



COMMUNITY PROFILE REPORT

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Qualitative Data Sources

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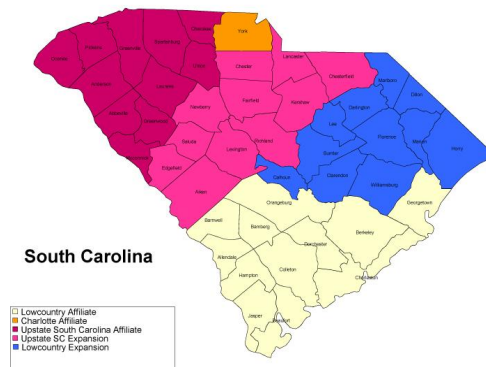
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Executive Summary

Introduction

Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982, that promise became Susan G. Komen for the Cure® and launched the world's largest grassroots network of breast cancer survivors and activists. Susan G. Komen for the Cure's promise is to save lives and end breast cancer forever by empowering people, ensuring quality care for all, and energizing science to find the cures. In 1995, the first Upstate Race for the Cure® was brought to Greenville, South Carolina. In 2000, the Komen Upstate South Carolina Affiliate was established and covered eleven counties; in 2009, the Affiliate expanded and was renamed the Komen SC Mountains to Midlands Affiliate. The Affiliate currently covers Abbeville, Aiken, Anderson, Cherokee, Chester, Chesterfield, Edgefield, Fairfield, Greenville, Greenwood, Kershaw, Lancaster, Laurens, Lexington, McCormick, Newberry, Oconee, Pickens, Richland, Saluda, Spartanburg, and Union counties. Since 1995, the Affiliate has awarded \$4.3 million in funding to local breast cancer programs and breast cancer research. Of that amount, \$3.14 million has been awarded in grants to local not-for-profit organizations to fund innovative breast cancer education, screening, and treatment programs.



In order to effectively and efficiently serve the SC Mountains to Midlands service area, the Affiliate has completed this Community Profile to better understand its service area and the needs that are not being met. As a part of this effort, many different types of data were collected, such as breast cancer statistics, information about programs and available services, and qualitative data from surveys and focus groups. From the comprehensive evaluation of this information, priorities and barriers were identified. The completed report will guide every strategic effort of the Affiliate. The Community Profile illuminates areas of greatest need for outreach and areas targeted for increased funding through grants as well as areas of greatest strength for fundraising. With this completed Profile, the Affiliate can be certain that the efforts put forth are impactful, meeting needs, filling gaps, and are original and non-duplicative.

Statistics and Demographic Review

For the completion of this Community Profile, the Affiliate used a compilation of statistics from South Carolina Department of Health and Environmental Control, US Census, Healthy People 2010, and NCI State Cancer Profiles. Data from each of these sources was combined and analyzed. Counties with the highest burden of breast cancer were determined by looking at a composite of all the statistics, rates, and demographics. Komen's promise is to save lives by ending breast cancer forever; therefore, breast cancer mortality is the key variable in breast cancer burden analysis. High mortality rates, combined with the issues that contribute to those rates (late stage diagnosis and low mammography rates) drive this section of the Profile and illuminate counties of interest.

South Carolina, as compared to the United States, has lower average income levels and education levels. The Hispanic and Latino populations are much smaller throughout the state than the nationwide average. South Carolina also has a larger population of African Americans than the United States average. Within South Carolina, there are pockets where these differences are more emphasized and noticeable than others (US Census, 2009). The highest breast cancer mortality rates for all races are found in Edgefield, McCormick, Fairfield, Cherokee, Greenwood, Richland, and Spartanburg. In these counties, there are specific populations that have high mortality rates compared to the county as a whole. When broken down by race, African Americans in Edgefield, Cherokee and Spartanburg counties have the highest rates. In Cherokee, Greenwood, Richland and Spartanburg counties, Caucasians have the highest rates. In general, mortality rates for African Americans are higher than those of Caucasians for every county except Greenwood. Large disparities between the mortality rates of each race exist in Pickens, Oconee, Edgefield, and Abbeville counties. Rates of stage at diagnosis are important when determining which counties to target for increased breast health programs. Generally, African American women have higher rates of distant stage breast cancer than Caucasian women. Of the counties that have been identified as having high mortality rates, all are associated with high rates of late stage diagnosis (SCDHEC SCAN, 2010).

The analysis of breast cancer statistics and demographics in this section of the Profile reveal several target counties and populations. Edgefield, Cherokee, Greenwood, Richland, and Spartanburg were chosen because of the impact of the burden of breast cancer on these counties. Specifically, when broke down by race, African Americans in Edgefield, Cherokee, and Spartanburg have a disproportionate burden of breast cancer, as well as Caucasians in Cherokee, Greenwood, Richland, and Spartanburg. These counties and populations have high mortality rates, high rates of late stage diagnosis, and low socioeconomic status indicators.

Health Systems Analysis

The analysis of available and needed health systems is vital to the community needs assessment process. To gain knowledge and take inventory of existing services and programs in the target counties, the Affiliate consulted the Internet, SCDHEC officials, American Cancer Society community outreach employees, the SC Cancer Alliance,

health care workers in each target county, and other non-profits in the health field. Once all resources in the target counties were identified, an asset map using Google Maps was created. Key informant interviews were completed with sixteen knowledgeable community leaders from the target counties. In total, sixteen interviewees participated in a comprehensive open-ended questionnaire. The questions addressed resources available, barriers to receiving care, current and need partnerships, and the success and limitations of the current system.

The SC Mountains to Midlands Affiliate knows that ending breast cancer is about more than curing a medical condition – it's about overcoming the cultural, social, and financial conditions that prevent women from receiving life-saving breast health care and treatment. Since 1995, the Affiliate has partnered with local organizations and invested more than \$3.1 million in community breast health programs. There are several key organizations that present great opportunities for partnership in the future, especially within the newly acquired 11 counties. Building new partnerships for funding and fundraising is a major part of the Affiliate's multi-year strategic plan moving forward. Because of South Carolina's unique placement in the 'Bible Belt' of America, partnerships with faith based communities and churches are valuable and should continue to be a means of education and in-roads for the community.

Breast Health Patient Navigator Programs have been shown to be a promising practice in the SC area. This position guides patients through the diagnosis and treatment of breast cancer. Interdisciplinary treatment of cancer has become the standard of care for cancer and required the coordinator of complex treatment schedules. Because of the numerous benefits of this type of position, this is a promising granting opportunity for the future. Provider education is another opportunity that has yet to be taken advantage of. Providers' lack of knowledge seems to be a source of breakdown in the referral and access cycle.

