COMMUNITY PROFILE REPORT 2015

SUSAN G. KOMEN®
CHARLOTTE

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Acknowledgments

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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.

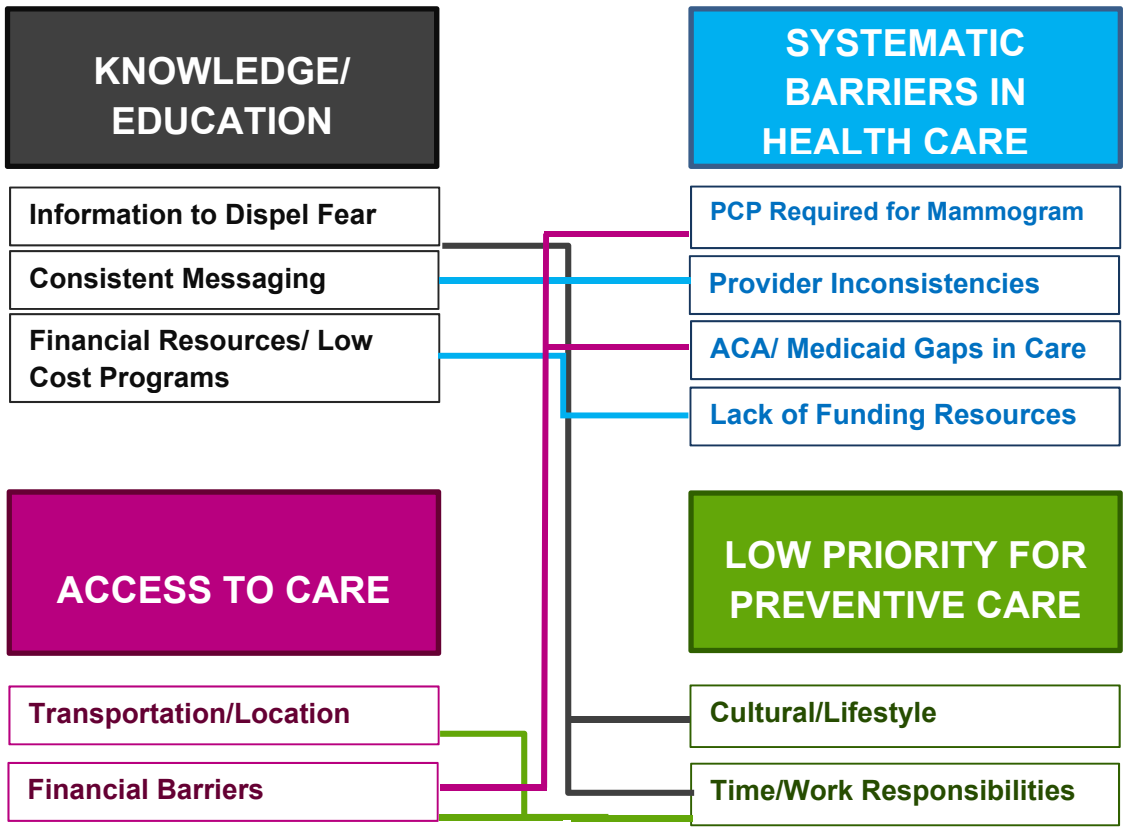


Figure 1. Factors in high late-stage diagnosis and death rate

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 2019, meet with at least three community-based organizations in Cabarrus County and at least five in Mecklenburg County to discuss how to prioritize prevention and address cultural and/or language barriers in the Black/African-American and Hispanic/Latina populations.
- *Objective 3:* By 2019, 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 2019, 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.

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 2019, 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 2019, 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 2019, 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 2019, 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 2019, collaborate with community-based organizations to identify at least one initiative to address transportation issues in Cabarrus County.
- *Objective 4:* From FY 2016 – FY 2019, 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.

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 2019, 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 2019, annually attend at least one NC Advisory Committee on Cancer Coordination and Control meeting(s) and/or subcommittee meetings.
- *Objective 3:* From FY 2016 – FY 2019, 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.

References

Breast and Cervical Cancer Control Program. (2014, January 1). Retrieved March 10, 2014, from http://bcccp.ncdhhs.gov/eligibility.asp

Cabarrus County Transportation System, personal communication, July 10, 2014

Cancer Facts & Figures for African-Americans 2013-2014 (2013). Atlanta, GA: American Cancer Society

Florida, R. (2014, March 28). America's biggest metros are growing much faster than other cities. Retrieved from http://www.citylab.com/politics/2014/03/americas-biggest-metros-are-growing-much-faster-other-cities/8746/

Liptak, A (2015, June 25). Supreme Court Allows Nationwide Healthcare Subsidies. *The New York Times.* Retrieved from http://www.nytimes.com/2015/06/26/us/obamacare-supreme-court.html

Mecklenburg County Board Bulletin. (2014, September 22). Retrieved February 6, 2015, from http://charmeck.org/mecklenburg/county/CountyManagersOffice/Board-Bulletins/Pages/September-22-2014.aspx

North Carolina Point-in-Time Count Data. (2014, January 29). *Practice:Point-in-time counts*. Retrieved May 12, 2014, from http://www.ncceh.org/PITdata/

Preventive Services Covered Under the Affordable Care Act. (2012, September 20). *United States Department of Health and Human Services*. Retrieved July 25, 2014, from http://www.hhs.gov/healthcare/facts/factsheets/2010/07/preventive-services-list.html#CoveredPreventiveServicesforAdults

Susan G. Komen. (2014). *Susan G. Komen Charlotte quantitative data report: 2014.* Dallas, TX: Author.

The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid – An Update. (2015, April 17). Retrieved April 29, 2015.

Tippet, R. (2013, October 14). Population Growth & Population Aging in North Carolina Counties. *Carolina Demography*. Retrieved May 12, 2014, from http://demography.cpc.unc.edu/2013/10/14/population-growth-population-aging-in-north-carolina-counties/

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

Introduction

Affiliate History

The first Susan G. Komen Charlotte Race for the Cure® was held October 4, 1997, and subsequently Susan G. Komen® Charlotte was established in 1999. Traditionally, the Affiliate holds the Komen Charlotte Race for the Cure on the first Saturday in October. Laugh for the Cure®, the Affiliate's second largest fundraiser, was created in Charlotte and has now expanded to five other Affiliates. Seventy-five percent of net proceeds stay in the local community to fund community outreach programs. The remaining net twenty-five percent supports vital breast cancer research through Susan G. Komen's Research Programs. Since 1997, Komen Charlotte has awarded more than $14 million to local nonprofit organizations through community grants contributing to screening, education, survivorship and treatment support programs in the 13-county service area.

Komen Charlotte engages the service area through education programs including its Education Ambassador Program, participation in health fairs and breast health awareness presentations. The Affiliate has also engaged more than 370 faith organizations through Pink Sunday/Worship in Pink.

The Affiliate is an active partner of the NC Advisory Committee on Cancer Coordination and Control and early detection and prevention subcommittees. 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 engages the community and strives to use evidence-based interventions to further its mission.

Komen Charlotte has also contributed $5.3 million to Susan G. Komen's Research Programs, funding groundbreaking breast cancer research, meritorious awards and educational and scientific programs around the world. Komen research has contributed more than half a million dollars in South Carolina (SC) to investigate cancer biology, early detection, prevention, and treatment. The scientific investment in North Carolina (NC) has been substantial with nearly $31 million awarded to advance the Komen vision of a world without breast cancer.

Affiliate Organizational Structure

Komen Charlotte has eight staff members and is governed by a board of directors with executive and board nominating committees (Figure 1.1). Each department, as depicted below, has contributing volunteer committees (Figure 1.2).

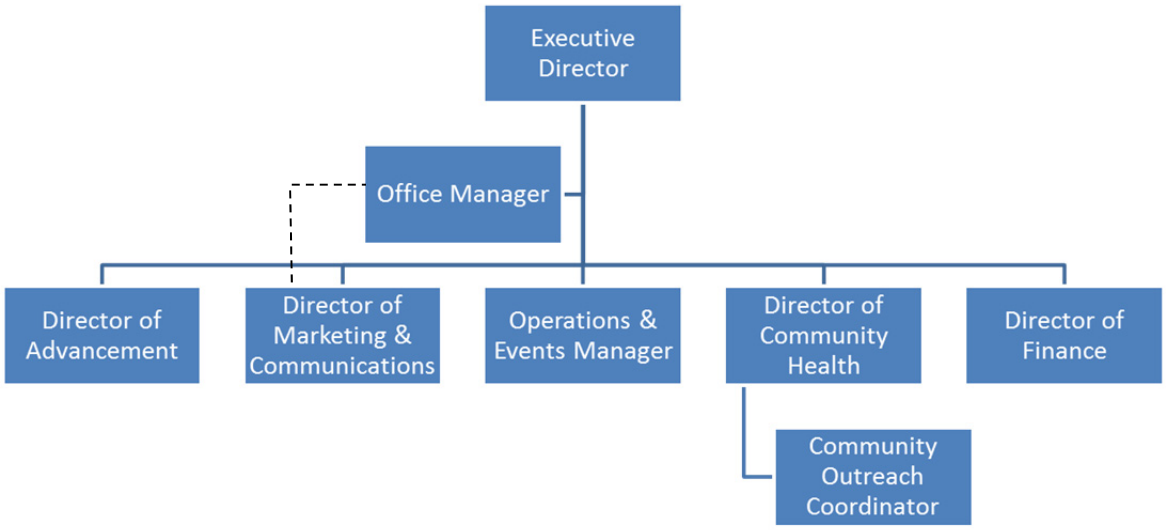
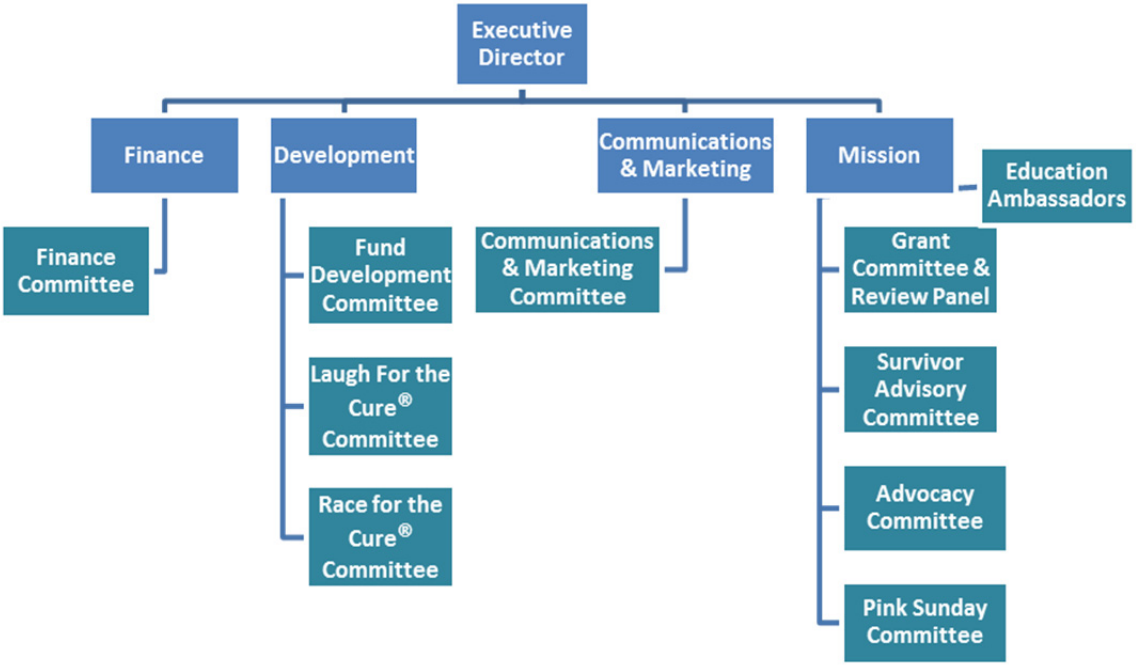


Figure 2.1. Susan G. Komen Charlotte staff organization



[Note: Staff (blue squares) lead volunteer committees (teal)].

Figure 2.2. Susan G. Komen Charlotte committee organization

The Finance Committee reviews the Affiliate financial position and approves the annual budget. The Fund Development Committee focuses on increasing revenue through personal contacts, idea generation of potential sponsors and resources, and aiding in relationship management of sponsors and top fundraisers on behalf of the Affiliate. The Race for the Cure Committee is an extension of the Komen staff to organize, coordinate and execute Race for the Cure. The Marketing and Communications Committee aids in implementing the strategic marketing plans

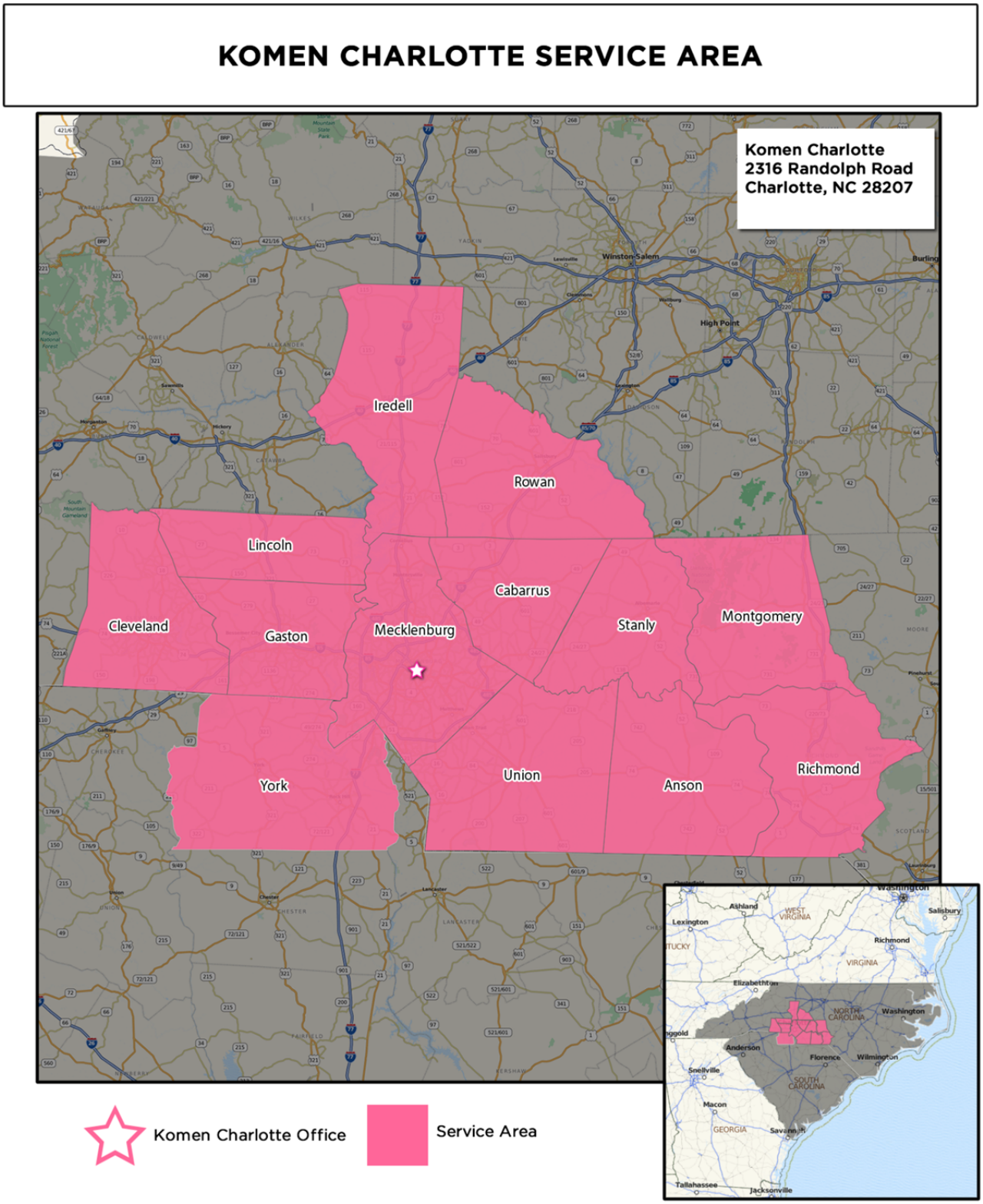
for Race for the Cure and Laugh for the Cure, as well as designing and distributing event marketing materials.

The Grant Committee reviews grant reports and oversees the integrity of the grantmaking process. The Grant Review Panel is an independent group of volunteers who score and rank grant applications to recommend a grant slate to the board of directors. The Survivor Advisory Committee leverages survivors' experience to ensure ongoing involvement and thought leadership on issues and topics that are relevant to the survivor community. The Pink Sunday Committee recruits participation from churches and faith-based organizations, and helps with education materials distribution for the event. The Advocacy Committee is responsible for the overall planning, implementation and coordination of Komen-related advocacy issues in the Komen Charlotte service area. The committee also engages constituents regarding breast cancer policy needs for the US Congress and state legislatures. Komen Charlotte Education Ambassadors are trained volunteers who raise awareness about the importance of breast health and breast cancer issues through speaking engagements, health fairs and events, especially in medically underserved communities.

Affiliate Service Area

Komen Charlotte's service area is located in the Carolina Piedmont and is made up of 13 counties including Anson, Cabarrus, Cleveland, Gaston, Iredell, Lincoln, Mecklenburg, Montgomery, Richmond, Rowan, Stanly and Union Counties in NC, and York County, SC (Figure 1.3). Mecklenburg County is a large metropolitan area surrounded by three urban fringe counties: Cabarrus, Rowan, NC and York, SC. The rest of the counties are rural: Anson, Cleveland, Gaston, Iredell, Lincoln, Montgomery, Richmond, Stanly and Union. When 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 a slightly larger percentage of people who live in rural areas, are without health insurance and are in medically underserved areas.

Counties in NC and SC are classified by Tiers which are based on unemployment percentages, household income, percentage growth in the population and adjusted property tax base per capita (North Carolina Rural Economic Development Center, Inc., 2014). In NC, Tier 1 is the most economically distressed category while Tier 3 is the least distressed. The service area has five NC Tier 3 counties (Cabarrus, Iredell, Lincoln, Mecklenburg and Union); four Tier 2 counties (Cleveland, Gaston, Rowan and Stanly); and three Tier 1 counties (Anson, Montgomery and Richmond). In SC, Tier 1 is the most developed county and Tier 4 is the most distressed and least developed county. In SC, York County is a Tier 2 county (Job Tax Credit - County Rankings for 2015, 2015).



