

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



SUSAN G. KOMEN®
CHARLOTTE
EXECUTIVE SUMMARY

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Executive Summary

Introduction to the Community Profile Report

Susan G. Komen® Charlotte was founded by Penelope Wilson. The first Susan G. Komen Charlotte Race for the Cure® was held October 4, 1997, and subsequently Komen Charlotte was established in 1999. Each year, the Komen Charlotte Race for the Cure is held the first Saturday in October. Currently, Komen Charlotte serves 13 counties in the Carolina Piedmont – 12 in North Carolina (NC) including Anson, Cabarrus, Cleveland, Gaston, Iredell, Lincoln, Mecklenburg, Montgomery, Richmond, Rowan, Stanly and Union Counties and York County in South Carolina (SC).

Through Race for the Cure®, Laugh for the Cure® and other fundraising events, Komen Charlotte has awarded more than \$14 million to local nonprofit organizations through community grants that fund screening, education, survivorship, and treatment support programs and contributed nearly \$5.3 million to the Susan G. Komen Research Programs.

Komen Charlotte engages the service area through outreach and education programs including its Education Ambassador Program, participation in health fairs and breast health awareness presentations. Also, the Affiliate has partnered with more than 370 faith-based organizations through Pink Sunday/Worship in Pink.

Komen Charlotte is an active partner of the NC Advisory Committee on Cancer Coordination and Control and early detection and prevention subcommittees, and the SC Cancer Alliance. In 2013, the Affiliate founded the Mecklenburg Breast Health Coalition with the mission to decrease high late-stage breast cancer incidence rates in the county. The coalition strives to use evidence-based interventions to further its mission.

The Community Profile Report will be used to define outreach and education efforts, specifically to mobilize Education Ambassadors and develop existing and potential outreach programs. The report will be used to guide Komen Charlotte's grantmaking programs. In addition, it will be used to illustrate the unique and vital contributions made by the Affiliate as it collaborates with state government officials, partners and sponsors in the community.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

The quantitative data report combines data from multiple sources to identify the highest priority areas for evidence-based breast cancer programs. Data included incidence rates, death rates, late-stage diagnosis, mammography screenings and population characteristics.

Healthy People 2020 (HP2020) is a federal government initiative that has set specific health objectives for improving the health of communities, and for the country as a whole, by the year 2020. Target communities were prioritized based on the time needed to reach the HP2020 objectives listed for breast cancer late-stage incidence and deaths.

The objectives specific to breast cancer include:

- Reducing the rate of late-stage breast cancer diagnoses to 41.0 cases per 100,000 women (US late-stage incidence rate is 43.7 cases per 100,000 women).
- Reducing the death rate from breast cancer to 20.6 per 100,000 women (US death rate is 22.6 per 100,000 women).

After the initial data review, the Affiliate focused on a few additional factors. The Affiliate service area has a significantly higher incidence rate when compared to the state of SC as a whole. Rowan County also has a significantly higher incidence rate when compared to the Affiliate service area (Susan G. Komen, 2014). Since incidence rates are not part of the HP2020 objectives and Rowan County will likely meet all HP2020 targets, this community was not selected for further analysis. Breast cancer death rates in the Affiliate service area were similar to the US. When compared to the Affiliate service area, Iredell County has a significantly higher late-stage incidence rate. However, Iredell will meet the HP2020 goal for late-stage diagnosis in six years. The Komen Charlotte service area does not have significantly different screening proportions compared to the US as a whole.

The data also showed health disparities are still prevalent in the Affiliate service area, especially for Black/African-American women. Death rates for Black/African-American women are higher than any other race, with a death rate of 27.3 per 100,000 women compared to 21.1 for White women and 9.6 for Hispanic/Latina women. However, incidence rates (122.2 per 100,000 women) for Black/African-American women are lower than White women (127.5 per 100,000 women). This is also seen in the US as a whole as breast cancer incidence in Black/African-American women is lower than White women but Black/African-American women have a higher breast cancer death rate than any other race. Black/African-American women also have higher late-stage diagnosis rates than other races and ethnicities, locally and nationally. Factors that contribute to higher death rates and late-stage diagnosis include access to care, lack of early detection and treatment, aggressive tumor characteristics, socioeconomic status and lack of timely follow-up. Even with these reasons, the factors that contribute to these statistics are not completely understood (“Cancer Facts & Figures for African-Americans 2013-2014”, 2013).