The Best Chance Network is a part of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and implemented through the S. C. Department of Health and Environmental Control and the American Cancer Society. Since 1991, the Best Chance Network has received federal funding to screen eligible women, but 2008 and 2009 was the first time state funds have been allocated for screening. The South Carolina Affiliates are gravely concerned about substantial cuts to South Carolina's "Best Chance Network (BCN)," which provides breast cancer screening services to low-income, uninsured and underinsured women in our state. Due to state budget cuts in 2010, SC did not use any state dollars to match the federal NBCCEDP (called Best Chance Network in SC) funding as it had in the past. Because this BCN funding is crucial to the increasing number of uninsured women in the state, regaining state funding for this program is at the top of the Affiliate's legislative agenda. Because the majority of the target counties are also the counties with the lowest average income and highest unemployment rates, the women in these counties need this funding reinstated.

From the asset map created, it is clear that three of the target counties (Edgefield, Cherokee, and Greenwood) are lacking resources. This makes the burden that much greater and creates a need for newly available programs for these populations to

reduce the barriers that keep them from receiving appropriate education and screening. The other two target counties (Richland and Spartanburg) have a wealth of resources available, but there are clear breakdowns in the continuum. Analysis of health systems in the SC Mountains to Midlands Affiliate service area reveal several gaps, needs, and barriers that prevent women from transitioning successfully through the Continuum of Care. Access to care isn't equally available to all women. Because of structural barriers such as financial cost and the State's cuts to the Best Chance Network, women are not receiving the care and screenings needed.

Qualitative Data Overview

As part of the exploratory data section of the Community Profile that probes deeper and fills in the gaps where statistics leave questions unanswered, the Affiliate conducted focus group, surveys, and interviews. Three focus groups were completed, two of which were in the target areas identified in the previous sections (Cherokee and Greenwood). During each focus group, the facilitators guided discussion to determine the needs for each of the breast cancer patients during their treatments. Obstacles regarding screening, treatment, recovery, and support were identified and the survivors expressed their greatest needs that were not met. The women were asked (in low health literacy appropriate words) about their experiences with the breast health continuum of care, barriers that kept them from entering or continuing in the cycle, and what services would keep women from falling out of the cycle. After each initial answer given, the moderator would use probing and clarification questions as necessary. A brief key informant survey completed by sixteen local residents highlighted areas of greatest need for the service area. In addition to the survey, eleven key informants were formally interviewed. By getting this first hand information, themes were discovered that showed the beliefs and perceived needs about breast health issues in the area. The key informants surveyed are knowledgeable of the needs in the area, work in and around breast cancer patients on a daily basis, and have first-hand experience with trying to meet needs to reduce the burden of the disease. Detailed notes were recorded during the focus groups and were then color coded to find repetitive themes or similar threads running throughout. The analysis began by categorizing the data and themes found, then using them to answer the questions presented in the previous sections.

Defined needs among the underserved, uninsured, and low-income female population in the SC Mountains to Midlands service area include:

- Transportation assistance
- Reduced-cost or free breast health procedures
- Increased survivor support
- Community awareness about resource availability.

Increased transportation assistance programs translate into women being more likely to seek treatment and keep appointments. The financial barriers and providers' heavy reliance on Best Chance Network for free or reduced price mammograms can also be eliminated with the implementation of free screening programs using Komen grant dollars. Programs that address this barrier are crucial to filling gaps, meeting needs, and reducing mortality rates in this area. Structural barriers were not the only variables

affecting access for women; a lack of both patient and provider education about available programs breaks the continuum of care cycle. It is evident that community education about available resources and the importance of early detection is an important factor in reducing breast cancer burdens in each of these target counties. To improve life for breast cancer survivors, it was determined that women need more comprehensive care from providers, which could be achieved through provider education, letting physicians know of these desires and how to address them. The need for better support after treatment was expressed and is very suitably addressed by implementing a support program that links patients to a survivor mentor and other community support programs available during treatment as well as recovery. The survey and the focus groups show that convenient support group times and child care provision are also steps in the right direction to eliminating barriers to support. A nurse navigator program that allows all breast cancer patients continuous access to medical support is needed to answer all questions for women going through treatment who may be feeling that they are experiencing abnormal side effects or experiences.

Conclusions

By researching breast cancer and demographic statistics, analyzing health systems in the SC Mountains to Midlands Affiliate service area, and evaluating qualitative data gathered using several methods, a few common themes of unmet needs and unbridged gaps in services became evident. The statistics of breast cancer mortality and stage at diagnosis, screening rates, and demographics of the area laid a good foundation for where to start digging deeper and examining the area more closely. These statistics produced target counties (Edgefield, Cherokee, Greenwood, Richland, and Spartanburg) which were given more attention in the health system analysis section. By identifying resources available for the counties most burdened by breast cancer, the Affiliate can begin filling in the gaps and meeting the needs. In keeping with the Susan G. Komen for the Cure's promise of saving lives and ending breast cancer forever by empowering people, the SC Mountains to Midlands Affiliate gathered information from key informants, breast cancer survivors, and community leaders about barriers and survival issues that keep women from receiving mammograms or hinder women from moving through the continuum of care successfully. By combining all of the data collected, it is very clear what efforts the Affiliate needs to continue and what new efforts need to be launched to be effective in delivering our promise to the community.

Action Plan

Priority 1: Reduce mortality rates by increasing breast screenings for Edgefield, Cherokee, Greenwood, Richland, and Spartanburg Counties through reduction of structural barriers and knowledge barriers. Structural barriers may include, but are not limited to, financial cost, lack of transportation, and limited access to the continuum of care. Knowledge barriers include, but are not limited to, low breast health education, limited community outreach, and lack of awareness about available programs.

- Objective 1.1: Increase investment of grant funds in non-profit organizations in these counties to provide free breast screening and diagnostic services to low-income and underinsured women by 10% each year.

- Objective 1.2: Partner with programs that can implement programs to provide access to transportation to and from screening, diagnostic, and treatment services every fiscal year.
- Objective 1.3: Unite local stakeholders in each target county to organize community breast health programs to reach and educate the underserved populations by start of fiscal year 2012-2013.
- Objective 1.4: Evaluate long-term benefits and outcomes of allowing grant funding to be used for small amounts of advertising along with the main grant program by 2012.

Priority 2: Increase survivor support services (counseling, support groups, transitional assistance, co-survivor network, children's counseling, etc.) for breast cancer survivors in all counties of the service area.

- Objective 2.1: Increase awareness among Breast Health Patient Navigators, providers, social workers, etc. about the importance of Cancer Survivor Planning to transition patients from treatment to 'normal' by 2013.
- Objective 2.2: In the coming grant cycles, fund pilot support programs for families, children, and friends of Survivors and/or a co-Survivor network.
- Objective 2.3: Initiate conversations and relationships with providers in order to educate on the need for quality follow-through with breast cancer patients and Survivors.

Priority 3: Build partnerships with key organizations and individuals in all counties for fundraising, granting, and outreach outlets.

- Objective 3.1: Meet with providers in the newly acquired eleven counties to develop partnerships for future funding and/or fundraising efforts throughout fiscal year 2011-2012.
- Objective 3.2: Seek out opportunities for grantmaking with free clinics, nonprofits, faith based organizations, etc. in the newly acquired eleven counties.
- Objective 3.3: Foster relationships with any organizations in the entire service area that may have been past recipients of grant funding and/or fundraising sponsors, but have not participated in recent years.
- Objective 3.4: Mandate that Best Practices and Evidence-Based Programs be incorporated into all grant programs by 2013.
- Objective 3.5: Using evidence-based programming, educate providers about the most current breast health recommendations, resources available in the community, and other evidence-based programs that would increase their patients' screening rates.