(York County is located in South Carolina)

Figure 1.3. Susan G. Komen Charlotte service area

Purpose of the Community Profile Report

The purpose of the Community Profile Report is to:

- Align the strategic and operational plans
- Drive inclusion efforts in the community
- Drive public policy efforts
- Establish focused granting priorities
- Establish focused education need
- Establish directions for marketing and outreach
- Strengthen sponsorship efforts

The Affiliate will use the Community Profile Report to define outreach and education efforts specifically to mobilize education ambassadors and develop existing and potential outreach programs. In addition, the Community Profile will be used to guide the Affiliate's grantmaking programs. The report 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. The Community Profile Report will be published on the Affiliate website and emailed to all constituents in the database as well as distributed to current and potential grantees and key contacts in priority counties. The Affiliate and community partners will use the report for program planning, service delivery, grant writing and leveraging Komen Charlotte resources to maximize the impact in the community.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Quantitative Data Report

Introduction

The purpose of the quantitative data report for Susan G. Komen® Charlotte 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 Charlotte'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/). State and national reporting usually uses the SEER Summary Stage. It provides a consistent set of definitions of stages for historical comparisons.

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

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

		Incidence Rates and Trends			Death Rates and Trends			Late-stage Rates and Trends		
Population Group	**Female Population (Annual Average)**	**# of New Cases (Annual Average)**	**Age-adjusted Rate/ 100,000**	**Trend (Annual Percent Change)**	**# of Deaths (Annual Average)**	**Age-adjusted Rate/ 100,000**	**Trend (Annual Percent Change)**	**# of New Cases (Annual Average)**	**Age-adjusted Rate/ 100,000**	**Trend (Annual Percent Change)**
US	154,540,194	198,602	122.1	-0.2%	40,736	22.6	-1.9%	70,218	43.7	-1.2%
HP2020	.	-	-	-	-	20.6*	-	-	41.0*	-
North Carolina	4,751,657	6,681	124.9	0.1%	1,260	23.1	-1.7%	2,401	45.4	-0.5%
South Carolina	2,316,194	3,267	122.3	-0.7%	638	23.5	-1.7%	1,212	45.9	-1.0%
Komen Charlotte Service Area	1,171,635	1,565	127.5	-0.2%	273	22.3	NA	547	44.5	0.2%
White	858,466	1,243	128.9	0.2%	208	21.1	NA	414	43.2	1.1%
Black/African-American	272,591	295	122.2	-2.0%	63	27.3	NA	126	51.4	-2.8%
American Indian/Alaska Native (AIAN)	7,999	SN	SN	SN	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	32,577	11	57.5	0.3%	SN	SN	SN	SN	SN	SN
Non-Hispanic/ Latina	1,083,566	1,532	129.1	0.0%	270	22.6	NA	534	45.0	0.3%
Hispanic/ Latina	88,069	33	83.2	-6.3%	3	9.6	NA	13	27.2	0.3%
Anson County - NC	12,886	19	118.0	-4.4%	5	28.3	-1.9%	6	40.5	-9.7%
Cabarrus County - NC	86,941	113	124.9	0.2%	21	23.1	-0.6%	44	47.8	-0.9%
Cleveland County - NC	50,643	72	114.1	7.3%	13	20.7	-4.2%	24	38.1	12.2%
Gaston County - NC	104,568	153	124.1	-2.0%	29	23.1	-1.9%	55	45.2	0.7%
Iredell County - NC	78,476	109	122.1	1.7%	22	24.4	-0.7%	52	58.5	-6.2%
Lincoln County - NC	38,211	56	122.4	2.2%	8	17.7	-3.4%	17	37.0	11.4%
Mecklenburg County - NC	455,176	556	130.7	1.9%	97	23.3	-1.6%	191	44.4	2.2%
Montgomery County - NC	14,122	20	109.0	-4.2%	4	19.2	NA	8	47.1	-3.8%
Richmond County - NC	23,632	34	120.0	-5.6%	7	23.5	-2.9%	14	49.4	-3.9%
Rowan County - NC	69,349	130	161.2	-5.0%	18	20.4	-2.4%	34	42.7	-0.6%
Stanly County - NC	30,256	44	116.5	0.4%	8	20.4	-0.9%	16	44.5	13.7%
Union County - NC	96,250	117	125.1	0.7%	16	17.5	-2.8%	37	39.2	-3.9%
York County - SC	111,124	143	121.7	-4.6%	27	23.1	-1.8%	48	41.5	-4.9%

*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 incidence and late-stage data: North American Association of Central Cancer Registries (NAACCR) – Cancer in North America (CINA) Deluxe Analytic File.
Source of death rate data: Centers for Disease Control and Prevention (CDC) – National Center for Health Statistics (NCHS) mortality 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 Charlotte service area was higher than that observed in the US as a whole and the incidence trend was similar to 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. The incidence rate of the Affiliate service area was **significantly higher** than that observed for the State of South Carolina and the incidence trend was not significantly different than the State of South 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 Asians and Pacific Islanders (APIs) and American Indians and Alaska Natives (AIANs) were lower than for Non-Hispanic Whites and Blacks/African-Americans. The most recent estimated incidence rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the incidence rate was lower among Blacks/African-Americans than Whites 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 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:

- Rowan County, NC

The rest of the counties had incidence rates and trends that were not significantly different than the Affiliate service area as a whole.

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

Death rates and trends summary

Overall, the breast cancer death rate in the Komen Charlotte 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. The death rate of the Affiliate service area was not significantly different than that observed for the State of South 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.

None of the counties in the Affiliate service area had substantially different death rates 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 Charlotte service area was similar to 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. The late-stage incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of South 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. 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 late-stage incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

The following county had a late-stage incidence rate **significantly higher** than the Affiliate service area as a whole:

- Iredell County, NC

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.

Mammography Screening

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

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

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

*As of October 2015

Because having regular mammograms lowers the chances of dying from breast cancer, it's important to know whether women are having mammograms when they should. This information can be used to identify groups of women who should be screened 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

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
US	174,796	133,399	77.5%	77.2%-77.7%
North Carolina	4,324	3,445	79.4%	77.9%-80.9%
South Carolina	5,066	3,875	74.7%	73.1%-76.2%
Komen Charlotte Service Area	883	685	76.5%	72.8%-79.8%
White	716	551	76.5%	72.5%-80.1%
Black/African-American	142	114	76.2%	66.8%-83.6%
AIAN	SN	SN	SN	SN
API	SN	SN	SN	SN
Hispanic/ Latina	SN	SN	SN	SN
Non-Hispanic/ Latina	868	674	76.5%	72.8%-79.8%
Anson County - NC	14	9	81.1%	50.4%-94.8%
Cabarrus County - NC	55	42	75.1%	58.6%-86.5%
Cleveland County - NC	40	34	82.5%	64.5%-92.5%
Gaston County - NC	142	112	78.1%	67.6%-85.9%
Iredell County - NC	58	43	74.3%	58.2%-85.7%
Lincoln County - NC	40	30	78.3%	57.9%-90.4%
Mecklenburg County - NC	165	132	76.2%	68.0%-82.8%
Montgomery County - NC	21	16	80.9%	52.8%-94.1%
Richmond County - NC	21	15	75.7%	49.7%-90.7%
Rowan County - NC	74	56	74.0%	61.0%-83.8%
Stanly County - NC	32	27	90.4%	70.1%-97.4%
Union County - NC	142	115	81.0%	71.2%-87.9%
York County - SC	79	54	67.3%	54.3%-78.1%

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 Charlotte service area was not significantly different 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 and was not significantly different than the State of South 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. 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. Also, there were not enough data available within the Affiliate service area to report on Hispanics/Latinas so comparisons cannot be made for this group.

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 2.4. Population characteristics – demographics

Population Group	White	Black/ African-American	AIAN	API	Non-Hispanic /Latina	Hispanic /Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
US	78.8 %	14.1 %	1.4 %	5.8 %	83.8 %	16.2 %	48.3 %	34.5 %	14.8 %
North Carolina	72.3 %	23.4 %	1.6 %	2.6 %	92.2 %	7.8 %	48.6 %	34.5 %	14.8 %
South Carolina	68.2 %	29.6 %	0.5 %	1.6 %	95.4 %	4.6 %	49.5 %	36.0 %	15.5 %
Komen Charlotte Service Area	72.4 %	23.8 %	0.7 %	3.0 %	91.5 %	8.5 %	46.6 %	31.5 %	12.8 %
Anson County - NC	48.8 %	49.2 %	0.6 %	1.3 %	97.9 %	2.1 %	53.0 %	39.4 %	18.4 %
Cabarrus County - NC	79.9 %	16.9 %	0.7 %	2.5 %	90.8 %	9.2 %	46.8 %	31.1 %	12.9 %
Cleveland County - NC	76.6 %	22.2 %	0.3 %	0.9 %	97.3 %	2.7 %	52.8 %	38.4 %	17.1 %
Gaston County - NC	81.3 %	16.6 %	0.6 %	1.5 %	94.3 %	5.7 %	50.6 %	35.8 %	15.3 %
Iredell County - NC	83.8 %	13.4 %	0.6 %	2.1 %	93.4 %	6.6 %	50.7 %	34.7 %	14.7 %
Lincoln County - NC	92.5 %	6.2 %	0.5 %	0.8 %	93.7 %	6.3 %	52.9 %	36.8 %	14.9 %
Mecklenburg County - NC	60.3 %	33.9 %	0.8 %	5.0 %	88.6 %	11.4 %	42.3 %	27.5 %	10.3 %
Montgomery County - NC	76.9 %	20.7 %	0.8 %	1.6 %	86.6 %	13.4 %	51.8 %	38.6 %	17.1 %
Richmond County - NC	63.4 %	32.1 %	3.1 %	1.3 %	94.6 %	5.4 %	50.5 %	37.2 %	16.4 %
Rowan County - NC	81.1 %	17.1 %	0.5 %	1.3 %	92.8 %	7.2 %	51.1 %	37.1 %	16.6 %
Stanly County - NC	86.2 %	11.4 %	0.4 %	2.0 %	96.6 %	3.4 %	53.2 %	38.9 %	18.1 %
Union County - NC	84.4 %	12.9 %	0.6 %	2.1 %	90.0 %	10.0 %	46.0 %	28.7 %	11.1 %
York County - SC	76.7 %	20.5 %	0.9 %	1.9 %	95.7 %	4.3 %	47.3 %	32.2 %	12.7 %

Data are for 2011.
Data are in the percentage of women in the population.
Source: US Census Bureau – Population Estimates

Table 2.5. Population characteristics – socioeconomics

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistic-ally Isolated	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age: 40-64)
US	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
North Carolina	15.9 %	16.1 %	37.2 %	9.7 %	7.4 %	2.7 %	33.9 %	45.9 %	18.3 %
South Carolina	16.4 %	17.0 %	39.5 %	10.2 %	4.8 %	1.8 %	33.7 %	41.8 %	19.0 %
Komen Charlotte Service Area	15.0 %	14.1 %	34.2 %	10.3 %	8.6 %	3.2 %	21.4 %	27.6 %	18.2 %
Anson County - NC	23.2 %	21.6 %	52.4 %	14.9 %	2.7 %	1.2 %	78.5 %	100.0 %	19.1 %
Cabarrus County - NC	14.5 %	11.9 %	31.7 %	10.4 %	7.1 %	2.7 %	19.3 %	26.8 %	18.4 %
Cleveland County - NC	20.5 %	19.4 %	44.3 %	13.1 %	2.1 %	0.9 %	55.8 %	100.0 %	17.6 %
Gaston County - NC	19.9 %	16.6 %	40.3 %	12.8 %	4.8 %	1.7 %	19.6 %	29.3 %	18.7 %
Iredell County - NC	16.0 %	12.3 %	33.1 %	9.5 %	4.9 %	2.1 %	37.9 %	8.8 %	17.3 %
Lincoln County - NC	17.9 %	13.7 %	35.2 %	11.2 %	4.9 %	1.8 %	54.6 %	19.8 %	19.0 %
Mecklenburg County - NC	11.4 %	13.6 %	31.3 %	9.5 %	13.6 %	4.9 %	1.1 %	9.8 %	18.2 %
Montgomery County - NC	28.0 %	25.9 %	49.5 %	12.6 %	8.7 %	4.0 %	76.8 %	100.0 %	23.7 %
Richmond County - NC	22.9 %	24.9 %	54.2 %	15.9 %	4.4 %	2.4 %	45.5 %	100.0 %	22.5 %
Rowan County - NC	19.6 %	16.9 %	39.8 %	10.1 %	5.6 %	2.6 %	38.8 %	1.1 %	19.3 %
Stanly County - NC	20.4 %	14.1 %	39.1 %	11.3 %	2.8 %	0.7 %	67.7 %	39.7 %	18.6 %
Union County - NC	13.0 %	8.7 %	26.3 %	8.3 %	8.4 %	2.7 %	27.3 %	100.0 %	17.0 %
York County - SC	14.0 %	12.9 %	31.6 %	10.0 %	4.3 %	1.5 %	23.0 %	0.0 %	17.0 %

Data are in the percentage of people (men and women) in the population.
Source of health insurance data: US Census Bureau – Small Area Health Insurance Estimates (SAHIE) for 2011.
Source of rural population data: US Census Bureau – Census 2010.
Source of medically underserved data: Health Resources and Services Administration (HRSA) for 2013.
Source of other data: US Census Bureau – American Community Survey (ACS) for 2007-2011.

Population characteristics summary

Proportionately, the Komen Charlotte service area has a substantially smaller White female population than the US as a whole, a substantially larger Black/African-American female population, a smaller Asian and Pacific Islander (API) female population, a 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 lower than and income level is about the same as 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 slightly larger percentage of people living in rural areas, a slightly larger percentage of people without health insurance, and a slightly 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:

- Anson County, NC
- Mecklenburg County, NC
- Richmond County, NC

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

- Anson County, NC
- Stanly County, NC

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

- Anson County, NC
- Cleveland County, NC
- Montgomery County, NC
- Richmond County, NC
- Stanly County, NC

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

- Anson County, NC
- Cleveland County, NC
- Montgomery County, NC
- Richmond County, NC

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

- Anson County, NC
- Richmond County, NC

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

- Montgomery County, NC

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: 41.0 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 Charlotte service area are progressing toward these targets, the report uses the following information:

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

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

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

Identification of priority areas

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

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

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

Counties are classified as follows (Table 2.6):

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

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

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

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

Affiliate Service Area Healthy People 2020 Forecasts and Priority Areas

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

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

Trends can change for a number of reasons, including:

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

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

Table 2.7. Intervention priorities for Komen Charlotte service area with predicted time to achieve the HP2020 breast cancer targets and key population characteristics

County	Priority	Predicted Time to Achieve Death Rate Target	Predicted Time to Achieve Late-stage Incidence Target	Key Population Characteristics
Cabarrus County - NC	Highest	13 years or longer	13 years or longer	
Mecklenburg County - NC	High	8 years	13 years or longer	%Black/African-American, foreign
Cleveland County - NC	Medium High	1 year	13 years or longer	Education, poverty, rural, medically underserved
Gaston County - NC	Medium High	6 years	13 years or longer	
Iredell County - NC	Medium High	13 years or longer	6 years	Rural
Anson County - NC	Medium	13 years or longer	Currently meets target	%Black/African-American, older, education, poverty, employment, rural, medically underserved
Lincoln County - NC	Medium	Currently meets target	13 years or longer	Rural
Stanly County - NC	Medium	Currently meets target	13 years or longer	Older, education, rural, medically underserved
York County - SC	Medium	7 years	1 year	
Montgomery County - NC	Medium Low	NA	4 years	Education, poverty, rural, insurance, medically underserved
Richmond County - NC	Medium Low	5 years	5 years	%Black/African-American, education, poverty, employment, rural, medically underserved
Rowan County - NC	Medium Low	Currently meets target	7 years	Rural
Union County - NC	Lowest	Currently meets target	Currently meets target	Rural, medically underserved

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.

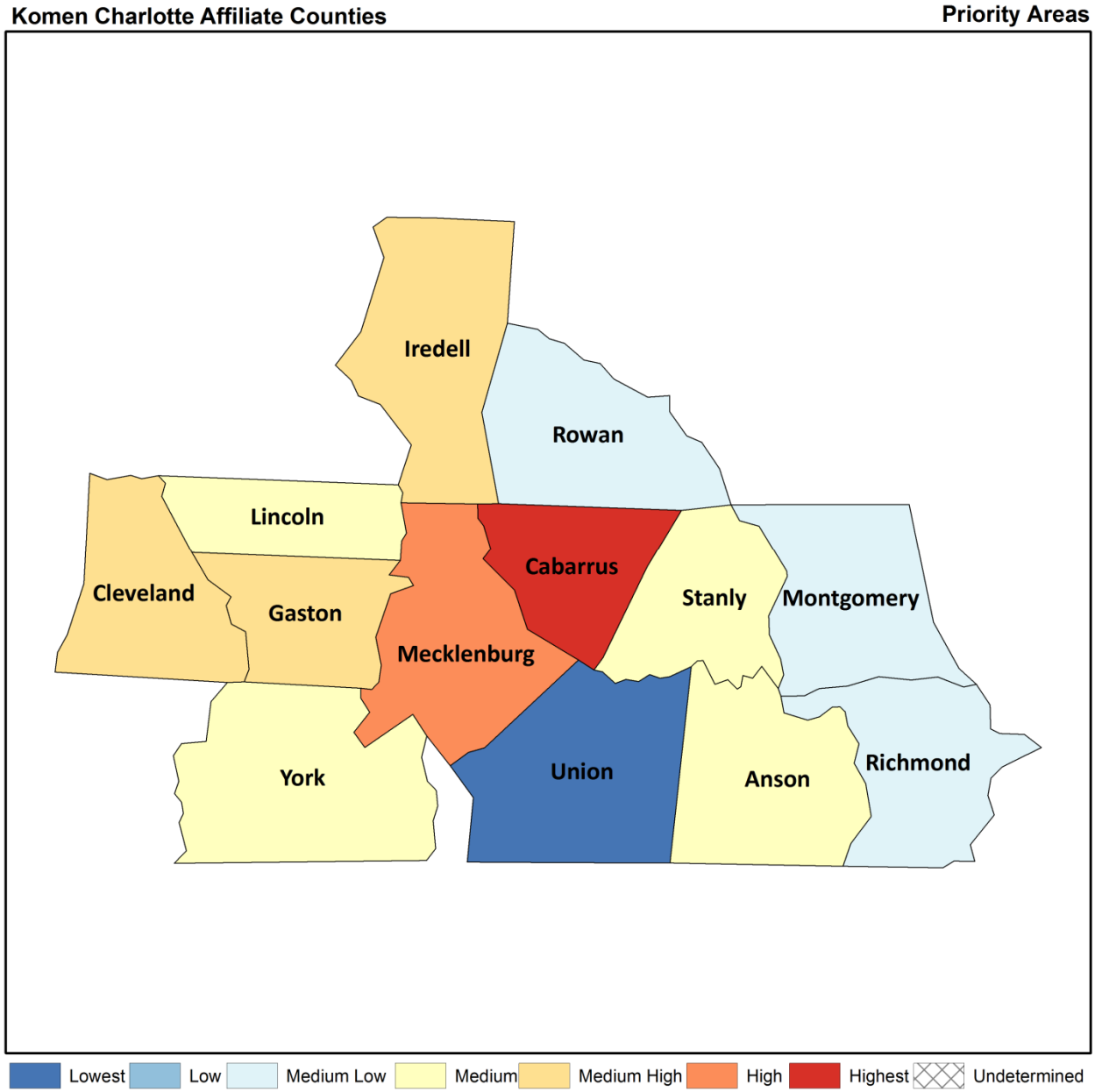


Figure 2.1. Intervention priorities

Data Limitations

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

- The most recent data available were used but, for cancer incidence and deaths, these data are still several years behind.
- For some areas, data might not be available or might be of varying quality.

