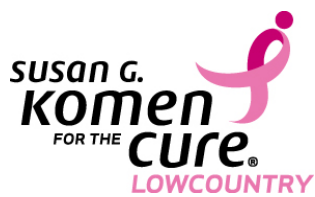




# COMMUNITY PROFILE REPORT

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# 2011

**Disclaimer:**

The information in this Community Profile Report is based on the work of Lowcountry Affiliate of Susan G. Komen for the Cure® in conjunction with key community partners. The findings of the report are based on a needs assessment public health model but are not necessarily scientific and are provided "as is" for general information only and without warranties of any kind. Susan G. Komen for the Cure and its Affiliates do not recommend, endorse or make any warranties or representations of any kind with regard to the accuracy, completeness, timeliness, quality, efficacy or non-infringement of any of the programs, projects, materials, products or other information included or the companies or organizations referred to in the report.

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### Sources of Qualitative Data

Alabama Cancer Society	Loris Health System
Allendale Hospital	Low Country Health Care System
American Cancer Society	McLeod Regional Medical Center
Beaufort Jasper Hampton Comprehensive Health Services	Neighbors Helping Neighbors
Beaufort Memorial Hospital	North Strand Ob/Gyn
Clemson Extension Services	Our Lady of Mercy
East Cooper Regional Medical Center	Roper St. Francis Healthcare
Georgetown Hospital System	Salkehatchie Healthy Communities Collaborative
Hampton Regional Medical Center	SASSY support group
Hilton Head Regional Medical Center	Share Our Suzy
MUSC Hollings Cancer Center	South Carolina DHEC region 5
Integrative Cancer Care	SC DHEC region 6
Keyserling Cancer Center	State Baptist Young Women's Association
Little River Medical Center	

**Sources of Qualitative Data (cont.)**

St. James-Santee Family Health Center  
The Regional Medical Center of Orangeburg and-Calhoun Counties  
Trident Health System  
United Way of Bamberg, Colleton, and Hampton  
University of South Carolina  
Volunteers in Medicine

**Community Focus groups:**

Bamberg, Barnwell, Hampton, and Orangeburg communities (2)  
Bosom Buddies support group  
Georgetown community  
Gullah nurses  
Latinas of Allendale, Hampton and Jasper counties (2)  
Latinas of Charleston area  
Our Lady of Mercy rural outreach  
Our Lady of Mercy Hispanic outreach  
Parris Island active duty  
Parris Island dependants  
Paula Williams support group  
Salkehatchie community

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## Executive Summary

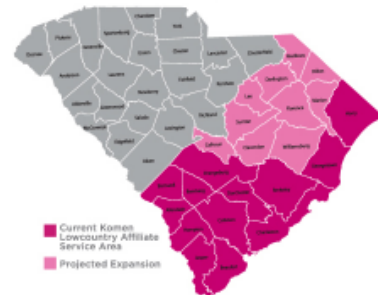
### Introduction

Susan G. Komen for the Cure® is the world's largest source of nonprofit funds dedicated to curing breast cancer at every stage. Virtually every major advance in breast cancer research has been touched by a Komen grant. The Lowcountry Affiliate of Susan G. Komen for the Cure is an independent, tax-exempt 501(c) (3) organization and was incorporated in 1999. Our funds support community based breast health programs, while also investing in national research initiatives. Since 2001, the Lowcountry Affiliate has invested over \$4 million in grant funding to our service area, providing breast health and breast cancer education, screening, and diagnostics services to those in need. The 2010 Susan G. Komen for the Cure Lowcountry Race for the Cure® raised over \$840,000 to support our mission and grants.

Komen Lowcountry is active in advocacy and public policy on local, state, and national levels. In 2008, the affiliate and its partners were successful in procuring the first-ever state funding of \$2 million for Best Chance Network (BCN), the state's National Breast and Cervical Cancer Early Detection Program (NBCCEDP). Although the funding is no longer in place, Lowcountry continues to collaborate with our partners to reach legislators with the importance of early detection and the need for funding this life-saving program.

The Lowcountry affiliate currently covers thirteen eastern South Carolina counties stretching from the coast to the piedmont area:

- Allendale
- Bamberg
- Barnwell
- Beaufort
- Berkeley
- Colleton
- Charleston
- Dorchester
- Georgetown
- Hampton
- Horry
- Jasper
- Orangeburg



The Affiliate intends to expand into the following counties: Calhoun, Clarendon, Darlington, Dillon, Florence, Marion, Lee, Sumter, and Williamsburg. The following counties are slated for the first step towards this goal: Calhoun, Florence, Marion, and Williamsburg. Full affiliate expansion is expected to take 2-5 years. This long-term expansion will insure that the entire state of South Carolina is covered by one of the two SC affiliates. The other SC Komen affiliate is the Mountains to Midlands Affiliate, located in Greenville, and serving the western portion of the state (grey on map above).

### Statistics and Demographic Review

The Affiliate serves approximately 1,350,632 people, of whom an estimated 690,315 are female. Our service area is primarily rural with four urban centers: Myrtle Beach, Charleston, Beaufort, and Orangeburg. Although the state population is predominantly White non-Hispanic (68.9%), many of the counties we serve are not. African Americans represent the largest population in five of our counties, and the Hispanic population is growing. Seven Affiliate counties have over 20 percent of the population living below poverty level, with Allendale the highest at 41 percent (U.S. Census Bureau, "State and County QuickFacts: South Carolina," 2010).

In order to identify needs in our service area, the Community Profile team collected data on several factors related to breast cancer in each county: mortality, incidence, race/ethnicity, socioeconomic status, stage and grade of diagnosis, and screening rates. This statistical information came from the South Carolina Cancer Registry, maintained by the Department of Health and Environmental Control (DHEC), and Thompson Reuters ©2009. Mortality and incidence statistics are age-adjusted rates and indicate breast cancer deaths or cases per 100,000 people. Population data was derived from the county population estimates made by the United States Census Bureau in July 2009. Some data was not listed for smaller counties due to small sample sizes of incidence and/or mortality. Although completed, 2010 census information had not been publicly released at the time of this writing.

The highest mortality rates in our service area were seen in Allendale, Bamberg, and Orangeburg counties, with increases in mortality rates in recent years (2002-2007) in Bamberg, Colleton, and Hampton counties. In our service area, African American women had higher mortality rates than Caucasian women in all counties. The highest rates of late stage diagnosis were seen in Allendale, Barnwell, Jasper, Georgetown, and Orangeburg counties (South Carolina Department of Health and Environmental Control (SCDHEC), "SCAN Cancer Incidence and Mortality," 2010). The highest percentages of women in 2009 who did not receive a yearly mammogram were seen in Allendale, Barnwell, and Hampton counties. The counties with high mortality rates and late stage diagnosis often correlate with a lower socioeconomic status and rural geography. Allendale, Bamberg, Barnwell, and Orangeburg counties have the highest rates of uninsured women, ages 18-64, and Allendale, Bamberg, Hampton, and Orangeburg counties have the highest percentages of people living below the poverty level (SCDHEC, "SCAN Cancer Incidence and Mortality," 2010; Thompson Reuter, 2009). The counties slated for Stage I expansion have demographics very similar to those just mentioned. Florence County is the largest service provider for Williamsburg and Marion counties; Orangeburg serves Calhoun County's residents.

Based on the findings from the statistical data, the team chose to further investigate African American women and rural populations. African American women were chosen due to their overall high mortality rates and late stages of diagnosis. Rural counties tended to have high mortality rates and low screening percentages. In addition, many of the rural counties have large African American populations. Based on these factors, targeted counties include Allendale, Bamberg, Barnwell, Colleton, Georgetown, Hampton, Jasper, and Orangeburg counties.

Three additional communities were selected for further review: Hispanic, military, and breast cancer survivors. South Carolina has a growing Hispanic/Latino population. Jasper County's 2009 population is estimated to be 14.1 percent Hispanic. Beaufort, Berkeley, Charleston, and Horry counties also have a growing number of Hispanics (U.S. Census Bureau, "State and County QuickFacts: South Carolina," 2010). Concerns about the military populations in Beaufort and Charleston were presented to the team by members of those communities. The initial concern was related to access to care, but our findings did not support the concern. However, support for educating wives and young female recruits about their risk for breast cancer is needed. Finally, breast cancer survivors are facing issues not previously addressed in our reports. Young survivors face different issues than their older counterparts, and metastatic and male survivors have their own unique issues. Also, more effective treatments are allowing

survivors to live longer after a breast cancer diagnosis, leading to questions related to post-treatment follow up care.

### **Health Systems Analysis**

In order to evaluate health systems, we analyzed available health care services as well as gaps in the continuum of care. To determine the available health care resources and programs, we compiled a list of free clinics, hospitals, Best Chance Network providers, and breast cancer support groups within our service area. The name and location of these facilities were obtained from the South Carolina Free Clinics Association, American Cancer Society, and hospital databases. Hospitals located in each county were contacted to determine if they provide breast cancer screening and diagnostic services. After compiling this information, services and programs were plotted using an asset map.

The geographic gaps in rural health care services create barriers for screening, which in turn may perpetuate the high mortality and low screening rates seen in the statistics. In most cases, there is no local public transportation, and those needing diagnostic services must travel to another county. Health care facilities in rural counties are smaller and typically do not have the equipment to provide diagnostic services. In addition, these communities tend to have less employment opportunities, leading to low socioeconomic status and high uninsured rates. Those who are employed often have to travel out of their county of residence, spending several hours a day traveling to and from work. This leaves very limited time for healthcare appointments.

Creative approaches are necessary to reduce the gaps in care. Partnership opportunities are greatest with churches and collaborative community groups. These are groups with a vested interest and strong ties in the local community. They are also trusted in their communities, which is crucial to successful programs. The Links, one of the nation's oldest and largest volunteer service organizations, is an excellent partner in reaching the African American community in the Orangeburg area. Church health ministers are excellent partners for outreach and policy collaborations with African Americans and rural populations.

Several collaborative groups have been formed in an effort to ease some of the constraints of individual budgets in addressing various issues within the community. One example of this is the recently formed Coastal Cancer Collaborative, comprised of a variety of organizations in Horry, Georgetown, and Williamsburg counties. The goal of the coalition is to reduce the burden of cancer on the community through education, improved access to care, and public policy. Partnering with the Department Health and Environmental Control (DHEC) is another opportunity that should not be overlooked. One of the greatest challenges will be the funding of Best Chance Network. With the state facing a budget shortfall this year of \$877 million (17.4 percent), funding for those in greatest need is in jeopardy (McNichol, E., Oliff, P., & Johnson, N., 2011). Partnership opportunities also exist with the medical community, including those not directly related to breast health. For instance, diabetes educators promote a healthy lifestyle, which is a natural tie-in to breast cancer risk reduction. In fact, this is an especially promising partnership as 65 percent of our residents are obese, a known risk factor for both diabetes and breast cancer (SCDHEC, "Obesity Prevention & Control").



