Awareness campaigns are helpful reminders for women to get screened. Most community-based health centers offered breast cancer education during routine and well visits.

### *Access to Care*

- The state mandates that all residents must obtain health insurance. Residents have ample services within the community and online that provide guidance to obtain the insurance. Premium costs have deterred few residents from obtaining insurance.
- Those who possess insurance have access to routine screenings. Community health centers offered services to enroll uninsured with coverage. Two community health centers report having payment plans available to patients with limited incomes.
- Out of pocket costs for diagnostic screenings and breast cancer care were a barrier to accessing services.
- Participants reported local breast health centers provided immediate care for those with abnormal breast screenings (clinical breast exams and mammograms).

### *Barriers to Care*

- Participants were first seen at a community-based health centers. All reported having interpreters and community health workers that offer guidance into breast cancer treatment once diagnosed. Cancer centers provided interpretive services, specifically to Spanish- and Portuguese-speaking patients.
- Most participants were bilingual. However, it was preferred to have medical staff communicate in their native language.
- Reliable transportation was presented as an issue for women in treatment. Patients rely on volunteer cancer services for transportation to treatment. Inclement weather prevented some from attending medical visits.
- Psychosocial support for individuals with limited English was not available.

## **Target Community: Boston**

### *Breast Cancer Awareness*

- Community health workers from local FQHCs provided education at community events (health fairs).
- Boston residents obtain breast cancer education through health fairs, community symposiums and mobile health vans. Community health centers are active year-round, hosting health events in underserved communities in Boston.

### *Access to Care*

- One mobile mammography unit provides outreach education and breast cancer screenings to women in underserved communities in Boston. *"I had a mammogram on*

*the van, it was very easy. From there, because I needed more exams, I was referred to the breast center.”*

- The state mandates that all residents must obtain health insurance. Residents have ample services within the community and online that provide guidance to obtain insurance. Premium costs have deterred few residents from obtaining insurance.
- Those who possess insurance have access to routine screenings. Community health centers currently offers navigation services to enroll eligible residents with health coverage through the insurance marketplace
- Out of pocket costs for diagnostic screenings and breast cancer care were a barrier to accessing services.
- Participants reported local breast health centers provided immediate care for those with abnormal breast screenings (clinical breast exams and mammograms).
- Patient navigators and community health workers based in FQHCs and cancer centers were available to most participants. Patients in treatment at two cancer centers had access to bilingual patient navigators.

#### **Barriers to Care**

- Most participants were bilingual. However, it was preferred to have medical staff communicate in their native language.
- Reliable transportation was presented as an issue for women in treatment. Patients rely on volunteer cancer services for transportation to treatment. Inclement weather prevented some from attending medical visits.
- African-American participants reported that messaging needs to be tailored to African-American women.
- Women representing Latina, African-American and Portuguese communities reported that navigation from early detection into treatment needs to improve. Participants that utilized the navigation services felt that *“more time is needed to navigate patients.”* Additionally, they weren’t clear what role the navigator played in their medical team.
- Few participants were not aware that navigation service was available to them.
- Single parent households and women who receive hourly and/or minimum wages had difficulty taking time off work for routine breast cancer services.

#### **Summary of Focus Group Results**

Participants confirmed that guidance and support from their health care providers alleviated the stress of enrolling in a health insurance plan. Uninsured women reported there was limited advertisement of free and low-cost breast health services. In addition, results identified gaps in health care coverage. Patients and key informants recommend changes to policies that lead to extending coverage for diagnostic imaging. Women in the target communities with limited English proficiency expressed frustration with accessing services. Implementing culturally tailored supportive services within the cancer center would alleviate stress associated with breast cancer treatment for women of diverse ethnic groups.

## **Surveys**

A total of 21 participants comprising oncology and radiology staff, nurses, community health leaders, and outreach workers completed the 2015 Community Profile Survey. Table 4.2 presents the results of the types of breast cancer services provided by individuals surveyed.

**Table 4.2. Survey results**

Early Detection Services	
Breast Health Awareness	100%
Patient Navigation Services (community based)	20%
Patient Navigation (cancer center)	80%
Early Detection Screening	95%
Diagnostic Screening	60%
Common Barriers to Care	
Providers reporting offering reduced cost or free early detection screenings	21%
Interpretive services for patients with limited English	20%
Patient Navigation/Oncology Social Workers	78%
Transportation to early detection or treatment	33%

### **Common Barriers to Care**

Most residents in Massachusetts are enrolled in a health plan. Women faced a multitude of barriers that prevented their access to routine screenings and treatment. Providers surveyed reported that patients often prioritized family responsibilities and work before obtaining early detection screenings.

Provider surveys also reveal the following barriers to care:

- 23.0 percent reported that women with late-stage diagnosis did not seek routine screenings as they did not have a primary care physician or medical home.
- 10.0 percent reported a lack of knowledge of breast health practices and importance of obtaining early detection screenings.
- 11.0 percent reported treating women who prioritized other health-related issues above breast cancer screenings and treatment.
- 8.0 percent reported that patients were reluctant to receive care due to high cost of premiums or costs that would be incurred if they were to self-pay.

The provider survey included a comment section in which providers expressed other concerns. A Worcester-based provider stated a patient was convinced “*any cancer diagnosis was a death*

*sentence.” Another provider stated, “fear is instilled in some patients, they do not fully understand that the early detection of breast cancer will save their life.”*

Often, transportation is seen as a barrier to accessing health services. Though residents in each target community had access to personal or public transportation, there were still barriers experienced by community members. Public transportation forced some individuals to take full days off from work as a 1.5-hour commute needed to be factored in to their day. This barrier also resulted in providers logging no-show and cancelled appointments. Only eight percent of providers reported offering a form of transportation assistance as an incentive to patients who made their appointment. Incentives were given to patients in the form of bus tokens, gas cards and taxi fares.

Boston-based medical practices reported having a number of certified interpreters. Among the languages spoken by interpreters at two Boston based practices were Spanish, Portuguese, Arabic, Vietnamese, Chinese, Creole, and Polish. In Springfield and Worcester, limited certified interpreters were based in locations where women would receive breast health or breast cancer medical services. Providers in Springfield and Worcester reported having onsite interpreters translating for patients in Spanish and Portuguese. In Springfield, home to a Vietnamese community, providers did not report having interpreters for education or early detection screening services in the Vietnamese language. Medical facilities in all communities utilized a language line service for all other languages where interpreters were not available. Interpretive services play a key role for patient interaction with their oncology medical teams. Only two practices in Boston reported having bilingual navigators who provided linguistically and culturally competent services to meet the needs of diverse community members.

