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Acknowledgments

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

Susan G. Komen® North Carolina Triangle to the Coast would like to extend its deepest gratitude to the Board of Directors and the following individuals who participated on the 2015 Community Profile Team:

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

- The Public Health Group, LLC
  Peter J. Costa, MPH, MCHES
  Sherry G. Rigouard, MPH
- Comprehensive Cancer Consulting Services
  Walter Shepherd, Principal
- North Carolina State Center for Health Statistics

Thanks also go to the following organizations for their assistance, support and graciousness in hosting focus groups in the target communities:

- Roanoke Valley Breast Cancer Coalition
- Vidant Edgecombe Hospital
- Wilson County Health Department

And to:

The many breast cancer survivors, caregivers and family members, who gave so freely of their time and spoke candidly about their experiences allowing the Affiliate to capture the information necessary to write this report.

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Introduction to the Community Profile Report

Susan G. Komen® North Carolina Triangle to the Coast (NCTC) was founded in 1997 and incorporated in 2000 when the first board of directors identified a service area encompassing 13 counties around the Research Triangle region of North Carolina. Since its inception, Komen NCTC has raised more than $18 million dollars through events like the Komen Triangle Race for the Cure®, the Komen Wilmington Race for the Cure®, individual donations, corporate philanthropy and third party events. Beginning in 2009, the Affiliate embarked on a multi-year expansion effort; six counties were added prior to the 2011-2012 Community Health Grants Cycle, and a seventh was added early in calendar year 2011. In 2012, nine additional counties in eastern North Carolina were added to the Affiliate service area bringing the total counties served to 29. For the first time, this Community Profile includes data from all 29 counties.

Since 1998, when the Affiliate awarded the first community health grants, Komen NCTC has invested nearly $14,000,000 in education, screening, treatment and support programs in local communities. In the 2015-16 community health grants program, the Affiliate awarded $550,000 to 12 nonprofit organizations that serve uninsured, underinsured and underserved residents in the service area. The funds the Affiliate grants to community programs have made a positive difference in the lives of those living with this deadly disease.

Also of note, in December 2015, the Affiliate completes the “Area L Breast Cancer Initiative” which was a multi-year national Komen grant which focused on reducing breast health disparities in a five county region in north eastern North Carolina whose breast cancer death rates are some of the highest, not only in the state, but in the country.

Additionally, the Affiliate invests in community mobilizing and provider capacity-building activities, including networking events, workshops and training, and site visits that focus on several key principles: program development, program evaluation, evidence-based strategies, the continuum of care, cultural competency and collaboration among organizations.

Komen NCTC is host to two Komen Race for the Cure® events including the Triangle Race which started in 1997 and is one of the largest 5K races in the Carolinas and the Wilmington Race which was started in 2013.

The Community Profile Report will serve as the Affiliate’s main mission communication tool and will help educate and inform Affiliate stakeholders (e.g. grantees, partners, donors, sponsors, legislators, other breast cancer-focused organizations and the community-at-large) regarding the state of breast cancer in the service area, the Affiliate’s current mission priorities, and the plan to address the identified breast health and breast cancer needs within target communities that were identified as part of the community profile process.
Quantitative Data: Measuring Breast Cancer Impact in Local Communities

The quantitative data portion of this report provides the following data at the Affiliate and county-level, as well as for North Carolina and the United States: Female breast cancer incidence (new cases); Female breast cancer death; Late-stage diagnosis; Screening mammography; Population demographics; and Socioeconomic indicators.

Incidence rates
Overall, the breast cancer incidence rate in the Komen North Carolina Triangle to the Coast service area was slightly higher than that observed in the US as a whole and the incidence trend was higher than the US as a whole. The incidence rate and trend of the Affiliate service area were not noticeably different than that observed for the State of North Carolina. Pitt County had an incidence rate much higher than the Affiliate service area as a whole: The incidence rate was much lower in the following counties: Bladen County, Columbus County, Duplin County, Person County, and Scotland County. The rest of the counties had incidence rates and trends that were similar to the Affiliate service area as a whole or did not have enough data available. 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
Overall, the breast cancer death rate in the Komen North Carolina Triangle to the Coast service area was similar to that observed in the US as a whole and the death rate trend was not available for comparison with the US as a whole. The death rate of the Affiliate service area was similar to that observed for the State of North Carolina. The following counties had a death rate much higher than the Affiliate service area as a whole: Edgecombe County, Halifax County, and Wilson County. The death rate was much lower in Chatham County. The rest of the counties had death rates and trends that were similar to the Affiliate service area as a whole or did not have enough data available.

Late-stage incidence rates
Overall, the breast cancer late-stage incidence rate in the Komen North Carolina Triangle to the Coast service area was slightly higher than that observed in the US as a whole and the late-stage incidence trend was higher than the US as a whole. The late-stage incidence rate and trend of the Affiliate service area were not noticeably different than that observed for the State of North Carolina. For the United States, late-stage incidence rates in Blacks are higher than among Whites. Hispanics/Latinas tend to be diagnosed with late-stage breast cancers more often than Whites. For the Affiliate service area as a whole, the late-stage incidence rate was higher among Blacks than Whites and lower among Asian and Pacific Islander than Whites. There were not enough data available within the Affiliate service area to report on American Indian and Alaska Native so comparisons cannot be made for this racial group. The late-stage incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas. The late-stage incidence rate was significantly lower in Brunswick and Person Counties. Markedly more favorable trends in breast cancer late-stage incidence rates were observed in Scotland.
County. The rest of the counties had late-stage incidence rates and trends that were similar to the Affiliate service area as a whole or did not have enough data available.

**Screening**
The breast cancer screening proportion in the Komen North Carolina Triangle to the Coast service area was significantly higher than that observed in the US as a whole although it was not significantly different than the State of North Carolina.

**Population & Socioeconomic Characteristics**
Proportionately, the Komen North Carolina Triangle to the Coast service area has a substantially smaller White female population than the US as a whole, a substantially larger Black/African-American female population, a slightly smaller Asian and Pacific Islander female population, a slightly smaller American Indian and Alaska Native female population, and a substantially smaller Hispanic/Latina female population. The Affiliate’s female population is slightly younger than that of the US as a whole. The Affiliate’s education level is slightly higher than and income level is slightly lower than those of the US as a whole. There are a slightly larger percentage of people who are unemployed in the Affiliate service area. The Affiliate service area has a slightly smaller percentage of people who are foreign born and a slightly smaller percentage of people who are linguistically isolated. There are a substantially larger percentage of people living in rural areas, a slightly larger percentage of people without health insurance, and a substantially larger percentage of people living in medically underserved areas.

Additional quantitative data was explored to assist the Affiliate in the selection of the target communities. The following data were provided by a statistician at the North Carolina Central Cancer Registry in the Division of Public Health, Department of Health and Human Services: 2012 Female Breast Cancer Death Rates by Race and County, 2011 Female Breast Cancer Incidence Rates by Race and County, and 2011 Female Breast Cancer Stage at Diagnosis by Race. The additional data provides additional insight and uses the most current data available. The “incidence and death rate by race” data helps to highlight the disparities that exist within the service area. Also, stage at diagnosis incidence rates were collected for each county.

The following additional data were collected and or compiled by the Affiliate: 2006-2010 female breast cancer death rate by county benchmarked against the Healthy People 2020 target of 20.1/100,000; 2006-2010 female breast cancer late-stage incidence rate by county benchmarked against the Healthy People 2020 target of 41.0/100,000; 2014 Tier Designations by County shows a ranking of the Affiliate’s 29 counties by economic well-being, 2010-2014 Homeless Point-in-Time Count Data by County provides a five year perspective on the total number of homeless persons per county. The Edgecombe, Halifax and Wilson county profiles provide a snapshot of each county’s incidence, death and screening proportions in addition to demographic and socioeconomic information that justify each County’s selection as a target community. This data complements the Quantitative Data Report by showing additional needs in the service area that contribute to access to care and gaps in the continuum of care; and specifically in the priority areas of Edgecombe County, Halifax County and Wilson County.
In order to best meet the community need, Susan G. Komen North Carolina Triangle to the Coast selected three target counties in the North Central, Eastern region of the service area: Edgecombe, Halifax and Wilson. Target communities were prioritized based on the time needed to reach Healthy People 2020 objectives for breast cancer deaths and late-stage incidence. Edgecombe and Halifax Counties are projected not to reach the Healthy People 2020 targets for deaths and late-stage incidence. Wilson County is projected not to reach the Healthy People 2020 target for deaths. Table 1 provides a summary of incidence rates, death rates, and late-stage diagnosis rates for the target communities, Komen NCTC service area and the United States.

Edgecombe has been identified as a high priority county due to the amount of intervention time needed to achieve the Healthy People 2020 targets. For instance, the county’s death rate of breast cancer was 33.2 per 100,000 women. This is higher than the United States rate (22.6), as well as the Affiliate service area’s rate (23.5). The death rate decreased slightly from 2006-2010. Currently, the county continues to have one of the highest rates of breast cancer death in the service area. Additionally, Edgecombe County’s rate of late-stage diagnosis was 47.7 per 100,000 women. This is higher than the United States (43.7), as well as the Affiliate service area’s rate (45.8). The rate of late-stage diagnosis increased from 2006-2010. Screening percentage in Edgecombe County is in fact higher than the United States and the service area averages, yet according to the socioeconomic data for the county, Edgecombe residents are substantially more likely to have less than a high school education, an income below 250 percent of the federal poverty level, and be unemployed than others in the United States and the Affiliate service area.

Halifax has been identified as a high priority county due to the amount of intervention time needed to achieve the Healthy People 2020 targets. For instance, the county’s death rate of breast cancer was 36.6 per 100,000 women. This is higher than the United States rate (22.6), as well as the Affiliate service area’s rate (23.5). The death rate decreased from 2006-2010. Currently, the county has the highest rate of breast cancer death in the service area. Additionally, Halifax County’s rate of late-stage diagnosis was 48.5 per 100,000 women. This is higher than the United States (43.7), as well as the Affiliate service area’s rate (45.8). The rate of late-stage diagnosis increased from 2006-2010. Although the screening percentage in Halifax County is higher than the United States and the service area averages, the socioeconomic data for the county shows that Halifax County residents are substantially more likely to have less than a high school education, an income below 250 percent of the federal poverty level, and be unemployed than others in the United States and the Affiliate service area.

Wilson has been identified as a high priority county due to the amount of intervention time needed to achieve the Healthy People 2020 death target. For instance, the county’s death rate of breast cancer was 33.9 per 100,000 women. This is higher than the United States rate (22.6), as well as the Affiliate service area’s rate (23.5). The death rate decreased. Currently, the county has one of the highest rates of breast cancer death in the service area. Wilson County’s rate of late-stage diagnosis was 53.1 per 100,000 women. This is higher than the United States (43.7), as well as the Affiliate service area’s rate (45.8). The rate of late-stage
diagnosis decreased from 2006-2010 and screening percentages in Wilson County are lower than the United States and the service area, which is concerning. The socioeconomic data shows that Wilson County residents are more likely to live in a rural area, have less than a high school education, be unemployed and have no health insurance than others in the United States and the Affiliate service area.

Table 1. Summary table of target community data, 2006-2010

<table>
<thead>
<tr>
<th></th>
<th>Edgecombe County</th>
<th>Halifax County</th>
<th>Wilson County</th>
<th>Service Area</th>
<th>US</th>
<th>Healthy People 2020 Target</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rate</td>
<td>Trend</td>
<td>Rate</td>
<td>Trend</td>
<td>Rate</td>
<td>Trend</td>
</tr>
<tr>
<td>Incidence Rate</td>
<td>120.4</td>
<td>0.5%</td>
<td>135.5</td>
<td>-5.6%</td>
<td>130.2</td>
<td>-4.2%</td>
</tr>
<tr>
<td>Death Rate</td>
<td>33.2</td>
<td>-1.0%</td>
<td>36.6</td>
<td>-0.7%</td>
<td>33.9</td>
<td>-0.1%</td>
</tr>
<tr>
<td>Late-stage Rate</td>
<td>47.7</td>
<td>4.4%</td>
<td>48.5</td>
<td>1.1%</td>
<td>53.1</td>
<td>-6.8%</td>
</tr>
</tbody>
</table>

Health Systems and Public Policy Analysis

The comprehensive cycle of services known as the continuum of care (CoC) is an integrated system of breast health programs and services including varying levels of education, screening, diagnosis, treatment, post-diagnosis, and follow-up. Using the three selected target communities, a Health Systems Analysis was conducted to better understand the gaps, needs and barriers throughout the continuum of care. Edgecombe County has been part of the service area since the Affiliate incorporated in 2000. Halifax County was added to the service area in 2010 and Wilson County was added in the most recent expansion in 2012.

The strengths and weaknesses of the CoC within the target communities are:

- Each county has a major hospital which is now linked to or owned by a larger hospital system.
- There is a county health department located in each of the three communities.
- Each county has one or more North Carolina Breast and Cervical Cancer Control Program (NC BCCCP) providers located within the county.
- Each county is located in a region of the state referred to as Area L or the Upper Coastal Plain and is characterized as having breast cancer death rates that are considerably higher than the average rates in both North Carolina and the United States
- The three county area consists of 229 MD’s (1 per 838 person and 88 Primary Care Physicians (1 per 2183 persons).
- Although hospitals and health care providers are represented throughout the three county region, data reveals that often breast cancer patients travel to Greenville in Pitt County despite the further distance to receive consolidated services and unified medical records.
After conducting an assessment on what health systems are available in the target communities and how the CoC is executed by the facilities, the current and future partnerships in these communities, what state policy work is being done and finally the impact of the Affordable Care Act; the Affiliate can see that there are some positives for the area and much work that needs to be completed to reach Affiliate goals.

Positives in this area are the availability of a hospital and the NC BCCCP in each county. The three counties have resources for screenings from each of the identified health systems. The state’s Cancer Control Plan addresses breast cancer as a priority with strategies and objectives designed to reduce disparity. The Affiliate continues to work with legislators to provide affordable co-pays and treatment options for breast cancer patients.

All three counties are lacking services that facilitate easy progression through the CoC. Improvements to existing providers could bridge some of the gaps in the CoC, such as availability of care in one facility. This could also make it easier for a woman to seek screening, diagnosis, treatment, follow-up and education.

Health systems survey tools were mailed or emailed to 22 entities with only a 30 percent return rate. Since the majority of the staff at the Affiliate is relatively new, relationships with the health system providers as well as NC BCCCP need to be better established to work on sharing of data and resources. This will be a priority over the next few years.

There are twenty-eight providers serving the three target counties chosen. One provider services all three areas and therefore is counted only once in the total, but included in each total for the target counties. With this information, the Affiliate understands that some providers could be overlooked. As relationships are built, outreach and education improved; a more inclusive list of resources can be achieved.

None of the target communities have mobile mammography available which could be an obstacle for those lacking good transportation. Neither Edgecombe nor Wilson County offer patient navigation from screening to diagnosis. Wilson County has the highest percentage of navigation from diagnosis to treatment at 20.0 percent. Edgecombe County offers the highest percentage (23.3 percent) of navigation from treatment to support services. Increasing the percentage of patient navigation could help women receive education and information throughout each stage of the CoC.

While there are multiple providers in each target community, the percentage of each specific service is not higher than forty percent. This illustrates that while there are multiple providers, there are few providers with consolidated service, thereby causing patients to visit multiple providers to follow the CoC from screening to diagnosis to treatment and finally follow-up care. As aforementioned, a facility in Edgecombe County provides service to women from all three of the target counties. Wilson County has only one provider for biopsies, treatment and support/survivorship that is located within the county.
Key partnerships in this area include past and current grantees funded by Komen NCTC. Potential new partners could be the community health centers in the target counties and the BCCCP coordinators at the county health departments. Another partner could be the University of North Carolina School of Public Health for interns who could potentially complete ongoing survey projects to measure the impact of current partnerships and assess the opportunities of untapped grass-root partnerships with churches or other community groups which may exist. Using the National Cancer Institute (NCI), the Affiliate noted there are 37 existing clinical trials. Partnerships with the researchers could provide additional service avenues to the target counties. An Area Health Education Center exists in Rocky Mount that could be another potential partner for an educational partnership.

North Carolina’s decision not to expand Medicaid coverage and to have a federally managed health insurance exchange has caused little impact by the Affordable Care Act on those uninsured and underinsured people in the state. A measure to help this group is ensuring eligible women are enrolled in the NC BCCCP before a cancer diagnosis is imperative so they will not be left struggling to afford treatment and care. The Affiliate needs to educate providers in the area to have their eligible patients enrolled in this program at the time of screening to meet the requirements of the NC BCCCP.

The Affiliate’s policy work is targeted to assist the women in its service area. The Affiliate may have more work to do once the outcome of House Bill 609 is known. The Affiliate will continue to strive for better, more affordable breast health care for the women in its service area by monitoring the state budget and working with legislators.

Qualitative Data: Ensuring Community Input

Comprehensive Cancer Consulting Services (CCCS) of Chapel Hill, NC was retained by the Affiliate to assist in the collection, analysis, and reporting for the Qualitative Data Section of the 2015-2019 Community Profile.

Utilizing the Komen-provided "Qualitative Data Toolkit: Qualitative Question Bank", Affiliate staff and CCCS selected and refined one-hundred and sixteen potential questions from among those provided which were determined to be useful for assessing the issues in each of the three target counties. Each question was classified according to key breast health/cancer issues:

- What General Social and Health Care Indicators Are There in the County? (30 items)
- What Access to Care Initiatives and Issues Are There in the County? (6 items)
- Are There Specific Barriers Affecting Utilization of Breast Health Resources? (21 items)
- What Overarching Community Problems Are There? (2 items)
- Are There Any Disparities That Might Impact the Continuum of Care? (11 items)
- What Educational and Awareness Efforts Are Employed? (20 items)
- Are There Health Care System Bottlenecks That Affect Patients? (5 items)
- What Health Care System Performance Improvements Need to Be Considered? (6 items)
- Is Care Provided in a Timely Fashion? (2 items)
- What Quality of Care Issues Are There? (6 items)
- Are There Specific Survivorship Issues That Are Identified? (7 items)
- What Other Issues Were Identified? (open-ended question)

Questions were then selected to be used in interviews/discussions identified as being most appropriate for each of the four groups:
- Organizations (67 questions)
- Health Care Providers (General) & Advocates (65 questions)
- Health Care Providers - MD's (47 questions + additional 18 questions for PCP's)
- Focus Groups - Survivors and Family (46 questions + 12 questions on profile form)

To gather the data necessary to qualitatively assess breast health issues in the three targeted counties, it was determined that two primary methods would be employed: structured interviews and focus group interviews. The structured interviews (quota sampling) would be conducted with general health care providers, clinical health care providers (MD - Cancer Specialties, MD - Primary Care), and health care organizations (delivery and advocacy) in each of the counties. Focus groups would be conducted with breast cancer survivors and family members recruited (convenience sampling) in each of the three counties.

CCCS, who conducted all key informant interviews and moderated all focus group sessions, has almost forty years of experience in conducting health services research in Eastern North Carolina. Coupled with academic training in Medical Sociology and Anthropology and doctoral in Sociology of Community/Social Change & Development and Adult Education, it was easy to select the best approaches and methods for collecting data. This is how personal interviews and focus group discussions were selected. Rationale for these methods had been established based on many years of success in the region.

In all cases, key informant interviews were conducted with individuals who have previously known and worked with CCCS and, consequently, there was already trust and validation present. Interviews were conducted at the offices of each key informant, where they would feel most comfortable and be able to access information if required.

Focus group sessions were organized on behalf of Komen by trusted community leaders in each of the three counties. And although some participants knew the CCCS facilitator, his presence was validated by those local leaders, as they had known and worked with him for several years. Sessions were conducted in locations that the participants were comfortable and familiar with and at times that were most convenient to them.

The organizations that assisted with the sponsorship of the focus group meetings provided meals and refreshments and although they did not know it ahead of time, each participant received a small gift as a token of appreciation for their participation.
Summary of Qualitative Data Findings:

1. High poverty, un- and under-employment, lack of health insurance or being under-insured appear to be associated with low rates of screening and timely diagnosis, the quality of care provided by physicians, and access to local health care resources.

2. Basic, daily survival needs (food, shelter, safety) over-ride personal and family health care needs.

3. Many of those who do not enter the health care system for screening or diagnosis, as well as those who are moving through the system, are affected by the fear of cancer and also tend to deny the possibility of having cancer.

4. Access to and the availability of transportation is seen as a major problem to screening and care.

5. Knowledge of and outreach to the Hispanic/Latinas population is lacking.

6. There is concern regarding poor primary care physician knowledge of cancer and with them not routinely encouraging or discussing screening and early detection.

7. Physicians providing diagnostic and treatment services do not routinely discuss or involve patients and family in a discussion of options and are generally either not aware of or do not provide information about community resources.

8. Physicians providing diagnostic and treatment services do not routinely discuss the side effects of treatment and how to deal with them, nor do they discuss the long-term effects of treatment.

9. The need for a more personalized approach to care is widely desired.

10. The pain or the fear of pain is considered to be a major factor associated with poor compliance with screening or re-screening participation.

11. The various parts of the cancer care system are not connected to the benefit of effective continuum of care.

12. Rural areas of the three counties are generally excluded from outreach and other health care services.

13. Support for families and caregiver is not widely available or practiced.

14. The entire breast health care system is relatively fragile. There are missing pieces, some services and resources are only "one deep", many services rely on year-to-year funding, and other health care system or community needs may replace any emphasis on breast cancer.
Mission Action Plan

Problem: According to Quantitative Data, Edgecombe, Halifax and Wilson Counties are unlikely to meet Healthy People 2020 targets for both breast cancer death and late-stage incidence and are located far from most breast health providers.

Priority: Reduce the number of late-stage diagnoses among women in Edgecombe, Halifax and Wilson Counties.
- **Objective 1:** In FY 2016, hold at least one collaborative meeting in each of the three target communities aimed at hospitals, primary care providers, local health departments, and community-based organizations to foster the discussion around how to improve access, financial assistance and continuity of care between referral, screening, diagnosis, treatment, and support services within Edgecombe, Halifax and Wilson Counties.
- **Objective 2:** In FY2018, hold rural breast cancer summit with providers in Edgecombe, Halifax and Wilson Counties to discuss possible partnership opportunities with the goal of increasing access to and seamless progression through the breast health continuum of care.