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

Quantitative Data Report Conclusions

Highest priority areas

One county in the Komen Charlotte service area is in the highest priority category. Cabarrus County, NC is not likely to meet either the death rate or late-stage incidence rate HP2020 targets.

High priority areas

One county in the Komen Charlotte service area is in the high priority category. Mecklenburg County, NC is not likely to meet the late-stage incidence rate HP2020 target. Mecklenburg County, NC has a relatively large Black/African-American population and a relatively large foreign-born population.

Additional Quantitative Data Exploration

Additional quantitative data were explored to assist in the selection of the target communities.

Additional data collected:

- Table 2.8 shows the age-adjusted female breast cancer death rate by race for each county in the Affiliate service area (2008-2012).
- Table 2.9 shows age-adjusted five-year female breast cancer incidence rates for each county in the Affiliate service area (For NC Counties-1998-2002, 2003-2007, 2008-2012 and for York, SC - 1996-2000, 2001-2005, 2006-2010).
- Table 2.10 shows the age-adjusted female breast cancer incidence rate by race for each county in the Affiliate service area (2007-2011).
- Table 2.11 shows the age-adjusted female breast cancer incidence by stage (2007-2011) for each county in the Affiliate service area.

Data for tables 2.8-2.11 was collected by an epidemiology specialist at the Mecklenburg County Health Department. The North Carolina Central Cancer Registry, the South Carolina Central

Cancer Registry, and the office of Public Health Statistics and Information Services at the South Carolina Department of Health and Environmental Control were used to collect the data.

This additional data enhances the Quantitative Data Report, as well as provides data for the most recent years available. Five-year incidence rates provide a 15-year surveillance period to observe increasing and decreasing rates. The incidence and death rate data by race highlights the service area race disparities by county. Also, late-stage incidence rates were collected for specific breast cancer stage data by county.

The Affiliate collected the remaining additional data. Table 2.12 shows county homeless point-in-time data for 2011-2014 and compared Cabarrus and Mecklenburg counties to other counties of like population size. Figure 2.2 shows the population change in the Affiliate service area (2010-2013) and used the analysis conducted by UNC Charlotte Urban Institute from the US Census Bureau data (2010-2013).

This data complements the Quantitative Data Report by showing additional needs in the service area. Homelessness and rapid growth rate are socioeconomic and population factors that contribute to access to care and gaps in the continuum of care.

Potential limitations to the additional quantitative data may include: numbers are subject to change as files are updated, the most recent data collected lags a few years behind the current year, cases may not sum to totals due to unknown values, cases include in situ cases, and rates based on counts fewer than 20 are unstable. In addition, Homeless Point-in-Time data counts are based on a one-day count of unsheltered and sheltered individuals, homeless families who live doubled up with family or friends are not included in the Point-in-Time data, migration from one location to another is difficult to forecast through growth rates and areas reported in the US Census Bureau may not match the true geographic area of the reported economic data.

Table 2.8. Female breast cancer death rate by race, 2008-2012

Female Breast Cancer Death by Race Per 100,000 Population Age-Adjusted to the 2000 Census 2008-2012												
	White		**Black/African-American**		**American Indian**		**Other**		**Hispanic**		**Total**	
	#	**Rate**	**#**	**Rate**	**#**	**Rate**	**#**	**Rate**	**#**	**Rate**	**#**	**Rate**
Anson	12	SN	11	SN	0	NA	0	NA	0	NA	23	28.1
Cabarrus	86	21.0	25	40.4	0	NA	1	SN	2	SN	114	23.3
Cleveland	55	21.0	16	SN	0	NA	0	NA	1	SN	72	22.2
Gaston	133	24.6	19	SN	0	NA	2	SN	0	NA	154	24.1
Iredell	90	22.5	18	SN	0	NA	0	NA	0	NA	108	23.2
Lincoln	36	16.6	8	SN	0	NA	0	NA	0	NA	44	18.4
Mecklenburg	305	21.1	176	26.8	1	SN	3	SN	7	SN	492	21.9
Montgomery	15	SN	3	SN	0	NA	0	NA	0	NA	18	SN
Richmond	23	20.9	8	SN	1	SN	0	NA	1	SN	33	21.7
Rowan	78	20.6	17	SN	0	NA	0	NA	1	SN	96	21.4
Stanly	37	20.2	4	SN	0	NA	0	NA	0	NA	41	20.2
Union	65	15.9	22	40.3	0	NA	1	SN	3	SN	91	18.6
York, SC*	129	24.6	31	30.0	0	NA	1	SN	NA	NA	162	25.5

*Counties listed are in North Carolina unless otherwise noted
NA- data not available
SN- data suppressed due to small numbers (15 cases or fewer for the 5-year data period).
Data from 2008-2012
Source of North Carolina data: NC Central Cancer Registry
Source of York, SC data: SC Central Cancer Registry (SCCCR), Office of PHSIS, SC DHEC

Four of the 13 counties, Cabarrus, Mecklenburg, Union, NC and York, SC have data available that show that Black/African-American women have a higher death rate than White women.

Table 2.9. Female breast cancer incidence five-year rates

Female Breast Cancer Incidence by County Per 100,000 Population Age-Adjusted to the 2000 Census						
	1997-2001		2002-2006		2007-2011	
	#	Rate	#	Rate	#	Rate
Anson	96	131.5	91	124.3	122	158.3
Cabarrus	515	149.9	575	149.0	766	167.3
Cleveland	390	138.9	534	177.7	420	132.3
Gaston	744	141.9	812	142.4	896	142.5
Iredell	434	129.6	513	132.5	712	155.4
Lincoln	228	135.7	260	136.4	336	143.1
Mecklenburg	2,548	165.1	2,898	153.8	3,737	169.9
Montgomery	114	157.8	106	130.5	114	134.0
Richmond	186	137.9	188	133.5	208	144.1
Rowan	443	121.1	526	136.8	733	174.2
Stanly	267	159.5	243	138.8	279	147.7
Union	318	112.1	435	120.9	767	157.0

	1996-2000		2001-2005		2006-2010	
	#	Rate	#	Rate	#	Rate
York, SC*	605	147.4	688	140.4	848	143.9

*Counties listed are in North Carolina unless otherwise noted
Source of North Carolina data: NC Central Cancer Registry from 1997-2001, 2002-2006, 2007-2011
Source of York, SC data: SC Central Cancer Registry (SCCCR), Office of PHSIS, SC DHEC from 1996-2000, 2001-2005, 2006-2010

Most recent data available for South Carolina was 2010, while the most recent data available for North Carolina was 2011.

Anson, Cabarrus, Gaston, Iredell, Lincoln, Mecklenburg, Richmond, Rowan, and Union, NC have increasing rates of breast cancer incidence. Cleveland, Montgomery, and Stanly Counties in NC and York County in SC show a decreasing breast cancer incidence rate.

After Rowan County, Mecklenburg and Cabarrus Counties have the highest five-year incidence rates between 2007-2011. The incidence rates for these three counties are increasing.

Table 2.10. Female breast cancer incidence by race, 2007-2011

Female Breast Cancer Incidence by Race Per 100,000 Population Age-Adjusted to the 2000 Census 2007-2011												
	White		Black/African-American		American Indian		Other		Hispanic		Total	
	#	Rate	#	Rate	#	Rate	#	Rate	#	Rate	#	Rate
Anson	69	162.4	51	155.9	0	0	SN	SN	SN	SN	122	158.3
Cabarrus	617	165.8	101	161.4	0	0	14	209.2	34	191.8	766	167.3
Cleveland	332	130.9	81	142.1	SN	SN	5	251.3	SN	SN	420	132.3
Gaston	764	145.4	102	123.6	SN	SN	6	91.6	21	190	896	142.5
Iredell	606	156.3	81	153.9	0	0	10	256.9	15	130.9	712	155.4
Lincoln	309	143.8	16	137.9	0	0	SN	SN	8	86.3	336	143.1
Mecklenburg	2,514	183.2	999	153.6	SN	SN	104	131.2	118	111.6	3,737	169.9
Montgomery	96	146.1	15	103.5	SN	SN	0	0	SN	SN	114	134
Richmond	155	149.8	45	119.3	SN	SN	SN	SN	SN	SN	208	144.1
Rowan	594	170.9	121	209.3	0	0	8	241.5	10	127.3	733	174.2
Stanly	256	151.9	22	131.6	0	0	0	0	SN	SN	279	147.7
Union	651	160.5	89	162.9	SN	SN	SN	SN	22	106.2	767	157
York, SC*	710	147.7	128	130.0	0	NA	0	NA	10	SN	848	143.9

*Counties listed are in North Carolina unless otherwise noted
NA- data not available
SN- data suppressed due to small numbers (15 cases or fewer for the 5-year data period).
Data from 2007-2011
Source of North Carolina data: NC Central Cancer Registry
Source of York, SC data: SC Central Cancer Registry (SCCCR), Office of PHSIS, SC DHEC

Hispanic/Latina women and the “other” race category in Cabarrus, Cleveland, Gaston, Iredell and Rowan counties may appear to have high incidence rates, but because the number of cases reported are small, the rates calculated are unstable. The cases reported above 20 for Hispanic/Latina women and other races may indicate more women are being screened, therefore incidence may be increasing.

If Hispanic/Latina women and other races are not included, White women have the highest incidence rates in Anson, Cabarrus, Gaston, Iredell, Lincoln, Mecklenburg, Montgomery, Richmond, Stanly, NC, and York, SC. Black/African-American women have the highest incidence rates in Cleveland, Rowan, and Union, NC counties.

Unfortunately, breast cancer incidence data for American Indians is too small and therefore, comparisons cannot be made between the counties.

An additional limitation of this table data is that the rates are based on lower counts of female breast cancer cases. In the next four years, the Affiliate will continue to monitor the trends in incidence by race to determine if the incidence and death rate data stays consistent over time.

Table 2.11. Female breast cancer by stage, 2007-2011

Female Breast Cancer Stage Per 100,000 Population Age-Adjusted to the 2000 Census 2007-2011												
	In-situ		Localized		Regional		Distant		Regional/Distant		N/A or Unstaged	
	#	Rate	#	Rate	#	Rate	#	Rate	#	Rate	#	Rate
Anson	22	27.7	68	86.3	26	36.4	5	7.0	31.0	43.5	SN	SN
Cabarrus	166	36.1	346	75.9	202	43.8	38	8.5	240	52.3	14	3.0
Cleveland	45	14.2	242	75.2	111	35.9	16	5.4	127	41.3	6	1.6
Gaston	141	22.3	470	74.3	215	34.7	56	9.1	271	43.8	14	2.1
Iredell	107	23.2	321	70	235	51.6	32	7.0	267.0	58.5	17	3.6
Lincoln	63	26.1	178	76.8	69	29.2	17	7.1	86	36.2	9	4.0
Mecklenburg	755	33.8	1902	87.3	863	38.8	156	7.2	1019	46	61	2.7
Montgomery	19	23.3	57	64.9	34	41.3	SN	SN	37	44.9	SN	SN
Richmond	34	22.4	105	73.6	55	38.7	9	6.0	64.0	44.7	5	3.4
Rowan	109	25	276	63.9	146	35.1	20	4.8	166	39.9	182	45.4
Stanly	47	24.8	140	72.2	81	45.4	8	3.9	89	49.3	SN	SN
Union	161	31.7	400	82.7	166	34.0	29	6.3	195	40.2	11	2.4
York, SC*	131	22.1	434	73.3	212	36.4	30	5.1	242	41.5	41	6.9

*Counties listed are in North Carolina unless otherwise noted
SN- data suppressed due to small numbers (15 cases or fewer for the 5-year data period).
Data from 2007-2011
Source of North Carolina data: NC Central Cancer Registry
Source of York, SC data: SC Central Cancer Registry (SCCCR), Office of PHSIS, SC DHEC

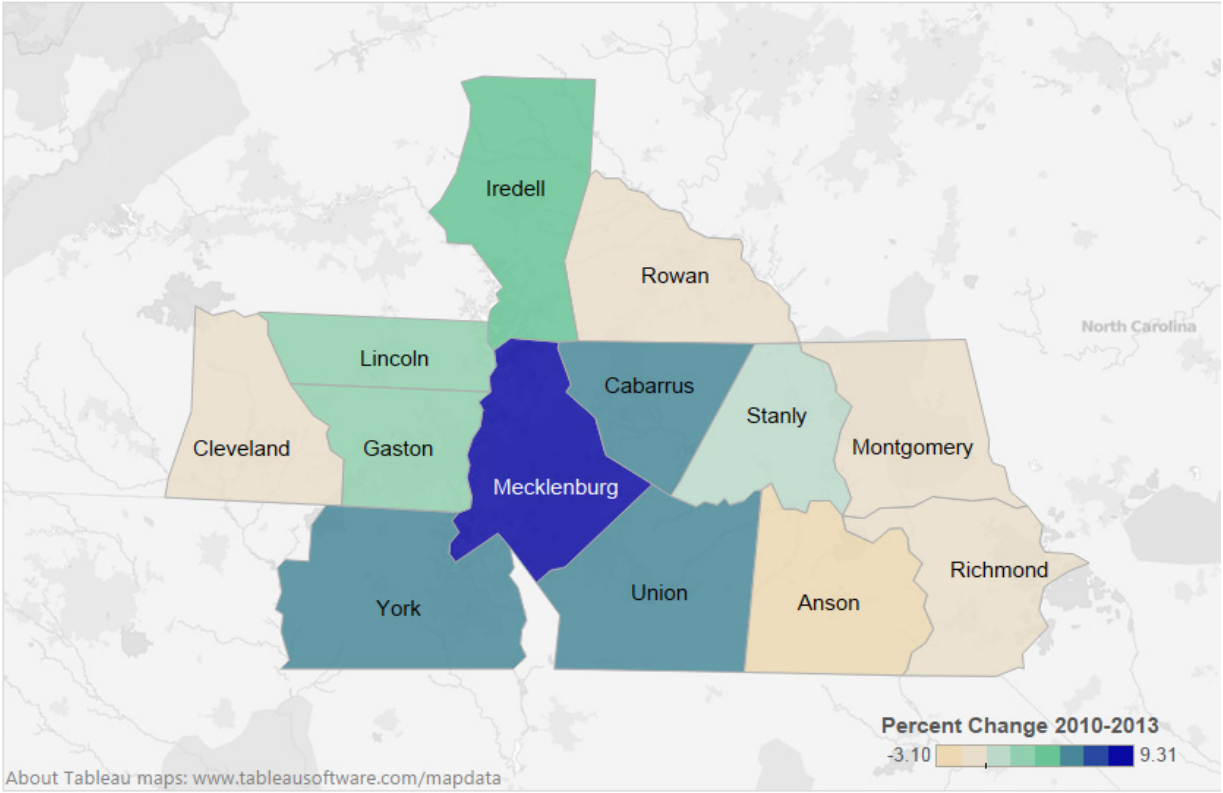
Distant female breast cancer incidence rates per 100,000 population from 2007-2011 indicate Gaston (9.1), Cabarrus (8.5) and Mecklenburg (7.2) have the highest rates across the Affiliate service area. Regional/distant female breast cancer incidence rates per 100,000 population from 2007-2011 indicate Iredell (58.5), Cabarrus (52.3), Stanly (49.3) and Mecklenburg (46.0) have the highest rates across the Affiliate service area.

Table 2.12. Homeless point-in-time count data comparison

County	Total Population Est. 2013	2011	2012	2013	2014
Cabarrus	187,226	189	183	283	309
Iredell	164,517	97	144	127	110
Johnston	177,967	33	32	43	52
Union	212,756	81	88	272	209
Mecklenburg	990,977	2,848	2,567	2,418	2,014
Montgomery, MD	1,016,677	1,132	982	1,004	891
Franklin, OH	1,212,263	1,418	1,434	1,488	NA
Wake	974,289	1,150	1,132	1,098	1,170

*Counties listed are in North Carolina unless otherwise noted
NA- data not available
Source of Montgomery, MD data: Homelessness in Metropolitan Washington for 2011- 2014
Source of North Carolina data: North Carolina Point-in-Time Count Data for 2011- 2014
Source of Franklin, OH data: 2013 Ohio Homeless Report for 2011-2013

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



County, State	Pop 2010	Pop 2013	Change 2010-13	% Change 2010-13
Anson, N.C.	26,948	26,161	-787	-2.9
Cabarrus, N.C.	178,072	187,226	9,154	5.1
Cleveland, N.C.	98,083	97,047	-1,036	-1.1
Gaston, N.C.	206,081	209,420	3,339	1.6
Iredell, N.C.	159,440	164,517	5,077	3.2
Lincoln, N.C.	78,265	79,740	1,475	1.9
Mecklenburg, N.C.	919,568	990,977	71,409	7.8
Montgomery, N.C.	27,798	27,571	-227	-0.8
Richmond, N.C.	46,639	46,405	-234	-0.5
Rowan, N.C.	138,448	138,323	-125	-0.1
Stanly, N.C.	60,585	60,635	50	0.1
Union, N.C.	201,291	212,756	11,465	5.7
York, S.C.	226,905	239,363	12,458	5.5
Grand Total	2,368,123	2,480,141	112,018	*

Source: US Census Bureau data for 2010-2013

Figure 2.2. Population change and growth rates by county in Susan G. Komen Charlotte service area

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

Selection of Target Communities

Overview of the Affiliate service area population

The total population in the Affiliate service area is 2,028,119 ("State and County Quick Facts," 2013). The Affiliate service area female population is 1,171,635 (Table 2.1). The female population broken down by race is 72.4 percent White, 23.8 percent Black/African-American, 8.5 percent Hispanic/Latina, 3.0 percent Asian and Pacific Islander (API) and 0.7 percent American Indian and Alaska Native (AIAN). Compared to the US as a whole, the Affiliate service area has considerable smaller White, API, AIAN and Hispanic/Latina female populations (Table 2.4).

Disparities

Black/African-American women comprise approximately 23.8 percent of the female population within the Affiliate service area. The Affiliate service area has a substantially larger Black/African-American female population than the US as a whole at 14.1 percent, but has a comparable proportion with NC, 23.4 percent and SC, 29.6 percent (Table 2.4).

Black/African-American women in the US have a higher breast cancer death rate than White women. In the Affiliate service area, death rates for Black/African-American women are higher than any other race, with a death rate of 27.3 per 100,000 females compared to 21.1 for White women and 9.6 for Hispanic/Latina women. From the additional data, the Affiliate found Black/African-American women in Cabarrus County have a death rate of 40.4 per 100,000 females, compared to White women with 21.0 per 100,000 females. In Mecklenburg County, Black/African-American women have a death rate of 26.8 per 100,000 females compared to White women with a rate of 21.1 per 100,000 females (Table 2.8).

For the US, the late-stage incidence rate for Black/African-American women is higher than in White women. In addition, in the Affiliate service area, the late-stage incidence rate is higher among Black/African-American women. The late-stage incidence rate was 51.4 per 100,000 females compared to 43.2 per 100,000 females in White women (Table 2.1).