### Qualitative Data Overview

For a more complete picture of the communities of concern, nineteen key informants and twenty-one providers representing the target populations were interviewed via surveys and personal interviews. The key informants included: grantees (past, current and prospective), members of the medical community, community leaders, social workers, cultural experts, government agency employees, and other community partners. Represented organizations included: South Carolina Cancer Registry, DHEC, United Way, Best Chance Network, University of South Carolina Office of Latin American Studies, South Carolina Cancer Alliance, Clemson Extension Services, Coastal Cancer Collaborative, Salkehatchie Healthy Communities, SC Baptist Young Women's Association, Beaufort military bases, and breast cancer support group members among others. Participating providers represented primary care physicians, free clinics, hospitals, surgeons, and patient navigators. Twenty-four federally qualified clinics and Best Chance Network (BCN) providers, as well as seven free clinics, were contacted for their input. Unfortunately, the vast majority of the clinics and BCN providers chose not to participate in the project, citing time constraints. Three group discussions were held, one with three members of the medical community at Beaufort Memorial Hospital and Keyserling Cancer Center, another with three staff members of Beaufort-Jasper-Hampton Comprehensive Health. The third was at McLeod Hospital in Florence.

To get the community's perspective, we held 14 focus groups. Key community leaders invited the attendees, and the sessions were facilitated by the affiliate's Mission Coordinator who has professional interviewing experience. Several groups were representative of more than one target population and addressed multiple issues. For example, a group of Gullah (a distinct local African American population) nurses spoke about the barriers for African American women, as well as those for rural women. Some groups also included members of the medical community. Below are the numbers of focus groups that included the target populations:

County	# FG	Population	# FG
Allendale/Barnwell	3	rural	11
Georgetown	1	African-American	4
Hampton	5	Hispanic	2
Jasper	3	survivors	3
Bamberg/Colleton/Orangeburg	3	military	2

*Table 1.* The number of focus groups held in the Lowcountry affiliate service area, broken down by county (left) and population group (right).

The themes were consistent with almost every population. Primary barriers were lack of services, education, and cost. The lack of services impacted time and transportation. The education barrier was the most complex because there are several factors involved. Education about screening remains an issue for the public. This includes dispelling myths about breast cancer, some of which may be unique to a specific culture. Young women and lesbians also need to be educated about their risk for the disease.

Most participants, regardless of demographics, also commented on the need for educating healthcare providers and patients about available resources (Best Chance Network, Komen, financial aid, etc.), as well as screening guideline recommendations. Overall, this was seen as an

even greater need than educating the public about general “breast cancer awareness”. Fear is also a piece of the education barrier and is more than a single issue. Fear may include the perceived pain of a mammogram, fear of a cancer diagnosis, or fear of financial hardship due to medical procedures (including screening). Fear also included embarrassment at being seen by the community as weak or questioning “God’s plan”.

Financial concerns were raised in all groups, but often with the caveat that there are programs available. However, patients and their doctors are either unaware of them or don’t know how to access them. This was seen as an extremely important issue. Transportation cost is another common barrier. Rural residents often have to travel 50 miles or more for breast care. For some, this means an all day trip and lost wages for medical care. Many who work are unable to get the time off, and the medical facilities are not open during the hours that the women are not working. For others, the time barrier is simply not taking the time to care for themselves.

In addition to the barriers mentioned previously, Hispanic women have the added barrier of language. Often young children have to interpret for their parents. There is also the fear of deportation. This was shown to be true for both documented and undocumented women. Latinas also stated that they felt they were treated differently due to the language barrier. A number of African-American women also said that they were treated differently than their white peers.

Two additional groups presented their own challenges. The concern heard for the military was reduced spending on education about breast cancer, raising the risk of later detection in young women. Survivors were concerned about the lack of support services for specific survivor populations. Young survivors felt their needs were different than most women in traditional support groups, and male survivors face their own challenges. Women with metastatic disease commented that there was a lack of support for women with their unique issues. Lymphedema prevention and post-treatment follow up plans were concerns of survivors of all ages and prognoses.

The Affiliate will use the findings of the qualitative data coupled with the statistical findings to determine the priorities of the organization. Those priorities will guide the affiliate’s education, outreach, and grants programs. Public policy efforts will also be guided by these issues.

## **Conclusions**

The statistics, surveys, and focus groups highlighted the need to reach specific communities with breast health education and resources. Overall, rural and African-American women in our service area face the greatest barriers in access to care. Culturally appropriate education is needed for the Hispanics as well as African-Americans, and it should come from trusted members of their communities. Education must include screening guidelines and community resources, i.e. where to get screening, financial aid, transportation, etc. Health care professionals also need this information as many are unaware of available programs, leaving their patients feeling they have nowhere to turn for help. Breast cancer survivors’ needs are relative to their age and prognosis. Overall, the need is for peer to peer support. Survivors as a whole need an established plan for follow-up care after treatment. In addition, they need access to lymphedema education and garments.

The specific impact of healthcare reform, legislative budgets, and the recession on the communities we serve is unknown. Any significant impact will be addressed with an addendum or update to this review.

The Community Profile team charted the responses from surveys, interviews, and focus groups. The most common concerns within each target population were used to determine the priorities for the affiliate. A strategic plan based on the priorities will be developed by Affiliate leadership. Often the goals set forth will be accomplished through collaboration with other organizations and key community leaders. It is the Affiliate's responsibility to the communities we serve to address the needs highlighted in the Community Profile through our mission, grants, and public policy programs. By working together with our partners in the communities we serve, we will reduce the burden of breast cancer on the people of South Carolina.

### **Affiliate Priorities**

- Priority 1: Reduce the barriers to screening and treatment, especially for rural populations:
  - Objective 1: In FY 2011 and FY 2012, hold 2 grant writing workshops to solicit evidence-based grants that address the barriers to screening and diagnostics for medically underserved rural populations
  - Objective 2: In FY 2011 partner with the South Carolina Cancer Alliance to promote additional state funding of Best Chance Network
  - Objective 3: By end of FY 2011, include Calhoun, Florence, Marion, and Williamsburg in the affiliate service area
  
- Priority 2: Increase education about breast health, breast cancer screenings, and available resources:
  - Objective 1: By end of FY 2011, develop and distribute community resource list to healthcare providers and consumers throughout the affiliate service area
  - Objective 2: By October 2011 and recurring each subsequent October, partner with African American and Hispanic community leaders to provide culturally sensitive educational materials to their specific populations through Pink Sunday
  - Objective 3: In FY 2012 solicit evidence-based grants that address the barriers to care faced by Hispanic/Latino women
  - Objective 4: In FY 2012, provide breast health materials to Beaufort Naval Hospital
  
- Priority 3: Improve support services for survivors:
  - Objective 1: In FY 2012 and 2013, solicit evidence-based grants that address support services for specific populations of survivors, i.e. young women, metastatic, men, etc. This includes prevention of lymphedema
  - Objective 2: By end of FY 2012, host a survivor workshop regarding post-treatment follow up care for survivors

## **Introduction**

The Lowcountry Affiliate of Susan G. Komen for the Cure®, along with those who generously support us with their time, talent, and resources, is working to reduce the burden of breast cancer in our community. Since 2001, the affiliate has provided nearly four million dollars in grant funding to our service area, providing breast health and breast cancer education, screening, and diagnostic services to those in need. We strive to empower the community through education and dedicate ourselves to supporting programs addressing outreach and education, screening, treatment, and survivorship issues that target services not otherwise available to those in need. Grants for screening and diagnostics are for the medically underserved, while outreach and education are needed for all. It is our belief that all people deserve equal access to quality care, regardless of race or socio-economic status.

### **Affiliate History**

The first Charleston Race for the Cure was held in 1994, with proceeds funding programs in the Charleston area. The affiliate officially incorporated as the Charleston Affiliate of Susan G. Komen for the Cure in 1999. In order to reflect the growing service area, the name was changed in 2004 to Lowcountry Affiliate of Susan G. Komen for the Cure.

The Komen Lowcountry Affiliate is an independent, tax-exempt 501(c)(3) organization. Among over 1000 charities, Komen was ranked as the number one in brand equity and number two most trusted (following St. Jude's Children's Research Hospital) by the 2010 Harris Poll. The survey also found that Komen is the charity to which people say they are most likely to donate money (Harris Interactive, 2010). Komen has also received Charity Navigator's highest rating - four stars - for the fourth consecutive year. With this rating, Komen for the Cure becomes one of only 9 percent of the approximately 5,400 charities that Charity Navigator evaluates which has received at least four straight 4-star ratings ("Charity Navigator: Your Guide To Intelligent Giving," 2011).

Typically throughout the United States, non-profits allow up to 25 percent of their budget towards administrative and fundraising. Although National Komen also sets that as the guideline, Komen Lowcountry expends around 18-19% towards those costs, allowing for greater investment in grants and education. Seventy-five percent of the money raised locally is re-invested in community projects and initiatives within our service area. The remaining 25 percent of funds raised locally helps support the national Susan G. Komen for the Cure Award and Research Grant Programs, which in turn have funded some of the most significant breast cancer medical investigations of the last 25 years.

The Susan G. Komen Lowcountry Race for the Cure® is our signature fund-raising event, raising over \$840,000 in 2010 to use on our efforts to address disparities related to breast cancer in our service area. As the affiliate expands, additional fundraising opportunities are being developed. The affiliate is also embarking on a capital campaign. Although the race is our most significant fund raising event, there are many additional opportunities for financial development including third party events, annual giving, private donations, and grant opportunities for our mission programs.

## Organizational Structure

Volunteers are the backbone of the organization, providing thousands of hours in support of our projects. Over 700 dedicated advocates and breast cancer survivors from the community contribute their time and talents to our mission. They assist in all aspects of affiliate work and come from all walks of life. We are supported by the efforts of young children, students, business men and women, the unemployed, retirees, and the elderly. Like breast cancer, our volunteer base knows no boundaries.

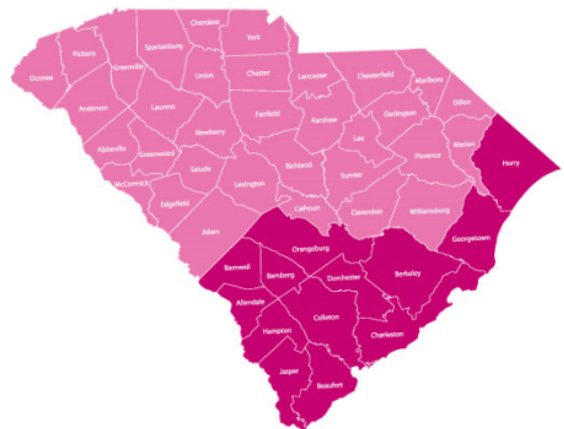
The Lowcountry Affiliate currently has a staff of 4: Executive Director, Fund Development Manager, Mission Coordinator, and Affiliate Coordinator. The Executive Director oversees all aspects of the affiliate's work and is ultimately responsible for assuring that the affiliate works towards our mission to end breast cancer forever. Taffy Tamblyn, the Executive Director, has held this position since 2001. The Mission Coordinator is responsible for ensuring that the mission of the affiliate is accomplished through education, outreach, and grants within the community. This is accomplished through collaborative efforts with other community partners. Advocacy and public policy are also key components of affiliate mission work. The Fund Development Manager is primarily responsible for coordinating all fundraising programs including the Race for the Cure® and the capital campaign. The Fund Development manager is also the affiliate liaison for Passionately Pink and third party events. The Affiliate Coordinator assists with all major projects, as well as the daily tasks of the organization. Although each staff member has specific duties and responsibilities, all work closely together to ensure the success of the affiliate.

