



COMMUNITY

PROFILE REPORT 2015



SUSAN G. KOMEN®
LOWCOUNTRY

Table of Contents

Table of Contents	2
Acknowledgments	3
Executive Summary	5
Introduction to the Community Profile Report	5
Quantitative Data: Measuring Breast Cancer Impact in Local Communities	6
Health System and Public Policy Analysis	7
Qualitative Data: Ensuring Community Input	9
Mission Action Plan	12
Introduction	16
Affiliate History	16
Affiliate Organizational Structure	16
Affiliate Service Area	18
Purpose of the Community Profile Report	20
Quantitative Data: Measuring Breast Cancer Impact in Local Communities	21
Quantitative Data Report	21
Selection of Target Communities	38
Health Systems and Public Policy Analysis	47
Health Systems Analysis Data Sources	47
Health Systems Overview	48
Public Policy Overview	59
Health Systems and Public Policy Analysis Findings	63
Qualitative Data: Ensuring Community Input	65
Qualitative Data Sources and Methodology Overview	65
Qualitative Data Overview	69
Qualitative Data Findings	78
Mission Action Plan	82
Breast Health and Breast Cancer Findings of the Target Communities	82
Mission Action Plan	86
References	90

Acknowledgments

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

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

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

- Allendale County Hospital
- American Cancer Society
- Bamberg County Senior Center
- Beaufort Jasper Hampton Comprehensive Health Services
- Best Chance Network
- Carolinas Hospital System
- Coastal Carolinas Hospital
- Colleton Medical Center
- Lowcountry Area Health Education Center
- Magnify
- McLeod Medical Center
- Medical University of South Carolina

- The Regional Medical Center of Orangeburg and Calhoun Counties
- The Witness Project
- South Carolina Cancer Alliance
- South Carolina Cancer Disparities Community Network
- South Carolina Rural Health Research Center
- University of South Carolina Cancer Prevention and Control Program
- United Way of Bamberg, Colleton and Hampton
- Volunteers in Medicine-Hilton Head

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Executive Summary

Introduction to the Community Profile Report

Since 1993, Susan G. Komen® Lowcountry has been working to reduce the burden of breast cancer in South Carolina. The first Charleston Race for the Cure was held in 1993, with proceeds funding a grant to The Medical University of South Carolina. By 2002, the Affiliate had expanded to include 13 counties. In 2004, the name was changed to the Komen Lowcountry to better reflect the growing service area. Komen Lowcountry now serves 17 counties and more than 800,000 women and their families (Figure 1). The counties currently served by the Affiliate reach from the coast to the PeeDee and Piedmont regions:

- Allendale
- Bamberg
- Barnwell
- Beaufort
- Berkeley
- Calhoun
- Charleston
- Colleton
- Dorchester
- Florence
- Georgetown
- Hampton
- Horry
- Jasper
- Marion
- Orangeburg
- Williamsburg



Figure 1. Komen Lowcountry Service Area

The diverse population includes Whites, Blacks/African-Americans and Hispanics/Latinos among others. Although the state's population is predominantly White, many of the counties served by the Affiliate are not. For example, the Black/African-American population accounts for more than 72.0 percent in Allendale. Jasper has a large Hispanic/Latina population of more than 14.0 percent.

The majority of the Lowcountry's service area is rural with five metropolitan areas: Charleston, Beaufort, Myrtle Beach, Orangeburg, and Florence. Incomes vary greatly among the communities served by the Affiliate. Wealthy locales have median household incomes as high as \$160,000, while poorer areas are closer to \$25,000.

There are also disparities in insurance status. Kaiser Family Foundation reports that more than 40.0 percent of the state's poorest residents are without insurance due to the state's rejection of Medicaid expansion. Jasper County has the highest percentage of uninsured residents ages 40-64 at 27.0 percent. The majority of rural counties in the Affiliate's region also have high unemployment figures.

The purpose of the Affiliate's Mission programs, including grantmaking, education and advocacy, is to provide access to quality care for those who face barriers to breast care services. Since 2001, the Affiliate has invested more than \$6.5 million dollars in community health grant funding to community nonprofits, as well as state and federal agencies. This investment has provided more than 56,700 breast cancer screening, diagnostic and treatment support services to those in need. The Affiliate has also funded more than 1,202,000 breast health education services. More than \$2.5 million dollars has been invested by Komen Lowcountry in ground-breaking breast cancer research through Susan G. Komen's Research Program.

As a noted community health partner in South Carolina, Komen Lowcountry is a member of several collaboratives and advisory groups including:

- Coastal Cancer Collaborative
- Partners in Pink
- South Carolina Cancer Alliance (SCCA)
- South Carolina Cancer Disparities Network- Community Advisory Group

The Affiliate has hosted two Partner Summits, strengthening collaborations among providers and partners in the PeeDee and Coastal regions. In addition to providing breast health education to the service area, the Affiliate has contributed to the writing of the South Carolina Cancer Report Card. The Affiliate is also a member of both the SCCA's Public Policy and Breast and Female Cancers workgroups. In 2009, the Affiliate's exemplary advocacy efforts were recognized by the awarding of the Komen Advocacy Alliance's State Policy Collaborative of the Year.

The 2015 Community Profile will guide Komen Lowcountry's work for the coming years, aligning strategic and operational efforts to better address the region's breast health needs and disparities. This needs assessment is compiled to assist the Affiliate and its partners in identifying breast cancer disparities within the 17 county region. By incorporating focused grantmaking, education and advocacy policies, Komen Lowcountry can make a greater impact on the lives of South Carolinians.

The Community Profile will be shared in the local region and beyond. Health care systems and community advocates around the globe can access it via the Affiliate's website. It will be a resource for college students, especially those in the field of public health.

The Community Profile will be distributed electronically to South Carolina's Governor and legislators so they may have a deeper understanding of challenges within the communities they serve. It will also serve as a resource for media outlets such as local television and editorials. The report will also be used to drive public policy and advocacy efforts in the community.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Komen Lowcountry recognizes that each county it serves faces unique challenges. By focusing strategic efforts on specific populations in target communities over the next four years, the Affiliate can continue to be efficient stewards of its limited resources. The Affiliate also understands that the health care landscape is evolving and it may be necessary to update this report.

The Community Profile Team referred to data from Healthy People 2020 (HP2020), a national health promotion and disease prevention initiative, in order to identify high priority areas. Based on several key indicators, four I-95 Corridor regions were identified for further exploration:

- Southern Region: Jasper, Hampton and Colleton Counties
- Southwestern Region: Allendale, Bamberg and Barnwell Counties
- Western Region: Orangeburg and Calhoun Counties
- Marion County

HP2020 includes two breast cancer targets: reduce the female breast cancer death rate and reduce late-stage female breast cancer incidence. With the exception of Jasper County, each of the target counties is unlikely to meet one or both of the HP2020 breast cancer targets. Six counties in Komen Lowcountry's service area are in the highest priority category; they are unlikely to meet either one or both target goals. Three of the six, Colleton County, Marion County and Orangeburg County, are not likely to meet the death rate and the late-stage incidence rate HP2020 targets. The other three, Barnwell County, Calhoun County and Hampton County, are not likely to meet the late-stage incidence rate HP2020 target. The death rates in Orangeburg County are considerably higher than the Affiliate service area as a whole.

In the Affiliate service area, Black/African-American women have a higher death rate to incidence ratio than their White counterparts. Rural women face a direct correlation between being medically underserved and living in a rural community, both of which may create barriers to care. Those barriers may in turn lead to late-stage diagnosis and increased death rates. These two vulnerable populations represent the predominant populations of the I-95 Corridor Region.

The third population of concern is the growing Hispanic/Latino population. This population's rising trend of late-stage diagnosis is more than that of any other named racial or ethnic group within the Affiliate's service area. Jasper County is home to the Affiliate's largest percentage of female Hispanic/Latinas and is therefore included in the high priority regions.

The four I-95 regions have similar demographics and key health indicators of vulnerable populations. Combined, these are indicative of a high risk for experiencing gaps in breast health services and access to care. Every county in the target regions has a relatively large Black/African-American population, low education levels, high poverty percentages and high unemployment.

Health System and Public Policy Analysis

A woman should move through the Breast Cancer Continuum of Care (CoC) quickly and seamlessly, meaning she should receive timely, quality care in order to have the best outcomes (Figure 2). Breast cancer in men is rare, but they should also move through the CoC appropriately. Men and women without access to care are more likely to face late-stage diagnoses and have worse outcomes than those who receive appropriate care.

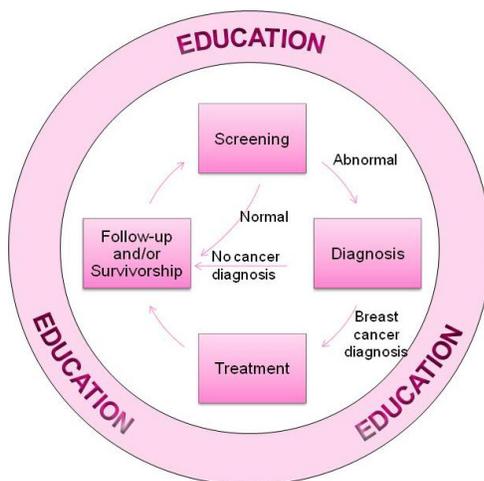


Figure 2. Breast Cancer Continuum of Care (CoC)

Advancing through the CoC is a struggle in the target communities. The greatest challenges are directly related to lack of locally available services. Orangeburg County is the only county in these regions with screening, diagnostic and treatment services readily accessible, as well as financial aid. It is also the only county in these regions with chemotherapy available.

Clinical breast exams are available in every county, but most residents must travel an hour or more for a screening mammogram. For many, diagnostic and treatment services are more than two hours away. Those living in Allendale, Barnwell, Calhoun, and Jasper Counties have no local access to diagnostic or treatment services. Hampton County residents have very limited diagnostic and surgery services and are dependent on physicians' schedules. Limited services are available in Marion and Colleton Counties and there is no financial aid. Breast reconstruction services are not available in any of the nine counties. All of the target counties struggle with health education efforts. Survivor support services are few and far between.

Public policy has a direct impact on breast cancer in South Carolina. At times, state policy is not consistent with the state's Cancer Control Plan. The SC Cancer Control Plan, authored and implemented by the SCCA, provides data and recommendations specific to breast cancer. The 2011-2015 SC Cancer Control Plan breast cancer goals are:

1. To reduce breast cancer deaths in South Carolina through increased awareness, early detection and diagnosis
2. To reduce the burden of breast cancer in South Carolina through high quality cancer treatment

South Carolina's decision not to expand Medicaid leaves the state's poorest without access to affordable care. This leads to late-stage diagnosis and higher death rates. The Healthy Connections Check-up initiative, a limited benefit Medicaid plan, has created additional challenges for the most vulnerable populations. The program serves men and women of all ages with an income at or below 194 percent of Federal Poverty Level (FPL) who are ineligible for any other Medicaid program. Enrollees are allowed one primary care visit every two years.

Screening mammograms are available only to women over the age of 50 and there is no coverage for follow-up, diagnostic or treatment services. Women under 50 are not eligible for screening mammograms through the program. This is in contrast to the State Cancer Control Plan, which recommends annual screening starting at age 40 for women at average risk. Men are also ineligible for breast care coverage through Healthy Connections. With physicians refusing Medicaid patients and community hospitals closing, it has become more difficult for residents to find a local provider.

The Best Chance Network (BCN) is South Carolina's program of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). BCN provides free breast and cervical cancer screening to uninsured women between the ages of 40-64 whose family income is at or below 200 percent of FPL. If a woman is found to be in need of treatment for breast or cervical cancer or pre-cancerous lesions, she may qualify for full Medicaid benefits through NBCEEDP. Women must meet a number of criteria for BCN eligibility, including a very specific enrollment process. The enrollment process creates a barrier because women often are not provided with accurate information by their physicians. It is unclear at this time how BCN will be affected by the state's policy decisions.

The Affiliate's public policy work will continue to focus on those things that can reduce the disparities seen in the service area including Medicaid expansion, continued state funding for BCN, oral drug parity, and affordable access to quality care. The expansion of Medicaid could provide affordable access to care for thousands of women and men. Funding for BCN is not a recurring budget item, so must be advocated for annually. Oral parity would allow some patients the opportunity to be treated without a daily visit for chemotherapy. Public policy is key to Komen's mission of providing equal access to quality care for all.

Qualitative Data: Ensuring Community Input

In order to identify additional key variables likely to influence breast cancer outcomes in the target communities, the Community Profile Team reached out to members of the target communities. The goal was to identify physical access to and utilization of breast care services, as well as potential cultural and socio-economic barriers. Key questions were formed to help identify possible barriers to screening and/or treatment in the priority regions:

1. Where does the target population receive their breast health information?
2. Where does the target population go for breast cancer screening, diagnostic and treatment services? Why do they make those choices?
3. What are some socio-economic or cultural barriers to breast health services faced by the target populations?
4. How do insurance status and ability to pay affect access to care?

Several data collection methods were used including key informant and provider interviews, focus groups and document review. Surveys were also developed and distributed via email to providers and key informants. Additionally, the Team hosted one round-table discussion with key informants working with the priority populations.

These methods were chosen to provide the most detailed insight into the barriers faced within the target communities. Getting the community's perspective allowed for a greater understanding of the challenges they faced, giving more detail than what is provided by quantitative statistics. Personal conversations allowed for deeper discussion and follow up questions for clarification. The Team also reviewed the 2011 Komen Lowcountry Community Profile which included qualitative information collected from focus groups and interviews within these priority populations. This allowed for perspectives from a larger sampling and broader range of participants.

The qualitative data for the Southern, Southwestern and Western Regions, as well as Marion County, underscores the quantitative data and the health systems analysis. Focus group participants and providers spoke of the challenges faced by rural medically underserved communities. Regardless of race or ethnicity, women in every priority region appear to face similar challenges to getting medical care. These primary barriers correlate to the quantitative data and the health systems analysis of the Region:

- Health education, which may be tied to low literacy percentages
- Transportation outside of the region due to lack of providers within the county
- Ability to pay for care, which may be tied to insurance status, income level, and unemployment percentages

The data gathered from all participants indicated that travel is a primary barrier to care. Focus group participants and key informants pointed out that there are few local providers and they frequently have limited hours. In many of the target communities, physicians visit several times a month on a rotating basis. Focus group participants also noted that free clinics are typically in larger cities, far away from these rural counties. Providers and focus group participants noted that patients often travel to the cities of Charleston, Beaufort or Columbia for their medical care, a trip that requires hours of travel time. Overnight and long-term accommodations are sometimes necessary, especially for those undergoing treatment. Providers and focus group participants agreed that in addition to assistance with transportation costs, residents need to know about local options for public transportation, such as HandyRide and rural transit services.

Regardless of insurance status, health care costs are a factor in delaying care. The same issues were identified and commented on by focus group participants, key informants, and providers. The working poor seem to have the greatest barriers. They lose pay if taking time off from work and do not have access to free services that may be available to those that are uninsured or unemployed. The underinsured face the financial burden of high deductibles and high out of pocket expenses for medical care. While there are more financial aid programs available for the uninsured, they also face financial barriers.

Quality of care is another concern for focus group participants in these rural communities, especially in Marion, Hampton and Colleton Counties. Although local physicians are not distrusted, focus group participants commented that women receive better treatment and more respect at facilities outside of their own counties. They want their local providers to show more empathy and compassion. The women believe much of this is directly related to their own ability to pay or the type of insurance they have.

“They treat you to what they feel you can afford to pay.”

(focus group participant)

This is especially relevant to the for-profit facilities in the three counties noted. Focus groups participants suggested that referring patients to nonprofit organizations may help address this perception and develop a more trusting environment.

Focus group participants commented that privacy is greatly valued by the women in these regions, especially by Black/African-American women. Women do not want others to know about their health issues. Participants also noted that open discussion about breast health may allay some of the fears expressed.

Another concern voiced in the focus groups, as well as providers, is that education of the public and providers is needed in every region. Both physicians and the public need to know the recommended breast cancer screening guidelines, financial aid resources and the Best Chance Network. Focus group participants commented that their providers did not offer any of this information.

Focus group participants and providers noted that the medical system can be confusing and women need to know how to navigate it. Focus groups members also noted that women need better communication with their doctors. These concerns were echoed by providers. Both groups agreed that knowing which questions to ask and what financial aid are available may assist in the navigation of the health care system.

“If you don’t know the right questions, they (doctors) ain’t gonna tell you nothing”

(focus group participant)

Focus group participants also noted that breast health education should begin at a younger age so it becomes more acceptable. The belief that mammograms hurt and other misconceptions may also prevent women from routine screenings. It is important that the education be year-round, not just during October. These comments were supported by similar concerns raised by providers.

A common source reported by focus group participants for health education in these regions is the television show “The Dr. Oz Show.” The women also reported receiving health information from newspapers and word of mouth. For those with internet access, the web and Facebook are also sources. Interestingly, local physicians are not considered a regular source of breast health information in any of these regions. Focus group participants recommended an education program to assist doctors in educating patients.

Focus group members noted that breast health education programs must be sustainable. Churches were identified as an appropriate source of health information for Black/African-American women in particular. However, the participants commented that it is important to not rely solely on the faith community as a resource.

Key Informants and providers described the county's Hispanic/Latino population in Jasper County as a close-knit community that relies on one another and places a great deal of trust in their chosen health care providers. The population faces the same primary barriers to health care as the other target communities. However, there are also some unique challenges specific to the large Hispanic/Latino population. Providers observed that they are more likely than any other group to follow "doctor's orders" and follow through with the prescribed care.

Both key informants and providers agreed that there are two issues surrounding travel for health care that are unique to the Hispanic/Latino community in Jasper County compared to the other target communities. Most families in this population share a single vehicle. Typically, the husband or father uses the vehicle for work during the time that doctor offices are open. The women are left carpooling and searching for transportation to appointments. This transportation issue becomes a barrier to care.

Key informants and providers were especially concerned by a greater impact on travel for Jasper County's Hispanic/Latinos: the population's fear of being arrested and/or deported. Regardless of immigration status, Hispanic/Latinos fear leaving Jasper County. They believe they will be arrested as soon as they cross the Beaufort County line. This is of particular concern because the most trusted providers are located in Beaufort County.

*"They won't leave the county for nothing. They're afraid."
S. (key informant)*

Providers agreed that documentation is an additional barrier, noting many Hispanic/Latinas work in service industries or private homes. Because they are paid in cash, they do not receive paycheck stubs. This leaves them without proof of income, which is an eligibility requirement for most financial aid programs.

Another barrier faced by this population is language. Key informants stated that Spanish interpreters are not available on the rural bus system, making travel even more complicated. The community also needs culturally sensitive breast health education in Spanish. Both providers and key informants commented that this population will use the education and follow through with the recommendations.

Mission Action Plan

Three overarching issues are evident throughout the four I-95 Corridor Regions: access to the full continuum of care, education of both the general population and medical providers, and the lack of Medicaid expansion. These problems were chosen for Affiliate intervention because each negatively impacts breast health disparities in the Affiliate's predominant populations- rural and Black/African-American women. If these issues are addressed appropriately, these populations may have better health outcomes. Komen Lowcountry will continue to work with community partners to improve the lives of all South Carolinians, recognizing that some disparities are created by issues beyond the Affiliate's ability to address.

Problem Statement:

Access to the full continuum of care for the uninsured and working poor is a major challenge throughout the Affiliate's entire service area. Those living in the I-95 Corridor regions especially suffer from the lack of physical access to providers. This problem can be addressed through grantmaking and community partnerships. Appropriate access to care can positively impact both late-stage diagnosis and death trends in every I-95 Corridor Region.

Priority: Increase access to the full breast health continuum of care in the I-95 Corridor regions through developing partnerships and grantmaking.

- **Objective 1:** By August 31, 2015, revise the Community Grant RFA to include:
 - A. Priority consideration to programs that result in documented links to breast cancer screening, diagnostic and treatment support services for residents of the counties located in the target regions. This will be accomplished by citing the following counties as funding priorities in the RFA: Allendale, Barnwell, Bamberg, Calhoun, Colleton, Jasper, Hampton, Marion, and Orangeburg. The reviewers' weighted scoring will be revised to allow for higher scoring under the "Impact" category of those applications meeting this priority.
 - B. Employer/provider partnership as a funding priority for nonprofits serving the working poor by providing employee breast health education and on-site screening services in the following counties: Allendale, Barnwell, Bamberg, Calhoun, Colleton, Jasper, Hampton, Marion, and Orangeburg. This will be accomplished by including these employer/provider partnerships as a funding priority in the RFA. The reviewers' weighted scoring will be revised to allow for higher scoring under the "Collaboration" category of those applications meeting this priority.
 - C. Fostering of collaborations (for-profit/nonprofit, employer/provider, or local providers/larger hospital systems) as a funding priority to preserve and strengthen the breast health continuum of care in the target communities, including transportation for diagnostic and treatment services to Beaufort, Charleston, Florence or Orangeburg. The reviewers' weighted scoring will be revised to allow for higher scoring under the "Collaboration" category of those applications that include collaborations to support transportation to diagnostic and treatment services.
- **Objective 2:** By March 31, 2018, hold one collaborative meeting in Hampton County and one in Marion County inviting representatives from local hospitals, health care providers and community members to foster discussion about how to improve relationships between patients and the hospitals in the respective counties.
- **Objective 3:** By March 2016, develop one Community Advisory Board (CAB) comprised of at least one individual from each of the following I-95 Corridor regions: Southern, Southwestern, Western and Marion County. The CAB will meet semi-annually and report to the Affiliate's Board of Directors on an annual or "as needed" basis. The goal of the CAB is to ensure that the breast health care needs of rural communities in the service area are clearly represented. The members of the CAB may include medical, public health, and nonprofit professionals, community stake-holders, and survivors.

Problem Statement:

Breast health education is needed in every target region. Culturally sensitive education of both the public and providers may lead to increased follow through of screening and health care recommendations. If patients know help is available, they are more likely to follow through with recommended care.

It is particularly concerning that providers are not a recognized source for breast health education in any target region. Educating providers about available breast health care and local resources may assist in developing trust within their local communities. By sharing the information with their patients, providers can become a trusted partner. This may be especially helpful in Hampton County (Southern Region) and Marion County, where distrust is most evident. This distrust of the community in the local providers leads to delayed screening and treatment. Improved trust between patients and providers may have a positive impact on breast health outcomes by improving screening rates and reducing late-stage and death trends.

Priority: Increase the dissemination of trusted breast health care education and information about Best Chance Network, local breast health providers, and financial aid in the four target communities.