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:

- Improvements to media campaigns
- Increase breast health awareness and enhance existing outreach programs in all target communities
- Collaborate with hospitals and cancer centers to support and sustain programs that were once managed through grant funds. Community members need to become familiar with services. For this reason, programs must be present and visible long-term.
- Encourage health systems to increase navigation services in Western Massachusetts

### **Limitations**

The Affiliate encountered challenges due to time and capacity constraints. During the initial phase of the assessment, the Affiliate recruited volunteers who would play a role in collecting and analyzing data. Volunteers were restricted to a short-term commitment on the project.

The Affiliate was also challenged when conducting interviews, as the target communities were located over 90 miles apart. Staff and volunteers strived to plan, conduct and complete all interviews in a timely manner. Medical staff, often burdened with high caseloads, were unable to

accommodate the Affiliate's request to be interviewed. Few providers were accepting of telephone interviews.

### **Summary of Results**

The results of the key informant interviews, focus groups and surveys, when taken together, have provided substantial insight into the strengths, challenges and barriers of the current system of breast health care for women in the unique target communities. The delivery of services varied in each of the metro areas. It is important to note that the triangulation of data (i.e., combining the perspectives of key informant interviews, surveys and focus groups) reflects some 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 need for improved navigation services (e.g. increasing the number of bilingual/bicultural navigators) and increasing awareness, education and outreach.

### **New Hampshire and Vermont**

#### **Addison County, Vermont:**

In review, it is expected to take thirteen years or longer to reach the HP2020 targets for reducing female breast cancer late-stage incidence and death rates in Addison County. In addition, 78.4 percent of residents live in geographically rural areas. This is slightly higher than the State of Vermont (61.1 percent) and higher than the United States (19.3 percent).

Breast cancer incidence rates for Addison County are increasing at a trend of 6.6 percent. Compared to the -0.8 rate for the Affiliate service area, this elevated number warrants further analysis. The death rate trend in this area exhibited a dramatic rise of 24.1 percent as compared to the decreasing trends of -2.7 percent in Vermont and -1.9 percent in the United States as a whole. In addition, late-stage diagnosis trends are also increasing. Addison County shows an elevated annual change in this trend of 15.3 percent compared to 1.9 percent in Vermont and -1.2 percent in the United States.

Questions will be focused on obtaining a better understanding of the increasing rate of breast cancer incidence in Addison County. Factors that may be contributing to the dramatic rise in death rates in this county and possible correlations or causes will be considered. Rural geography will be looked at in terms of influencing access, utilization, and quality of care for breast cancer incidence and death rates. This inquiry will impart a better understanding of the strengths and weaknesses of the health care system in Addison County in regard to quality performance and accessibility for women along the continuum of care.

#### **Bennington County, Vermont**

In review, demographic data shows Bennington County to have a substantially older female population. It is known that 58.7 percent of the women in this area are age 40 plus which is higher than the Affiliate service area of 53.7 percent and the United States as a whole at 48.3 percent. It also shows that 44.6 percent of women are 50 plus compared to the Affiliate service area of 38.6 percent, and the United States average of 34.5 percent. Finally, 21.1 percent of

women are 65 plus which is higher than the United States average of 14.8 percent and the Affiliate service area average of 15.7 percent.

Residents of Bennington County have a higher chance of having less than a high school education and living with an income 100-250 percent below poverty. For these reasons, it can be assumed that women in Bennington County, Vermont are more likely to face financial challenges in obtaining and accessing care.

In respect to Bennington County, the questions that need further study relate to gaining knowledge of the relationship between increasing age of the female population and possible influences on the unfavorable trends in this county. Another key area is the high rate of poverty in this community and how it plays a role for women making their way along the continuum of care. Additionally, understanding how level of educational influences breast cancer risk reduction, awareness messages and seeking services for early detection will be addressed.

### **Belknap, New Hampshire**

In review, female breast cancers occurred more often in Belknap County than in the Affiliate service area as a whole. There is an increasing trend in the number of new cases in Belknap County, especially in comparison to the Vermont-New Hampshire service area and United States as a whole. The Affiliate has no existing relationships in this community at this time.

The Affiliate would like to gain a better understanding of factors that are contributing to this increasing trend and what resources or partnerships could be cultivated in order to reverse the unfavorable breast cancer incidence and late-stage trends in this county. Other factors that are contributing to the unfavorable status of this county will be explored.

### **Hillsborough County, New Hampshire**

Socioeconomic factors such as being foreign-born and linguistically isolated are notable in Hillsborough County in comparison to other counties in the Affiliate service area. Hillsborough County reflects the most diverse population in comparison to the Vermont-New Hampshire service area as a whole. Women in Hillsborough County, New Hampshire, confront numerous disparities that influence health outcomes and achievement of the HP2020 targets.

Some of the questions that the Affiliate would like to address include the role of linguistic isolation as it relates to the unfavorable trends in this county. Since the data show an increased area of diversity, further information about minority women and foreign-born women would be useful. This might prompt questions such as, "Are women receiving information about services and risk reduction in a language they can understand and in a manner that is culturally sensitive?" The Affiliate would like to know if disparities are being addressed in order to increase access, utilization and quality of care for the diverse population of women living in this county. Finally, it would be valuable to know if adequate numbers of breast health navigators are available to help women make their way through the system.

## **Strafford County, New Hampshire**

In review, a striking figure of 100 percent of residents live in medically underserved areas in this county. Of the population aged 40-64 living in this county, 13.5 percent has no health insurance. In addition to this, Strafford County exhibits high levels of poverty which demonstrates areas of vulnerability. This could be interpreted to mean that multiple barriers are interfering with access and utilization of care, both important pieces of information relevant in this county.

Questions to be investigated will strive to gain an understanding of the sparse medical service availability and how that may be a factor for unfavorable breast cancer outcomes in this county. In addition, qualitative data collection will focus on the topics of access, utilization and quality of care for women living in poverty in this county. The possible correlation of lack of health insurance and lower levels of education contributing to unfavorable outcomes will be considered. Other unidentified factors will be explored. Vermont-New Hampshire hopes to play a role in improving outcomes for women in this community and to better understand ways to make a positive impact.

## **Methodology & Sampling**

Data collection methods for this study included key informant interviews with breast cancer survivors, health care providers and those involved in related breast health services. The informants were residents of either Vermont or New Hampshire and lived or worked in one of the five target communities. Due to limited availability of willing participants, the Affiliate included a select number of key informants that did not live or work in the target communities but were knowledgeable of statewide issues because of their work. A total of fourteen key informants were interviewed or surveyed. This data collection method was determined as best practice in order to obtain the voice of each community to be used in conjunction with the raw statistical data that has been previously reviewed.