Problem: Based on Qualitative Data collected during focus groups, women cannot afford out-of-pocket costs associated with primary medical care nor breast health services.

Priority: Increase the number of health services and providers available in Edgecombe, Halifax and Wilson Counties by funding health system partnerships to increase access to services.
- **Objective 1:** By December 2015 hold at least one grant writing workshop in the Area L region aimed at existing breast health providers identified on the resource map.
- **Objective 2:** In FY 2017, develop a collaborative RFA grant encouraging providers to submit proposals that offer subsidies for mammograms for uninsured women in Edgecombe, Halifax, and Wilson Counties.
- **Objective 3:** For FY 2016, boost funding to patient navigator programs aimed specifically at working with minority residents in Edgecombe, Halifax, and Wilson Counties.

Problem: Based on Qualitative Data, in Edgecombe, Halifax and Wilson Counties women do not have easy access to affordable mammography.

Priority: Investigate ways to make screening more accessible and affordable for women residing in each of the three target communities including but not limited to the possibility of obtaining mobile mammography through the one hospital that provides service to all three counties.
- **Objective 1:** In FY 2016 meet with Vidant Edgecombe Hospital to discuss the possibility of obtaining mobile mammography through the Greenville-based
hospital care system network and strategize about other ways to increase access to breast cancer screening.

**Problem:** Based on Qualitative Data, Halifax County has the highest death rate in the service area.

**Priority:** Reduce the breast cancer death rate for all women in Halifax County.

- **Objective 1:** In FY 2016, meet with the Roanoke Valley Breast Cancer Coalition, to strategize how to effectively reach more women in the county of all racial groups.
- **Objective 2:** Meet with Halifax Regional Hospital, the largest provider of breast cancer screenings in the county, to strategize how to educate all women in the county about screening recommendations and how to provide those women with cost-effective screening based on the guidelines.

**Problem:** Based on information gathered in the Health System and Public Policy Analysis, here is not adequate support for community mobilizing and provider capacity building in the three target communities.

**Priority:** Actively participate in creating community partnerships and programs to address the lack of available services due to inadequate capacity to offer such services.

- **Objective 1:** By FY 2018, begin offering small grants, $10,000 or less, to providers to build their capacity to address breast health/cancer issues specifically identified for their communities.
- **Objective 2:** By FY 2018, the Small Grants RFA will give priority to organizations that collaborate with one or more providers in their region to mobilize their communities to create an information network that would allow them to promote the availability of these services.

**Problem:** All three of the identified target communities are all classified as Tier One counties by the North Carolina Department of Commerce making them some of the most economically distressed in North Carolina.

**Priority:** Create a system that allows Tier One counties in the Komen NCTC service area to receive priority when applying for funding through the Community Health Grants Program.

- **Objective 1:** In FY 2016-2019, county tier designation will be one of the selection criteria for consideration for grant funding. Counties designated as Tier One will receive additional points during the scoring of applications by the independent review committee.

**Disclaimer:** Comprehensive data for the Executive Summary can be found in the 2015 Susan G. Komen® North Carolina Triangle to the Coast Community Profile Report.
Affiliate History

In 2015, Susan G. Komen® North Carolina Triangle to the Coast embarks on the 19th anniversary of its presence in this community with the knowledge that they have created a culture that has focused on bringing the Komen mission to as many individuals in central and eastern North Carolina as possible.

In 1996, the Susan G. Komen granted the right to host a Komen Race for the Cure® event in Raleigh, North Carolina (Figure 1.1). This was a grassroots effort spearheaded by the late Jeanne Peck, founder of Komen North Carolina Triangle to the Coast (NCTC). That first Race on June 7, 1997 had 2,500 participants and raised close to $100,000. By contrast, on June 13, 2015, Komen NCTC hosted the 19th annual Komen Triangle Race for the Cure® which raised close to $1,000,000 with over 8,200 participants.

In 2000, Komen NCTC board of directors incorporated the organization and selected a service area consisting of 13 counties in east central North Carolina. The current service area has been expanded several times to reach the current 29-county area served today.

In 2008, the Affiliate was recognized as the Komen Headquarters Affiliate of the Year as a result of a focused effort to maximize the impact of mission spending, Affiliate-facilitated community mobilizing and provider capacity building, and organizational development designed to create a strong staff and volunteer network. Rankings of over 100 Susan G. Komen Affiliates in 2014

Figure 1.1. Komen North Carolina Triangle to the Coast timeline

In 2015, Susan G. Komen® North Carolina Triangle to the Coast embarks on the 19th anniversary of its presence in this community with the knowledge that they have created a culture that has focused on bringing the Komen mission to as many individuals in central and eastern North Carolina as possible.
placed Komen North Carolina Triangle to the Coast 30th overall based on gross revenues without in-kind. In addition, several individuals have received the Promise of One award, which is presented by Komen Headquarters to volunteers who have made contributions to their local Affiliates.

The Affiliate has been awarded two national Komen grants, “The Area L Breast Cancer Initiative” is a multi-year effort focused on reducing breast health disparities in a five-county region in the Upper Coastal Plain region of northeastern North Carolina. The project is in the third and final phase scheduled to be completed in August 2015. The Affiliate is currently working with a consultant to conduct a thorough evaluation of the Area L project to assist Komen NCTC in planning future initiatives in the region.

The Affiliate also received funding from Yoplait Fondo Para la Mujer for the “Latino/Hispanic Community Advisory Group: A Plan for NC Triangle and Beyond.” This grant allowed Komen NCTC to work with Hispanic and Latino leaders to create a community action plan to provide breast health services to this targeted population.

Komen North Carolina Triangle to the Coast funds programs that provide essential direct patient care services for breast cancer screening and treatment as well as programs that provide education and social support. The goal is to encourage ingenuity, innovation and collaboration among existing and potential new service providers. The Affiliate looks for outcomes that address both the longevity of life after diagnosis and the quality of care across the entire continuum of care. In considering the balance of funds awarded during each grant cycle, the Affiliate strives to minimize duplication of services and maximize the use of existing structures by encouraging partnerships and collaborations within communities. In the 2014-15 grant cycle, Komen NCTC awarded 11 community health grants to community-based, nonprofit organizations providing breast health and breast cancer services. The total amount of funds granted out was $475,000. This included ten direct patient service grants for screening and treatment and one social support program. Since its inception, Komen NCTC has invested more than $14 million in local breast cancer services and breast health awareness programs throughout central and eastern North Carolina.

Komen North Carolina Triangle to the Coast is recognized as a leader in the breast cancer community in not only central and eastern North Carolina where the Affiliate is located but in the state as a whole. Representatives from the Affiliate serve on a variety of boards, coalitions, committees and advisory groups and the Affiliate’s expertise, advice, influence and participation are requested by numerous entities when breast cancer and breast health are part of the agenda.

Some of the committees and organizations on which either Komen NCTC board members or staff serve are the North Carolina Cancer Coalition, NC Comprehensive Cancer Control Plan Implementation Advisory Committee, North Carolina Breast and Cervical Cancer Control Program Advisory Committee, NC Medicaid Expansion Coalition, Upper Coastal Plain Breast
Cancer Advisory Group, Roanoke Valley Breast Cancer Coalition, the NC Foundation for Advanced Health Programs Board of Directors and the Duke Patient Advocacy Council.

**Affiliate Organizational Structure**

Komen NCTC went from being a completely volunteer run organization to having paid staff when the first executive director was hired in 2004. The current staff consists of seven full-time and two part-time positions which includes experts in development, event planning, communications, health education and data management (Figure 1.2).

![Organizational Structure Diagram](image)

**Figure 1.2.** Komen North Carolina Triangle to the Coast organizational structure

The 12-15 member Komen NCTC Board of Directors is a diverse group of individuals representing health care and hospitals, financial institutions, accounting and law firms and corporations and includes community and business leaders, accountants, lawyers, physicians and survivors. The Board serves primarily as a governing board but does necessary work through a committee structure consisting of governance, finance, development and executive committees. The Board meets bi-monthly with the executive committee meeting during the other months. Periodically, the Board creates task forces who meet for a specified amount of time to work on specific issues that may arise.

**Affiliate Service Area**

Komen NCTC encompasses a 29-county service area in central and eastern North Carolina (Figure 1.3). From incorporation in 2000 with 13 counties, the service area was expanded to 20 counties in 2010 and an additional nine counties were added in 2012 giving the Affiliate the
current service area. Counties that are served by the Affiliate are Bladen, Brunswick, Caswell, Chatham, Columbus, Duplin, Durham, Edgecombe, Franklin, Granville, Halifax, Harnett, Johnston, Lee, Moore, Nash, New Hanover, Northampton, Onslow, Orange, Pender, Person, Pitt, Sampson, Scotland, Vance, Warren, Wake, and Wilson.

**KOMEN NC TRIANGLE TO THE COAST SERVICE AREA**

![Map of service area](image)

*Figure 1.3. Susan G. Komen North Carolina Triangle to the Coast service area*
The Affiliate service area is both demographically and geographically diverse; spanning from predominantly metropolitan, high-density communities such as Raleigh (Wake County), Durham (Durham County) and Chapel Hill (Orange County) to largely rural, low-density regions such as Caswell, Columbus, Duplin, Edgecombe, Halifax and Vance Counties. Additionally, several regions are characterized by mid-sized towns with above average wealth surrounded by low-density, less affluent regions, such as Pinehurst in Moore County which is a golf and retirement resort area and home to both the US Open Men’s and Women’s golf tournaments in 2014 and Greenville, located in Pitt County, home to East Carolina University and Brody School of Medicine. The economic profile and racial/ethnic composition of these North Carolina communities have undergone challenges and changes that have influenced availability of and access to breast health services. Also, a five-county region in the northeastern part of the service area, known as Area L, has some of the highest breast cancer death rates in the United States and has been the focus of a multi-year grant from Komen Headquarters to reduce breast cancer disparities in the region.

**Purpose of the Community Profile Report**

The purpose of the Community Profile Report is to:
- Align strategic and operational plans
- Drive inclusion efforts in the community
- Drive public policy and advocacy efforts
- Establish focused granting priorities
- Establish focused education needs within the service area
- Establish directions for marketing and outreach
- Strengthen sponsorship efforts

The information contained in this report comes from local, state and national sources, including agencies, organizations and individuals, in order to provide an accurate portrayal of the service area. The use of key informant interviews in the target communities allows the Affiliate to include diverse perspectives of survivors, health care providers, and community members and leaders to get a well-rounded perspective of breast health and cancer services in the community. The demographic and statistical breast cancer data will assist the Affiliate in identifying where the mission efforts will be most effective and to expand the reach of existing and future programs.

The Community Profile Report will serve as the Affiliate’s main mission communication tool and will help educate and inform Affiliate stakeholders (e.g. grantees, partners, donors, sponsors, legislators, other breast cancer-focused organizations and the community-at-large) regarding the state of breast cancer in the service area, the Affiliate’s current mission priorities, and the plan to address the identified breast health and breast cancer needs within target communities that were identified as part of the Community Profile process.

The 2015 Community Profile Report, in its entirety, is located on the Affiliate website but with direct links to the Executive Summary and the Mission Action Plan for those not interested in
reading the full report. The report will be disseminated in a variety of ways to ensure that those who can benefit from this information will have access to it. News releases will go out to all media outlets in the Affiliate service area making them aware that the 2015 North Carolina Triangle to the Coast Community Profile Report is now available.

All members of the NC General Assembly who represent the 29 county service area will receive a copy of the Community Profile. In addition, the Affiliate will schedule a meeting with each member of Congress from its Region. A Komen NCTC staff member and volunteer will share the report and discuss it in more detail with emphasis on how it will directly impact their constituents and the communities they serve. Also, all current Komen NCTC grantees will receive a copy of the report as well as any organizations who have received Komen funding since the last profile was released. Future grantees will receive a copy of the Report at the time they sign a contract to accept Komen funds and all applicants for funding will be notified about how to access the Community Profile online.

Availability of and data from the Profile will be promoted on social media and general data as well as data targeted to specific audiences will be incorporated into presentations and speeches delivered by Affiliate staff and board members. The Affiliate has divided the service area into four regions and will be conducting an analysis of each individual region. When this data is ready to be released, the Affiliate will hold regional town meetings to share the 2015 Community Profile and the region specific information gathered from the analysis.
Quantitative Data Report

Introduction
The purpose of the quantitative data report for Susan G. Komen® North Carolina Triangle to the Coast 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 North Carolina Triangle to the Coast’s Quantitative Data Report. 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/](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

<table>
<thead>
<tr>
<th>Population Group</th>
<th>Incidence Rates and Trends</th>
<th>Death Rates and Trends</th>
<th>Late-stage Rates and Trends</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female Population (Annual Average)</td>
<td># of New Cases (Annual Average)</td>
<td>Age-adjusted Rate/100,000</td>
</tr>
<tr>
<td>US</td>
<td>154,540,194</td>
<td>198,602</td>
<td>122.1</td>
</tr>
<tr>
<td>HP2020</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>North Carolina</td>
<td>4,751,657</td>
<td>6,681</td>
<td>124.9</td>
</tr>
<tr>
<td>Komen North Carolina Triangle to the Coast Service Area</td>
<td>1,631,994</td>
<td>2,188</td>
<td>125.0</td>
</tr>
<tr>
<td>White</td>
<td>1,122,307</td>
<td>1,591</td>
<td>125.5</td>
</tr>
<tr>
<td>Black/African-American</td>
<td>445,235</td>
<td>548</td>
<td>124.5</td>
</tr>
<tr>
<td>American Indian/Alaska Native (AIAN)</td>
<td>18,323</td>
<td>8</td>
<td>57.5</td>
</tr>
<tr>
<td>Asian Pacific Islander (API)</td>
<td>46,128</td>
<td>22</td>
<td>69.2</td>
</tr>
<tr>
<td>Non-Hispanic/ Latina</td>
<td>1,510,859</td>
<td>2,147</td>
<td>126.3</td>
</tr>
<tr>
<td>Hispanic/ Latina</td>
<td>121,135</td>
<td>40</td>
<td>85.5</td>
</tr>
<tr>
<td>Bladen County - NC</td>
<td>18,030</td>
<td>17</td>
<td>78.5</td>
</tr>
<tr>
<td>Brunswick County - NC</td>
<td>51,994</td>
<td>89</td>
<td>116.8</td>
</tr>
<tr>
<td>Caswell County - NC</td>
<td>11,727</td>
<td>22</td>
<td>139.5</td>
</tr>
<tr>
<td>Chatham County - NC</td>
<td>31,690</td>
<td>57</td>
<td>133.7</td>
</tr>
<tr>
<td>Columbus County - NC</td>
<td>29,059</td>
<td>37</td>
<td>102.4</td>
</tr>
<tr>
<td>Duplin County - NC</td>
<td>28,792</td>
<td>34</td>
<td>100.8</td>
</tr>
<tr>
<td>Durham County - NC</td>
<td>134,994</td>
<td>175</td>
<td>134.9</td>
</tr>
<tr>
<td>Edgecombe County - NC</td>
<td>30,165</td>
<td>44</td>
<td>120.4</td>
</tr>
<tr>
<td>Franklin County - NC</td>
<td>29,429</td>
<td>41</td>
<td>121.6</td>
</tr>
<tr>
<td>Granville County - NC</td>
<td>27,150</td>
<td>38</td>
<td>117.0</td>
</tr>
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<td>Halifax County - NC</td>
<td>28,868</td>
<td>50</td>
<td>135.5</td>
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<td>Harnett County - NC</td>
<td>55,606</td>
<td>65</td>
<td>117.7</td>
</tr>
<tr>
<td>Johnston County - NC</td>
<td>81,472</td>
<td>95</td>
<td>113.2</td>
</tr>
<tr>
<td>Lee County - NC</td>
<td>28,350</td>
<td>41</td>
<td>122.6</td>
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<tr>
<td>Moore County - NC</td>
<td>44,764</td>
<td>90</td>
<td>138.7</td>
</tr>
<tr>
<td>Nash County - NC</td>
<td>48,828</td>
<td>77</td>
<td>129.2</td>
</tr>
<tr>
<td>New Hanover County - NC</td>
<td>101,808</td>
<td>151</td>
<td>130.8</td>
</tr>
<tr>
<td>Northampton County - NC</td>
<td>11,469</td>
<td>19</td>
<td>118.0</td>
</tr>
<tr>
<td>Onslow County - NC</td>
<td>77,084</td>
<td>74</td>
<td>118.1</td>
</tr>
</tbody>
</table>
## Incidence Rates and Trends

<table>
<thead>
<tr>
<th>Population Group</th>
<th>Female Population (Annual Average)</th>
<th># of New Cases (Annual Average)</th>
<th>Age-adjusted Rate/100,000</th>
<th>Trend (Annual Percent Change)</th>
<th># of Deaths (Annual Average)</th>
<th>Age-adjusted Rate/100,000</th>
<th>Trend (Annual Percent Change)</th>
<th># of New Cases (Annual Average)</th>
<th>Age-adjusted Rate/100,000</th>
<th>Trend (Annual Percent Change)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orange County - NC</td>
<td>67,855</td>
<td>89</td>
<td>135.5</td>
<td>-4.1%</td>
<td>16</td>
<td>25.6</td>
<td>-1.4%</td>
<td>29</td>
<td>45.1</td>
<td>-13.4%</td>
</tr>
<tr>
<td>Pender County - NC</td>
<td>25,162</td>
<td>40</td>
<td>126.0</td>
<td>6.8%</td>
<td>7</td>
<td>22.7</td>
<td>-2.6%</td>
<td>15</td>
<td>46.0</td>
<td>2.7%</td>
</tr>
<tr>
<td>Person County - NC</td>
<td>20,095</td>
<td>25</td>
<td>97.6</td>
<td>12.0%</td>
<td>6</td>
<td>24.6</td>
<td>-3.9%</td>
<td>7</td>
<td>30.4</td>
<td>4.3%</td>
</tr>
<tr>
<td>Pitt County - NC</td>
<td>85,266</td>
<td>114</td>
<td>144.1</td>
<td>3.6%</td>
<td>18</td>
<td>22.6</td>
<td>-1.4%</td>
<td>42</td>
<td>53.8</td>
<td>0.9%</td>
</tr>
<tr>
<td>Sampson County - NC</td>
<td>31,980</td>
<td>41</td>
<td>108.4</td>
<td>2.3%</td>
<td>9</td>
<td>23.7</td>
<td>-2.3%</td>
<td>15</td>
<td>40.4</td>
<td>16.8%</td>
</tr>
<tr>
<td>Scotland County - NC</td>
<td>18,858</td>
<td>22</td>
<td>98.2</td>
<td>-7.3%</td>
<td>5</td>
<td>23.1</td>
<td>-1.4%</td>
<td>7</td>
<td>32.6</td>
<td>-33.2%</td>
</tr>
<tr>
<td>Vance County - NC</td>
<td>23,764</td>
<td>31</td>
<td>114.2</td>
<td>9.9%</td>
<td>5</td>
<td>17.8</td>
<td>-2.8%</td>
<td>14</td>
<td>52.3</td>
<td>9.9%</td>
</tr>
<tr>
<td>Wake County - NC</td>
<td>435,750</td>
<td>530</td>
<td>131.0</td>
<td>-0.1%</td>
<td>88</td>
<td>22.7</td>
<td>-2.0%</td>
<td>198</td>
<td>47.7</td>
<td>1.5%</td>
</tr>
<tr>
<td>Warren County - NC</td>
<td>10,346</td>
<td>16</td>
<td>112.1</td>
<td>-0.7%</td>
<td>4</td>
<td>24.9</td>
<td>NA</td>
<td>7</td>
<td>56.8</td>
<td>-15.4%</td>
</tr>
<tr>
<td>Wilson County - NC</td>
<td>41,639</td>
<td>64</td>
<td>130.2</td>
<td>-4.2%</td>
<td>17</td>
<td>33.9</td>
<td>-0.1%</td>
<td>26</td>
<td>53.1</td>
<td>-6.8%</td>
</tr>
</tbody>
</table>

*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 US standard population.
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 rate in the Komen North Carolina Triangle to the Coast service area was slightly higher than that observed in the US as a whole and the incidence trend was higher than the US as a whole. The incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of North Carolina.

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 APIs and AIANs were lower than for Non-Hispanic Whites and Blacks/African-Americans. The most recent estimated incidence rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the incidence rate was slightly lower among Blacks/African-Americans than Whites, lower among APIs than Whites, and lower among AIANs than Whites. The incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

The following county had an incidence rate significantly higher than the Affiliate service area as a whole:
- Pitt County
The incidence rate was significantly lower in the following counties:

- Bladen County
- Columbus County
- Duplin County
- Person County
- Scotland County

**Significantly less favorable trends** in breast cancer incidence rates were observed in the following county:

- Person County

The rest of the counties had incidence rates and trends that were not significantly different than the Affiliate service area as a whole or did not have enough data available.

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

**Death rates and trends summary**

Overall, the breast cancer death rate in the Komen North Carolina Triangle to the Coast service area was similar to that observed in the US as a whole and the death rate trend was not available for comparison with the US as a whole. The death rate of the Affiliate service area was not significantly different than that observed for the State of North Carolina.

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

The following counties had a death rate significantly higher than the Affiliate service area as a whole:

- Edgecombe County
- Halifax County
- Wilson County

The death rate was significantly lower in the following county:

- Chatham County

The rest of the counties had death rates and trends that were not significantly different than the Affiliate service area as a whole or did not have enough data available.
Late-stage incidence rates and trends summary
Overall, the breast cancer late-stage incidence rate in the Komen North Carolina Triangle to the Coast service area was slightly higher than that observed in the US as a whole and the late-stage incidence trend was higher than the US as a whole. The late-stage incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of North Carolina.

For the United States, late-stage incidence rates in Blacks/African-Americans are higher than among Whites. Hispanics/Latinas tend to be diagnosed with late-stage breast cancers more often than Whites. For the Affiliate service area as a whole, the late-stage incidence rate was higher among Blacks/African-Americans than Whites and lower among APIs than Whites. There were not enough data available within the Affiliate service area to report on AIANs so comparisons cannot be made for this racial group. The late-stage incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

The late-stage incidence rate was significantly lower in the following counties:
- Brunswick County
- Person County

Significantly more favorable trends in breast cancer late-stage incidence rates were observed in the following county:
- Scotland County

The rest of the counties had late-stage incidence rates and trends that were not significantly different than the Affiliate service area as a whole or did not have enough data available.