Priority 4: Provide increased access to breast health screening through Best Chance Network and other state policies regarding health access.

- Objective 4.1: Build and cultivate a comprehensive group of advocates in each county and legislative district in the service area to call to action when necessary.
- Objective 4.2: Continue to partner with the Lowcountry Affiliate and the South Carolina Cancer Alliance on all advocacy and public policy efforts for the state of South Carolina.
- Objective 4.3: Identify and train several key volunteers to serve on the public policy committee to carry out the majority of the public policy efforts of the Affiliate.

Introduction

Affiliate History

Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982, that promise became Susan G. Komen for the Cure® and launched the global breast cancer movement. Today, Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists. Susan G. Komen for the Cure's promise is to save lives and end breast cancer forever, ensuring quality care for all, and energizing science to find the cures.

In 1995 the first Upstate Race for the Cure® was brought to Greenville, South Carolina. In 2000, the Komen Upstate SC Affiliate was established and covered eleven counties. Nine years later, the Upstate SC Affiliate became the SC Mountains to Midlands Affiliate and took on an additional eleven counties, stretching to the heart of the state. Since 1995, the Affiliate has awarded \$4.3 million in funding to local breast cancer programs and breast cancer research. Of that amount, \$3.14 million has been awarded in grants to local not-for-profit organizations to fund innovative breast cancer education, screening, and treatment programs. In 2011, the Affiliate will celebrate its 17th anniversary of the Race for the Cure®. The Race for the Cure series is the largest series of 5K runs/fitness walks in the world. Across the country, more than one hundred Races will be held in 2011, expected to attract more than one million participants. The event raises significant funds and awareness for the fight against breast cancer, celebrates breast cancer survivorship, and honors those who have lost their battle with the disease.

Organizational Structure

The SC Mountains to Midlands Affiliate is governed by a Board of Directors that sets the vision and direction of all efforts and initiatives for the Affiliate. There are four staff positions (Executive Director, Grants and Outreach Coordinator, Affiliate Coordinator, and Administrative Assistant) that execute the work of the Affiliate. Committees are organized for individual events or efforts and are essential to the success of the Affiliate. The Organizational Chart in Figure A represents the structure of the SC Mountains to Midlands Affiliate.

South Carolina Mountains to Midlands 2010-2011 Organizational Chart

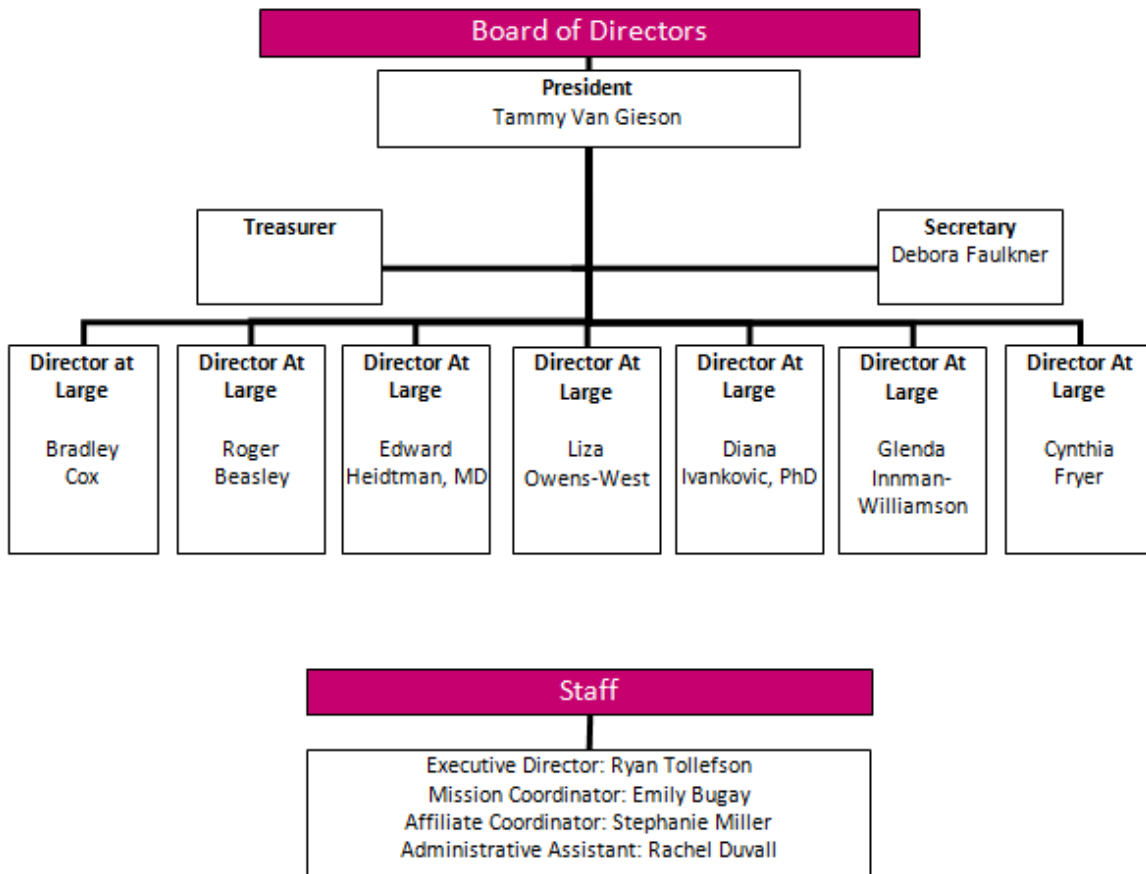


Figure A. SC Mountains to Midlands Affiliate Organizational Chart

Description of Service Area

The SC Mountains to Midlands Affiliate currently covers twenty-two counties in the state of South Carolina. As shown in Figure B, these counties are Abbeville, Aiken, Anderson, Cherokee, Chester, Chesterfield, Edgefield, Fairfield, Greenville, Greenwood, Kershaw, Lancaster, Laurens, Lexington, McCormick, Newberry, Oconee, Pickens, Richland, Saluda, Spartanburg, and Union. Eleven of these counties are relatively new to the Affiliate. In 2009, the Affiliate proposed an expansion strategy that was approved.