In recent years, breast cancer incidence rates in Black/African-American women have increased while incidence rates among White women have decreased. However overall, cancer incidence rates in Black/African-American women are still lower than in White women. 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, this complex disparity is not yet completely understood ("Cancer Facts & Figures for African Americans 2013-2014", 2013).

Other key population characteristics

As compared to the Affiliate service area, Cleveland, Anson, Montgomery and Richmond Counties have lower education and income levels. In addition, Anson and Richmond Counties have lower employment levels and much larger Black/African-American female populations, Anson County has an older female population and Montgomery County has a larger portion of adults who are uninsured (Table 2.4). These four counties were added to the Affiliate service area, in January, 2013.

Statistically significant data points

After the initial data review, there were a few statistically significant data points. When compared to the Affiliate service area and to NC, Iredell County has a significantly higher late-stage incidence rate. However, Iredell will likely meet the HP2020 goal for late-stage diagnosis in six years. 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, the state of NC and the US (Table 2.1). Since incidence rates are not part of the HP 2020 objectives, and Rowan County will likely meet all HP 2020 targets, this community was not selected for further analysis.

When selecting target counties, the Affiliate reviewed the following key indicators, among others:

- Incidence rates
- Death rates
- Late-stage rates
- Homeless Point-in-Time counts
- County growth rates

In order to best meet the community need, Susan G. Komen Charlotte has chosen two target communities within the service area (Table 2.13). Target communities were prioritized based on the time needed to reach the Healthy People 2020 (HP 2020) objectives listed for breast cancer late-stage incidence and death rate.

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 HP 2020 target for late-stage incidence rate

Table 2.13. Summary table of Cabarrus County and Mecklenburg County data, 2006-2010

	Cabarrus County		Mecklenburg County		Affiliate Service Area Rate	US Rate	HP 2020 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

Cabarrus County is situated in the rolling foothills of the NC Piedmont. The total population estimate for 2013 is 187,226, with 51.2 percent females ("State and County Quick Facts," 2013). Of the 13 counties in the service area, Cabarrus County has the fifth largest population. Cabarrus County grew 35.8 percent from 2000 to 2010 (Figure 2.2). The largest city is Concord, with a total population of approximately 80,000. Following is the ethnic breakdown for the county ("State and County Quick Facts," 2013):

- 2013 Population Estimate: 187,226
- White: 70.5 percent
- Black/African-American: 16.2 percent
- Hispanic/Latino: 9.7 percent
- American Indian: 0.6 percent
- Asian: 2.4 percent

The following statistics highlight the need for breast health programs and services within Cabarrus County:

- Breast Cancer Death Rate – Compared to the Affiliate service area rate of 22.3 deaths per 100,000 females and the US at 22.6, Cabarrus County has a higher death rate of 23.1 per 100,000 females with a decreasing trend of 0.6 percent (Table 2.13).
    - It is projected Cabarrus County will take 13 years or longer to reach the HP 2020 death rate target (Table 2.7).

- Breast Cancer Age-Adjusted Late-Stage Rate – Compared to NC (45.4 per 100,000 females) and the United States (43.7), Cabarrus County has a higher late-stage incidence rate at 47.8 per 100,000 females with a decreasing trend of 0.9 percent (Table 2.13).
    - It is projected Cabarrus County will take 13 years or longer to reach the HP 2020 late-stage incidence rate target (Table 2.7).
    - Additional data shows Cabarrus County has the second highest female breast cancer distant incidence rates in the Affiliate service area at 8.5 per 100,000 population from 2007-2011 (Table 2.11).

- Breast Cancer Age-Adjusted Incidence Rate – Compared the United States (122.1), Cabarrus County has a higher incidence rate at 124.9 per 100,000 females (Table 2.13).
    - When looking at incidence rates from 1997-2011 in five-year increments, the additional data confirmed Cabarrus County has increasing rates (Table 2.9).
    - Additional data (Table 2.9) also validates quantitative data report trends for the most recent years available (2011).

- Geography – Cabarrus County has the second most urban population (80.7 percent urban) compared to the Affiliate service area (78.6 percent), NC (66.1 percent) and the US as a whole (80.7 percent) (Table 2. 5).

- Population Growth Rate – Cabarrus County growth rate from 2010-2013 is 5.1 percent (Figure 2.2), 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 grew 9.2 percent in 2014, following a 54.6 percent increase between the years 2012-2013 (Table 2.12).

Mecklenburg County is the largest, most populous and most urban county in NC. The total population estimate in 2013 is 990,977, with 51.7 percent females ("State and County Quick Facts," 2013). Mecklenburg County grew 32.2 percent from 2000 to 2010 (Figure 2.2). The largest city is Charlotte, with a total population of approximately 775,202. Mecklenburg County is considerably more diverse than Cabarrus County with the following ethnic breakdown ("State and County Quick Facts," 2013):

- 2013 Population Estimate: 990,977
- White: 49.8 percent
- Black/African-American: 31.8 percent
- Hispanic: 12.5 percent
- American Indian: 0.8 percent
- Asian: 5.1 percent

The following statistics highlight the need for breast health programs and services within Mecklenburg County:

- Breast Cancer Death Rate – Compared to the Affiliate service area rate of 22.3 deaths per 100,000 females, NC at 23.1 and the US at 22.6, Mecklenburg County has a higher death rate of 23.3 per 100,000 females with a decreasing trend of 1.6 percent (Table 2.13).
    - It is projected Mecklenburg County will take eight years to meet the HP 2020 death rate target (Table 2.7).

- Breast Cancer Age-Adjusted Late-Stage Rate – Compared to the United States (43.7), Mecklenburg County has a higher late-stage incidence rate at 44.4 percent per 100,000 females with an increasing trend of 2.2 percent (Table 2.1).
    - It is projected Mecklenburg County will take 13 years or longer to reach the HP 2020 late-stage rate target (Table 2.7).
    - Additional data shows that Mecklenburg County has the third highest female breast cancer distant incidence rates at 7.2 per 100,000 population from 2007-2011 in the Affiliate service area (Table 2.11).

- Breast Cancer Age-Adjusted Incidence Rate – Compared to the Affiliate service area (127.5 per 100,000 females), NC (124.9), and the United States (122.1), Mecklenburg County has a higher incidence rate at 130.7 per 100,000 females (Table 2.13).
    - When looking at incidence rates from 1997-2011 in five-year increments, the additional data confirmed Mecklenburg County has increasing rates (Table 2.9).
    - Additional data (Table 2.9) also validates quantitative data report trends for the most recent years available (2011).

- Demographic – Compared to the Affiliate service area rate of 23.8 percent Black/African-American persons, Mecklenburg County has 33.9 percent Black/African-American persons. This rate is also higher than NC at 23.4 percent and the US at 14.1 percent (Table 2.4).
    - Compared to the service area rate of 8.6 percent foreign-born, Mecklenburg County has a higher rate at 13.6 percent foreign-born. The rate is also higher than NC at 7.4 percent and the US at 12.8 percent (Table 2.5).

- Compared to the service area rate of 3.2 percent linguistically isolated persons, Mecklenburg County has a higher rate at 4.9 percent linguistically isolated persons. The rate is also higher than NC at 2.7 percent and the US at 4.7 percent (Table 2.5).

- Geography – Mecklenburg County is the most urban county (98.9 percent urban) compared to the Affiliate service area (78.6 percent), NC (66.1 percent), and the US as a whole (80.7 percent) (Table 2.5).

- Population Growth Rate – Mecklenburg County growth rate is 7.8 percent (Figure 2.2), compared to the US as a whole with a growth rate of 2.4 percent (Florida, 2014). In addition, Mecklenburg County is projected to continue experiencing rapid growth rates through 2020 (Tippett, 2013).

- 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).

Conclusions

Cabarrus County is the fifth largest county in the Affiliate service area and shares its Western border with Mecklenburg County. Cabarrus is the highest priority county in the quantitative data report.

Mecklenburg County is the largest county in all of NC and SC, with just under one million residents in 2013. The quantitative data report found Mecklenburg County has large percentages of linguistically isolated, Black/African-American and foreign-born women, and is the second highest priority county.

The health systems analysis will explore the availability of breast health resources in underserved areas and identify gaps in services to residents in Cabarrus County and Mecklenburg County. As health systems often affect or share resources with neighboring counties, the Affiliate will explore how each county's health systems interact with one another and the availability of the NC Breast and Cervical Cancer Control Program (NC BCCCP).

Although both Mecklenburg and Cabarrus counties have NC BCCCP programs, the Affiliate will examine the extensiveness of these programs and the funding available. The Affiliate will also be looking into any possible breaks in the continuum of care, as some patients may be utilizing resources in both counties.

Homelessness and rapid growth rate are socioeconomic and population factors that contribute to access to care and gaps in the continuum of care. A research study that examined homeless adults, cancer risk factors and screening rates found 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 which emphasizes the need for increased education and availability of services to this population (Chau et al., 2002). Even though Cabarrus and Mecklenburg Counties have comparable screening rates to the service area, state and US per the quantitative data report, the high homeless population may indicate targeted interventions are needed.

Another factor to explore further is the relationship between breast cancer risk, high population growth rates and urbanization in Cabarrus and Mecklenburg Counties. Increasing growth rates demonstrates the fact that more people are moving into the Affiliate service area. This means there are many more people who will need to find a primary care doctor or medical home, which may take some time and could delay necessary medical services.

Hall et al. conducted a study on the relationship between urbanization and breast cancer incidence in North Carolina. This study concludes that urban counties may have higher incidence rates because of increased detection and access to care (Hall, Kaufman, Millikan, Ricketts, Herman, & Savitz, 2005). Further analysis of health systems may help inform Affiliate priorities on this relationship.

The health systems analysis component of this report will take a deeper look at the existing breast health services in the priority counties. Due to the varying landscapes of Cabarrus and Mecklenburg counties, it is critically important to understand how accessible breast health services are in these areas.

Health Systems Analysis Data Sources

An inventory was conducted of programs and services available to individuals in Cabarrus and Mecklenburg Counties using short, informal email and phone surveys as well as website research.

The following criteria and sources were used to identify the providers of services in the breast cancer continuum of care (CoC) and quality care indicators:

- Approved mammography centers through the US Federal Drug Administration (FDA)
- Free clinics through the National Association of Free Clinics and Charitable Clinics and key community contacts
- Federally qualified health centers identified through Health Resources and Services Administrations
- Individual private breast reconstruction practices and private physician practices through websites and phone calls to offices for detailed information
- Individual contacts and organization websites were used to obtain specific service information for hospitals, health departments, radiology locations, support organizations and free clinics
- Information about Cabarrus Kannapolis Area Transit and Charlotte Area Transit System provided through email and phone communication with offices
- Detailed NC BCCCP description through NC BCCCP website and from emails with the program consultant for NC BCCCP
- Description of NC Comprehensive Cancer Control Coalition through meeting notes from the NC partnership meeting
- Description of SC Best Chance Network (BCCCP Program) through the Best Chance Network website
- Description of SC Cancer Alliance through the South Carolina Cancer Alliance cancer report card and cancer plan
- Affordable Care Act summaries and uninsured details through North and South Carolina Institutes of Medicine, North Carolina Hospital Association, Kaiser Family Foundation research and healthcare.gov
- Public Policy information through various emails, phone conferences and meetings in which Komen Charlotte public policy advocates participated
- American College of Surgeons Commission on Cancer Certification
- American College of Surgeons National Accreditation Program for Breast Centers
- American College of Radiology Breast Imaging Centers of Excellence

After compiling the health systems data, the resources and services available were reviewed in Cabarrus and Mecklenburg Counties, determining their strengths and weaknesses in relation to the established breast cancer CoC. Also, Google Maps was utilized to visualize county provider locations and service areas.

Health Systems Overview

Figure 3.1 illustrates the breast cancer continuum of care (CoC) – a model that shows how a woman or man typically moves through the health care system for breast care. Individuals can enter the CoC at any stage, and the goal for all individuals is to remain in the CoC and go through it in a timely, smooth manner. Ideally, a woman would enter the CoC by getting screened for breast cancer – with a clinical breast exam and/or a screening mammogram. If the screening test results are normal, she would loop back into follow-up care, where she would get another screening exam at the recommended interval. Education is not included directly in the CoC steps as it plays an important role throughout the CoC, not only at specific phases.

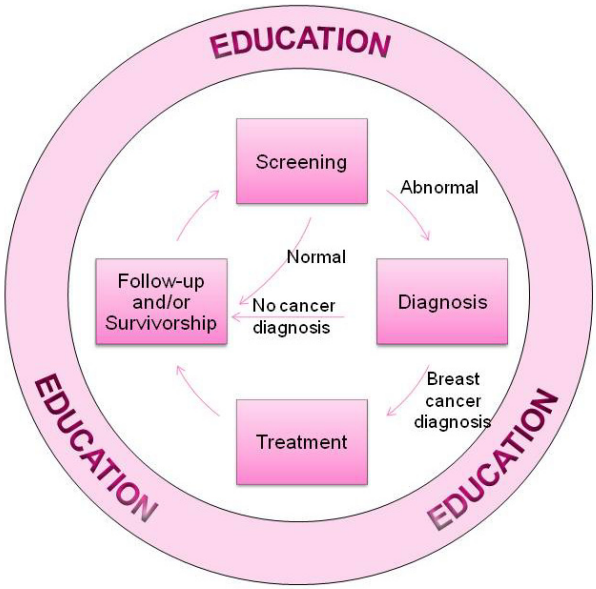


Figure 3.1. Breast Cancer Continuum of Care (CoC)

Screening

"Screening" is a general term covering various types of breast examinations. Age and risk of breast cancer usually determine the screening needs. Women are recommended to receive a clinical breast exam at least every three years beginning at ages 20-39 and every year beginning at age 40. Clinical breast exams are usually conducted by a primary care physician during a physical (well person visit). Women at average risk should start getting a mammogram every year beginning at age 40, in addition to the clinical breast exam. Women at higher risk should discuss when to start getting mammograms with a health care provider. Clinical breast exams and mammograms are complementary because they are more accurate than either screening test used alone. Education plays a role in both encouraging women to get screened and reinforcing the need to continue to get screened routinely thereafter. Also, education can empower a woman and help manage any anxiety and fear throughout the continuum.

Diagnosis

If patients receive abnormal results from a clinical breast exam or mammogram, they may need diagnostic procedures to better identify the nature of the abnormality. These procedures include, but are not limited to, a diagnostic mammogram, ultrasound and biopsy.

Treatment

If the diagnosis is breast cancer, the patient and provider together determine the best course of treatment. Treatment may include surgery, chemotherapy, radiation, hormone therapies and targeted therapies (depending on receptor positivity). Education can cover topics such as treatment options, how a pathology report determines the best options for treatment, understanding side effects and how to manage them, and helping to formulate questions an individual may have for his/her providers.

Follow-up Care

Whether diagnosed with breast cancer or not, all women should have regular screenings as recommended by a health care provider. For survivors, this may include side-effect management, long-term treatment, reconstruction (if not part of treatment), survivorship/co-survivorship and, if needed, end-of-life care. Education may address topics such as making healthy lifestyle choices, long-term effects of treatment, managing side effects, the importance of follow-up appointments and communication with providers.

The goal for every individual diagnosed with breast cancer is to keep him/her in the continuum of care. It is important to consider issues and barriers that prevent women from entering the CoC and at which stages women may fall out of the CoC. These barriers can include things such as lack of transportation, system issues including long waits for appointments and inconvenient clinic hours, language barriers, fear and lack of information - or the wrong information (myths and misconceptions). Education can address some of these barriers and help a woman progress through and remain in the CoC.

Cabarrus County

Cabarrus County has a health department (Cabarrus Health Alliance), a free clinic (Community Free Clinic) and Cabarrus Rowan Community Health Center, the federally qualified health center (FQHC) which is the parent organization encompassing Logan Family Resource Center and McGill Family Medicine (Figure 3.2). All except the free clinic provide clinical breast exams to patients. Cabarrus Health Alliance is the Breast and Cervical Cancer Control Program (BCCCP) provider and provides screening mammograms and diagnostics if needed through the local hospital, Carolinas HealthCare System-NorthEast (CHS NorthEast).

CHS NorthEast Breast Health Center, CHS NorthEast and Levine Cancer Institute-Concord are all part of Carolinas HealthCare System and considered one unified hospital system. The hospital provides all services throughout the continuum of care including lymphedema support through Carolinas Rehabilitation. CHS NorthEast contracts with Charlotte Radiology, an independent radiology group, to provide all screening and diagnostic services.

Unfortunately, uninsured or underinsured individuals may not have a primary care provider. A clinical breast exam has to be conducted in order to have a mammogram. For someone who is uninsured, the lack of a provider may cause delays for getting screened as well as access into the CoC.

The health department and clinics are ways uninsured patients can enter the CoC. These organizations regularly communicate with the hospital. CHS NorthEast has one mobile mammography coach that visits eight clinic locations each month, and many churches and local community organizations multiple times each year to decrease barriers to access.

Though Cabarrus County has one end-of-life care provider (Hospice and Palliative Care of Cabarrus County) with an office physically in the county, it is also served by Hospice & Palliative Care Center of Rowan County in the east and Hospice & Palliative Care Lake Norman in the west. This provides locations closer to some outlying rural areas in Cabarrus County.

The hospital is approximately 30 minutes by car from the most rural towns in Cabarrus County. The local bus system, Concord Kannapolis Area Transit, only serves these two cities in which

only one of the seven lines connects to the hospital. Public bus transportation is not available outside of these cities. The rural transportation service, Cabarrus Links, discontinued service in July 2014. Other transportation services are only provided to residents going from rural areas to urban areas or urban areas to rural areas and those who qualify for Medicare, Medicaid and disability. Though much of Cabarrus appears to be in rural areas, recently many of those areas were qualified as urban areas, therefore limiting transportation options for residents (Cabarrus County Transportation System, personal communication, July 10, 2014).

The Affiliate has working relationships with both CHS NorthEast and Cabarrus Health Alliance. For example, Komen Charlotte has partnered with both of these organizations to provide breast health education to the community through Pink Sunday, an annual breast health education event in faith-based organizations. The Affiliate has started communication with the free clinic and FQHC and will continue to build relationships with other organizations to help alleviate the access to care barriers faced by individuals living in Cabarrus County.