Population characteristics collected for the service area included demographic and socioeconomic data. As compared to the US, the Komen Charlotte service area has a substantially smaller White female population, substantially larger Black/African-American female population, smaller Asian and Pacific Islander and American Indian and Alaska Native female population, and substantially smaller Hispanic/Latina female population. In addition, the service area as a whole has slightly larger percentages of people who have no health insurance, live in rural areas and live in medically underserved areas.

Anson, Mecklenburg and Richmond Counties have relatively larger populations of Black/African-American women and Mecklenburg County has a larger population of foreign-born women as compared to the US, NC and the total Komen Charlotte service area.

In order to best meet the community need, Komen Charlotte has chosen two target communities within the service area (Table 1). Target communities were prioritized based on the time needed to reach the HP 2020 objectives listed for breast cancer late-stage incidence and deaths.

Komen Charlotte will concentrate strategic efforts on these target communities for the next four years:

- 1) Cabarrus County – Projected not to reach the HP 2020 targets for late-stage incidence and death rate.
- 2) Mecklenburg County – Projected not to reach the HP2020 target for late-stage incidence rate and has a large percentage of linguistically isolated, Black/African-American and foreign-born women.

Table 1. Summary of Cabarrus County and Mecklenburg County data, 2006-2010

	Cabarrus County		Mecklenburg County		Affiliate Service Area Rate	US Rate	HP2020 Target
	Rates age-adjusted / 100,000 women	Trend (Annual Percent Change)	Rates age-adjusted / 100,000 women	Trend (Annual Percent Change)	Rates age-adjusted / 100,000 women		
Incidence Rate	124.9	0.20%	130.7	1.90%	127.5	122.1	-
Death Rates	23.1	-0.60%	23.3	-1.60%	22.3	22.6	20.6
Late-Stage Rates	47.8	-0.90%	44.4	2.20%	44.5	43.7	41

Additional data collected included homelessness and growth rates which are socioeconomic and population factors that can contribute to more difficult access to care and gaps in the continuum of care. Komen Charlotte also collected 15 year data on the most recent breast cancer death rate and incidence rates by race, county and stage.

Death rates of Black/African-American women in four of the 13 counties including Cabarrus, Mecklenburg, Union, NC and York, SC are higher than death rates in White women. In Anson, Cabarrus, Gaston, Iredell, Lincoln, Mecklenburg, Richmond, Rowan, and Union Counties in NC, there are increasing rates of breast cancer incidence over the last 15 years. Cleveland, Montgomery, and Stanly Counties in NC and York County in SC show a decreasing breast cancer incidence rate. Rowan County, Mecklenburg and Cabarrus Counties have the highest five-year incidence rates from 2007-2011, and the incidence rates are increasing.

Hispanic/Latina women and other races are not included in additional breast cancer incidence analysis because of the small numbers. White women have the highest incidence rates in Anson, Cabarrus, Gaston, Iredell, Lincoln, Mecklenburg, Montgomery, Richmond, Stanly Counties in NC and York County, SC. Black/African-American women have the highest incidence rates in Cleveland, Rowan, and Union, NC counties. In the next four years, Komen Charlotte will continue to monitor the trends in incidence rates by race. Incidence rates by stage confirmed that along with Gaston County, Cabarrus and Mecklenburg Counties have the highest distant rates across the service area.

When compared with counties of equivalent population sizes, Cabarrus and Mecklenburg Counties have higher homeless populations. Mecklenburg County has decreasing counts of homeless people and Cabarrus has increasing counts of homeless persons over the last four

years. Mecklenburg County, NC has the highest growth rate in the Affiliate service area at 7.8 percent followed by Union County, NC at 5.7 percent, York County, SC at 5.5 percent, and Cabarrus County, NC at 5.1 percent. Five of the 13 counties have a declining growth rate.

Cabarrus County has a growth rate of 5.1 percent from 2010-2013, compared to the US as a whole with a growth rate of 2.4 percent (Florida, 2014). In addition, Cabarrus County is projected to continue experiencing rapid growth rates through 2020 (Tippett, 2013). The total number of homeless people in the county grew 9.2 percent in 2014, following a 54.6 percent increase between the years 2012-2013. Cabarrus County was chosen as the highest priority county because of these statistics combined with the predicted amount of time it will take to reach the HP2020 goals.