- *Objective 1:* By January 2016, develop sustainable year-round education and outreach opportunities designed to develop and educate local community ambassadors by hosting 1 workshop in each of the following I-95 Corridor regions: Southern Region, Southwestern Region, Western Region and Marion County.
- *Objective 2:* By November 2017, conduct two mailings to educate providers about the most current breast health recommendations, resources available in their local community, Best Chance Network enrollment process, and other locally available evidence-based programs that may increase their patients' screening rates. The mailings will be sent to all providers in the following counties: Allendale, Barnwell, Bamberg, Calhoun, Colleton, Jasper, Hampton, Marion, and Orangeburg.
- *Objective 3:* In FY 2016 and FY 2017, at least once a month include breast health education, local resources or regional breast health happenings in one of the Affiliate's social media outlets (Facebook, Twitter and e-mail campaigns).
- *Objective 4:* By September 2017, partner with a health organization that predominantly serves the Hispanic/Latina community in Jasper County (Southern Region) to hold one breast cancer community outreach presentation.

Problem Statement:

The current state funded health care system does not provide adequate coverage for South Carolina's most vulnerable women and men. The working poor and underinsured face additional barriers to care. For example, Healthy Checkups provides screening mammography. However, it is exclusionary and does not provide coverage for diagnostic or treatment services. Improved access to care for the underserved can be addressed through the Affiliate's advocacy efforts, as well as grantmaking. Improved access for early detection will lead to improved outcomes.

Priority: Reduce financial barriers to care for the working poor, underinsured, and medically underserved in the four I-95 Corridor regions, including those who would have been Medicaid eligible had the state expanded it.

- *Objective 1:* By August 31, 2016, Revise FY Community Grant RFA to include the following priorities that reduce financial barriers to the full continuum of care faced by the working poor, uninsured and underinsured including free or reduced cost access to:
 - A. Screening and diagnostic services that are not available through Healthy Checkups for residents of the following counties: Allendale, Barnwell, Bamberg, Calhoun, Colleton, Jasper, Hampton, Marion, and Orangeburg.
 - B. Treatment support services including transportation in the following counties: Allendale, Barnwell, Bamberg, Calhoun, Colleton, Jasper, Hampton, Marion, and Orangeburg.
 - C. Worksite screenings in the following counties: Allendale, Barnwell, Bamberg, Colleton, Jasper, Hampton, Marion, and Orangeburg.
- *Objective 2:* By September 2016, re-establish Small Grant opportunity for the Affiliate's service area to provide transportation and education programs that focus on current breast health recommendations, financial aid resources, and the Best Chance Network enrollment process, that result in documented access to screening and care.
- *Objective 3:* In FY 2016 and FY 2017, the Affiliate will maintain membership in the SCCA and attend at least one meeting of the SCCA or the SC Cancer Disparities Network's Community Advisory Group pertinent to breast cancer legislation, including maintaining Best Chance Network funding and supporting Medicaid expansion.
- *Objective 4:* In FY 2016 and FY 2017 include two public policy updates annually in Affiliate's social networking (Facebook, Twitter or e-mail campaigns).
- *Objective 5:* In FY 2016-FY2018, conduct a bi-annual mailing to all state and federal legislators in the Affiliate's service area to increase understanding of:
 - A. The impact of the lack of Medicaid expansion on women and men needing diagnostic services and other breast health services not covered by Health Check-ups.
 - B. Komen as a local resource providing funds for women and men who would have been Medicaid eligible to access breast cancer services.

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

Introduction

Affiliate History

Since 1993, Susan G. Komen® Lowcountry has been working to reduce the burden of breast cancer in South Carolina. The first Charleston Race for the Cure was held in 1993, with proceeds funding programs in the Charleston area. The Affiliate officially changed its name to Susan G. Komen Charleston in 1999 and served 12 counties. In order to better reflect the entire service area, the name was changed in 2004 to Susan G. Komen Lowcountry. Horry County was added to the service area in 2009. In 2011, the Affiliate added four more counties: Calhoun, Florence, Marion and Williamsburg.

Since 2001, the Affiliate has invested more than \$6.5 million dollars in grant funding to its 17 county service area, providing more than 56,700 breast cancer screening, diagnostic and treatment support services to those in need. The Affiliate has also funded more than 1,202,000 breast health education services. All of these services are provided through annual grant funding opportunities to area nonprofits, as well as state and federal agencies. The goal is to provide access to quality care for those who might otherwise go without breast care services. All grantees are required to assure that any patient seen within their Komen funded program has access to the full continuum of care. Komen Lowcountry believes it is unethical for a patient to be diagnosed with breast cancer yet have no access to appropriate treatment. The Affiliate has also invested more than \$2.5 million dollars in ground-breaking breast cancer research through Susan G. Komen Research Program.

The Affiliate's exemplary advocacy efforts were recognized by the awarding of the Komen Advocacy Alliance's 2009 State Policy Collaborative of the Year. As a noted community health partner in South Carolina, Komen Lowcountry is a member of several collaboratives and advisory groups including:

- Coastal Cancer Collaborative
- Partners in Pink
- South Carolina Cancer Alliance (SCCA)
- South Carolina Cancer Disparities Network- Community Advisory Group

The Affiliate has led two Partner Summits, strengthening collaborations among providers and partners in the PeeDee and Coastal regions. In addition to providing breast health education to the service area, the Affiliate has partnered on the writing of the South Carolina Cancer Report Card. It is also a member of both the Public Policy and Breast and Female Cancers Workgroups within the South Carolina Cancer Alliance (SCCA).

Affiliate Organizational Structure

Komen Lowcountry is supported by hundreds of volunteers contributing their time, talents and resources. They assist in all aspects of Affiliate work and come from all walks of life. Like breast

cancer, the Affiliate’s volunteer base knows no boundaries. The Affiliate is also fortunate to have an internship program, supported by local colleges and universities.

Komen Lowcountry currently has a staff of four employees: Executive Director, Mission Programs Manager, Marketing and Events Manager, and Affiliate Administrator. The Affiliate Administrator is part time; the others are full time employees. The Executive Director oversees all aspects of the Affiliate’s work and is ultimately responsible for ensuring that the Affiliate continues to work towards its mission to ensure access to quality care for all and end breast cancer forever. Fund development is a cornerstone in reaching this goal. The Mission Programs Manager is responsible for ensuring that the Affiliate’s mission is accomplished through its grantmaking, education and advocacy programs. This occurs through collaborative efforts with other community, state and national partners. The Events and Marketing Manager is responsible for the coordination and marketing of all Affiliate events, as well as Affiliate communications. The Affiliate’s primary fund-raising event is the annual Lowcountry Race for the Cure. In addition to handling the daily tasks of the organization, the Affiliate Administrator assists with major projects and oversees volunteer and intern management. Although each staff member has specific duties and responsibilities, all work closely together to ensure the success of the Affiliate.

In 2015, there were 12 members on the Board of Directors. Although it is primarily a governing board, members also take on specific projects such as fund development and Board governance. Board leadership positions currently include: President, Secretary and Treasurer. Board members represent a variety of backgrounds and the diverse population served by the Affiliate. The Board holds annual strategic planning sessions to review and recommend strategies developed with achieving the Affiliate’s mission as the overarching goal. Regular meetings are held on a monthly basis with the exception of December and July. Term limits are in place to foster growth and encourage and new ideas. Figure 1.1 displays the organization of Komen Lowcountry.

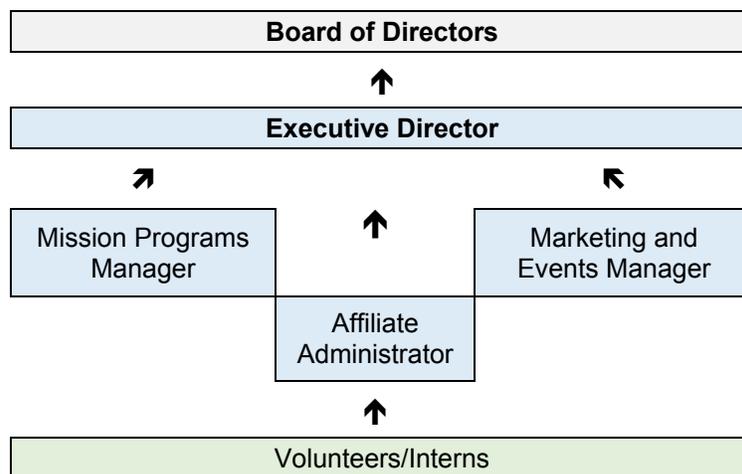


Figure 1.1. Komen Lowcountry Organizational Chart

Affiliate Service Area

Komen Lowcountry currently serves 17 South Carolina counties, from the coast to the PeeDee and Piedmont regions (Figure 1.2):

- Allendale
- Bamberg
- Barnwell
- Beaufort
- Berkeley
- Calhoun
- Charleston
- Colleton
- Dorchester
- Florence
- Georgetown
- Hampton
- Horry
- Jasper
- Marion
- Orangeburg
- Williamsburg

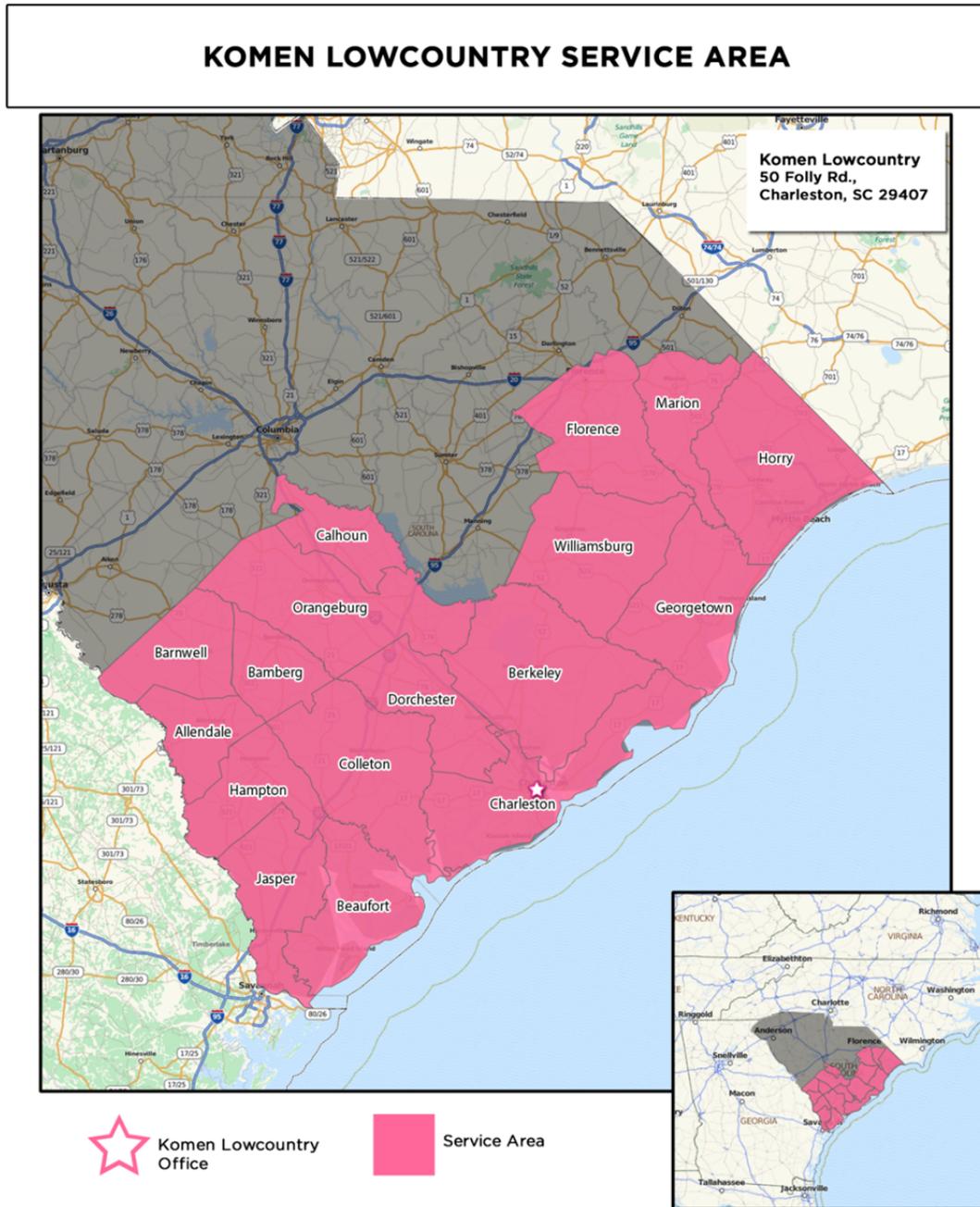


Figure 1.2. Susan G. Komen Lowcountry Service Area

Predominantly rural, the region is characterized by beaches, wetlands, swamps, and forests. Traveling west from the coast, roads wind through farmlands and swamps into rolling hills. Cotton, corn and livestock dot the inland landscape while ocean waves from the Atlantic lap at the coast. A haze lingers in the air from paper mills and power plants in Charleston and Georgetown. I-26 crosses the region from East to West and I-95 cuts through the region from North to South. The I-95 “Corridor of Shame” is aptly named due to the high level of poverty, failing schools, and the poor health of its residents.

The US Census estimates for 2013 reports that South Carolina’s population includes 4,774,839 residents. Komen Lowcountry’s service area is home to approximately 1,675,800 people, of whom more than half are female. The diverse population includes Whites, Blacks/African-Americans and Hispanics/Latinos among others. Although the state’s population is predominantly White, many of the counties served by the Affiliate are not. For example, the Black/African-American population accounts for 72.9 percent in Allendale and 65.5 percent in Williamsburg. Jasper is predominantly White with a large Hispanic/Latina population of 14.4 percent (<http://www.census.gov/quickfacts/table/>).

The majority of the Lowcountry’s service area is rural with five distinct metropolitan areas: Charleston, Beaufort, Myrtle Beach, Orangeburg, and Florence. Major employers include hospitals, school systems, colleges and universities, and state government. Tourism is a leading industry in coastal counties while agricultural and factory work provide sustenance for much of the rural population. Lumber has a large impact on the area, providing jobs in rural counties and resources for factories and paper mills. Factories are also large employers, though several have recently shut their doors.

Transportation has a major influence on mobility within the region. Many of the area’s inhabitants rely on shared rides and carpooling. Rural transportation is extremely limited and unreliable. Bus systems are available in several of the larger cities, including Charleston and Myrtle Beach. Cab services are also available in the larger cities.

There are large differences in income among those in the Affiliate’s service area. Wealthy locales include Kiawah Island and Isle of Palms, where median household incomes are \$160,083 and \$80,556 respectively. For comparison, the median household income in Allendale is \$25,252 (<http://factfinder2.census.gov>).

Although South Carolina’s unemployment percentage is falling, the majority of rural counties in the Affiliate’s region have high unemployment figures. Allendale County leads the region with unemployment at 25.2 percent. In Colleton County, 15.30 percent of the population is unemployed. The urban counties of Beaufort and Charleston are on the low end with unemployment percentages at 8.6 and 8.7 percent respectively (Table 2.5). The overall drop in unemployment percentages might be deceiving because many people are essentially underemployed, meaning they may hold a part-time job but continue to live in poverty.

The Kaiser Family Foundation reports that more than 40.0 percent of the State's poorest residents are without insurance due to the state's rejection of Medicaid expansion. These adults are between the ages of 19-64 and have incomes below 200.0 percent of Federal Poverty Level. Overall, more than 19.0 percent of South Carolina's residents between the ages of 40-64 remain uninsured. Jasper County has the highest percentage of uninsured residents ages 40-64 at 27.0 percent (Table 2.5).

Purpose of the Community Profile Report

The 2015 Community Profile is a needs assessment of the Komen Lowcountry service area. It is compiled to assist the Affiliate and its partners in identifying breast cancer disparities within the 17 county region. This profile will guide Komen Lowcountry's work, aligning strategic and operational efforts to better address the region's breast health needs and disparities.

The Community Profile will be used in the Affiliate's development of focused grantmaking, education and outreach policies. It will also be used to drive public policy and inclusion efforts in the community. This may be accomplished through the Affiliate's marketing and social media campaigns. By educating the public about breast cancer disparities and survivorship needs, sponsorship efforts may also be strengthened. This would allow the Affiliate to reach more who might otherwise be without health care.

The 2015 Community Profile will be shared in the local region and beyond. It will be available to health care systems and community advocates via the Affiliate's website. It will be a resource for college students, especially those in the field of public health. It will be distributed electronically to South Carolina's Governor and legislators so they may have a deeper understanding of the communities they serve. It will also serve as a resource for media outlets such as local television and editorials.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Quantitative Data Report

Introduction

The purpose of the quantitative data report for Susan G. Komen® Lowcountry 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 Lowcountry'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.

Population Group	Incidence Rates and Trends				Death Rates and Trends			Late-stage Rates and Trends		
	Female Population (Annual Average)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of Deaths (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)
US	154,540,194	182,234	122.1	-0.2%	40,736	22.6	-1.9%	64,590	43.8	-1.2%
HP2020	.	-	-	-	-	20.6*	-	-	41.0*	-
South Carolina	2,316,194	3,267	122.3	-0.7%	638	23.5	-1.7%	1,212	45.9	-1.0%
Komen Lowcountry Service Area	801,280	1,140	121.2	1.2%	218	23.0	NA	428	46.0	1.8%
White	515,036	802	122.5	0.7%	140	20.8	NA	277	43.2	1.9%
Black/African-American	270,411	318	116.1	1.8%	78	28.5	NA	145	53.0	1.8%
American Indian/Alaska Native (AIAN)	4,164	SN	SN	SN	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	11,669	10	97.0	7.0%	SN	SN	SN	SN	SN	SN
Non-Hispanic/ Latina	768,430	1,127	121.7	0.9%	213	22.7	NA	421	46.1	1.7%
Hispanic/ Latina	32,850	14	81.7	20.6%	SN	SN	SN	7	43.5	5.2%
Allendale County - SC	4,974	8	126.1	0.5%	SN	SN	SN	SN	SN	SN
Bamberg County - SC	8,481	12	115.3	13.0%	SN	SN	SN	4	36.5	NA
Barnwell County - SC	11,859	16	112.4	7.4%	SN	SN	SN	6	45.4	11.8%
Beaufort County - SC	78,504	130	126.8	-1.6%	23	21.2	-2.7%	47	49.1	-0.7%
Berkeley County - SC	84,840	96	112.8	-1.2%	17	21.2	-2.7%	36	42.1	-4.4%
Calhoun County - SC	7,802	14	140.5	22.7%	SN	SN	SN	6	59.5	21.4%
Charleston County - SC	176,426	261	134.0	-2.6%	48	23.5	-1.9%	98	51.0	-3.5%
Colleton County - SC	20,141	27	104.8	8.9%	6	22.9	-0.8%	9	36.7	16.8%
Dorchester County - SC	66,540	84	125.3	6.8%	13	19.6	-0.1%	33	49.3	7.8%
Florence County - SC	71,547	100	122.0	-1.1%	22	26.5	-1.9%	41	51.1	-5.9%
Georgetown County - SC	31,535	57	129.5	0.1%	9	21.5	-0.9%	21	49.2	2.4%
Hampton County - SC	10,346	14	117.5	10.2%	SN	SN	SN	5	39.2	17.3%
Horry County - SC	131,798	194	114.1	1.5%	35	20.8	-2.5%	66	38.7	4.7%
Jasper County - SC	11,216	11	91.7	-4.8%	SN	SN	SN	5	44.4	-4.8%
Marion County - SC	18,183	25	112.2	7.9%	6	28.5	0.4%	9	42.8	20.9%
Orangeburg County - SC	49,126	70	122.5	3.2%	18	30.8	-0.8%	31	55.6	7.4%
Williamsburg County - SC	17,962	23	97.8	0.3%	6	30.2	-3.4%	8	36.1	-3.7%

*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 Lowcountry service area was similar to that observed in the US as a whole and the incidence trend was higher than the US as a whole. The incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of 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:

- Charleston County

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

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

Death rates and trends summary

Overall, the breast cancer death rate in the Komen Lowcountry 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 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. 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.

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

- Orangeburg County

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

Late-stage incidence rates and trends summary

Overall, the breast cancer late-stage incidence rate in the Komen Lowcountry service area was slightly higher than that observed in the US as a whole and the late-stage incidence trend was higher than the US as a whole. The late-stage incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of 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 slightly lower than among Non-Hispanics/Latinas.

The late-stage incidence rate was significantly lower in the following county:

- Horry County

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

Mammography Screening

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

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

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 Latina, but only 10.0 percent of the total women in the area are 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%
South Carolina	5,066	3,875	74.7%	73.1%-76.2%
Komen Lowcountry Service Area	2,300	1,781	76.9%	74.6%-79.1%
White	1,542	1,177	75.9%	73.2%-78.5%
Black/African-American	704	566	80.3%	75.8%-84.1%
AIAN	15	8	54.0%	25.3%-80.3%
API	SN	SN	SN	SN
Hispanic/ Latina	17	13	80.9%	32.6%-97.4%
Non-Hispanic/ Latina	2,232	1,729	76.9%	74.5%-79.1%
Allendale County - SC	SN	SN	SN	SN
Bamberg County - SC	39	28	71.6%	52.6%-85.1%
Barnwell County - SC	39	24	64.1%	45.7%-79.1%
Beaufort County - SC	367	301	77.9%	71.8%-83.0%
Berkeley County - SC	157	119	81.0%	71.5%-87.9%
Calhoun County - SC	42	34	70.0%	48.9%-85.0%
Charleston County - SC	389	313	82.2%	76.7%-86.7%
Colleton County - SC	126	91	69.6%	58.2%-79.1%
Dorchester County - SC	70	51	76.2%	62.4%-86.1%
Florence County - SC	98	70	73.9%	61.9%-83.1%
Georgetown County - SC	166	136	82.7%	74.7%-88.5%
Hampton County - SC	57	46	82.5%	62.9%-92.9%
Horry County - SC	300	224	71.8%	65.3%-77.6%
Jasper County - SC	53	42	78.8%	62.8%-89.1%
Marion County - SC	71	51	69.9%	55.9%-81.0%
Orangeburg County - SC	187	150	80.2%	71.2%-86.9%
Williamsburg County - SC	139	101	77.2%	65.8%-85.5%

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 Lowcountry 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 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 and not significantly different among AIANs than Whites. There were not enough data available within the Affiliate service area to report on APIs so comparisons cannot be made for this racial group. The screening proportion among Hispanics/Latinas was not significantly different than among Non-Hispanics/Latinas.