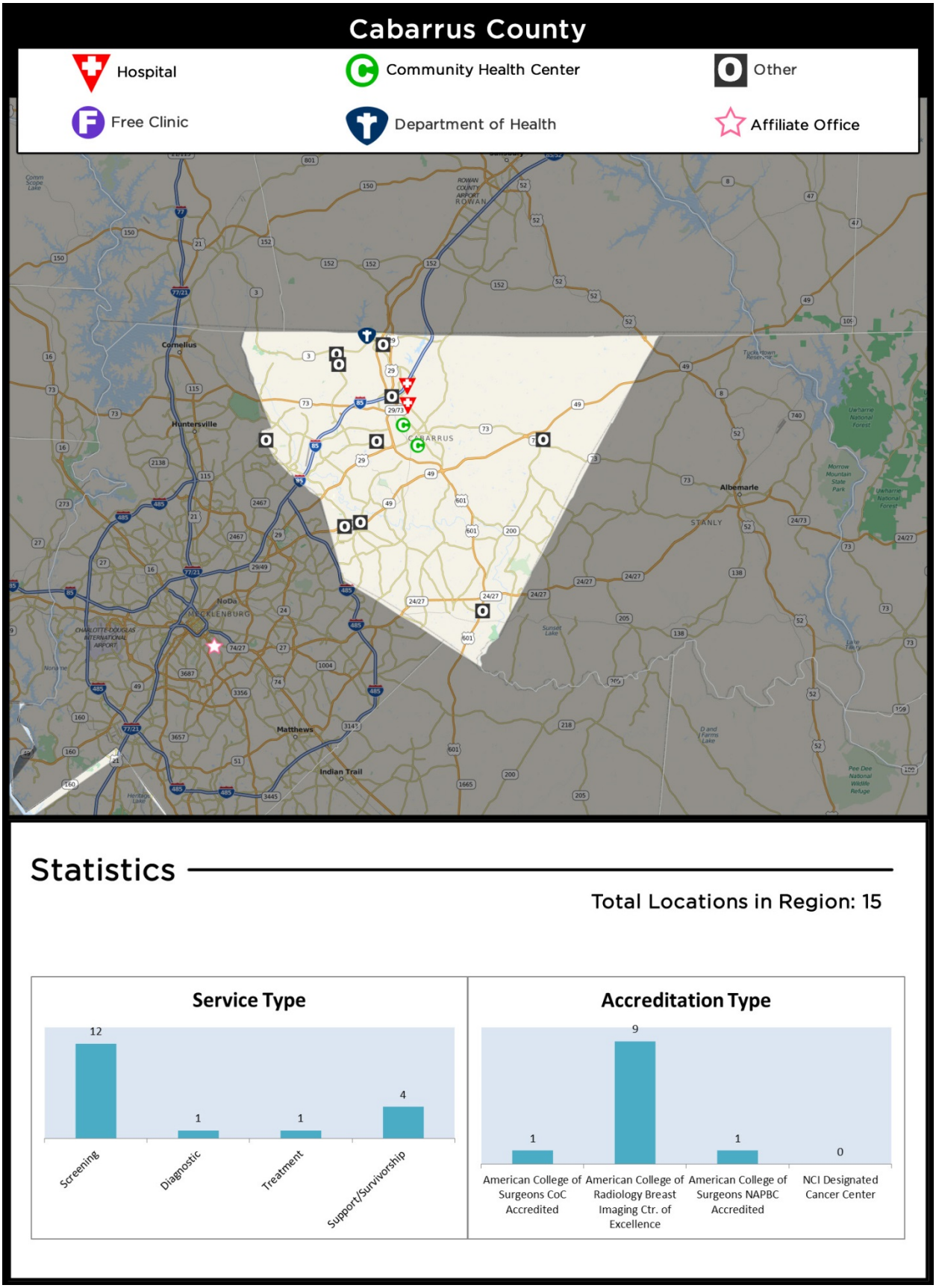


Figure 3.2. Breast cancer services available in Cabarrus County

Mecklenburg County

As the largest county in North Carolina, this county is served by two different hospital systems: Novant Health and Carolinas HealthCare System's Levine Cancer Institute (LCI)/Carolinas Medical Center (CMC) (Figure 3.3). There are quite a few independent providers at each stage of the continuum allowing patients to select their provider of choice.

Mecklenburg County has a health department (Mecklenburg County Health Department) with two locations, eight free clinics, one federally qualified health center and 12 independent family practice and internal medicine providers and organizations. The 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). There are four low-cost clinics associated with Carolinas Medical Center. All provide clinical breast exams to patients.

A similar CoC access problem to Cabarrus County is seen in Mecklenburg County. In order for uninsured and underinsured patients to enter the CoC, they must first establish a PCP or medical home. This ensures the patient will receive a clinical breast exam, which is needed before receiving a mammogram. It also provides necessary follow-up for diagnostic procedures if needed. Further analysis will be conducted qualitatively to determine and better understand the specific barriers to access.

Mecklenburg County Health Department is the only BCCCP provider in the county and provides screening mammograms and diagnostics if needed through Charlotte Radiology. Charlotte Radiology provides services at nine radiology locations that cover a range of screenings and diagnostics for Carolinas HealthCare System. Novant Health provides screenings and diagnostics at seven imaging and medical center locations. Novant Health partners with Mecklenburg Radiology Associates (independent radiology group) to conduct the radiology procedures and interpretations.

There are two Charlotte Radiology mobile mammography units and one Novant Health mobile mammography unit. The mobile units do not have specific locations set on a regular calendar basis. Many clinics and shelters work with the mobile units to ensure screening mammography access for their clients as most are uninsured or underinsured.

Each of the hospital systems provides all parts of the CoC though services vary at each location. Novant Health provides cancer care in Mecklenburg County at three medical centers: Matthews, Huntersville and Presbyterian. Novant Health works with individual private oncologist practices (Southern Oncology Specialists, Matthews Hematology Oncology and Oncology Specialists of Charlotte) to get patients through breast cancer treatment. Novant Health also has three rehabilitation clinics that support breast cancer survivors through recovery with lymphedema support. In addition, Buddy Kemp Cancer Support Center provides support and survivorship services to anyone in Mecklenburg County and surrounding counties.

CMC provides Carolinas HealthCare System's inpatient breast cancer care through three medical centers: Main, Pineville and University. LCI provides outpatient cancer care at the three main medical centers as well as six additional outpatient facilities that provide treatment. Three locations provide exercise programs and Carolinas Rehabilitation provides lymphedema support at two locations.

There are six private breast reconstruction surgeons whowork with both hospital systems. The hospital systems and independent providers together cover the entire CoC. However, due to the number of organizations involved in the CoC in Mecklenburg County, communication may be difficult between providers, and patients may find navigation through this system complex.

Mecklenburg County's end-of-life care is provided by Novant Health and Hospice & Palliative Care Charlotte Region. Also, Mecklenburg County has six breast cancer organizations that provide a range of support and survivorship services including financial assistance and support groups.

Public transportation with Charlotte Area Transit System is available through the local bus and light rail. Only the bus lines go to all medical centers ("CATS Riders Guide", 2014).

The Affiliate works closely with both hospital systems, the health department and many of the free clinics and breast cancer nonprofits. In 2013, the Affiliate established the Mecklenburg Breast Health Coalition (MBHC) to address late-stage breast cancer diagnosis in the states' most populous county. As the first county-wide gathering of key breast health stakeholders, MBHC has conducted two focus groups of late-stage breast cancer survivors to help determine the most feasible means of alleviating the concern. A Susan G. Komen Headquarters Community Organizing Grant funded the coalition development.

In the past year, new collaborations have started with local organizations, shelters and low-income housing areas to expand education and outreach, as well as provide needed breast health services. Komen Charlotte plans to continue these relationships and further efforts to lessen access to care barriers in the community.

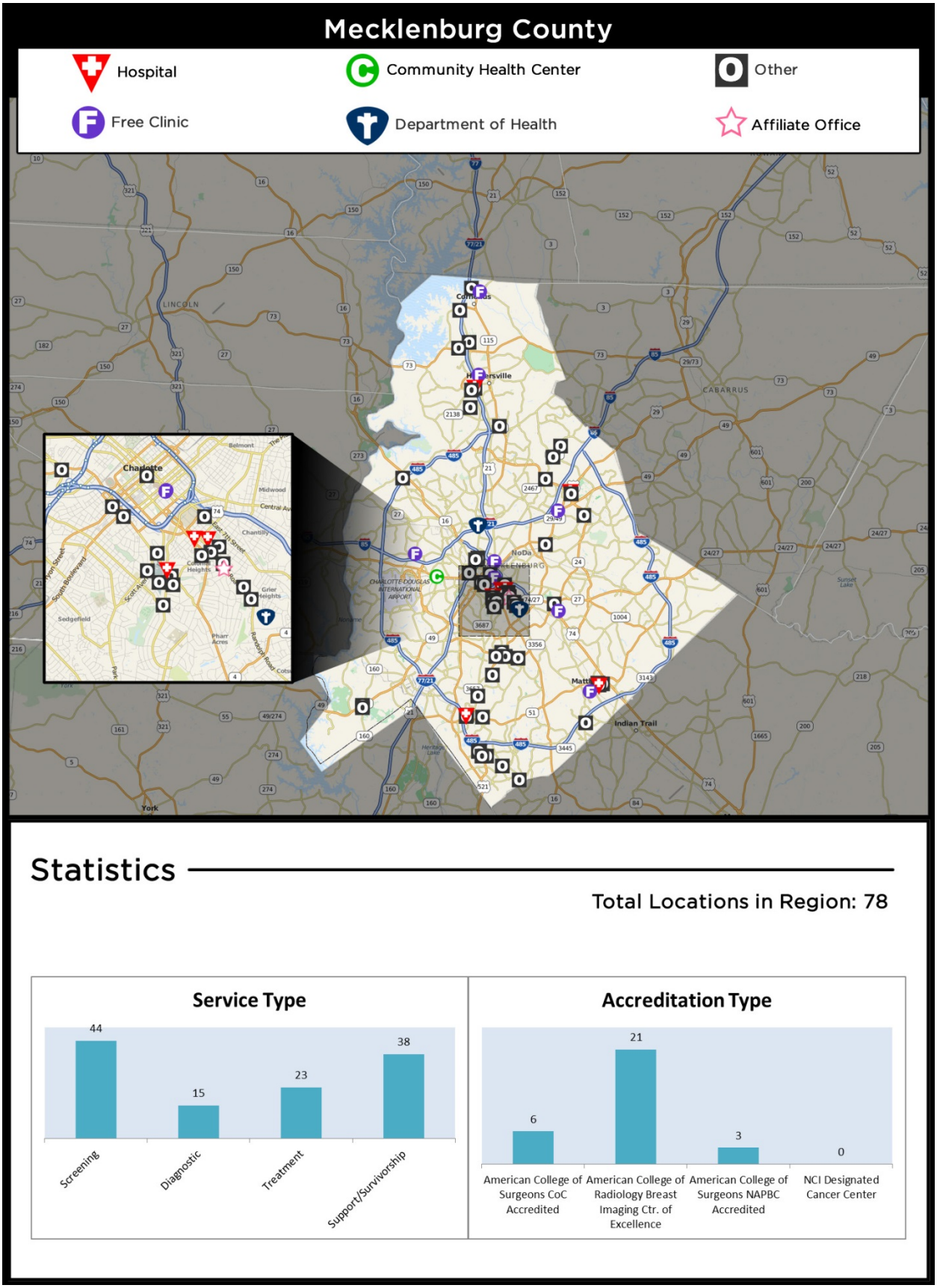


Figure 3.3. Breast cancer services available in Mecklenburg County

Public Policy Overview

National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

Federal legislation in 1990 authorized the US Centers for Disease Control and Prevention (CDC) to provide state grants to fund breast and cervical cancer screening services to underserved women who meet specific poverty and age guidelines. In addition, ethnic minorities received preference because of higher incidence of and/or death from these cancers. The states agreed to provide non-federal cash or in-kind contributions for the program as well.

In 2000, the US Congress passed a bill allowing states to provide medical assistance through Medicaid to eligible women diagnosed with breast cancer who used NBCCEDP funds for screenings (“Breast and Cervical Cancer Prevention and Treatment Act of 2000”, 2013).

North Carolina Breast & Cervical Cancer Control Program (NC BCCCP)

The NC BCCCP program is available to uninsured or underinsured women age 40-64 and have a household income that is 250 percent of the federal poverty level or less and are not covered by Medicare Part B or Medicaid ("Breast and Cervical Cancer Control Program", 2014).

The NC Department of Health and Human Services designates entities such as county health departments, hospitals and clinics as NC BCCCP providers. The providers determine eligibility. On average, more than 16,000 women in NC received free or low-cost breast and cervical cancer screening through the program. NC BCCCP funding amount covers than less than 8 percent of those eligible.

In NC, women must meet NC BCCCP requirements and be referred to a local NC BCCCP provider *before* diagnosis to be eligible for Breast and Cervical Cancer Medicaid ("Breast and Cervical Cancer Control Program", 2014).

South Carolina Breast and Cervical Cancer Early Detection Program

In South Carolina, the Best Chance Network (BCN) provides free screening for women between the ages of 47 and 64 who are uninsured or underinsured and have a household income at or below 200 percent of poverty level. The CDC funds BCN for the NBCCEDP. The American Cancer Society and the SC Department of Health and Environmental Control coordinate BCN services. Providers include more than 200 entities, including federally funded primary care centers, private physicians, clinics and others.

In July 2005, the state legislature appropriated additional funding to expand Medicaid coverage for treatment. This covers women diagnosed with breast cancer who are under the age of 65, not enrolled in the BCN program and who meet the income and insurance guidelines (“Best Chance Network”, 2014).

Komen Charlotte and BCCCP

Federal and state funding is insufficient to meet the breast cancer screening and treatment needs of the state’s eligible population. Komen Charlotte partners with local BCCCP providers in many ways to best meet the community need (Table 3.1). Komen Charlotte’s community health grants in its 13-county service area become a lifeline when state and federal funds are no longer available, and when women and men do not meet the program requirements for BCCCP.

Table 3.1. BCCCP providers in Komen Charlotte's 13-county service area

County	BCCCP Provider
Anson	None (refers to neighboring county)
Cabarrus	Cabarrus Health Alliance
Cleveland	Cleveland County Health Department
Gaston	Gaston County Health Department
Iredell	None (refers to neighboring county)
Lincoln	Lincoln County Health Department
Mecklenburg	Mecklenburg County Health Department
Montgomery	Robeson Health Care
Richmond	Richmond County Health Department
Rowan	None (refers to neighboring county)
Stanly	Stanly County Health Department
Union	Union County Health Department
York, SC*	Best Chance Network

*All counties are in NC unless noted ("Best Chance Network", 2014; "Breast and Cervical Cancer Control Program", 2014).

Komen Charlotte maintains an effective working relationship with BCCCP officials through meetings, telephone and email. That relationship will strengthen as Komen Charlotte and BCCCP work together to address potential changes with the implementation of the Affordable Care Act.

North Carolina Cancer Control Coalition (NCCCC)

NC has three components to its coalition: the Advisory Committee on Cancer Coordination and Control, NC Cancer Partnerships and the NC Comprehensive Cancer Control Program.

The Advisory Committee is appointed to identify limitations and problems of existing cancer control related laws, regulations, programs and services, to recommend a plan for statewide implementation of the comprehensive and coordinated cancer control program (NC Comprehensive Cancer Control Plan), and to examine financing and accessing cancer control services for NC citizens. The NC Comprehensive Cancer Program uses the CDC Comprehensive Cancer Control model and aims to reduce the burden of cancer through reducing cancer risk, finding cancer earlier, improving treatment and increasing the number of survivors. This program forms partnerships with community organizations to carry out the cancer plan, oversees cancer issues that focus on six cancers and provides evaluation services, epidemiology reports and consultation.

Breast cancer objectives for the North Carolina Comprehensive Cancer Control Plan 2014-2020 are as follows:

- Reduce the death rate in women due to breast cancer from the current 21.4 deaths per 100,000 to 16.8 deaths per 100,000 by 2020.
- Reduce the rate of stage III and IV breast cancer in women from the current 46.3 incidents per 100,000 to 40.9 per 100,000 by 2020.
- Increase the percentage of women over age 50 who have had mammograms within the past two years from 79.4 percent to a higher percentage yet to be determined.

("A Call to Action: North Carolina Comprehensive Cancer Control Plan", 2014)

Komen Charlotte attends meetings of the NCCCC and participates in the coalition's subcommittees. Through the network and relationships with other Komen NC Affiliates, Komen Charlotte has helped initiate expansion of partner organizations throughout NC.

South Carolina Cancer Alliance

South Carolina Cancer Alliance's (SCCA) mission is to reduce the impact of cancer on all people in SC. The SCCA is made up of a coordinating council and staff members.

In its 2010 Cancer Report Card, SCCA highlighted 2008-09 advocacy efforts by the American Cancer Society and Susan G. Komen to obtain $2 million in the state budget to expand breast and cervical cancer screening to 9,000 low-income, uninsured women, considerably supplementing the number of women screened through USCDC funds ("South Carolina Cancer Report Card", 2010).

SC Cancer plan goals are to reduce breast cancer deaths in South Carolina through increased awareness, early detection and diagnosis and to reduce the burden of breast cancer in SC through high quality cancer treatment. Breast cancer objectives for the South Carolina Comprehensive Cancer Control Plan (2011) are as follows:

- To secure recurring state funding for breast and cervical cancer screening through the Best Chance Network program
- To increase from 83.6 percent to 86 percent the proportion of women age 40 and older who have received a clinical breast exam within the preceding two years
- To increase from 74.5 percent to 80 percent the proportion of women age 40 and older who have received a mammogram within the preceding two years
- To reduce the gap in late-stage diagnosis of breast cancer between European Americans and African-Americans from 17.2 percent to 13.8 percent
- To increase by 20.0 percent the percentage of women with non-metastatic breast cancer who receive surgical resection
- To increase by 20.0 percent the percentage of women under age 70 who receive breast-conserving surgery and radiation therapy within 365 days of their diagnosis
- To increase by 20.0 percent the percentage of women under 70 with American Joint Committee on Cancer (AJCC) T1cN0M0, or Stage II or III hormone receptor negative breast cancer for whom combination chemotherapy is considered or administered within 120 days of their diagnosis
- To increase by 20.0 percent the percentage of women with AJCC T1cN0M0, or Stage II or III hormone receptor positive breast cancer for whom Tamoxifen or third generation aromatase inhibitor is considered or administered within 365 days of their diagnosis
- To increase by 20.0 percent the percentage of patients receiving lumpectomy instead of mastectomy when appropriate ("South Carolina Cancer Control Plan 2011-2015", 2011).

Komen Charlotte joined the SCCA and plans to attend the yearly meeting and stay up to date with current events through email correspondence. Komen Charlotte will be leveraging relationships through the coalition in order to further the Komen mission through breast health education and outreach.

Affordable Care Act

The Affordable Care Act (ACA) as passed in 2010 would extend health insurance coverage to millions of nonelderly, uninsured people and would aim to protect consumers, improve quality

and lower health care costs. In North Carolina, before the ACA implementation, the uninsured population numbered approximately 1.6 million, according to the Kaiser Foundation ("How Will the Uninsured in North Carolina Fare Under the Affordable Care Act?", 2014). In South Carolina, approximately 778,101 individuals were uninsured before the ACA implementation ("How Will the Uninsured in South Carolina Fare Under the Affordable Care Act?", 2014).