**Table 4.1.** Breakdown of key informant interviews by target community and state

Target Community/State	Professional	Survivor
Addison County, Vermont	1	2
Bennington County, Vermont	1	0
Belknap County, Vermont	1	1
Strafford County, NH	1	0
Hillsborough County, NH	2	0
Vermont Statewide	2	0
New Hampshire Statewide	2	1

The Affiliate selected key informant phone interviews as one qualitative data collection method because it was the most practical and efficient manner of obtaining a large amount of qualitative data in a short scope of time with limited resources. Vermont-New Hampshire covers 26 counties across the two states. Although there are numerous methods to collect data, key informant interviews were determined to be a manageable, cost-efficient, and reliable way of obtaining data.

The Community Profile Team Lead contacted providers and survivors by phone or email in each of the target communities. Questions used during the key informant interviews were obtained from the database provided by Komen Headquarters and can be located in Appendix A and Appendix B. Outreach included conversations about Vermont-New Hampshire and an explanation of the study being conducted. The purpose of improving the unfavorable status in each of the target communities, future grantmaking, and building partnerships to close gaps in breast health care, was explained.

In addition, two surveys were designed (one specific to breast health professionals and one specific to survivors) using Survey Monkey. Survey requests were sent to breast health professionals in the target areas and also posted on the Affiliate Facebook page for 10 days. To supplement key findings throughout the report, a review of relevant published articles was included in some sections. These resources allowed the voice of each community to be heard in order that an appropriate response can be designated by the Affiliate.

### **Ethics**

The data were recorded as hand written notes taken during phone interviews with key informants. It was then typed in to a Word Document. Each Informant was e-mailed a consent form and request to return with a signature explaining details of the study, how the information will be used and when it will be published, as well as the right to discontinue the interview at any time without penalty or repercussions. In addition, the scope of consent was discussed over the phone with each key informant before the phone interview and permission was requested to continue or not. All informants were provided with verbal and written information explaining the confidentiality and anonymity of their responses. All data collected was coded by county and separated by survivor or health professional status. No other identifying information was recorded or shared for the purpose of this study. Each key informant was asked if they would like to be quoted or remain anonymous. Those who elected to be quoted were allowed to review statements prior to publication. Upon completing the typed interview for each interviewee, the data were coded and given a number code based on themes that reoccurred. These themes were then highlighted and brought forth.

The online survey generated with Survey Monkey targeted the same audience as the original key informant interviews and the same questions were used. The Facebook post on the Affiliate's Facebook page included an introduction explaining the purpose of the study, how it would be used, and full disclosure of confidentiality. The emailed survey request was sent to selected health care providers and included the same information. The survey was posted on Facebook for ten days before the data were collected. Two informants from Belknap County, New Hampshire, responded and the data has been coded and included within the overall common findings section.

### **Qualitative Data Overview**

The format of the original data were handwritten interview notes from phone conversations with key informants in each of the target communities. These notes were later typed in Word

document for closer review and coding for themes. Some informants were health professionals aware of statewide issues and concerns but did not live or work in the target communities. This information, along with the survey responses and literature review data, were hand coded to condense a large amount of qualitative information into useful concepts and themes. These themes were analyzed and briefly summarized by topic.

### **Common Findings**

The goal was to speak to at least twelve key informants per community. As a result of small populations and time constraints of many potential informants, the Affiliate collected less overall data than originally anticipated. Ethical standards and best practices were diligently maintained throughout the duration of the qualitative data collection and the Affiliate extracted valuable material from the data. However, conclusions from this data must be considered limited due to low response rates and should not be generalized.

Fortunately, the fourteen key informants that agreed to participate in this study provided new insight that was valuable to the Affiliate and future planning. The conversations and survey responses brought to light concepts and themes that may not have been voiced in the past. The Affiliate extracted key findings from this data and the highlights are as follows:

#### ***Knowledge deficit:***

Numerous key informant health professionals from Vermont commented that women reported not knowing who should be screened and when. The key informants indicated that these women had misinformation or had not been exposed to risk reduction messaging or assumed they would not need screening mammograms if they did not have a family history. Many informants noted that women were not aware of the age to obtain screenings. Key informants indicated that women who were aware of the need for screening were often unaware that screening mammograms are covered through the Affordable Care Act.

Additionally, in all of the target communities, health professional informants reported that women were confused about the screening message. Those who had been exposed to publicity and marketing materials such as brochures and posters still reported feeling uncertain about the guidelines as they often received conflicting messages from their providers. It appears that providers are not giving all women the same message and these inconsistencies negatively impact health outcomes. They reported that women do not know how to reach out for resources unless they are already seeing a provider. In addition to uncertainty about screening needs, there may also be a limited number of providers in the more rural communities. Several of the same informants mentioned expanding community outreach to minimize known gaps.

All target communities reported a need for more funds to be allotted for marketing and outreach to convey the Komen message of early detection and risk reduction. In conjunction with this, there was a theme from most health professional informants of needing a standard, more uniform message from health care providers to inform women of the benefits of screening mammography and guidelines that explain when and how often. Both health professionals and

survivors in Vermont expressed concern that paperwork to obtain financial assistance is lengthy and intimidating which may cause women to further delay seeking care they need. Some women may not have the skills to easily manage this process. Comments were made about the benefits of patient navigation or a knowledgeable volunteer to assist in this process when needed.

***Financial:***

Financial issues were repeated throughout each key informant interview and should be highlighted. In spite of the benefits of the Affordable Care Act, gaps still exist. For example, health professional key informants from Vermont and New Hampshire reported that women cannot afford co-pays and are forced to choose paying basic living expenses over health-related bills. In all counties, it was noted that women would delay seeking care until the health issue could no longer be ignored. According to the informants, this often resulted in a more serious condition that would be more difficult and more expensive to treat. In some cases, these women also had fewer treatment choices as a result.

Another issue that was noted relates to those women who did not meet eligibility guidelines for financial assistance from various programs both in Vermont and New Hampshire. Although it is uncertain how many women are affected, this is a gap in the continuum of care. Some target communities have very few grants and/or supplemental funds available and in turn experience financial hardships.

Finally, key informants from Belknap County, New Hampshire, reported that financial and transportation issues hinder access to breast cancer screening in both states. They also reported that money and health insurance were barriers in their county.

***Fears:***

Many health professional key informants in Vermont and New Hampshire, reported that women would postpone preventative screening due to fears of discovering cancer. This also brought up financial concerns of how to pay for treatment in the event that cancer was found. They noted that women often care for everyone else before they sought out care for themselves. This is something that is common for them to observe and report women would wait until they could not ignore the issue due to increasing severity. These informants reported that being self-conscious about screening, worries about discomfort and exposure to radiation, cultural myths and previous bad experiences lead to fears that result in women not seeking breast health care.