There are currently 11 members on the 2010-2011 Board of Directors, which is in the process of transitioning from a working board to a governing board. The board meets on a monthly basis (except for December and July), with individual committees meeting as needed. The board leaders include the President, Treasurer, and Secretary. Board members come from a variety of backgrounds and represent the diverse population we serve. Term limits are in place to encourage growth and new ideas. A strategic planning session is held annually by the board. At this planning session, the affiliate's goals and objectives are set for the coming years.

## Description of Service Area

The Lowcountry affiliate currently covers thirteen eastern South Carolina counties stretching from the coast to the piedmont area:

- Allendale
- Bamberg
- Barnwell
- Beaufort
- Berkeley
- Colleton
- Charleston
- Dorchester
- Georgetown
- Hampton
- Horry
- Jasper
- Orangeburg



Predominantly rural, the region is characterized by beaches, wetlands, swamps, and forests. Traveling west from the coast, the roads wind through farms and swamps and into rolling hills. Cotton, corn, and livestock dot the inland landscape, with ocean waves from the Atlantic lapping at the coast. A haze lingers in the air from paper mills and power plants in Charleston and Georgetown. I-95 cuts across the region from north to south. The I-95 “Corridor of Shame” is aptly named due to the high level of poverty and failing schools. The area represents a primarily poor population with 86 percent of the students on free and reduced lunch. The percentage of schools in these districts that ranked unsatisfactory and below average is 75 percent (Ferillo & Associates, Inc., 2006).

The 2010 Census reports that South Carolina’s population has grown 15.3 percent and includes 4,625,384 residents. The Lowcountry is home to approximately 1,360,458 people, of whom 695,918 are female. Our diverse population includes Whites, Blacks and Hispanics among others. For the purposes of this report, Hispanics are considered a separate population from Whites. This is in order to best account for disparities in education, screening, and services related to cultural and ethnic differences. The 2009 census estimates for South Carolina show predominantly White non-Hispanic (68.9 percent), Black (28.2 percent), and Hispanic (4.5 percent) populations. Although the state population is predominantly White non-Hispanic, many of the counties we serve are not. For example, the Black population accounts for 71.9 percent in Allendale and 61.9 percent in Bamberg, while Jasper is predominantly White with a significantly large Hispanic population of 14.1 percent. The chart below illustrates the racial & ethnic population percentages within the counties we serve based on 2009 estimates (U.S. Census Bureau, “State and County QuickFacts: South Carolina ,” 2010).

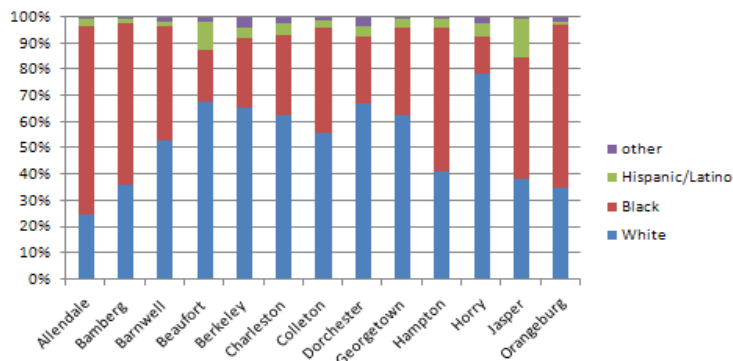


Figure 1. Racial demographics by county in 2009. Thompson Reuters ©2009.

The majority of the Lowcountry service area is rural with several distinct metropolitan areas: Charleston, Beaufort, Myrtle Beach, and Orangeburg. Major employers include hospitals, school systems, colleges and universities, as well as state government. Tourism is a leading industry in Beaufort, Charleston, and Horry counties. Farming provides sustenance for much of the rural population. Lumber also has a significant impact on the area, providing some inland jobs in rural counties and the resources for the paper mills.

Although South Carolina’s unemployment rate is 10.7 percent, the majority of the rural counties of the affiliate have unemployment rates above 12 percent. Marion County leads the state in unemployment with 19.7 percent. Allendale is third with an unemployment rate of 18.3 percent.

The Pee-Dee region, which includes Marion and Florence, has an unemployment rate of 13.5 percent. The urban counties of Beaufort and Charleston counties are on the low end with rates of 8.5 percent and 8.6 percent respectively. Although unemployment rates did rise prior to 2009, the state has seen an overall decline in unemployment rates between December 2009 and December 2010 (South Carolina Department of Employment and Workforce, 2010). This drop in unemployment can be deceiving because many people are still underemployed, meaning they may be working a part-time job but continue to live in poverty. According to 2007 estimates, over 20 percent of South Carolina's residents are uninsured. Jasper County has the highest percentage of uninsured residents at 31.2 percent (South Carolina Budget and Control Board, 2011).

The Lowcountry Affiliate intends to expand into the following counties in the future: Calhoun, Clarendon, Darlington, Dillon, Florence, Marion, Lee, Sumter, and Williamsburg. The 2010 Community Profile includes information about the following counties: Calhoun, Florence, Marion, and Williamsburg. These are the counties under consideration for recent expansion due to their geographic locations and largely rural populations. In order to properly address each area, a long term plan for expansion will be developed before incorporating additional counties. Full affiliate expansion is expected to take 2-5 years. This long-term expansion will insure that the entire state of South Carolina is covered by one of the two SC affiliates.

### **Purpose of the Report**

The 2011 Community Profile is a needs assessment of our service area compiled to assist the Lowcountry affiliate and its partners in addressing breast cancer disparities within the region. The reader will be introduced to the Lowcountry affiliate, the region it serves, and the burden of breast cancer on it. This profile will be a guide for affiliate work and expansion of services by identifying the breast health needs and disparities to be addressed by the affiliate.

Material in this report is derived from the most recent information available. Although the 2010 Census is complete, South Carolina's county data has not been released to the public at the time of this writing. This information will be available by April 1, 2011 and may impact the findings of this report. Healthcare reform, state and federal budget deficits, and the current recession are other factors that may significantly impact the affiliate service area. Much is still to be determined in health care reform and economic recovery is tenuous, at best. South Carolina's new governor, Nikki Haley, faces a budget shortfall of \$877 million, or 17.4 percent of the 2011 fiscal year budget (McNichol, E., Oliff, P., & Johnson, N., 2011). Recent legislative changes may also have a significant impact. An addendum to this needs assessment will be written if any significant changes impact the overall findings of this report.

## **Breast Cancer Impact in Affiliate Service Area**

### **Methodology**

In order to identify needs in our service area, the Community Profile team collected data on several factors related to breast cancer in each county: mortality, incidence, racial demographics, socioeconomic status, stage and grade of diagnosis, and mammography rates. The service area is diverse, especially in population size. Total population ranges from 10,195 in our smallest county (Allendale) to 355,276 in our largest county (Charleston) (U.S. Census Bureau, "South Carolina by County: GCT-T1 Population Estimates," 2009). These variances posed some

challenges when analyzing the statistical data. When comparing rates, the smallest counties tended to have the highest mortality rates, which may be due in part to the small sample size. However, the largest counties tended to have the highest numbers affected by breast cancer due in part to the large sample size.

Counties were analyzed by comparing tables and charts of variables related to breast cancer. The majority of the statistics came from the South Carolina Cancer Registry, which is maintained by the Department of Health and Environmental Control (DHEC). Information from Thompson Reuters Data Pack ©2009 (T-R 2009) was used as an additional source, although the data from T-R 2009 was extrapolated in smaller population areas. Because many of our counties are in rural areas, we believe that the statistics from the South Carolina Cancer Registry (SCCR) would be most reflective of our service area. In addition to interpolating data, the South Carolina Cancer Registry allowed us to control for several variables, such as year, age, and race. T-R 2009 did not have these capabilities. Therefore, we pulled mortality and incidence rates from the South Carolina Cancer Registry and modified the constraints to further analyze these rates by race, stage, and grade. More obscure data, such as mammography screening rates, was then obtained from T-R 2009 and used to supplement the statistics obtained through the South Carolina Cancer Registry. Population data and socioeconomic status were derived from United States Census Bureau estimates for 2008-2009. The 2010 census information for South Carolina was not available at the time of this writing and may impact the communities addressed.

The statistical data relating to female breast cancer among all age groups in South Carolina was taken from the South Carolina Cancer Registry. The incidence rates included in situ cases. Both incidence and mortality rates were age-adjusted and calculated based on the United States Standard Population in 2000. In addition, statistical data was compiled in two ways. First, we looked at mortality and incidence rates over the course of 11 years (from 1996-2007), which allowed a view of longitudinal trends within counties. Next, we compiled mortality and incidence rates from the most recent years (from 2002-2007) and compared them to rates in years prior (from 1996-2001). In this way, we analyzed recent changes within our service area.

The statistical information from T-R 2009 related to female breast cancer in 2009. Mammography screening data was quantified as a percentage and only included women age 40 and older. Socioeconomic status was quantified based on percentage of uninsured women, percentage of people living below the poverty line, and median household income. All statistics and findings were reviewed for accuracy by Dr. Joan Cunningham and Dr. Erika Brown, the team's statistical consultants.

### **Overview of the Affiliate Service Area**

To compare counties, we focused on mortality and incidence rates, which reflect the number of cases occurring within a population size of 100,000. The breast cancer mortality rates in our service area showed a wide range of variability, from 20.7 to 41.5 between 1996 and 2007 (see Figure 2). Overall, the rural counties tended to have the highest mortality rates. However, due to small population sizes, these counties often had the largest confidence intervals as well. Large confidence intervals indicate that these rates may be much higher or much lower than the indicated value. For instance, Allendale County had a mortality rate of 41.5 with a large confidence interval from 27.58 to 59.98. This interval shows that the mortality rate could be as



high as 59.98 or as low as 27.58. The smaller the vertical line in Figure 2, the more confident we can be that the mortality rate is representative of the county. In addition, Figure 3 compares mortality rates over two six year periods, from 1996-2001 and 2002-2007. In recent years, some counties have seen increases in mortality rates, while others have seen decreases in comparison to past years (see Figure 3). The only increases in mortality rates were seen in Hampton, Colleton, and Bamberg counties. The largest decreases were seen in Barnwell, Berkeley, and Georgetown counties. For Allendale County from 2002-2007 and for Calhoun County from 1996-2001, there were less than 10 deaths over the 6 year time span. Therefore, rates were not calculated because small sample sizes lead to unreliable statistics (SCDHEC, “SCAN Cancer Incidence and Mortality,” 2010).