None of the counties in the Affiliate service area had substantially different screening proportions than the Affiliate service area as a whole.

Population Characteristics

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

It is important to note that the report uses the race and ethnicity categories used by the US Census Bureau, and that race and ethnicity are separate and independent categories. This means that everyone is classified as both a member of one of the four race groups as well as either Hispanic/Latina or Non-Hispanic/Latina.

The demographic and socioeconomic data in this report are the most recent data available for US counties. All the data are shown as percentages. However, the percentages weren't all calculated in the same way.

- The race, ethnicity, and age data are based on the total female population in the area (e.g. the percent of females over the age of 40).
- The socioeconomic data are based on all the people in the area, not just women.
- Income, education and unemployment data don't include children. They're based on people age 15 and older for income and unemployment and age 25 and older for education.
- The data on the use of English, called "linguistic isolation", are based on the total number of households in the area. The Census Bureau defines a linguistically isolated household as one in which all the adults have difficulty with English.

Table 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 %
South Carolina	68.2 %	29.6 %	0.5 %	1.6 %	95.4 %	4.6 %	49.5 %	36.0 %	15.5 %
Komen Lowcountry Service Area	64.9 %	33.0 %	0.6 %	1.6 %	95.3 %	4.7 %	50.1 %	37.1 %	16.1 %
Allendale County - SC	24.1 %	75.2 %	0.2 %	0.5 %	97.9 %	2.1 %	53.2 %	40.4 %	16.9 %
Bamberg County - SC	35.8 %	63.3 %	0.4 %	0.5 %	98.6 %	1.4 %	51.9 %	39.7 %	18.3 %
Barnwell County - SC	52.6 %	46.3 %	0.4 %	0.6 %	98.5 %	1.5 %	51.1 %	37.6 %	16.3 %
Beaufort County - SC	76.6 %	21.3 %	0.5 %	1.6 %	89.4 %	10.6 %	54.6 %	43.6 %	22.1 %
Berkeley County - SC	69.0 %	27.4 %	0.8 %	2.8 %	94.6 %	5.4 %	45.0 %	30.7 %	11.3 %
Calhoun County - SC	53.3 %	45.9 %	0.4 %	0.4 %	97.3 %	2.7 %	56.5 %	42.5 %	18.1 %
Charleston County - SC	66.2 %	31.6 %	0.5 %	1.8 %	95.6 %	4.4 %	47.3 %	34.5 %	14.5 %
Colleton County - SC	57.0 %	41.5 %	0.9 %	0.6 %	97.6 %	2.4 %	52.7 %	39.1 %	17.3 %
Dorchester County - SC	69.5 %	27.5 %	0.7 %	2.3 %	95.7 %	4.3 %	45.7 %	30.8 %	11.7 %
Florence County - SC	54.5 %	43.8 %	0.4 %	1.3 %	97.9 %	2.1 %	48.8 %	35.3 %	15.1 %
Georgetown County - SC	63.8 %	35.3 %	0.3 %	0.6 %	97.4 %	2.6 %	59.2 %	46.7 %	21.5 %
Hampton County - SC	43.3 %	55.8 %	0.3 %	0.5 %	98.0 %	2.0 %	50.8 %	37.3 %	15.9 %
Horry County - SC	83.1 %	14.8 %	0.6 %	1.5 %	94.7 %	5.3 %	54.0 %	41.1 %	18.6 %
Jasper County - SC	50.0 %	48.4 %	0.5 %	1.0 %	87.7 %	12.3 %	46.7 %	33.0 %	13.3 %
Marion County - SC	40.4 %	58.4 %	0.5 %	0.7 %	97.8 %	2.2 %	52.6 %	39.8 %	16.8 %
Orangeburg County - SC	34.2 %	64.2 %	0.6 %	0.9 %	98.4 %	1.6 %	50.2 %	37.6 %	16.8 %
Williamsburg County - SC	31.9 %	67.2 %	0.4 %	0.4 %	99.0 %	1.0 %	53.8 %	40.8 %	17.3 %

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 – socioeconomic.

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistically Isolated	In Rural Areas	In Medically Underserved Areas	No Health Insurance (Age: 40-64)
US	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
South Carolina	16.4 %	17.0 %	39.5 %	10.2 %	4.8 %	1.8 %	33.7 %	41.8 %	19.0 %
Komen Lowcountry Service Area	14.6 %	17.5 %	40.4 %	10.3 %	5.2 %	1.9 %	32.9 %	59.2 %	20.1 %
Allendale County - SC	28.0 %	40.2 %	64.2 %	25.2 %	1.1 %	1.3 %	68.3 %	100.0 %	20.4 %
Bamberg County - SC	21.7 %	30.6 %	51.5 %	9.4 %	1.6 %	0.0 %	54.5 %	100.0 %	19.0 %
Barnwell County - SC	22.0 %	26.4 %	51.2 %	15.0 %	1.2 %	1.3 %	82.5 %	100.0 %	18.4 %
Beaufort County - SC	9.4 %	10.7 %	29.9 %	8.6 %	10.5 %	3.8 %	19.6 %	40.1 %	18.2 %
Berkeley County - SC	14.0 %	13.9 %	36.9 %	10.0 %	6.1 %	2.3 %	29.0 %	7.3 %	19.8 %
Calhoun County - SC	16.9 %	17.4 %	43.9 %	11.4 %	1.5 %	0.6 %	100.0 %	100.0 %	18.0 %
Charleston County - SC	12.1 %	16.8 %	35.2 %	8.7 %	5.6 %	1.8 %	10.9 %	29.3 %	17.7 %
Colleton County - SC	24.0 %	22.8 %	53.6 %	15.3 %	2.3 %	0.8 %	75.6 %	100.0 %	23.4 %
Dorchester County - SC	11.1 %	12.1 %	33.0 %	8.8 %	4.1 %	1.3 %	19.5 %	100.0 %	17.5 %
Florence County - SC	18.4 %	19.4 %	44.8 %	11.0 %	2.7 %	1.1 %	38.5 %	33.9 %	18.2 %
Georgetown County - SC	15.5 %	20.9 %	41.6 %	12.3 %	2.6 %	1.0 %	41.5 %	30.1 %	21.3 %
Hampton County - SC	23.4 %	22.6 %	51.9 %	14.2 %	2.5 %	0.9 %	78.5 %	100.0 %	20.9 %
Horry County - SC	12.6 %	16.7 %	41.2 %	9.8 %	6.6 %	2.4 %	30.4 %	100.0 %	24.3 %
Jasper County - SC	24.2 %	21.4 %	52.6 %	9.7 %	9.7 %	2.3 %	66.7 %	100.0 %	27.0 %
Marion County - SC	19.8 %	24.2 %	58.4 %	13.0 %	2.6 %	1.1 %	60.8 %	64.1 %	21.8 %
Orangeburg County - SC	21.6 %	24.5 %	51.7 %	13.7 %	1.9 %	1.2 %	63.8 %	100.0 %	21.5 %
Williamsburg County - SC	22.2 %	32.8 %	59.2 %	10.8 %	1.1 %	0.0 %	81.9 %	100.0 %	22.4 %

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 Lowcountry service area has a substantially smaller White female population than the US as a whole, a substantially larger Black/African-American female population, a substantially smaller Asian and Pacific Islander (API) female population, a slightly smaller American Indian and Alaska Native (AIAN) female population, and a substantially smaller Hispanic/Latina female population. The Affiliate’s female population is slightly older than that of the US as a whole. The Affiliate’s education level is similar to and income level is slightly lower than those of the US as a whole. There are a slightly larger percentage of people who are unemployed in the Affiliate service area. The Affiliate service area has a substantially smaller percentage of people who are foreign born and a slightly smaller percentage of people who are linguistically isolated. There are a substantially larger percentage of people living in rural areas,

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

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

- Allendale County
- Bamberg County
- Barnwell County
- Calhoun County
- Colleton County
- Florence County
- Hampton County
- Jasper County
- Marion County
- Orangeburg County
- Williamsburg County

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

- Beaufort County
- Jasper County

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

- Beaufort County
- Georgetown County

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

- Allendale County
- Bamberg County
- Barnwell County
- Colleton County
- Hampton County
- Jasper County
- Marion County
- Orangeburg County
- Williamsburg County

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

- Allendale County
- Bamberg County
- Barnwell County
- Colleton County
- Hampton County

- Marion County
- Orangeburg County
- Williamsburg County

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

- Allendale County
- Barnwell County
- Colleton County
- Hampton County
- Orangeburg County

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

- Jasper County

Priority Areas

Healthy People 2020 forecasts

Healthy People 2020 (HP2020) is a major federal government initiative that provides specific health objectives for communities and for the country as a whole. Many national health organizations use HP2020 targets to monitor progress in reducing the burden of disease and improve the health of the nation. Likewise, Komen believes it is important to refer to HP2020 to see how areas across the country are progressing towards reducing the burden of breast cancer.

HP2020 has several cancer-related objectives, including:

- Reducing women's death rate from breast cancer (Target as of the writing of this report: 20.6 cases per 100,000 women).
- Reducing the number of breast cancers that are found at a late-stage (Target as of the writing of this report: 41.0 cases per 100,000 women).

To see how well counties in the Komen Lowcountry 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 rates and key breast cancer death determinants such as poverty and linguistic isolation.

Table 2.7. Intervention priorities for Komen Lowcountry 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
Barnwell County - SC	Highest	SN	13 years or longer	%Black/African-American, education, poverty, employment, rural, medically underserved
Calhoun County - SC	Highest	SN	13 years or longer	%Black/African-American, rural, medically underserved
Colleton County - SC	Highest	13 years or longer	13 years or longer	%Black/African-American, education, poverty, employment, rural, medically underserved
Hampton County - SC	Highest	SN	13 years or longer	%Black/African-American, education, poverty, employment, rural, medically underserved
Marion County - SC	Highest	13 years or longer	13 years or longer	%Black/African-American, education, poverty, rural
Orangeburg County - SC	Highest	13 years or longer	13 years or longer	%Black/African-American, education, poverty, employment, rural, medically underserved
Beaufort County - SC	Medium High	2 years	13 years or longer	%Hispanic/Latina, foreign
Charleston County - SC	Medium High	7 years	7 years	

County	Priority	Predicted Time to Achieve Death Rate Target	Predicted Time to Achieve Late-stage Incidence Target	Key Population Characteristics
Florence County - SC	Medium High	13 years or longer	4 years	%Black/African-American, rural
Georgetown County - SC	Medium High	5 years	13 years or longer	Older, rural
Horry County - SC	Medium High	1 year	13 years or longer	Medically underserved
Dorchester County - SC	Medium	Currently meets target	13 years or longer	Medically underserved
Berkeley County - SC	Medium Low	2 years	1 year	
Jasper County - SC	Medium Low	SN	2 years	%Black/African-American, %Hispanic/Latina, education, rural, insurance, medically underserved
Williamsburg County - SC	Medium Low	12 years	Currently meets target	%Black/African-American, education, poverty, rural, medically underserved
Allendale County - SC	Undetermined	SN	SN	%Black/African-American, education, poverty, employment, rural, medically underserved
Bamberg County - SC	Undetermined	SN	NA	%Black/African-American, education, poverty, 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.

Komen Lowcountry Affiliate Counties

Priority Areas

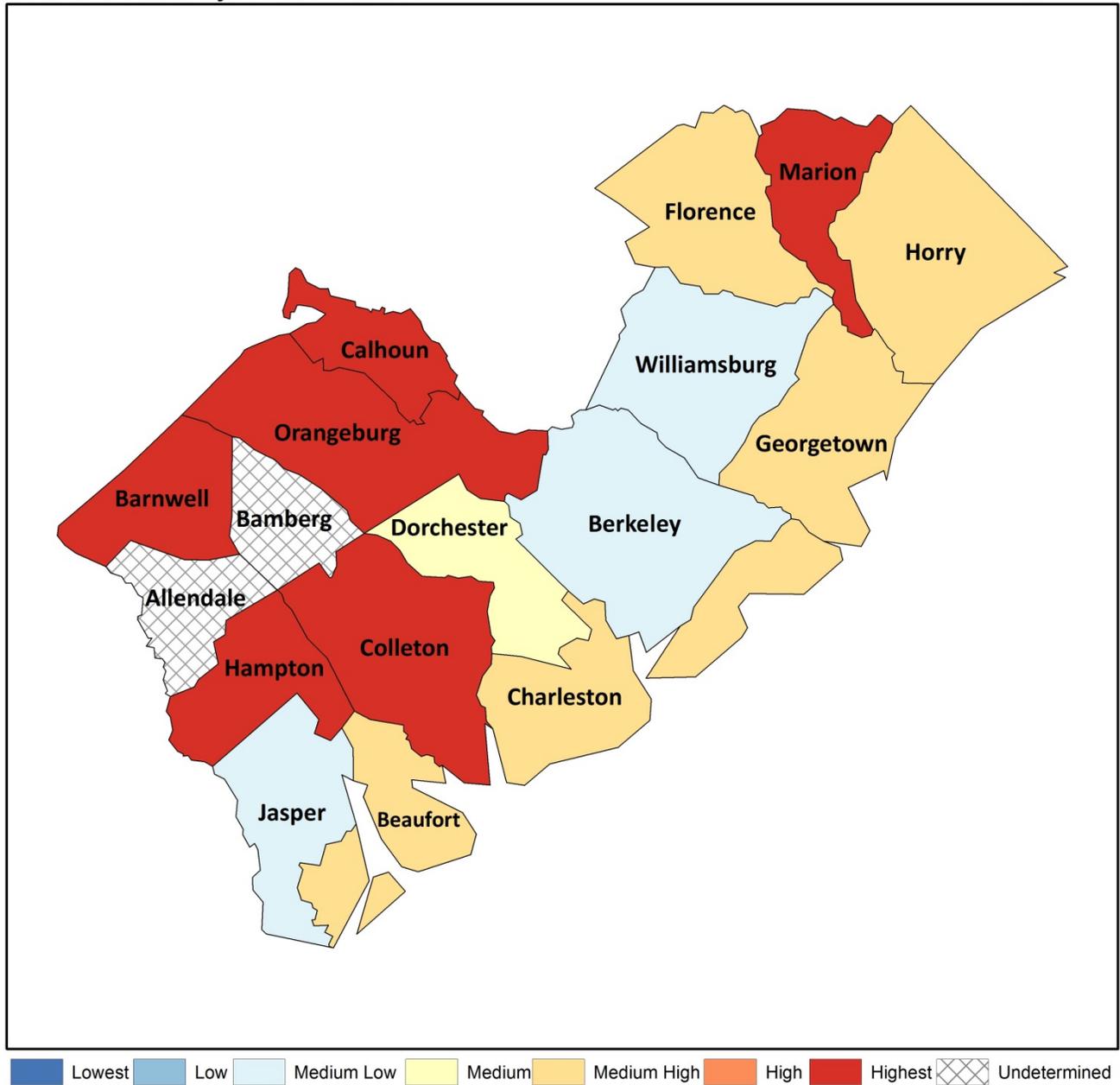


Figure 2.1. Intervention priorities.

Data Limitations

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

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

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

Quantitative Data Report Conclusions

Highest priority areas

Six counties in the Komen Lowcountry service area are in the highest priority category. Three of the six, Colleton County, Marion County and Orangeburg County, are not likely to meet either the death rate or late-stage incidence rate HP2020 targets. Three of the six, Barnwell County, Calhoun County and Hampton County, are not likely to meet the late-stage incidence rate HP2020 target.

The death rates in Orangeburg County (30.8 per 100,000) are significantly higher than the Affiliate service area as a whole (23.0 per 100,000).

Barnwell County has a relatively large Black/African-American population, low education levels, high poverty and high unemployment. Calhoun County has a relatively large Black/African-American population. Colleton County has a relatively large Black/African-American population, low education levels, high poverty and high unemployment. Hampton County has a relatively large Black/African-American population, low education levels, high poverty and high unemployment. Marion County has a relatively large Black/African-American population, low education levels and high poverty. Orangeburg County has a relatively large Black/African-American population, low education levels, high poverty and high unemployment.

Medium high priority areas

Five counties in the Komen Lowcountry service area are in the medium high priority category. One of the five, Florence County is not likely to meet the death rate HP2020 target. Three of the five, Beaufort County, Georgetown County and Horry County, are not likely to meet the late-stage incidence rate HP2020 target. One of the five, Charleston County is expected to take seven years to reach both the death rate and late-stage incidence rate HP2020 targets.

The incidence rates in Charleston County (134.0 per 100,000) are significantly higher than the Affiliate service area as a whole (121.2 per 100,000).

Beaufort County has a relatively large Hispanic/Latina population and a relatively large foreign-born population. Florence County has a relatively large Black/African-American population. Georgetown County has a relatively older population.

Selection of Target Communities

Komen Lowcountry recognizes that each county it serves faces unique challenges. By focusing strategic efforts on specific populations in target communities over the next four years, the Affiliate can continue to be efficient stewards of its limited resources. The Affiliate also understands that the health care landscape is evolving and it may be necessary to update this report.

Four I-95 Corridor regions have been named the high priority areas in which vulnerable populations will be of focus for the health system analysis and qualitative data collection. These regions include eight contiguous counties with similar demographics and key health indicators of vulnerable populations. Combined, these are indicative of a high risk for experiencing gaps in breast health services and access to care. The ninth county, which is not contiguous, also faces a high risk for gaps in care.

The following I-95 Corridor regions and neighboring counties were identified as target communities based on the review of Healthy People 2020 and other key indicators:

- Southern Region: Jasper, Hampton, Colleton
- Southwestern Region: Allendale, Bamberg, Barnwell
- Western Region: Orangeburg, Calhoun
- Marion

Throughout the Lowcountry service area, there are three female populations of particular concern:

- Black/African-American
- Rural
- Hispanic/Latina

In every Affiliate county, Black/African-American women have a much higher deaths to incidence ratio than their White counterparts. Rural women face a direct correlation between being medically underserved and living in a rural community, both of which may create barriers to care. Those barriers may in turn lead to late-stage diagnosis and increased death rates. These two vulnerable populations represent the predominant populations of the I-95 Corridor Region. Therefore they will be of focus for the health system analysis and qualitative data collection in each target community.

The third population of concern is the growing Hispanic/Latino population. This population's rising trend of late-stage diagnosis is considerably more than that of any other named racial or ethnic group within the Affiliate's service area. Because Jasper County is home to the Affiliate's largest percentage of female Hispanics, this group will also be included in the health systems analysis and qualitative data collection for the Southern Region of the I-95 Corridor.

I-95 Corridor Regions

South Carolina's I-95 Corridor includes eleven Affiliate counties: Beaufort, Jasper, Hampton, Colleton, Bamberg, Dorchester, Calhoun, Williamsburg, Florence, and Marion. For the purposes of this report, the Community Profile Team has chosen to include Allendale and Barnwell due to their proximity to the corridor and key demographics.

In order to select the priority communities, the Affiliate reviewed Healthy People 2020 (HP2020), a major federal government initiative providing specific health objectives for communities and the US as a whole. Komen Lowcountry focused on the HP2020 goals pertinent to reducing women's death rates from breast cancer and reducing the number of late-stage diagnosis of breast cancer. Through an analysis of this data, priority counties were identified based on the estimated time to meet HP2020 targets for breast cancer.

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

- Incidence rates and trends
- Death rates and trends
- Late-stage rates and trends
- Below average screening percentages
- Residents living below poverty level
- Residents living without health insurance
- Unemployment percentages

Although unemployment is one key indicator, insurance status and poverty level must also be considered. There are areas where the unemployment percentage is comparatively low, yet both the poverty level and percentage of uninsured are high. This points to the challenges faced by the "working poor", those who are employed but lack wages above the poverty level. For example, Bamberg County has one of the region's lowest unemployment figures at 9.4 percent (Table 2.5). Although this is a relatively high employment percentage, 30.6 percent of Bamberg's population have an annual income below 100 percent of the poverty level; and Bamberg's percentage of uninsured is one of the highest at 19.0 percent. This uninsured figure is similar to Allendale's (20.4 percent) where the unemployed total is the highest in the service area (25.2 percent). Jasper County, home to the region's largest Hispanic/Latino population, has the most apparent discrepancy between employment and insurance status. Unemployment is relatively low at 9.7 percent. However, the number of uninsured is the highest in the Lowcountry (27.0 percent). The "working poor" in the affiliate's region may face the same challenges as those who are without work.

It is notable that all of the highest priority counties are located in the I-95 "Corridor of Shame" (Table 2.7). This low-income region is dominated by struggling schools, cyclical poverty, and lagging health and social well-being. As a whole, it is a rural, medically underserved area. For

this reason, the Community Profile Team selected the I-95 Corridor as a focus region rather than the individual counties. Counties of concern were assigned to geographical regions based

on their location within the I-95 Corridor. Four I-95 Corridor counties (Beaufort, Dorchester, Florence, and Williamsburg) are not high priority and are not included in the target communities.

Southern Region: Colleton, Hampton, Jasper

Colleton County

Colleton County has a relatively large Black/African-American population, low education levels, high poverty and high unemployment. Twenty-three percent of the residents are uninsured and more than 53.0 percent have incomes below 250 percent of Federal Poverty Level (FPL) (Table 2.5). There are also a large number of residents with less than a high school education. These socioeconomic factors may create barriers to care.

Although a for-profit hospital is located in the county, the area is identified as 100 percent medically underserved. It is a predominantly rural county with few local providers. Screening rates in the area are the second lowest in the Affiliate's service area. Of particular concern is the rapidly increasing trend of late-stage diagnosis at 16.8 percent annually (Table 2.1). Like other high priority counties, it is estimated to take more than 13 years to reach both of the HP2020 targets.

Hampton County

Hampton County has a predominantly Black/African-American population, low education levels, high poverty and high unemployment. More than fifty percent of the residents live below 250 percent of FPL and 23.4 percent have less than a high school education (Table 2.5). Like other rural areas, there is no public transportation available. Any of these factors may impede access to care on its own. Combined, they may create an overwhelming barrier to care.

Hampton is similar to Colleton in that it is home to a hospital, yet it is 100 percent medically underserved. It has one of the highest rising trends of late-stage diagnosis rates among the affiliate's counties. This data is of particular concern, especially when coupled with the forecast of 13 years or longer to meet the HP2020 late-stage incidence target (Table 2.7). The screening proportion is 82.5 percent but has a relatively broad confidence interval of 62.9-92.9 percent (Table 2.3). Although the hospital is located in Hampton County, there is a lack of physicians. As in other Affiliate counties, physicians travel to the area but are not available on a daily basis.