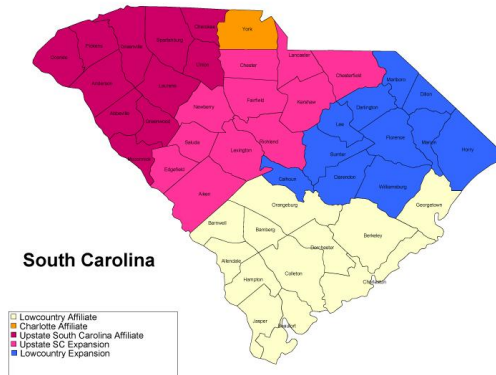


Figure B. SC Mountains to Midlands Affiliate service area map

These twenty-two counties are mostly rural and are located in the northwestern half of the state of South Carolina. The total population of the SC Mountains to Midlands Affiliate service area is 2,427,997 according to the US Census Report. The Cities of Greenville, Columbia, Spartanburg, and Anderson make Greenville, Richland, Spartanburg, and Anderson counties, respectively, less rural than the other eighteen counties in the service area. Of these, Greenville is the largest county with 455,637 total population. McCormick County is the smallest with only 10,763 residents. Overall, the SC Mountains to Midland’s population is 50.98% female (US Census, 2009).

The Affiliate service area is comprised of predominately Caucasian (69.73%) and African American (26.74%), with only small populations of Hispanic (3.49%). Pickens, Oconee, and Anderson Counties are majority Caucasian. All counties except McCormick have a higher percentage of Caucasians than African Americans. Greenville and Saluda Counties have the highest percentage of Hispanic with Chester and McCormick having the smallest Hispanic population (US Census, 2009).

The average family income in the Affiliate service area is \$41,419 with 16.78% of the population living below the poverty level. Seventy-two percent of the population in the entire area are high school graduates with only 16.01% having a Bachelor’s Degree or higher. Lexington, Richland, and Greenville have the highest average family incomes, while Chesterfield, Union, Fairfield, and Chester have the lowest. Fairfield County has the highest percentage of families living below the poverty level (US Census, 2009).

Purpose of the Report

In order to effectively and efficiently serve the SC Mountains to Midlands Affiliate service area, the Affiliate has completed this Community Profile to better understand its service area and the needs that are not being met. As a part of this effort, many different types of data were collected, such as breast cancer statistics, information about programs and available services, and qualitative data from surveys and focus groups. From the comprehensive evaluation of this information, priorities and barriers were identified.

The completed report will guide every strategic effort of the SC Mountains to Midlands Affiliate. The Community Profile will illuminate areas of greatest need for outreach and

areas targeted for increased funding through grants as well as areas of greatest strength for fundraising. With a completed Community Profile, the SC Mountains to Midlands Affiliate can be certain that the efforts put forth are impactful, meeting needs, filling gaps, and are original and non-duplicative.

The priorities set forth in this report will guide grant-making, outreach efforts, educational programming, and advocacy efforts. The information gained will be useful for every facet of the Affiliate's work and will ensure that endeavors are targeted and specific.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Data Source and Methodology Overview

For the completion of this Community Profile, the SC Mountains to Midlands Affiliate used a compilation of statistics from South Carolina Department of Health and Environmental Control (SCDHEC), United States Census, Healthy People 2010, and National Cancer Institute (NCI) State Cancer Profiles. SCDHEC's data system and statistical files are part of the SC Community Assessment Network (SCAN). SCAN is interactive and includes information categorized by DHEC region, county, and zip code. Cancer incidence and mortality rates are pulled from the South Carolina Central Cancer Registry and are accessed via SCAN. The US Census is a comprehensive demographics project completed every four years. Healthy People 2010 is a set of specific goals set forth by the government for the overall health of the US population. The NCI State Cancer Profiles are a compilation of health surveillance data for each state presented by cancer type.

Data from each of these sources was combined and analyzed. In the analysis, each statistic or rate was reviewed independently and then compared to the other sources. Counties with the highest burden of breast cancer were determined by looking at a composite of all the statistics, rates, and demographics. Komen's promise is to save lives by ending breast cancer forever; therefore, breast cancer mortality is the key variable in breast cancer burden analysis. High mortality rates, combined with the issues that contribute to those rates (late stage diagnosis and low mammography rates) drive this section of the Community Profile and will illuminate counties of interest.

Breast Cancer Statistics Overview

A mortality rate is a comparable number of deaths divided by the population. Compared to the breast cancer mortality rates of South Carolina as a whole (23.9 per 100,000), the SC Mountains to Midlands twenty-two county service area has similar mortality rates (24.4 per 100,000). There are counties and populations that do not follow this trend and have higher rates. The highest mortality rates for all races are found in Edgefield (32.5 per 100,000), McCormick (31.8 per 100,000), Fairfield (30.3 per 100,000), Cherokee (30.0 per 100,000), Greenwood (29.9 per 100,000), Richland (29.4 per 100,000), and Spartanburg (28.9 per 100,000) (SCDHEC SCAN, 2010).

In these counties, there are specific populations that have high mortality rates compared to the county as a whole. When broke down by race, African Americans in Edgefield (43.8 per 100,000), Cherokee (42.0 per 100,000), and Spartanburg (41.5 per 100,000) have the highest rates. Caucasians in Cherokee (27.7 per 100,000), Greenwood (29.8 per 100,000), Richland (26.2 per 100,000), and Spartanburg (26.1 per 100,000) also have high rates, shown in Figure C (SCDHEC SCAN, 2010).

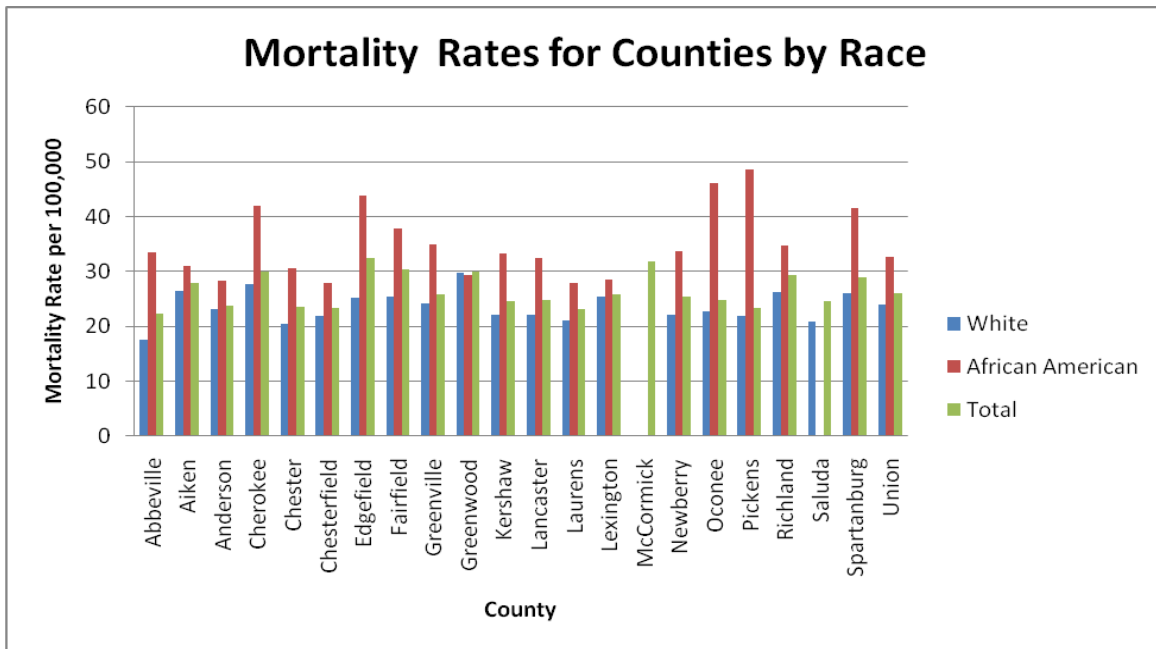


Figure C. Mortality Rates for Counties by Race (SCDHEC SCAN, 2010)

When a county is extremely small and the population is low, numbers of deaths due to breast cancer are difficult to translate into rates per 100,000. This accounts for the absence of data for some of the counties in the service area.