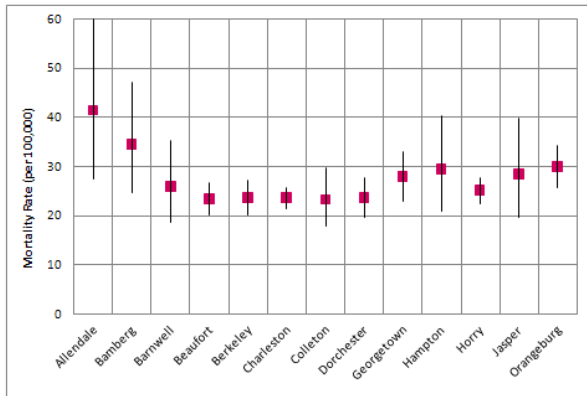


Figure 2. Age-adjusted, female breast cancer mortality rates by county from 1996-2007. SC Dept of Health and Environmental Control, South Carolina Community Assessment Network, 1996-2007 Cancer Mortality Module.

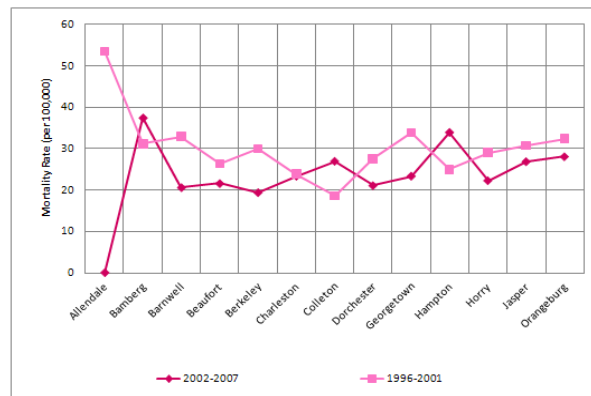


Figure 3. Six year comparison of age-adjusted, female breast cancer mortality rates in recent years vs. past years. SC Dept of Health and Environmental Control, South Carolina Community Assessment Network, 1996-2007 Cancer Mortality Module.

As seen in Figure 4, the percentage of women over 40 without a mammogram in the past year ranged from 36 percent to 44.6 percent (Thompson Reuter, 2009). As seen in Figure 5, the incidence rate of late stage diagnosis was between 40 and 60, while early stage diagnosis was between 80 and 120. The exception to this trend was Jasper County, where early stage diagnosis was extremely low (SCDHEC, “SCAN Cancer Incidence and Mortality,” 2010).

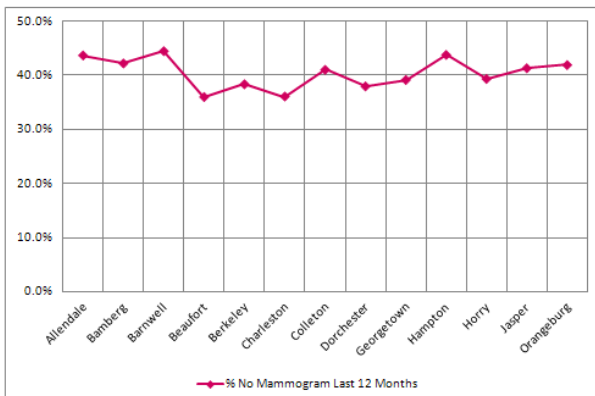


Figure 4. Percentage of women (ages 40+) in 2009 who had not received a mammogram in the last 12 months. Thompson Reuters ©2009.

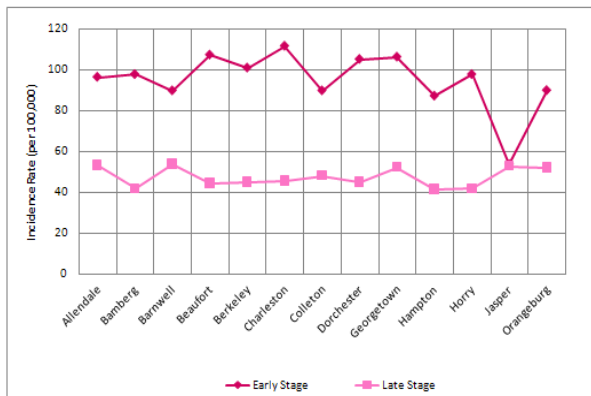


Figure 5. Comparison of female breast cancer incidence rates by stage from 1996-2007. SC Dept of Health and Environmental Control, South Carolina Community Assessment Network, 1996-2007 Cancer Incidence: Full File.

The counties with the highest mortality rates were Allendale (41.5), Bamberg (34.6), Orangeburg (30), Hampton (29.5), and Jasper (28.5). These are all predominantly rural counties that are characterized by low socioeconomic status and large African American populations. Barnwell (44.6 percent), Hampton (43.9 percent), and Allendale (43.8 percent) counties had the highest percentages of women who did not receive a mammogram in 2009. The highest rates of late stage diagnosis were seen in Barnwell (54), Allendale (53.4), Jasper (53.1), Georgetown (52.5), and Orangeburg (52.2) counties (SCDHEC, "SCAN Cancer Incidence and Mortality," 2010).

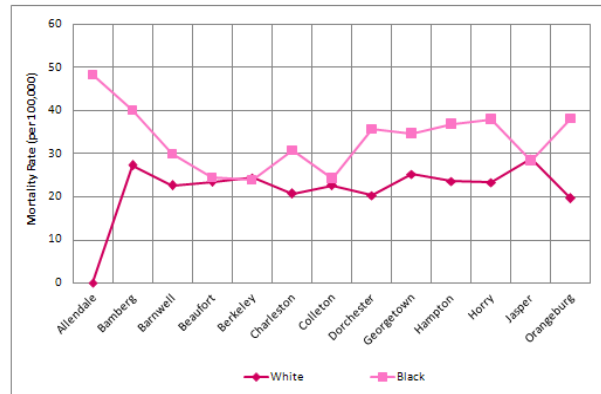


Figure 6. Comparison of age-adjusted, female breast cancer mortality rates by race from 1996-2007. SC Dept of Health and Environmental Control, South Carolina Community Assessment Network, 1996-2007 Cancer Mortality Module.

To further understand the possible influences on mortality rates, we analyzed them by race, stage of diagnosis, and grade of diagnosis. Generally speaking, stage of diagnosis pertains to how early the cancer is detected. The grade describes how aggressive the cancer is with a higher grade being more aggressive. In our service area, African American women had higher mortality rates than Caucasian women, as seen in Figure 6. Considering that African American women typically have more aggressive forms of breast cancer, this trend was to be expected (Amend, K., Hicks, D., Ambrose, C., 2006). The highest mortality rates for African American women were seen in Allendale (48.2), Bamberg (40), Orangeburg (38.1), and Horry (37.9) counties. Exceptions to this trend were Beaufort, Berkeley, Jasper, and Colleton counties. Their African American and Caucasian mortality rates were almost identical (SCDHEC, "SCAN Cancer Incidence and Mortality," 2010). Reliable mortality statistics for other minority populations were difficult to obtain. According to HealthLandscape Beta, Beaufort and Jasper counties have the largest Hispanic populations in our service area, ranging anywhere from 8.4-25.5 percent ("HealthLandscape Beta," 2010). However, reliable breast cancer statistics on this demographic were not readily available.

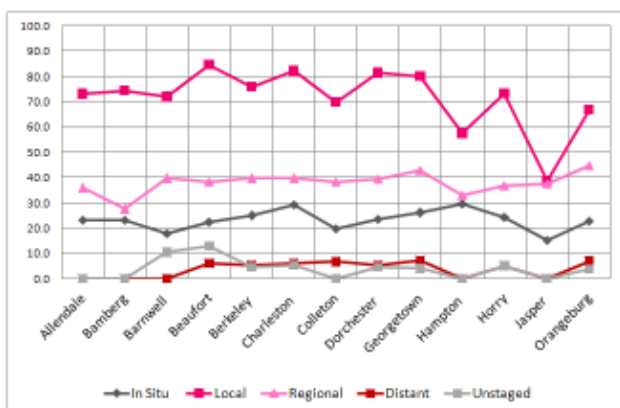


Figure 7. Female breast cancer incidence rates by stage from 1996-2007. SC Dept of Health and Environmental Control, South Carolina Community Assessment Network, 1996-2007 Cancer Incidence: Full File.

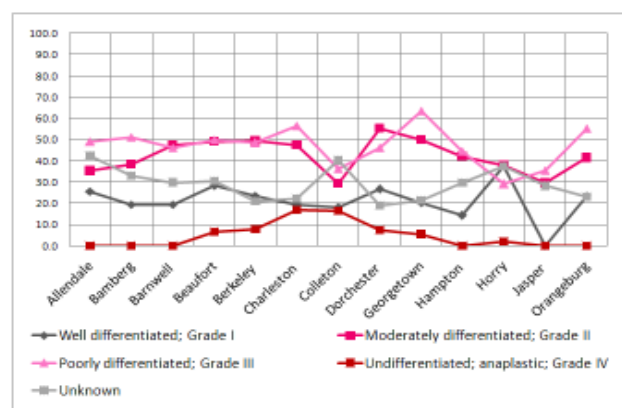


Figure 8. Female breast cancer incidence rates by grade from 1996-2007. SC Dept of Health and Environmental Control, South Carolina Community Assessment Network, 1996-2007 Cancer Incidence: Full File.

As seen in Figure 7, incidence rates by stage followed a fairly linear pattern. Exceptions to this trend were Hampton and Jasper counties, which had low incidence rates of local stage diagnosis. Figure 8 shows that Charleston (16.9) and Colleton (16.5) counties had high incidence rates of Grade IV/undifferentiated cancer compared to other counties in our service area. The highest incidence rates of Grade III cancer were seen in Georgetown (63.5), Orangeburg (55.3), and Charleston (56.4) counties. High Grade III rates are logical in counties such as Orangeburg, Allendale, and Bamberg, which have high African American populations. However, they are unusual in counties such as Georgetown and Charleston, where the majority of the population is Caucasian (SCDHEC, “SCAN Cancer Incidence and Mortality,” 2010).

Counties with high mortality rates often coincide with low socioeconomic indicators. These areas have high percentages of uninsured women and people living below the poverty line. The highest percentages of uninsured women are seen in Allendale (48.7percent), Bamberg (39.9 percent), Barnwell (39.8 percent), and Orangeburg (34.2 percent) counties. However, due to large population size, Charleston, Horry, and Orangeburg counties have the largest numbers of uninsured women: approximately 27,000 in Charleston, 15,500 in Horry, and 10,000 in Orangeburg (Thompson Reuter, 2009). Likewise, the highest percentages of people living below the poverty line are in Allendale (41.8 percent), Bamberg (28 percent), Orangeburg (23.8 percent), and Hampton (23.4 percent). Allendale and Bamberg counties have the lowest median household incomes in our service area, \$25,329 and \$30,305 respectively (U.S. Census Bureau, “State and County QuickFacts: South Carolina,” 2010). However, Charleston and Horry counties had the highest number of families living below the poverty line, approximately 11,300 families in Charleston and 6,500 families in Horry (Thompson Reuter, 2009). In many ways, these factors limit the patient’s ability to obtain medical care.