Mecklenburg County is the county with the largest population in the Affiliate service area. Mecklenburg County has a growth rate of 7.8 percent, compared to the US as a whole with a growth rate of 2.4 percent (Florida, 2014). Mecklenburg County has the largest amount of homeless persons in the service area and NC at 2,014 ("North Carolina Point-in-Time Count Data," 2014). Mecklenburg County has large percentages of linguistically isolated, Black/African-American and foreign-born women, and is the second highest priority county.

Health System and Public Policy Analysis

The health systems analysis took an in-depth look at access to care and identified gaps in the breast cancer continuum of care (CoC). The analysis of Cabarrus County and Mecklenburg County showed that both counties provide services in all stages of the breast cancer CoC. Komen Charlotte has existing partnerships with all breast cancer care providers and seeks to strengthen relationships with breast health care providers. One systematic access to care barrier is finding a primary care provider (PCP) for uninsured women. Having a provider is essential so woman can receive a clinical breast exam, as well as establish a medical home before having a mammogram. If the mammogram has any abnormal findings, the woman will need to get any diagnostics ordered from her PCP. In Mecklenburg County, the only federally qualified health clinic (FQHC) is undergoing changes and may not be able to meet the community's need. In September 2014, one other clinic applied to become an FQHC (Mecklenburg County Board Bulletin, 2014).

Additionally, transportation issues were explored in both counties. In Cabarrus County, the hospital is located in an urban area and is about 30 minutes by car from many rural towns in the county. The transportation system in Cabarrus County recently re-categorized some locations to be urban instead of rural. This means transportation options are limited, as residents are not able to use the rural-urban transit system to get to the hospital (Cabarrus County Transportation System, personal communication, July 10, 2014). In Mecklenburg County, transportation to the hospitals is available through the bus system, though direct routes are not available. Most routes go through the central bus station before going to specific locations ("CATS Riders Guide", 2014).

In Mecklenburg County, Komen Charlotte created the Mecklenburg Breast Health Coalition to address the high incidence of late-stage breast cancer diagnosis. The coalition, funded through

a Komen Headquarters Community Organizing Grant, works to improve this issue by providing more education, resources and easier access to breast care.

The public policy section reviewed state public policy efforts on breast health and breast cancer care. This included the Breast and Cervical Cancer Control Program (BCCCP), the Affordable Care Act (ACA) and other important policy issues.

Other than Anson County and Rowan County, all counties in the Komen Charlotte service area have a provider for the NC BCCCP or SC Best Chance Network. Funds for the program have decreased over the past decade. To continue receiving state and federal funds, programs are restricted to serving low-income women ages 40-64. Because of the age guidelines, uninsured younger women are not able to use the program for screenings and may not be able to afford a PCP (Breast and Cervical Cancer Control Program, 2014).

The ACA, as passed in 2010, aimed to extend health insurance coverage, improve health care quality, provide lower costs and protect consumers. NC and SC elected not to expand Medicaid and both have a federally facilitated health insurance marketplace. This created a coverage gap that means individuals with income below the lower limit to receive insurance subsidies will most likely not have insurance. The gap in NC and SC totals about 535,000 individuals ("The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid – An Update", 2015). Insurers are required to cover preventive screenings, including a well-woman visit (includes a clinical breast exam) and mammogram with no cost sharing ("Preventive Services Covered Under the Affordable Care Act", 2012).

In 2015, the US Supreme Court ruled federally facilitated marketplaces are still eligible to award individuals insurance subsidies (Liptak, 2015).

Health Systems and Public Policy Analysis Findings

Based on these findings, the interaction between Komen Charlotte and government entities will continue to be a high priority. Although implementation of the ACA may decrease the number of uninsured nonelderly adults, this population remains in the hundreds of thousands in the Carolinas, signaling the need for Komen to help elected officials understand the ongoing requirement for breast health services. Komen Charlotte must join with other cancer organizations to further explore the implications of decisions by NC and SC policymakers to not expand Medicaid under the ACA.

In addition, continuing pressures on federal and state budgets put such services at risk, as demonstrated by recently decreased allocation for state BCCCP funds. Fortunately, Komen Charlotte and its sister Affiliates have collaborated effectively in recent years on maintaining some funding, however inadequate, for the program. Komen Charlotte's working relationships with BCCCP providers highlights the strong partnership with the state program. Komen Charlotte will continue attending state coalition meetings and work towards building a mutually beneficial relationship.

In conjunction with the statewide coalition of the American Cancer Society and other cancer-related organizations, Komen Charlotte will advocate for passage of the Cancer Treatment

Fairness Act. Also, Komen Charlotte will continue active support of public policies together with Affiliates in the Carolinas that benefit breast cancer patients.