Figure C illustrates that the mortality rate for African Americans is noticeably higher than other races. In fact, the mortality rate for African Americans is higher than that of Caucasians in every county except Greenwood, where the rates are similar with the Caucasian mortality rate being slightly higher.

A disparity is an inequality or incongruity between two groups. In the case of mortality rates in the Mountains to Midlands, there are large disparities between Caucasians and African Americans in Pickens, Oconee, Edgefield, and Abbeville counties (SCDHEC SCAN, 2010).

According to NCI’s State Cancer Profile for South Carolina, mortality rates for females with breast cancer are experiencing a falling trend. However, the same report shows a rising trend for the diagnosis of female breast cancer (State Cancer Profiles, 2010).

Only a few counties in the SC Mountains to Midlands service area met the Healthy People 2010 Objective to reduce the breast cancer death rate. Those counties are Pickens, Kershaw, Oconee, Aiken, Chester, and Union. None of the target counties met objective. Also, NCI’s State Cancer Profile for South Carolina lists Edgefield, Fairfield, Cherokee, Greenwood, Richland, and Spartanburg counties within highest mortality rates in the state (Healthy People 2010).

Rates of stage at diagnosis are important when determining which counties to target for increased breast health programs. Nationally, for all races, the five-year relative survival

rate for women with localized cancer is 98 percent, 84 percent for regional disease, and 23 percent for distant stage disease. African American women have higher rates of distant stage breast cancer than Caucasian women. Rates of distant stage breast cancer among African American women in the US have increased by 0.5 percent per year since 1975 (ACS, 2010).

Of the SC Mountains to Midlands counties that have been identified as having high mortality rates, all are associated with high rates of late stage diagnosis, as visible in Figure D. Edgefield, Cherokee, and Spartanburg have particularly high late stage diagnoses for African Americans; and Greenwood and Richland have high rates for Caucasians. This corresponds directly with the counties with highest mortality. High rates of diagnoses at distant stage indicate a need for targeted breast health programs in that area. When breast cancer is caught early, the rate of survival is much higher.

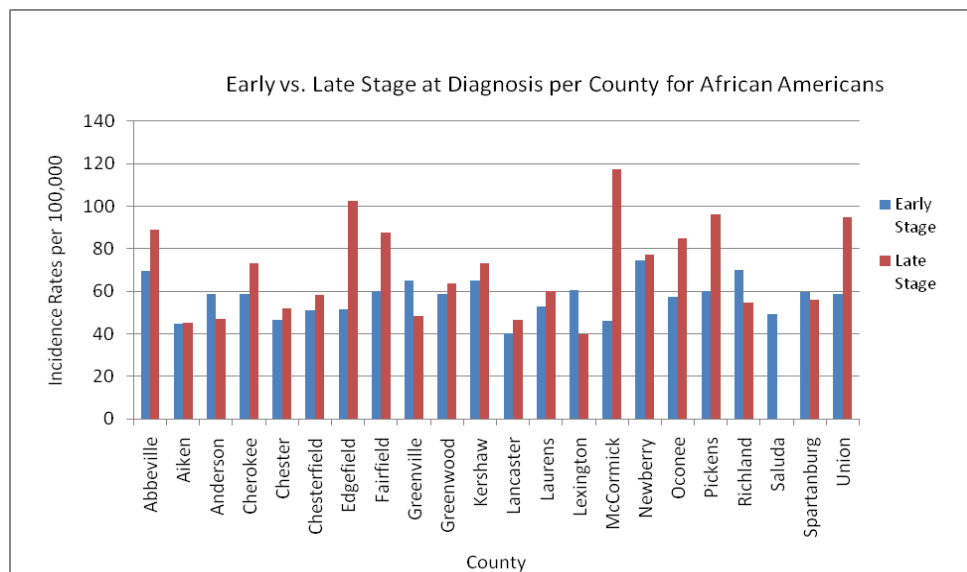


Figure D. Early vs. Late Stage at Diagnosis per County for African Americans (SCDHEC SCAN, 2010)

Recent studies suggest that many women in the US are getting their first mammogram later than recommended, not having mammograms at recommended intervals, or not receiving appropriate and timely follow-up of positive screening results. This may lead to more advanced tumor size and stage at diagnosis (ACS, 2010).

Nationally, only 51.2 percent of women forty and older in the US reported having a mammogram in the last year (ACS, 2010). About 80-90 percent of breast cancers in women without symptoms in the US will be detected by mammography (ACS, 2010).

Demographics

South Carolina, as compared to the United States, has lower average income levels and education levels. The Hispanic and Latino populations are much smaller throughout the state of South Carolina than the nationwide average. SC also has a larger population of African Americans than the United States average. Within South Carolina,

there are pockets where these differences are more emphasized and noticeable than others. Overall, the SC Mountains to Midlands twenty-two county service area accounts for the northwest half of the state and has the same demographic trends as the state when compared to the national averages (US Census, 2009).

These differences in socioeconomic status and race are significant in the counties noted as having the highest breast cancer mortality rates. Edgefield, McCormick, Fairfield, and Cherokee have low education levels (high school diplomas, undergraduate, and graduate degrees) when compared to the service area as a whole, the state, and the nation. Low income levels (median household income, per capita income, and percent below poverty level) are found in Edgefield, McCormick, and Fairfield counties, as shown in Figures E and F. Counties with large populations of African Americans are Edgefield, McCormick, and Richland. Greenwood and Spartanburg have high percentages of Hispanic population (US Census, 2009).