To provide health care coverage under the ACA, states would expand Medicaid eligibility to all low-income individuals (138 percent of the federal poverty line), provide an insurance marketplace, and employers with 50 or more employees would offer health insurance coverage to full-time employees. In 2012, the US Supreme Court ruled that states had the option to expand Medicaid (North Carolina Hospital Association, 2014). Medicaid is the long-standing, government-funded program that pays the medical expenses of low-income residents who fit eligibility categories (pregnant women, children under 19, elderly older than 65 or disabled). Individuals above 100 percent and below 400 percent of the federal poverty line would also be eligible to receive insurance subsidies when purchasing through the Insurance Marketplace based on income. As of January 2014, citizens and residents will pay a penalty if they do not have qualified health insurance from any of the above sources, unless they are exempt ("Qualifying for an Exemption from Health Insurance", 2014).

Coverage Gaps in NC and SC

North Carolina and South Carolina chose a federally facilitated health insurance marketplace and did not choose to expand their Medicaid programs. This created "coverage gaps" in both states. Individuals in the coverage gap have an income below the lower limit to receive insurance subsidies (100 percent of the federal poverty line), and will most likely not have insurance coverage. These individuals will not need to pay the penalty ("The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid – An Update", 2015).

Although it did not expand Medicaid, SC has implemented the "Healthy Outcomes Plan" (HOP) to coordinate care for the chronically ill, uninsured and high users of emergency departments. All 58 acute care hospitals and emergency departments submitted a HOP and were approved (SC Institute of Medicine & Public Health, 2014).

According to the Kaiser Family Foundation, NC's coverage gap contains about 319,000 uninsured individuals. In SC, 194,000 individuals are estimated to be in the gap ("The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid – An Update", 2015).

In addition to those ineligible for expanded Medicaid in NC and SC, other groups are unable to receive financial assistance for health benefits under the ACA, yet inevitably will require health care services, including undocumented immigrants. Since the first marketplace enrollment ended in March 2014, an estimated 702,524 South Carolinians (SC Institute of Medicine & Public Health, April 2014) and an estimated 1,184,409 North Carolinians are still uninsured. Future marketplace enrollment periods will be available on a yearly basis (North Carolina Hospital Association, 2014). In 2015, the US Supreme Court ruled federally facilitated marketplaces are still eligible to award individuals insurance subsidies (Liptak, 2015).

Implications of the ACA
As of August 2014, it is difficult to project its effect on health providers and health funders. At this point, neither NCBCCCP officials nor health care providers have sufficient operating data under the ACA to make evaluations.

Provisions of the ACA relating to breast cancer care include the following ("Preventive Services Covered Under the Affordable Care Act", 2012):

- Eliminates cost sharing for breast health preventive care
    - No cost sharing (co-pays) on the following preventive services* provided by Medicare and all new insurance plans. This does not necessarily apply to grandfathered insurance plans (already existing March 23, 2010).
        - Screening Mammography every 1-2 years for women over 40
        - Chemoprevention counseling
        - Genetic counseling
- Individuals with pre-existing conditions cannot be denied coverage and cannot be charged more
- No annual or lifetime limits on essential health benefits for all new plans and most grandfathered plans ("Rights & Protections", 2014).
- All new health plans must cover routine patient care costs in connection with clinical trials and cannot deny participation in approved trials ("Affordable Care Act Provision Requiring Insurance Coverage of Clinical Trials", 2014).

As ACA operating data becomes available, Komen Charlotte will determine whether priorities in its community health grant programs and education/outreach need to change. Komen Charlotte will continue as a leader in breast health information and services in its 13-county service area in two states with substantial health insurance coverage gaps.

Affiliate's Public Policy Activities
Komen Charlotte continues its active support of public policies that benefit breast cancer patients. For example, advocacy efforts have focused on introduction and passage in North Carolina of House Bill 609 (HB 609), the Cancer Treatment Fairness Act. The Act would ensure all chemotherapy, whether intravenous or oral, would be accessible and affordable to cancer patients.

When relevant committees held hearings on the issue in the spring of 2013, Komen Charlotte public policy advocates visited numerous state legislators and staff members to spread awareness of the need to eliminate the disparity in co-pays between chemotherapy by injection and chemotherapy by pill. In April of 2015, Komen Charlotte staff and public policy advocates again met with legislators and staff members this time on Capitol Hill to educate and emphasize the importance of the Cancer Treatment Fairness Act.

Medical plans cover intravenous chemotherapy, while prescription drug plans cover oral chemotherapy and typically require high out-of-pocket costs that can prevent patients from receiving the treatment deemed most appropriate by their physician. As introduced in 2013, the Act would authorize co-pays for oral chemo with a $100 cap. Forty states and the District of Columbia have enacted oral chemo parity legislation with either zero co-pays or co-pays no higher than $100.

Under the leadership of Komen Charlotte, all five NC Susan G. Komen Affiliates generated emails and phone calls from their boards of directors, grantees and advocacy ambassadors to urge NC legislators to support the Cancer Treatment Fairness Act. Together, the NC Komen Affiliates have been working with a strong coalition including the American Cancer Society's Cancer Action Network, the Leukemia & Lymphoma Society, the NC Oncology Association and others committed to the legislation (Weason, 2015).

During the 2013 legislative process, however, a higher $300 cap replaced the $100 cap in the House legislation that passed. Anything more than $100 can be detrimental to the patient, as higher caps are associated with medication/prescription non-adherence and ultimately worse health outcomes (Prime Therapeutics, 2012). Therefore, in 2015 Komen and coalition efforts have targeted Senators to pass a bill that would contain a co-pay cap no higher than $100. As of May 2015, the Cancer Treatment Fairness Act in NC was passed in the House of Representatives and was referred to the Senate Committee on Rules and Operations.

Komen Charlotte and its sister NC and SC Affiliates also monitor the state's budget to ensure legislators do not cut funding for the Breast & Cervical Cancer Control Program, which provides mammograms and treatment for women not eligible for Medicaid.

Ongoing public policy activities in NC and SC include providing information to local, state and federal legislators on Komen Charlotte community grants, major findings of the Community Profile and breast cancer research grants awarded through Komen Research Programs. Komen Charlotte will work with NC and SC Affiliates to collaborate on advocacy efforts in the future.

Health Systems and Public Policy Analysis Findings

All stages of the CoC are represented in Cabarrus and Mecklenburg Counties. Though the analysis indicates that services are available, substantial barriers are most likely present and contribute to the high late-stage diagnosis and death rates. Specific barriers will be examined during the qualitative analysis and will lead to the development of the Affiliate Mission Action Plan.

Based on findings in this Community Profile, 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 North Carolina's recently decreased allocation for state BCCCP funds. Fortunately, Komen Charlotte and its sister NC 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 a statewide coalition of the American Cancer Society and other cancer-related organizations, Komen Charlotte will continue to advocate for passage of HB 609, the Cancer Treatment Fairness Act.

The Affiliate will continue to further develop and maintain partnerships with clinics, breast cancer nonprofits, BCCCP providers and the cancer coalitions. The Affiliate will work to ensure relationships are maintained with all organizations providing services along the CoC.

Qualitative Data Sources and Methodology Overview

Methodology

Following the health systems and public policy analysis, 16 key informant (KI) interviews and four focus groups were conducted to seek necessary information from residents, breast cancer survivors and the health care community in Cabarrus and Mecklenburg Counties. KI interviews focused on health care provider perspectives. Through focus groups, emphasis was placed on further exploring findings from KI interviews to gain insight regarding breast health from survivors and the general population of the target areas. The focus groups and the KI interviews also afforded an opportunity to explore information about residents' attitudes, beliefs and practices related to breast health care. In addition, the focus groups and KI interviews provided vital information to help identify possible reasons affiliated with the high death rate and high late-stage incidence rate in the two target areas of Cabarrus and Mecklenburg Counties.

KI interviews and focus groups were chosen as the selected data collection methods by the Community Profile (CP) Team for the following reasons. Both methods allowed the CP Team to gain necessary in-depth knowledge into the areas and variables in question. They also allowed informants to clarify issues as needed and offered the opportunity for the Affiliate to build new relationships within the target communities. In addition, the CP Team chose KI interviews and focus groups because the necessary resources were available.

Fourteen key informant assessment questions targeted informants' perceptions of the factors for late-stage diagnoses; demographics prone to these diagnoses; changes in local, state and national events that have affected the ability to access care; current programs and resources available for breast health information within each respected county; and programs and steps necessary to reduce the incidence of late-stage diagnoses and deaths.

Informed by KI interview results, scientific articles, consultant recommendations and sample questions from the Susan G. Komen Community Profile guide, the qualitative data experts and key members of the CP Team created a script and questionnaire for use during the focus group sessions. The interview guide for all focus groups consisted of primary questions and guided sub-questions structured to probe additional information. The focus groups included the following question types: Mecklenburg general population group, 15 open-ended questions; Mecklenburg survivor group, 19 open-ended questions; Cabarrus general population group, 13 open-ended questions; and Cabarrus survivor group, 17 open-ended questions. The purpose of these questions was to learn about the perceptions, beliefs and experiences which may prevent or encourage women to seek breast cancer screenings and treatment.

The KI interview data were collected by Affiliate staff with assistance from a University of North Carolina at Charlotte (UNCC) graduate student. The interviews were audio recorded and saved using a free audio recording program on the Internet. In conjunction with the audio recording, an Affiliate staff member or the UNCC graduate student took notes during the interview. The recordings and notes were sent to the qualitative data consultants to review and create both detailed and summary reports from the data. One of the qualitative data consultants moderated

the focus groups. The focus group data were recorded on videotape by a professional videographer and was coded, analyzed and summarized by the qualitative data consultants.

Sampling

For the KI interviews, the population of interest was breast health care providers and educators in Cabarrus and Mecklenburg Counties. Key informants were selected through purposive sampling which allowed the CP Team to select participants from all segments of the CoC. To capture a wide range of perspectives from the health care field, 16 one-on-one interviews were conducted with health care providers. In Cabarrus County, nine health care providers were selected from a variety of clinics, practices and medical facilities. Within Mecklenburg County, seven health care providers represented Novant Health, Carolinas HealthCare System and additional clinics and service providers.

For the focus groups, the target populations in Cabarrus and Mecklenburg Counties were breast cancer survivors and women ages 20 and up — referred to throughout this section as 'general population.' In each county, one focus group for survivors and one general population focus group were conducted. Participants were recruited via phone, using the existing Komen Charlotte database. Snowball sampling was also used for recruitment of participants through distribution of flyers and emails sent throughout the community to partners and constituents. Emails sent to partners were forwarded to the appropriate target populations. These emails and flyers extended the opportunity to reach a more diverse population through schools, community organizations, providers and partners.

A total of 35 females participated in the focus groups. There were a total of 22 participants within Mecklenburg County with 10 identifying as breast cancer survivors, 15 Black/African-American females, and seven White females. Within Cabarrus County, there were 13 female participants with three identifying as breast cancer survivors, six Black/African-American, four White, one Hispanic/Latina, and one Asian/Pacific Islander. A participant screener was used to determine eligibility for participation in the focus groups. Target sample selection included 12 participants for each focus group in each county in hopes of obtaining eight to 10 participants and a mix of education, income, race, ethnicity and ages over 20. General population focus groups excluded men and residents outside of respective counties. Survivor focus groups excluded non-breast cancer survivors, those diagnosed more than 10 years prior and survivors living outside of the respective counties. Survivors who were diagnosed more than 10 years prior may not have experience with the current health care system. The rationale for targeting these demographics was to obtain a wide array of perspectives across socio-economic status and to include cultural and ethnic diversity within Cabarrus and Mecklenburg County focus groups.

Ethics

Before the KI interviews were conducted, consent to record and use data were obtained in the form of a written agreement from all KI interviewees. In addition, before the focus groups were conducted, consent to video record and use all data were obtained in the form of a signature on the respondent sign-in/sign-out sheets. Confidentiality agreements were obtained from all individuals who helped with interview notes and transcription, staff and consultants working with the CP qualitative data.

Confidentiality and anonymity of the data was kept in a variety of ways. KI interviews were recorded by cell phone and a conference recording system. The conference calls were protected by a host security code and participant count to ensure only the facilitator and interviewee were on the secure lines. Access to the online account is protected by username and password provided only to Affiliate staff on the CP team. The recordings were coded to protect anonymity on the online account and will be deleted upon completion of the 2015 CP process. Individuals who transcribed recordings deleted data after transferring the data to the Affiliate database. Recordings and transcriptions were kept on a secure password protected computer and only shared with qualitative data consultants. Recordings and transcriptions were labeled with a number that was assigned to each interviewee to de-identify the data. Qualitative data consultants submitted all recordings and transcriptions to Komen Charlotte after analysis was complete.

Focus groups were video recorded by a videographer and only two copies of the data were produced. One copy was given directly to the Affiliate and one copy was used by the qualitative data consultants to analyze, code and draw conclusions. These copies were kept in locked offices. All copies were given to Komen Charlotte and kept in a locked office once the data were analyzed. All qualitative data notes, recordings and participant information will be kept in a locked office by the Affiliate until the 2019 CP is initiated.

Qualitative Data Overview

Komen Charlotte used a variety of formats to collect the original data including verbatim transcripts, interview notes and audio and video recordings. Two qualitative data consultants were contracted by the Affiliate to provide their expert services. Their services included assistance with development of the KI question guide, KI interview data analysis, assistance with the focus group screener and discussion guide, facilitating and managing the focus groups, and coding/analyzing the focus group data.

Themes from the KI interviews and elements of the CoC were used to create the focus group discussion guide. A transcriber provided the qualitative data consultants with summary notes of the focus groups after viewing the video recordings. The qualitative data consultant then used the notes and his facilitation skills while moderating the groups to summarize the data. The notes were “time stamped” so he could go back to specific places in the video recording to provide additional context or amplification on the comments.

The KI interviews were accompanied by notes and audio recordings. The qualitative data consultant who worked on this summary report first organized the responses by question and by county. He then developed a list of topics looking specifically for factors that contribute to late-stage incidence rates and death rates, as well as recommendations for addressing these issues. Sections of the notes were coded and the search function in Microsoft Office Word was utilized to identify key words and phrases.

A summary report and interview transcripts from the KI interviews were provided to the Affiliate, as well as the summary report and video recordings from the focus groups. Both summary reports and transcripts were utilized by the Affiliate to identify key themes (recurring statements/ideas) within each county.

Several themes highlighting potential factors for high late-stage diagnosis and death rates within Cabarrus and Mecklenburg Counties emerged throughout the KI interviews and focus groups. The predominant themes that arose were knowledge, access to care, systematic barriers in health care and low priority for preventive care. Figure 4.1 below summarizes the themes, subthemes and relationships among each. Relationships stem from the original section color affecting the connecting subtheme.

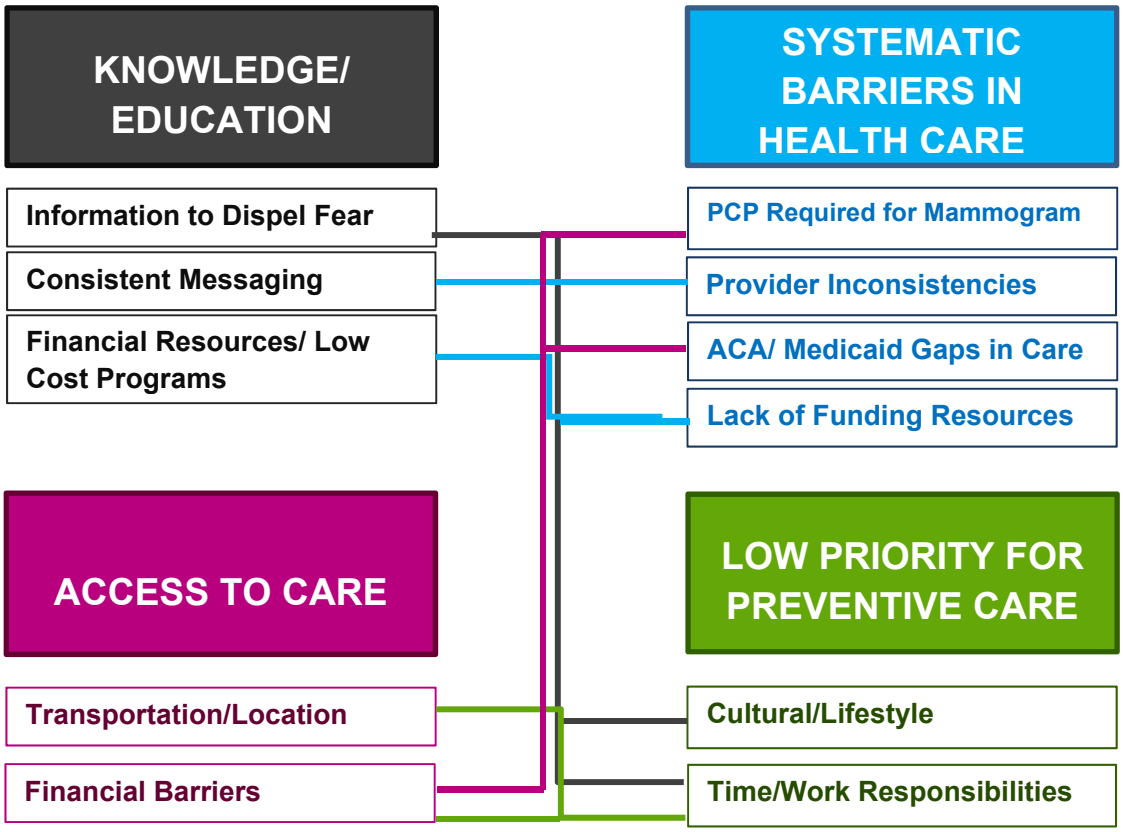


Figure 4.1. Factors in high late-stage diagnosis and death rate

Knowledge

There was a consensus among the four focus groups, as well as in the KI interviews, for the need to promote awareness and knowledge of breast cancer prevention throughout the year. Suggestions for year-round messaging included: availability of financial resources and low-cost programs, consistent recommendations for screenings, general information regarding breast cancer and procedures to dispel fear, and appropriate venues and language for educating community members. Participants felt the overall lack of knowledge of the disease was a factor for the high death rate within Cabarrus and Mecklenburg Counties.

Cabarrus County health care providers expressed concern for the lack of knowledge where women can get screened stating women do not realize they can get mammograms free of charge. Focus group participants also said many women are unaware of these available programs. It was stated that some Cabarrus County health care providers serve 30.0 to 60.0 percent undocumented Hispanic/Latina patients at their facilities, thus demonstrating the importance of language appropriate education. Mecklenburg County survivor group participants

expressed that some women avoid getting mammograms because there is no point in having them since they do not have the resources to pay for medical screenings and treatment. One participant responded that even though there are resources to help with costs, many women do not always know where to find the resources. A Mecklenburg County health care provider stated, "*For the underserved population there is definitely a health literacy problem; once again, the lack of affordable care for them. Some of the patients that I may screen for services haven't had a mammogram in years because they don't have a doctor; it's not a priority for them.*" While many health care providers felt the death rate is related to a lack of early detection, one health care provider went further to say, "*The community needs to embrace preventive care.*" She expressed that overall, there is a need to demonstrate the importance of preventive screening, educate on where and how to locate resources and how to navigate the health care system.