The affiliate intends to expand its service area to include Calhoun, Florence, Marion, and Williamsburg counties. Similar to many counties already in our service area, these counties are predominantly rural and have high breast cancer mortality rates. The mortality rates from 1996-2007 ranged from 20.7 in Calhoun County to 30.8 in Marion County. However, in recent years, 2002-2007, the mortality rate in Calhoun County was 31.7 (SCDHEC, “SCAN Cancer Incidence and Mortality,” 2010). Williamsburg County has a high African American population at 67.2 percent (U.S. Census Bureau, “State and County QuickFacts: South Carolina,” 2010). In both Williamsburg and Marion counties, approximately one-third of women are uninsured and one-fourth of families live in poverty (Thompson Reuter, 2009).

## **Conclusions**

- **African American women** comprise 29 percent of our service area, but have higher mortality rates compared to Caucasian women in every Lowcountry county (Thompson Reuter, 2009). They tend to have more aggressive forms of breast cancer, making early detection imperative. In our service area, African American women have significantly lower rates of early stage diagnosis. From 1996-2007, the average rate of local stage diagnosis in our service area was 81.0 for Caucasian women and only 53.1 for African American women (SCDHEC, “SCAN Cancer Incidence and Mortality,” 2010).
- **Rural counties** have the highest mortality rates in our services area. These counties include, but are not limited to:

- **Allendale and Bamberg Counties** have the highest mortality rates in our service area from 1996-2007, with 41.5 in Allendale and 34.6 in Bamberg. In recent years, the mortality rate in Bamberg County has also increased from 31.2 between 1996-2001 to 37.5 between 2002-2007. Both counties have large African American populations, and the highest African American mortality rates (SCDHEC, “SCAN Cancer Incidence and Mortality,” 2010; U.S. Census Bureau, “State and County QuickFacts: South Carolina ,” 2010). In Allendale, 43.8 percent of women did not receive a mammogram in 2009 (Thompson Reuter, 2009). Large confidence intervals associated with Allendale and Bamberg county statistics emphasize the need to depend on focus groups and key informant interviews to achieve a holistic and reliable view of our small, rural counties.
- **Orangeburg County** has the third highest mortality rate (30) from 1996-2007 and a high incidence rate of Grade III and late stage diagnosis. Orangeburg is tied for the second largest African American population in our service area (61.9 percent), which reflects the county’s high mortality rate among African American women (SCDHEC, “SCAN Cancer Incidence and Mortality,” 2010; U.S. Census Bureau, “State and County QuickFacts: South Carolina ,” 2010).
- **Hampton and Colleton Counties** have seen increases in their mortality rates in recent years. Hampton County has the fourth highest mortality rate in our service area, and the mortality rate has increased from 25 in 1996-2001 to 34 in 2002-2007. In Colleton County, the mortality rate has increased from 18.7 in 1996-2001 to 27 in 2002-2007. Both counties have a low incidence rate of early stage diagnosis. Colleton has a high incidence rate of aggressive grade cancers (SCDHEC, 2010). Hampton County has a relatively high mortality rate among African American women, and 43.9 percent of women were not screened in 2009 (Thompson Reuter, 2009).
- **Jasper County** had the fifth highest mortality rate in our service area from 1996-2007. Jasper County is unique in that their mortality rates for African American and Caucasian women are almost identical. They have the highest mortality rate for Caucasian women (28.8). Similarly, their rates of early vs. late stage of diagnosis are almost identical. They have the lowest rate of early stage diagnosis (SCDHEC, “SCAN Cancer Incidence and Mortality,” 2010).
- **Georgetown County** ranks sixth in the state for incidence of all cancers, and third for incidence of breast cancer (Bolick, 2010). Georgetown has high incidence rate of late stage diagnosis and aggressive grade cancers (SCDHEC, “SCAN Cancer Incidence and Mortality,” 2010).

## **Health Systems Analysis of Target Communities**

### **Overview of Continuum of Care**

In order to address the needs of our service area, it is important to understand the barriers to care that women face. To do this, we must see how a woman moves through the full circle of care from education and screening to diagnosis and treatment if necessary. This is called the continuum of care, illustrated in Figure 9. The continuum begins with breast health education and screening guidelines. Next, one must actually be screened and receive appropriate follow-

up. For most that simply means continuing regular screenings. However, for women (and men) with a suspicious mass, diagnostics and treatment may follow. Treatment may include surgery, radiation, and chemotherapy. After the initial treatment, there may be years of post-treatment care, which can include additional cancer preventive drugs and follow-up tests. These breast cancer survivors will also need to continue regular breast cancer screenings. Each step in this continuum is essential, and missing one piece can substantially impact one's chance of survival. When looking at the health systems of the target communities, the focus is on the gaps in care due to their impact on the mortality rates of that community.

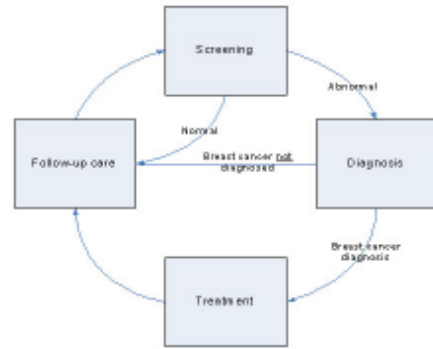


Figure 9. The breast health continuum of care. Susan G. Komen for the Cure, 2011 Community Profile Guide, 2010.

### Methodology

A list of all breast cancer screening, diagnostic, and treatment facilities in the service area was compiled for a detailed view of existing health resources. Information on major hospitals and medical centers was gathered using the South Carolina Hospital Association website and free clinic services using the South Carolina Free Clinics Association website. In addition, the American Cancer Society provided a list of 2005 Best Chance Network providers in the Lowcountry. This was the most recent list available and it should be noted that this list changes regularly as providers are added or dropped. Using the mapping software HealthLandscape Beta, these facilities were plotted on maps to find physical gaps in breast health services. As seen in Figure 10, the counties with the least breast health services are seen in rural areas.

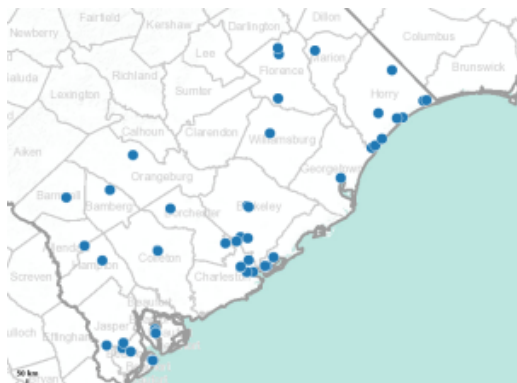


Figure 10. Hospitals and medical centers that provide mammography services to the affiliate service area (including 2011 expansion). Hospital Directory, South Carolina Hospital Association, 2010. Mammography Facilities, Food and Drug Administration, 2011.

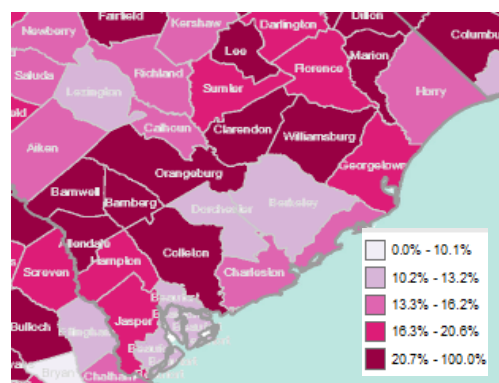


Figure 11. Percentage of people living in poverty in the Lowcountry. HealthLandscape, 2005-2009.

### Overview of Community Assets

Health systems within the Lowcountry are fragmented, largely due to geographic location. Primary care physician shortages have heavily impacted the rural communities, leaving many residents with no medical home. The News and Courier reported that 45 of the state's 46 counties have a shortage of primary care physicians. For example, Hampton County has seven

doctors to serve more than 22,000 people. In Williamsburg, the patient to doctor ratio is 3,300 to one. Patients of rural physicians are more likely to be on Medicare or Medicaid, which means lower reimbursement rates for the physicians (Dudley, 2010).

The affiliate service area includes 52 major medical facilities that offer breast cancer screening. Unfortunately, only a handful of these providers offer diagnostic services, and treatment facilities are located in only five affiliate counties: Horry, Charleston, Beaufort, Georgetown, and Orangeburg. With the exception of Orangeburg, Lowcountry's rural counties are served by small community hospitals with minimal staff and often have older film mammography services. It has been suggested that several of these small county hospitals are in danger of losing their mammography departments due to lack of funding. The Medical University of South Carolina (MUSC) has a mobile wellness unit that provides screening to rural populations. Additionally, McLeod Health Systems in Florence has a one for the Pee Dee region.

There are 13 free clinics, located in Beaufort, Charleston, Georgetown, Horry, and Orangeburg counties. Fifty-three federally funded health clinics serve the area, some of which provide free breast and cervical cancer screening through Best Chance Network (Health Resources and Services Administration, 2011). Horry, Charleston, and Orangeburg counties have the most federally funded clinics, while Bamberg and Colleton counties have the least, with only one in each county. These medical resources provide care to the estimated 1.36 million people living in our service area (U.S. Census Bureau, "State and County QuickFacts: South Carolina ," 2010).

Lowcountry hospital systems offer a variety of services to surrounding counties. Primary care physicians, as well as specialists, are part of these larger systems. Collaborations and partnerships with other facilities have formed between health care systems to reach new areas. For instance, Roper-St. Francis provides services in Charleston, Berkeley and Colleton counties. It is also affiliated with Hampton County Hospital. Hilton Head Regional Healthcare partners with MUSC. In addition to the main hospital, The Regional Medical Center of Orangeburg-Calhoun includes primary care doctors in both Orangeburg and Calhoun counties. Although there are still geographic barriers, these system partnerships allow patients to stay within a hospital system even when they have to travel out of county for services.

### **Partnerships and Opportunities**

Komen Lowcountry has established strong alliances within the communities it serves through grants and collaborative work. Despite the geographic gaps, Lowcountry grants serve every county with screening and diagnostic services. Grants for education are in targeted communities. Several partnerships have been formed through our grants, including those between non-profit and for-profit organizations. One is between United Way of Colleton and Bamberg (non-profit) and Colleton County Hospital (for-profit entity). Because there are no non-profit hospital services in Colleton or Bamberg counties, United Way partnered with the hospital to meet the screening needs of those counties. Unfortunately like many other rural counties, diagnostics and treatment must be received out of county.