Health professional key informants from New Hampshire, reported that fears were not only from uninformed women but also highly educated women. Informants noted that some women choose a “natural approach” to screening such as thermography or would forgo screening entirely for various personal reasons. Some women choosing not to access screening intended to avoid exposure to radiation or held negative perceptions concerning conventional interventions. Key informants from Belknap County, New Hampshire, also indicated that money, side-effects of medication and lack of a support system as contributing factors.

***Health:***

Health professional key informants from Vermont indicated that women were sometimes not in good physical health. Some were carrying extra weight and were not practicing healthy eating habits or exercising regularly. Health professional key informants from Hillsborough County, New Hampshire, expressed that women with numerous medical co-morbidities also reported a lack of funds to assist with types of risk reduction such as a gym membership or nutritional counseling. Overall awareness of breast cancer risk factors was limited according to all informants. Knowledge of family history and precautions to reduce risk was also uncommon according to all key informants. Following preventative health guidelines was reported as the exception, rather than the rule for many women according to survivors in Addison County, Vermont.

Survivors from Addison County, Vermont, stressed the importance of a “plant-based diet,” regular exercise and vitamin supplements to cope with the diagnosis and to improve quality of life. Survivors from this county reported that this advice was encouraged by their medical providers from diagnosis, through treatment and survivorship. One survivor from Addison County, Vermont, was very outspoken about the importance of healthy eating and exercise in regard to risk reduction of breast cancer. Another survivor reported that although she maintained a healthy diet and exercise regularly, she was still diagnosed with breast cancer. However, she also reported that she believed this was beneficial for risk reduction and survivorship.

***Paid time off from work:***

Health professional key informants from Vermont reported that although many women would like to obtain an annual mammography screening and either have insurance or are eligible for funding, they are not able to take time off from work or get paid time off. They noted that women working in minimum wage jobs may not have the flexibility in their work schedule to allow for medical appointments for screening mammography even though they may have insurance. Single parent families and women with small children may not have a flexible schedule or the freedom to easily obtain screenings after work. They commented that basic preventive measures can become very challenging in some situations even when the financial aspect is not a factor.

***Delays:***

Health professional key informants from Vermont and New Hampshire (and one survivor from Addison County, Vermont) reported certain delays that influenced the continuum of care for women. Most notable of these is the lengthy paperwork needed to obtain financial assistance for gaining supplemental funding for support and services. Key informants indicated that these delays could very likely lead to a more advanced cancer stage and medical complications which may have been prevented.

Key informant health professionals indicated that although women may be aware of and actually seek supplemental funding, the arduous tasks of paperwork and/or searching for grant funding

often prevents them from doing so. It was also reported that there was a lack of standardized reminders to patients to get screening.

Key informants from Belknap County, New Hampshire, reported that both a tendency to put the needs of others ahead of themselves and self-justified procrastination were factors in late-stage diagnosis.

***Rural Nature of Counties:***

Key informant survivors from Addison County, Vermont, and one health professional informant from Vermont, explained that many women in these counties have issues with travel to seek breast health services. Lengthy travel times, lack of transportation, cost of gas among other issues prevent women from making the trip for a screening appointment. Limited facilities available for screening mammography, combined with longer wait times to get an appointment was evident in rural communities. Self-employed key informants living in rural communities reported inadequate insurance coverage, inability to take time off from work, transportation issues and longer wait times as barriers when initiating screening and treatment. Other health professional informants from Vermont, reported that due to the rural nature of the communities, fewer women were exposed to the messages regarding early detection, risk reduction and the availability of financial assistance unless they were already seeing a provider (possibly for another reason).

***Language barriers and cultural differences:***

It was noted by health professional key informants from Hillsborough County, New Hampshire, that language barriers influence many different aspects along the continuum of care. Key informants in this highly diverse area of Hillsborough County pointed out the need for more outreach. They reported that as a result of cultural differences, often women in this community are misinformed about breast cancer care and treatment. It was reported that some women believe treatment in the United States will be barbaric as it can be in other areas of the world and therefore are afraid to seek routine screening. One facility in Hillsborough County reported seeing women of numerous nationalities but this was not proportionate to the diversity of women living in the area. The need to target these women and educate them to overcome the fears that prevent them from good care is warranted according to these informants.

***Social support:***

The key informant survivors from New Hampshire reported the need for increased social support following a diagnosis as well as clearer linkage to support. A lack of advertising and good communication of the message of when and where to find social support was identified as a gap in care to patients. Lack of support that was suitable for the stage of cancer and distance of travel to obtain the support were common themes from the key informant survivors from New Hampshire. Inconsistencies were experienced by women when trying to take advantage of basic and critical social support to improve quality of life while in treatment. Some informants reported that referrals to groups did not match the support needed, and in some cases no recommendations were made, in some cases travel distances to groups were not convenient or groups did not meet at times that were accessible.

Key informants from Belknap County, New Hampshire, also indicated a greater need for social support overall, more compassion and understanding for survivors, more outreach through public service and social media to get the word out, more talking and sharing of information, as well as financial support such as simple gas cards and grocery gift cards to ease the financial burden during treatment.

### **Qualitative Data Findings**

The qualitative data findings are based on the key questions arising from the Quantitative Data Report and Health Systems Analysis. Questions were asked to key informants to obtain a “voice of the community.” The responses were based on opinions and the personal experiences of the person being interviewed. The Affiliate selected questions in order to clarify what might be contributing factors leading to the unfavorable status in the five target communities. The responses provided new information that was interpreted in conjunction with the quantitative (statistical) data and areas of concern derived during the Health Systems and Public Policy Analysis.

Weaknesses and limitations of this study are related to the low number of volunteers participating in key informant interviews. Due to the low numbers it is difficult to generalize the data or make definitive statements. Numerous contacts were made with individuals, groups and organizations. Many expressed regret for not having extra time to be interviewed even for 20-30 minutes. Finding willing participants that both qualified for the interviews and had time was challenging. Although the original expectation of meeting the minimum criteria of twelve key informants per target community was not met, the reduced number of total key informant interviews (14) and survey responses must be considered as the Affiliate reviews findings and conclusions drawn from the qualitative data.

To supplement key findings throughout the report, a review of available published articles was included in sections as additional research. Further, the effect of the reduced participation in the assessment is mitigated by the quality of insights from the professionals and survivors that did share their expertise. The rich information complimented the quantitative data from the previous sections and advanced areas for further study about the barriers and gaps that exist in the target communities. The key informants not only shared their experiences and thoughts about barriers along the continuum of care, they also offered valuable networking possibilities as the Affiliate seeks to generate new partnerships. These new relationships may allow the Affiliate to connect with organizations that share similar goals of reducing breast cancer death rates and late-stage diagnosis. Overall, the Affiliate needs to continue further study of the gaps and barriers to gain a deeper understanding of the breast cancer burden in the five target counties.