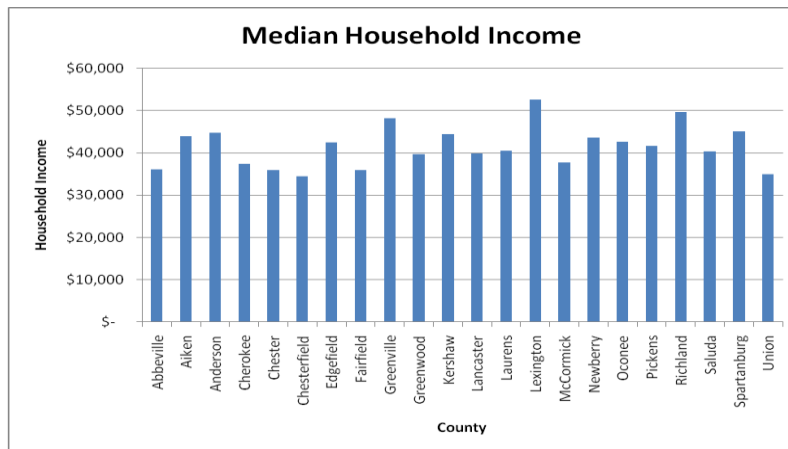


Figure E. Median Household Income by County (US Census, 2009)

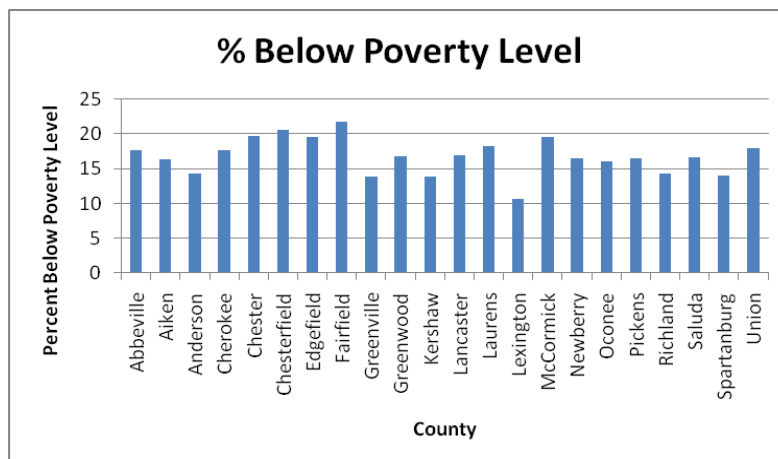
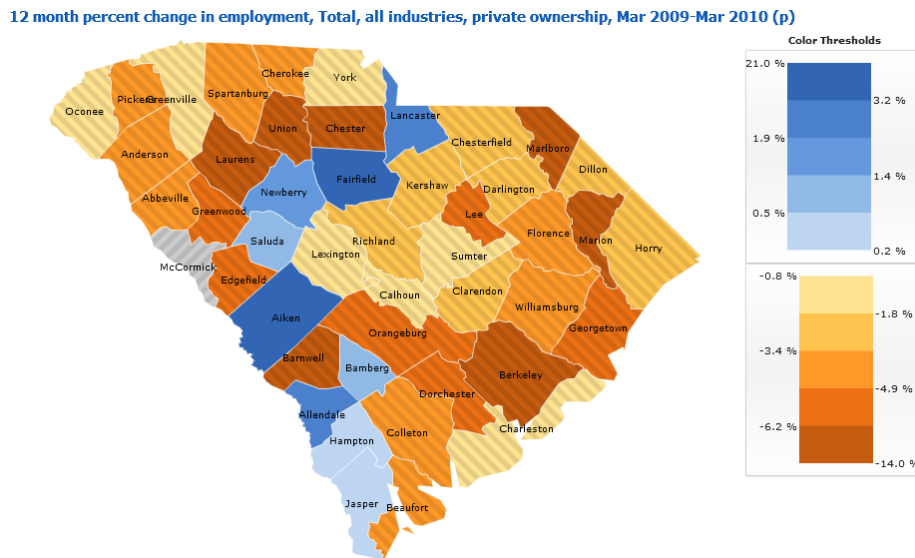


Figure F. Percent Below Poverty Level by County (US Census, 2009)

Given the economic downturn of recent years and the unstable market, unemployment rates in South Carolina are changing constantly and while trending downward, are still significantly higher than in years past. The industries that are most common in the area

are textiles and manufacturing, both of which have experienced some of the most dramatic downturns in the economic slump. This translates into high rates of unemployment in the area, and therefore high percentages of uninsured individuals. Figure G shows the twelve month percent change in unemployment for the counties in South Carolina from 2009-2010 (US Bureau of Labor Statistics, 2010).



Source: U.S. Bureau of Labor Statistics (www.bls.gov)

Figure G. Twelve month percent change in employment for each county (US Bureau, 2010)

Section Findings

The analysis of breast cancer statistics (mortality, stage at diagnosis, mammography) and demographics in the section reveal several target counties and populations. Edgefield, Cherokee, Greenwood, Richland, and Spartanburg were chosen because of the impact of the burden of breast cancer on these counties. Specifically, when broken down by race, African-Americans in Edgefield, Cherokee, and Spartanburg; and Caucasians in Cherokee, Greenwood, Richland, and Spartanburg, have a disproportionate burden of breast cancer. The counties and populations have high mortality rates, high rates of late stage diagnosis and low socioeconomic status indicators.

Edgefield County

- High mortality rates for all races (32.5 per 100,000)
- Large disparity in mortality rates between races
- High late stage diagnoses for African Americans
- Low education levels
- Low income levels
- Limited resources available

Cherokee County

- High mortality rates for all races (30.0 per 100,000)
- High late stage diagnoses for African Americans

- Low education levels

Greenwood County

- High mortality rates for all races (29.9 per 100,000)
- Only county with higher mortality rates for Caucasians than African Americans
- High late stage diagnoses for Caucasians
- High percentage of Hispanic population
- Only county in service area with larger African American population than Caucasian

Richland County

- High mortality rates for all races (29.4 per 100,000)
- High late stage diagnoses for Caucasians

Spartanburg County

- High mortality rates for all races (28.9 per 100,000)
- High late stage diagnoses for African Americans

Health Systems Analysis of Target Communities

Overview of the Breast Cancer Continuum of Care

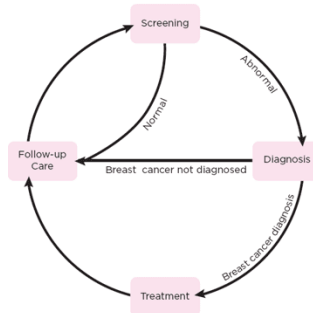


Figure H. The Breast Cancer Continuum of Care

The Breast Cancer Continuum of Care, shown in Figure H, is a diagram that represents movement through the healthcare system from screening for breast cancer, to diagnosis and treatment, to follow up care. The continuum is broken up into four stages: Screening, Diagnosis, Treatment, and Follow-up Care. Unfortunately, this is not a perfect circle for all women. Some do not enter the cycle to begin with and some experience barriers that keep them from moving to the next step seamlessly. Examples of barriers that may disturb the continuum of care are language barriers, financial costs, lack of available transportation, low self-efficacy, cultural stigmas, sexual orientation, age, modesty, gender, disability, citizenship status, and fear. The Continuum of Care is an important aspect to the Health Systems Analysis because it guides the process to focused stages, organizes the vast array of needs into four categories, and helps paint a visual picture of both existing and needed partnerships. The Continuum guides the question-making process for the key informant interview. Most importantly, it systematically sections the questions to focus on each of the four stages. Once the answers are gathered, it provides a system for arranging and classifying the gaps identified.

