

# Executive Summary

## **Introduction to the Community Profile Report**

The North Carolina Triangle to the Coast (NCTC) Affiliate of Susan G. Komen 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, the Komen NCTC Affiliate 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 \$12,000,000 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 non-profit organizations that serve uninsured, underinsured and underserved residents in our 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 mortality 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.

The Komen NCTC Affiliate 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 mortality; 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 Affiliate 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.

### *Mortality rates*

Overall, the breast cancer mortality rate in the Komen North Carolina Triangle to the Coast Affiliate service area was similar to that observed in the US as a whole and the mortality rate trend was not available for comparison with the US as a whole. The mortality rate of the Affiliate service area was similar to that observed for the State of North Carolina. The following counties had a mortality rate much higher than the Affiliate service area as a whole: Edgecombe County, Halifax County, and Wilson County. The mortality rate was much lower in Chatham County. The rest of the counties had mortality 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 Affiliate 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 Affiliate 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 Affiliate service area has a substantially smaller White female population than the US as a whole, a substantially larger Black 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 Mortality 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 mortality 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 mortality 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, mortality and screening rates 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 Affiliate selected three target counties in the North Central, Eastern region of our 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.

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 rates in Edgecombe County are 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 screening rates in Halifax County are 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 rates 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.

**Summary Table of Target Community Data 2006-2010**

	Edgecombe		Halifax		Wilson		Service Area	US	Healthy People 2020 Target
	Rate	Trend	Rate	Trend	Rate	Trend	Per 100,000 women		
Incidence Rate	120.4	0.5%	135.5	-5.6%	130.2	-4.2%	125.0	122.1	-
Mortality Rate	33.2	-1.0%	36.6	-0.7%	33.9	-0.1%	23.5	22.6	20.1
Late-stage Rate	47.7	4.4%	48.5	1.1%	53.1	-6.8%	45.8	43.7	41.0

**Health System 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 mortality 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 research 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 research, we understand 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%) 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 the Komen NCTC Affiliate. 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 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 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 Healthcare 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 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 mortality 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 mortality rate in the service area.

**Priority:** Reduce the breast cancer mortality 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, there 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.