Qualitative Data: Ensuring Community Input

The qualitative section examined the following questions that originated from the quantitative and health systems data:

- What factors contribute to delaying or not seeking breast health care? (with an emphasis on determining whether PCPs and transportation were factors)
- How much of a problem is decreasing BCCCP funding?
- What implications from the ACA can already be seen?

Komen Charlotte conducted 16 key informant (KI) interviews with breast health and breast cancer providers and four focus groups, two in each target county (Cabarrus and Mecklenburg), which recorded breast cancer survivors and general population opinions.

Consistent themes that arose in Cabarrus County and Mecklenburg County included knowledge, access to care, systematic barriers in health care and low priority for preventive care. Figure 1 (below) summarizes the themes, subthemes and relationships among each. Relationships stem from the original section color affecting the connecting subtheme.

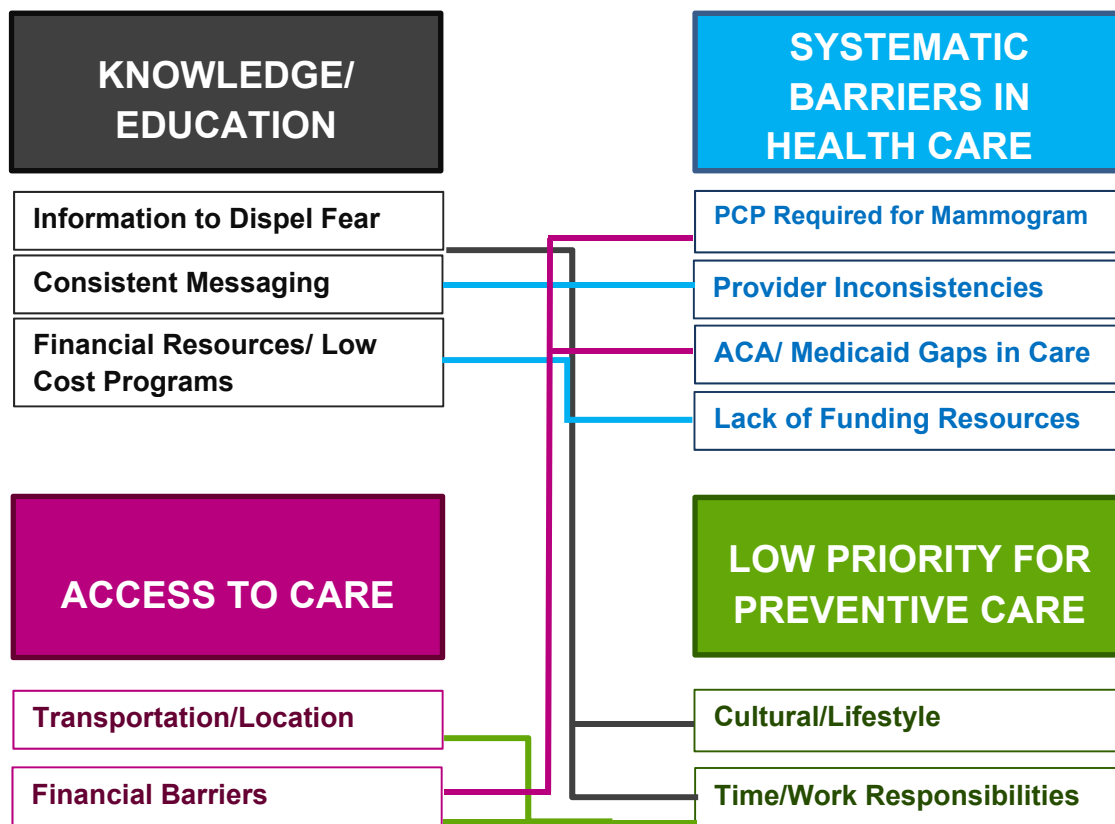


Figure 1. Factors in high late-stage diagnosis and death rate

Knowledge

Participants in both KI interviews and focus groups expressed a lack of knowledge of resources and breast health basics are key factors in the high death and late-stage incidence rates in both counties. An emphasis was put on providing education and outreach to provide underserved populations with resources and breast health information. Education and outreach could also address emotional barriers to care involving trust, fear and myths. Providers and individuals in the focus groups also expressed concern for consistency in screening guidelines. Many noted this mixed messaging confuses individuals, as well as causes distrust in the system (this is also a systematic barrier). Education on screening recommendations, the importance of preventive health care, available resources and low-cost programs will continue to be a high priorities for Komen Charlotte.