Methodology

The analysis of available and needed health systems is vital to the community needs assessment process. To gain knowledge and take inventory of existing services and programs in the target counties, the Affiliate consulted the Internet, SCDHEC officials, American Cancer Society community outreach employees, the SC Cancer Alliance, health care workers in each target county, and other non-profits in the health field. Community information was found using the SClway.net and Google search engine. Once all resources in the target counties were identified, an asset map using Google Maps was created, plotting each resource at its physical location.

For the interviews, key informants were selected by reaching out to local public health (DHEC) offices, area hospitals, cancer societies, and related non-profits. In total, sixteen key informants participated in the comprehensive questionnaire and represented fourteen different organizations in all target areas. The questionnaire

included seven open-ended questions and was executed with a mix of conference calls and in person meetings. The questions addressed known barriers such as transportation and financial assistance, needed partnerships, success and/or limitations of the current health care system, and gaps in access to service for underserved women. Ideas and suggestions about how to meet the needs identified and decrease the gaps in access or service were discussed following the formal questionnaire. Limitations to the key informant interview data collected include possible selection bias and scheduling conflicts. Two of the selected key informants were not available at the scheduled interview time.

Overview of Community Assets

The SC Mountains to Midlands Affiliate of Susan G. Komen for the Cure knows that ending breast cancer is about more than curing a medical condition – it's about overcoming the cultural, social, and financial conditions that prevent women from receiving life-saving breast health care and treatment. Since 1995, the Affiliate has invested more than \$3.1 million in community breast health programs serving underinsured and underserved women and men in the twenty-two county service area.

As of March 10, 2011, there are Komen Affiliate-funded grantees in two of the target counties (Cherokee and Spartanburg). These are neighboring counties and have several resources that overlap to serve both counties. The Komen-funded projects include the Stay the Course – One Woman at a Time at the Cancer Association of Spartanburg and Cherokee Counties, Inc. and the SRHS Mammogram Program at Spartanburg Regional Health Services District, Inc. Self Regional Healthcare in Greenwood County has been funded by the Affiliate for several grant cycles in the past, but did not receive a grant for the 2010-2011 grant cycle. The remaining two target counties do not currently have and have not had Komen Affiliate grant funding in the past. This is due to the service area expansion that was approved in 2009. Edgefield and Richland counties will be priority counties for the announcement of grant funding availability and for hosting grantwriting workshops in the future years. Several institutions in Richland County have expressed interest in grant funding and have submitted applications for the 2011-2012 fiscal year. The Affiliate has relationships with most of the major hospitals in the original eleven county service area and will be reaching out to build partnerships with healthcare organizations in the counties that were recently added as a part of the multi-year strategic plan. Local for-profit hospitals are also an area for partnership building to further breast health awareness in the area even though these organizations are not eligible for funding. Upstate Carolina Medical Center and Mary Black Hospital are examples of these type organizations. Of the free clinics in the service area, the Affiliate has partnered with four, all located in the original counties. Relationships with the remaining free clinics are prime targets for outreach and partnership building as the success of the expansion moves forward.

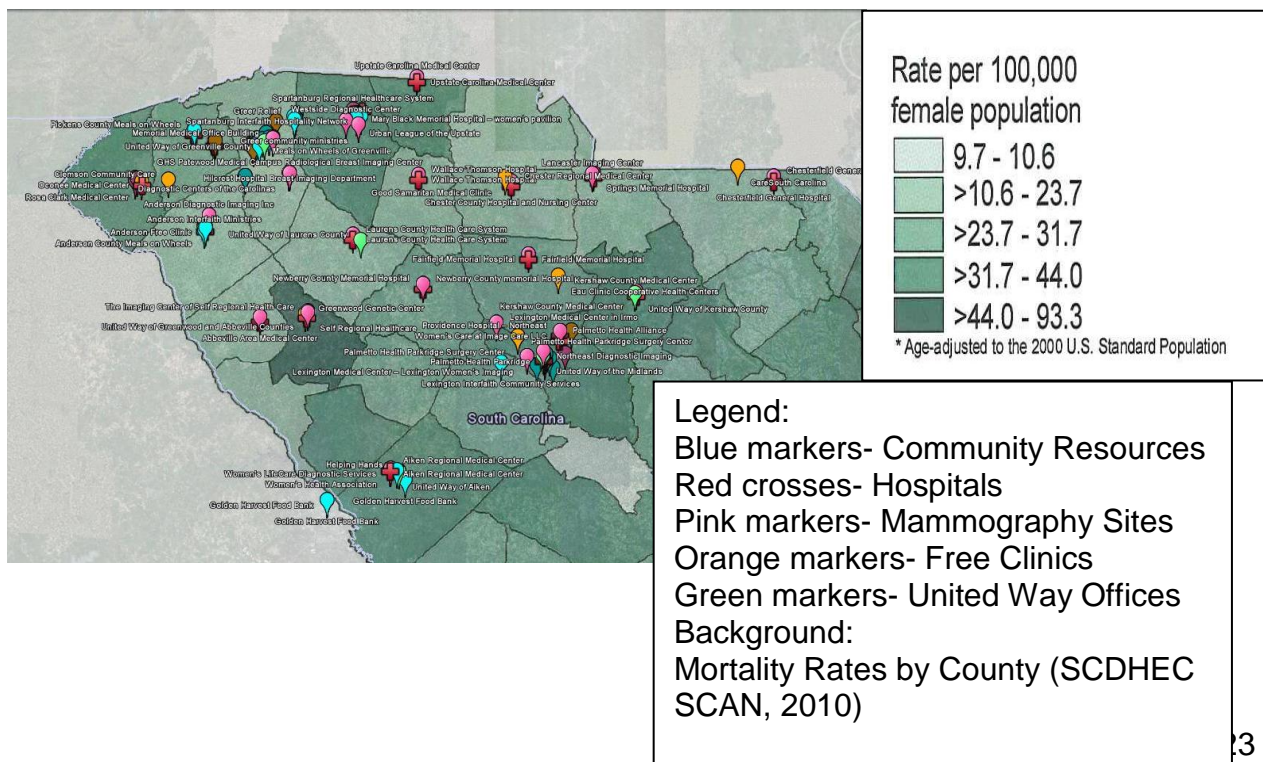
Breast Health Patient Navigator Programs have been shown to be a promising practice in the South Carolina area. This position guides patients through the diagnosis and treatment of breast cancer. Interdisciplinary treatment of cancer has become the standard of care for cancer and requires the coordination of complex treatment

schedules. A seamless approach to educating the patient and communication between the multidisciplinary treatment team is essential. The Patient Navigator functions as a clinician, educator, researcher, counselor, healthcare liaison, consultant, and patient advocate. Because of the numerous benefits of this type of position, this is a promising grant-making opportunity that would benefit the community greatly. Another grant opportunity that has yet to be taken advantage of is provider education. This seems to be a source of breakdown in the referral and access cycle. Providers' lack of education and awareness about available resources can be remedied by programs targeted at increasing education efforts to providers. While a major free mammography program at a large hospital is a great resource and service, it is not as effective as it could be if referring physicians are not aware of the availability or scope of the program.