Our partners include the major hospital systems, as well as community hospitals and clinics. Major hospital systems are also the home for physicians of varied disciplines including family practice, OB/GYN, surgeons, and oncologists. Each hospital system also has a financial aid

program, though they differ in eligibility requirements. The Medical University of South Carolina (MUSC) and Roper/St. Francis Healthcare System have affiliates in several counties including Beaufort and Hampton. MUSC also has a mobile mammography unit serving rural areas. The weakest partnerships in our rural counties are with primary care physicians. McLeod Health Systems (non-profit) has the state's only free cancer clinic and serves the Pee Dee region of South Carolina including Florence, Marion and Williamsburg, with breast health education and services. McLeod also has a mobile health unit. Partnering with McLeod will be essential in reaching the women of Florence, Marion and Williamsburg.

The majority of Latinos are served by Volunteers in Medicine (Beaufort), Lowcountry Healthcare (Allendale), St. James-Santee Family Health (Georgetown), and Little River Medical Center (Horry). All of these facilities provide screening services, but patients are referred elsewhere for diagnostics and treatment.

Partnership opportunities include churches and collaborative community groups. These groups have a vested interest and strong ties in the local community. The Links, one of the nation's oldest and largest volunteer service organizations, is an excellent partner in reaching the African American community in the Orangeburg area. Churches throughout the service area are also a tremendous asset. Over 150 churches already partner with the affiliate on Pink Sunday as well as a number of other educational programs. Similarly, the Witness Project reaches African-American women throughout the lowcountry through survivors and lay health advisors. Our Lady of Mercy Wellness House, sponsored by the Sisters of Charity of Our Lady of Mercy, serves Latinos in rural areas of Charleston County. Another partnership opportunity is through the colleges and universities in our service area. Many of them have students studying public health or health promotion. Partnering with them would allow for additional outreach. Partnership opportunities also exist with the medical community, including those not directly breast health related. For instance, diabetes educators promote a healthy lifestyle, which is a natural tie-in to breast cancer risk reduction. In fact, this is an especially promising partnership as 65 percent of our residents are obese, a known risk factor for both diabetes and breast cancer (SCDHEC, "Obesity Prevention and Control").

Collaborative groups have been formed in an effort to address various issues within the rural communities. The Coastal Cancer Collaborative is comprised of a variety of organizations within Horry, Georgetown, and Williamsburg counties. The goal of the collaborative is to reduce the burden of cancer on the community through education, improved access to care, and public policy. The Salkehatchie Healthy Communities Collaborative was a similar group serving Barnwell, Bamberg, Allendale, Hampton, and Colleton counties. Members of these groups include DHEC, Clemson University Extension Services, churches, local physicians, and other community leaders. Unfortunately, the Salkehatchie group is no longer funded, leaving the members to continue the partnerships on their own. Survivor support groups are especially strong in Beaufort, Orangeburg, and Charleston counties and continue to be Lowcountry partners.

## **Legislative Issues:**

### **National Breast and Cervical Cancer Early Detection Program (NBCCEDP)**

A key component to breast health services in South Carolina is Best Chance Network (BCN). This federally mandated program of the NBCCEDP provides free breast and cervical cancer screening to South Carolina women who are uninsured or have insurance that only covers hospitalization and whose family income is at or below 200 percent of poverty level. To be eligible for the program, these women must be screened through BCN providers. In 2008, the state made its first-ever appropriation of \$2 million dollars, allowing the program to see an additional nine thousand women and lowering the age of eligibility from 47 to 40 (SCDHEC, "Cancer Prevention and Control"). However, due to budget constraints the additional state funding is no longer in place, leaving thousands of women without the means for recommended screenings. The program continues through the support of federal funds, but the age of eligibility has returned to 47-64. BCN patients who are diagnosed with breast or cervical cancer are treated through the state's Medicaid program.

With the state facing a budget shortfall this year of \$877 million (17.4 percent), funding for those in greatest need remains in jeopardy (McNichol, E., Oliff, P., & Johnson, N., 2011). The Department of Health and Human Services, which runs BCN, projects a \$663 million shortfall for the new budget year ("New budget forecast, agency cuts trim SC deficit," 2010). *The News and Courier* reports that South Carolina's Medicaid budget is \$1 billion and it serves nearly one million people. Currently, the federal government matches state funds four to one. However, this match will be reduced to three to one as federal stimulus money is no longer available (Davenport, 2011).

Women who are screened through BCN experience many of the same issues as the other groups. This is a low-income group and expenses such as travel and lost wages remain a financial barrier. Because women must reapply for BCN on an annual basis, follow-up screenings are often neglected.

State lawmakers recently lifted the only proviso on reimbursement rates to doctors in the country, meaning that doctors and hospitals will be paid less to care for Medicaid patients. Reimbursement rates have been cut by 3 percent and are expected to save the state \$7.5 million. This should eliminate the need for further cuts in Medicaid services. However, doctors are concerned because they expect the rate could be cut by as much as ten percent by July (Dudley, 2011). This is likely to impact the number of doctors willing to see the state's poorest patients, especially in rural areas.

Komen is proud to partner with the South Carolina Cancer Alliance (SCCA) in its efforts to save crucial funding for BCN and Medicaid programs. Many insurance companies do not provide coverage related to clinical trials and oral chemotherapy. Komen is also partnering with the SCCA on these issues.

## **Conclusion**

The Lowcountry suffers from a lack of medical services in the rural areas, due largely to a lack of physicians. Residents often do not get routine or preventive care because there are not enough primary care physicians. Although basic mammography screening is available in nearly every



county, women must travel to one of the larger counties such as Charleston or Beaufort for complete care. The trip alone can cost hundreds of dollars in gas and lost wages. Best Chance Network provides free screening to eligible women, but many are unable to access it because there are no nearby providers. In addition, funding cuts mean that thousands of women are no longer eligible for the program. BCN does not cover men, so they do not have this resource. Those with limited resources but who do not qualify for BCN also have limited access to care. Access to care is especially difficult for our rural populations, which are predominantly African-American.

## **Breast Cancer Perspectives in the Target Communities**

### **Methodology**

For a more complete look at the barriers to care, the team conducted surveys and interviews with 50 experts in the field. Nineteen key informants and thirty-one providers working with the populations identified as communities of interest were interviewed using written surveys and interviews. Each interview was conducted in person by a team member with professional interviewing experience. An intern took notes and each interview lasted approximately one hour. Three group discussions were held with providers, one with three members of the medical community at Beaufort Memorial Hospital and Keyserling Cancer Center and the second with three staff members of Beaufort-Jasper-Hampton Comprehensive Health. The third was with staff at McLeod Hospital. In order to capture the most information possible, an intern who was not part of those discussions took notes. Surveys were emailed to 19 key informants and medical providers. Respondents of interviews and surveys included: eight grantees, five physicians (OB/GYN, family practice, and oncology), ten hospital systems, one surgeon, six community health clinics, two county cancer coalitions, one state cancer coalition, one state cancer registry expert, two government health agencies, four members of the state breast cancer workgroup, two Latino cultural experts, and seven nonprofits serving low-income residents. Five patient navigators also responded. Twenty-four federally qualified clinics and Best Chance Network (BCN) providers, as well as seven free clinics, were also contacted. Unfortunately, the vast majority of the clinics and BCN providers chose not to participate in the project, citing time constraints. This was the primary limitation to the data because we were unable to get a complete picture of some communities through providers. The Community Profile team reviewed the responses and created a chart that identified common themes.

To get the community's perspective, we held 14 focus groups. The participants were selected and invited by a respected member of the target community. This might be a church leader, an outreach worker or a local breast cancer survivor, among others. Each discussion was facilitated by a team member, with notes taken by an intern or staff member not involved in the discussion. Questions were formulated based on the background of the group and follow-up questions were asked as appropriate. Each discussion lasted one to two hours. As noted in the chart below, several groups represented multiple target populations. Some groups were representative of a specific community or county, others of a more general demographic such as "rural". The smallest group had four participants and the largest eleven. Most groups had five to seven participants. Additionally, surveys were emailed to members of a breast cancer support group in the Charleston area. Three of the surveys were completed and returned.

Because much of the Lowcountry service area is rural, most focus groups addressed this group. However, four focus groups were specifically formed to address our rural counties. Most participants are low to middle income and have little, if any, insurance. Like the key informant and provider interviews, common themes were identified.

Focus Groups	Target Population	
Gullah Nurses	AA/ rural	<u>Specific Races/Ethnicities</u> AA=African American L=Latino
Our Lady of Mercy 1	AA/rural	
Our Lady of Mercy 2	L/ rural	
Georgetown	AA/ G'town	
Bamberg #2	Bamberg/Barnwell/Orangeburg/AA/rural	
Bamberg #1	Bamberg/rural	
Allendale	Allendale/Bamberg/Hampton/rural	
Jasper-Hampton	L/Jasper/Hampton/rural	
Florence	Florence/Williamsburg/Marion/rural	
Allendale	L/rural	
Parris Island 1	military- active duty	
Parris Island 2	military- spouses	
Paula Williams group	survivors- Beaufort	
Bosom Buddies	survivors- Hampton	

Table 2. The target populations addressed at each focus group held in the Lowcountry affiliate service area.

### Key Informant Responses

Caucasians, African-Americans and Hispanics were all noted to be in need by most informants and providers. Gaps in care were noted as being the result of a lack of services, resources and education. Low socio-economic status and lack of insurance were seen as major obstacles to screening and treatment. These barriers are common in rural, African American, and Hispanic populations.

The women noted by this group as least likely to receive regular breast screening and care were described as low to middle income, uninsured, usually between the ages of 40-64, and both employed and unemployed. Of particular concern were the “working poor” and the “newly poor”. These are people who may have at one time held good jobs with benefits in the past, but have lost hours and benefits due to budget cuts. Many now have much lower incomes and have no insurance or poor coverage, leaving them to choose between groceries and healthcare. In addition, insurance plans may not provide preventive care coverage, so patients wait until they have a medical emergency before getting care. These women are often heads of single parent households. Low income women do not see screening as high priority, feeling there are other much more pressing issues such as paying bills and buying groceries. It was noted by one key informant in Allendale that “they want to do the right thing but often put themselves last.”

The low-income and uninsured were most likely to be lost early in the continuum due to the financial burden (including travel and time off work) of screenings and doctor visits. Even with financial aid, rural women can be lost due to the sheer distance of services. Insured women are most likely to follow through with treatment if needed, but may be lost during post-treatment follow-up. The primary concern for this group was adherence to prescribed breast cancer preventive regimens, including chemo-preventive drugs such as Tamoxifen or aromatase inhibitors. However, providers noted that there are quite a few women who have the insurance and the financial means for regular screening yet they choose not to get it.

Medicaid decisions also impact the privately insured. Insurance companies often take the lead from Medicaid to define their coverage limits. For instance, Medicaid does not cover the cost of lymphedema sleeves. Therefore many insurance companies do not either. This affects out of pocket costs for the insured, raising concerns for underinsured women.

Health literacy and education are of particular concern in African-American, Latino, and rural populations. It was noted that some women, especially in the African American community, do not understand the importance of screenings and do not believe that treatment is successful or accessible.