Jasper County

Of concern in Jasper County are demographic and socioeconomic factors which may be key health indicators. At 12.3 percent, Jasper has the largest population of Hispanic/Latino females in the Affiliate's service area. Jasper also has the highest percentage of uninsured residents (27.0 percent). One hundred percent of the population live in medically underserved areas. More than 24.0 percent of Jasper County's residents have less than a high school education.

Overall, there are positive breast health trends in Jasper County. Both incidence and late-stage trends are falling for the county as a whole. Death rates are suppressed due to small numbers (Table 2.1). The predicted time to achieve the death rate target is suppressed in the county's HP2020 forecast. It is the growing Hispanic/Latino population and the barriers they may face,

as well as the county's socioeconomic factors, which are of particular concern to the Community Profile team.

Southwestern Region: Allendale, Bamberg, Barnwell

Due to their small population size, data was suppressed for Allendale and Bamberg counties. These two counties are contiguous and border Barnwell. For the purposes of this report, these counties are included in the Southwestern Region of the I-95 Corridor.

The Southwestern Region of the I-95 Corridor was selected for a number of reasons. Although Allendale and Bamberg are not technically within the "Corridor of Shame", they share similar demographic and socioeconomic characteristics with Barnwell. All three are rural, 100 percent medically underserved counties. The counties have high poverty percentages, high unemployment, and low education levels. The largest portion of the population residing in the area is Black.

Allendale County

Allendale's population is 75.2 percent Black. More than 64.0 percent of Allendale's residents between the ages of 40-64 are below 250 percent of FPL, and more than forty percent are below 100 percent of FPL (Table 2.5). These are the highest poverty figures in the Affiliate's service area. Reported screening proportion for Allendale are not available due to small numbers.

Allendale's death rates and trends are suppressed, as are the county's late-stage rates and trends. The incidence trend is rising slightly with a change of 0.5 percent over the five year data period (Table 2.1). Due to small numbers, the data for the HP2020 forecast is suppressed.

Bamberg County

Bamberg's population is 63.3 percent Black. This county's population has the Affiliate's service area's second highest poverty rate with 30.6 percent below 100 percent of FPL. Also of concern is the fact that Bamberg's incidence rate is rising. Both the death and late-stage diagnosis rates are suppressed due to small numbers. With a confidence interval of 52.6-85.1 percent, the weighted average of women who have received screening within the past two years is one of the lowest in the Affiliate's service area (Table 2.3).

The data from the HP2020 forecast is not sufficient to determine Bamberg County's ranking as an intervention priority for the Affiliate. The predicted time to achieve the death rate target is suppressed due to small numbers. The data necessary to establish the predicted time to achieve the late-stage incidence target is not available.

Barnwell County

Barnwell's population is 46.3 percent Black. More than one fourth of the residents (26.4 percent) have incomes below 100 percent of poverty level and more than half (51.2 percent) are below 250 percent of FPL (Table 2.5). Of particular concern is the county's screening proportion of 64.1 percent, the lowest in the Affiliate's service area (Table 2.3). The late-stage diagnosis rate for Barnwell is rising annually (11.6 percent), possibly due to the lack of locally available screening services (Table 2.1).

Based on the data from the HP2020 forecast, Barnwell County is a high priority for the Affiliate. The predicted time to achieve the death rate target is suppressed due to small numbers. The predicted time to achieve the late-stage incidence target is 13 years or longer (Table 2.7).

Western Region: Orangeburg, Calhoun

Orangeburg and Calhoun counties are contiguous within the I-95 Corridor and share many of the same services. The Regional Medical Center of Orangeburg and Calhoun Counties is the region's only hospital. The counties also share similar socioeconomic factors and key health indicators.

Orangeburg County

Orangeburg County has similar characteristics to the other high priority counties along the I-95 Corridor. The majority of residents are Black/African-American, representing 64.2 percent of the population (Table 2.4). More than 21.0 percent of the population is without health insurance (Table 2.5). A large number of residents have incomes below 100 percent of FPL (24.5 percent), substantially more than the affiliate service area as a whole (Table 5). More than thirteen percent are unemployed. The county is considered 100 percent medically underserved, with more than 63.0 percent of the residents living in rural areas.

Orangeburg is home to The Regional Medical Center of Orangeburg and Calhoun Counties, which may account for why trends in incidence, death, and late-stage diagnosis rates are not rising as significantly as other high priority counties. However, all three rates are on the rise. The current projection is that the county will require more than thirteen years to reach both HP 2020 breast cancer targets (Table 2.7).

Calhoun County

Calhoun County was included as a target community based on socioeconomic factors and key health indicators. Calhoun County is located within the I-95 corridor and has a relatively large Black/African-American population (45.9 percent). Like its neighboring counties, Calhoun is 100 percent medically underserved and completely rural. Table 2.1 shows that the trend in late-stage diagnosis is rising significantly (21.4 percent), as is the trend in incidence rates. In fact, these are the largest increases in trends throughout the Affiliate's service area. The weighted average of the proportion of women who reported being screened is 70.0 percent. However, there is a very broad confidence interval of 48.9-85.0 (Table 2.3), leaving ambiguity as to how many were actually screened. Current projections are that it will require over 13 years to accomplish both breast cancer related HP2020 targets.

Socioeconomic characteristics of the area create a concern for access to care. Over 40.0 percent of the population has income below 250 percent of FPL and 18.0 percent are uninsured. As a rural area with no access to public transportation or a local screening site, residents must travel to Orangeburg for the nearest screening or treatment facility.

Marion County

Like the other high priority counties, socioeconomic and health indicators led to the identification of Marion as a community for concern. Marion County has a relatively large Black/African-

American population, low education levels and high poverty. More than 21.0 percent of the residents between the ages of 40-64 are without health insurance (Table 2.5). Well over half of the residents have incomes below 250 percent of FPL, and more than 24.0 percent are below 100 percent of FPL. As in other rural areas, these socioeconomic factors create additional barriers to care.

It is estimated that the county will take more than 13 years to reach both breast cancer related HP2020 targets. Marion County’s rising trend in the late-stage diagnosis rate is of particular concern. At 20.9 percent, the county ranks second only to Calhoun (Table 2.1). It is higher than the state’s falling trend of one percent. It is noteworthy that although this rate is high, the area is not identified as medically underserved as other areas with similar rates (Table 2.8).

Table 2.8. County comparison of medically underserved and late-stage diagnosis trend

County	Medically Underserved*	Late-stage Diagnosis Trend (Annual Percent Change)**
Calhoun	100%	21.4
Marion	64.1%	20.9
Hampton	100%	17.3
Colleton	75.6%	16.8

Source of late-stage data: NAACCR-CIBNA Deluxe Analytic File

Source of medically underserved data: Health Resources and Services Administration (HRSA) for 2013

The Community Profile Team noted that those counties least likely to meet the HP2020 breast cancer targets had several common factors. Every county noted as “highest priority” based on HP2020 projected outcomes has similar key population characteristics, most notably the high percentage of Black/African-American and rural populations. For this reason, the team conducted further research to determine if Black/African-American and rural populations in other Lowcountry counties had similar breast cancer trends. The goal was to determine if these two populations should be considered as target communities in addition to the I-95 Corridor regions.

Few statistics about breast cancer disparities among various races and ethnicities on the state level are readily available. Information specific to disparities in rural communities is nearly non-existent. To find pertinent information, the Community Profile Team contacted the Department of Epidemiology and Biostatistics and the SC Cancer Prevention and Control Research Network at the University of South Carolina. Leading researchers provided the team with several published articles related to breast cancer disparities in SC. It should be noted that some of the articles are over 5 years old. The data may have changed since the writing of the articles but the researchers believe it has not been a significant change. Additionally, the 2010 SC Cancer Report Card supports the information about racial disparities (South Carolina Cancer Alliance, 2010).

“Mapping Cancer Mortality-to-Incidence Ratios to Illustrate Racial and Sex Disparities in a High-Risk Population” (Hébert et al., 2009) looks at health disparities in South Carolina. The most compelling findings are related to mortality-to-incidence ratios (MIRs) between two specific populations. The ratio of Black/African-American women who were diagnosed with breast cancer and died from the disease were compared with White women’s incidence and deaths. Compared to European Americans, the MIRs in SC African-Americans are significantly higher in

all Lowcountry service area counties (Figure 2.2). In fact, Black/African-American women with breast cancer have a 55.0 percent higher MIR than their White counterparts in the same counties. This information is important because MIR is an indicator of death after accounting for the incidence of that cancer. Overall, White women have higher incidence rates than Black/African-American women (SCCA Cancer Report Card, 2010). Dr. Swann Arp Adams, one of the authors of the report, writes:

“... if you use just straight cancer mortality statistics, it just looks like AA women are at an ~ 35% increase in mortality- however, this has not accounted for the fact that AA women, in fact, are less likely to get breast cancer in the first place. So the fewer numbers that do, are actually at greater risk. When we did the calculation with the MIR, you find that the difference is actually greater than 60%!”

Komen Lowcountry’s service area includes SC DHEC regions 4,5,6,7, and 8, or portions thereof. The maps shown in Figure 2 illustrate the glaring differences in MIRs between the two groups of women across SC. Although the DHEC Regions have changed recently, the disparity within the counties has not. These findings led the Community Profile team to conclude that the affiliate’s Black/African-American community as a whole warrants further consideration as a high priority population.

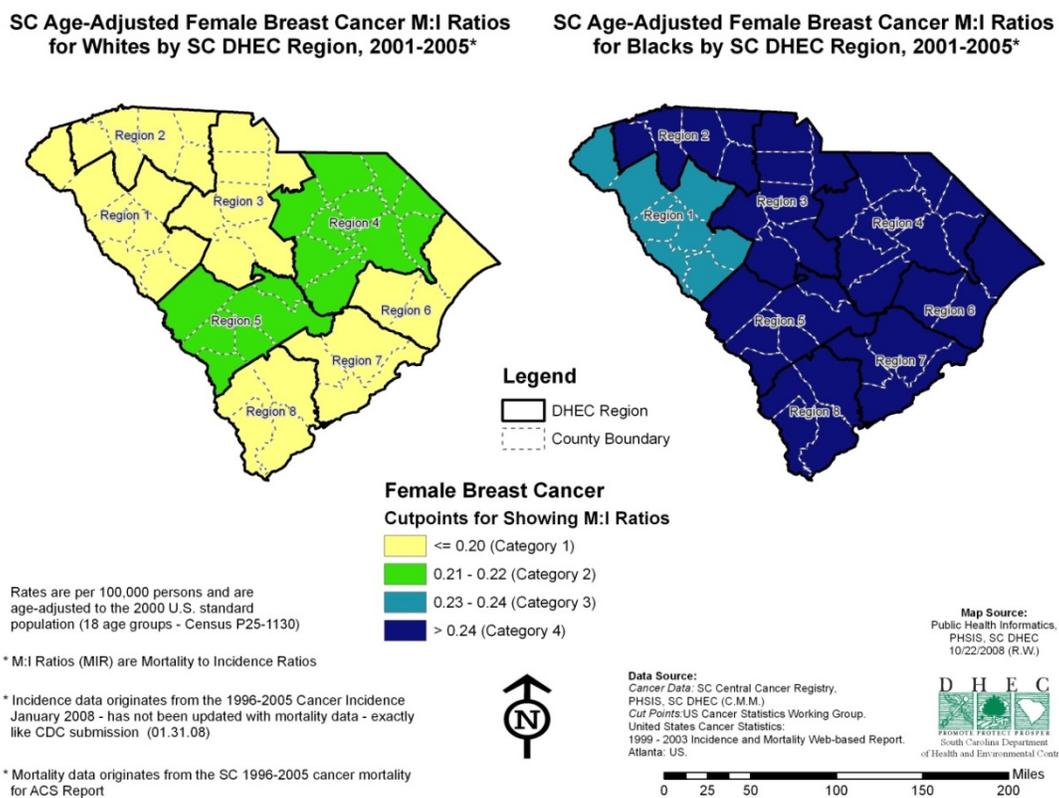


Figure 2.2. Mortality-to-incidence rate (MIRs) ratios of South Carolina Department of Health and Environmental Control (SC DHEC) Health Region for female breast cancer.

As previously noted, statistics specific to breast cancer in rural communities are difficult to find. However, there is documentation to support the lack of access to mammography in rural areas. Findings from the study *“Geographic Disparities in Mammography Capacity in the South: A Longitudinal Assessment of Supply and Demand”* show a decrease of mammography availability and capacity during 2002-2008 across the South (Eberth et al., 2008). It is important to note that this study accounts for geographical locations as well as supply points, rather than simply aggregating data over boundaries such as counties. Evidence showed that large contiguous areas remained without adequate access throughout the period studied. Additionally, even though the balance of supply and demand improved, places with poor capacity remained unchanged. In fact, the researchers found that the number of women living in poor capacity areas rose by ten percent over the six year study period.

Dr. Jan Eberth summarizes her findings on the use of mammography in rural areas in the presentation *“Access and Utilization of Mammography in SC”* (2014). She notes that the demand for mammography is expected to increase as more women age into the recommended screening group, and uninsured women get insurance through the Affordable Care Act. However, the workforce is declining and there has been a reduction in the supply of mammography machines across the state. This leaves women in rural areas without access to mammography services.

A third population of concern to the Community Profile Team is the growing Hispanic/Latino population. The largest Hispanic/Latino communities are located in Beaufort (10.6 percent and Jasper (12.3 percent) counties (Table 2.4). Breast cancer is the most common cancer among Hispanic/Latino women, though incidence and death rates are lower than non-Hispanic and Black/African-American women. The primary concern is the late-stage diagnosis Rates and Trends of Hispanic/Latino women in South Carolina (Table 2.1). This population’s rising trend of 5.2 percent is considerably more than that of any other named racial or ethnic group. When reviewing the proportion of women who’ve been screened within the last two years, it is important to note the confidence interval. The weighted average is higher (80.9 percent for Hispanics and Latinas than any other group. However, the confidence interval is 32.6-97.4 percent, a huge variation (Table 2.3).

Another challenge for the Hispanic/Latino community is isolation. Those counties with the largest Hispanic/Latino populations have higher percentages of residents who are foreign born and linguistically isolated. These communities also face social and medical isolation. The Community Profile Team recognizes the need to investigate the issues surrounding late-stage diagnosis for the Hispanic/Latina population. Barriers may include language and health literacy, as well as geographical distance from providers.

Komen Lowcountry recognizes that Black/African-American, rural, and Hispanic/Latino women face challenges throughout the entire service area. However, those counties within the I-95 Corridor regions face the most significant ones and will be the focus of further investigation for the purposes of this report.

The Health Systems Analysis

A comprehensive health systems analysis is necessary to understand the challenges of the priority populations in the target communities. The analysis will include a closer look at available resources, as well as the impact of public policy and the Affordable Care Act.

The Health Systems Analysis (HSA) will study access to breast cancer screening and treatment for the Affiliate's especially vulnerable low-income populations within the target communities. This will include area providers participating in the Best Chance Network, South Carolina's breast and cervical cancer early detection program. As a predominantly rural, medically underserved region, this is of particular importance. If services are not locally available, women may delay screening and treatment. Due to the large percentage of Hispanics in Jasper County, the health systems analysis will delve into health care resources specifically available for this population. Specific to Marion County, the Health Systems Analysis will look into possible factors, such as quality of care, for the discrepancy between service availability and late-stage diagnosis.

Health Systems and Public Policy Analysis

Health Systems Analysis Data Sources

A comprehensive understanding of available services and programs is necessary to identify potential barriers to care faced by those living within the target communities. One goal of the Health Systems Analysis is to determine where there is a physical lack of medical services, which may in turn lead to gaps in the continuum of care. It is also important to understand the quality of those services that are available. Major changes have occurred in the diagnosis and treatment of breast cancer over the past decade, leading to better and more individualized options for patients. Those living in medically underserved communities may not have access to these advancements.

As a grantmaker in the area for more than twenty years, the Affiliate has established strong relationships with the local providers serving these regions. To confirm currently available services, the Community Profile Team called each provider's office and asked about their services specific to breast health and breast cancer. Providers' websites were also reviewed for pertinent information. The list of providers included current and past grantees of the Affiliate, as well as those found through a number of additional resources. A spreadsheet was used to track available services within each target community. These services included mammography, diagnostic services and treatment. Survivor support services were also noted. The Team then identified the gaps in care based on a review of the information gathered.

All mammography centers are required by law to be FDA certified, meeting baseline quality standards for equipment, personnel, and practices. The FDA's list is updated weekly on <http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMQSA/mgsa.cfm> and was accessed on July 13, 2014, for this report. Additional providers were identified by internet searches. The following list includes the type of providers searched and where the information was found:

Hospitals registered with Medicare: The Centers for Medicare & Medicaid Services
<https://data.medicare.gov/Hospital-Compare/Hospital-General-Information/v287-28n3>

Local health departments: The National Association of County and City Health Officials (NACCHO)
<http://www.naccho.org/about/lhd/>

Community health centers, including federally qualified health centers (FQHC) and FQHC look-alikes: the Health Resources and Services Administration (HRSA)
http://findahealthcenter.hrsa.gov/Search_HCC.aspx

Free and charitable clinics: The National Association of Free and Charitable Clinics
<http://www.nafclinics.org/clinics/search>

In an effort to determine quality of care, providers were also asked about accreditation. However, the contact person rarely knew what, if any, accreditations their organization had received. Internet searches provided the majority of this information, which was also tracked on the spreadsheet. Mammography centers with the American College of Radiology (ACR) Breast

Imaging Center of Excellence gold seal were noted. All recorded accreditations were found on the following websites:

- American College of Radiology Centers of Excellence
 - <http://www.acr.org/Quality-Safety/Accreditation/Accredited-Facility-Search>
- The American College of Surgeons Commission on Cancer
 - http://datalinks.facs.org/cpm/CPMAApprovedHospitals_Search.htm
- The American College of Surgeons National Accreditation Program for Breast Centers (NAPBC)
 - <http://napbc-breast.org/resources/find.html>
- National Cancer Institute Designated Cancer Centers
 - <http://www.cancer.gov/researchandfunding/extramural/cancercenters/find-a-cancer-center>

Health Systems Overview

An understanding of the process a woman would ideally follow for breast care is important to identify potential gaps in care. The Breast Cancer Continuum of Care (CoC) is a model showing how a woman typically moves through the health care system for breast care. Breast cancer in men is rare. Therefore the CoC addresses women for the purposes of this report.

A woman should move through the CoC quickly and seamlessly, meaning she should receive timely, quality care in order to have the best outcomes. Education can play an important role throughout the entire CoC.

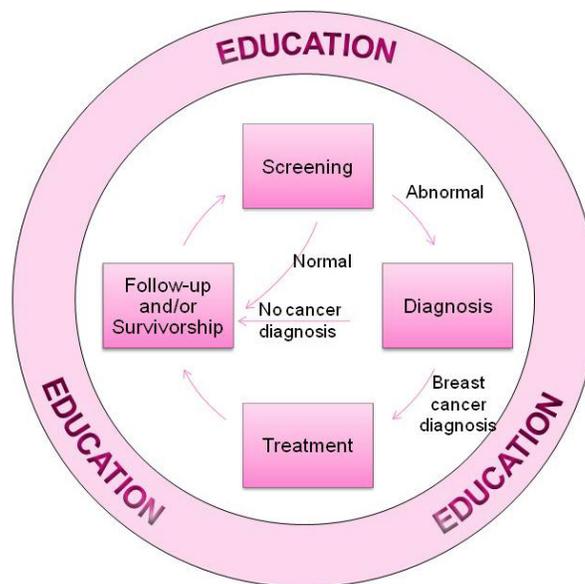


Figure 3.1. Breast Cancer Continuum of Care (CoC)

A woman may enter the continuum of care at any point. Ideally she would enter with an initial recommended screening- a clinical breast exam or a screening mammogram. If the screening test results are normal, she would loop back into follow-up care, where she would get another screening exam at the recommended interval.

If a screening exam resulted in abnormal results, diagnostic tests would be needed to determine if the abnormal finding is breast cancer. These tests might include a diagnostic mammogram, breast ultrasound or biopsy or a combination of these. If the tests were negative (or benign) and breast cancer was not found, she would go into the follow-up loop, and return for screening at the recommended interval. The prescribed intervals may range from three to six months for some women to 12 months for most women.

If breast cancer is diagnosed, she should proceed to treatment. For some breast cancer patients, treatment may last a few months. For others, it may last years. Although the CoC model shows that follow up and survivorship follow treatment, they might actually occur at the same time. Follow up and survivorship may include navigating insurance issues, locating financial assistance and symptom management (pain, fatigue, sexual issues, bone health, etc.). Most women will return to screening at a recommended interval after treatment ends, or for some, during treatment (such as those taking long term hormone therapy).

Education plays a role throughout the CoC. It encourages women to get an initial screening and reinforces the need to continue routine screening thereafter. It also plays a role in communicating the importance of keeping all appointments, proactively getting test results and understanding them, and learning how to use the information. Education can empower a woman and help manage anxiety and fear.

Education at the diagnosis and treatment stages is also important. It can cover topics such as treatment options, how pathology reports help determine the best options for treatment, understanding side effects and their management, and helping to formulate questions a patient may have for her providers.

Post-treatment and follow-up education may address topics such as making healthy lifestyle choices, long term effects of treatment, managing side effects, the importance of follow-up appointments, and communication with their providers. Overall, education is a key component throughout the CoC.

Although regular screening is not recommended for men, their CoC is similar to women's. The steps to diagnose breast cancer in men include a complete medical history, clinical breast exam, mammogram and biopsy. Men should report any unusual breast changes to their doctors and request appropriate screening or diagnostic services. Treatments for breast cancer are the same for both sexes.

There are often delays in moving from one point to another in the continuum- at the point of follow-up of abnormal screening exam results, starting treatment, and completing treatment - any of which can contribute to poorer outcomes. There are also many reasons why someone does not enter or continue in the breast cancer CoC. These barriers can include things such as lack of locally available services, lack of insurance or financial aid, 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). Culturally sensitive education can address some of these barriers and help a woman progress through the CoC more quickly. Women also need education about locally available resources such as transportation and translation services and financial aid.

There are major gaps in the continuum of care in each target community in the I-95 Corridor. It is important to remember that most of these communities encompass several counties. Although a service may be available within a region, a patient may have to travel one or more counties away from home in order to access it.