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*

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

*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 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 age 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 age 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 age 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 ages 50-74 with screening mammography in the last two years, self-report

<table>
<thead>
<tr>
<th>Population Group</th>
<th># of Women Interviewed (Sample Size)</th>
<th># w/ Self-Reported Mammogram</th>
<th>Proportion Screened (Weighted Average)</th>
<th>Confidence Interval of Proportion Screened</th>
</tr>
</thead>
<tbody>
<tr>
<td>US</td>
<td>174,796</td>
<td>133,399</td>
<td>77.5%</td>
<td>77.2%-77.7%</td>
</tr>
<tr>
<td>North Carolina</td>
<td>4,324</td>
<td>3,445</td>
<td>79.4%</td>
<td>77.9%-80.9%</td>
</tr>
<tr>
<td>Komen North Carolina Triangle to the Coast Service Area</td>
<td>1,333</td>
<td>1,089</td>
<td>81.7%</td>
<td>78.9%-84.2%</td>
</tr>
<tr>
<td>White</td>
<td>993</td>
<td>803</td>
<td>81.5%</td>
<td>78.3%-84.3%</td>
</tr>
<tr>
<td>Black/African-American</td>
<td>286</td>
<td>243</td>
<td>82.6%</td>
<td>76.2%-87.6%</td>
</tr>
<tr>
<td>AIAN</td>
<td>11</td>
<td>9</td>
<td>71.1%</td>
<td>36.0%-91.5%</td>
</tr>
<tr>
<td>API</td>
<td>SN</td>
<td>SN</td>
<td>SN</td>
<td>SN</td>
</tr>
<tr>
<td>Hispanic/ Latina</td>
<td>20</td>
<td>14</td>
<td>74.3%</td>
<td>49.2%-89.6%</td>
</tr>
<tr>
<td>Non-Hispanic/ Latina</td>
<td>1,311</td>
<td>1,074</td>
<td>81.9%</td>
<td>79.1%-84.4%</td>
</tr>
<tr>
<td>Bladen County - NC</td>
<td>17</td>
<td>12</td>
<td>79.7%</td>
<td>51.3%-93.6%</td>
</tr>
<tr>
<td>Brunswick County - NC</td>
<td>82</td>
<td>70</td>
<td>87.9%</td>
<td>77.3%-93.9%</td>
</tr>
<tr>
<td>Caswell County - NC</td>
<td>15</td>
<td>13</td>
<td>77.3%</td>
<td>47.0%-92.9%</td>
</tr>
<tr>
<td>Chatham County - NC</td>
<td>33</td>
<td>29</td>
<td>91.4%</td>
<td>73.5%-97.6%</td>
</tr>
<tr>
<td>Columbus County - NC</td>
<td>24</td>
<td>19</td>
<td>69.7%</td>
<td>46.7%-85.8%</td>
</tr>
<tr>
<td>Duplin County - NC</td>
<td>22</td>
<td>18</td>
<td>75.6%</td>
<td>49.3%-90.8%</td>
</tr>
<tr>
<td>Durham County - NC</td>
<td>140</td>
<td>122</td>
<td>87.9%</td>
<td>78.4%-93.6%</td>
</tr>
<tr>
<td>Edgecombe County - NC</td>
<td>25</td>
<td>21</td>
<td>89.4%</td>
<td>64.1%-97.6%</td>
</tr>
<tr>
<td>Franklin County - NC</td>
<td>15</td>
<td>10</td>
<td>77.5%</td>
<td>48.0%-92.7%</td>
</tr>
<tr>
<td>Granville County - NC</td>
<td>24</td>
<td>21</td>
<td>90.7%</td>
<td>66.8%-97.9%</td>
</tr>
<tr>
<td>Halifax County - NC</td>
<td>39</td>
<td>32</td>
<td>88.0%</td>
<td>71.1%-95.6%</td>
</tr>
<tr>
<td>Population Group</td>
<td># of Women Interviewed (Sample Size)</td>
<td># w/ Self-Reported Mammogram</td>
<td>Proportion Screened (Weighted Average)</td>
<td>Confidence Interval of Proportion Screened</td>
</tr>
<tr>
<td>---------------------------</td>
<td>--------------------------------------</td>
<td>------------------------------</td>
<td>---------------------------------------</td>
<td>--------------------------------------------</td>
</tr>
<tr>
<td>Harnett County - NC</td>
<td>43</td>
<td>28</td>
<td>68.9%</td>
<td>49.7%-83.3%</td>
</tr>
<tr>
<td>Johnston County - NC</td>
<td>60</td>
<td>49</td>
<td>80.2%</td>
<td>64.7%-90.0%</td>
</tr>
<tr>
<td>Lee County - NC</td>
<td>26</td>
<td>25</td>
<td>96.6%</td>
<td>74.6%-99.6%</td>
</tr>
<tr>
<td>Moore County - NC</td>
<td>51</td>
<td>38</td>
<td>69.1%</td>
<td>50.9%-82.9%</td>
</tr>
<tr>
<td>Nash County - NC</td>
<td>57</td>
<td>48</td>
<td>86.5%</td>
<td>71.8%-94.1%</td>
</tr>
<tr>
<td>New Hanover County - NC</td>
<td>166</td>
<td>138</td>
<td>87.6%</td>
<td>79.5%-92.8%</td>
</tr>
<tr>
<td>Northampton County - NC</td>
<td>13</td>
<td>12</td>
<td>88.0%</td>
<td>60.1%-97.3%</td>
</tr>
<tr>
<td>Onslow County - NC</td>
<td>42</td>
<td>33</td>
<td>80.9%</td>
<td>62.8%-91.4%</td>
</tr>
<tr>
<td>Orange County - NC</td>
<td>66</td>
<td>56</td>
<td>88.3%</td>
<td>75.6%-94.8%</td>
</tr>
<tr>
<td>Pender County - NC</td>
<td>24</td>
<td>21</td>
<td>83.3%</td>
<td>59.5%-94.4%</td>
</tr>
<tr>
<td>Person County - NC</td>
<td>19</td>
<td>15</td>
<td>77.3%</td>
<td>49.2%-92.3%</td>
</tr>
<tr>
<td>Pitt County - NC</td>
<td>54</td>
<td>42</td>
<td>76.8%</td>
<td>60.7%-87.7%</td>
</tr>
<tr>
<td>Sampson County - NC</td>
<td>26</td>
<td>21</td>
<td>81.2%</td>
<td>56.3%-93.5%</td>
</tr>
<tr>
<td>Scotland County - NC</td>
<td>21</td>
<td>17</td>
<td>81.0%</td>
<td>55.6%-93.6%</td>
</tr>
<tr>
<td>Vance County - NC</td>
<td>17</td>
<td>14</td>
<td>78.8%</td>
<td>48.1%-93.7%</td>
</tr>
<tr>
<td>Wake County - NC</td>
<td>155</td>
<td>119</td>
<td>77.2%</td>
<td>68.7%-84.0%</td>
</tr>
<tr>
<td>Warren County - NC</td>
<td>14</td>
<td>13</td>
<td>97.8%</td>
<td>69.3%-99.9%</td>
</tr>
<tr>
<td>Wilson County - NC</td>
<td>43</td>
<td>33</td>
<td>74.0%</td>
<td>55.0%-86.9%</td>
</tr>
</tbody>
</table>

SN – data suppressed due to small numbers (fewer than 10 samples).
Data are for 2012.
Source: CDC – Behavioral Risk Factor Surveillance System (BRFSS).

**Breast cancer screening proportions summary**

The breast cancer screening proportion in the Komen North Carolina Triangle to the Coast service area was significantly higher than that observed in the US as a whole. The screening proportion of the Affiliate service area was not significantly different than the State of North Carolina.

For the United States, breast cancer screening proportions among Blacks/African-Americans are similar to those among Whites overall. APIs have somewhat lower screening proportions than Whites and Blacks/African-Americans. Although data are limited, screening proportions among AIANs are similar to those among Whites. Screening proportions among Hispanics/Latinas are similar to those among Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the screening proportion was not significantly different among Blacks/African-Americans than Whites and not significantly different among AIANs than Whites. There were not enough data available within the Affiliate service area to report on APIs so comparisons cannot be made for this racial group. The screening proportion among Hispanics/Latinas was not significantly different than among Non-Hispanics/Latinas.
None of the counties in the Affiliate service area had substantially different screening proportions than the Affiliate service area as a whole.

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

It is important to note that the report uses the race and ethnicity categories used by the US 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 US 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 age 15 and older for income and unemployment and age 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>
<thead>
<tr>
<th>Population Group</th>
<th>White</th>
<th>Black /African-American</th>
<th>AIAN</th>
<th>API</th>
<th>Non-Hispanic /Latina</th>
<th>Hispanic /Latina</th>
<th>Female Age 40 Plus</th>
<th>Female Age 50 Plus</th>
<th>Female Age 65 Plus</th>
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<tbody>
<tr>
<td>US</td>
<td>78.8%</td>
<td>14.1%</td>
<td>1.4%</td>
<td>5.8%</td>
<td>83.8%</td>
<td>16.2%</td>
<td>48.3%</td>
<td>34.5%</td>
<td>14.8%</td>
</tr>
<tr>
<td>North Carolina</td>
<td>72.3%</td>
<td>23.4%</td>
<td>1.6%</td>
<td>2.6%</td>
<td>92.2%</td>
<td>7.8%</td>
<td>48.6%</td>
<td>34.5%</td>
<td>14.8%</td>
</tr>
<tr>
<td>Komen North Carolina Triangle to the Coast Service Area</td>
<td>68.6%</td>
<td>27.1%</td>
<td>1.2%</td>
<td>3.1%</td>
<td>91.7%</td>
<td>8.3%</td>
<td>46.7%</td>
<td>32.8%</td>
<td>13.6%</td>
</tr>
<tr>
<td>Bladen County - NC</td>
<td>59.4%</td>
<td>37.5%</td>
<td>2.7%</td>
<td>0.4%</td>
<td>93.9%</td>
<td>6.1%</td>
<td>53.9%</td>
<td>40.8%</td>
<td>18.2%</td>
</tr>
<tr>
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<td>86.2%</td>
<td>12.2%</td>
<td>0.8%</td>
<td>0.9%</td>
<td>95.7%</td>
<td>4.3%</td>
<td>61.1%</td>
<td>49.3%</td>
<td>22.6%</td>
</tr>
<tr>
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<td>0.5%</td>
<td>97.3%</td>
<td>2.7%</td>
<td>58.5%</td>
<td>44.3%</td>
<td>19.2%</td>
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<td>14.5%</td>
<td>1.2%</td>
<td>1.5%</td>
<td>87.9%</td>
<td>12.1%</td>
<td>57.9%</td>
<td>43.9%</td>
<td>20.5%</td>
</tr>
<tr>
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<td>65.1%</td>
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<td>3.7%</td>
<td>0.5%</td>
<td>95.9%</td>
<td>4.1%</td>
<td>52.7%</td>
<td>39.5%</td>
<td>18.1%</td>
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<td>1.4%</td>
<td>1.0%</td>
<td>81.2%</td>
<td>18.8%</td>
<td>49.5%</td>
<td>36.3%</td>
<td>16.2%</td>
</tr>
<tr>
<td>Durham County - NC</td>
<td>52.8%</td>
<td>41.4%</td>
<td>1.0%</td>
<td>4.8%</td>
<td>88.3%</td>
<td>11.7%</td>
<td>42.2%</td>
<td>29.2%</td>
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<tr>
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<td>0.6%</td>
<td>0.4%</td>
<td>96.6%</td>
<td>3.4%</td>
<td>52.2%</td>
<td>38.8%</td>
<td>16.8%</td>
</tr>
<tr>
<td>Franklin County - NC</td>
<td>69.8%</td>
<td>28.5%</td>
<td>0.9%</td>
<td>0.9%</td>
<td>92.8%</td>
<td>7.2%</td>
<td>51.4%</td>
<td>36.5%</td>
<td>15.0%</td>
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<tr>
<td>Granville County - NC</td>
<td>65.6%</td>
<td>32.7%</td>
<td>0.9%</td>
<td>0.8%</td>
<td>93.4%</td>
<td>6.6%</td>
<td>52.7%</td>
<td>36.9%</td>
<td>15.3%</td>
</tr>
<tr>
<td>Halifax County - NC</td>
<td>40.7%</td>
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<td>3.7%</td>
<td>0.8%</td>
<td>98.0%</td>
<td>2.0%</td>
<td>54.8%</td>
<td>41.2%</td>
<td>18.8%</td>
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<td>2.0%</td>
<td>1.6%</td>
<td>89.8%</td>
<td>10.2%</td>
<td>41.8%</td>
<td>28.5%</td>
<td>11.7%</td>
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<tr>
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<td>0.9%</td>
<td>88.3%</td>
<td>11.7%</td>
<td>46.3%</td>
<td>30.5%</td>
<td>11.9%</td>
</tr>
<tr>
<td>Lee County - NC</td>
<td>75.7%</td>
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<td>1.2%</td>
<td>1.4%</td>
<td>82.9%</td>
<td>17.1%</td>
<td>48.2%</td>
<td>34.8%</td>
<td>15.6%</td>
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<tr>
<td>Moore County - NC</td>
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<td>1.0%</td>
<td>1.4%</td>
<td>94.5%</td>
<td>5.5%</td>
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<td>1.0%</td>
<td>1.1%</td>
<td>94.1%</td>
<td>5.9%</td>
<td>52.3%</td>
<td>38.2%</td>
<td>16.2%</td>
</tr>
<tr>
<td>New Hanover County - NC</td>
<td>81.6%</td>
<td>16.1%</td>
<td>0.6%</td>
<td>1.7%</td>
<td>95.1%</td>
<td>4.9%</td>
<td>48.8%</td>
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<td>15.8%</td>
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<td>0.3%</td>
<td>98.9%</td>
<td>1.1%</td>
<td>60.5%</td>
<td>47.6%</td>
<td>23.6%</td>
</tr>
<tr>
<td>Onslow County - NC</td>
<td>77.3%</td>
<td>18.3%</td>
<td>0.9%</td>
<td>3.4%</td>
<td>90.3%</td>
<td>9.7%</td>
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<td>23.5%</td>
<td>9.4%</td>
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<td>7.6%</td>
<td>92.7%</td>
<td>7.3%</td>
<td>43.2%</td>
<td>29.8%</td>
<td>11.0%</td>
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<td>0.7%</td>
<td>94.4%</td>
<td>5.6%</td>
<td>53.2%</td>
<td>38.8%</td>
<td>16.7%</td>
</tr>
<tr>
<td>Person County - NC</td>
<td>70.4%</td>
<td>28.3%</td>
<td>0.8%</td>
<td>0.5%</td>
<td>96.5%</td>
<td>3.5%</td>
<td>54.1%</td>
<td>39.9%</td>
<td>17.4%</td>
</tr>
<tr>
<td>Pitt County - NC</td>
<td>60.9%</td>
<td>36.6%</td>
<td>0.5%</td>
<td>2.0%</td>
<td>95.0%</td>
<td>5.0%</td>
<td>40.2%</td>
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<td>11.1%</td>
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<td>85.0%</td>
<td>15.0%</td>
<td>50.0%</td>
<td>36.8%</td>
<td>16.7%</td>
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<tr>
<td>Scotland County - NC</td>
<td>48.2%</td>
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<td>11.5%</td>
<td>0.9%</td>
<td>97.8%</td>
<td>2.2%</td>
<td>50.4%</td>
<td>37.6%</td>
<td>16.1%</td>
</tr>
<tr>
<td>Vance County - NC</td>
<td>46.6%</td>
<td>52.2%</td>
<td>0.7%</td>
<td>0.5%</td>
<td>93.9%</td>
<td>6.1%</td>
<td>50.8%</td>
<td>37.3%</td>
<td>16.4%</td>
</tr>
<tr>
<td>Wake County - NC</td>
<td>70.1%</td>
<td>23.2%</td>
<td>0.9%</td>
<td>5.8%</td>
<td>90.8%</td>
<td>9.2%</td>
<td>43.1%</td>
<td>27.4%</td>
<td>9.9%</td>
</tr>
<tr>
<td>Warren County - NC</td>
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<td>5.9%</td>
<td>0.3%</td>
<td>97.2%</td>
<td>2.8%</td>
<td>58.1%</td>
<td>46.2%</td>
<td>22.0%</td>
</tr>
<tr>
<td>Wilson County - NC</td>
<td>56.8%</td>
<td>41.7%</td>
<td>0.6%</td>
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<td>8.3%</td>
<td>50.9%</td>
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<td>16.4%</td>
</tr>
</tbody>
</table>

Data are for 2011.
Data are in the percentage of women in the population.
Source: US Census Bureau – Population Estimates
<table>
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<th>Foreign Born</th>
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<td>1.7 %</td>
<td>54.1 %</td>
<td>100.0 %</td>
<td>18.5 %</td>
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<td>6.9 %</td>
<td>12.8 %</td>
<td>3.7 %</td>
<td>6.1 %</td>
<td>4.7 %</td>
<td>13.9 %</td>
</tr>
</tbody>
</table>
## Population characteristics summary

Proportionately, the Komen North Carolina Triangle to the Coast service area has a substantially smaller White female population than the US as a whole, a substantially larger 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 substantially smaller Hispanic/Latina female population. The Affiliate’s female population is slightly younger than that of the US as a whole. The Affiliate’s education level is slightly higher than and income level is slightly lower than those of the US as a whole. There are a slightly larger percentage of people who are unemployed in the Affiliate service area. The Affiliate service area has a slightly smaller percentage of people who are foreign born and a slightly smaller percentage of people who are linguistically isolated. There are a substantially larger percentage of people living in rural areas, a slightly larger percentage of people without health insurance, and a substantially larger percentage of people living in medically underserved areas.

The following counties have substantially larger Black/African-American female population percentages than that of the Affiliate service area as a whole:

- Bladen County
- Caswell County
- Durham County
- Edgecombe County
- Granville County
- Halifax County
- Nash County
- Northampton County
- Pitt County
- Scotland County
- Vance County
- Warren County
- Wilson County
The following county has substantially larger API female population percentages than that of the Affiliate service area as a whole:

- Orange County

The following counties have substantially larger AIAN female population percentages than that of the Affiliate service area as a whole:

- Scotland County
- Warren County

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

- Duplin County
- Lee County
- Sampson County

The following counties have substantially older female population percentages than that of the Affiliate service area as a whole:

- Brunswick County
- Caswell County
- Chatham County
- Halifax County
- Moore County
- Northampton County
- Warren County

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

- Bladen County
- Caswell County
- Columbus County
- Duplin County
- Edgecombe County
- Franklin County
- Halifax County
- Northampton County
- Sampson County
- Scotland County
- Vance County
- Warren County
- Wilson County
The following counties have substantially lower income levels than that of the Affiliate service area as a whole:
- Bladen County
- Columbus County
- Duplin County
- Edgecombe County
- Halifax County
- Northampton County
- Pitt County
- Sampson County
- Scotland County
- Vance County
- Warren County
- Wilson County

The following counties have substantially lower employment levels than that of the Affiliate service area as a whole:
- Brunswick County
- Caswell County
- Edgecombe County
- Halifax County
- Northampton County
- Scotland County
- Wilson County

The following counties have substantially larger percentage of adults without health insurance than does the Affiliate service area as a whole:
- Duplin County
- Sampson 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 Komen North Carolina Triangle to the Coast 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

<table>
<thead>
<tr>
<th>Time to Achieve Death Rate Reduction Target</th>
<th>Time to Achieve Late-stage Incidence Reduction Target</th>
</tr>
</thead>
<tbody>
<tr>
<td>13 years or longer</td>
<td>13 years or longer</td>
</tr>
<tr>
<td>Highest</td>
<td>Highest</td>
</tr>
<tr>
<td>High</td>
<td>Medium High</td>
</tr>
<tr>
<td>Medium</td>
<td>Medium High</td>
</tr>
<tr>
<td>Low</td>
<td>Low</td>
</tr>
<tr>
<td>Lowest</td>
<td>Lowest</td>
</tr>
<tr>
<td>Unknown</td>
<td>Highest</td>
</tr>
<tr>
<td>Medium</td>
<td>Medium High</td>
</tr>
<tr>
<td>Low</td>
<td>Medium Low</td>
</tr>
<tr>
<td>Lowest</td>
<td>Lowest</td>
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<td>Highest</td>
<td>Highest</td>
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<td>High</td>
<td>Medium High</td>
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<td>Medium Low</td>
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<tr>
<td>Low</td>
<td>Low</td>
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<tr>
<td>Unknown</td>
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<tr>
<td>Medium</td>
<td>Medium High</td>
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<td>Low</td>
<td>Low</td>
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<td>Lowest</td>
<td>Lowest</td>
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<td>Highest</td>
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<tr>
<td>High</td>
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<td>Medium</td>
<td>Medium Low</td>
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<td>Medium</td>
<td>Medium High</td>
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<tr>
<td>Low</td>
<td>Low</td>
</tr>
<tr>
<td>Lowest</td>
<td>Lowest</td>
</tr>
</tbody>
</table>

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 North Carolina Triangle to the Coast service area with predicted time to achieve the HP2020 breast cancer targets and key population characteristics

<table>
<thead>
<tr>
<th>County</th>
<th>Priority</th>
<th>Predicted Time to Achieve Death Rate Target</th>
<th>Predicted Time to Achieve Late-stage Incidence Target</th>
<th>Key Population Characteristics</th>
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<tbody>
<tr>
<td>Edgecombe County - NC</td>
<td>Highest</td>
<td>13 years or longer</td>
<td>13 years or longer</td>
<td>%Black/African-American, education, poverty, employment, rural, medically underserved</td>
</tr>
<tr>
<td>Granville County - NC</td>
<td>Highest</td>
<td>13 years or longer</td>
<td>13 years or longer</td>
<td>%Black/African-American, rural, medically underserved</td>
</tr>
<tr>
<td>Halifax County - NC</td>
<td>Highest</td>
<td>13 years or longer</td>
<td>13 years or longer</td>
<td>%Black/African-American, older, education, poverty, employment, rural, medically underserved</td>
</tr>
<tr>
<td>Lee County - NC</td>
<td>Highest</td>
<td>NA</td>
<td>13 years or longer</td>
<td>%Hispanic/Latina, language, rural</td>
</tr>
<tr>
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<td>10 years</td>
<td>13 years or longer</td>
<td>%Black/African-American, education, poverty, rural, medically underserved</td>
</tr>
<tr>
<td>Durham County - NC</td>
<td>High</td>
<td>13 years or longer</td>
<td>10 years</td>
<td>%Black/African-American, foreign</td>
</tr>
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<td>Nash County - NC</td>
<td>High</td>
<td>13 years or longer</td>
<td>8 years</td>
<td>%Black/African-American, rural, medically underserved</td>
</tr>
<tr>
<td>Northampton County - NC</td>
<td>High</td>
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<td>13 years or longer</td>
<td>%Black/African-American, older, education, poverty, employment, rural, medically underserved</td>
</tr>
<tr>
<td>Pitt County - NC</td>
<td>High</td>
<td>7 years</td>
<td>13 years or longer</td>
<td>%Black/African-American, poverty, medically underserved</td>
</tr>
<tr>
<td>Sampson County - NC</td>
<td>High</td>
<td>7 years</td>
<td>13 years or longer</td>
<td>%Hispanic/Latina, education, poverty, rural, insurance, medically underserved</td>
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<tr>
<td>Brunswick County - NC</td>
<td>Medium High</td>
<td>1 year</td>
<td>13 years or longer</td>
<td>Older, employment, rural, medically underserved</td>
</tr>
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<td>Harnett County - NC</td>
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<td>6 years</td>
<td>13 years or longer</td>
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<td>13 years or longer</td>
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<td>Older, rural</td>
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<td>1 year</td>
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<td>County</td>
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<td>Predicted Time to Achieve Late-stage Incidence Target</td>
<td>Key Population Characteristics</td>
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<td>13 years or longer</td>
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<td>13 years or longer</td>
<td>Rural, medically underserved</td>
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<td>13 years or longer</td>
<td>Rural, medically underserved</td>
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<td>4 years</td>
<td>%Black/African-American, education, poverty, rural, medically underserved</td>
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<td>Older, rural, medically underserved</td>
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<td>13 years or longer</td>
<td>Education, rural, medically underserved</td>
</tr>
<tr>
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<td>13 years or longer</td>
<td>%Black/African-American, education, poverty, rural, medically underserved</td>
</tr>
<tr>
<td>Caswell County - NC</td>
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<td>SN</td>
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<td>%Black/African-American, older, education, employment, employment, rural, medically underserved</td>
</tr>
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<td>Duplin County - NC</td>
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<td>2 years</td>
<td>Currently meets target</td>
<td>%Hispanic/Latina, education, poverty, language, rural, medically underserved</td>
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</table>

NA – data not available.
SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period).
**Map of Intervention Priority Areas**

Figure 2.1 shows a map of the intervention priorities for the counties in the Affiliate service area. When both of the indicators used to establish a priority for a county are not available, the priority is shown as “undetermined” on the map.

