

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



SUSAN G. KOMEN<sup>®</sup>  
LOWCOUNTRY  
EXECUTIVE SUMMARY

# Acknowledgments

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

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

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- Colleton Medical Center
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# Executive Summary

## Introduction to the Community Profile Report

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

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



**Figure 1.** Komen Lowcountry Service Area

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

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

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

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

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

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

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

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

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

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

### **Quantitative Data: Measuring Breast Cancer Impact in Local Communities**

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

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

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

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

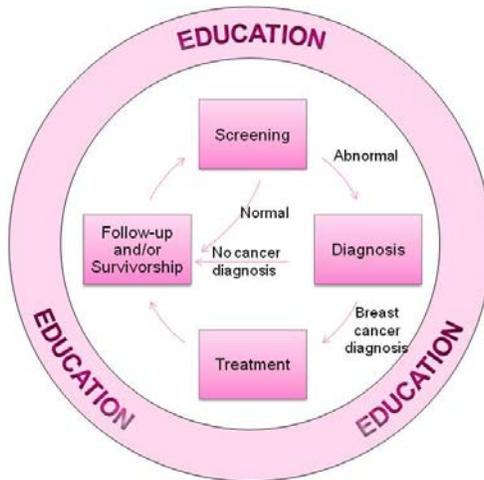
In the Affiliate service area, Black/African-American women have a higher death rate to incidence ratio than their White counterparts. Rural women face a direct correlation between being medically underserved and living in a rural community, both of which may create barriers to care. Those barriers may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

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

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

### **Health System and Public Policy Analysis**

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



**Figure 2.** Breast Cancer Continuum of Care (CoC)

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

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

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

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

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

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

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

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

### **Qualitative Data: Ensuring Community Input**

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

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

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

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

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

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

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

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

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

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

*(focus group participant)*

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

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

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

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

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

*(focus group participant)*

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

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

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

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

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

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

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

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

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

### **Mission Action Plan**

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

**Problem Statement:**

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

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

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

**Problem Statement:**

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

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

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

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

**Problem Statement:**

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

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

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

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