The quantitative data noted Mecklenburg County's larger population of Black/African-American and foreign-born women and the qualitative data demonstrated the need to continue targeted education efforts to address emotional barriers to care, especially for Black/African-American women. In addition, the qualitative data found cultural barriers to breast health care were prevalent in Black/African-American and Hispanic/Latina communities in both target counties. Participants identified working through faith communities as one way to address these barriers.

Both Cabarrus County and Mecklenburg County have growing homeless populations, as indicated in the quantitative data. The homeless population was mentioned in qualitative data as it relates to the populations least likely to have access to breast health services, but was not a consistent theme. Cabarrus County is less urban than Mecklenburg County. Focus group participants noted there are pockets of lower income and less educated individuals who do not typically see doctors. KI interviews also noted it is more difficult to reach individuals in this Cabarrus County through education and services because some residents are more isolated. Komen Charlotte will continue education initiatives to the identified target populations.

Access

Access to care barriers was a prominent theme, especially cost of services and transportation. The quantitative data and health systems analysis demonstrated the availability of breast health resources throughout the county, but in underserved areas there may be gaps in services. This was found to be true in the focus groups and KI interviews, although participants did not directly link resource availability or gaps to the rapid growth of the county. In Cabarrus County, focus group participants noted getting to a facility for testing and treatment is difficult for residents who do not have access to a car. They noted there is a bus system, but the service is inconsistent and may not be viable in terms of time or travel locations for many lower income residents. Taking a taxi cab was another option, but a costly one. This is consistent with the health systems data that shows there is a need to find a transportation solution in Cabarrus County. Focus groups in Cabarrus County revealed some individuals who live in Cabarrus County utilize doctors and health services in Mecklenburg County. For some, this referral can also be difficult due to lack of transportation. This shows the need for individuals and providers to understand what services are provided in Cabarrus County.

Mecklenburg KI interviews noted transportation may be an issue, but focus group data did not. This may mean transportation is more of a problem on an individual basis. All focus groups

noted mobile mammography may be a way to decrease this screening barrier, especially for rural and underserved communities.

Financial costs were emphasized as a barrier to care throughout the qualitative data in terms of lack of insurance, high deductibles or adequate coverage and overall expense of breast health screenings and treatments for both Cabarrus County and Mecklenburg County. KI interviews noted if a woman had to prioritize going for an annual doctor visit and buying her family food, she would choose to buy food. For low-income individuals the cost of getting mammograms is an issue. Even with insurance, some people still cannot afford necessary examinations.

Systematic Barriers in Health Care

Systematic barriers in relation to the ACA – lack of federal and state funding and PCP access – were also found in the qualitative data. KI interviews and focus groups participants were asked how the ACA impacted health care. Most individuals noted they could not see any difference, and it was too early to tell, although some people had examples of both positive and negative effects on health care. Because of the changing health care climate with the ACA, Komen Charlotte will continue monitoring how this may change the breast health needs in the service area.

KI interviews in Mecklenburg County confirmed BCCCP funds are insufficient for covering the number of women who need breast health and breast cancer care. A high priority for Komen Charlotte is to continue to encourage state and federal legislators to maintain BCCCP funding in the budget. Also, screenings and diagnostics will remain a funding priority as there currently is not enough funding to meet the need.

Another systematic barrier first seen in the health systems analysis was the need for a PCP in order for individuals to receive a mammogram. Mecklenburg County KI interviews and focus groups especially stated their concern for the large number of individuals without a PCP. The qualitative data confirmed the FQHC, some free and low cost clinics do not have the capacity to take on additional patients or they have long wait lists. Solutions are needed to provide this missing link for the persons who remain uninsured.

Navigation was suggested as an important way to keep individuals in the CoC throughout all data; therefore, Komen Charlotte will support efforts in the community to provide navigation services.

Low Priority for Preventive Care

A low priority for preventive health care was also a consistent theme in both Cabarrus County and Mecklenburg County. This was not a topic considered during the quantitative data and health systems analysis. Prevention was recognized as a key component to reducing late-stage incidence and death rates in focus groups. Reasons for a low priority on screenings and prevention provided through qualitative data were family and cultural beliefs, as well as time and work responsibilities. KI interviews revealed it was common for women of all races to delay scheduling an appointment. The idea of women prioritizing family before their personal health was echoed in focus groups. Participants mentioned expanded clinic hours may help address time and work concerns for women.