Breast health education is also very limited in all four target regions due to financial constraints and lack of resources. Overall, the majority of breast health education is done by individuals. The primary source for formalized breast health education in these four regions has been The Witness Project. This community-based program is a National Cancer Institute (NCI) research-tested intervention designed to increase breast cancer screening and promote the practice of mammography among underserved Black/African-American women. Due to lack of funding, The Witness Project has had to greatly reduce their programs. Komen Lowcountry is a past funder of the program and continues to work closely with those trained in the program. The Affiliate continues to provide education materials to organizations and individuals in the region through Mission programs including Worship in Pink, a faith-based community initiative reaching Black/African-American, Hispanic/Latino and rural women.

Southern Region: Colleton, Hampton, Jasper

The Southern region of the I-95 Corridor has limited access to the full continuum of care. Most patients needing anything beyond a screening mammogram must travel outside the region. Clinical breast exams are available through five FQHCs in the region but patients must be referred elsewhere for all other services. These FQHCs are providers for the Best Chance Network (BCN), South Carolina's National Breast and Cervical Cancer Detection Program (NBCCEDP). Treatment and support services are especially hard to find and reconstruction is not available within any of these counties. There are no known breast health education programs currently serving these counties.

Hampton Regional Medical Center, a nonprofit community hospital in Varnville, offers digital mammograms for Hampton County residents. Additional services include diagnostics, ultra-sounds, MRIs, and surgery. However, access is very limited due to the lack of physicians in the area. The region is primarily served by doctors who visit on a rotating basis. The hospital's radiology department is designated an American College of Radiology Breast Imaging Center of Excellence and is a BCN provider.

Screening mammography is also available at Colleton Medical Center, a for-profit hospital located in Walterboro, SC. Services include diagnostics, ultra-sounds, MRIs, and surgery. The hospital is an American College of Radiology Breast Imaging Center of Excellence and a BCN provider. Financial aid is available on a very limited basis.

Screening services for Jasper County are available through the Chelsea Clinic of Beaufort-Jasper-Hampton Comprehensive Health Services (BJHCHS). BJHCHS has four locations within

the region but only the Chelsea Clinic provides mammography. The other clinics provide clinical breast exams (CBE) and refer patients to Chelsea or Port Royal (Beaufort) for mammograms. BJHCHS is an FQHC and services are typically paid on a sliding scale. BJHCHS is an American College of Radiology Breast Imaging Center of Excellence and a BCN provider. BJHCHS is also a long-time grantee of Komen Lowcountry. Their Komen funded program provides free screening and limited funding for diagnostic services. BJHCHS also provides Spanish translation services and patient navigation. There are no other breast care services available within the county. Residents needing diagnostic or treatment services are typically referred to Beaufort Memorial Hospital because it is closer than Charleston.

Chemotherapy is not readily available in the region. It is not offered at all in Colleton or Jasper and only with very limited access in Hampton, where an oncologist visits on a rotating basis. Patients in the region needing radiation or more comprehensive treatment must travel to Charleston, Beaufort or Orangeburg.

Survivor support groups are also very limited in these counties. Hampton Regional Medical Center has a survivor support group which meets on a monthly basis. The United Way of Colleton and Hampton Counties has a newly established support group for survivors in Colleton. There are no survivor support groups in Jasper County. There are also no survivor support services such as wigs, prosthetics, etc. in the Southern region of the I-95 Corridor.

Colleton, Hampton, & Jasper Counties

 Hospital	 Community Health Center	 Other
 Free Clinic	 Department of Health	 Affiliate Office



Statistics

Total Locations in Region: 6

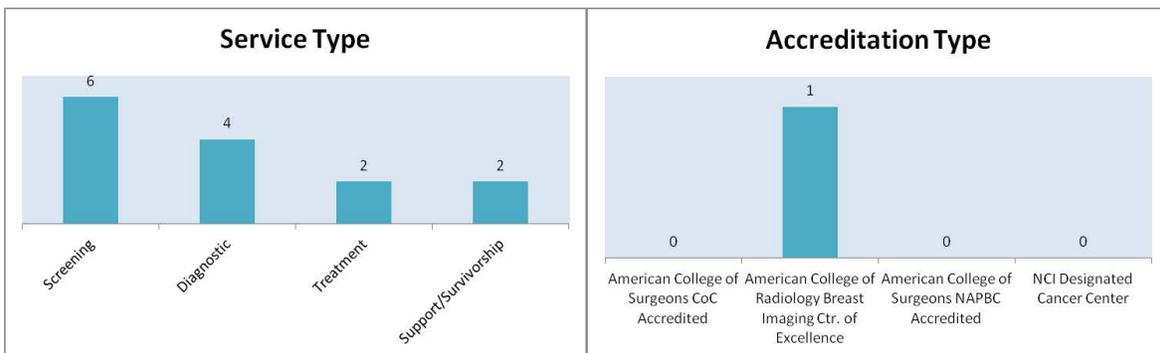


Figure 3.2. Breast Cancer Services Available in Southern Region: Colleton, Hampton, Jasper

Southwestern Region: Allendale, Bamberg, Barnwell

The Southwestern region of the I-95 Corridor is lacking most CoC services. Residents of this region must travel outside of their home counties for most services. The community hospitals in Barnwell and Bamberg counties recently closed. Clinical breast exams and screening mammograms are available on a very limited basis in Allendale and Barnwell counties. No breast care services are available in Bamberg County. No reconstruction services are available locally, and survivor support groups and services are seemingly non-existent in the region. Breast health education is provided on a limited basis through Allendale County Hospital and Low Country Health Care System, both of which are located in Allendale. Education is available in both English and Spanish.

CBEs are available through the health department in Denmark and at Low Country Health Care System. Both are located in Allendale County. Neither the Allendale nor Barnwell county health departments offer any direct services for breast care.

Allendale County Hospital (ACH) provides screening mammograms for all three counties, but other services must be accessed in Orangeburg, Charleston or Columbia. ACH is a long time Komen Lowcountry grantee and partners with The Regional Medical Center of Orangeburg and Calhoun Counties (TRMC) for diagnostic and treatment services. The ACH grant provides free mammograms to uninsured and underinsured patients. Patients requiring diagnostic services and treatment are referred to TRMC. The partnership includes limited funding through the organizations' Komen funded grants for diagnostic procedures. ACH is also a BCN provider.

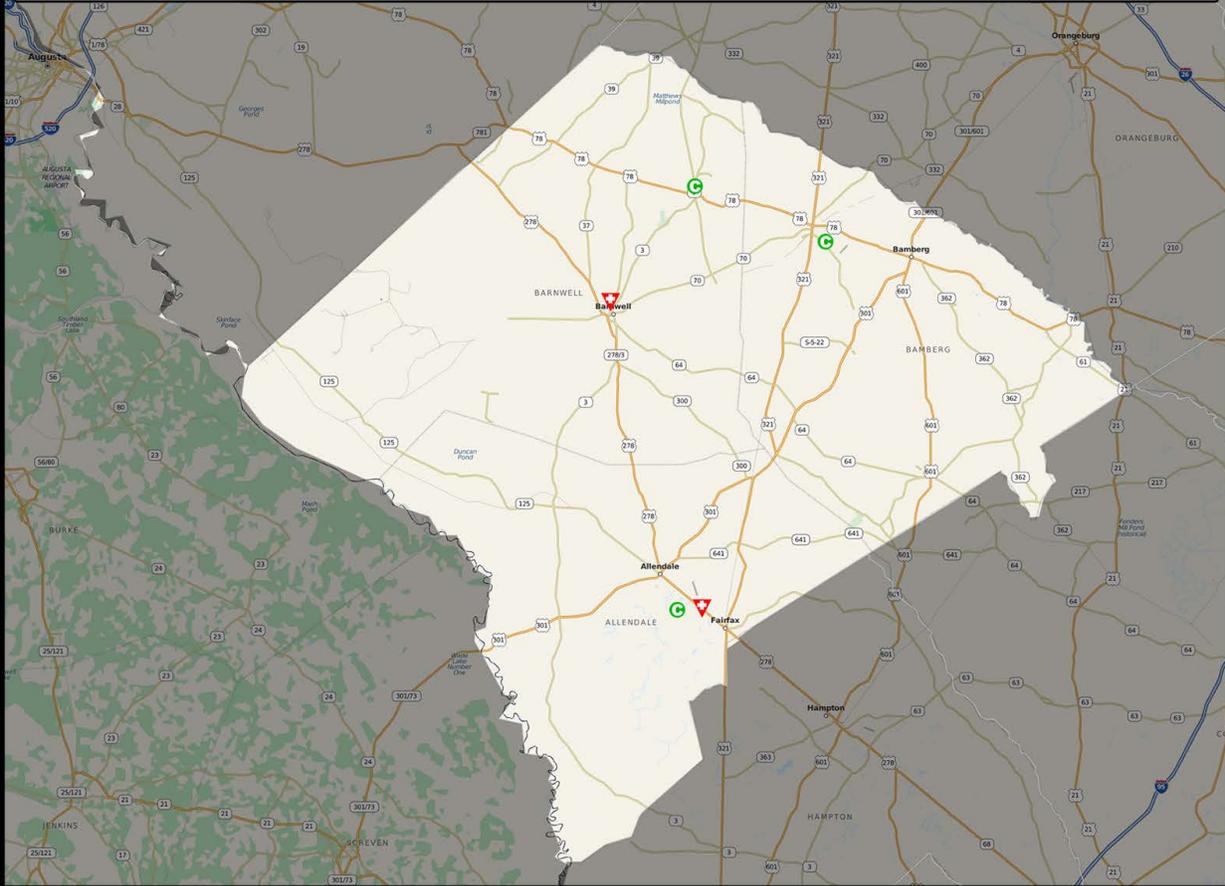
Low Country Health Care System (LHCS), an FQHC and a BCN provider, has three locations serving Allendale and Barnwell counties. Their Family Medical Center of Blackville in Barnwell provides screening mammograms. Patients at the other LHCS sites are referred elsewhere for screening. The Allendale site is located next door to ACH, so those patients are screened at the hospital. LHCS also provides interpreters for the Spanish speaking population. Barnwell patients are referred to the Blackville site for screening.

Southern Palmetto Hospital recently moved into the former Barnwell County Hospital location and is a BCN provider. Southern Palmetto offers screening and diagnostic mammograms as well as ultrasounds but provides no financial aid. Southern Palmetto Hospital is the only provider in the three-county region that is designated an American College of Radiology Breast Imaging Center of Excellence. This information was provided by hospital staff. The organizations' website was under development at the time of this report.

Survivor support services are also lacking in the Southwestern Region. No support groups were identified in the Community Profile Team's research. Additionally, there are no local providers of wigs, prosthetics, lymphedema treatments, etc.

Allendale, Bamberg & Barnwell Counties

+ Hospital
 C Community Health Center
 O Other
F Free Clinic
 + Department of Health
 ☆ Affiliate Office



Statistics

Total Locations in Region: 5

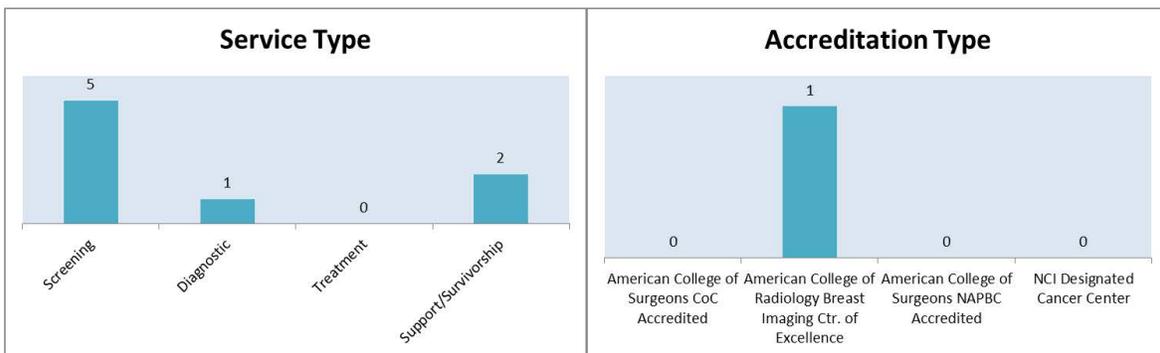


Figure 3.3. Breast Cancer Services Available in Southwestern Region: Allendale, Bamberg, Barnwell

Western Region: Orangeburg, Calhoun

The Western region of the I-95 Corridor is primarily served by The Regional Medical Center of Orangeburg and Calhoun Counties (TRMC), located in Orangeburg. No breast care services are physically located in Calhoun County. In Orangeburg, CBEs are available at two family health centers and a free clinic. Family Health Centers and Norfield Medical Center are BCN providers. However, the free clinic is not.

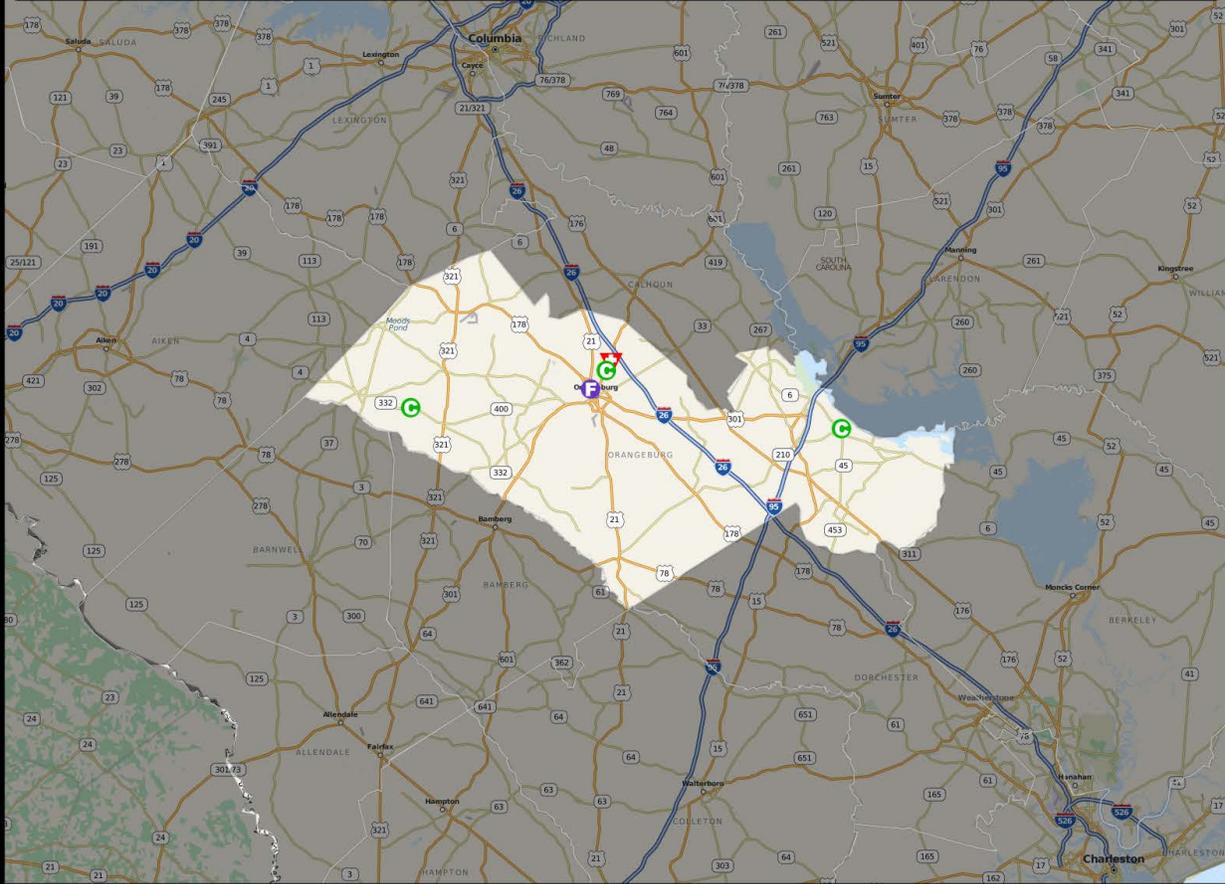
TRMC services cover the full continuum of care and is a BCN provider. Screening and diagnostic mammograms, ultrasounds, biopsies, chemotherapy, surgery and radiation are all available on site. This is the location residents from many other counties in the I-95 Corridor travel to for services. TRMC also has a mobile mammography unit which has begun serving the surrounding counties. A committed staff provides navigation for patients seen in the TRMC Breast Center.

TRMC is a long-time grantee of Komen Lowcountry and is therefore able to offer financial aid providing free screenings and diagnostic services. Additionally, the hospital has a Pink Ribbon Fund to offset patient expenses. The hospital is designated an American College of Radiology Breast Imaging Center of Excellence and is accredited by the American College of Surgeons Commission on Cancer. RMC is also the sole provider in the region for survivor support services. The hospital has an active survivor support group, as well as a well-stocked shop offering bras, wigs, lymphedema garments, etc.

The current lead mammographer at TRMC has been heavily involved with the local community, using her personal time to provide breast health education at numerous locations including local colleges and churches for more than ten years. She is an example of the individuals striving to decrease the impact of breast cancer on their communities.

Orangeburg & Calhoun Counties

 Hospital	 Community Health Center	 Other
 Free Clinic	 Department of Health	 Affiliate Office



Statistics

Total Locations in Region: 5

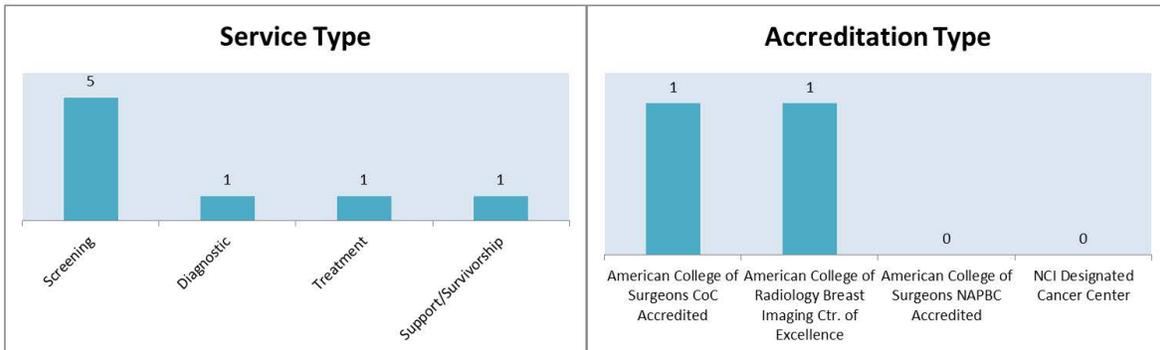


Figure 3.4. Breast Cancer Services Available in Western Region: Orangeburg, Calhoun

Marion County

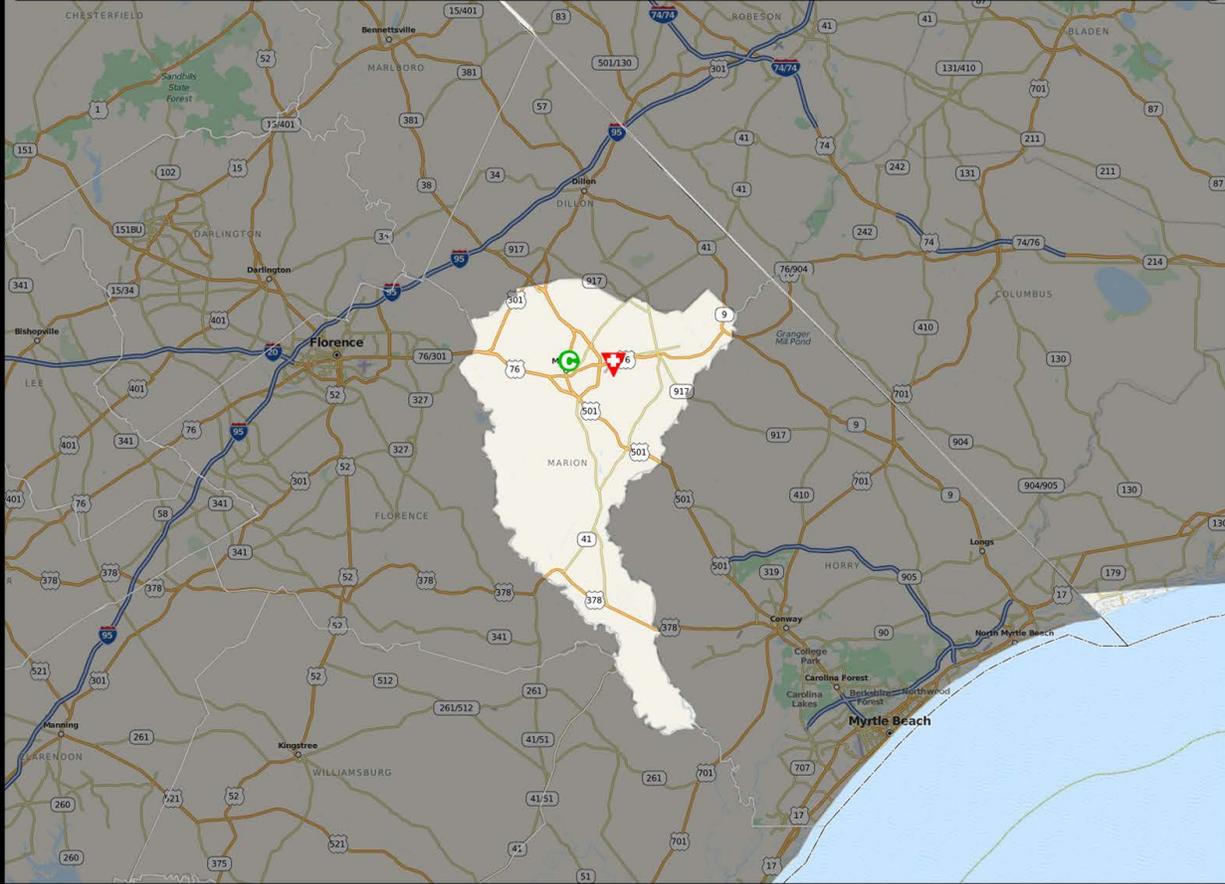
Like other target communities, Marion County is severely lacking in services. The Carolinas Hospital System (CHS), a for-profit entity, is the sole local provider of screening and diagnostic services in Marion. CHS also offers ultrasounds, MRIs, biopsies and surgery in Marion County. The hospital is accredited by both the National Accreditation Program for Breast Centers (NAPBC) and the American College of Surgeons Commission on Cancer. CHS does not provide financial aid. However, it is a BCN provider.