### **Addison County, Vermont**

Conclusions are representative of those who participated in the key informant interviews. Addison County offers conventional medical interventions at the local hospital. It was reported that personalized attention and care was exceptional by those interviewed. One weakness

reported was longer wait times for routine appointments reducing convenience compared to larger facilities that provide screening mammography. This may result delays for women getting screening or the need to travel longer distances outside of the county to obtain care.

Additionally, it was reported that oncology treatment such as chemotherapy was not offered on a daily basis in Addison County. Patients may be required to wait for an open chair or choose to travel a distance to a neighboring county for daily care. This travel can be an hour or more each way and was reported by some key informants as a potential barrier. It was noted that due to the associated discomfort of cancer, including pain, these factors could make travel more difficult, increasing the possibility of opting out of treatment.

Addison County offers complimentary cancer care such as acupuncture and supportive herbal remedies for breast cancer treatment and symptom management which can be utilized alone or in conjunction with conventional treatment. This is an asset to the community and a well utilized holistic approach to care. There is a well-established telephone support network that is growing in the area, Kindred Connections, for cancer patients of all types. It is becoming more widespread throughout the state of Vermont and a source of social support for those who may not have the access or desire to attend traditional support groups. This group also provides networking to assist with ride sharing to and from appointments. This is particularly beneficial to rural areas and for women with transportation obstacles. However, many women may not be aware of this support in spite of its positive value in the communities of Vermont. Helping women to become aware of the supports and services in their community would be advantageous.

Rural geography was reported as a factor in regard to travel distances to care, obtaining breast cancer risk reduction and early detection messaging, awareness of supplemental funding and programs that help cover screening and treatment costs, and having time off from work to get to appointments. Self-employed women reported financial concerns due to limited or no health insurance. Key informants reported that Ladies First, The Vermont Breast and Cervical Cancer Program provider, delivered a great deal of financial assistance and this was considered an asset. Some key informants reported not having the ability to obtain care without this assistance and expressed sincere gratitude for the program.

While relevant and important information concerning Addison County was derived from the initial key informant interviews, these interviews did not lead to a greater understanding of the dramatic negative death rate trends in this County. In order to gather data about this statistic, the Affiliate contacted the Public Health Analyst from the Vermont Cancer Registry. She provided a wealth of information for the purpose of this study and explained that, "based on the available data, breast cancer deaths are not actually elevated in Addison County. On average, there are approximately six deaths from breast cancer per year. In most years there are four or fewer. In 2010 there was a greater number of deaths compared to previous years and the following year in 2011. This one year, because of small numbers, strongly influenced the calculations (that are in the Quantitative Data Report)." She also commented that the Vermont Cancer Registry will be, "calculating incidence and deaths for 2012 later this spring and will be

looking to see if the trend continues to level out again.” This key informant helped gain a better understanding of the breast cancer burden in Addison County.

Women in Addison County continue to face challenges that arise as a result of living in a rural community and would benefit from additional support and services. Collectively, more organizations, along with Vermont–New Hampshire, are observing trends that may negatively impact these women. In the future, the Affiliate intends to collaborate with the efforts of these organizations to improve the lives of women living in this county and to reach HP2020 goals.

### **Bennington County, Vermont**

In agreement with the Quantitative Data Report, Bennington County was found to be economically depressed. Numerous themes emerged from key informant interviews with health professionals such as limited knowledge of breast cancer guidelines, lack of awareness of financial resources available, and the inability to complete eligibility paperwork for reduced cost programs. The key informants explained that women reported believing that those without a family history of breast cancer would not need mammogram screenings. In addition, they reported that although women from Bennington County in the health care system were regularly presented with information about financial assistance programs for low or reduced cost screenings such as Ladies First, these women were often overwhelmed by the paperwork involved and required assistance in navigating the process. This assistance was provided but limited due to time constraints of professionals providing help.

Health professional key informants explained that many women living in this economically depressed area do not have a primary care provider as a result of not having insurance in the past and/or living with a very low income. Women living in Bennington County who have never had a primary care provider report a severe lack of knowledge of preventive health management, lack awareness of free or low-cost preventative health care programs, do not know how to navigate the health care system, or where to seek help. In turn, key informants report that local women often wait until very serious symptoms arise, such as those associated with late-stage breast cancer for example, before seeking care. Key informants report that this results in more limited treatment options and increased death rates.

In addition, males with breast cancer in this county (and all other rural target communities) experience obstacles obtaining breast cancer education and support. A qualitative study from 2000 found that not only is there a shortage of information available specific to male breast cancer, there are unique needs that must be addressed in targeting early detection and treatment for men. The study indicated concerns such as, “delays in diagnosis shock, stigma, body image, causal factors, the provision of information and emotional support (S. Michie et al., 2000).” The study recommended structured education aimed at primary care providers to alleviate potential psychological problems associated with diagnosis and provision of appropriate support/counseling services for partners of patients (2000). Although fewer men are diagnosed, males face many challenges along the continuum of care. Addressing the factors contributing to the unfavorable status of this county will result in better outcomes and help achieve HP2020 goals.

Another concern for this target community is increasing age and how it impacts the unfavorable status of this area. Age as a factor was assessed through a review of published articles as the key informants were unable to provide sufficient insight on the subject. In a qualitative study undertaken to understand the effect of older age on supportive care needs, information satisfaction and service needs in the year following a cancer diagnosis, it was determined that “With a few exceptions, individual rather than age-specific needs determine supportive and informational care requirements (Watson et al., 2015).” With that in mind, it was discovered that, “Older patients differ on information satisfaction showing a preference for doctors to make treatment decisions and preferred positive information. (2015).” This research review demonstrates how providers may improve communication with older patients in order to facilitate informed decision making along the continuum of care from screening, diagnosis and treatment to survivorship needs. Also, this research highlights the importance of sensitivity to the individual needs of the patient regardless of age, and the merit of the physician-patient relationship.

A qualitative study by Puts et al (2015) found that, “Important factors for accepting treatment were convenience and success rate of treatment, seeing necessity of treatment, trust in the physician and following the physician's recommendation.” “Factors important for declining cancer treatment included concerns about the discomfort of the treatments, fear of side effects and transportation difficulties (2015).” The conclusion of this study was that, “though the reasons why older adults with cancer accepted or declined treatment varied considerably, the most consistent determinant was physician recommendation (2015).” The reliance on and importance of physician recommendations on treatment decisions is relevant to the older population of Bennington County and furthermore emphasizes physician sensitivity to this population in the continuum of care and reinforces the value a physician-patient relationship.