Consistent recommendations for screenings was another concern raised by Cabarrus County focus groups and both Cabarrus and Mecklenburg county key informants. Participants noted contradictory information regarding protocols related to when and how often women should receive mammograms. This information adds to the confusion regarding screening expectations. An example provided (referencing the US Preventive Services Task Force Screening Guidelines) was "*government propaganda*" on television promoting breast health screenings beginning at the age of 50 which contradicts the recommendations of Susan G. Komen, the American Cancer Society (ACS), and many health care providers in the Komen Charlotte service area who recommend starting screenings at age 40, if at average risk. Focus group and KI interview participants suggested that such inconsistencies may lead to a lack of trust within the health care system.

One health care provider stated, "*There's still some distrust among certain communities and stigma about research and health care in general. I would say key factors include distrust of the whole system, or ignorance of the whole system, and what they culturally believe*." In the Mecklenburg County general population focus group, one participant said she had some concerns about the level of exposure from radiation over time from mammograms. The lack of consistent and accurate information about mammograms is considered by these women as troublesome. Another Mecklenburg participant stated, "*I think [women avoid tests] because they think it's going to hurt*." This idea was consistent within Cabarrus County as well. A health care provider stated, "*A lot of [women] may be afraid to do it, that it may hurt them or a lot of them don't know that that's what they're supposed to do. They've never really been under a doctor's care and don't know what normal health screenings are supposed to be*."

Trust among the Black/African-American and Hispanic/Latina communities was also a prevalent issue found within the qualitative data. Multiple Cabarrus County participants and healthcare providers discussed the large Hispanic/Latina population, most of whom are undocumented, do not have health care, and/or may have stigmas around the health care system. A Cabarrus County participant stated, "*There is a hesitation to give out personal information for fear that it would not be used correctly. You have to try and win their trust when it comes to health care*." Undocumented residents fear their undocumented status will be discovered and this could have life-changing consequences.

Within Mecklenburg County, participants noted there are family and generational issues when it comes to seeking medical care within the Black/African-American community. Some Black/African-American women do not visit doctors because it was not common among family

elders. Also, due to religious beliefs, some women say they will "*pray [the cancer] away*." All focus group participants agreed fear and denial from a lack of trust, lack of education or cultural beliefs are primary reasons why women avoid mammograms. One Cabarrus County participant expressed the, "*fear of knowing, fear of finding out*." Another woman expressed, "*people hear things and read things that are not correct, sometimes fear of radiation, sometimes money.*" It was suggested that education through language-appropriate print materials and having screenings at locales of comfort may help to dispel myths and alleviate the fear of breast health screenings. Cabarrus County participants suggested educating at churches, employers and community centers. Mecklenburg County participants recommended consistent, year-round messaging at high schools and stressed the importance of *"getting in front of African-American women where African-American women go, and that is church*."

In summary, focus group and KI interview participants felt more education is needed on what breast cancer is, what happens for someone who does get breast cancer, the available resources and the importance of early detection. These are all essential as the increase in the chance of survival is greater when cancer is detected early rather than when the patient puts off screening because of fears or other barriers. "*More education, encouragement for women, dispelling the fear, making it easy to get to and not cost prohibitive; using media, churches, anything you can, you don't know what's going to connect with that woman*," said one Mecklenburg County health care provider in response to increased education to combat late-stage incidence and death rates.

Access

While multiple barriers to access were noted, transportation and finances were recurring themes throughout focus groups and KI interviews within both Cabarrus and Mecklenburg Counties. Participants acknowledged the potential lack of transportation among lower income individuals within both counties. Although transportation was discussed as a barrier among both counties, it is important to differentiate between the transportation limitations faced by residents of each county.

First, due to the high rate of Hispanic/Latina residents within Cabarrus County, it was suggested that many of the female residents may not have a car and, therefore, are limited to public transportation options making it difficult to utilize health care services. Focus group participants noted there is a lack of good public transportation in Cabarrus County which still consists of rural, outlying areas. One participant stated that bus schedules in Cabarrus County are not convenient, and cab fares can be quite expensive. Cabarrus County health care providers echoed this concern by sharing that for women with limited financial resources, transportation may be difficult enough to discourage them from pursuing medical services. One Cabarrus health care provider felt "*the transportation issues to get from one of the outlying areas to Concord can be a little daunting.*" Another provider shared that the *"biggest barriers are that it's difficult to get here. [Some] women find it difficult to get here or don't even bother because it's too far. People, who don't have gas money or a vehicle, may need to ride the bus for 30 minutes or an hour and a half*."

One health care provider believes they are likely reaching two thirds of the county not including outlying areas. In the survivor focus group, none of the three participants indicated any barriers to obtaining breast cancer screenings. One survivor noted that "*there was a breast imaging mobile unit that came to the office every three months,*" and another pointed out there is value in

getting the test done at a consistent location, "*I learned you should go back to the same place as your previous test (mammogram) so they have something to compare the new test to*." These women saw benefit in providing free screening services via a mobile mammography unit.

Transportation was a noted barrier to access within Mecklenburg County primarily by health care providers. One provider shared, *"[patients] don't show up for appointments because they don't have transportation…so compliance is an issue even if we've got a pathway to get a treatment they need*." Another Mecklenburg County health care provider stated, "*I'm amazed what a big issue [transportation] is for a lot of people, practical things you wouldn't think would be such barriers.*" Among the focus groups, one participant noted, "*Providing accessibility to mammograms via mobile units would help some members of the community*." Even with public transportation available, it can still be burdensome and prevent patients from seeking or continuing medical services, thus participants feel mobile mammography units may provide convenience and help encourage women to get screenings.

Focus group participants, as well as breast health care providers in both counties, expressed concern regarding the financial barriers women face especially in underserved populations. One provider talked about the impact of income on whether or not a woman will get a mammogram. She brought up the point that if the woman only has enough money for basic essentials such as food, she will choose food over paying for a mammogram. This subtheme emerged a number of times in the qualitative data. Within Mecklenburg County one participant noted that, "*Some African-American women feel like they don't have the resources to treat the disease, so there is no point getting the test done*." For low-income individuals the cost for getting mammograms is an issue. Even with insurance, some people still cannot afford necessary examinations. There was general agreement that screenings should be free.

Cabarrus County focus group participants also felt that cost is a factor in getting a mammogram. They agreed the lack of insurance, the high co-payments and the deductibles contribute to this factor. Key informants shared that there is a "*high rate of uninsured residents within the county and people do not get regular checkups due to being uninsured along with other financial barriers. By the time the patients do come in, they are in the later stages.*" A focus group participant noted, "*Individuals who do not have access to a primary care physician [because of lack of finances and/or insurance] have nowhere to send their medical tests such as a mammogram.*" Another provider shared that within the Hispanic/Latina community, most residents do not have a primary care provider (PCP) which is needed in order to receive a free mammogram. (The need to have a PCP for referrals and interpretation of screenings is discussed further under systematic barriers to health care.) While the large population of Hispanic/Latina women in Cabarrus County was mentioned by several focus group and KI interview participants, multiple health care providers also mentioned these women may not be eligible for available resources because of their legal status in the US. Undocumented residents cannot obtain insurance which makes it more difficult for these patients to get care. One provider in particular expressed her concern for the lack of resources available for undocumented female residents diagnosed with breast cancer. She stated that these individuals are most likely referred to hospital charity care programs, and she is unsure of the quality of care that they will ultimately receive.

It is also important to note that the barrier to access for the large population of homeless people in Mecklenburg County was mentioned twice throughout the focus groups; however, this was

not a prominent theme. One participant who once worked for the prison system noted that in her experience individuals who are incarcerated or homeless do not have access to mammograms. Another participant shared her experience with being homeless and the limitations that she felt in communicating her concerns with her physician.

It was mentioned within Cabarrus County that families are still recovering from the loss of their jobs. A health care provider stated, "*A major factor has been the loss of employers and jobs in the area. Many people lost their jobs at Cannon Mills and Phillip Morris along with benefits and insurance*." For those who do have jobs, work responsibilities can serve as a barrier. Trying to find a time to schedule an appointment and request time off from work can be challenging. A Cabarrus County health care provider acknowledged this barrier but shared that although "*women are busy, we have extended hours at our breast health centers to allow women to schedule a mammogram before or after work*." Another provider stated, "*Many people are trying to maintain their jobs as they go through treatment so they must balance work with time off*." The qualitative data analysis suggested some low-income women circumvent breast cancer screenings due to the cost of screenings and cancer treatments, if diagnosed. Financial barriers may include the lack of adequate health insurance, the overall expenses of cancer treatment and the need to balance work schedules and medical appointments.

Systematic Barriers in Health Care

A variety of systematic barriers in the health care system were identified in the qualitative data analysis including provider inconsistencies, requirement of a PCP before obtaining a mammogram, implications of the ACA/gaps in care and a lack of resources. These factors were identified in both the KI interviews and focus groups in both Cabarrus and Mecklenburg Counties.

Provider inconsistencies identified included information regarding the age to begin mammogram screenings, even within the same hospital system, and the lack of a clinical breast exam from a PCP, except when requested (noted by two focus group participants). One health care professional revealed that, *"there is a bit of confusion with some physicians I have spoken with where the guidelines of when they have to have a mammogram is starting at forty, [some others] might say you have to start at fifty and something our hospital is working on right now is trying to set those guidelines across the board for our physicians so that we are all on the same page and send the same message to patients. There's a lot of mixed messages from media as well that say you do not need a mammogram at 40*." In addition, it was noted some providers advise women to discontinue mammography screenings at a certain age, even though the risk of breast cancer increases as a woman gets older. Many patients listen to their doctors and take their advice, so consistent and accurate messaging is very important. Focus group participants echoed these opinions, citing many times that mammography screening guidelines are unclear.

Prevention was identified throughout the focus groups and KI interviews as a key to reducing late-stage incidence rate and decreasing death rates. A Cabarrus County health care provider shared that prevention is the key to success which begins at the primary care level. PCP's must think about prevention and ensure clinical breast exams are being completed. Although this is important, it can only work with those individuals who have a PCP who they see on a regular basis. The PCP is needed to read the results of the mammogram for the individual and to provide a medical home for the individual if follow-up care is needed. It was mentioned throughout the KI interviews and the focus groups in both counties that the lack of a PCP is a

barrier for women getting their mammograms, even if the mammogram is free. A Cabarrus County health care provider expressed, "*If I could only do one program, I would sit down with all the community clinics to see if they could increase the number of patients that they see. This would help ensure that patients have a primary care doctor and then in return could qualify for the free mammogram*." A few health care providers mentioned it is difficult for women to understand they need a doctor before getting the mammogram.

The survivors in Cabarrus County expressed there is a need to encourage doctors to volunteer or donate their time since there are women who could obtain a screening mammogram via a mobile mammography van, but are unable to utilize this method due to a lack of a PCP. In general, the mobile mammography units are useful because they are convenient for people, but one noteworthy barrier is the need to have a PCP or OB/GYN. If the patient does not have a PCP, they cannot get their mammogram on the mobile unit.

There have been some implications of the ACA that have affected individuals in Cabarrus and Mecklenburg Counties. For example, one focus group participant said she has a friend who had to change doctors under the ACA because her original doctors were out of network. One of the health care providers mentioned this was the case with some of their hospital patients as well. As one provider said and others echoed, *"with NC not expanding Medicaid, there are a lot of people that still fall in the gap with no health care coverage. This program opened the door for some but still leaves a large number of people without the access to care that they need.*" This sentiment was also heard from other providers who said, "*We were hoping that with the ACA, more people would have insurance and would feel more comfortable coming in for routine check-ups. However, since the state of NC chose not to expand, many people fell into the Medicaid gap and, unfortunately, these people are left with no real resources*."

In some cases, a slight increase in patients has been seen, while for other providers, there have been no visible changes. In addition, some people with insurance are still unable to afford the care they need. For example, *"I've seen patients, [who] realize, 'yes I have it (insurance),' but the co-pays are huge and the out of pocket cost is so significant that it may only help them if there was something catastrophic. Now, for some it will help because if the [screening] mammogram is covered, that's good, but if there's a problem, it opens you up to diagnostic biopsy and then you've got huge co-pays*."

A lack of financial resources for additional breast health navigators, low-cost programs and clinics was addressed throughout the qualitative data. Breast health navigators were mentioned numerous times as being essential and very beneficial for patients; they assist with education, scheduling, and address issues and barriers for patients. One focus group participant did not have a navigator, and as a result her experience after diagnosis was more difficult. She had to go out to an office supply store to get folders, "post-it" notes and markers to help her track her situation. *"I felt like I needed an assistant after I was diagnosed. It would have been a lot easier to have someone like that [a navigator*]." In addition, the importance of the navigation role was also mentioned regarding compliance to treatment and recommended procedures. One health care provider (a navigator) explained what patients have told her, "*You listened, you really understood my concerns. I left with a plan. I had somebody to call if I had questions.' I feel like my role as a navigator, I navigate women into the clinic and then they stay with us for years and we do all their breast health services, that helps them stay compliant.*"

An overall need for additional funding for many areas along the breast cancer CoC was also mentioned in both the focus groups and the KI interviews. One health care provider expressed more help is needed throughout the CoC from screenings to diagnostics, biopsies, treatment and support. It was also mentioned a few times that it is more difficult for individuals in need when funding is cut for the BCCCP program, Medicaid and private/nonprofit grants. As one provider said, *"but funding is again a problem. If they're diagnosed with breast cancer and they don't have any insurance, the grant's been able to cover them for their screening and their diagnostic, then what's going to cover them for the rest of their cancer care*?" A lack of funding was also named the "*number one barrier to cancer care treatment*."

In addition to the overall lack of funding available, it was also mentioned multiple times that many free/low-cost clinics or FQHCs do not have the capacity to take on additional patients or have wait lists for people that can span months. This causes an issue of accessibility for any individual needing breast health services who does not already have a PCP or OB/GYN.

Low Priority for Preventive Care

The last prominent theme that emerged from focus groups and KI interviews was the lack of priority and time females give to preventive care. Throughout all four focus groups, reference was made to how women generally put their families first and assign a low priority to their own health needs. Several reasons cited for the low priority included family and cultural beliefs and time and work responsibilities (which could potentially be classified as a barrier to access). The emphasis given on the low priority for preventive care requires adequate consideration, even though multiple reasons and overlapping themes may play a part in the low priority.

Two Cabarrus County focus group participants stated the importance of raising women's awareness of their own health. They noted women often put their personal concerns at the end of the line while taking care of family. One said this is especially true in the Hispanic/Latina community where husbands and children come first. In many underserved populations, people are "*just so busy with their living life from day to day, making ends meet, and trying to figure out how things are going to happen, how they're going to live, preventive health care as a whole just suffers*," stated a Cabarrus County health care provider. Another provider shared, "*for the underserved population there is definitely a health literacy problem there, once again the lack of affordable care to them, some of the patients that I may screen for services haven't had a mammogram in years because they don't have a doctor, it's not a priority for them.*" As discussed earlier, the lack of priority can often be due to family and cultural beliefs passed down through family members.

In addition to family and cultural beliefs, several participants noted that people often have so many competing life priorities, that preventive care is simply not a top priority. This includes the underserved populations who may not be aware of the importance of preventive screening and also educated individuals who have the means to obtain screenings. A Mecklenburg County health care provider stated, "*It's not always who I think. I have worked with women who it's an issue of not understanding, not having the education, I see women who are incredibly bright and know they're at high risk for family history and just don't do it, are afraid, or time slips by because they're busy with life and work and don't get in to get a mammogram*." Several health care providers stated that women, regardless of their socioeconomic backgrounds, often wait until something is wrong to schedule an appointment, potentially leading to late-stage diagnosis.

Qualitative Data Findings

Cabarrus County

In Cabarrus County, many of the findings from the qualitative data collection linked back to the findings in the quantitative data report, as well as the health systems and public policy analysis. The health systems analysis addressed potential barriers related to not having a PCP. Health care providers and focus group participants confirmed this concern regarding uninsured and/or underinsured individuals not having access into the CoC because of the need to have a PCP for referral and screening interpretation. The capacity of clinics/health centers to accept new patients and the barriers related to not having a PCP were key points seen throughout the Community Profile Report.

In addition, the quantitative data and health systems analysis addressed the availability of breast health resources in underserved areas and gaps in services. This was also a common theme found throughout the focus groups and KI interviews, although participants did not directly link the availability or gaps to the rapid growth of the county. During the focus groups, it was found that some individuals who live in Cabarrus County are either referred to or choose to utilize doctors and health services in Mecklenburg County due to the lack of available service providers in Cabarrus County. For some, this referral to another county can be difficult due to barriers to transportation.

With regard to barriers to transportation, the health systems analysis outlined the available health systems, locations and transportation options available within Cabarrus County. Focus group participants as well as health care providers confirmed the barriers to transportation residents face including the financial cost, not owning a vehicle and the lack of adequate public transportation options throughout Cabarrus County. Many clinics and shelters work with mobile mammography units to ensure access to screening mammography for their clients who are primarily uninsured or underinsured. It is important to note that two of the three survivors in the Cabarrus County focus group shared they were screened through mobile units available at their employer, emphasizing how mobile mammography units increase access to screenings, especially for rural and underserved communities.

One point that came up twice in the qualitative data findings was the large percentage of individuals who are homeless. Overall, this was not a consistent theme found in the data, but the homeless population was mentioned as it relates to the populations least likely to have access to breast health services.

A prominent theme found throughout both Cabarrus and Mecklenburg Counties was the low priority for preventive health care. This was stated throughout focus groups as well as KI interviews but was not a topic considered under the quantitative data and health systems analysis. Reasons provided for potential low priority for screenings focused predominately around family and cultural beliefs, as well as time and work responsibilities. Education on accurate preventive measures, the importance of preventive health care, available resources and low-cost programs, providing more accessible screening opportunities through mobile units and worker-friendly hours, and dispelling breast cancer myths may help to promote prioritization for preventive screenings.

Mecklenburg County

Within the Mecklenburg County qualitative analysis, there were a few themes consistent with findings in the quantitative and health systems analysis sections. As mentioned in the quantitative analysis, urban counties may have higher incidence rates because of increased detection and access to care. At least one provider indicated that Mecklenburg County has the resources individuals need, but some individuals are just not aware of these resources. This could be indicative of the high late-stage incidence rate. Residents of Cabarrus County stated they were being referred to services in Mecklenburg County. While this highlights the limited access and resources for Cabarrus County residents, this demonstrates the capacity to meet more needs of residents within Mecklenburg County.

While transportation systems were noted as a potential barrier in the health systems analysis, it found that bus lines run to all major hospital systems. There were few instances noted in the qualitative data with regard to transportation barriers. Financial barriers included lack of insurance or adequate coverage and the overall expenses of breast health screenings and treatments.

The quantitative data and health systems analysis addressed the availability of breast health resources in underserved areas and also gaps in services to residents within the priority counties. As mentioned above, there are several service providers within Mecklenburg County; however, focus group participants as well as breast health care providers, stated the need for increased education and availability of breast health resources for underserved communities, especially among the Black/African-American female population. This is consistent with the barriers to access of care and the need for education on breast cancer, procedures, and available low-cost programs/resources to gain trust and encourage underserved populations to seek preventive care and early diagnosis. The high late-stage incidence and death rate could be linked to generational hesitancy of going to the doctor, the lack of trust of the health care system and the religious beliefs of Black/African-American females. To increase the availability of breast health resources in underserved areas, Mecklenburg County participants recommended increasing accessibility to mammograms via mobile units and increasing breast health education at schools and churches.