Marion's residents typically travel to Florence for services at either the Carolinas Hospital System or McLeod Regional Medical Center (MRMC). MRMC is a Komen Lowcountry grantee and the nonprofit hospital serving the region. The center is able to offer financial aid to those in need. MRMC is the only "Comprehensive Community Cancer Program" in the region accredited by the American College of Surgeons' Commission on Cancer. The McLeod Breast Health Center is recognized by the NAPBC, and the McLeod Radiation Oncology Department has earned accreditation from the American College of Radiology (ACR). McLeod also has a mobile mammography unit (MMU) that travels to Marion County on a routine basis. By partnering with local community health centers, screening services are provided on site. However, any follow up or diagnostic services must be received in Florence. The MMU's services are partially funded by a Komen Lowcountry grant and the McLeod Foundation.

One option for screening in some of these medically under-served regions is the use of The Medical University of South Carolina's (MUSC) mobile mammography unit. However, MUSC is located in Charleston so travel to these areas is expensive for the unit. Patients needing follow-up or treatment would likely have to travel to Charleston. For many, one-way travel is two hours or more.

Marion County

 Hospital	 Community Health Center	 Other
 Free Clinic	 Department of Health	 Affiliate Office



Statistics

Total Locations in Region: 2

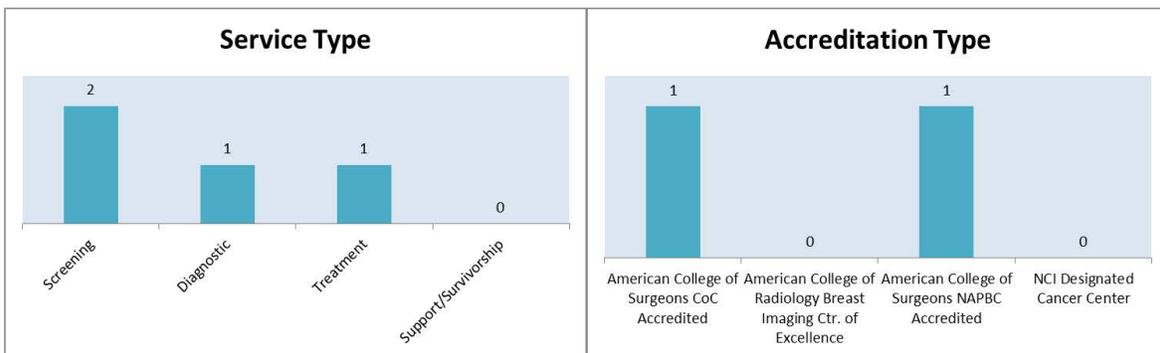


Figure 3.5. Breast Cancer Services Available in Marion County

Target Community Partnerships

Throughout these four I-95 Corridor regions, the Affiliate must strengthen current relationships and develop new ones. Current partnerships include McLeod Regional, Allendale County Hospital, The Regional Medical Center, Beaufort-Jasper-Hampton Comprehensive Health, Lowcountry Health Care System, United Way of Colleton and Bamberg, MUSC, and the Best Chance Network. The Affiliate is establishing new relationships with the Carolinas Hospital System and Colleton Medical Center.

Komen Lowcountry is actively involved in several key initiatives serving these regions and is a member of the Community Advisory Group for the South Carolina Cancer Disparities Network. Another key partnership for the Affiliate is with the faith-based community. Churches are a primary source of information for Black/African-American and rural communities. Working with the South Carolina Cancer Alliance on education and policy is another opportunity to reach these underserved populations. Local organizations and hospitals must collaborate to improve access to the limited services. Creating regional collaboratives or joining existing ones may provide additional opportunities to address the needs of these communities.

Public Policy Overview

National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

South Carolina's National Breast and Cervical Cancer Early Detection Program (NBCCEDP) is the Best Chance Network (BCN). BCN has been funded through the Centers for Disease Control and Prevention (CDC) since 1991. Since 2000, the program has been federally funded on an annual basis with additional state funding periodically. The state budget has included a one million dollar appropriation for BCN for the past two years. Additionally, Komen Lowcountry granted funds for the program in 2012 and 2013. Amelyn Olson, BCN Program Director, reports that 11,703 women were served this past program year (June 30, 2013 to June 29, 2014). Since 1991, 101,361 women have been served by the program.

BCN provides free breast and cervical cancer screening tests to women. Women may qualify if they are South Carolina residents, between the ages of 40-64, uninsured, and have a household income at or below 200 percent of federal poverty guidelines. For this program year, the minimum age requirement is 40, but it may go back to age 47 if the state does not continue to support the program financially. For more information, a woman must call the American Cancer Society at 800-227-2345 and ask about the South Carolina Best Chance Network. She will then be directed to a local provider, although the full range of covered services may not be available there.

Women screened through BCN are eligible to apply for Medicaid coverage for treatment of breast and cervical cancer. In July 2005, the State Legislature appropriated additional funding to expand the Medicaid coverage for breast and cervical treatment to women under the age of 65 who are not enrolled in the BCN program and who meet the income and insurance guidelines. This was considered NBCCEDP Treatment Option 3, though the terminology is no longer used.

The Healthy Connections Check-up initiative has created additional barriers for the most vulnerable populations. It is a limited benefit Medicaid plan, formerly known as Family Planning,

and serves men and women of all ages with an income at or below 194 percent of Federal Poverty Level (FPL) who are ineligible for any other Medicaid program. The program provides a comprehensive physical examination every two years for those SC residents who would have been covered under Medicaid had the state expanded it. However, patients are left without coverage for follow-up or treatment. Screening mammograms are available only to women over the age of 50 and there is no coverage for follow-up, diagnostic or treatment services. Women under 50 are not eligible for screening mammograms through the program. This is in contrast to the State Cancer Control Plan, which recommends annual screening starting at age 40 for women at average risk.

Healthy Connections' Breast and Cervical Cancer program is directly linked to BCN, providing full Medicaid benefits to uninsured women who are in need of treatment for breast or cervical cancer or pre-cancerous lesions. A woman must meet the following criteria for eligibility:

- Be under age 65
- Be screened by a physician or through BCN and found in need of treatment for one of the following:
 - Breast cancer
 - Cervical cancer
 - Pre-cancerous lesions (CIN 2/3 or atypical hyperplasia)
- Not have other insurance coverage that would cover treatment for breast or cervical cancer or pre-cancerous lesions, including Medicare Part A or B
- Income at or below 200 percent of federal poverty level (FPL)
- Not be eligible for another Medicaid eligibility group

Because access to treatment for breast cancer is through BCN, men are ineligible for coverage. This was a well-publicized issue for a SC man diagnosed with breast cancer in 2011. He was not eligible for Medicaid funded treatment due to his sex but met all other requirements for coverage. It required the work of a state legislator to get the patient access to treatment under Medicaid.

Komen Lowcountry has a strong relationship with BCN. Over the years the Affiliate's advocacy work has been key in gaining state funding for the program. In 2009, Komen Lowcountry joined other cancer organizations in successfully advocating for a \$2 million appropriation in the state budget. Though the same level of funding has not been received since then, the last two budgets have included a \$1 million appropriation. Additionally, the Affiliate has provided grants to BCN (2012 and 2013) and continues to work closely with program staff on education initiatives. Affiliate staff have also been instrumental in opening dialogue between BCN and area providers. BCN representatives are featured speakers at a number of Affiliate events including grantee workshops and trainings. The Affiliate values this partnership and will continue to nurture it for the next four years and beyond. Plans include on-going advocacy for BCN funding, partnering on education and outreach opportunities, and educating the public and providers about the program.

State Comprehensive Cancer Control Coalition

The South Carolina Cancer Alliance (SCCA) is the state Comprehensive Cancer Control Coalition and the author of the state's Comprehensive Cancer Control Plan. Komen Lowcountry has been an active member since 2007, participating on the Breast and Female Cancer Workgroup and Public Policy Task Force. The Cancer Control Plan is being updated for 2015. The current version (2011-2015) can be found at online at www.sccanceralliance.org and includes the following breast cancer goals and objectives:

Goal 1: To reduce breast cancer deaths in South Carolina through increased awareness, early detection and diagnosis.

- Objective 1: By December 31, 2013, to secure recurring state funding for breast cancer screening through the Best Chance Network program.
- Objective 2: By December 31, 2015 to increase from 83.6 percent to 86.0 percent the proportion of women age 40 and older who have received a clinical breast exam within the preceding two years.
- Objective 3: By December 31, 2015, to increase from 74.5 percent to 80.0 percent the proportion of women age 40 and older who have received a mammogram within the preceding two years.
- Objective 4: By December 31, 2015, 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.

Goal 2: To reduce the burden of breast cancer in South Carolina through high quality cancer treatment

- Objective 1: By December 31, 2015, to increase by 20 percent the percentage of women with non-metastatic breast cancer who receive surgical resection.
- Objective 2: By December 31, 2015, to increase by 20 percent the percentage of women under age 70 who receive breast-conserving surgery and radiation therapy within 365 days of their diagnosis.
- Objective 3: By December 31, 2015 to increase by 20 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.
- Objective 4: By December 31, 2015, to increase by 20 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.
- Objective 5: By December 31, 2015, to increase by 20 percent the percentage of patients receiving lumpectomy instead of mastectomy when appropriate.

The Affiliate will continue to be an active partner with the SCCA to reduce the burden of breast cancer on the state. Affiliate staff and volunteers will attend alliance meetings and participate on work groups and task forces pertinent to Komen's mission. The Affiliate will also encourage its constituents to learn more about the SCCA.

Affordable Care Act

The state of South Carolina did not expand Medicaid or accept federal funding for the program. Had the state expanded Medicaid in 2014, the federal match would be 100 percent. The match would continue to adjust until 2020 when the match would stay at 90.0 percent. The lack of Medicaid expansion will have a major impact on the poor in the state, as well as medical providers. In South Carolina, 194,000 uninsured adults (a quarter of the uninsured in the state) making below 138 percent of FPL are left without affordable coverage (<http://kff.org/health-reform/fact-sheet/state-profiles-uninsured-under-aca-south-carolina/>). Providers' reimbursement rates have been reduced, forcing some to close their practices and others to refuse Medicaid patients. As mentioned previously, several community hospitals have already closed.

The Affordable Care Act (ACA) was not welcomed by the majority of South Carolina's political leaders. In fact, the state has joined several lawsuits to repeal all or parts of it. The ACA requires that each state have an insurance marketplace. South Carolina did not create its own and therefore defaulted to a Federal Exchange.

The Kaiser Family Foundation reports that prior to the implementation of ACA, an estimated 771,000 South Carolinians (17.0 percent) were uninsured. Approximately 213,974 residents were eligible for Marketplace coverage but only 118,324 had selected a plan as of March 19, 2014. An estimated 189,000 were not eligible for the Marketplace due to income, employer provided insurance or immigration status. It should be noted that those who enrolled in the marketplace included individuals who had insurance prior to ACA as well as individuals who were previously uninsured. As of June, 2014, there were approximately 6,000 more insured residents since the implementation of ACA (<http://kff.org/health-reform/state-indicator/state-marketplace-statistics/>).

It is difficult to determine the full impact of ACA on NBCCEDP at this time. ACA requires coverage of Essential Health Benefits, including recommended screening for breast cancer. With more women accessing insurance, there may be a drop in the number of women eligible for BCN. However the gap in access to insurance will continue to impact the program. There are also populations that will remain uninsured including:

- Undocumented immigrants
- Individuals eligible for Medicaid but not enrolled
- Individuals exempt from mandate (i.e. no income tax, religious exemptions, or other hardships)
- Those who choose to remain uninsured and pay the penalty

Navigation will likely be a key component for both the insured and uninsured. Although ACA provides Essential Health Benefits, patients need assistance with the complexities of health care regardless of their insurance status. A woman receiving abnormal results from a screening mammogram may not know the next steps for appropriate follow-up and care. This is of particular concern in those regions without local providers.

ACA may impact physicians in a number of ways, most of which affect profitability. This will likely have the greatest impact in rural areas already struggling economically. ACA requires an investment in electronic health records. Additionally, patients' high out-of-pocket payments may

create a cash flow issue for physicians if not carefully monitored. Medscape reports that it may be difficult for a practice to know how much a patient is responsible for because the deductible changes each time the patient pays for care. Usually a practice has to collect these charges up front, before providing care. Some practices require credit card authorization prior to seeing the patient (http://www.medscape.com/viewarticle/809357_3). With more people having insurance, doctors may also see an increase in their patient loads.

Recent lawsuits in response to ACA have led to confusion about eligibility for subsidies and mandates related to employer coverage. The Affiliate will continually re-assess the impact and implications of ACA as it progresses. By staying informed of the evolving medical landscape, Komen Lowcountry will have the information necessary to make appropriate decisions guiding grantmaking and Mission programs.

Affiliate's Public Policy Activities

Komen Lowcountry is active in the public policy arena, primarily through its work with the SCCA. Fourteen volunteers joined Affiliate staff at the most recent SCCA Lobby Day at the State Capital in 2012. Volunteers also attend legislative breakfasts sponsored by the SCCA where they have the opportunity to speak one-on-one with political leaders. SCCA member meetings are held on a semi-annual basis, with monthly work group meetings. Public Policy work that the Affiliate is currently focused on includes:

- Protecting federal and state funding for the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), to ensure all women have access to potentially lifesaving breast cancer screening
- Ensuring continued federal investment in cancer research through the National Institutes of Health (NIH), National Cancer Institute (NCI) and Department of Defense (DOD), to discover and deliver the cures
- Requiring that insurance companies provide coverage for oral anti-cancer drugs on a basis that is no less favorable than what's already provided for intravenously-administered chemotherapy, to protect patients from high out-of-pocket costs
- Expanding Medicaid coverage to ensure the availability of the full-range of breast health services to low-income women, including cancer screening, diagnostics and treatment

Health Systems and Public Policy Analysis Findings

The greatest needs of the target communities are directly related to lack of locally available services. Clinical breast exams and BCN providers are available in every county but most residents must travel an hour or two for a screening mammogram. For many, diagnostic and treatments services are more than two hours away. Those living in Allendale, Barnwell, Calhoun, and Jasper have no local access to diagnostic or treatment services. Hampton's residents have limited diagnostic, ultrasounds and surgery services dependent on physicians' schedules. Limited services are available in Marion and Colleton Counties but there is no financial aid. Orangeburg County is the only county in these regions that has both diagnostic and treatment services readily available, as well as financial aid. It is also the only county in these regions with readily available chemotherapy. Reconstruction is not available in any of these nine counties. All of these target counties struggle with education efforts and survivor support services are few and far between.

A collaborative effort is necessary to truly make an impact in these communities. It is through partnerships with community hospitals, local health departments and clinics, churches, colleges and universities, and community leaders that disparities can be reduced. The Affiliate will continue to build on existing relationships and foster new ones including Palmetto Southern Hospital and Carolinas Hospital System.

Current state public policy creates barriers to breast health care for many and is a major issue for the South Carolina Cancer Alliance. South Carolina's decision not to expand Medicaid leaves the poorest South Carolinians without access to affordable care. These women and men are more likely to face a late-stage diagnosis and have worse outcomes than those who are able to access care. With physicians refusing Medicaid patients and community hospitals closing, it has become more difficult to find a local provider. It is unclear at this time how BCN will be affected by the state's policy decisions.

Public policy is key to Komen's mission of providing equal access to quality care for all. The expansion of Medicaid could provide affordable access to care for thousands of women. Funding for BCN is not a recurring budget item, so must be advocated for annually. Oral parity would allow some patients the opportunity to be treated without a daily visit for chemotherapy. The Affiliate's policy work will continue to focus on those things that can reduce the disparities seen in the service area including Medicaid expansion, continued state funding for BCN, oral drug parity, and affordable access to quality care.

Qualitative Data: Ensuring Community Input

Qualitative Data Sources and Methodology Overview

Methodology

A review of the Health Systems Analysis allowed the Community Profile Team to identify physical gaps in care faced by the identified priority populations. In order to identify additional key variables likely to influence breast cancer outcomes in these medically underserved communities, the Team used several data collection methods including key informant and provider interviews, focus groups and document review. Additionally, surveys were developed and distributed via email to providers and key informants. The Team also hosted one round-table discussion.

These methods were chosen to provide the most detailed insight into the barriers faced within the target communities. Getting the community's perspective allowed for a greater understanding of the challenges before them, giving more detail than what is provided by quantitative statistics. Speaking directly to them allowed for deeper discussion and follow up questions for clarification. The Team also reviewed the 2011 Komen Lowcountry Community Profile (2011CP) which included qualitative information collected from focus groups and interviews within these priority populations. This allowed for perspectives from a larger sampling and broader range of participants.

After reviewing the Quantitative Data and the Health Systems Analysis, several questions were raised:

1. Where does the target population go for breast health information?
2. Where does the target population go for breast health/cancer care?
3. What additional barriers to care does the target population face?

The goal was to identify physical access to and utilization of breast care services, as well as potential cultural and socio-economic barriers. Key assessment and variable questions were formed to help identify potential barriers to screening and/or treatment in these communities:

1. Where does the target population receive their breast health information?
2. Where does the target population go for breast cancer screening, diagnostic and treatment services? Why do they make those choices?
3. What are some socio-economic or cultural barriers to breast health services faced by the target populations?
4. How do insurance status and ability to pay affect access to care?

Focus groups were held in order to obtain the target populations' perspectives. Six to eight key community leaders within each region were asked to invite five to seven attendees to a focus group. The group coordinators were found through the Affiliate's work in the regions and included Affiliate grantee employees, church and civic leaders, and community advocates. The Team believed it was important to the success of the groups that they be coordinated by members of the local community rather than an Affiliate staff member. The goal was to host a minimum of three focus groups for each target population: three groups of Black/African-American women in each region, three groups of rural women in each region, and three groups of Hispanic/Latina women in Jasper County. The focus group coordinators were provided with

information to share with prospective attendees explaining the purpose of the meeting. Incentives including gas cards and meals were offered to encourage participation. Four groups came to fruition.

The focus group sessions were facilitated by the Affiliate's Mission Programs Manager, who had professional interview experience. Detailed notes were taken by the Affiliate Administrator and each discussion lasted approximately one hour. Prior to each discussion, the facilitator explained the purpose of the focus group and how the information would be used. It was also explained to all participants that this was voluntary and they were free to remove themselves from the discussion at any point. All participants were then asked to sign releases informing them of this information and allowing them the opportunity to note their preference on whether or not to be quoted in the report.

Short surveys which included respondents' demographics were completed by the participants prior to each discussion session. The use of the surveys allowed the Community Profile Team to accurately identify if the participants were within the target populations and note other factors, such as income or insurance status, which may influence their individual perspectives. No names or identifying information were recorded on the surveys.

The CP team requested participation from 37 key informants in the target populations. Seven responded and were interviewed by either the Mission Programs Manager or the Affiliate Administrator. Two interviews were conducted over the phone, all others in person. Each interview lasted approximately 45 minutes. All participants were given the opportunity to stop the interview at any time. They were also asked whether or not they would like to be quoted. Detailed notes were taken by the interviewer using the same format as the focus groups.

Eighteen providers identified during the Health Systems Analysis phase of the report were contacted to request their participation. Five providers responded, all of whom were grantees of the Affiliate. Each participated in face to face interviews lasting approximately one hour with the Affiliate's Mission Programs Manager, who took detailed notes. An excel sheet was used to schedule phone interviews with the remaining providers on the list. Notes were taken by the Affiliate Administrator during the phone calls to indicate the providers' accessibility. One additional provider responded to the request and agreed to be interviewed in person. The provider was interviewed by the Mission Programs Manager and notes were taken by the Affiliate Administrator. Providers were also emailed a survey to complete but none responded to the request. Due to the low response rate of key informants and providers, the Team reviewed the *"2011 Community Profile Report"* (2011CP) for additional qualitative information relevant to the target populations. This review provided findings from focus groups, key informants and provider interviews that were conducted in 2010.

The data collection methods used allow for triangulation of key findings by illustrating the synergy between the quantitative data, Health Systems and Public Policy Analysis and qualitative data. The use of focus groups and interviews with providers and community advocates allowed the Affiliate to compare and contrast the different perspectives of the barriers to breast health services in each region. The communities' beliefs and perspectives may correlate to the quantitative data. For instance, if there is no trusted source of information locally, people may not get the care needed. In fact, they may not even be aware of the

recommended screening guidelines. This may lead to late-stage diagnosis and high death rates. Likewise, the Health Systems Analysis may show a region is medically underserved. It is the community's input that may provide insight on how to improve access; thereby potentially lowering late-stage diagnosis rates. All three pieces (qualitative, quantitative, and HSA) are necessary to develop a broader understanding of the issues and how they might be addressed.

Sampling

The populations of interest were chosen respective to the priority populations identified by the Community Profile Team. The Team's focus was on Black/African-American and rural women residing in the priority regions and Hispanic/Latina women residing in Jasper County. The goal was to gather information relevant to uninsured or under-insured, low-income women within these populations who were within the recommended ages for breast health screening. This included young women as well as breast cancer survivors of all ages. The key questions developed for discussion were based on the potential issues faced within these groups.

Focus groups were coordinated in each region for specific populations: three in each region for Black/African-American women, three in each region for rural women, and three in Jasper County for Hispanic/Latina women. Due to a number of circumstances including difficulty recruiting participants, transportation and scheduling meetings, only four focus groups were completed (Table 4.1). No focus groups were held specific to the Western Region or the Hispanic/Latina population in Jasper County. The Team had to rely on the providers' and key informants' viewpoints as to the barriers faced by these populations. This created limitations to the data gathered; small sample sizes may not be reflective of the overall community's perceptions. Additionally providers' and key informants' perceptions may differ from the community at large. The Team also reviewed the 2011CP for additional information.

The sample sources were selected by a simple random method and by convenience. For focus groups, community members invited participants to attend. Coordinators were asked to reach out to a specific population such as Black/African-American breast cancer survivors or rural women over the age of 40. The focus group in the Southern Region (Hampton) was comprised entirely of Black/African-American breast cancer survivors from the area, all over the age of 60. The two focus groups in the Southwestern Region included rural women over the age of 40. Most of the women were over 60, with two who were over 40. One group also included breast cancer survivors. The Marion County focus group was attended by three Black/African-American women, one of whom was a breast cancer survivor. Two women were between the ages of 50-59; one was under 40. Both Black/African-American and White women participated in the two Southwestern Region groups. All focus groups were comprised entirely of rural women. All participants who identified their insurance status had some form of insurance (Table 4.2). This is an additional limitation of the data as those without insurance may not have been represented.