**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**

Four counties in the Komen North Carolina Triangle to the Coast service area are in the highest priority category. Three of the four, Edgecombe County, Granville County and Halifax County, are not likely to meet either the death rate or late-stage incidence rate HP2020 targets. One of the four, Lee County is not likely to meet the late-stage incidence rate HP2020 target.

The death rates in Edgecombe County (33.2 per 100,000) and Halifax County (36.6 per 100,000) are significantly higher than the Affiliate service area as a whole (23.5 per 100,000).

Edgecombe County has a relatively large Black/African-American population, low education levels, high poverty and high unemployment. Granville County has a relatively large Black/African-American population. Halifax County has a relatively large Black/African-American population, an older population, low education levels, high poverty and high unemployment. Lee County has a relatively large Hispanic/Latina population and a relatively large number of households with little English.

**High priority areas**

Six counties in the Komen North Carolina Triangle to the Coast service area are in the high priority category. Two of the six, Durham County and Nash County, are not likely to meet the death rate HP2020 target. Four of the six, Bladen County, Northampton County, Pitt County and Sampson County, are not likely to meet the late-stage incidence rate HP2020 target.

The incidence rates in Pitt County (144.1 per 100,000) are significantly higher than the Affiliate service area as a whole (125.0 per 100,000).
Bladen County has a relatively large Black/African-American population, low education levels and high poverty. Durham County has a relatively large Black/African-American population and a relatively large foreign-born population. Nash County has a relatively large Black/African-American population. Northampton County has a relatively large Black/African-American population, an older population, low education levels, high poverty and high unemployment. Pitt County has a relatively large Black/African-American population and high poverty. Sampson County has a relatively large Hispanic/Latina population, low education levels and high poverty.

**Additional Quantitative Data Exploration**

Additional quantitative data was explored to assist the Affiliate in the selection of the target communities. The following data were provided by a statistician at the North Carolina Central Cancer Registry in the Division of Public Health, Department of Health and Human Services.

- Table 2.8: 2012 Female breast cancer death rates by race and county
- Table 2.9: 2011 Female breast cancer incidence rates by race and county
- Table 2.10: 2011 Female breast cancer stage at diagnosis by race

This additional data enhances the Quantitative Data Report because it provides additional insight and uses the most current data available. The “incidence and death rate by race” data helps to highlight the disparities that exist within the service area. Also, stage at diagnosis incidence rates were collected for each county.

The following additional data were collected and or compiled by the Affiliate:

- Figure 2.4 shows 2006-2010 female breast cancer death rate by county benchmarked against the Healthy People 2020 target of 20.1/100,000; represented on the graph as a horizontal black line
- Figure 2.5 shows 2006-2010 female breast cancer late-stage incidence rate by county benchmarked against the Healthy People 2020 target of 41.0/100,000; represented on the graph as a horizontal black line
- Table 2.11: 2014 Tier Designations by County shows a ranking of the Affiliate’s 29 counties by economic well-being
- Table 2.12: 2010-2014 Homeless Point-in-Time Count Data by County provides a five year perspective on the total number of homeless persons per county
- Edgecombe county profile provides a snapshot of the county’s incidence, death and screening proportions in addition to demographic and socioeconomic information that justify Edgecombe’s selection as a target community
- Halifax county individual profile provides a snapshot of the county’s incidence, death and screening proportions in addition to demographic and socioeconomic information that justify Halifax’s selection as a target community
- Wilson county individual profile provides a snapshot of the county’s incidence, death and screening proportions in addition to demographic and socioeconomic information that justify Wilson’s selection as a target community
This data complements the Quantitative Data Report by showing additional needs in the service area that contribute to access to care and gaps in the continuum of care; and specifically in the priority areas of Edgecombe County, Halifax County and Wilson County.

Limitations to the additional quantitative data may include: numbers are subject to change as files are updated, cases may not sum to totals due to unknown or other values, rates based on counts fewer than 16 are unstable and the most recent data collected lags a few years behind the current year. Additional death, incidence, and late-stage data are only presented for one year, so counts and rates can be unstable. Data presented over multiple years tends to be more stable. In addition, Homeless Point-in-Time counts are based on a one day count of unsheltered and sheltered individuals. Homeless families who live with family or friends are not included in the Point-in-time data.
Table 2.8. Female breast cancer death rates by race, 2012

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<td>Cases</td>
<td>Rate</td>
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Per 100,000 population
Age-adjusted to the US 2000 Census
Produced by the NC Central Cancer Registry, 07/2014
Numbers are subject to change as files are updated.
Cases may not sum to totals due to unknown or other values.
Rates based on counts fewer than 16 are unstable. Use with caution.
Vintage 2012 bridged-race postcensal population estimates were obtained from the National Center for Health Statistics (www.cdc.gov/nchs/nvss/bridged_race/data_documentation.htm#vintage2012).
### Table 2.9. Female breast cancer incidence rates by race, 2011

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Per 100,000 population
Age-adjusted to the US 2000 Census
Produced by the NC Central Cancer Registry, 07/2014
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**Table 2.10. Female breast cancer incidence rates by stage at diagnosis, 2011**

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<th>Localized Cases</th>
<th>Localized Rate</th>
<th>Regional Cases</th>
<th>Regional Rate</th>
<th>Distant Cases</th>
<th>Distant Rate</th>
<th>N/A or Unstaged Cases</th>
<th>N/A or Unstaged Rate</th>
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<td>11.9</td>
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</tbody>
</table>

Per 100,000 population
Age-adjusted to the US 2000 Census
Produced by the NC Central Cancer Registry, 07/2014
Numbers are subject to change as files are updated.
Cases may not sum to totals due to unknown or other values.
* Counts fewer than 5 are suppressed.
Rates based on counts fewer than 16 are unstable. Use with caution.
Cancers of the urinary bladder and female breast include in situ cases.
Vintage 2011 bridged-race postcensal population estimates were obtained from the National Center for Health Statistics
Figure 2.4. Female breast cancer death rate by county with Healthy People 2020 benchmark

Figure 2.5. Female breast cancer late-stage incidence rate by county with Healthy People 2020 benchmark
### Table 2.11. 2015 Tier designations by county

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<th>Tier Designation</th>
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<tr>
<td>Caswell</td>
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<tr>
<td>Chatham</td>
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<td>Columbus</td>
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<td>Duplin</td>
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<td>Nash</td>
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<td>Warren</td>
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<td>Wilson</td>
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</table>

North Carolina Department of Commerce

The North Carolina Department of Commerce annually ranks the state’s 100 counties based on economic wellbeing and assigns each a Tier designation. The most distressed counties are designated as Tier 1. Edgecombe, Halifax and Wilson are all designated as Tier 1 counties. For
For more information on how tier designations are assigned please see: [http://www.nccommerce.com/research-publications/incentive-reports/county-tier-designations](http://www.nccommerce.com/research-publications/incentive-reports/county-tier-designations)

**Table 2.12. Homeless point-in-time count data by county**

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<th>County</th>
<th>Total Population Est. 2013</th>
<th>Total Homeless People</th>
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<th>2011</th>
<th>2012</th>
<th>2013</th>
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* Data not available

Annual Estimates of the Resident Population by Sex, Race, and Hispanic Origin for the United States, States, and Counties: April 1, 2010 to July 1, 2013

Source: US Census Bureau, Population Division

Release Date: June 2014

When compared to counties of similar population sizes, Edgecombe County has a higher homeless population and increasing counts of homeless persons.
Selection of Target Communities

In order to best meet the community need, Susan G. Komen North Carolina Triangle to the Coast has chosen three target communities within the service area. Target communities were prioritized based on the time needed to reach Healthy People 2020 objectives for breast cancer deaths and late-stage incidence.

Additional key indicators the Affiliate reviewed when selecting target counties included, but were not limited to:
- Incidence rates
- Death rates
- Late-stage rates
- Tier designations
- Homeless Point-in-Time counts

Komen North Carolina to the Coast will concentrate strategic efforts on these target communities for the next four years (Table 2.13):
- Edgecombe County – projected not to reach the Healthy People 2020 targets for deaths and late-stage incidence
- Halifax County – projected not to reach the Healthy People 2020 targets for deaths and late-stage incidence
- Wilson County – projected not to reach the Healthy People 2020 target for deaths

Table 2.13. Summary table of target community data, 2006-2010

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<th>US</th>
<th>Healthy People 2020 Target</th>
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<td>Death Rate</td>
<td>Late-stage Rate</td>
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<td>47.7</td>
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<td>-0.7%</td>
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<td>53.1</td>
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<tr>
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<td>-0.1%</td>
<td>-6.8%</td>
</tr>
<tr>
<td>Per 100,000 women</td>
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<td>23.5</td>
<td>45.8</td>
</tr>
<tr>
<td>Halifax</td>
<td>135.5</td>
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<td>48.5</td>
</tr>
<tr>
<td>Rate</td>
<td>-5.6%</td>
<td>-0.7%</td>
<td>1.1%</td>
</tr>
<tr>
<td>Trend</td>
<td>-4.2%</td>
<td>-0.1%</td>
<td>-6.8%</td>
</tr>
<tr>
<td>Wilson</td>
<td>130.2</td>
<td>33.9</td>
<td>53.1</td>
</tr>
<tr>
<td>Rate</td>
<td>-4.2%</td>
<td>-0.1%</td>
<td>-6.8%</td>
</tr>
<tr>
<td>Trend</td>
<td>-4.2%</td>
<td>-0.1%</td>
<td>-6.8%</td>
</tr>
</tbody>
</table>

Edgecombe County, North Carolina

Edgecombe County, North Carolina is comprised largely of the city of Rocky Mount. It is a rural county with a population of 56,552 people, approximately 30,313 of which are female. 59.1 percent of these women are Black/African-American, a percentage substantially higher than the national average and more than double that of the service area average (Figure 2.6). This is significant due to the high death rates Black/African-American women experience from breast cancer when compared to other races. Additionally, 14.9 percent of residents are unemployed.
and 18.6 percent do not have health insurance. Of those between the ages 40-64, 53.4 percent are living at 250 percent below the poverty level and 45.3 percent live in a rural area. More than half (52.2 percent) of the female population is age 40 plus. All of these percentages are substantially higher than the Affiliate service area's averages.

Figure 2.6. Edgecombe County population data

Edgecombe has been identified as a high priority county due to the amount of intervention time needed to achieve the HP2020 targets. For instance, the county’s death rate of breast cancer was 33.2 per 100,000 women. This is higher than the United States rate (22.6), as well as the Affiliate service area’s rate (23.5). The death rate decreased slightly from 2006-2010. Currently, the county continues to have one of the highest rates of breast cancer death in the service area (Table 2.14). Additionally, Edgecombe County’s rate of late-stage diagnosis was 47.7 per 100,000 women. This is higher than the United States (43.7), as well as the Affiliate service area’s rate (45.8). The rate of late-stage diagnosis increased from 2006-2010.

Table 2.14. Edgecombe County breast cancer data, 2006-2010

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<th>Service Area Rate</th>
<th>US Rate</th>
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<td>Death Rate*</td>
<td>33.2</td>
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<tr>
<td>Late-stage Rate*</td>
<td>47.7</td>
<td>45.8</td>
<td>43.7</td>
</tr>
</tbody>
</table>

*Rates are age-adjusted and figured per 100,000 women

Screening percentages in Edgecombe County are in fact higher than the United States and the service area averages, yet the socioeconomic data for the county show several concerning areas. Edgecombe residents are substantially more likely to have less than a high school education, an income below 250 percent poverty, and be unemployed than others in the United States and the Affiliate service area.

Halifax County, North Carolina

Halifax County, North Carolina is comprised largely of the city of Roanoke Rapids. It is a rural county with a population of 54,691 people, approximately 28,554 of which are female. 54.8 percent of these women are Black/African-American, a rate substantially higher than the national average and more than double that of the service area average (Figure 2.7). This is
significant due to the high death rates Black/African-American women experience from breast cancer when compared to other races. Additionally, 15.5 percent of residents are unemployed and 18.4 percent do not have health insurance. Of those between the ages 40-64, 54.7 percent are living at 250 percent below the poverty level and 54.7 percent live in a rural area. More than half (54.8 percent) of the female population is age 40 plus. All of these percentages are substantially higher than the Affiliate service area's averages.

Figure 2.7. Halifax County data

Halifax has been identified as a high priority county due to the amount of intervention time needed to achieve the HP2020 targets. For instance, the county’s death rate of breast cancer was 36.6 per 100,000 women. This is higher than the United States rate (22.6), as well as the Affiliate service area’s rate (23.5). The death rate decreased from 2006-2010. Currently, the county has the highest rate of breast cancer death in the service area (Table 2.15.). Additionally, Halifax County’s rate of late-stage diagnosis was 48.5 per 100,000 women. This is higher than the United States (43.7), as well as the Affiliate service area’s rate (45.8). The rate of late-stage diagnosis increased from 2006-2010.

Table 2.15. Halifax County breast cancer data, 2006-2010

<table>
<thead>
<tr>
<th></th>
<th>Halifax County</th>
<th>Service Area Rate</th>
<th>US Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incidence Rate*</td>
<td>135.5</td>
<td>125.0</td>
<td>122.1</td>
</tr>
<tr>
<td>Death Rate*</td>
<td>36.6</td>
<td>23.5</td>
<td>22.6</td>
</tr>
<tr>
<td>Late-stage Rate*</td>
<td>48.5</td>
<td>45.8</td>
<td>43.7</td>
</tr>
</tbody>
</table>

*Rates are age-adjusted and figured per 100,000 women

Screening percentages in Halifax County are in fact higher than the United States and the service area averages, yet the socioeconomic data for the county show several concerning areas. Halifax County residents are substantially more likely to have less than a high school education, an income below 250 percent poverty, and be unemployed than others in the United States and the Affiliate service area.

Wilson County, North Carolina
Wilson County, North Carolina is comprised largely of the city of Wilson. It is a rural county with a population of 81,234 people, approximately 42,450 of which are female. 41.7 percent of these women are Black/African-American, a rate substantially higher than the national average and
more than that of the service area average (Figure 2.8). This is significant due to the high death rates Black/African-American women experience from breast cancer when compared to other races. Additionally, 12.6 percent of residents are unemployed and 20.3 percent do not have health insurance. Of those between the ages 40-64, 45.1 percent are living at 250 percent below the poverty level and 38.7 percent live in a rural area. More than half (50.9 percent) of the female population is age 40 plus and 3.1 percent are linguistically isolated. All of these percentages are on par or higher than the Affiliate service area’s averages.

![Wilson County Female Population by Race](image)

**Figure 2.8.** Wilson County data

Wilson has been identified as a high priority county due to the amount of intervention time needed to achieve the HP2020 death target. For instance, the county’s death rate of breast cancer was 33.9 per 100,000 women. This is higher than the United States rate (22.6), as well as the Affiliate service area’s rate (23.5). The death rate decreased from 2006-2010. Currently, the county has one of the highest rates of breast cancer death in the service area (Table 2.16). Wilson County’s rate of late-stage diagnosis was 53.1 per 100,000 women. This is higher than the United States (43.7), as well as the Affiliate service area’s rate (45.8). The rate of late-stage diagnosis decreased from 2006-2010.

<table>
<thead>
<tr>
<th></th>
<th>Wilson County</th>
<th>Service Area Rate</th>
<th>US Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Incidence Rate</strong></td>
<td>130.2</td>
<td>125.0</td>
<td>122.1</td>
</tr>
<tr>
<td><strong>Death Rate</strong></td>
<td>33.9</td>
<td>23.5</td>
<td>22.6</td>
</tr>
<tr>
<td><strong>Late-stage Rate</strong></td>
<td>53.1</td>
<td>45.8</td>
<td>43.7</td>
</tr>
</tbody>
</table>

*Rates are age-adjusted and figured per 100,000 women

Screening percentages in Wilson County are lower than the United States and the service area, which is concerning. The socioeconomic data for the county also show several concerning areas. Wilson residents are more likely to live in a rural area, have less than a high school education, be unemployed and have no health insurance than others in the United States and the Affiliate service area.

**Conclusions**

Edgecombe County has the third highest rate of death from breast cancer in the Affiliate service area. Key characteristics contributing to this disparity include it being a medically underserved
rural county with a large percentage of Black/African-American women, low education levels, high poverty and high unemployment.

Halifax County has the highest rate of death from breast cancer in the Affiliate service area. Key characteristics contributing to this disparity include it being a medically underserved rural county with an older female population largely comprised of Black/African-American women, low education levels, high poverty and high unemployment.

Wilson County has the second highest rate of death from breast cancer in the Affiliate service area. Key characteristics contributing to this disparity include it being a medically underserved rural county with a large percentage of Black/African-American women, low education levels, high poverty and high unemployment.

All three of these counties reside in a region of North Carolina classified as Area L. Area L, also referred to as the Upper Coastal Plain, is characterized as having low socioeconomic status, high minority populations, high numbers of uninsured and underinsured residents, low education and vast rural communities. Area L has been singled out by Susan G. Komen Headquarters as having one of the highest breast cancer death rates in the United States. An in-depth analysis of the breast health resources that are available in Area L will be conducted in the Health System and Public Policy Section of this report.

These counties each have numerous factors contributing to access to care and gaps in the continuum of care. For example, one research study found that homeless women were less likely to receive mammograms in the past year than the general population. They had less access to care and higher risk factors; emphasizing the need for increased education and services (Chau et al, 2002). Edgecombe County’s higher homeless population may indicate that targeted interventions are needed.

It is critically important to understand how accessible breast health services are in these areas. The health systems analysis will explore the availability of breast health resources in underserved areas and identify gaps in services to residents in these priority counties. As health systems often affect and/or share resources with neighboring counties, the Affiliate will explore how each county’s health systems interact with one another. The availability and usage of the North Carolina Breast and Cervical Cancer Control Program (NC BCCP) will also be explored.
The analysis of health systems in the target counties of Edgecombe, Halifax and Wilson provides insights to what is available and how residents are utilizing those resources. The Affiliate can see the gaps that are present in the continuum of care and try to close those gaps. The Affiliate examines partnerships to determine how to strengthen existing ones and if new partnerships could be established for more efficient care of women in the service area. Any obstacles women face while seeking breast health care can be identified and addressed.

**Health Systems Analysis Data Sources**

After reviewing and analyzing the breast cancer impact in the Affiliate service area, several data sources were used to assess the continuum of care and complete the health system analysis for the target communities.

- Demographic data in this section were collected from the US Census Bureau and the North Carolina Central Cancer Registry.
- Secondary data were collected from multiple websites and documents contained within those websites. Sites searched include: county websites, US Department of Health and Human Services; the Upper Coastal Plain Breast Cancer Resource Directory October 2013; the Breast Cancer Resource Directory of North Carolina, Fourth Edition; Medicaid; North Carolina BCCC; State Cancer Control Program: A Call to Action, North Carolina Comprehensive Cancer Control Plan 2014-2020; National Cancer Institute for clinical trial information; Area Health Education Centers; National Association of Schools of Public Health; Federal Drug Administration; Health Resources and Services Administration; National Association of Free and Charitable Clinics; American College of Surgeons Commission on Cancer; American College of Radiology Centers of Excellence; American College of Surgeons National Accreditation Program for Breast Centers (NAPBC); and National Cancer Institute Designated Cancer Centers.
- A health systems survey tool was developed and sent to service providers throughout the three county target area including hospitals, health departments, community health centers, and free clinics.