Another vulnerable population that would benefit from additional resources and support is women with intellectual disabilities. A qualitative study from 2013 found that, “Women with intellectual disability do not receive cervical and breast cancer screening at the same number as women without disabilities (Swaine et al.).” “Caregivers reported a number of barriers to care including not knowing or not believing the exam was needed for their family member and discomfort during exams (2013).” The study also discovered that “a significant portion of the sample of family caregivers lacked knowledge about the need for cervical and breast cancer screening by women with intellectual disability (2013).” This study highlights the importance of assisting women with disabilities and focusing outreach toward their caregivers to increase risk reduction and early detection of breast cancer.

### **Belknap County, New Hampshire**

Key informants and survey respondents from this county reported financial issues hindering access to breast cancer screening as well as overall financial hardships in relation to care. They mentioned that more inquiry should be made by health care providers to assess the needs of all family members in order to support access to information about low cost, affordable, or “free” programs for general and breast health care. They noted the need for more compassion

and understanding toward survivors and their unique needs in addition to increased financial support via gas and grocery cards throughout treatment. It was also noted that more outreach was desired. Word of mouth messaging by providers, other survivors and support groups about programs for risk reduction and survivorship was requested. This county reported a severe shortage of resources in their area and women “going broke” during breast cancer treatment.

The qualitative data collected, although limited, confirms that statistical analysis of this county. Serious financial concerns and a need for financial support in Belknap County is very important to address. With additional resources this area will be more likely to reach HP2020 goals.

### **Hillsborough County, New Hampshire**

Health professional key informants from New Hampshire and Hillsborough County reported that there are a high number of minority women that are in need of risk reduction and early detection education. According to the key informants, many of these women have not sought out health care due to misinformation and myths surrounding breast cancer. Many of these women are reported to be refugees in a Federal program located in Hillsborough County. Some foreign-born women have reported to health professional key informants that they have very different and brutal methods of dealing with breast cancer in their home countries and therefore fear and avoid medical interventions in the United States. The informants reported that they have limited opportunities in which to provide outreach and education to foreign born women often due to the time constraints and nature of their work. In addition to this, informants noted that these women often have language barriers that interfere with understanding early detection and risk reduction messages, as well as utilizing the health care system in general. On the positive side, it was noted that hospitals offer translation services for all languages in order to make care accessible.

Given the increased diversity of the population in this target community, more effort needs to be directed toward understanding the needs of and reaching out to these women and men. The population requires more sensitivity from health professionals about the unique beliefs and decisions that are part of this diversity. In a qualitative study of breast cancer survivors from various ethnic groups, it was noted that differences exist in types of treatment chosen. For example, “Asians and Latinas were more likely to receive mastectomies and African-American breast cancer survivors were least likely to receive adjuvant therapies including radiation and chemotherapy (Ashing-Giwa, et al., 2004).” This study also noted similar findings such as language barriers, cultural factors and beliefs related to illness, that highlight the importance of acknowledging these issues to minimize gaps in the continuum of care. In addition, it was found in the same qualitative study that coping styles, such as spiritual beliefs, were central to survivorship especially for women of color (2004).

The overreaching concern for Hillsborough County is the increased diversity of the population and the unique concerns, from screening to survivorship, that must be addressed in order to achieve HP2020 goals of reducing late-stage diagnosis and deaths from breast cancer. This is especially imperative in light of the finding that “ethnic minority women are diagnosed with more advanced stage disease and experience greater morbidity (2004).”

Another qualitative study examining breast cancer screening and Black/African-American women found that “fear was the predominant feeling expressed in all groups.” “This fear was a primary reason for not engaging in breast cancer screening (Phillips et al. 1999).” “Because it was found that breast cancer is seldom discussed among African-American women, there is a need to tailor interventions to address these needs (1999).” The Affiliate can use this data to make a larger impact on this community.

Another qualitative study (Morgan et al, 1995) that was reviewed for this report, concluded “that cancer prevention programs targeting the Hispanic/Latino populations should emphasize the provision of factual information about cancer and cancer-screening behaviors in the context of an exploration of inaccurate beliefs about cancer that may inhibit preventive health behaviors.” This is in reaction to what the study (1995) found which was the “greatest indicator of inadequate cancer screening (for this population) was lack of knowledge.”

### **Strafford County, New Hampshire**

Although there were few key informants from Strafford County, the data collected was insightful. The additional responses by key informant health professionals for the State of New Hampshire demonstrated themes that will be considered. The limited data once again plays a role in future decision making and supplemental information that will be needed.

This target community has the fewest number of medical providers. However, financial assistance is available through the local hospital and a patient navigator exists to help. Some of the issues specific to this area were related to financial hardships including lack of insurance, being underinsured with high out-of-pocket expenses and not meeting eligibility guidelines for free or reduced-cost programs. Key informants made several suggestions regarding possible ways to reduce the burden for these women and improve the breast health continuum of care. It was noted that a guaranteed funding program specific for those who are not eligible under current programs as well as a coordinator that could help link and refer women to the appropriate resources and even help in arranging appointments and/or transportation if needed would be beneficial.

In reference to late-stage diagnosis, health professional key informants agreed that the known factors such as lack of health insurance and financial hardships play a role. Others commented that inconsistencies among providers regarding screening guideline messaging exist. This was noted as a barrier in identifying breast cancer at its earliest stages thereby increasing the odds of a late stage diagnosis. Health professional key informants indicated that residents are well provided for in regard to screening access and rural geography does not appear to negatively impact this area as noted in other communities. However, financial challenges do exist, and the County would benefit greatly from additional support and partnerships in the future.

The limited number of primary care providers in the area is another concern. Additional support across the continuum of care would be beneficial, as would building partnerships, to allow supplemental funding to assist with financial burdens. Vermont-New Hampshire is not currently partnered with agencies in this community but would like to increase collaboration in the future.

In conclusion, more assistance is needed to increase knowledge of the basic Susan G. Komen breast health guidelines for women in all five counties. Providers must be diligent about informing patients of these guidelines in order to reduce confusion and prevent a paralysis in seeking early detection and risk reduction services. Augmented financial resources and patient navigation is needed to support women who do not meet eligibility guidelines for supplemental funding. Assistance in shared decision making with providers for preventative care as well as treatment is also required. Consideration of how Komen funds can be best utilized to meet the changing needs of women in the landscape of new health care programs should be explored. This may include assistance with out-of-pocket costs, transportation, or helping covering costs other than screening mammography. Partnering with other like-minded agencies such as the New Hampshire Comprehensive Cancer Coalition, New Hampshire Comprehensive Cancer Collaboration, and Vermonter's Taking Action Against Cancer, could maximize the potential for supplemental resources to be made available to fill the financial gaps along the continuum of care. Ensuring these funds are recommended and publicly presented to women in the community will increase utilization. Increasing navigation services could prevent delays and reduce frustrations related to paperwork in obtaining supplemental funding.