Table 4.1. Focus Group Participation

<i>Location</i>	<i>Number of Focus Groups</i>	<i>Number of Participants</i>	<i>Black</i>	<i>Rural</i>	<i>Survivors</i>
Southern Region	1	5	5	5	3
Southwestern Region	2	15	12	15	1
Western Region	0	2*	0	2	0
Marion County	1	3	3	3	1

**2 participants from Orangeburg (Western Region) attended a focus group in the Southwestern Region. The participants' answers were analyzed separately from those from the Southwestern Region.*

Table 4.2. Focus Group Participants' Insurance Status

<i>Location</i>	<i>Privately Insured</i>	<i>Medicaid or Medicare</i>	<i>Uninsured</i>	<i>Did Not Answer</i>
Southern Region	5*	5	0	0
Southwestern Region	2*	12	0	5
Western Region	1*	1	0	1
Marion County	2	1	0	0

**noted private insurance in addition to Medicaid*

Key informant (KI) and provider interviews were conducted based on convenience. The Community Profile Team used the data compiled for the Health Systems Analysis (HSA) to identify providers in the four regions serving at-risk populations. A total of 21 providers were contacted; eight responded. Five respondents were current Affiliate grantees. Representatives from two primary care providers and six community hospitals were interviewed. The primary care providers were all from the same provider network, a Federally Qualified Health Center (FQHC), and were also Affiliate grantees. Two of the hospitals were not located in the priority regions but served those populations. They worked with the populations of concern and were well aware of the challenges they face.

For a community perspective, the Team contacted 37 community advocates and civic leaders identified through the Affiliate's work in these regions (Table 4.3). These key informants worked closely with the Affiliate on several advisory groups and collaboratives serving the priority populations. Six interviews were conducted.

Table 4.3: Region, Number of Key Informants and Providers Contacted, and Number of Key Informants and Providers Interviewed

<i>Region</i>	<i>Key Informants Contacted</i>	<i>Key Informants Interviewed</i>	<i>Primary Care Providers Contacted</i>	<i>Primary Care Providers Interviewed</i>	<i>Hospitals Contacted</i>	<i>Hospitals Interviewed</i>
Southern Region	8	4*	3	2	3	2
Southwestern Region	10	1	5	0	3	2**
Western Region	14	1	4	0	1	1
Marion County	5	1	1	0	2	2

** one interviewee served both Southern and Southwestern regions*

*** one interviewee served both Southwestern and Western regions*

In addition to focus groups and interviews, the Team hosted a round table discussion with six experts from the University of South Carolina's Arnold School of Public Health. Five attended the meeting and one called in to the meeting. Participants included representatives from:

- South Carolina Rural Health Research Center (1)
- Witness Project (2)
- SISTAS Network (1)
- USC Center for Cancer Prevention and Control Program (2)

These professionals shared their thoughts on the barriers facing Black/African-American, rural and Hispanic/Latino populations in the priority regions. As researchers and community members, they had worked closely with the target populations and had studied the barriers they faced.

The Team's rationale for using a broad range of participants was two-fold. First, a larger sample size would allow for stronger data. Secondly, the Team's concern was about access to care for all women in these medically underserved regions, not a single demographic. Although it was important to discover whether or not different racial/ethnic populations faced different barriers, the Team wanted the insight of women of a variety of ages and socio-economic backgrounds in these communities.

Ethics

To ensure compliance and understanding of the participants, a consent form was read and signed prior to each interview, focus group and round table discussion. No names were recorded on the demographics documents and all the information was anonymous. Participant's names were used for note-taking and analysis, but were not included in the report without participant's consent. Each consent form was reviewed during the examination of the data to ensure names were replaced by a single initial or entirely omitted from the notes. After the data was reviewed by the Mission Programs Manager and Affiliate Coordinator, it remained locked in the Affiliate's office.

Qualitative Data Overview

Each focus group participant completed a short survey that included participant demographics and questions related to the key themes of breast health education and access to breast health/cancer care. The responses were recorded on an Excel spreadsheet and color-coded by theme and like answers. Each spreadsheet included the following categories with notations:

1. Education
 - a. Where does the target population receive their breast health information?
2. Access to Services
 - a. Where does the target population go for breast cancer screening, diagnostic and treatment services?
 - b. Notations- Why do they make those choices?
3. Potential barriers
 - a. Does the target population face specific socio-economic or cultural barriers to breast health services?
 - b. Notations-If so, what are they?

4. Insurance status
 - a. Does insurance status affect access to or quality of care?
 - b. Notations-If so, in what way?

The notes taken during the discussion were transcribed to Word documents and highlighted, using the same color scheme. This allowed the Team to quickly compare the survey answers to the notes taken during the discussions. The Team also used the same color scheme for highlighting key informant and provider interviews. This aided in identifying common themes among the varying sources.

An excel spreadsheet was then developed for each region. Each region, with the exception of the Southern Region, was to include two target populations (Black/African-American and rural). The Southern region was to include the third target population of Hispanic/Latina women in Jasper County. Due to the low response rates, the Team determined that these additional spreadsheets were unnecessary.

Color-coding allowed the Team to easily assess common themes among the varying sources. After reviewing the recorded information, the Team identified the most common responses for each target population (Black/African-American, rural and Hispanic/Latina) in each region. The Team then compared the responses for all regions to determine if there might be similar findings among the target populations. The Team also reviewed the original notes for any outlying themes, those comments which may not have been identified as major themes but might be relevant to the issues discussed.

After completing the spreadsheets and reviewing the notes, the Team reviewed the 2011 Lowcountry Community Profile (2011CP) and noted the common themes identified within it. Because the 2011CP did not identify specific regions, the Team was unable to assess common themes by region. However, the 2011CP did include the same priority populations (Black/African-American, rural and Hispanic/Latina). By comparing and contrasting the information from the 2011CP to the newly gathered data, the Team was able to identify common perceptions and potentially shifting attitudes within the target populations.

The rationale for data management was simple. Participation was low, which made recording and reviewing the information manageable. Color coding allowed the Team to visually identify commonalities among the regions of interest as well as the individual populations of concern. Notations were used to elaborate on the major themes and provided a more in depth perspective.

Southern Region

All focus group participants, KIs and providers noted the same issues facing Black/African-American and rural women in the Southern Region. The primary barriers were identical: transportation, the cost of accessing care, and educating both the general public and providers about breast screening and financial aid programs. These were also the primary barriers noted in the 2011CP.

The consensus of the focus group, the KIs and providers was that the number one barrier was travel. Providers commented that residents often work outside the county they reside in, leaving no time to go to the doctor for routine services. Four of the five focus group participants traveled an hour or more for their care. They were not comfortable with the local hospitals and believed that care is better in Charleston or Beaufort. All three groups indicated the hospitals in the Region did not offer comprehensive breast cancer care.

One example of the travel challenge was given by a breast cancer survivor who traveled to Charleston several times a week for medical appointments. She saw her podiatrist on Wednesdays but her oncologist was only available on Thursdays. She also travelled to Charleston for her prosthetics and any other medical issues. Another participant noted that while she underwent treatment in Charleston, she had to stay in a hotel, adding to her financial burden.

Fear was another barrier noted by the focus group. That fear included the fear of a diagnosis of breast cancer as well as the fear of the actual cost of screening and additional care. The providers concurred their patients shared these fears. The working poor were of particular concern, even if they had insurance. Although insurance may cover the cost of a mammogram, it often did not cover the cost of additional images or diagnostic services. Although all focus group participants were insured (primarily Medicaid), one survivor summed it up with:

*“\$250 for co-pay, I have retired now, so they take more money from me.”
(focus group participant)*

Another participant mentioned that she was able to get financial aid due to “hardship”. However, none of the other women knew of any financial aid resources. Although several providers interviewed offered free or reduced rates for the uninsured, the hospitals did not. All agreed that patients were unaware of any available financial aid and therefore did not get routine care. Focus group participants and KIs also concurred that ability to pay directly impacted quality of care. The following illustrative comments were made by two survivors in the focus group:

“Rich people get the fancy tests. Their politicians up there, they don’t wanna help us.”

“They treat you to what they feel you can afford to pay.”

The KIs and focus group participants agreed that, overall, the local physicians were not compassionate towards their patients. The KIs commented that only a few physicians look at their patients as human beings. Similar to the focus group perception, one KI stated:

“(hospital) doesn’t cooperate. The admin is from (90 miles away) and doesn’t have any community buy-in or understanding of the needs.”

Every provider noted education as a barrier and the focus group agreed. They also agreed that many of the primary care physicians were not aware of the recommended screening guidelines or available financial assistance. Several women in the focus group commented that women

often don't take the initiative to ask questions because they saw the doctors as knowing more than they did. The group agreed with a comment made by one participant related to the issue:

"If you don't know the right questions, they (doctors) ain't gonna tell you nothing"

When it came to health education, the primary source for these women was the television show "The Dr. Oz Show." Newspapers and word of mouth were also cited as popular sources. Interestingly, local physicians were not recognized as a source of breast health information. The group also came to the conclusion that some women may have actually had the information but were unwilling to read it.

Key informants, all of whom were White, believed there may be cultural barriers faced by the Black/African-American population. One KI put it this way:

"The African-American barrier is cultural...If they're diagnosed, they'll follow through with care. The White population's issue is apathy... If they're diagnosed, they may or may not follow through with care."

J. (key informant)

The same KI noted a belief in "God's will" as a potential barrier to care for Black/African-American women. Two KIs and one provider also believed that breast cancer was a subject not often discussed within this population. The 2011CP also includes these two cultural barriers the qualitative data findings.

These perceptions were in contrast with the focus group. When asked if there were any cultural barriers to care for Black/African-American women, the women stated that they didn't think so. These women expressed that they were treated by their physicians the same as their White counter-parts. The women also commented that breast cancer was discussed within their community, which was supported by the Columbia round table discussion.

"I think it's changing. The programs that are being administered to get people to talk about things has helped."

H. (round table participant)

Another participant noted that often women do not realize they are participating in a cancer prevention program, with which the others agreed.

"They will go to a program concerning healthy nutrition and not realize they're talking about cancer prevention. "

J. (round table participant)

Southwestern Region

The focus groups and KI and provider interviews revealed similar themes for rural and Black/African-American women in the Southwestern Region. Education was one noted barrier. Women might not have been aware of the screening recommendations or how to access appropriate care. The education concern included how to navigate the health care system. One survivor commented that "you have to work the process," with which the others agreed. These

women agreed with the provider who suggested local providers also needed education about breast cancer screening guidelines and available funding sources. .

As in other regions, there was a consensus among the participants that the cost of care was a major concern. That cost included taking time off from work in addition to actual health care services. This was also identified in the 2011 CP. One focus group discussed that Orangeburg had a free clinic for those without insurance, but there was no assistance for those with insurance. The participants in this region agreed that those with insurance were the ones most likely to delay care:

*“The insured people are the ones that have the most difficult time getting to the doctor...
You pay insurance every month and you don’t get the same low cost-free care.”
F. (participant)*

The interviewed provider agreed that finances were not a major concern to her low-income, uninsured patients. They were aware of the financial aid programs available and made use of them. She, too was concerned about the insured working poor with high deductibles and high co-pays.

Another barrier the group discussed was embarrassment and the need for privacy. Women did not want others to know their health concerns. An example given at the Columbia round table discussion was when a mobile mammography unit went to Walmart on a Saturday morning. Women would not go on the van because everyone would see them.

The lack of physicians in the area was noted as another major barrier for the Southern Region, especially in Bamberg County where there is no hospital. Often the physicians travel from Orangeburg and have very limited hours. In reference to the lack of doctors, one participant noted:

“The older ones have gone. The new doctors do not stay when they find them.”

Transportation was also a concern for the respondents. All Bamberg County focus group participants reported traveling outside of their county of residence for breast health care, most going to Orangeburg. Travel for medical services often took an hour or more, likely preventing many from seeking care. Several women noted that transportation was available but people either didn’t know or didn’t want to pay for it. For example, HandyRide could transport people for a small fee even if they were not on Medicaid but few people were aware of the service. The Allendale provider concurred on all of these points.

Another common theme was the belief that mammograms hurt. The CP Team heard this from several women at both focus groups, as well as the round table discussion. The KI also mentioned it as a potential barrier and it was acknowledged in the 2011 CP.

Two women in the focus group commented that the church was a primary source of health information, especially for Black/African-American women. The round table participants agreed and the 2011 CP also identified churches as a trusted source of information in this population.

However, this was not agreed upon by all respondents. Several focus group members stated that their churches had no health ministry and the KI noted that “some churches can be clannish,” explaining that they don’t promote health as part of their ministry. Another respondent commented on the lack of consistency within the churches:

“A lot of people in the churches comes with ideas and when they leave the resources leave.”

Western Region

Two participants from the Southwestern focus groups resided in Orangeburg and remarked that the barriers were the same in both the Western and Southwestern Regions, though there were more physicians in Orangeburg. Both also noted that if they needed to go to the hospital, they would go to Columbia because they felt there were more options there than in Orangeburg. Both women were insured, which may have provided them with additional options. They also agreed that they were not aware of any barriers specific to Black/African-American women in the Western Region nor did the interviewed provider note any.

The provider spoke of the same barriers to care as those identified in the other regions: education, transportation and ability to pay. The focus group participants also noted these. All of these barriers were reported in the 2011 CP.

The participants saw education as a barrier to breast health care in several ways. Women needed more on-going education about the importance of mammograms. Health literacy was also a barrier because women may not understand a letter for follow-up. They needed to know what to do next. Additionally, both the general public and primary care providers needed education about available financial aid programs. All of the women agreed that ability to pay was not an issue if the patient knew the services were covered. Patients and providers needed to be educated that there were programs to cover the costs.

Cost was also noted as a barrier by both the provider and the focus group participants. Most employers in the Region did not allow their employees paid time off. The financial cost also included the cost of transportation and child care in addition to the actual medical services. Again, concern was for the working poor and underinsured who may not have access to the financial aid available for the unemployed or uninsured.

Insurance status was seen as another barrier for women in the Region. This was true for both the uninsured and the insured. Those without insurance were less likely to get routine health care. Those with insurance faced copays, high deductibles and high out of pocket costs. One round table participant noted that even state employees face challenges.

“(Our employee) health plan does not cover well visits. You have to be sick to go in and get a breast exam. It requires the doctor to be willing and the patient to be aware of how to get their (routine mammogram) paid for.”

J. (round table participant)

Marion County

Both providers and the focus group members noted the same barriers facing rural and Black/African-American women in Marion County: education, ability to pay, transportation, and trust. However, the focus group had a different perspective from the Marion provider on the trust issue.

The lack of trust in a local provider was a primary point of discussion in the focus group. All three participants believed that women were afraid to go there for fear of being turned away and left to die. This was the perception for both rural and Black/African-American women, especially for those without insurance. One of the women in agreement with this indicated that she would go to the hospital in Marion because she is insured. The others stated they would not, even though they, too were insured.

“A lady in our (support) group with stage IV cancer... (local provider) told her they couldn’t do anything for her because she didn’t have insurance.”
(focus group participant)

The group agreed that for-profit providers in Marion County should refer patients to an outside agency able to help with financial aid. The group also discussed the fact that women often have to choose between their health and paying the bills. Both sentiments were echoed by the Florence provider.

The Marion provider also cited trust as an issue in the community. However she offered a differing perspective, stating that there had been a well-publicized data security breach within the provider network which may have impacted community trust.

Another concern for the group was the lack of breast health education. This was true for young women as well as older women. The youngest in the group commented:

“Young women, we don’t talk about it. We need to be aware of our health.”
L. (focus group participant)

The group agreed that women in Marion County were not well-educated and believed “it won’t happen to me.” This was echoed by the Marion provider who described it as apathy. Everyone agreed that women needed to be encouraged to ask questions and myths needed to be dispelled. One of the myths discussed by the focus group was that cancer will spread if you remove the breast. The Florence provider used the same example when discussing the need for better health education. The focus group pointed to television and social media as popular resources. Facebook and Twitter were identified as favored social media platforms.

Everyone agreed that women needed better communication with their doctors. Providers stated that an education program to assist doctors in educating patients would be beneficial. The focus group reported that women were reluctant to return for follow-up because they were scared. More information from their doctors could ease this worry. They agreed that while some doctors provided easy to understand information, others

“...figure you can go get a dictionary.”

(focus group participant)

Fear of the disease was also perceived as a major barrier by the Florence provider and the focus group participants. This prevented women from checking their breasts because they were afraid they might feel something unusual. This notion was also supported by comments made by round table participants. One focus group member said that even though she felt something, she didn't want to go to the doctor. The others concurred that many women felt the same way. It was agreed that education about early detection may help with the issue.

Cost was a concern from every participant's perspective. Help may be available but patients would have to research how to find the resources. The group agreed that most women would not take the time to do it or know where to find it. They would need the physicians and advocates to help them find it.

Working women were a concern for all respondents. Providers and focus group participants concurred that employers would not give time off. Many women in Marion worked long hours at low paying jobs in factories. They agreed women would not take the time off from work and health care was not available after hours. The group spoke of people losing jobs if they were sick.

The providers and the group members also noted transportation as a challenge. The Marion provider commented that the PeeDee Rural Transit bus did not get people to their appointments on time. The Florence provider noted the travel distance required for Marion residents to get to Florence. The focus group participants also noted the distance to Florence, which is where the low income and uninsured had to go for care.

The focus group agreed that the primary challenges for Black/African-American women were the same as those for rural women. However, there were several issues they believed were specific to Black/African-American women.

The theme of shame and secrecy was a large portion of the group's discussion. The women shared stories about survivors who didn't tell anyone about their disease. They said the women were ashamed and afraid others would look at them differently. One woman commented *“They don't want the pity”* and others nodded in agreement. They spoke of family members who had cancer but had not told anyone. One group member told the story of her aunt who was so sick that she was in a wheelchair, but never told her family that she had breast cancer:

“On the Saturday before she died, I saw that glossy look in her eyes. She was gone on Tuesday...”

L. (focus group participant)

The women also talked about the reaction of people in the community if they knew someone had cancer. The comments were that people weren't necessarily concerned, just nosy. One woman said *“They talk about you and say you is dead,”* with which the others agreed.

There was discussion about the importance of faith in the Black/African-American community. The women talked about the importance of their faith but were concerned about those who relied solely on faith to heal them. They all agreed that women put their faith in God and it gave them strength but they also needed to use the common sense God gave them. One participant put it this way:

“God can heal you spiritually but you’ve got to have human confirmation.”

N. (survivor)

After this comment, the three talked about a woman who was certain she had been healed by prayer and didn’t need a doctor, only to find out later that her breast cancer had metastasized, further illustrating the validity of their concern.

Jasper County- Hispanic/Latina

The primary source of information was gathered from providers and two key informants, both of whom were members of this population. They all described the same challenges faced by other rural women: lack of transportation, lack of providers, lack of insurance, the cost of accessing care, and the continuing need for breast health education. This population also faced the additional burden of being immigrants, regardless of their legal status. Getting documentation for eligibility of most financial aid programs was especially challenging.

The population was described as a close knit community who looked after one another. The overall perception voiced was that, if they had the tools, these women would follow through on the care they needed.

“Hispanic women are more interested in preventive health screenings, doesn’t seem to matter what the age.”

J. (provider)

Transportation was the theme that created the most discussion. Both KIs reported that, regardless of immigration status, the women of Jasper County were afraid to go to Beaufort, the closest county with breast care facilities. The providers and KIs also noted that Beaufort was the location of this population’s most trusted providers.

“If they don’t come here, they don’t go anywhere.”

J. (provider)

The KIs and providers reported police profiling in Beaufort County, causing Jasper’s Hispanic/Latina residents to stay within Jasper County. One example given by a provider was of a Jasper woman who was in the country legally. She crossed the county line into Beaufort and was arrested while with her five children. The woman was jailed for several days before being released. The providers and KIs all commented that this population’s fear of the police and imprisonment had caused women to go without medical care until they were very sick. Describing the issue, one KI said:

“They won’t leave the county for nothing. They’re afraid.”
S. (key informant)

The KIs both noted that most of these families shared rides and traveled in groups. Often the family had one vehicle, which was used by the husband/father for work. For those that used rural or Medicaid transportation, there were no Spanish speaking interpreters on the buses. In addition to the transportation challenges, childcare was unavailable. All of these perceptions were supported by the qualitative data reported in the 2011 CP.

Documentation was also barrier. For routine mammograms, this was not usually a problem. However, for further diagnostic or treatment services, these women usually had to present documentation in order to receive financial aid. Documentation included not only immigration status, but also wages earned. Many of these women worked in hotels, restaurants and private homes and were paid in cash. They did not receive a paycheck and were therefore unable to provide proof of income, a requirement for most financial aid programs.

Qualitative Data Findings

The CP Team carefully selected participants who were well informed about their communities and each was a respected member of their community. All key informants and focus group coordinators had worked with the most at-risk populations. They included community educators, retired health care workers, and employees of county agencies and area nonprofits. Providers were primarily former Komen Lowcountry grantees and were known by the Team to have a history of working with the low income and uninsured in these regions. The round table discussion included women who not only worked with the target populations, but were qualified researchers in public health and the priority populations. They were able to share their thoughts as well as some of the findings of their own research pertinent to the discussions. All of the participants’ close ties with target communities provided clear, informed perspectives and strengthened the qualitative data.

Several qualitative data limitations may have impacted generalizations that were made. The response rate was low in all priority regions. This was especially true for the Western Region, where only a single provider participated. The key informant from the region had a simple comment:

“It’s getting even harder to reach people in Orangeburg.”
C. (key informant)

There was limited participation from White women outside of the medical community. Although all of the regions were predominantly Black/African-American, this potentially left opinions of rural White women suppressed. It should be noted that all of the health care providers, with one exception, were White and members of the local community. The data on Hispanic/Latina women of Jasper County had similar limitations due to the lack of community participation. This was also true for residents of Colleton, Barnwell, Orangeburg, and Calhoun Counties where no focus groups were successfully held. Consequently, assumptions and generalizations cannot be made about the target communities as a whole. The data collected only represents the views of those who participated.

The demographics of the focus group revealed several similarities that may cause limitations. All had some form of insurance and most were over 60. These factors may have skewed some perceptions and left the uninsured and younger women without a voice. There may have also been unintended biases because all participating providers and key informants had worked closely with the Affiliate in the past. This may have caused them to inadvertently provide answers they believed the Affiliate wanted or expected to hear. It also does not necessarily include the view of those who are not directly involved with breast health or breast cancer.

The age of the 2011 Community Profile was also a limitation. The data was gathered in 2010 and personal attitudes and the health care landscape may have changed since then. The qualitative data was reported for target populations (Black/African-American, rural and Hispanic/Latina), but not by specific regions. Report findings may have been generalized for the priority regions.