Data were reviewed from the websites and then summarized. The data from the survey tools that were returned were added to the Health Systems Analysis spreadsheets to determine what is available in each of the target counties. For the service providers that did not respond to the survey, data were completed utilizing web information and historic data.

**Health Systems Overview**

**Overview of Continuum of Care**

The continuum of care (CoC) graphic (Figure 3.1) illustrates how a woman systematically progresses, ideally, from screening all the way through to follow-up and/or survivorship. Examining each step of the process, with education being a part of every step, helps determine where there are strengths in the CoC and where improvements can be made.
The comprehensive cycle of services known as the continuum of care is an integrated system of breast health programs and services including varying levels of education, screening, diagnosis, treatment, post-diagnosis, and follow-up. After reviewing the breast health statistics, programs, and services in the Komen NC Triangle to the Coast service area, the Affiliate selected three counties in the North Central, Eastern region of the service area to be the focus of the health system analysis: Edgecombe, Halifax and Wilson. A Health Systems Analysis was conducted to better understand the gaps, needs and barriers throughout the continuum of care. Edgecombe County has been part of the service area since the Affiliate incorporated in 2000. Halifax County was added to the service area in 2010 and Wilson County was added in the most recent expansion in 2012.

Analysis of the health systems in each target community found the following (Figures 3.2, 3.3 and 3.4):

- Each county has a major hospital which is now linked to or owned by a larger hospital system.
- There is a county health department located in each of the three communities.
- Each county has one or more NC BCCCP (Breast and Cervical Cancer Control Program) providers located within the county.
- Each county is located in a region of the state referred to as Area L or the Upper Coastal Plain and is characterized as having breast cancer death rates that are considerably higher than the average rates in both North Carolina and the United States.
- The three county area consists of 229 physicians (1 per 838 persons) and 88 Primary Care Physicians (1 per 2183 persons).
- Although hospitals and health care providers are represented throughout the three county region, data reveal that often breast cancer patients travel to Greenville in Pitt County despite the further distance to receive consolidated services and unified medical records.
- Area L AHEC is located in Rocky Mount and serves all three target communities. Komen NC Triangle to the Coast is a partnering organization but sees the potential to strengthen and expand collaborative efforts.
Figure 3.2. Breast cancer services available in Edgecombe County
Figure 3.3. Breast cancer services available in Halifax County
Figure 3.4. Breast cancer services available in Wilson County
Public Policy Overview

North Carolina Breast and Cervical Cancer Control Program

The North Carolina Breast and Cervical Cancer Control Program (NC BCCCP) provides free or low-cost breast and cervical cancer screenings and follow-up to eligible women in North Carolina. Each year, NC BCCCP strives to provide services to over 12,000 women. NC BCCCP services are offered at most local health departments as well as some community health centers, hospitals and private physicians’ offices across the state. Approximately 102 local health agencies work in cooperation with physicians, hospitals, and other health care facilities to provide services to eligible North Carolina women. Services offered include: clinical breast exams; screening mammograms; Pap tests; diagnostic procedures, as indicated (diagnostic mammograms, ultrasounds, colposcopies, breast and cervical biopsies); and medical consultations.

To be eligible for the NC BCCCP women must be: uninsured or underinsured; without Medicare Part B or Medicaid; between ages 40 - 64 for breast screening services and 21 - 64 for cervical screening services; and have a household income at or below 250 percent of the federal poverty level Table 3.1. Breast and Cervical Cancer Medicaid (BCCM) provides funding for treatment to NC BCCCP enrolled clients who are diagnosed with breast or cervical cancer and who meet additional requirements. BCCM eligible women must be enrolled in NC BCCCP prior to a cancer diagnosis. Women are enrolled by their physician. If a physician is unaware of the program, a qualified woman could potentially face the high costs of treatment that could have otherwise been covered by the program. For the eligibility flow chart for breast screening, which illustrates where women could potentially lose a good flow in the continuum of care, see Appendix A. Women who are ages 40-49 are only eligible if they are symptomatic or if NC BCCCP funding is available. Similarly women who are ages 65-75 are eligible if NC BCCCP funding is available.

Because of higher death rates, NC BCCCP has focused increased recruitment and education strategies to prompt more Black/African-American, Hispanic/Latina, and American Indian women to get breast and cervical cancer screenings.

The current relationship with NC BCCCP is a partnership. The NC BCCCP has assisted the Komen North Carolina Triangle to the Coast with Mission activities and the Affiliate participates in their Advisory committee. The Affiliate is invited to attend all meetings and participate with subcommittees on prevention and early detection of cancer. Since much of the staff at Komen NCTC are new, over the next several years, developing strong relationships with local BCCCP providers in the 29 county service area will be a key priority.
Table 3.1. NC BCCCP current income guidelines

<table>
<thead>
<tr>
<th>Household Size</th>
<th>Gross Yearly Income</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>$29,175</td>
</tr>
<tr>
<td>2</td>
<td>$39,325</td>
</tr>
<tr>
<td>3</td>
<td>$49,475</td>
</tr>
<tr>
<td>4</td>
<td>$59,625</td>
</tr>
<tr>
<td>5</td>
<td>$69,775</td>
</tr>
<tr>
<td>6</td>
<td>$79,925</td>
</tr>
<tr>
<td>7</td>
<td>$90,075</td>
</tr>
<tr>
<td>8</td>
<td>$100,225</td>
</tr>
<tr>
<td>For each additional family member (beyond 8)</td>
<td>Add $10,150</td>
</tr>
</tbody>
</table>

Source: NC Department of Health and Human Services, Breast and Cervical Cancer Control Program, 2014

To locate a NC BCCCP provider in the Susan G. Komen North Carolina Triangle to the Coast Service Area, go to the following website: http://bcccp.ncdhhs.gov/Eligibility.asp.

State Comprehensive Cancer Control Program

In 2014, the State of North Carolina released The North Carolina Comprehensive Cancer Control Plan 2014-2020: A Call to Action. This plan was developed by a large and diverse group dedicated to saving lives and improving the quality of life for North Carolinians affected by cancer. The Cancer Plan serves as a working guide to help public health and health care groups, community organizations, institutions, agencies and individuals across NC work together to address cancer prevention and control. It is designed to address the barriers to cancer prevention and care while outlining a plan of action for cancer programs, community organizations, policymakers and individuals in North Carolina. The overarching goals of the plan are:

- Prevent new cancers
- Detect cancer at its earliest stages
- Treat all cancer patients with the most appropriate and effective therapy
- Enhance the quality of life for every person affected by cancer
- Reduce cancer-related disparities in North Carolina

In order to meet these goals the Cancer Plan has specific objectives and strategies to address the cancer continuum, the six specific cancers, including breast cancer, cancer surveillance and plan evaluation. The cancer continuum, which includes prevention, early detection, care and treatment and survivorship, is a useful framework to view plans, priorities and progress, as well as identifying research and resource needs. The Action Plan will be implemented by a diverse partnership of NC cancer programs, organizations and individuals to assure North Carolinians timely and equitable access to health care throughout the cancer care continuum.

The efforts to reduce the cancer burden in NC will require a coordinated and collective effort of communities, public and private organizations and individuals. Representatives of many
agencies and organizations such as the North Carolina Advisory Committee for Cancer Coordination and Control, North Carolina Cancer Partnership, North Carolina Department of Health and Human Services, American Cancer Society and many others, including Susan G. Komen North Carolina Triangle to the Coast, are working together to develop the strategies and action plan for the successful implementation of the comprehensive cancer plan. Affiliate staff serves on the implementation workgroup of both the Early Detection and the Care and Treatment Subcommittees of the NC Advisory Committee for Cancer Coordination and Control.

Breast cancer has been designated as one of six priority cancers in the Cancer Plan, therefore a section of the plan includes information summarizing breast cancer risk factors, prevention and treatment. It includes objectives and specific strategies for addressing these objectives. The three identified breast cancer objectives for the plan are (Table 3.2):

1. Reduce the death rate in women due to breast cancer.
2. Reduce the rate of stage III and IV breast cancer in women.
3. Increase the percentage of North Carolina women over the age of 50 who have had a mammogram according to the recommended guidelines within the past two years.

The breast cancer strategies included in the plan are:

- Conduct targeted outreach using evidence-based strategies to decrease disparities in breast cancer death among women who experience high death rates from breast cancer.
- Partner with NC BCCCP and WISEWOMAN providers and other agencies to improve data sharing and patient tracking to assure that eligible patients get appropriate screening and treatment services for breast cancer.
- Promote the use of the guidelines and recommendations of the North Carolina Advisory Committee on Cancer Control and Coordination.

Table 3.2. North Carolina Comprehensive Cancer Control plan breast cancer objectives

<table>
<thead>
<tr>
<th>Measures</th>
<th>Baseline</th>
<th>2020 Target</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast Cancer Death Rate</td>
<td>21.4/100,000</td>
<td>16.8/100,000</td>
</tr>
<tr>
<td>Stage III and IV Breast Cancer Rate</td>
<td>46.3/100,000</td>
<td>40.9/100,000</td>
</tr>
<tr>
<td>% Women Over Age 50 Who Had Mammograms within the Past Two Years</td>
<td>79.4%</td>
<td>TBD*</td>
</tr>
</tbody>
</table>

*NOTE: Recommendations have changed recently and awaiting BRFSS data changes

Over the next four years, Komen NCTC will continue to work with the Advisory committee for the successful implementation of the Cancer Plan to ensure the goals, specifically as they relate to breast cancer, are achieved.
**Affordable Care Act**

The Affordable Care Act provides Americans with better health security by putting in place comprehensive health insurance reforms that expand access to care through insurance coverage, lower health care costs making it more affordable, guarantee more choices, improve coverage for those with health insurance, enhance the quality of health care for all Americans and hold insurance companies accountable.

The Affordable Care Act (ACA) actually refers to two separate pieces of legislation - the Patient Protection and Affordable Care Act (P.L. 111-148) and the Health Care and Education Reconciliation Act of 2010 (P.L. 111-152) - that together expand Medicaid coverage to millions of low-income Americans and make numerous improvements to both Medicaid and the Children’s Health Insurance Program (CHIP).

Medicaid is a long-standing government-funded health insurance program for low-income individuals and families who cannot afford health care costs. Eligibility requirements were determined by each state individually. Under the ACA, states were to expand their Medicaid programs, making more people eligible by specifically raising the household income requirement to at or below 138 percent of the federal poverty level. In 2013, in North Carolina, this equaled approximately $32,000 for a family of four, according to a 2014 Fact Sheet published in January of that year by the Henry J. Kaiser Family Foundation (KFF) entitled “How Will the Uninsured in North Carolina Fare Under the Affordable Care Act?”.

The US Federal Government offered to pay 100 percent of the costs of newly enrolled Medicaid patients from 2013 to 2016. After that time, the federal share of the reimbursement rate would decrease, reaching 90 percent in 2020.

In 2012, the US Supreme Court ruled that individual states could decide whether to expand their Medicaid programs and North Carolina chose not to expand thus creating gaps in coverage within the state. These coverage gaps mean income is above the current Medicaid eligibility rate but below the lower limit to receive ACA tax credits. According to the 2014 Fact Sheet published by the KFF, 319,000 uninsured individuals in NC who would have been insured if NC had expanded, fall into the coverage gap. This represents 20 percent of the uninsured in the state. These adults are all below the poverty line and have very limited incomes. Since they will not receive an affordable coverage option under the ACA, they will most likely continue to be uninsured. The KFF Fact Sheet also states that uninsured undocumented immigrants, who make up 16 percent of the uninsured non-elderly in the state, were ineligible to enroll in Medicaid before the ACA and under the ACA that has remained the same making the gaps in coverage even greater.

The ACA will increase access to breast and cervical cancer screening services for many low-income, underserved women through expanded insurance coverage and eliminating cost-sharing. Other provisions of the ACA and the American Reinvestment and Recovery Act will also improve delivery of these essential services by improving health care quality. However, all ACA provisions will not be implemented until 2015 and some effects will take even longer.
Currently, many women will still face barriers to obtaining breast and cervical cancer screening such as geographic isolation, limited health literacy, inconvenient times to access services, and language barriers.

It is important to note that under the health care reform, all of Susan G. Komen’s priorities were included. These include: mammography as a required benefit, breast cancer education for young women, access to clinical trials and patient navigation, elimination of pre-existing condition exclusions, and lifetime and annual caps on out of pocket spending limits. A recent study found a significant increase in the number of women with Medicaid coverage who received mammograms when compared to those who applied for coverage but were unable to enroll. This reinforces the fact that access to Medicaid makes a big difference in who receives mammograms and adheres to current screening guidelines. North Carolina’s decision not to expand Medicaid coverage will result in fewer women in the state having access to mammography services making the Affiliate’s role in providing funds for free services to uninsured women even more critical than ever.

The Affordable Care Act in NC has not had a large impact on the intended target population. NC decided not to expand Medicaid coverage and the health insurance exchange is federally managed.

According to the Fact Sheet, “A Closer Look at the Impact of State Decisions Not to Expand Medicaid Coverage for Uninsured Adults,” published by the Kaiser Family Foundation in April 2014; 549,000 persons are eligible for Medicaid coverage under the Affordable Care Act’s expanded coverage. Since NC decided not to expand coverage, this leaves only 38,000 (6.9 percent) eligible for Medicaid in the state. In NC, 193,000 (35.2 percent) persons may be eligible for Marketplace Tax credits, while 319,000 (58.1 percent) fall into the coverage gap (Table 3.3).

<table>
<thead>
<tr>
<th>State</th>
<th>Total</th>
<th>Currently Eligible for Medicaid</th>
<th>Currently in the Coverage Gap (&lt;100% FPL)</th>
<th>Currently May be Eligible for Marketplace Tax Credits (100%-138% FPL)</th>
<th>Excluded from Medicaid due to State Decisions not to Expand Medicaid</th>
</tr>
</thead>
<tbody>
<tr>
<td>NC</td>
<td>549,000</td>
<td>38,000</td>
<td>319,000</td>
<td>193,000</td>
<td>511,000</td>
</tr>
</tbody>
</table>

Source: Kaiser Family Foundation, (excerpt): Current Eligibility Among Uninsured Adults in Non-Expansion States Who Would be Eligible for Medicaid if their State Expanded.

The NC BCCCP program director noted that with all of the changes happening with the Affordable Care Act and the state’s position on expanding coverage there has been little change to a slight decrease in utilization of programs.
Affiliate’s Public Policy Activities
Komen North Carolina Triangle to the Coast (NCTC) Affiliate’s public policy activities include providing information to local, state and federal legislators on the Affiliate’s community health grants program, the Area L special grants program in North Central, Eastern NC, major findings of the Community Profile including the state of breast cancer in the Affiliate’s 29 county service area and breast cancer research grants awarded in North Carolina through the Komen Headquarters Research Programs. Duke Cancer Institute and UNC Lineberger Cancer Center, both located in the service area, received $3.6 million in 2013-14.

Komen NCTC has been actively supporting public policies that benefit breast cancer patients in North Carolina. The most recent activity has focused on the introducing and passing House Bill 609, the Cancer Treatment Fairness Act. This Act would modernize insurance laws to ensure that all chemotherapy treatment drugs, whether intravenous (IV) or oral, would be accessible and affordable to all cancer patients.

When relevant committees held hearings on the issue in the spring of 2013, Komen NCTC public policy advocates visited numerous state legislators and staff members to spread awareness of the need to eliminate the disparity in co-pays between IV chemotherapy and oral chemotherapy. Thirty-five states and the District of Columbia have enacted oral chemo parity legislation with either zero co-pays or co-pays no higher than $100.

Medical plans cover intravenous chemotherapy, while prescription drug plans cover oral chemotherapy. Most prescription drug plans require high out-of-pocket costs that can prevent patients from receiving the treatment that is recommended most appropriate by their oncologist. As introduced in 2013, the Cancer Treatment Fairness Act specified zero co-pays for oral chemotherapy. As passed in the House, however, the legislation included a $100 cap. In addition to all five of the North Carolina Affiliates, and under the leadership of Komen Charlotte, Komen NCTC generated emails and phone calls from its boards of directors, staff, grantees and public policy advocates to urge North Carolina legislators to support the Act. Together, the NC Affiliates have been working with a strong coalition including the North Carolina Oncology Association, the Leukemia & Lymphoma Society, the American Cancer Society Cancer Action Network and others committed to the legislation.

During the legislative process, a $300 cap replaced the $100 cap. Therefore, Komen and coalition efforts targeted Senators to pass a bill that would contain a co-pay cap no higher than $100. The $100 co-pay was reinstated, but the proposed legislation then became part of a large regulatory reform bill.

Komen NCTC and the other NC Affiliates also monitor the state’s budget to ensure legislators do not cut funding for the North Carolina Breast & Cervical Cancer Control Program. NCBCCCCP provides mammograms and treatment for women not eligible for Medicaid. Current funding has been $1.2 million annually. That amount covers less than eight percent of those eligible. Additional funding cuts would be devastating for women in North Carolina, so advocating for those dollars remains a critical part of the Affiliate’s public policy efforts.
Health Systems and Public Policy Analysis Findings

After conducting an assessment on what health systems are available in the target communities and how the CoC is executed by the facilities, the current and future partnerships in these communities, what state policy work is being done and finally the impact of the ACA; the Affiliate can see that there are some positives for the area and much work that needs to be completed to reach Affiliate goals.

Positives in this area are the availability of a hospital and the NC BCCP in each county. The three counties have resources for screenings from each of the identified health systems. The state’s Cancer Control Plan addresses breast cancer as a priority with strategies and objectives designed to reduce disparity. The Affiliate continues to work with legislators to provide affordable co-pays and treatment options for breast cancer patients.

All three counties are lacking services that facilitate easy progression through the CoC. Improvements to existing providers could bridge some of the gaps in the CoC, such as availability of care in one facility. This could also make it easier for a woman to seek screening, diagnosis, treatment, follow-up and education.

Health systems survey tools were mailed or emailed to 22 entities with only a 30 percent return rate. Since the majority of the staff at the Affiliate is relatively new, relationships with the health system providers as well as NC BCCCP need to be better established to work on sharing of data and resources. This will be a priority over the next few years.

There are twenty-eight providers serving the three target counties chosen. One provider services all three areas and therefore is counted only once in the total, but included in each total for the target counties. With this assessment, the Affiliate understands that some providers could be overlooked. As relationships are built, outreach and education improved; a more inclusive list of resources can be achieved.

None of the target communities have mobile mammography available which could be an obstacle for those lacking good transportation. Figure 3.5 shows the percentage of patient navigation provided in each county. Neither Edgecombe County nor Wilson County offer patient navigation from screening to diagnosis. Wilson County has the highest percentage of navigation from diagnosis to treatment at 20.0 percent. Edgecombe County offers the highest percentage (23.3 percent) of navigation from treatment to support services. Increasing the percentage of patient navigation could help women receive education and information throughout each stage of the CoC.
While there are multiple providers in each target community, the percentage of each specific service is not higher than forty percent (Figure 3.6). This illustrates that while there are multiple providers, there are few providers with consolidated service, thereby causing patients to visit multiple providers to follow the CoC from screening to diagnosis to treatment and finally follow-up care. As aforementioned, a facility in Edgecombe County provides service to women from all three of the target counties. Wilson County has only one provider for biopsies, treatment and support/survivorship that is located within the county.
Key partnerships in this area include past and current grantees funded by the Komen NCTC. Potential new partners could be the community health centers in the target counties and the BCCCP coordinators at the county health departments. Another partner could be the UNC School of Public Health for interns who could potentially complete ongoing survey projects to measure the impact of current partnerships and research the opportunities of untapped grass-root partnerships with churches or other community groups which may exist. Using the National Cancer Institute (NCI), the Affiliate noted there are 37 existing clinical trials. Partnerships with the researchers could provide additional service avenues to the target counties. An Area Health Education Center exists in Rocky Mount that could be another potential partner for an educational partnership.

North Carolina’s decision not to expand Medicaid coverage and to have a federally managed health insurance exchange has caused little impact by the ACA on those uninsured and underinsured people in the state. A measure to help this group is ensuring eligible women are enrolled in the NC BCCCP before a cancer diagnosis is imperative so they will not be left struggling to afford treatment and care. The Affiliate needs to educate providers in the area to have their eligible patients enrolled in this program at the time of screening to meet the requirements of the NC BCCCP.

The Affiliate’s policy work is targeted to assist the women in its service area. The Affiliate may have more work to do once the outcome of HB 609 is known. The Affiliate will continue to strive for better, more affordable breast health care for the women in its service area by monitoring the state budget and working with legislators.
Qualitative Data: Ensuring Community Input

Comprehensive Cancer Consulting Services (CCCS) of Chapel Hill, NC was retained by the Affiliate to assist in the collection, analysis, and reporting for the Qualitative Data Section of the 2015-2019 Community Profile. CCCS has been involved in several projects with the Affiliate since July, 2011, and the Principal of CCCS, Walter L. Shepherd, is a long-time Komen supporter and volunteer, who served as Director of North Carolina's Comprehensive Cancer Program and Executive Director of the NC Advisory Committee on Cancer Coordination & Control from 2005 until his retirement in 2010. He also served as Assistant of the East Carolina University Medical School and directed the University's Center for Health Services Research & Development for fifteen years. By having intimate familiarity with the counties being assessed and possessing long-term relationships with the people and organizations in those counties, Mr. Shepherd was able to easily manage this project.

Qualitative Data Sources and Methodology Overview

Methodology
To gather the data necessary to qualitatively assess breast health issues in the three targeted counties, it was determined that two primary methods would be employed: structured interviews and focus group interviews. The structured interviews (quota sampling) would be conducted with general health care providers, clinical health care providers (MD - Cancer Specialties, MD - Primary Care), and health care organizations (delivery and advocacy) in each of the counties. Focus groups would be conducted with breast cancer survivors and family members recruited (convenience sampling) in each of the three counties.

Rationale for Data Collection Methods
CCCS, who conducted all key informant interviews and moderated all focus group sessions, has almost forty years of experience in conducting health services research in Eastern North Carolina. Coupled with academic training in Medical Sociology and Anthropology and doctoral in Sociology of Community/Social Change & Development and Adult Education, it was easy to select the best approaches and methods for collecting data. This is how personal interviews and focus group discussions were selected. Rationale for these methods had been established based on many years of success in the region.