More breast health outreach could allow uninsured and under-insured women to become aware of early detection and risk reduction guidelines and learn how to access care in ways they may not have experienced in the past. In a report from 2007 that reviewed several previous studies, it was found that "rural women desire greater health-related information about their breast cancer (A. Bettencourt et al., 2007)." Ideally, this should result in fewer barriers, improve knowledge for women navigating the system and overcome obstacles that result in late-stage diagnosis and breast cancer deaths.

Not only do more women benefit from increased breast health education, a study concluded that "rural survivors, regardless of stage at diagnosis, reported needing more education about breast cancer and more emotional support after diagnosis. Further efforts to facilitate support and education within the context of medical care and to improve patient-clinician relationships are needed (S. Wilson et al., 2000)." This study supports the Affiliate findings that an increase in breast health education and linkage to psychosocial support would greatly benefit all five target communities.

The Affordable Care Act and expanded Medicaid have helped many women obtain medical services they need, yet there are still gaps. For some, there are fears that must be dispelled. Others require additional effort addressing language barriers or intellectual disabilities. Cultural sensitivity and attention to individual differences by providers and care givers is critical. An individualized approach toward women (and some men) will enable education and outreach that facilitates a better understanding about risk reduction early detection and informed treatment decision making, while concurrently reducing fears.

Although more women have insurance, some are still not aware of the health guidelines such as when to start routine breast cancer screening mammography and how often to go. They may

have never had a health care provider in the past and have little or no knowledge of navigating the system. Still, many women have opted out of the Affordable Care Act and/or do not qualify for a variety reasons. These women remain in need of supplemental funding. Another pressing issue is that under the Affordable Care Act, mammography screening is covered yet many women are not aware of this. Furthermore, while the Affordable Care Act pays for screening costs, very often it will not cover diagnostics, presenting a financial obstacle to many. This further exacerbates the problem and negatively impacts outcomes.

Streamlining follow up calls to remind patients to schedule screenings and required care would be beneficial. A universal and standardized system for providers to accomplish this was mentioned as a way to increase favorable outcomes for women as they make their way through the health care system. This is especially important if they are going from one provider to another and information is required to be shared.

Educational outreach on topics such as healthy diet and exercise could also be beneficial. Key informants reported that these lifestyles increased longevity and quality of life following a diagnosis and decreased breast cancer incidence rates. Social support and referral to support groups is indispensable for all women diagnosed with breast cancer and efforts to introduce this frequently along the continuum of care is crucial. Extra attention to cultivate social connections in rural communities is vital as it is well documented that this results in improved quality of life and better treatment outcomes.

Overall, the Affiliate received helpful feedback from health care professionals and breast cancer survivors. The themes and common findings will be considered by the Affiliate for future planning and supplemental information will be needed to impact the target communities and to reach HP 2020 goals.

Although the cure for breast cancer has not yet been discovered, the findings from this study point to areas of need that can make a difference in the lives of many women making their way along the breast health continuum of care. Vermont-New Hampshire has and will continue to make contributions to the community and direct funds in a way that will be valuable to the service area. Komen will continue to search for the answers to questions around eliminating breast cancer forever and grant money will be supplied for this cause. In the interim, the Affiliate intends to promote risk reduction, early detection and provide supplemental funding in areas of known gaps. In this way, the Affiliate can optimize the best possible outcomes for women living in the service area and become a resource for these communities.

There were no qualitative data collected in Maine or Rhode Island.

# Mission Action Plan

## **Breast Health and Breast Cancer Findings of the Target Communities**

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.

## **Breast Health and Breast Cancer Findings of the Target Communities**

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

For the duration of the 2015 Community Profile, the following target areas are:

- Fairfield, New Haven, Hartford, Litchfield, and New London Counties, Connecticut
- Boston, Worcester, and Springfield, Massachusetts
- Vermont
- New Hampshire
- Maine
- Rhode Island

**Table 3. Mission Action Plan for New England Target Communities**

<b>Problem/Needs Statements</b>	
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.
<b>Affiliate Action Plan</b>	
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"><li>10. 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.</li><li>11. In FY2016-FY2019, solicit grant applications from organizations experienced in delivering messages about early detection and breast</li></ol>

	<p>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.</p> <ol style="list-style-type: none"> <li>12. 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.</li> <li>13. 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.</li> <li>14. 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.</li> <li>15. 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.</li> <li>16. 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.</li> <li>17. 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.</li> <li>18. 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.</li> </ol>
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<b>Problem/Needs Statements:</b>	
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.
<b>Affiliate Action Plan</b>	
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:	<ul style="list-style-type: none"> <li>4. 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.</li> <li>5. 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.</li> <li>6. 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.</li> </ul>
<b>Problem/Needs Statement</b>	
Quantitative	Quantitative data reports reveal Boston to have a high breast cancer incidence, number of late-stage diagnosis cases and deaths, with death rates higher than that of Massachusetts as a whole.
Health Systems	Residents reported gaps in health care coverage for diagnostic screening services. Access to breast cancer early detection services was lower among low income and ethnically diverse populations.
Qualitative	Early detection services and treatment services were available but limited for individuals of culturally and ethnically diverse backgrounds in neighborhoods of Boston.
<b>Affiliate Action Plan</b>	

<i>Priority</i>	Increase knowledge and use of breast health and breast cancer navigation programs among low income and culturally/ethnically diverse populations in Boston.
<i>Objectives</i>	<p>4. In FY 2016-2019 Develop and issue a request for applications soliciting grants from early detection service providers committed to improving breast health and breast cancer resources for underserved, low income and culturally diverse communities in Boston. Grants will support programs that increase community awareness of services and availability of screenings for uninsured and underinsured patients.</p> <p>5. In FY 2016-2019 Solicit grant applications from organizations seeking opportunities to implement or expand patient navigation programs among low income and culturally/ethnically diverse populations in Boston.</p> <p>6. In FY 2016-2019 Coordinate Affiliate breast cancer wellness events to increase provider knowledge of the Community Profile. Consumers will become informed of breast cancer resources through health events coordinated by the Affiliate in partnership with Komen-funded programs and local breast cancer centers.</p>
<b>Problem/Needs Statement</b>	
<i>Quantitative</i>	Quantitative data reports reveal Springfield and Worcester to have a high breast cancer incidence and number of late-stage cases and deaths, with death rates higher than that of Massachusetts as a whole.
<i>Health Systems</i>	Health systems seldom promoted early detection breast health and breast cancer services for individuals in low-income communities, medically uninsured and ethnic and cultural diverse populations.
<i>Qualitative</i>	Early detection services and treatment services were available but limited for individuals of culturally and ethnically diverse backgrounds in neighborhoods of Springfield and Worcester.
<b>Affiliate Action Plan</b>	
<i>Priority</i>	Increase breast health and breast cancer knowledge and expand access to and use of breast cancer care and navigation programs among low income and culturally/ethnically diverse populations in Springfield and Worcester.
<i>Objectives</i>	<p>4. In FY 2016-2019 Develop and issue a request for applications soliciting grants from early detection service providers committed to eliminating barriers to breast health and breast cancer services for underserved, low income and culturally diverse communities. Grant opportunities will be available for organizations to implement or expand patient navigation programs.</p> <p>5. By December 2016 Explore opportunities with local Women's Health Network providers and cancer centers in Springfield and Worcester to form a breast cancer task force to increase provider</p>