*“She came to the ER bleeding from the sore on her breast. She said she knew she was going to die from it and just wanted something so that it wouldn’t smell so bad and wouldn’t bleed through her clothes. Even though she knew she had breast cancer, she never went to a doctor about it. She died a few days later”*

*T. (Georgetown/Horry)*

## **Community Input**

### **Rural Women**

Providers and key informants pointed to lack of services in rural communities as the biggest concern. Regardless of insurance status, this was a common barrier. Shortages of physicians in rural areas create longer wait times. As a result, many patients do not receive preventive care and only go to the doctor once they are very sick. With healthcare reform, the expectation is that everyone will have insurance, increasing demand for primary care and further straining these gaps in healthcare. Residents of rural counties often have to go to other counties for diagnostic and treatment services, often over 50 miles one way. The costs associated with travel and health care were noted by the respondents as major barriers to healthcare.

The issues raised in the focus groups were the same as those identified by the statistics and provider responses: lack of services and physicians, low socio-economic status, lack of insurance, and transportation. Similar to the African American groups, health education of both patients and providers was seen as an issue.

The obstacle mentioned the most for rural women is the lack of locally available services. Physicians and hospitals may be miles away. This leads to transportation problems because patients often have to travel out of county for extended care. Rural residents often have to travel 50 miles or more for breast care. For instance, women in Hampton County travel to Orangeburg, Charleston or Beaufort for diagnostics and treatment. There is no public transportation and gas

for the trip could cost as much as 50 to 100 dollars. For those who have their own transportation, gas and time off work are the primary concerns. For those without transportation, finding someone to take them to an appointment is difficult. The problem is made worse by the cost of gas and the time off for both the driver and the patient. Although there is no public transportation in the rural counties, there is a bus which takes Medicaid patients to their appointments in Charleston. Using the service is inconvenient in two ways: appointments must be scheduled well ahead of time and it is a shared ride. The shared ride means that everyone on the bus is subject to the scheduling of both the first appointment and the last. For instance, a woman may have a biopsy scheduled for ten a.m., but another rider has an eight o'clock appointment. The biopsy patient must be picked up at six a.m. so that the other patient arrives on time. Likewise, the biopsy patient cannot return until the last appointment is completed. This can mean a ten or twelve hour day for passengers.

The lack of local services also creates an issue of time because many women often have to travel an hour or more one way to reach an appropriate medical facility. For some, this means an all day trip and lost wages for diagnostic services. Many who work are unable to get the time off, and the medical facilities are not open during the hours that the women are not working. For others, the time barrier is simply not taking the time to care for themselves.

A unique issue that came up in the rural focus groups was the impact of living in a small community. There is little privacy and everyone knows who goes to the doctor. For some, there is an embarrassment associated with the visit. Although men seem to be the most influenced by this, some rural women also suffer the stigma of being "weak" if they are seen going into the doctor's office.

Another issue presented in the focus groups is distrust in federally and state funded programs aimed at improving life in these areas. It was noted that programs are often started but funding runs out. Residents are suddenly left without those services they had come to rely on. This has led to a mistrust of programs such as Best Chance Network, which at one time covered women starting at the age of 40. As mentioned previously, BCN recently raised the age of eligibility to 47, leaving women 40-46 without coverage. It was also noted that women on Medicaid were treated differently by medical staff than those with private insurance. This was similar to a concern expressed by African American women.

### **African American Women**

African American women were represented at twelve focus groups. Four groups were conducted solely with African American women. Common barriers to care noted were low-income, lack of insurance, lack of transportation, and low health literacy. These barriers were also noted by providers.

Two additional themes that had not been previously identified became evident in the focus groups: faith and racial bias. Faith plays a strong role in this community, and many look to church leaders for answers. They believe that "God will take care of them" and therefore do not see the need for screening or treatment. In fact, going to the doctor was seen by some as questioning God's plan. For these women, a diagnosis shows a lack of faith.

Racial bias was raised as a concern by several women. This bias leads to mistrust in the medical community which becomes another barrier to care. Tales were told of having to use the back door to a physician's office and receiving substandard care in an emergency room. One woman spoke of technicians who did not wash hands between seeing Black patients, but did before working with White patients. Another shared the story of her daughter who was in the hospital to deliver her baby. Her daughter was put in a shared room. When she asked why, she was told welfare patients had to share rooms. It was assumed that because she was Black, she was on welfare. The reality was that the woman was fully insured and was actually the new head of the department. She was immediately moved to a private room when this was discovered. These are just a few of the stories told that illustrate a common bias against African American women in our community.

After some discussion, one African American group came to the conclusion that the disparities in care they had seen may also be financially based. Comments were made that perceptions are often based on how much money someone seemed to have, even within the same race.

*"We do it, too. It all depends which side of the track you're from."  
T. (Georgetown)*

Women thought to be on Medicaid are treated differently than those with private insurance. Doctors also seem to spend less time with them. The perception is that medical staff members do not treat them as respectfully as those with full insurance. The majority of the African American focus group participants also saw these issues but felt they are likely race related.

The discussion with Gullah nurses in Beaufort County was especially enlightening. These parish nurses and health educators work with the Gullah people on the Sea Islands of South Carolina. The Gullah were isolated from the mainland for many years, both culturally and physically. As a result, they have maintained their African culture, including their own creole language. The Gullah nurses create a bridge to modern society. They shared stories of deep faith and "complete trust in the Lord." They spoke of women who have never been to a medical doctor but will try the herbs from the local root doctor. Some Gullah women live on small islands that are only reached by boat, making transportation even more difficult.

The African American focus groups saw lack of health education as a barrier in several ways. Although most women are aware of breast cancer, they have received little breast health education. They are also not familiar with the four points of Breast Self Awareness (BSA):

- Know your risk
- Get screened
- Know what is normal for you
- Make healthy lifestyle choices

Several women commented that they are afraid to get mammograms because it will hurt. Women are also not aware of the available resources in the community, including financial aid and BCN. Another piece of health education for this population is the understanding that receiving medical care does not mean losing faith.

A recent review of the literature exploring some of the social elements affecting African American women supported the findings of these focus groups. Studies show that there are cultural factors that affect this population's decision to be screened and treated for breast cancer. This includes low perception of risk for breast cancer, myths handed down within families and communities, and mistrust of the health care system. In reference to the racial biases presented, studies have shown that racial prejudice may result in African American women being referred for mammography less frequently. (Gerend & Pai, 2008).

Education of medical professionals is also important. We heard from women whose doctors told them there was no financial aid for the uninsured in need of screening. Some women were told by their doctors that they did not need a mammogram because they were too young or had no family history. In some cases, the doctors knew of programs or services but did not know how patients could access them. This education of both patients and the medical community was a recurrent theme with each target population we researched.

### **Latinas**

Providers, key informants and focus group participants raised several concerns for Latinas. Leading the list were fear of deportation (regardless of documentation status) and language barriers. Despite these barriers, respondents felt this was a community that, when given the tools, would access the care they need.

Three focus groups were held with Latinas. Both migrant workers and settled immigrants were included. Key informants had suggested that there was a difference in available services for the two groups because migrant workers could likely access healthcare through the farmers they worked for. Also, it had been suggested that Hispanic women are not in charge of the healthcare decisions and defer to their spouses. None of our focus groups confirmed either point. The women we spoke to saw themselves as the primary person responsible for healthcare decisions for the family. Migrant workers spoke of the same burdens of accessing care as settled immigrants. If care is available to farm workers, they are unaware of it. Overall, the women understand the need for screenings but face the same challenges as the other groups we spoke with: finances, available services, and transportation. The women did confirm that there are myths surrounding breast cancer. This includes the belief that only women over forty can get it. Another misconception is that a woman will develop breast cancer if she is hit in the chest.

A key issue is the language barrier. Most of the women speak little, if any, English and usually rely on their children to translate for them. One woman shared a story about a seven year old boy who had to translate for his mother when she found a lump in her breast. Although some clinics have interpreters, language was still seen as a problem. Latinas in two of the three focus groups commented that they were treated differently because they do not speak English which makes them apprehensive about going to the doctor.

*"...people have a bad attitude if you don't speak English"*

*M. (Charleston)*

For some Latinas, there is confusion about the cost of medical services. For instance, in Mexico the costs are usually listed like a menu so that the patient knows ahead of time what they will

pay. Those that are accustomed to this find the American system confusing because there is no “menu”.

### **Military**

Both the Marine Corps Air Station and the Marine Corps Recruit Depot (MCRD) are located in Beaufort County. Approximately 18,000 male and female recruits are trained each year at the Parris Island MCRD (SCIWAY: South Carolina’s Information Highway, 2011). Charleston County is home to the Air Force Base. Two focus groups were held with members of the military family due to concerns that had been raised by key informants about access to care for military dependants. One group was with active duty members and the other with military spouses. The initial concerns were not substantiated. However, concerns were raised about breast health education for female recruits and the wives of male recruits. These young women are not required to receive breast health education; priorities are placed on other issues though to be more relevant to their age and lifestyle. This was of particular concern to one woman who was diagnosed with breast cancer while in her twenties. Education was also a concern raised for male recruits. For these physically fit young women and men, there is a stigma attached to what is considered an older woman’s disease. Without proper breast health education, they may not seek appropriate medical attention.

### **Breast Cancer Survivors**

Two focus groups were held with breast cancer survivors. In addition, three survivors completed surveys and four were interviewed personally. The themes were consistent, with confusion about appropriate follow-up care topping the list. The women commented that they did not know what they were supposed to do after completing treatment.

*“The scariest day was when I finished treatment. The doctor said ‘don’t worry about every pain but call me about every pain.’ ”*

*J. (survivor)*

Women feel lost after completing treatment, and none of the respondents had a post-treatment plan.

Another issue for survivors is the lack of available lymphedema education and products. Products such as lymphedema sleeves help reduce the buildup of lymph fluid that may occur in women who have had lymph nodes removed. Because sleeves are not considered “medically necessary”, most women do not receive coverage for these products. Although the providers we spoke with saw this as an issue, several survivors commented that doctors do not discuss lymphedema at all.

Overall, survivors feel the need to be with others with similar experiences. Young survivors view their needs as different from older women and are not comfortable in traditional support groups. They prefer to talk with their contemporaries about issues such as sexuality and raising children. A woman with metastatic disease said she felt “left off in a corner” because there was no group for women in her situation. We also heard from a woman whose husband had breast cancer. She spoke of the difficulty he had when faced with a “woman’s” disease. Because so few men have breast cancer, he knows no one who can relate to his situation. Emotional side effects of

diagnosis and treatment were a primary concern for all. They are also looking for ways to improve their survivorship, including exercise and nutrition.