Mentioned twice in the qualitative data findings was the large percentage of individuals who are homeless and the lack of access to care for this population. Although this was a theory for high late-stage diagnoses and death rates within the quantitative section, overall, this was not a consistent theme found in the qualitative data.

As addressed in the health systems analysis, uninsured and/or underinsured individuals may not have a PCP which can prevent them from gaining access into the CoC. Several health care providers within Mecklenburg County stated their concern for the large number of individuals without a PCP and the barrier to access this presents. Focus group participants also stated their concern about the need to first have a PCP before having a mammogram.

Limitations of the Qualitative Data

There are a number of strengths with the data sources and methods used. The KI interviews allowed for in-depth exploration of each question. The informants were given an opportunity to provide clarification when necessary, and also provided an opportunity for the Affiliate to build and strengthen relationships within each priority county. The Affiliate was provided with in-depth information regarding specific barriers, differences and possible factors contributing to the late-stage incidence rate and high death rate in each county.

The focus groups allowed the Affiliate to obtain a range of in-depth information in a short amount of time. Comprehensive and detailed data were captured in each group, as the individuals who participated spoke openly about their experiences and opinions. Throughout the focus groups, the Affiliate uncovered factors that influence the opinions, behaviors and motivation of both breast cancer survivors and the general public. These factors and findings will help Komen Charlotte determine grantmaking and Affiliate priorities going forward.

There are also a number of limitations to the data. First and foremost, due to the sheer nature of the structure of focus groups, the data cannot be generalized to the entire target population. In addition, the number of participants in each focus group was not within the best practice range of six to eight individuals. The survivor focus group in Cabarrus County had only three participants. However, the general population focus group for Cabarrus County also had three survivors, for a total of 10 participants. Recruitment for participants for the Cabarrus County survivor focus group was extremely difficult, even after the date of the groups was pushed back two weeks. Reasons for the difficulties with recruitment are unknown at this time.

The survivor focus group in Mecklenburg County was comprised of 11 women, 10 of whom were survivors. This group included one woman, not a survivor, who arrived early for the general population group and was unable to stay for that group's time slot. The general population group in Mecklenburg County also had 11 women, several of whom were also breast cancer survivors. One focus group limitation specific to Mecklenburg County was naming the exact location on the focus group flyers. This allowed two non-registered individuals to show-up for the focus groups. Because these individuals were not registered, prequalifying data including age, demographic information, employment status, and education background were not collected and, therefore, unable to be reported.

In addition, it is best practice to conduct three focus groups per priority county, and the Affiliate (due to available resources) was only able to conduct two per priority county. Overall, this report details the results of those who participated in the focus groups and KI interviews, and the data does not represent the entire population.

Limitations with the use of KI interviews include the selection of interviewees (done primarily through purposive sampling), number of interviewees, possible interviewer/interviewee bias and the difficulty again of generalizing the results to the larger population. Although the best practice for KI interviews includes 12 per target county, the Affiliate was only able to interview 16 total key informants (nine in Cabarrus County and seven in Mecklenburg County). Also, as the interviews were conducted by Komen Charlotte staff members and not trained interviewers, the potential for bias exists.

Predominate themes that emerged throughout the qualitative data collection and analysis include knowledge, access, systematic barriers in health care and a low priority for preventive care. These themes were consistent across both of the Affiliate priority counties, Cabarrus and Mecklenburg. The need for consistent and year-round breast health messaging was deemed important. In addition, it was found that there is a need to address individuals' psychological barriers such as fear and trust. Fear of the health care system, fear of the unknown, myths, pain and financial implications associated with receiving breast health services were all sub-factors under knowledge.

Access was the next theme identified which included financial and transportation barriers. Financial barriers were directly linked to access due to the large number of individuals who lack insurance or adequate coverage, and/or who do not have a primary care physician. Transportation was found to be an obstacle predominately in Cabarrus County due to its rural nature, but was also mentioned as a barrier in Mecklenburg County.

Systematic barriers in the health care system was a consistent theme across the qualitative analysis. This included provider inconsistencies with regard to screening recommendations and procedures and the need for a PCP before receiving a mammogram. In addition, the systematic barriers in the health care system included implications of the ACA (gaps in care due to NC not expanding Medicaid), and an overall lack of resources such as breast health navigators and low-cost or free breast health services to those in need.

The last theme that emerged was the low priority for preventive care. Family and cultural beliefs, as well as time constraints and work responsibilities, can contribute to the incompliance with Komen recommendations of receiving a yearly mammogram after age 40 if at average risk. In addition, many women prioritize their family first and themselves last, which can lead to delayed breast health services. Lastly, sometimes the demands of everyday life take precedent over breast health and all other health care needs.

The findings from the qualitative data section will assist with the creation of the Affiliate Mission Action Plan, which will be used for the next four years. The Mission Action Plan will drive the Affiliate's strategic plan and directly correlate with the Affiliate's grantmaking priorities and outreach efforts.

Breast Health and Breast Cancer Findings of the Target Communities

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.

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).

Based on the HP2020 benchmarks and the Komen Charlotte 2014 Quantitative Data Report, the two target communities selected were Cabarrus County and Mecklenburg County. Cabarrus County has a late-stage breast cancer incidence rate of 47.8 cases per 100,000 women and death rate of 23.1 deaths per 100,000 women. Cabarrus County will likely not reach both HP2020 goals of late-stage breast cancer incidence rate and death rate. Mecklenburg County has a late-stage breast cancer incidence rate of 44 cases per 100,000 women and death rate of 23.3 deaths per 100,000 women. Mecklenburg County may not reach the HP2020 target for late-stage incidence and will likely take eight years to reach the death rate target. Cabarrus and Mecklenburg Counties have comparable breast cancer screening percentages to the US.

These statistics led the Affiliate to gather more data on urbanization and growth rates in the area as well as other factors that may impact the ability of these counties to reach the HP2020 targets. Cabarrus County has a population growth rate of 5.1 percent, which is more than double the growth rate of the US. Mecklenburg County has a growth rate of 7.8 percent that is more than three times the growth rate of the US (Florida, 2014). Both counties are projected to continue experiencing rapid growth through 2020 (Tippett, 2013). Mecklenburg County is a large central metro county and Cabarrus County is a metro fringe county and the second most urban in the service area (Ingram DD, 2014). As noted by Hall et al. urban counties may have increased incidence rates because of higher detection and access to care (2005).

Also, Mecklenburg County has a relatively large population of Black/African-American and foreign-born women compared to the US, North Carolina (NC) and the Komen Charlotte service area. Black/African-American women, in particular, have higher late-stage diagnosis rates and death 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).

The health systems analysis looked at access to care more in depth and looked for any gaps in the breast cancer CoC. The analysis of both Cabarrus County and Mecklenburg County showed 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 women can receive a clinical breast exam as well as, establish care 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 and easier access to breast care.

The public policy section reviewed federal and state public policy efforts on breast health and breast cancer care. Both Cabarrus County and Mecklenburg County have the NC Breast and Cervical Cancer Control Program (BCCCP). Funds for the NC BCCCP program have decreased over the past decade. To continue receiving state and federal funds, the programs are restricted to serving low-income women ages 40-64 (Breast and Cervical Cancer Control Program, 2014). 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. This raised the question of how many women are not able to afford a PCP and was addressed through the qualitative analysis.

The Affordable Care Act (ACA) was passed in 2010 and aimed to extend health insurance coverage, improve health care quality, provide lower costs and protect consumers. 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). NC elected not to expand Medicaid and also 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 totals about 319,000 individuals ("The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid – An Update", 2015).

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

Komen Charlotte also participates in the NC Cancer Control Coalition. This coalition aims to meet the goals based on Healthy North Carolina 2020 targets for breast cancer and increase the percentage of women over age 50 that have had mammograms within the past two years.

Komen Charlotte participates in the prevention subcommittee and will work to help meet breast cancer related goals, especially in its service area.

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 finding out 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, which recorded survivor and general population opinions.

Consistent themes that arose in Cabarrus County and Mecklenburg County included access to care, low priority for preventive care, the need for knowledge and education and systematic barriers.

In the qualitative data, 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. This is just one example of how health care can be a low priority for individuals in need.

A low priority for preventive health care was 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.

Also, participants in 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 resource information 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 priority 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 Cabarrus County through education and services because some residents are more isolated. Komen Charlotte will continue education initiatives to the identified target populations.

Systematic barriers in relation to the ACA – lack of federal and state funding and PCP access – were also found in the qualitative data for both Cabarrus County and Mecklenburg County. 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.

BCCCP funding, as noted in the policy section is decreasing. KI interviews in Mecklenburg County reinforced the 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 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 the qualitative data; therefore Komen Charlotte will support efforts in the community to provide navigation services.

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 HP 2020 targets for late-stage incidence rates, and Cabarrus County will most likely not reach the HP 2020 target for death rates. Qualitative analysis indicated a lack of knowledge and resource availability 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 continuum of care. 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 2019, meet with at least three community-based organizations in Cabarrus County and at least five in Mecklenburg County to discuss how to prioritize prevention and address cultural and/or language barriers in the Black/African-American and Hispanic/Latina populations.
- *Objective 3:* By 2019, 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 2019, 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.

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 2019, 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 2019, 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 2019, 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 2019, 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 2019, collaborate with community-based organizations to identify at least one initiative to address transportation issues in Cabarrus County.
- *Objective 4:* From FY 2016 – FY 2019, 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.

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 2019, conduct annual meetings with at least two state legislators or local officials to increase their understanding of breast health issues and Komen Charlotte as a local resource on breast cancer.
- *Objective 2:* From FY 2016 – FY 2019, annually attend at least one NC Advisory Committee on Cancer Coordination and Control meeting(s) and/or subcommittee meetings.
- *Objective 3:* From FY 2016 – FY 2019, 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.

References

2013 Homelessness Report. (2013). Retrieved May 12, 2014, from http://www.cohhio.org/files/2013 Ohio Homelessness Report.pdf

A Call to Action: North Carolina Comprehensive Cancer Control Plan. (2014, November 9). Retrieved November 14, 2014, from http://publichealth.nc.gov/chronicdiseaseandinjury/cancerpreventionandcontrol/docs/ComprehensiveCancerControlPlan-2014-2020.pdf

Best Chance Network Provides Cancer Screening for South Carolina Women. (n.d.). *Best Chance Network Provides Cancer Screening for South Carolina Women*. Retrieved June 25, 2014, from http://www.cancer.org/myacs/southatlantic/programsandservices/best-chance-network-provides-cancer-screening-for-south-carolina-women

Breast and Cervical Cancer Control Program. (2014, March 14). *NC DPH*. Retrieved June 25, 2014, from http://bcccp.ncdhhs.gov/

Breast and Cervical Cancer Control Program. (2014, January 1). Retrieved March 10, 2014, from http://bcccp.ncdhhs.gov/eligibility.asp

Breast and Cervical Cancer Prevention and Treatment Act of 2000. (2013, November 5). *Centers for Disease Control and Prevention*. Retrieved June 25, 2014, from http://www.cdc.gov/cancer/nbccedp/legislation/law106-354.htm

Cabarrus County Transportation System, personal communication, July 10, 2014

Cancer Facts & Figures for African-Americans 2013-2014 (2013). Atlanta, GA: American Cancer Society

CATS Riders Guide, (2014). Retrieved July 2014, from http://charmeck.org/city/charlotte/cats/Bus/maps/Documents/RidersGuide.pdf

Chapman, H., Mintier, S., Goodwin, G., & Governments, C. o. (2014, May 14). Homelessness in Metropolitan Washington. Retrieved May 12, 2014, from https://www.mwcog.org/uploads/committee-documents/ZF1ZVllc20140507152952.pdf

Chau, S., Chin, M., Chang, J., Luecha, A., Cheng, E., Schlesinger, J., et al. Cancer Risk Behaviors and Screening Rates Among Homeless Adults in Los Angeles County. *Cancer Epidemiology, Biomarkers & Prevention*, *11*, 431-438. Retrieved May 15, 2014, from http://cebp.aacrjournals.org/content/11/5/431.full.pdf+html

Florida, R. (2014, March 28). America's biggest metros are growing much faster than other cities. Retrieved from http://www.citylab.com/politics/2014/03/americas-biggest-metros-are-growing-much-faster-other-cities/8746/

Hall, S., Kaufman, J., Millikan, R., Ricketts, T., Herman, D., & Savitz, D. Urbanization and Breast Cancer Incidence in North Carolina, 1995–1999. *Annals of Epidemiology*, *15*, 796-803. Retrieved May 15, 2014, from http://www.annalsofepidemiology.org/article/PIIS1047279705000591/fulltext

HP 2020. Healthy People 2020. US Department of Health and Human Services. December 2, 2010. Available online at http://www.healthypeople.gov/2020/about/ (accessed 8/2/2013).

Healthy People 2020. US Department of Health and Human Services. December 2, 2010. Retrieved May 12, 2014, from http://www.healthypeople.gov/2020/about/

How Medicaid Health Care Expansion Affects You. (2014, 25 July). *HealthCare.gov*. Retrieved August 4, 2014, from https://www.healthcare.gov/what-if-my-state-is-not-expanding-medicaid/

How Will the Uninsured in North Carolina Fare Under the Affordable Care Act?. (2014, January 6). *How Will the Uninsured in North Carolina Fare Under the Affordable Care Act?*. Retrieved August 4, 2014, from http://kff.org/health-reform/fact-sheet/state-profiles-uninsured-under-aca-north-carolina/

How Will the Uninsured in South Carolina Fare Under the Affordable Care Act?. (2014, January 6). *How Will the Uninsured in South Carolina Fare Under the Affordable Care Act?*. Retrieved June 23, 2014, from http://kff.org/health-reform/fact-sheet/state-profiles-uninsured-under-aca-south-carolina/

Ingram DD, Franco SJ. 2013 NCHS urban–rural classification scheme for counties. National Center for Health Statistics. Vital Health Stat 2(166). 2014.

Insurance Coverage for Clinical Trial Participants. (2014, March). Retrieved March 10, 2014, from http://www.asco.org/insurance-coverage-clinical-trial-participants

Job Tax Credit - County Rankings for 2015. (2015, January 8). Retrieved January 13, 2015, from http://www.sctax.org/policy/il13-19-doc

Liptak, A (2015, June 25). Supreme Court Allows Nationwide Healthcare Subsidies. *The New York Times.* Retrieved from http://www.nytimes.com/2015/06/26/us/obamacare-supreme-court.html

Mecklenburg County Board Bulletin. (2014, April 15). Retrieved February 6, 2015, from http://charmeck.org/mecklenburg/county/CountyManagersOffice/Board-Bulletins/Pages/April-15-2014.aspx

Mecklenburg County Board Bulletin. (2014, September 22). Retrieved February 6, 2015, from http://charmeck.org/mecklenburg/county/CountyManagersOffice/Board-Bulletins/Pages/September-22-2014.aspx

North Carolina Hospital Association. (2014, January 1). *NCHA: Federal Insurance Marketplace*. Retrieved July 25, 2014, from https://www.ncha.org/healthcare-topics/federal-insurance-marketplace

North Carolina Point-in-Time Count Data. (2014, January 29). *Practice: Point-in-time counts*. Retrieved May 12, 2014, from http://www.ncceh.org/PITdata/

North Carolina Rural Economic Development Center, Inc. (2014, November 1). Retrieved January 7, 2015, from http://www.ncruralcenter.org/index.php?option=com_content&view=article&id=399&Itemid=125

Preventive Services Covered Under the Affordable Care Act. (2012, September 20). *United States Department of Health and Human Services*. Retrieved July 25, 2014, from http://www.hhs.gov/healthcare/facts/factsheets/2010/07/preventive-services-list.html#CoveredPreventiveServicesforAdults

Prime Therapeutics. (2012, April). *Benefit Design Impacts Specialty Care*. Prime Therapeutics Specialty Pharmacy LLC. Retrieved from https://www.primetherapeutics.com/specialty/assets/pdf/4796_Oral_Oncology_Abandonment.pdf

Qualifying for an Exemption from Health Insurance. (2014, July 25). HealthCare.gov. Retrieved July 25, 2014, from https://www.healthcare.gov/exemptions/

Rights & Protections. (2014, January 1). *HealthCare.gov*. Retrieved August 4, 2014, from https://www.healthcare.gov/how-does-the-health-care-law-protect-me/rights-and-protections/

SEER Summary Stage. Young, J.L. Jr., Roffers, S.D., Ries, L.A.G., Fritz, A.G., Hurlbut, A.A. (eds). *SEER Summary Staging Manual - 2000*: Codes and Coding Instructions, National Cancer Institute, NIH Pub. No. 01-4969, Bethesda, MD, 2001. Available online at http://seer.cancer.gov/tools/ssm/ (accessed 8/2/2013).

South Carolina Cancer Control Plan 2011-2015. (2011, January 1). Retrieved July 25, 2014, from http://www.scdhec.gov/Health/docs/scca_cancerplan.pdf

South Carolina Cancer Report Card. (2010, January 29). Retrieved May 12, 2014.

South Carolina Central Cancer Registry. (2011, January 1). *DHEC: General Agency Information*. Retrieved March 1, 2014, from http://www.scdhec.gov/administration/phsis/scccr/scccrmain.htm

South Carolina Homeless Point in Time 2013 Results. (2013, June 13). Retrieved May 12, 2014, from http://www.schomeless.org/wp-content/uploads/2013/06/SCHC-2013-PIT-REPORT-FINAL-Post.pdf

State and County QuickFacts. (2014, March 27). Data derived from Population Estimates. *State and County QuickFacts*. Retrieved May 12, 2014, from http://quickfacts.census.gov/qfd/states/

Statistics and Reports. (2012). *NC SCHS-NC Central Cancer Registry*. Retrieved March 12, 2014, from http://www.schs.state.nc.us/data/cancer.cfm

Susan G. Komen. (2014). *Susan G. Komen Charlotte quantitative data report: 2014.* Dallas, TX: Author.

The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid – An Update. (2015, April 17). Retrieved April 29, 2015.

The Henry J. Kaiser Family Foundation (2014). How Will the Uninsured in North Carolina Fare Under the Affordable Care Act? Retrieved from http://kff.org/health-reform/fact-sheet/state-profiles-uninsured-under-aca-north-carolina/

The Henry J. Kaiser Family Foundation (2014). How Will the Uninsured in South Carolina Fare Under the Affordable Care Act?". Retrieved from http://kff.org/health-reform/fact-sheet/state-profiles-uninsured-under-aca-south-carolina/

Tippet, R. (2013, October 14). Population Growth & Population Aging in North Carolina Counties. *Carolina Demography*. Retrieved May 12, 2014, from http://demography.cpc.unc.edu/2013/10/14/population-growth-population-aging-in-north-carolina-counties/

Weason, C.(2015). NC Cancer Treatment Fairness Act. [Brochure]. Raleigh, NC: American Cancer Society Cancer Action Network