Because the Team used open ended questions, participant responses were not guided. This allowed more open discussion among participants and strengthened conclusions. By comparing the current responses with the previously reported information (2011 CP), the Team was better able to identify commonalities. Ultimately, the Team believed there was enough supporting qualitative evidence to understand the primary challenges to care faced by each community.

Southern, Southwestern and Western Regions and Marion County

The qualitative data for the Southern, Southwestern and Western regions, as well as Marion County, aligns with the quantitative data and the Health Systems Analysis. All of these regions along the I-95 Corridor are rural and medically-underserved. They also share similar socio-economic characteristics, including high unemployment percentages. These factors were underscored by the qualitative data gathered.

Focus group participants and providers spoke of the challenges faced by rural medically underserved communities. Regardless of race or ethnicity, women in every priority region appear to face the same challenges to getting medical care. These primary barriers correlate to the quantitative data and the health systems analysis of the Region:

- Health education, which may be tied to low literacy percentages
- Transportation due to lack of local providers
- Ability to pay for care, which may be tied to insurance status, income level, and unemployment percentages

The data gathered shows that women in these three regions receive their health education from several sources, the primary one being the television show “The Dr. Oz Show.” Women also receive the health information from newspapers and word of mouth. For those with internet access, it is another source. Interestingly, local physicians are not a regular source of breast health information in any of these regions. An education program to assist doctors in educating patients could be beneficial.

Education of the public and providers is needed in every region. Both physicians and the public need to know the recommended breast cancer screening guidelines. They also need to know

about financial aid resources and the Best Chance Network. It is important that the education be year-round, not just during October. The programs must also be sustainable.

*“Programs do not seem to be continuing and tend to die. But the need is still there.”
(focus group participant)*

Breast health education should also begin at an earlier younger age so it becomes more acceptable.

*“We need to talk to our daughters while they’re young...
Make it age appropriate but don’t wait ‘til they’re 18.”
P. (key informant)*

The belief that mammograms hurt and other misconceptions may also prevent women from routine screenings. The medical system can be confusing and women need to know how to navigate it. Patients need someone outside of the medical community to advocate for them. A focus group participant summed it up with:

*“A lot of people don’t have that knowledge.
There is a need for advocates with them in order to get the care they need.”*

Women also need better communication with their doctors. Knowing which questions to ask and what financial aid is available may assist in their navigation of the health care system. Churches may be an appropriate source of health information for Black/African-American women in particular. However, it is important to not rely solely on the faith community as a resource.

Travel is a primary concern. Women often travel to Charleston, Beaufort or Columbia for their medical care, a trip that requires hours of travel time. Overnight and long-term accommodations are sometimes necessary, especially for those undergoing treatment. This creates an additional financial burden. In addition to help with the cost of transportation, residents need to know about local options for public transportation, such as HandyRide and rural transit services.

Quality of care is another worry in these rural communities. Although local physicians are not distrusted, women believe they receive better treatment and more respect at facilities outside of their own counties. They want their local providers to show more empathy and compassion. The women believe much of this is directly related to their own ability to pay or the type of insurance they have. This is especially relevant to the for-profit facilities. Referring patients to nonprofit organizations may help address this perception and develop a more trusting environment.

Access to the physicians includes several barriers. There are few local providers and they often have limited hours. Regardless of insurance status, health care costs are a factor in delaying care. The working poor seem to have the greatest barriers. They lose pay if taking time off from work and do not have access to free services available to the uninsured or unemployed. It was also noted by the Columbia round table discussion group that free clinics are typically in larger cities, far away from these rural counties. The under-insured face the financial burden of high deductibles and high out of pocket expenses for medical care. There are more financial aid programs available for the uninsured but they, too, face the barrier of ability to pay.

Privacy is greatly valued by the women in these regions, especially by Black/African-American women. They do not want others to know about their health issues. However, open discussion about breast health may allay some of the fears expressed.

Jasper County- Hispanic/Latina

Jasper County is a rural medically underserved area with a large Hispanic/Latina population. As part of the Southern Region, their primary barriers to health care include education, transportation, and ability to pay. This is a close community that relies on one another and places a great deal of trust in their chosen health care providers. They are most likely to follow “doctor’s orders” and follow through with the care they know they need.

There are two issues unique to this community that affect travel for health care. Most families in this population share a single vehicle. Typically, the husband or father uses it for work. The women are left carpooling and searching for transportation to appointments. This transportation issue becomes a barrier to care.

The greater impact on travel to their health care providers is the fear of being arrested and/or deported. Regardless of immigration status, Hispanic/Latinas fear leaving Jasper County. They believe they will be arrested as soon as they cross the Beaufort County line. This is of particular concern because the most trusted providers are located in Beaufort County.

Documentation is an additional barrier. Many of these women work in service industries or private homes. Because they are paid in cash, they do not receive paycheck stubs. This leaves them without proof of income, which is an eligibility requirement for most financial aid programs.

Another barrier faced by this population is language. Spanish interpreters are not available on the rural bus system, making travel even more complicated. The community also needs culturally sensitive breast health education in Spanish. This is a group that will use the education and follow through with the recommendations.

Mission Action Plan

Breast Health and Breast Cancer Findings of the Target Communities

The Community Profile Team reviewed the predicted time of each Affiliate county to achieve Healthy People 2020 (HP2020) targets. Socioeconomic characteristics, screening rates and trends in death rates and late-stage diagnosis rates within the Affiliate's 17 county service area were also reviewed. Based on the integrated findings from these key data components, four regions were found to be most vulnerable and therefore chosen as target communities for Affiliate intervention. All four regions are along the I-95 Corridor and include the Affiliate's most medically underserved populations.

The target regions share a number of similar characteristics: the predicted time to achieve Healthy People 2020 (HP2020) targets, socioeconomic characteristics, screening rates and trends in death rates and late-stage diagnosis rates. With the exception of Allendale and Bamberg (whose numbers were suppressed), all of the counties in these regions have HP2020 projections of more than 13 years to meet either breast cancer goal. In addition to being rural and medically underserved, the regions share several other key indicators of vulnerable populations: large Black/African-American populations, high unemployment percentages, high levels of poverty, and high numbers of uninsured residents.

Low screening rates and rising trends for late-stage diagnosis and death rates are seen in nearly every county in the target regions, including Allendale and Bamberg. The highest incidence and late-stage diagnosis trends by race and ethnicity are in South Carolina's Hispanic/Latino population.

The Team also reviewed data pertinent to Black/African-American and rural populations throughout the Affiliate's service area. The review indicates that regardless of which county these populations are located, they face similar economic and physical barriers to care as those in the target regions.

Southern Region: Colleton, Hampton, Jasper

The Southern Region of the I-95 Corridor includes the rural, medically underserved counties of Colleton, Hampton and Jasper. These counties have large Black/African-American populations, low education levels, high poverty and high unemployment percentages. Jasper County has the Affiliate's largest Hispanic/Latino population.

Jasper County is home to the Affiliate's highest percentage of uninsured residents. Colleton and Hampton also have high percentages of uninsured. Residents in these counties face great poverty, with all three counties having more than 20.0 percent of the residents with incomes below 100 percent of FPL. More than half of each county's residents have incomes below 250 percent of FPL.

Screening rates in Colleton are the second lowest in the Affiliate's service area. Hampton County has one of the highest rising trends of late-stage diagnosis rates among the affiliate's counties. Colleton's rapidly rising trend of late-stage diagnosis is also of concern. Both

incidence and late-stage trends are falling for Jasper County as a whole. However, these trends are much higher in the Hispanic/Latino population than in any other race or ethnicity in South Carolina.

Southwestern Region: Allendale, Bamberg, Barnwell

The Southwestern Region of the I-95 Corridor includes Allendale, Bamberg and Barnwell counties. All three are rural, medically underserved counties with high poverty and unemployment percentages and low education levels. The largest portion of the population residing in the area is Black.

The highest poverty figures in the Affiliate's service area are seen in Allendale County. Bamberg County's population has the Affiliate's second highest poverty rate. More than one fourth of Barnwell County's residents have incomes below 100 percent of poverty level and more than half are below 250 percent of FPL.

Barnwell County's screening proportion is the lowest in the Affiliate's service area. Bamberg County's is also lower than most counties served by the Affiliate. Screening proportions for Allendale are not available due to small numbers.

The incidence trend of breast cancer in both Allendale and Bamberg counties is rising, as is the late-stage diagnosis rate for Barnwell. Both Allendale's and Barnwell's death and late-stage diagnosis rates and trends are suppressed due to low numbers.

Western Region: Orangeburg, Calhoun

Orangeburg and Calhoun counties share similar socioeconomic factors and key health indicators. Both counties are rural and medically underserved. In Orangeburg, nearly one fourth of the residents have incomes below 100 percent of FPL and more than half have incomes below 250 percent of FPL. Calhoun County residents as a whole also have low income. Both counties have high rates of unemployment and uninsured.

In Calhoun County, the trends in both incidence and late-stage diagnosis are rising. In fact, these are the largest increases throughout the Affiliate's service area. These rates are also rising in Orangeburg County.

Marion County

Unlike other priority counties, Marion County is not medically underserved. However it is rural and shares many of the same population characteristics as the other priority areas: a large Black/African-American population, low education levels and high poverty. Many of the residents are without health insurance. More than 24.0 percent of the residents have incomes below 100 percent of FPL; well over half have incomes below 250 percent of FPL.

Marion County's rising trend in late-stage diagnosis is concerning. It ranks second only to Calhoun and is in great contrast to the state's falling trend of one percent.

It is important to ascertain what factors may contribute to low screening rates and rising trends in late-stage diagnosis and death rates seen in the target regions. Hence, the Team sought answers to:

1. What physical and cultural barriers prevent these populations from getting breast health care and breast cancer treatment?
2. Where do residents of these regions go for breast health care and breast cancer treatment?
3. Where do these populations get their breast health education?

Physical barriers are easily identifiable. The Health Systems Analysis underscores the fact that the target regions are medically underserved. Most breast health services are physically unavailable in the priority regions. Breast cancer treatment is only available on a very limited basis in four of the counties.

Although there are two community hospitals in the Southern Region, the region is primarily served by doctors who visit on a rotating basis. Basic screening services (clinical breast exams and mammograms) are available at several Federally Qualified Health Clinics (FQHC) in the region. However, treatment and support services are extremely limited. Chemotherapy, reconstruction, and survivor support services are not available within any of the region's counties.

The Southwestern Region of the I-95 Corridor is lacking most breast health services. Residents in the area must travel to other counties for services. Clinical breast exams and screening mammograms are available in Allendale and on a very limited basis in Barnwell. No reconstruction services are available locally, and survivor support groups and services are seemingly non-existent.

The Western Region of the I-95 Corridor is primarily served by The Regional Medical Center of Orangeburg and Calhoun Counties (TRMC). Mammograms, diagnostic procedures and some breast cancer treatment services are performed at their Orangeburg facility. No breast care services are physically located in Calhoun County. In Orangeburg, clinical breast exams are available at two family health centers and a free clinic.

Like other target regions, Marion County is lacking in breast health services. The sole local provider of screening and diagnostic services in Marion is a for-profit entity and does not provide financial aid.

Breast health education is very limited in all four target regions. In every region, the majority of breast health education is provided by individuals. The primary source for formalized breast health education in these regions has been The Witness Project. Due to lack of funding, The Witness Project has greatly reduced their programs.

Public policy also negatively impacts these regions, as well as the state as a whole. South Carolina did not expand Medicaid, leaving nearly 200,000 residents making below 138 percent of FPL without affordable coverage. Additionally, providers' reimbursement rates have been reduced, forcing some community hospitals and physicians to close their practices. Others no

longer accept Medicaid patients.

The Healthy Connections Check-up initiative is a limited benefit Medicaid plan that has created additional challenges to the most vulnerable populations. The program provides one primary care visit every two years to those who would have been eligible for Medicaid had it been fully expanded. Screening mammograms are provided through Healthy Connections only to women over the age of 50 and there is no coverage for follow-up or treatment services. Women under 50 are not eligible for screening mammograms through the program. Healthy Connections' Breast and Cervical Cancer program is tied directly to Best Chance Network. The program provides full Medicaid benefits to uninsured women who are in need of treatment for breast or cervical cancer or pre-cancerous lesions. Women must meet a number of criteria for eligibility, including a very specific enrollment process. Men are ineligible for coverage.

Community input provided greater insight into the issues impacting breast health care in the target populations. Several themes were consistent in every I-95 Corridor Region: transportation, cost of accessing care, and education of the public and providers about breast health and available financial aid. Race does not appear to be an issue in the perception of quality of care and few cultural issues were identified. In fact, Black/African-American respondents stated they were treated by medical providers the same as their White counterparts. Concern was raised for the uninsured. However, the working poor are of particular concern in most regions. Although insurance may cover a screening mammogram, it often does not cover the cost of additional images, diagnostic services or treatment.

Southern Region

In addition to the aforementioned themes, the Southern Region faces an additional challenge. The two area hospitals are not trusted by the communities they serve. These hospitals do not offer free or reduced rates and most local physicians are not considered compassionate by their patients. Women in the Southern Region typically travel to Charleston or Beaufort for breast health services.

The Hispanic/Latina community in Jasper County faces the same challenges faced by other rural women in the Southern Region: lack of transportation, lack of providers, lack of insurance, the cost of accessing care, and the continuing need for breast health education. This population faces the additional burden of being immigrants, regardless of their legal status. Getting appropriate documentation for most financial aid programs is especially challenging. Additionally, the women of Jasper County do not want to leave the county for fear of being stopped by the Beaufort police.

Southwestern Region

The Southwestern Region faces the same primary challenges as the other regions. In addition to educating the public and health care providers about breast health screenings and available financial aid, navigation of the health care system is a concern. The use of mobile mammography units present additional issues related to embarrassment and lack of privacy. Patients in this region travel to Orangeburg, Columbia or Charleston for most breast health services.

Western Region

Transportation, education, and ability to pay remain the primary barriers in the Western Region. Education of both the public and providers is needed in the following areas: breast health and breast cancer screenings, financial aid, and navigation of the health care system. If patients know financial aid is available, they will likely follow through on care. Again, concern is for the working poor and underinsured. They may not have access to the financial aid available for the unemployed or uninsured.

Marion County

Rural and Black/African-American women in Marion County face the same barriers as those in the other regions. The lack of trust in a local provider is an additional concern. Women fear being turned away with nowhere to go. A referral to another agency could alleviate this fear. Women also need better communication with their doctors. Women in Marion County usually travel to Florence for breast health services.

Working women face specific challenges. Taking time off means risking losing their jobs. Even with a mobile mammography unit onsite, women are often unable to leave their jobs for scheduled screenings. Financial aid may be available but patients are unaware of them. Trained patient advocates and improved communication with physicians could be of great help with this.

Shame and secrecy about breast cancer must be addressed in this region, especially in the Black/African-American community. Women with breast cancer tend to gravitate towards privacy in response to the fear that others may look at them differently. This is one reason many do not discuss their own diagnosis and misperceptions about the disease continue.

It is evident that every target region faces the same primary challenges, though there may be nuances specific to a particular population: transportation, accessibility and cost of care, and breast health education. This is true not only for the uninsured, but also the working poor and underinsured. Additionally, trust must be developed between providers and the communities they serve.

As for breast health education in the four regions, local physicians are rarely a recognized source. Churches are highly influential sources of information in the Black/African-American community. However, programs are often fleeting and unsustainable. Many churches, especially those with White congregations, have no health ministry. Newspapers and word of mouth are also trusted sources, as is "The Dr. Oz Show." Social media platforms such as Facebook and Twitter are popular among younger women.

Mission Action Plan

Three overarching issues are evident throughout the four I-95 Corridor Regions: access to the full continuum of care, education of both the general population and medical providers, and the lack of Medicaid expansion. These problems were chosen for Affiliate intervention because each negatively impacts breast health disparities in the Affiliate's predominant populations- rural and Black/African-American women. If these issues are addressed appropriately, these

populations may have better health outcomes. Komen Lowcountry will continue to work with community partners to improve the lives of all South Carolinians, recognizing that some disparities are created by issues beyond the Affiliate's ability to address.

Problem Statement:

Access to the full continuum of care for the uninsured and working poor is a major challenge throughout the Affiliate's entire service area. Those living in the I-95 Corridor regions especially suffer from the lack of physical access to providers. This problem can be addressed through grantmaking and community partnerships. Appropriate access to care can positively impact both late-stage diagnosis and death trends in every I-95 Corridor Region.

Priority: Increase access to the full breast health continuum of care in the I-95 Corridor regions through developing partnerships and grantmaking.

- *Objective 1:* By August 31, 2015, revise the Community Grant RFA to include:
 - A. Priority consideration to programs that result in documented links to breast cancer screening, diagnostic and treatment support services for residents of the counties located in the target regions. This will be accomplished by citing the following counties as funding priorities in the RFA: Allendale, Barnwell, Bamberg, Calhoun, Colleton, Jasper, Hampton, Marion, and Orangeburg. The reviewers' weighted scoring will be revised to allow for higher scoring under the "Impact" category of those applications meeting this priority.
 - B. Employer/provider partnership as a funding priority for nonprofits serving the working poor by providing employee breast health education and on-site screening services in the following counties: Allendale, Barnwell, Bamberg, Calhoun, Colleton, Jasper, Hampton, Marion, and Orangeburg. This will be accomplished by including these employer/provider partnerships as a funding priority in the RFA. The reviewers' weighted scoring will be revised to allow for higher scoring under the "Collaboration" category of those applications meeting this priority.
 - C. Fostering of collaborations (for-profit/nonprofit, employer/provider, or local providers/larger hospital systems) as a funding priority to preserve and strengthen the breast health continuum of care in the target communities, including transportation for diagnostic and treatment services to Beaufort, Charleston, Florence or Orangeburg. The reviewers' weighted scoring will be revised to allow for higher scoring under the "Collaboration" category of those applications that include collaborations to support transportation to diagnostic and treatment services.
- *Objective 2:* By March 31, 2018, hold one collaborative meeting in Hampton County and one in Marion County inviting representatives from local hospitals, health care providers and community members to foster discussion about how to improve relationships between patients and the hospitals in the respective counties.
- *Objective 3:* By March 2016, develop one Community Advisory Board (CAB) comprised of at least one individual from each of the following I-95 Corridor regions: Southern, Southwestern, Western and Marion County. The CAB will meet semi-annually and report to the Affiliate's Board of Directors on an annual or "as needed" basis. The goal of the CAB is to ensure that the breast health care needs of rural communities in the

service area are clearly represented. The members of the CAB may include medical, public health, and nonprofit professionals, community stake-holders, and survivors.

Problem Statement:

Breast health education is needed in every target region. Culturally sensitive education of both the public and providers may lead to increased follow through of screening and health care recommendations. If patients know help is available, they are more likely to follow through with recommended care.

It is particularly concerning that providers are not a recognized source for breast health education in any target region. Educating providers about available breast health care and local resources may assist in developing trust within their local communities. By sharing the information with their patients, providers can become a trusted partner. This may be especially helpful in Hampton County (Southern Region) and Marion County, where distrust is most evident. This distrust of the community in the local providers leads to delayed screening and treatment. Improved trust between patients and providers may have a positive impact on breast health outcomes by improving screening rates and reducing late-stage and death trends.

Priority: Increase the dissemination of trusted breast health care education and information about Best Chance Network, local breast health providers, and financial aid in the four target communities.

- *Objective 1:* By January 2016, develop sustainable year-round education and outreach opportunities designed to develop and educate local community ambassadors by hosting 1 workshop in each of the following I-95 Corridor regions: Southern Region, Southwestern Region, Western Region and Marion County.
- *Objective 2:* By November 2017, conduct two mailings to educate providers about the most current breast health recommendations, resources available in their local community, Best Chance Network enrollment process, and other locally available evidence-based programs that may increase their patients' screening rates. The mailings will be sent to all providers in the following counties: Allendale, Barnwell, Bamberg, Calhoun, Colleton, Jasper, Hampton, Marion, and Orangeburg.
- *Objective 3:* In FY 2016 and FY 2017, at least once a month include breast health education, local resources or regional breast health happenings in one of the Affiliate's social media outlets (Facebook, Twitter and e-mail campaigns).
- *Objective 4:* By September 2017, partner with a health organization that predominantly serves the Hispanic/Latina community in Jasper County (Southern Region) to hold one breast cancer community outreach presentation.

Problem Statement:

The current state funded health care system does not provide adequate coverage for South Carolina's most vulnerable women and men. The working poor and underinsured face additional barriers to care. For example, Healthy Checkups provides screening mammography. However, it is exclusionary and does not provide coverage for diagnostic or treatment services. Improved access to care for the underserved can be addressed through the Affiliate's advocacy efforts, as well as grantmaking. Improved access for early detection will lead to improved outcomes.

Priority: Reduce financial barriers to care for the working poor, underinsured, and medically underserved in the four I-95 Corridor regions, including those who would have been Medicaid eligible had the state expanded it.

- *Objective 1:* By August 31, 2016, Revise FY Community Grant RFA to include the following priorities that reduce financial barriers to the full continuum of care faced by the working poor, uninsured and underinsured including free or reduced cost access to:
 - A. Screening and diagnostic services that are not available through Healthy Checkups for residents of the following counties: Allendale, Barnwell, Bamberg, Calhoun, Colleton, Jasper, Hampton, Marion, and Orangeburg.
 - B. Treatment support services including transportation in the following counties: Allendale, Barnwell, Bamberg, Calhoun, Colleton, Jasper, Hampton, Marion, and Orangeburg.
 - C. Worksite screenings in the following counties: Allendale, Barnwell, Bamberg, Colleton, Jasper, Hampton, Marion, and Orangeburg.
- *Objective 2:* By September 2016, re-establish Small Grant opportunity for the Affiliate's service area to provide transportation and education programs that focus on current breast health recommendations, financial aid resources, and the Best Chance Network enrollment process, that result in documented access to screening and care.
- *Objective 3:* In FY 2016 and FY 2017, the Affiliate will maintain membership in the SCCA and attend at least one meeting of the SCCA or the SC Cancer Disparities Network's Community Advisory Group pertinent to breast cancer legislation, including maintaining Best Chance Network funding and supporting Medicaid expansion.
- *Objective 4:* In FY 2016 and FY 2017 include two public policy updates annually in Affiliate's social networking (Facebook, Twitter or e-mail campaigns).
- *Objective 5:* In FY 2016-FY2018, conduct a bi-annual mailing to all state and federal legislators in the Affiliate's service area to increase understanding of:
 - A. The impact of the lack of Medicaid expansion on women and men needing diagnostic services and other breast health services not covered by Health Check-ups.
 - B. Komen as a local resource providing funds for women and men who would have been Medicaid eligible to access breast cancer services.

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