### **Lesbians**

Another group that several doctors identified as being in need of education is lesbian women. The concern raised was that these women do not go to the doctor or gynecologist regularly, and therefore do not get routine mammograms. These concerns are supported by a review of the literature exploring screening behaviors of lesbian and bisexual women. The researchers found that lesbian and bisexual women are less likely to have regular mammography screening. This may be because they have fewer triggers for routine gynecologic care and lower rates of insurance due to the absence of spousal health insurance (Cochran et al., 2001). Lesbian and bisexual women are also less likely to have had a full-term pregnancy (Cochran et al., 2001), a risk factor for breast cancer (American Cancer Society (ACS), 2009). A major barrier to breast health education and care is that these women are likely to have negative experiences with practitioners. This may lead to postponement of routine care. This is a difficult group to reach, and only three to four percent of adult women are lesbians (Cochran et. al., 2001). Because of the stigma of being a lesbian, these women are very cautious about making their status known. Unfortunately, we were unable to coordinate a focus group with them.

### **Section Findings**

The statistics and health systems analyses were supported by the discussions held. The gaps in care leading to high mortality rates were noted by all as being the result of a lack of services, resources and education. This was especially true in rural communities, as well as African American and Hispanic populations. Providers identified low-income and lack of insurance as major obstacles to screening and treatment. However, concern was also raised for those women with the financial means for screening who chose not to get it.

Although all three barriers were addressed by nearly every respondent, education was one thing that was perceived differently between the focus groups and the medical community. Members of the focus groups felt the doctors need education about screening recommendations as well as available services for their patients. African American women and Latinas also felt racial biases of health care staff should not interfere with the way they are treated.

## **Conclusion**

### **Target Community Findings**

The Lowcountry selected specific counties for further research based on their high mortality and low screening rates. The counties with the highest mortality rates were Allendale, Bamberg, Orangeburg, Hampton, Jasper, and Georgetown respectively. Statistics showed several other commonalities among these counties such as low-socioeconomic status and high uninsured rates. One thing they all have in common is that they are rural counties with large African-American populations.

### **Rural communities**

Rural populations, particularly rural minorities, experience marked disparities in health and health care access. (Bennett, K.J., et. al, June 2008). The Lowcountry's rural counties illustrate this as it relates to breast cancer. The statistics show that our rural counties have the highest



mortality rates, with Allendale and Bamberg leading the list. Bamberg, Hampton and Colleton Counties have seen increases in mortality rates in recent years. In Colleton County, mortality rate increased from 18.7 (1996-2001) to 27 (2002-2007). Both Hampton and Colleton have low incidence rates of early stage diagnosis. In Hampton, 43.9 percent of women were not screened in 2009, and in Allendale, 43.8 percent of women were not. Jasper County has the fifth highest mortality rate in our service area and is unique because the mortality rates for African American and Caucasian women are almost identical. In the other counties, African-American women have noticeably higher mortality rates. Although sixth in mortality, Georgetown has a high incidence rate of late stage diagnosis and aggressive grade cancers.

Providers, key informants, and focus group participants all pointed to the same issues for the rural communities: lack of resources, transportation, and education. The shortage of health care providers is of particular concern because, in many cases, people have to travel for their medical care. Transportation then becomes an issue, as does the added expense of gas and lost wages. This is a concern for both the insured and uninsured. Even in the more urban counties of Charleston, Beaufort and Horry, rural residents face these challenges. The lack of local services also affects the problem of time because rural women often travel an hour or more one way to reach a medical facility. This may mean an all day trip plus lost wages. Many who work are unable to get the time off, and most medical facilities are not open during the hours that women are not working.

When it comes to education, providers see the need to educate all women about the importance of mammograms. Focus group participants agree but also see the need to educate health care professionals. There is confusion about current screening recommendations, as well as BCN. Both medical professionals and the general public need more information about available resources. These resources include financial aid, transportation, and local agencies providing outreach services. African American women and Latinas feel education should include teaching medical staff to be more sensitive and to disregard their own racial biases. Education should also include BSA. Nutrition and exercise should also be addressed as they are part of BSA.

### **African Americans**

African-American women have higher mortality rates than Caucasian women in every Lowcountry county. From 1996-2007, the average rate of local stage diagnosis in our service area was 81.0 for Caucasian women and only 53.1 for African American women. African Americans also have higher mortality rates than White women in every county of our service area.

Providers pointed to several barriers to care for African American women: low income, poor health care education, and lack of transportation. In addition to these issues, focus group participants noted racial bias in the medical community as a barrier. These women also pointed to the need to educate providers about available services and resources. Many African Americans in our service area live in rural communities and suffer from the rural needs previously identified.

## **Latinas**

South Carolina has a growing Hispanic population. Beaufort and Jasper counties have the largest Hispanic populations in our service area, ranging somewhere between 8.4-25.5 percent. Because this population is largely undocumented, exact figures are unavailable.

Providers, key informants and focus group participants raised several concerns for Latinas. Leading the list were fear of deportation (regardless of documentation status) and language barriers. Unfortunately, there are a limited number of providers with whom Latinas feel comfortable and trust. Many do not speak English, and few doctors speak Spanish, leaving young children to interpret for their parents. Latinas feel they are treated differently by health care providers due to the language barrier. This is one thing that keeps them from going to the doctor for routine care and screenings.

The fear of deportation was shown to be true for both documented and undocumented women, though the fear was strongest for the undocumented. Undocumented women are especially difficult to reach and are unlikely to receive care unless they are very sick. Once identified, there are programs in place to help with some costs. Despite the barriers, providers and key informants felt this was a community that, when given the tools, would access the care they need.

## **Military**

Both the Marine Corps Air Station and the Marine Corps Recruit Depot (MCRD) are located in Beaufort. Approximately 18,000 male and female recruits are trained each year at Parris Island (SCIWAY: South Carolina's Information Highway, 2011). The concern heard for the military was reduced spending on education about breast cancer, raising the risk of later detection. Access to care is not an issue, but Breast Self Awareness education is. Both young female recruits and wives of male recruits need health education that includes BSA. Male recruits also need to understand their risk of breast cancer and know the warning signs. For these physically fit young women and men, there is a stigma attached to what is considered an older woman's disease. This is the primary barrier to care for this group.

## **Breast Cancer Survivors**

The themes for survivors were consistent, with confusion about appropriate follow-up care topping the list. The women commented that they did not know what they were supposed to do after completing treatment. Some providers raised concerns about women not following through with post-treatment follow up, including not continuing to take their prescribed cancer preventive medications.

When it comes to support, survivors prefer to find it with others in similar situations. Young survivors want to be with their peers and are not comfortable in traditional support groups. Women with metastatic disease and men are looking for others who can relate to their issues. Emotional side effects of diagnosis and treatment were a primary concern for all.

Survivors were concerned about the lack of support services for specific survivor populations. Young survivors felt their needs were different than most women in traditional support groups, and male survivors face their own challenges. Women with metastatic disease commented that

there was a lack of support for women with their unique issues. Lymphedema prevention and post-treatment follow up plans were concerns of survivors of all ages and prognoses. They are also looking for ways to improve their survivorship, including exercise and nutrition.

## **What We Learned, What We Will Do**

### **Review of the Findings**

For a complete picture of the needs of the communities the Lowcountry serves, the team drew from statistics and community input. Statistics provided the team's first look at the problems in our service area. The fact is African American and rural women are diagnosed at later stages and have higher breast cancer mortality rates. The next step was to determine what other factors influence these high rates of late stage diagnosis and death. Although our rural populations are largely African American, the team looked at each population separately. This helped assure that cultural influences were not overlooked. The analysis of available resources showed that rural areas have a major shortage of primary care physicians, as well as diagnostic and treatment services. Community input provided the insight into how this affected access to care. Other issues related to breast cancer were also brought up in these discussions, providing a more complete view of the barriers to care. The primary issues identified for rural populations related to lack of services, having a low income, and being uninsured. Transportation to appointments is an issue for many. Both patients and doctors need information about available resources, including BCN. There is a need for BSA education and a more complete understanding of recommended screening guidelines. It was also noted that those on Medicaid were treated differently than those with private insurance. In addition to the findings of the rural populations, African Americans presented two other issues impacting decisions related to care: faith and racial biases within the medical community.

Key informants and providers identified several other communities in need: Hispanic, military, survivors, and lesbians. Education was the number one issue raised for all, but focus groups determined that each population had a different perspective on it. Latinas felt that providers need to be educated to put their biases aside and treat all patients equally. This was also an issue for African Americans and Medicaid patients. All of the target populations addressed the need for BSA and screening guidelines education for their communities and health care providers. Survivors want to know what to do after treatment and are looking for support in non-traditional groups. Another problem for survivors is access to lymphedema care.

### **Selecting Affiliate Priorities**

We believe that all people deserve equal access to quality care, regardless of race or socio-economic status. The medically underserved are of particular concern, and different populations have different barriers. Our goal is to reduce barriers to screening and treatment. This is a grand plan and cannot be accomplished without individual steps. Therefore, the affiliate determined three priorities towards this ultimate goal based on the information gathered through the needs assessment. Our first priority was determined by the high mortality rates seen in rural areas. The barriers to care for a woman living in Awendaw (Charleston County) are the same as those for one in Bamberg. Both women face the same challenges and deserve equal care. Rather than choose specific counties, the need was seen for rural women in general. Because rural areas have such large African American populations, this priority will address both groups.

Education was addressed by every group, making it our second priority. For some, it was educating the public; for others, it was educating providers. For both groups the primary need was information about available services. BSA education, including nutrition and healthy lifestyle, is needed for all populations. Emphasis should be placed on the groups identified as most in need: African Americans, Latinas, and female military recruits. We chose not to prioritize lesbians individually because their population size is so small and difficult to identify. They are included in education as a whole. To be effective, education must be culturally appropriate for the audience.

The affiliate is committed to providing support for all phases of breast cancer, including long term survival. For this reason, the third priority addresses the unique set of issues survivors face. As survivors live longer, their needs evolve. Those needs include emotional support specific to their situation, as well as health care guidance for all.

### **Affiliate Priorities**

- Priority 1: Reduce the barriers to screening and treatment, especially for rural populations:
  - Objective 1: In FY 2011 and FY 2012, hold 2 grant writing workshops to solicit evidence-based grants that address the barriers to screening and diagnostics for medically underserved rural populations
  - Objective 2: In FY 2011 partner with the South Carolina Cancer Alliance to promote additional state funding of Best Chance Network
  - Objective 3: By end of FY 2011, include Calhoun, Florence, Marion, and Williamsburg in the affiliate service area
  
- Priority 2: Increase education about breast health, breast cancer screenings, and available resources:
  - Objective 1: By end of FY 2011, develop and distribute community resource list to healthcare providers and consumers throughout the affiliate service area
  - Objective 2: By October 2011 and recurring each subsequent October, partner with African American and Hispanic community leaders to provide culturally sensitive educational materials to their specific populations through Pink Sunday
  - Objective 3: In FY 2012 solicit evidence-based grants that address the barriers to care faced by Hispanic/Latino women
  - Objective 4: In FY 2012, provide breast health materials to Beaufort Naval Hospital
  
- Priority 3: Improve support services for survivors:
  - Objective 1: In FY 2012 and 2013, solicit evidence-based grants that address support services for specific populations of survivors, i.e. young women, metastatic, men, etc. This includes prevention of lymphedema
  - Objective 2: By end of FY 2012, host a survivor workshop regarding post-treatment follow up care for survivors

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