Mission Action Plan

Komen Charlotte strives to be an evidence-based and data-driven organization to best meet the needs in the community. Based on data collected throughout the Community Profile process, Komen Charlotte has identified the following problems with corresponding priorities and objectives to address the need in the target counties.

Problem: Cabarrus County and Mecklenburg County are not likely to reach the HP2020 targets for late-stage incidence rates, and Cabarrus County will most likely not reach the HP2020 target for death rates. Qualitative analysis indicated a lack of knowledge and resources in Cabarrus County and Mecklenburg County that may be addressed through education and resource identification and promotion. Due to the changing health care climate, both the health systems and qualitative analyses demonstrated the need to address gaps and barriers associated with the CoC. Also, the public policy review showed the need for continual partnership with local and state legislators to ensure prioritization of breast health legislation.

Priority 1: Increase breast health knowledge through education and outreach which may contribute to a reduction in late-stage breast cancer incidence and death rates with emphasis on Cabarrus County and Mecklenburg County.

- *Objective 1:* By 2017, partner with at least five additional faith-based organizations serving Black/African-American or Hispanic/Latina populations in each of the target counties through Pink Sunday/Worship in Pink.
- *Objective 2:* By 2020, meet with at least three health organizations in Cabarrus County and at least five in Mecklenburg County to discuss ways to work together to address breast health education needs in the respective counties, with particular emphasis on the Black/African American and Hispanic/Latina populations.
- *Objective 3:* By 2020, recruit and equip at least five new Komen Education Ambassadors in Cabarrus County to increase knowledge of the importance of breast health and breast cancer issues.
- *Objective 4:* From FY 2016 – FY 2020, annually participate in at least five education and outreach activities in Cabarrus County and at least ten in Mecklenburg County to address breast cancer fears and myths.
- *Objective 5:* From mid-year FY2018 – FY2020, implement pretests and posttests for all educational outreach presentations, gather contact information at each event and follow-up with participants in 3-6 months to determine if they have taken action for their breast health and/or need resources to take action.

Priority 2: Identify and communicate availability of Komen Charlotte grant resources and additional breast health resources in Cabarrus County and Mecklenburg County.

- *Objective 1:* From FY 2016 – FY 2020, annually update the online county breast health resources to ensure the most accurate and up-to-date information for Cabarrus County and Mecklenburg County.
- *Objective 2:* From FY 2016 – FY 2020, annually reach out to at least five community-based organizations in Cabarrus County and at least ten in Mecklenburg County to distribute updated county breast health and grant resources.
- *Objective 3:* By 2020, distribute education and mission resources to at least 10 sites within Cabarrus County and 50 sites in Mecklenburg County.

Priority 3: Increase access to the breast cancer continuum of care by addressing barriers and ensuring resources are available for individuals who are underserved in Cabarrus County and Mecklenburg County.

- *Objective 1:* By September 2015, revise the statement of need in the RFA to include a funding priority to decrease barriers to access through transportation and establishing a primary care physician prior to breast cancer screenings, for Cabarrus County and Mecklenburg County.
- *Objective 2:* By 2020, develop relationships with a total of three local clinics to address the primary care needs of Cabarrus County and Mecklenburg County residents.
- *Objective 3:* By 2020, collaborate with community-based organizations to identify at least one initiative to address transportation issues in Cabarrus County.
- *Objective 4:* From FY 2016 – FY 2020, annually assess the need to adapt the RFA to include changes that address gaps in care and the breast health needs of the community due to the implementation of the Affordable Care Act.
- *Objective 5:* By 2020, work with the Mecklenburg Breast Health Coalition to create a forum with the purpose to increase resource sharing and collaboration among nurses/nurse navigators in Mecklenburg and Cabarrus Counties, and ultimately increase the number of individuals who enter into and stay in the breast health/breast cancer continuum of care.

Priority 4: Develop and utilize local and state partnerships to enhance Affiliate public policy efforts in order to improve breast health outcomes (i.e. late-stage diagnosis and death rates) in the Affiliate service area.

- *Objective 1:* From FY 2016 – FY 2020, conduct annual meetings with at least two state legislators or local officials to increase their understanding of breast health issues and recognize Komen Charlotte as a local resource on breast cancer.
- *Objective 2:* From FY 2016 – FY 2020, annually partner with at least two other Komen Affiliates to discuss joint public policy efforts and pending breast cancer legislation including advocating to maintain BCCCP funding locally and federally.

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