In all cases, key informant interviews were conducted with individuals who have previously known and worked with CCCS and, consequently, there was already trust and validation present. Interviews were conducted at the offices of each key informant, where they would feel most comfortable and be able to access information if required.

Focus group sessions were organized on behalf of Komen by trusted community leaders in each of the three counties. And although some participants knew the CCCS facilitator, his presence was validated by those local leaders, as they had known and worked with him for several years. Sessions were conducted in locations that the participants were comfortable and familiar with and at times that were most convenient to them.
The organizations that assisted with the sponsorship of the focus group meetings provided meals and refreshments and although they did not know it ahead of time, each participant received a small gift as a token of appreciation for their participation.

**Sampling**

**Key Informant Interviews - Health Care Providers/Advocates**

In order to ensure that information would be obtained from the best participants in each of the three target counties, a list of organizations, agencies, and individuals who were intimately involved in breast health initiatives was developed and reviewed with the Affiliate leadership. Each of the three counties has a hospital that provides some level of breast cancer diagnosis and treatment, so individuals were selected who could knowledgeably provide information about their institutions services. In addition to the hospitals, health departments in each of the three counties have an important role in awareness and education efforts as well as providing the services of the Breast and Cervical Cancer Control Program (BCCCP), so key staff were contacted to be interviewed. Finally, if there were organized breast health advocacy programs, leadership associated with these groups were recruited; two of the three counties have such efforts. This resulted in selecting the following for key informant interviews:

**Edgecombe County**
- Health Department - Health Education Supervisor
- *Note: BCCCP Coordinator had recently retired, and no successor had been identified.*
- Hospital - Patient Navigator
- Advocacy Organization - Facilitator

**Halifax County**
- Health Department - Health Educator
- Health Department - BCCCP Coordinator
- Health Department - Nursing Director
- Hospital - Mammography Center Manager
- Hospital/Advocacy Organization - Two Leaders

**Wilson County**
- Health Department - Health Education Supervisor
- Health Department - BCCCP Coordinator
- Hospital - Patient Navigator
- *Note: No Advocacy Organization in County*

Personal interviews were conducted by CCCS with each key informant in a setting of their choosing, and a survey instrument was used that had been customized for their particular category (Health Care Provider - General, Organization, or Advocate). Interviews typically lasted one and one half hours.
Key Informant Interviews - Health Care Providers - MD’s

Physicians were also considered to be another group of key informants from which to solicit information. In each of the three target counties, physicians who are directly involved in breast cancer care (Medical Oncologists, Surgeons, Radiation Oncologists) and representative Primary Care Physicians were identified. A personal email (when emails addresses were available) and personal letters with enclosed survey forms and self-addressed stamped envelopes were sent to a total of twelve physicians. An optional in-person or telephone interview was also made available to them. There was also follow-up with several MD's through direct communication and working through local advocates and providers to encourage participation. Disappointedly, despite numerous and varied attempts, no surveys were returned by any of the physicians contacted.

Focus Groups

Having the input of those who are actually impacted by breast cancer was absolutely essential. And, it was important to have an appropriate environment in which they could share their experiences and express their opinions comfortably. Consequently, focus groups were selected as the preferred method. Working with and through local support groups and advocacy organizations, breast cancer survivors and family members were identified and recruited to participate in meetings. Table 4.1 shows the participation in each of the three targeted counties, the racial distribution, the number of different communities represented in each meeting, and the indication of the numbers of survivors and family members participating.

A data collection form, Focus Group Form and similar to the key informant Surveys, was developed that would allow for structured questions of the participants. Some items were designated as Yes or No responses followed by questions allowing respondents to explain their choices. For Yes or No questions, participants were asked to raise their hands while a count was made of each. All focus group sessions were moderated and participant responses were recorded on the Focus Group Form.
Table 4.1. Focus group participation in target counties

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**Ethics**

Key informants were contacted with an introductory email and a follow-up telephone call that described the purpose of the Community Profile, why the individual was being asked to participate in an interview, how the results of the interview would be reported and used, and an opportunity to ask any questions that they might have relative to the project or process. All informants readily provided their consent to participate.

Focus group participants were recruited by local advocates and health care providers, who provided basic information about the purpose of the Community Profile, why the individual was being asked to participate in an interview, how the results of the interview would be reported and used, and an opportunity to ask any questions that they might have relative to the project or process. An attempt was made to secure individuals who were generally representative of the respective target county.
At the beginning of each focus group meeting, a one-page information sheet describing the project and a one-page questionnaire/consent form were distributed. The consent form also provided a section to indicate if the individual wished to share information privately. A fifteen minute introduction to the process was given with an opportunity to ask questions. Participants were informed that their information would be kept confidential and none of their responses could be identified with an individual. The one-page questionnaires with names and contact information were utilized only if a participant wished to privately discuss their experiences or opinions or if there were any follow-up questions. All focus group attendees readily consented to participate. Sessions lasted approximately 90 minutes each.

CCCS will retain all data, except for the summary data provided to the Affiliate, and it will be secured with only one individual having access to identifying information for confidentiality reasons. This information will be retained in case there is a need for future follow-up.

**Post Interview & Focus Group Observations**

Another valuable component of the process utilized and the importance of having a single individual conduct the interviews and facilitate the focus groups is adding an observational component. This constitutes the third method employed of collecting data.

During and after interviews and focus group sessions, written notes were taken on the participants’ comments, facial expressions/body language, and casual and sometimes editorial remarks—items that may not fit neatly into any of the structure of the surveys and forms.

**How the Data Collection Methods Allow for Triangulation of the Findings**

By using three different but associated methods of collecting data, there is increased likelihood of more accurately determining what issues and opportunities exist in the target communities. Personal interviews, focus group sessions, and observations were the three methods utilized.

The personal interviews were conducted with key informants representing advocacy groups, health care providers, and representatives from health care organizations. The focus group sessions were conducted with breast cancer survivors, family members and caregivers. Observations were made by an experienced researcher, who recorded information about comments, side conversations, body language, and other expressions made during the interviews and group sessions.

The use of the three methods resulted in: 1) facts and opinions presented by those providing services to or advocating for breast cancers, 2) facts and opinions expressed by those who are most personally impacted by breast cancer and 3) observational information that confirmed or conflicted with the information provided by #1 or #2 and added information that was not captured by the formal methods during the interviews or focus groups. Essentially, by having the three methods, triangulation was achieved.
Qualitative Data Overview

Format of Original Data
As described extensively in the previous section, key informant Interviews and focus group sessions were recorded through the development and use of questionnaires. Questions/items for inclusion in each type of instrument were selected based on what things were more appropriate to the particular targeted group. In many cases, questions/items were the same or modified by using words that were changed to focus on the participant. All questions selected were added to the one-hundred, sixteen item question bank and cross-referenced.

Post Interview and focus group observations were recorded separately on blank pieces of paper as "notes" or in the margins of the interview and survey instruments. These were then organized and transcribed.

Typically the day following the key informant interviews and the focus group sessions, data from the paper surveys/forms were transferred to a spreadsheet that allowed for cross-referencing of items and subsequent analysis.

Rationale for Choice of Data Management/Tool/Package
By using a spreadsheet for the data, sorting could be done on specific values for subsequent coding, recording and analysis. As much as possible, verbatim responses were maintained during recording and analysis.

The one-hundred, sixteen item question bank was transferred to an Excel spreadsheet with the heading and content as shown in the Table 4.2.

<table>
<thead>
<tr>
<th>Item #</th>
<th>Issue</th>
<th>Question</th>
<th>Key Informant</th>
<th>Focus Group</th>
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<td>3</td>
<td>Barriers</td>
<td>What are the factors affecting whether or not women seek primary care and/or breast health services?</td>
<td>Extreme shortage of PCP's in county</td>
<td>Money. Time. Fear. Denial.</td>
</tr>
</tbody>
</table>

For Item #, there were one-hundred, sixteen rows. For Issue, there were eleven categories. Question, corresponding to Item #, were one-hundred, sixteen rows. Key Informant numbered twelve columns. And, there were three columns for Focus Group.

How Themes/Categories and/or Descriptions Were Generated
Utilizing the Komen-provided "Qualitative Data Toolkit: Qualitative Question Bank", Affiliate staff and CCCS selected and refined one-hundred and sixteen potential questions from among those provided which were determined to be useful for assessing the issues in each of the three target counties. Each question was classified according to key breast health/cancer issues:
- What General Social and Health Care Indicators Are There in the County? (30 items)
- What Access to Care Initiatives and Issues Are There in the County? (6 items)
- Are There Specific Barriers Affecting Utilization of Breast Health Resources? (21 items)
- What Overarching Community Problems Are There? (2 items)
- Are There Any Disparities That Might Impact the Continuum of Care? (11 items)
- What Educational and Awareness Efforts Are Employed? (20 items)
- Are There Health Care System Bottlenecks That Affect Patients? (5 items)
- What Health Care System Performance Improvements Need to Be Considered? (6 items)
- Is Care Provided in a Timely Fashion? (2 items)
- What Quality of Care Issues Are There? (6 items)
- Are There Specific Survivorship Issues That Are Identified? (7 items)
- What Other Issues Were Identified? (open-ended question)

Questions were then selected to be used in interviews/discussions identified as being most appropriate for each of the four groups:
- Organizations (67 questions)
- Health Care Providers (General) & Advocates (65 questions)
- Health Care Providers - MD's (47 questions + additional 18 questions for PCP's)
- Focus Groups - Survivors and Family (46 questions + 12 questions on profile form)

Common Findings With the Qualitative Data Collected From Each Method
- Breast cancer is seen as one of the top five health, mental health, and social problems in each of the targeted counties.
- Lack of money and no insurance/underinsurance are universal problems.
- Transportation, lack of and barriers to, is a major issue from accessing screening through treatment.
- Little or no knowledge of problems facing Hispanic/Latinas and minimal or no outreach activities.
- Primary care physicians are not accepting a role in educating, screening, and supporting breast cancer services.
- Poor physician knowledge of and referral to resources, especially for survivorship and for family support.
- Poor or no communication between and within different parts of the breast health system.
- For most people, basic, daily survival (food, shelter, safety) trumps concern about health care, including breast health.
- Resources and outreach are lacking in the more rural areas of each county.
- There is a need for more resources and free materials.
- Breast cancer in younger women (<40) is seen as a regional concern.
- There is little discussion and education regarding the long-term effects of treatment.
- People feel that they had to educate themselves to cope with diagnosis and beyond.
- Virtually no discussion taking place about treatment options; patients are told and directed.
• Need for more personalized approach to treatment and care (everyone's needs are different)
• Essentially no support services for family members.

There was remarkable similarity in responses obtained from key informant interviews, Focus groups, and observations on views of the community in general, barriers associated with breast health services, physicians, and real and perceived need for additional resources. What differences there were came from perspectives associated with health care systems' organization and delivery and responses that were based on the actual experience as a patient in the continuum of care from screening through post-treatment/survivorship. It was apparent that, in spite of professional expertise and empathy, those who provide or advocate for breast health services do not actually have the emotion and memory associated with being a breast cancer survivor or family member. The two complementary but different perspectives were valuable in gaining a more complete understanding than just one would provide. Then, adding the Observations from a trained, third-party recorder/researcher helped to further enhance the mosaic. Missing, however, and as described in other sections, was the perspective of the physicians in the community.

Qualitative Data Findings

Overall Findings Linked to Key Questions by Target County

Edgecombe County
1. What Overarching Community Problems Are There?
   • Community Health, Mental Health, and Social Concerns. Key informants and focus group participants concurred that breast cancer constituted a major community problem. It was ranked in the top five health, mental health and social concerns in their county. It was generally ranked from #2 to #5 after heart disease, diabetes, and obesity. Additionally, focus group participants felt that being healthy, finances, emotional support, lack of jobs, and poor access to medical care due to lack of insurance were the biggest issues.
   • Other Issues. Focus group participants named transportation and the availability of affordable testing.

2. What General Social and Health Care Indicators Are There in the County?
   • Demographics of Population Served. Key informants indicated that the demographics of the women served by their programs ranged in age from twenty to eighty, more than typical advanced breast cancer, and primarily Black/African-American followed by White but few Hispanics/Latinas.
   • Routine Mammograms Prior to Diagnosis. Thirty-eight percent of the focus group (Breast Cancer Survivors) did not get regular mammograms prior to their diagnosis.
   • Family History of Breast Cancer. Forty-six percent of the focus group participants had a family history of breast cancer.
3. What Access to Care Initiatives and Issues Are There in the County?

• **Initiatives.** Both the hospital and the health department engage in outreach efforts to women who typically lack access. The hospital, with Komen funding, started a Lay Health Advisor program that focuses on awareness and access to services. The health department works with local churches, networks with local groups and organizations, places ads in local, free media, and utilizes social media.

• **Issues.** One-third of the focus group participants did not have a regular source of health care at the time they were diagnosed with breast cancer. Those who didn't have a regular source of care indicated that they couldn't afford it, they typically did not go to an MD on a regular basis, or they put their own health care needs secondary to the needs of their family members.

4. Are There Specific Barriers Affecting Utilization of Breast Health Resources?

• **Barriers to Seeking Primary Care and/or Breast Health Services.** Key informants felt that lack of insurance, fear, lack of awareness, not recognizing the need for routine primary care, and an extreme shortage of primary care physicians were primary barriers. Focus group participants indicated that money, time, fear and denial were the primary factors.

• **Barriers to Breast Cancer Screening.** Key informants stated that lack of insurance, fear, lack of health system capacity, lack of effective marketing, and women not wanting to know if they’re positive were the main reasons for not getting screened. Focus group participants stated that money, fear, lack of information about the importance of screening, and pain affected participation.

• **Barriers to Breast Cancer Diagnosis.** Key informants felt that lack of insurance had been an issue previously, but efforts have been taken to eliminate barriers and they appeared to be successful. None of the focus group participants experienced any issues with transitioning from screening to diagnostic resources.

• **Factors Associated with Late-Stage Diagnosis.** Key informants expressed the belief that not having a Primary Care Physician and lack of insurance were the primary reasons. Also, women putting their health care secondary to the needs of their families contributed to this problem.

• **Barriers to Accessing Breast Cancer Treatment.** Key informants stated that little or no insurance, transportation problems, not having Radiation Oncology available locally, and disconnection between the two county health departments that serve the largest city in the county (the city of Rocky Mount is geographically located in both Edgecombe and Nash counties.) None of focus group participants experienced any barriers while going through their treatments.

• **Barriers Associated with Follow-up Care.** None of the focus group participants had any issues associated with receiving follow-up care after their treatment had ended.

• **Cultural Barriers to Seeking Care.** Two of the key informants and all of the focus group participants believe that there are cultural barriers associated with seeking care in the county.

• **Removing Barriers to Yearly Clinical Breast Exams and Mammograms.** Focus group participants indicated that providing free examinations, making mammograms less
painful, informing younger women about the need for exams, increasing general public awareness of the availability of BCCCP would all encourage women to access resources annually.

- **Motivations to Seeking Breast Cancer Screening.** Focus group participants stated that having a friend or acquaintance with breast cancer, having a family history of breast cancer, and doing self-exams were important motivators.
- **Other Comments from Focus Group Participants.** Several participants indicated that they were told that they were too young to be screened prior to being diagnosed. One woman indicated that other health issues took precedence over breast cancer screening. Another had been told by her primary care physician that she had caffeine cysts so she didn’t need to worry.

5. Are There Any Disparities That Might Impact the Continuum of Care?

- **Groups in the County Who Do Not Receive Services Due to Race, Ethnicity, Culture, or Language?** Key informants indicated that Hispanic/Latina women were not receiving services. Many are undocumented, and most have a fear of any governmental program, including the county health department. Although materials are available in Spanish, there is a limited availability of interpreters in the county. Also, it was stated that there are very limited or no outreach efforts for this population.
- **Geographic Areas Where Services Are Needed?** Key informants identified all areas outside of the two principal cities (Rocky Mount and Tarboro) and the Edgecombe county portion of Rocky Mount were lacking adequate services and resources.

6. What Educational and Awareness Efforts Are Employed?

- **Current Initiatives to Get Breast Cancer Messages Out.** Prior Komen funding allowed the hospital to develop a Lay Health Advisor program which is being effectively employed. And, the hospital hired a Patient Navigator who coordinates the breast cancer support group. There are also health fairs and community events where information is distributed, and presentations are routinely given in the county's churches. The hospital emergency department paperwork provided to patients includes a breast cancer message.
- **Possible Changes to Improve Efforts.** It was expressed that there needs to be more year-round, consistent education, awareness, and early detection activities and not just celebrations of pink in the month of October. Other recommendations include trying to get breast health messages out to younger people and people without insurance and regular sources of medical care. Challenges are also found due to an inadequate health workforce, existing agencies and organizations are overextended, and the needs of the rural areas of the county.
- **Sources of Health Information for Women.** The more common sources of information come from churches in the county, primary care physicians, and the various clinics.
- **Most Likely Sources of Breast Health Information.** Key informants indicated that the hospital and the health department were the primary sources; focus group participants felt that the health department, the Internet, and breast health resources in Greenville, NC were the main sources.
• **Most Credible People Providing Breast Health Information.** Both the key informants and the focus group participants named the hospital health educator, the patient navigator and the general surgeon, the hospital, the health department, and the Lay Health Advisors.

• **Most Effective Ways to Educate Women About Breast Health.** Key informants indicated that there needs to be different types and methods of messaging for different age groups (young people = social media, older people = newspaper and faith-based organizations), use of peer-to-peer programs, and church-oriented programs. Focus group participants made the statement, "You can lead a horse to water, but you can't make him drink," but they also added that including breast health content in school health education instruction, and distributing self-examination cards.

7. Are There Health Care System Bottlenecks That Affect Patients?
• **Tracking Mechanisms for Monitoring Compliance with Screening Recommendations.** At the health department, clients coming through their system through Komen funded resources do get tracked. For other providers, this is unknown.

• **Gaps That Impact Transition from Screening to Diagnosis.** Key informants expressed the need for a Patient Navigator who could focus exclusively on outreach and screening; the current Patient Navigator is hospital-based and becomes involved during treatment and post-treatment.

8. What Health Care System Performance Improvements Need to Be Considered?
• **Providers Encouraging Use of Breast Health Services.** Key informants believe that having more wellness screening available, more awareness of family medical histories, helping more women obtain health insurance coverage, and having all providers agree on reduced pricing for screening.

• **Needed New Programs, and Policies.** Key informants indicated that having an outreach and screening navigator, developing a shared position between the hospital and the health department to focus exclusively on breast health, and having cooperative marketing efforts between the hospital and health department.

• **Additional Breast Health Services Required.** Key informants stated that Radiation Oncology services were necessary as patients must leave the county.

• **Treatment Options Discussed.** A majority of focus group participants (fifty-six percent) shared that they were not provided with treatment options at the time of diagnosis.

9. Is Care Provided in a Timely Fashion?
• **Average Wait Time for Screening.** Key informants said that it could be as little as one day via the health department and a week to ten days otherwise.

• **Amount of Time Between Diagnosis and Beginning Treatment.** Key informants indicated that the hospital has a goal of five days with an observed time of five to ten days; a team had been put together to examine ways to reduce the time. Focus group participants related that it took between two weeks and three months for them. Most indicated no more than one month; one survivor was waiting for her Medicare to become effective, and this resulted in a three month wait.
10. What Quality of Care Issues Are There?
   - **What Quality Care Looks Like.** Key informants believe that quality care includes screening and treatment that is timely and accessible to all residents of the county, complies with recommended guidelines and evidence-based, and that there are no delays in transitioning from diagnosis to treatment.
   - **Changes Needed to Achieve Quality Care.** Key informants felt that overall more physicians were needed in the county, there needed to be a full-time oncologist available (currently three days/week), and there should be a "one-stop shop" for breast services.
   - **Current Screening Guidelines Used.** Key informants all stated that everyone is using the current American Cancer Society Guidelines for breast cancer screening.
   - **Factors Affecting Quality of Treatment Received.** Focus group participants, with one exception, indicated that treatment quality was predicated on patients' financial and insurance status. If you have insurance, better care is provided. The one person who did not agree stated that the hospital "wrote off" a considerable portion of her bill and put her on a reasonable payment plan.

11. Are There Specific Survivorship Issues That Are Identified?
   - **Breast Cancer Support Groups.** According to the key informants, their organizations do not offer breast cancer support groups.
   - **Post-Treatment Support Services.** Through the hospital, a survivorship care plan pilot project is underway, a Peer Connect initiative has been used, the hospital-based patient navigator supports survivorship services, and American Cancer Society offers the Look Good/Feel Better program.
   - **Information, Support, Resources or Activities That Are Lacking.** Focus group participants would like to see more support provided to family members and caregivers. They also said that physicians withheld information on future risks and long-term effects. They were also not made aware of retreats or other activities that might have been offered. And, those who had no local family and whose friends who were working felt that they were under stress, especially for transportation and caregiving.

12. What Other Issues Were Identified?
   - Wish that more information about long-term effects of chemo and radiation had been shared. I had to educate myself.
   - Helpful to have friends who work in health care to go with you.
   - Primary care physicians in the community don't talk about breast cancer.
   - Concern about not being given an opportunity for a second opinion.
   - Too many oncologists are coming and going in the community; can't keep anyone.
   - Physicians do not refer patients to support services and groups.

13. What Things Could Komen or Other Organizations Do in Your Community to Reduce the Burden of Breast Cancer?
   - Provide more outreach efforts to Hispanic/Latina population.
• Help with patient expenses.
• Provide funds for treatment.