	<p>and consumer awareness of breast cancer and Affiliate-funded programs.</p> <p>6. By June 2016 Form an educational advisory committee that will be responsible for participating in existing wellness community events. Advisory members will coordinate a series of breast cancer health workshops aimed at educating community leaders from the Springfield and Worcester area. Partner with at least five community leaders in each target area to distribute Komen educational materials and information about local breast cancer resources.</p>
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#### **Problem/Needs Statement**

Women in Addison County continue to face challenges that arise as a result of living in a rural community and would benefit from additional support and services. The Affiliate intends to collaborate with the efforts of similar organizations to improve the lives of women living in this county and to reach HP2020 goals.

#### **Affiliate Action Plan**

<i>Priority</i>	Increase access to the breast health continuum of care for rural women through developing partnerships in Addison County, Vermont.
<i>Objectives</i>	<p>4. In FY 2016, hold at least one grant writing workshop in Addison County, Vermont.</p> <p>5. By FY2017, add at least one medical, public health, or nonprofit professional from Addison County to the Affiliate's Board of Directors to ensure the needs of the county are represented on the Board.</p> <p>6. In FY2018, hold a rural breast cancer summit with providers from Addison County and neighboring counties to discuss possible partnership opportunities with the goal of increasing access to and seamless progression through the breast health continuum of care.</p>

#### **Needs Statement**

Bennington County has a substantially older female population. This county also demonstrates a higher rate of poverty and more residents with less than a high school education. Health professional key informants from this county as well as Vermont State have reported that many women never had health care in the past and have no existing provider. Even with the rollout of the Affordable Care Act, these women do not know who to call, how to access the system, lack general awareness about breast health, and are not aware of free or low-cost screening programs in their area. Additionally, when faced with paperwork for eligibility for these programs they are unable to complete the documents or require assistance to help with this process.

#### **Affiliate Action Plan**

<i>Priority</i>	Increase the quality of Affiliate funded grants to ensure identified gaps in the continuum of care are addressed in Bennington County.
<i>Objective</i>	<p>2. By the FY2017, a priority of the Community Grants Request for Applications will be increased access to breast health navigation</p>

	services to assist with education and outreach to uninsured and underinsured women, help complete paperwork, and provide patient advocacy and help with decision making about screening and treatment in Bennington County.
<b>Problem/Needs Statement</b>	
This is the most diverse county in the Affiliate service area resulting in a vulnerable population of women reported as not seeking screening and care due to language barriers and cultural beliefs. Outreach and education is key to increasing access to care.	
<b>Affiliate Action Plan</b>	
<i>Priority</i>	Increase breast health outreach and education to refugees and women of diversity in order to eliminate fears about health care and to facilitate access and utilization of care in Hillsborough County, NH.
<i>Objectives</i>	<ul style="list-style-type: none"> <li>3. In FY2016, develop at least one new collaborative relationship with community-based organizations that serve refugee and women of diversity in Hillsborough County, NH.</li> <li>4. From FY2016 through FY2019, include in the Vermont-New Hampshire Community Grant RFA, the need for programs addressing the educational needs of refugees and women of diversity in Hillsborough County, New Hampshire.</li> </ul>
<b>Problem/Needs Statement</b>	
Compared to the Affiliate service area as a whole, Belknap County possesses higher female breast cancer incidence rates and trends. Incidence rates in Belknap County, New Hampshire (152.4 per 100,000) are greater than the Affiliate service area as a whole (131.8 per 100,000). It is predicted to take thirteen years or longer to reach the HP2020 late-stage incidence target. The Affiliate has no existing relationships in this community at this time.	
<i>Priority</i>	Increase the health care system's capacity to provide quality breast health care in Belknap County, New Hampshire.
<i>Objective</i>	<ul style="list-style-type: none"> <li>2. In FY2016, hold at least two collaborative meetings aimed at hospitals, primary care providers, health clinics and community-based organizations to discuss improving continuity of care between referral, screening, diagnosis, treatment, and support services within Belknap County, New Hampshire.</li> </ul>
<i>Priority</i>	Establish new partnerships with community-based health organizations to effectively implement breast health education and services in Belknap County, New Hampshire.
<i>Objective</i>	<ul style="list-style-type: none"> <li>2. By FY 2019, partner with community-based health organizations to arrange at least two small group education classes on breast health, including risk reduction and early detection.</li> </ul>
<b>Needs Statement</b>	

An increased number of women in Strafford County live in poverty and are more likely to be uninsured or underinsured. It was reported that 25.1 percent of residents age 40-64 were living at 250 percent below the poverty level. Health professional key informants from New Hampshire have indicated that women cannot afford out-of-pocket costs including co-pays, high deductibles, and transportation costs which are financial barriers to early detection.

<i>Priority</i>	Increase access to services for women who do not meet eligibility guidelines for free or low-cost breast health programs to eliminate barriers and increase access.
<i>Objective</i>	2. From FY2016 through FY2019, the Vermont-New Hampshire Community Grant RFA will include patient navigator programs aimed specifically at working with uninsured and underinsured women in Strafford County, New Hampshire as a funding priority.
<b>Problem/Needs Statement</b>	
Target communities in Maine and Rhode Island with rising late-stage incidence rates.	
<i>Priority</i>	Increase availability of breast health resources for women Maine and Rhode Island in order to reduce late-stage diagnosis in the two target communities.
<i>Objective</i>	<ul style="list-style-type: none"> <li>3. Increase understanding of breast health needs through discussions with service providers in key areas throughout Maine and Rhode Island.</li> <li>4. Increase the number of grant applications from Maine and Rhode Island. Grant funds will support evidence-based programs that ensure breast health services are available to medically underserved communities.</li> </ul>

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