**Observations**

• There is uncertainty about the Hispanic/Latina population. They are known to be "out there" but not much is known about their problems. Consequently, there are few initiatives directed at them.
• There are too many people whose primary concern is survival on a day-to-day basis and to have food, shelter, and security. Health care is not a concern until an emergency occurs.
• It is difficult to get into the White churches; they may request materials but not speakers or activities. Black/African-American churches, however, are eager to participate.
• There is more focus on Tarboro, the county seat, and the immediate surrounding communities, and not much is done beyond that area. The City of Rocky Mount presents a special problem as it is shared with Nash County; the Edgecombe County part is generally more impoverished and has fewer resources.
• Transportation is always discussed as a barrier.
• There are few avenues for public awareness. Edgecombe County does not have a television station, the 125 year old newspaper ceased operation in the spring of 2014, and there are few other options that reach the general population.
• The health department is over-extended, understaffed, and underfunded. They are currently without a fulltime BCCCP Coordinator; the Health Education Supervisor (primary breast cancer facilitator) has multiple other responsibilities assigned to her.
• There is very good communication and collaboration with the local hospital, Vidant Edgecombe Hospital.
• The hospital became part of a Greenville-based health care system within the past few years; this has helped to provided more resources and referral links.
• The hospital has taken a leadership role in several of the recent breast cancer initiatives-Breast Cancer Task Force, Patient Navigator, public awareness efforts, and outreach.
• There is need for both more primary care providers as well as specialists within the county.
• There has been a high turnover in medical oncology specialists (currently, one comes from Greenville three days per week), and there is no radiation oncology provided.
• The county has been experiencing a substantial loss of jobs and employers, and this has resulted in greater challenges to county and tax-supported efforts. It also results in fewer persons with employer-provided health insurance.
• To get people to attend and participate in events, food must be served.
• There is a need to get breast cancer messages out throughout the year and not just during the month of October.
• Mammograms are very painful and this discourages screening.
• Clinical trials information is not routinely provided.
Halifax County

1. What Overarching Community Problems Are There?
   - Community Health, Mental Health, and Social Concerns. Key informants and focus group participants felt that breast cancer was in the top five problems behind diabetes, health disease, and mental health issues. Focus group participants particularly commented they see a great deal of cancer in their communities.
   - Other Issues. Focus group participants named high poverty, low wage jobs, having no sick leave provided by employers, racism, and classism.

2. What General Social and Health Care Indicators Are There in the County?
   - Demographics of Population Served. Primarily Black/African-American followed by White and then Hispanic/Latina.
   - Routine Mammograms Prior to Diagnosis. Fourteen percent of the focus group (Breast Cancer Survivors) did not get regular mammograms prior to their diagnosis.
   - Family History of Breast Cancer. Forty-three percent of the focus group participants had a family history of breast cancer.

3. What Access to Care Initiatives and Issues Are There in the County?
   - Initiatives. Key informants indicated that follow-up contacts are made with identified women, health fairs are conducted throughout the county, and radio/newspapers ads are utilized.
   - Issues. Twenty-eight percent of the focus group participants did not have a regular source of health care at the time they were diagnosed with breast cancer. Those who didn't have a regular source of care indicated that they were self-employed and did not seek routine care due to not being able to afford insurance or having to drop insurance when the premium doubled.

4. Are There Specific Barriers Affecting Utilization of Breast Health Resources?
   - Barriers to Seeking Primary Care and/or Breast Health Services. Key informants felt that transportation, lack of insurance, fear, lack of awareness, denial, and lack of access were primary barriers. Focus group participants indicated that finances, fear, lack of access to primary care, denial, myths, and confusion regarding importance of care were the primary factors.
   - Barriers to Breast Cancer Screening. Key informants stated that money, transportation, lack of MD referrals, fear, denial, fear of mammograms, and embarrassment were the main reasons for not getting screened. Focus group participants stated that fear, money and painful mammograms affected participation.
   - Barriers to Breast Cancer Diagnosis. Key informants felt that lack of insurance had been an issue previously, but efforts have been taken to eliminate barriers and they appeared to be successful. None of the focus group participants experienced any issues with transitioning from screening to diagnostic resources.
   - Factors Associated with Late-Stage Diagnosis. Key informants expressed the belief that denial, awareness, not having routine mammograms, not knowing where to go for screening, not doing self-screening and not following-up were the primary reasons.
• **Barriers to Accessing Breast Cancer Treatment.** Key informants stated that money, transportation, lack of understanding of what was recommended, denial, fear, and having a fragile family economic condition were main factors. None of the focus group participants experienced any barriers while going through their treatments.

• **Barriers Associated with Follow-up Care.** None of the focus group participants had any issues associated with receiving follow-up care after their treatment had ended.

• **Cultural Barriers to Seeking Care.** All of the Key informants and all of the focus group participants believe that there are cultural barriers associated with seeking care in the county.

• **Removing Barriers to Yearly Clinical Breast Exams and Mammograms.** Focus group participants indicated that getting more information out about early detection saving lives, that the mammogram is worth the pain, having more convenience (mobile units, more hours of screening), offering services in more comfortable settings (health fairs, churches).

• **Motivations to Seeking Breast Cancer Screening.** Focus group participants stated that knowledge about the high number of breast cancer diagnoses in the county, knowing others with breast cancer, having experienced the death of someone from breast cancer, and seeing women who successfully survive were motivators.

• **Other Comments from Focus Group Participants.** Several participants indicated that they were told that they were too young to be screened prior to being diagnosed.

5. Are There Any Disparities That Might Impact the Continuum of Care?

• **Groups in the County Who Do Not Receive Services Due to Race, Ethnicity, Culture, or Language?** Key informants indicated that Hispanic/Latina, Black, American Indian/Alaska Native and Asian women were not receiving services. Language barriers, transportation problems, lack of education on screening guidelines (Hispanic/Latina, Asian), and not having a regular health care provider were cited as problems.

• **Geographic Areas Where Services Are Needed?** Key informants identified all rural areas, Hollister, Tillery, Enfield, and Scotland Neck, were lacking adequate services and resources, although it was also stated that some of this was the community's perception.

6. What Educational and Awareness Efforts Are Employed?

• **Current Initiatives to Get Breast Cancer Messages Out.** The primary initiative mentioned was the existence of the Roanoke Valley Breast Cancer Coalition (RVBCC). Supported with Komen funding, the RVBCC has sponsored two well-attended breast cancer conferences (more than 250 participants for each), issued press releases, produced radio spots, newspaper articles, and conducted educational sessions in schools, churches, and community events.

• **Possible Changes to Improve Efforts.** It was expressed that there needs to be more educational outreach to the rural and targeted areas, provide physician referrals, get more health care providers engaged, and do more health fairs and events.

• **Sources of Health Information for Women.** The most common source of information comes from friends, families, and others. Primary care providers and OB/GYN physicians were other sources. And, the Internet and television were mentioned.
• **Most Likely Sources of Breast Health Information.** Key informants indicated that the health department was the main source with primary care providers next. Focus group participants felt that physicians, the Internet, friends, survivors, and a prominent community member, organizer and activist were the main sources.

• **Most Credible People Providing Breast Health Information.** Key informants named the health department, the Roanoke Valley Breast Cancer Coalition, Rural Health Group, OB/GYN physicians, and the hospital imaging center were the most credible. Focus group participants named breast cancer survivors and the same prominent community member, organizer and activist.

• **Most Effective Ways to Educate Women About Breast Health.** Key informants indicated that demonstrations, one-on-one sessions, small groups, support groups, worksite screening events, community events, and offering information in more and different locations.

7. Are There Health Care System Bottlenecks That Affect Patients?

• **Tracking Mechanisms for Monitoring Compliance with Screening Recommendations.** The health department tracks and does personal follow-ups with all clients utilizing their clinics. The hospital imaging center sends yearly notices to all mammogram patients and follows up with patients who do not return for yearly visits. For other providers, this is unknown.

• **Gaps That Impact Transition from Screening to Diagnosis.** Key informants expressed that initiatives that addressed fear, denial, money, transportation, low health literacy, and the availability of resources were needed.

8. What Health Care System Performance Improvements Need to Be Considered?

• **Providers Encouraging Use of Breast Health Services.** Key informants believe that providers need to have more knowledge about community resources, engage in a more holistic approach to care, having more female providers, provide more patient information and education through their practices, and be certain that they are ordering mammograms for all women age forty and over and continuing annual screenings.

• **Needed New Programs and Policies.** informants indicated that programs addressing affordability, transportation and education needed to be enhanced. It was also suggested that immediately after diagnosis all patients needed to be connected with resources and assigned a "buddy" to assist them.

• **Additional Breast Health Services Required.** Key informants stated that there needed to be “one-stop-shopping" for breast services, second opinions needed to be encouraged, more surgeons were needed, and greater collaboration along the cancer continuum.

• **Treatment Options Discussed.** Fifty percent of focus group participants shared that they were not provided with treatment options at the time of diagnosis.

9. Is Care Provided in a Timely Fashion?

• **Average Wait Time for Screening.** Key informants said that it could be one to two days up to two weeks for routine screening and next day or within a week for a detected lump.
• **Amount of Time Between Diagnosis and Beginning Treatment.** Key informants did not indicate a time as this was determined by the diagnosing physicians.

10. **What Quality of Care Issues Are There?**
   - **What Quality Care Looks Like.** Key informants believe that quality care includes provision of holistic care, patient satisfaction, adherence to guidelines, timeliness, compassion, clinical expertise, and follow-up care.
   - **Changes Needed to Achieve Quality Care.** Key informants felt that increased provider communication, support for second opinions, more breast cancer education, more yearly screenings, and quicker treatment were needed.
   - **Current Screening Guidelines Used.** Key informants all stated that everyone is using the current American Cancer Society Guidelines for breast cancer screening and also consult Komen recommendations and BCCCP guidelines.
   - **Factors Affecting Quality of Treatment Received.** Focus group participants felt that insurance status, amount of coverage included in policies, and issues with multiple insurers having conflicts over payments were problems.

11. **Are There Specific Survivorship Issues That Are Identified?**
   - **Breast Cancer Support Groups.** According to the Key informants, the Roanoke Valley Breast Cancer Coalition sponsors support groups in four areas of the county.
   - **Post-Treatment Support Services.** Other than the RVBCC support groups, no formal post-treatment support services are provided through the health department, hospital or physician practices.
   - **Information, Support, Resources or Activities That Are Lacking.** Focus group participants were all appreciative of the existing support groups. Those who had been treated prior to their establishment expressed that they wished they had been in place earlier.

12. **What Other Issues Were Identified?**
   - I was forced to make a choice between paying for care and medicine and paying for my groceries.
   - Concern was expressed about people who sit at home and don't access services or suffer alone.
   - I've always worked with patients but when I was diagnosed it hit me hard.
   - There is provider reluctance to participate in screening because of challenges and liability issues associated with follow-up.

13. **What Things Could Komen or Other Organizations Do in Your Community to Reduce the Burden of Breast Cancer?**
   - Continue to offer grants and educational materials.
   - The American Cancer Society needs to bring some of their programs to the county.
   - Help with patient expenses, especially co-pays.
   - Help ensure that resources get to the populations who need them.
**Observations**

- There is much discussion and concern expressed about what appears to be an excessive amount of all types of cancers in the county and more occurring in specific communities.
- Employees of small companies, companies that do not provide benefits, and self-employed individuals have more difficulty in getting care because of the high cost.
- There is a strong feeling that racism and classism are prevalent throughout the county and have an impact on the accessibility and quality of care.
- Some physicians who do accept Medicaid and BCCCP payments “work the system” by scheduling more appointments for those patients in order to bill for more visits and services.
- There has been minimal engagement by the medical community in breast health initiatives.
- The hospital has been working hard to enhance its services and has been an active supporter and participant in breast health efforts.
- The ownership and management status of the hospital is possibly changing from a not-for-profit community hospital to one that is managed and/or owned by an external hospital system. This could change services and resources for either better or worse.
- The Roanoke Valley Breast Cancer Coalition has been an important leader in the county. This has resulted in four breast cancer support groups (geographically dispersed), a biennial breast cancer conference, and the implementation of many initiatives. However, its mission is to focus on women of color and this has excluded widespread engagement of and participation by White and Hispanic/Latinas residents. Rural and lower-income White women are not typically participants in activities.
- There is concern about the large number of young women (under 40) who are diagnosed with breast cancer.
- Mammograms are very painful and this discourages screening.
- It is felt that some of the treatment facilities and services are outdated.
- Women diagnosed with breast cancer are generally not provided with opportunities to discuss treatment options; they are told by the physicians.
- There is an increase in the Asian population, and it is felt that little is known about them and what resources and services need to be provided.
- Information regarding clinical trials is not routinely available.
- Once a referral is made, the health department is typically not informed about what has happened.

**Wilson County**

1. What Overarching Community Problems Are There?

- **Community Health, Mental Health, and Social Concerns.** Key informants and focus group participants concurred that breast cancer constituted a major community problem. It was ranked in the top ten health, mental health, and social concerns in their county. It was generally ranked from #1 to #3 after mental health and hypertension. Additionally,
focus group participants felt that cancer, hypertension, and diabetes were the main health issues.

- Other Issues. Focus group participants named financial issues, lack of insurance, and transportation as other prevailing issues.

2. What General Social and Health Care Indicators Are There in the County?

- Demographics of Population Served. Key informants indicated that the demographics of the women served by the hospital’s services were sixty-one percent White, thirty-eight percent Black, and Others were negligible; health department distribution was estimated to be evenly split between White and Black/African-American.

- Routine Mammograms Prior to Diagnosis. Two-thirds of the focus group (Breast Cancer Survivors) did not get regular mammograms prior to their diagnosis.

- Family History of Breast Cancer. One-third of the focus group participants had a family history of breast cancer.

3. What Access to Care Initiatives and Issues Are There in the County?

- Initiatives. The health department provides educational programs. The hospital sponsors physician talks, free community events, and outreach events. The hospital foundation has a Pink Ladies Fund to support screening, and a private, nonprofit organization, Pennies from Angels, provides funds for wigs, bills, transportation, and specific, requested items.

- Issues. All of the focus group participants indicated that they did have a regular source of health care at the time they were diagnosed with breast cancer.

4. Are There Specific Barriers Affecting Utilization of Breast Health Resources?

- Barriers to Seeking Primary Care and/or Breast Health Services. Key informants felt that transportation, money, lack of insurance or not enough insurance, fear, and denial were all barriers. Focus group participants indicated that lack of insurance, money, transportation, putting family needs before self, primary care physicians not educating patients, and physicians not recommending tests were major factors.

- Barriers to Breast Cancer Screening. Key informants stated that lack of insurance, fear, physicians not accepting Medicaid patients, and education level were the main reasons for not getting screened. Focus group participants stated that money, fear, lack of information about the importance of screening, and pain affected participation.

- Barriers to Breast Cancer Diagnosis. Key informants felt fear, denial, money and transportation were the main problems. None of the focus group participants experienced any issues with transitioning from screening to diagnostic resources.

- Factors Associated with Late-Stage Diagnosis. Key informants expressed the belief that some women will wait to access care until they feel or see something. They also thought that lack of education, money, and fear contributed.

- Barriers to Accessing Breast Cancer Treatment. Key informants stated that fear, denial, money, and lack of transportation were the main barriers. None of focus group Participants experienced any barriers while going through their treatments.
• **Barriers Associated with Follow-up Care.** None of the focus group participants had any issues associated with receiving follow-up care after their treatment had ended.

• **Cultural Barriers to Seeking Care.** Two of the Key informants and all of the focus group participants believe this contributes to seeking care in the county.

• **Removing Barriers to Yearly Clinical Breast Exams and Mammograms.** Focus group participants indicated that providing free examinations and conducting outreach in churches and other locations would encourage women to access resources annually.

• **Motivations to Seeking Breast Cancer Screening.** Focus group participants stated that getting reminders from their physician, finding a lump in their breast, having family history, having been in an educational session, and learning from survivors motivated women to get screened.

• **Other Comments from Focus Group Participants.** Two participants indicated that they were told that they were too young to be screened prior to being diagnosed.

5. Are There Any Disparities That Might Impact the Continuum of Care?

• **Groups in the County Who Do Not Receive Services Due to Race, Ethnicity, Culture, or Language?** Key informants had differing opinions. One was not sure; while another indicated that possibly Hispanic/Latina women were not receiving services. A third key informant felt that it may affect Blacks more but she thought personal choice was a greater factor.

• **Geographic Areas Where Services Are Needed?** Key informants believed that areas in the eastern part of the county were lacking adequate services and resources.

6. What Educational and Awareness Efforts Are Employed?

• **Current Initiatives to Get Breast Cancer Messages Out.** Educational programs are provided by the health department, placing signage in the community (month of October), health fairs, meetings and events in churches and the agricultural center, and an annual Mother's Day mammography event sponsored by the hospital.

• **Possible Changes to Improve Efforts.** It was expressed that there needs to be more outreach in the community and in churches. Placing information in grocery stores, bus stations, and other public places were also suggested; too much reliance on materials only in the health department and physician offices.

• **Sources of Health Information for Women.** The more common sources of information come from physicians, the health department, hospital ER, urgent care centers and the community clinic.

• **Most Likely Sources of Breast Health Information.** Key informants indicated that the health department and emergency room were the primary sources; focus group participants felt that the best sources were located outside of the county in Greenville, NC in Pitt County.

• **Most Credible People Providing Breast Health Information.** Both the Key informants and the focus group participants named the health department and OB/GYN physicians. Nurses in physician offices, and the hospital imaging center were also mentioned by the key informants.
Most Effective Ways to Educate Women About Breast Health. Key informants indicated that providing information in group settings (churches) and classes and one-on-one were effective, as opposed to "pushing pamphlets."

7. Are There Health Care System Bottlenecks That Affect Patients?
- Tracking Mechanisms for Monitoring Compliance with Screening Recommendations. At the health department, clients coming through their system with Komen resources do get tracked and are provided with reminder phone calls.
- Gaps That Impact Transition from Screening to Diagnosis. Key informants expressed that lack of insurance or being underinsured, running out of BCCCP funding, transportation, money, and lack of family support contributed to gaps in care.

8. What Health Care System Performance Improvements Need to Be Considered?
- Providers Encouraging Use of Breast Health Services. Key informants suggested that physicians should talk with patients about breast health. Another key informant, however, felt that everything that needed to be done was being done.
- Needed New Programs and Policies. Key informants believe that having surgeons in the county who accept Medicaid (none currently participate), creating breast cancer specific support groups, address transportation problems, and having a dedicated volunteer group are needed.
- Additional Breast Health Services Required. Key informants stated that having Medicaid participating surgeons were needed. Also, there is a need for genetic testing/counseling, in-county plastic surgery and 3D imaging and having an oncology social worker would help.
- Treatment Options Discussed. Focus group participants shared that they were no other appropriate treatment options available at the time of diagnosis.

9. Is Care Provided in a Timely Fashion?
- Average Wait Time for Screening. Key informants said that it could be a week or less or immediately if a lump was present.
- Amount of Time Between Diagnosis and Beginning Treatment. Key informants could not provide this information.

10. What Quality of Care Issues Are There?
- What Quality Care Looks Like. Key informants felt that patient navigation with links to resources, good communication between physicians and other providers, and timely care with no gaps or delays were indicators of quality care.
- Changes Needed to Achieve Quality Care. No changes were suggested.
- Current Screening Guidelines Used. Key informants stated that current American Cancer Society and American Congress of Obstetricians and Gynecologists guidelines are being used for breast cancer screening.
- Factors Affecting Quality of Treatment Received. Focus group participants felt that the type of insurance that a person has and the amount of insurance coverage affected the
quality of treatment. There was also an expression that physicians lacked appropriate bedside manner and that they also appeared to lack adequate education about cancer.

11. Are There Specific Survivorship Issues That Are Identified?
   - **Breast Cancer Support Groups.** According to the key informants, their organizations do not offer breast cancer support groups.
   - **Post-Treatment Support Services.** According to the key informants, there are no breast cancer specific post-treatment support services. Pennies from Angels, a private, nonprofit provides funds for wigs, bills, transportation and specific items.
   - **Information, Support, Resources or Activities That Are Lacking.** Focus group participants would like to see a support group, one-on-one assistance, and that they should have been told that everyone is different, at different stages of treatment, and that patients needs are different (one size does not fit all).

12. What Other Issues Were Identified?
   - There is a need for more education about cancer for primary care physicians.
   - Normally, a regular physician will not check for cancer.
   - Primary care physicians are not doing breast checks.
   - For Blacks in the community, cancer is a taboo topic and it is denied.
   - Helpful to have friends who work in health care go with you to appointments.
   - Major surgical practice will not accept the BCCCP fee, and all patients have to be referred out of county for care.

13. What Things Could Komen or Other Organizations Do in Your Community to Reduce the Burden of Breast Cancer?
   - Provide grant opportunities, free literature, a resource directory, mobile mammography, and funds for free clinics.

**Observations**
   - It is felt that even with messages going out, many women are still being missed and left out.
   - There is generally no outreach occurring outside of the City of Wilson.
   - There is little communication and collaboration between and among the health department, the hospital, and physician offices.
   - Mammograms are very painful and this discourages screening.
   - There is big concern about the primary care physicians in the community not screening for cancer and their general lack of awareness and interest.
   - Overall, there is concern expressed about the current medical community and much longing for the physicians of "yesteryear."
   - There are no breast cancer-specific support groups in the county.
   - Support for breast cancer survivors is a big deficit.
Everyone shared their concern about the lack of a surgical practice participating in BCCCP and Medicaid. This results in those patients having to be referred to Greenville, NC which is thirty-five miles away.

Transportation difficulties are universally recognized.

The ownership of the hospital has recently changed from a not-for-profit, community hospital to corporate owned (Duke/LifePoint), and there is uncertainty about what this will mean for cancer care.

How the Qualitative Data Collection Findings Are Linked to the Quantitative Data and Health Systems and Public Policy Analysis Sections

The Quantitative Data show that the region in which all three target counties are located has a large Black/African-American population, high poverty and high unemployment, high breast cancer death rates, and late-stage breast cancer incidence rates.

The Health Systems and Public Policy Analysis revealed that the three counties are lacking services that facilitate easy progression through the continuum of care, the need for additional patient navigation services, the lack of consolidated breast care services, and the problems associated with the State’s decision not to expand Medicaid coverage.

Results from analysis of the Qualitative Data confirm, support, and enhance the above findings, as well as providing more depth to the identification and description of the issues associated with breast health services in the region.

The key informant interviews confirmed that the organizations and agencies in the three counties provide services to a predominantly Black/African-American population, that the high poverty and high unemployment rates are revealed in access to care problems, erecting barriers to care (from screening to diagnosis to treatment), late-stage diagnoses, poor compliance, and challenges to outreach efforts. Other conclusions from the Qualitative Data analysis confirmed the lack of services that facilitate easy progressions through the continuum of care as shown by the absence of local diagnostic and treatment resources, and the nonparticipation of certain medical specialists in Medicaid and BCCCP. The lack of consolidated breast care services was supported by the key informants indicating that holistic care and breast care services all located under one roof were among the necessary improvements.

Focus groups not only supported the above findings but also supported the possible impact of the State’s decision not to expand Medicaid by indicating that lack of health insurance was a major factor in not seeking screening, obtaining a diagnosis, and receiving care. Lack of insurance was also cited as a major reason for late-stage diagnosis.

Strengths and Weaknesses of the Data Sources and Methods

When designing a research project, there is always the intent to collect the most complete data possible and to obtain from the maximum number of sources. This is the ideal; the reality is compromise and acceptance. Such was the case with the qualitative data collection and analysis for this Community Profile.
The project started with determining the key sources of qualitative data in each of the three target counties. This resulted in developing ambitious lists of key individuals engaged in breast health programs and advocacy, the key organizations engaged in providing breast health services, health care providers, and, finally, facilitators who could assist with recruiting breast cancer survivors and family members/caregivers. Numerous emails, phone calls, and personal visits resulted in securing participation or, in some cases, non-participation.

Next, it was important to select the key issues to be examined for the project, the best methods for obtaining data from each category of participant, and the specific questions/items that would allow for capturing the information necessary to address each issue.

**Strengths**

**Project Implementation**

- In each of the three target counties, Komen was known and well-respected, and each participant appreciated the fact that their input would assist with developing guidance for future programs and initiatives.
- The engagement of an individual and organization to conduct the data collection and analysis that was known to the region was very helpful. In the case of all of the key informants, they had known and worked with CCCS for several years and felt comfortable sharing information, being candid, and knowing that their input would be effectively utilized and kept confidential. No introductions and building trust were necessary.
- Conducting data collection sessions personally and on-site were successful in having all participants feel at ease and able to conveniently participate.

**Key Informants**

- Success was achieved in each of the three target counties with identifying and conducting personal interviews with the most involved individuals in organizations and agencies engaged in either advocating for or engaged in the provision of breast health services. Each health department and hospital within the three counties was represented. And, in the two counties where there are advocacy efforts, representatives from those organizations participated.
- The method selected of conducting a one-on-one, personal, structured interview with each key informant proved to be very successful and resulted in quality information being shared in a comfortable manner.

**Focus Groups**

- Focus groups consisting of breast cancer survivors, family members and caregivers from each of the three target counties were recruited and participated.
- Each group was recruited by local and validated leaders/facilitators that helped to create a safe and comfortable environment for the group sessions.
• Being able to feel that they were contributing to the improvement of breast health care in their country by participating was a positive part of the process. They appreciated being asked.
• Local sponsoring organizations were able to provide meals for each session which greatly enhanced the setting for the session.
• The method selected of conducting structured but open discussion sessions proved to be highly successful. There appeared to be full participation, and attendees did not seem to be reticent in sharing their experiences and opinions.

**Observation**

• Structured interviews and discussion sessions are extremely valuable in obtaining data that can be easily placed into categories and analyzed, but sometimes the "essence" of the phenomenon or issue being explored can be missed. This is when making extra notes, recording off-hand remarks, listening to side conversations, and observing emotion and body language adds to the depth and breadth of data.
• Allowing a certain amount of free-form discussion and conversation added to the comfort and openness of the participants.
• Comments that went into describing the basis for providing a response to a specific question added more complete information.

**Weaknesses**

**Sampling**

• Even with success in being able to interview key informants representing advocacy organizations and health care agencies, there are obviously numerous other individuals who have something to say and contribute. Limitations of time and funding required the Affiliate to restrict the number of interviews conducted.
• Participants in the focus groups were selected and recruited by local leaders and facilitators. Typically, these were individuals who were known to and had been previously engaged in awareness activities. The hard-to-reach, those who do not come forward to be identified and participate are left out.
• Participants in the focus groups were not fully representative of the female population or breast cancer survivors in their respective counties. One of the three counties had a good mix of White and Black/African-American participants. Another county, however, had no White participants. The third had fewer total participants.

**Missing Participants**

• Hispanic/Latinas were missing from participation. Key informants had all expressed that they knew little about the issues and needs of this population. From their lack of participation, the Affiliate still knows little about them.
• No physicians agreed to participate. Physicians who provide cancer-specific services and representative primary care physicians in each of the three counties were identified and communicated with via email and mail correspondence. A cover letter tried to establish credibility for the project and the researchers and gave each potential participant the option of a personal interview or self-completion of a survey form. A self-
addressed, stamped envelope was provided. In several cases, emails were exchanged and participation was agreed upon or forms were personally provided to key staff persons in practices (who had already been interviewed), but no responses were received. Physicians, as a group, tend to be difficult to recruit for activities not directly benefiting their individual practice, but this was still a disappointment.

Conclusion Statements That Are Linked to the Qualitative Data
1. High poverty, un- and under-employment, lack of health insurance or being under-insured appear to be associated with low rates of screening and timely diagnosis, the quality of care provided by physicians, and access to local health care resources.
2. Basic, daily survival needs (food, shelter, safety) over-ride personal and family health care needs.
3. Many of those who do not enter the health care system for screening or diagnosis, as well as those who are moving through the system, are affected by the fear of cancer and also tend to deny the possibility of having cancer.
4. Access to and the availability of transportation is seen as a major problem to screening and care.
5. Knowledge of and outreach to the Hispanic/Latinas population is lacking.
6. There is concern regarding poor primary care physician knowledge of cancer and with them not routinely encouraging or discussing screening and early detection.
7. Physicians providing diagnostic and treatment services do not routinely discuss or involve patients and family in a discussion of options and are generally either not aware of or do not provide information about community resources.
8. Physicians providing diagnostic and treatment services do not routinely discuss the side effects of treatment and how to deal with them, nor do they discuss the long-term effects of treatment.
9. The need for a more personalized approach to care is widely desired.
10. The pain or the fear of pain is considered to be a major factor associated with poor compliance with screening or re-screening participation.
11. The various parts of the cancer care system are not connected to the benefit of effective continuum of care.
12. Rural areas of the three counties are generally excluded from outreach and other health care services.
13. Support for families and caregiver is not widely available or practiced.
14. The entire breast health care system is relatively fragile. There are missing pieces, some services and resources are only "one deep", many services rely on year-to-year funding, and other health care system or community needs may replace any emphasis on breast cancer.
Breast Health and Breast Cancer Findings of the Target Communities

In order to best meet the community need, Susan G. Komen North Carolina Triangle to the Coast has chosen three target communities within the service area: Edgecombe, Halifax and Wilson Counties. The Counties were prioritized based on the time needed to reach Healthy People 2020 objectives for breast cancer deaths and late-stage incidence. Edgecombe and Halifax Counties are projected not to reach the Healthy People 2020 targets for deaths and late-stage incidence. Wilson County is projected not to reach the Healthy People 2020 target for deaths.

Additional key indicators the Affiliate reviewed when selecting target counties included, but were not limited to:

- Incidence rates
- County tier designations
- The North Carolina Department of Commerce annually ranks the state’s 100 counties based on economic well-being and assigns each a Tier designation. The most distressed counties are designated as Tier 1. Edgecombe, Halifax and Wilson are all designated as Tier 1 counties.
- Homeless point-in-time counts.
- When compared to counties of similar population sizes, Edgecombe County has a higher homeless population and increasing counts of homeless persons.

All three of these counties reside in a region of North Carolina classified as Area L. Area L, also referred to as the Upper Coastal Plain, is characterized as having low socioeconomic status, high minority populations, high numbers of uninsured and underinsured residents, low education and vast rural communities. Area L has been singled out by Susan G. Komen Headquarters as having one of the highest breast cancer death rates in the United States.

Edgecombe County

The quantitative data revealed that Edgecombe County has a high breast cancer death rate of 33.2 per 100,000 women. This is higher than the United States rate (22.6), as well as the Affiliate service area’s rate (23.5). While the death rate decreased slightly from 2006-2010, it is still the third highest death rate in the service area. Additionally, Edgecombe County’s rate of late-stage diagnosis was 47.7 per 100,000 women. This is higher than the United States (43.7), as well as the Affiliate service area’s rate (45.8). It is a rural county with a population of 56,552 people, approximately 30,313 of which are female. Nearly fifteen percent (14.9) of residents are unemployed and 18.6 percent do not have health insurance. Of those between the ages 40-64, 53.4 percent are living at 250 percent below the poverty level and 45.3 percent live in a rural area. More than half (52.2 percent) of the female population is age 40 plus. All of these percentages are substantially higher than the Affiliate service area’s averages. The socioeconomic data for the county show several concerning areas: residents are substantially more likely to have less than a high school education, an income below 250 percent poverty, and be unemployed than others in the United States and the Affiliate service area.
The Health Systems analysis showed that in Edgecombe County there is one hospital in the area that offers the whole continuum of care for breast cancer. There is also a county health department and a community health center in the county. The hospital and health department both reach out to those who lack access to care. Focus groups indicated that women do not seek routine medical care or breast health care due to transportation, fear, lack of awareness, and financial reasons. The focus group also indicated that when diagnosed women are not given choices or additional information for resources from their providers.

To remove the perceived barriers to yearly exams, focus group participants indicated getting more information out about how early detection saves lives, that the mammogram is worth the pain, having more convenience (mobile units, more hours of screening), and offering services in more comfortable settings (health fairs, churches).

Motivational factors to have screening for the focus group participants were stated as: knowledge about the high number of breast cancer diagnoses in the county, knowing others with breast cancer, having experienced the death of someone from breast cancer, and seeing women who successfully survive.

The comparison of all three data methods (Quantitative Data Report, Health System and Public Policy Analysis, and Qualitative Data Report) show that women in Edgecombe County lack breast health educational and resource awareness, financial means and transportation to complete routine breast health care and treatment if diagnosed.

**Halifax County**

The quantitative data revealed that Halifax County has breast cancer death rate of 36.6 per 100,000 women. This is higher than the United States rate (22.6), as well as the Affiliate service area’s rate (23.5). The death rate decreased from 2006-2010. Currently, the county has the highest rate of breast cancer death in the service area. Additionally, Halifax County’s rate of late-stage diagnosis was 48.5 per 100,000 women. This is higher than the United States (43.7), as well as the Affiliate service area’s rate (45.8). The rate of late-stage diagnosis increased from 2006-2010. Halifax is a rural county with a population of 54,691 people, approximately 28,554 of which are female. Fifteen and a half percent of residents are unemployed and 18.4 percent do not have health insurance. Of those between the ages 40-64, 54.7 percent are living at 250 percent below the poverty level and 54.7 percent live in a rural area. More than half (54.8 percent) of the female population is age 40 plus. All of these percentages are substantially higher than the Affiliate service area’s averages. The socioeconomic data for the county show several concerning areas. Residents are substantially more likely to have less than a high school education, an income below 250 percent poverty, and be unemployed than others in the United States and the Affiliate service area.

The Health Systems analysis showed that in Halifax County there is one hospital in the county and one hospital in Edgecombe County that offers the whole continuum of care for breast cancer. There is also a county health department and several community health centers in the county offering limited care. Key informants felt that transportation, lack of insurance, fear, lack
of awareness, denial, and lack of access were primary barriers to breast health services. Focus group participants indicated that finances, fear, lack of access to primary care, denial, myths, and confusion regarding importance of care were the primary barriers to breast health services.

Also gleaned from the qualitative research is the impact of the Roanoke Valley Breast Cancer Coalition, supported with Komen funds is an important leader in the county. This has resulted in four breast cancer support groups (geographically dispersed), the only resource of support post-treatment, a biennial breast cancer conference, and the implementation of many initiatives. However, its mission is to focus on women of color and this has excluded widespread engagement of and participation by White and Hispanic/Latinas residents. Rural and lower income White women are not typically participants in activities.

The comparison of all three data methods (Quantitative Data Report, Health System and Public Policy Analysis, and Qualitative Data Report) show that women in Halifax County suffer the same obstacles as women in Edgecombe County, lack breast health educational and resource awareness, financial means and transportation to complete routine breast health care and treatment if diagnosed.

Wilson County
The quantitative data revealed that Wilson County has breast cancer death rate of 33.9 per 100,000 women. This is higher than the United States rate (22.6), as well as the Affiliate service area’s rate (23.5). The death rate decreased from 2006-2010. Currently, the county has the second highest breast cancer death rate in the service area. Wilson County’s rate of late-stage diagnosis was 53.1 per 100,000 women. This is higher than the United States (43.7), as well as the Affiliate service area’s rate (45.8). The rate of late-stage diagnosis decreased from 2006-2010. Wilson is a rural county with a population of 81,234 people, approximately 42,450 of which are female. Additionally, 12.6 percent of residents are unemployed and 20.3 percent do not have health insurance. Of those between the ages 40-64, 45.1 percent are living at 250 percent below the poverty level and 38.7 percent live in a rural area. More than half (50.9 percent) of the female population is age 40 plus and 3.1 percent are linguistically isolated. All of these percentages are equal to or higher than the Affiliate service area’s averages.

The Health Systems analysis showed that in Wilson County there is one hospital in the county and one hospital in Edgecombe County that offers the whole continuum of care for breast cancer. There is also a community health center and health department available for screening services. Key informants and focus group participants indicated the need for surgeons who accept NC BCCCP and/or Medicaid funding. Currently none in the county accept this coverage, therefore women must travel at least 35 miles to the nearest place that will accept this coverage. As with the other counties, all participants cited breast health awareness and education, financial means and transportation as barriers to care. It was also stated by focus group participants that pamphlets were not an effective means of education. They preferred more one-on-one, community health fair or church presentations as a means of education. Also worth noting is that focus group participants indicated that primary care physicians are not advocating breast screenings or exams.
To remove the perceived barriers to yearly exams, focus group participants indicated that providing free examinations and conducting outreach in churches and other locations would encourage women to access resources annually.

Motivational factors to have screening for the focus group participants were stated as: getting reminders from their physician, finding a lump in their breast, having family history, having been in an educational session, and learning from survivors.

The comparison of all three data methods (Quantitative Data Report, Health System and Public Policy Analysis, and Qualitative Data Report) show that women in Wilson County suffer the same obstacles as women in the two aforementioned counties, lack breast health educational and resource awareness, financial means and transportation to complete routine breast health care and treatment if diagnosed.

In summary, overall findings from the Qualitative Data Report relating to all three of the target communities are:

- High poverty, un- and under-employment, lack of health insurance or being under-insured appear to be associated with low rates of screening and timely diagnosis, the quality of care provided by physicians, and access to local health care resources.
- Basic, daily survival needs (food, shelter, safety) over-ride personal and family health care needs.
- Many of those who do not enter the health care system for screening or diagnosis, as well as those who are moving through the system, are affected by the fear of cancer and also tend to deny the possibility of having cancer.
- Access to and the availability of transportation is seen as a major problem to screening and care.
- Knowledge of and outreach to the Hispanic/Latinas population is lacking.
- There is concern regarding poor primary care physician knowledge of cancer and with them not routinely encouraging or discussing screening and early detection.
- Physicians providing diagnostic and treatment services do not routinely discuss or involve patients and family in a discussion of options and are generally either not aware of or do not provide information about community resources.
- Physicians providing diagnostic and treatment services do not routinely discuss the side effects of treatment and how to deal with them, nor do they discuss the long-term effects of treatment.
- The need for a more personalized approach to care is widely desired.
- The pain or the fear of pain is considered to be a major factor associated with poor compliance with screening or re-screening participation.
- The various parts of the cancer care system are not connected to the benefit of effective continuum of care.
- Rural areas of the three counties are generally excluded from outreach and other health care services.
- Support for families and caregiver is not widely available or practiced.
- The entire breast health care system is relatively fragile. There are missing pieces, some services and resources are only "one deep", many services rely on year-to-year funding, and other health care system or community needs may replace any emphasis on breast cancer.

**Mission Action Plan**

| Problem Statement | According to Quantitative Data, Edgecombe, Halifax and Wilson Counties are unlikely to meet Healthy People 2020 targets for both breast cancer death and late-stage incidence and are located far from most breast health providers. |
| Priority | Reduce the number of late-stage diagnoses among women in Edgecombe, Halifax and Wilson Counties. |

| Objectives | In FY 2016, hold at least one collaborative meeting in each of the three target communities aimed at hospitals, primary care providers, local health departments, and community-based organizations to foster the discussion around how to improve access, financial assistance and continuity of care between referral, screening, diagnosis, treatment, and support. |
| | In FY2018, hold rural breast cancer summit with providers in Edgecombe, Halifax and Wilson Counties to discuss possible partnership opportunities with the goal of increasing access to and seamless progression through the breast health continuum of care. |
Based on Qualitative Data collected during focus groups, women in Edgecombe, Halifax and Wilson Counties, women cannot afford out-of-pocket costs associated with primary medical care nor breast health services.

Increase the number of health services and providers available in Edgecombe, Halifax and Wilson Counties by funding health system partnerships to increase access to services.

By December 2015 hold at least one grant writing workshop in the Area L region aimed at existing breast health providers identified on the resource map.

In FY 2017, develop a collaborative RFA grant encouraging providers to submit proposals that offer subsidies for mammograms for uninsured women in Edgecombe, Halifax, and Wilson Counties.

For FY 2016, a granting priority will be patient navigation programs aimed specifically at working with minority residents in Edgecombe, Halifax, and Wilson Counties.
Problem Statement
Based on Quantitative Data, Halifax County has the highest death rate in the service area.

Priority
Investigate ways to make screening more accessible and affordable for women residing in each or the three target communities including but not limited to the possibility of obtaining mobile mammography through the one hospital that provides service to all three counties.

Objective
In FY 2016 meet with the Roanoke Valley Breast Cancer Coalition, to strategize how to effectively reach more women in the county of all racial groups.

Problem Statement
Based on Qualitative Data, in Edgecombe, Halifax and Wilson Counties women do not have easy access to affordable mammography.

Priority
Reduce the breast cancer death rate for all women in Halifax County.

Objective
In FY 2016 meet with Vidant Edgecombe Hospital to discuss the possibility of obtaining mobile mammography through the Greenville-based hospital care system network and strategize about other ways to increase access to breast cancer screening.

Based on Qualitative Data, in Edgecombe, Halifax and Wilson Counties women do not have easy access to affordable mammography.

Meet with Halifax Regional Hospital, the largest provider of breast cancer screenings in the county, to strategize how to educate all women in the county about screening recommendations and how to provide those women...
Based on information gathered in the Health Systems and Public Policy Analysis, there is not adequate support for community mobilizing and provider capacity building in Edgecombe, Halifax and Wilson Counties.

Actively participate in creating community partnerships and programs to address the lack of available services due to inadequate capacity to offer such services in Edgecombe, Halifax and Wilson Counties.

By FY 2018, begin offering small grants, $10,000 or less, to providers to build their capacity to address breast health/cancer issues specifically identified for their communities.

By FY 2018, the Small Grants RFA will give priority to organizations that collaborate with one or more providers in their region to mobilize their communities to create an information network that would allow them to promote the availability of these services.

All three of the identified target communities are classified as Tier One counties by the North Carolina Department of Commerce making them some of the most economically distressed in North Carolina.

Create a system that allows Tier One counties in the Komen NCTC service area to receive priority when applying for funding through the Community Health Grants Program.

In FY 2016-2019, county tier designation will be one of the selection criteria for consideration for grant funding. Counties designated as Tier One will receive additional points during the scoring of applications by the independent review committee.
References


Appendix A. BCCP screening and follow up protocol

BCCP SCREENING AND FOLLOW UP PROTOCOL

PATIENT INTAKE

AGE ELIGIBLE - 40-64 y.o. for mammogram*
and Pap tests. 21-39 y.o. only if symptomatic
INCOME ELIGIBLE - refer to eligibility
guidelines

PROVIDE CLINICAL SERVICES
History - breast and cervical
Pelvic exam, Pap test*
Clinical breast exam*
Education - BSE, need for rescreening
Referral for mammography*

*May or may not be needed. If this has already been done by an outside provider, obtain
documentation of the results and include in patient's chart

TRACKING - receive Pap test and/or mammogram reports. Use tickler or log system.

NORMAL RESULTS

NOTIFY PATIENT
RESCREENING DATE
RENDER OF APPOINTMENT
RESCREEN

ABNORMAL RESULTS

NOTIFY PATIENT
REFER TO APPROPRIATE PROVIDER

TRACKING - RECEIVE REPORTS

NORMAL - FOLLOW

RESCREEN

NO CANCER

CANCER OR PRECANCEROUS

ENROLL IN BCCM

RESCREEN

TREATMENT
RESCREEN

* Screening mammograms for women age 40-49 are provided only if state funding is available

Revised 03/05/2013

Susan G. Komen® North Carolina Triangle to the Coast
Appendix B. NC BCCCP eligibility flow chart- breast screening

NC BCCCP Eligibility Flow Chart
Breast Screening

CLINICAL BREAST EXAMS

- <250% FPL, not enrolled in Medicaid, Medicare Part B or Title X
  - No
    - Not Eligible
  - Yes
    - Determine Age
      - Age 40-64: Priority Population Provide CBE every year
      - Age 21-39: Eligible if symptomatic or if STATE BCCCP funding is available

MAMMOGRAMS

- <250% FPL, not enrolled in Medicaid, Medicare Part B or Title X
  - No
    - Not Eligible
  - Yes
    - Determine Age
      - Age 50-64: Priority Population Provide mammogram every year
      - Age 40-49
      - Age 21-39: Eligible only if symptomatic
      - Age 65-75: Eligible if STATE BCCCP funding is available

NOTE: The priority population for FEDERAL BCCCP mammography services is women between the ages of 50 and 64 who are low-income (up to 250% of federal poverty level), who have not been screened in the past year, and who have no other source of health-care reimbursement, such as insurance. Recruitment efforts should be concentrated on this population. A minimum of 75% of all FEDERAL BCCCP reimbursed mammograms should be provided to program-eligible women who are 50 years of age and older. Mammograms provided to program-eligible women less than 50 years of age should not exceed 25% of all mammograms provided by FEDERAL BCCCP and should be reserved for those women who present with clinical symptoms suspicious for breast cancer.

Revised 03/11/13