Because of South Carolina's unique placement in the 'Bible Belt' of America, there are a larger number of churches per capita than in other states. Taking this into consideration, the Affiliate works with over 400 area churches each year for the Pink Sunday program, educating women in congregations throughout the area about the importance of early detection. There are several counties where church participation is not as high as expected and presents a unique opportunity for partnership in the future. All five target areas have a large number of faith-based communities that have yet to take part of this program.

Asset Map

To visually determine where the areas are most concentrated with resource availability, the addresses of each known community service organization, hospital, mammography site, United Way office, and medical clinic in the service area was plotted on a map using Google Earth. Each category of resources was made into an image overlay so that each could be viewed and analyzed separately or in different combinations.



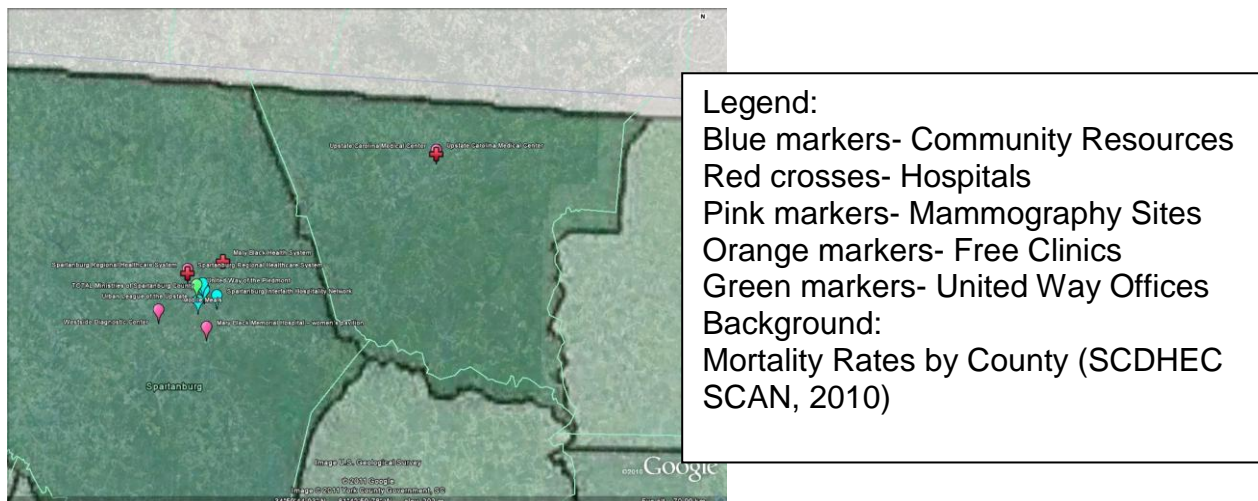


Figure I. Asset Maps (Entire Service Area, Cherokee County example).

As shown in Figure I, resources are concentrated in Greenville, Anderson, Spartanburg, Richland, and Aiken. Not shown in the asset map are the Best Chance Network providers. These are not pictured because there are a large number in each county. There is no lack of providers in the twenty-two county services area. However, because of the funding cuts to the program by the state government, the providers cannot provide routine screenings for eligible women.

Edgefield County has very limited resources, attributable to its small population. Citizens of this county receive care from Self Regional Healthcare in Greenwood County, resulting in transportation barriers. There are currently no known breast health programs available specifically to Edgefield County. The lack of resources, inconvenient access to resources, and lack of breast health programs lead to low perception of importance of screening and high mortality rates. Edgefield County does have one free medical clinic that would be a prime opportunity for partnership for an educational program.

Cherokee County's only hospital is Upstate Carolina Medical Center, a for-profit organization. The low incidence rates and high mortality rates may be indicative of the hospital's lack of services for low-income and uninsured/underinsured women. Though there are limited programs and services to assist in screening, the resources that are available remain largely unused. In the 2010-2011 fiscal year, one Komen grantee serving Cherokee found lack of education and awareness to be what kept women from accessing available resources.

Greenwood County has one major healthcare facility, Self Regional Healthcare, located centrally in the county. This county is also the only county in the service area with a larger African American population than Caucasian population. According to several key informant interviews, it seems that women aren't aware of screening recommendations or how to access appropriate resources. There is a definite lack of education, especially for low-literacy populations, that leads to low usage of available programs.

Richland County has five large hospital facilities, four free clinics, and six mammography facilities. The residents here have high average family incomes and education levels, yet have very high breast cancer mortality rates. High Stage IV diagnoses indicate that women are not utilizing the many services in their area as preventative services, but as treatment options. For the women in these areas diagnosed with breast cancer, there are several social services available to assist them with financial, nutritional, and other needs.

Spartanburg County is home to a large healthcare facility, Spartanburg Regional Health Services District, and has several education and screening resources available. However, the need is great and the programs have limited funding and cannot serve all eligible patients. Even though there are screening programs, there are no programs available to do clinical breast exams. Survivorship programs are available but remain underutilized by the community.

Best Practices and Evidence-Based Programs

Best Practices are programs that have been implemented and have been shown to be successful. Evidence-based Programs are intervention programs that have been proven to work during systematic reviews and research studies. The SC Mountains to Midlands Affiliate realizes the importance of Best Practices and funding evidence-based programs. For the 2011-2012 grant cycle, the grant applicants were heavily encouraged to use evidence-based programs in the development of their grant programs.

Evidence-based programs have been designed to increase screening rates by breaking down barriers and to address strategies that are client- and provider-oriented as well as breaking down barriers to screenings. The client-oriented evidence-based programs used to increase cancer screening rates are client reminders, small media, one-on-one education, reducing structural barriers, and out-of-pocket expenses. When messages are tailored to individuals rather than population groups, face-to-face encounters in low-key settings build rapport between provider and client. Reducing structural barriers, which increases availability and ease of access, can include components such as mobile mammography, free child care, expanded hours of operation, or incorporation of a patient navigator to guide clients through scheduling and procedures. Provider-oriented strategies that have been proven through research and reviews are provider assessment and feedback, as well as provider reminder/recalls. Any program incorporating multiple recommended components has an even more defined increase in screening rates.

Legislative Issues in Target Counties

The Best Chance Network is a part of the National Breast and Cervical Cancer Early Detection Program and implemented through the SCDHEC and the American Cancer Society. Since 1991, the Best Chance Network has received federal funding to screen eligible women, but 2008 and 2009 were the first time state funds have been allocated for screening. The South Carolina Affiliates are gravely concerned about substantial cuts to Best Chance Network (BCN), which provides breast cancer screening services to low-income, uninsured, and underinsured women in our state. When the state

budget was adopted for the 2010-2011 fiscal year, BCN funding was cut in half and 8,000 women lost access to the program. Many of the women who rely on this vital safety net program have nowhere else to go for affordable and life-saving breast health services. Currently, BCN is only accepting a small number of symptomatic patients per month per county. These budget cuts affect all counties in SC. Because this BCN funding is crucial to the increasing number of uninsured women in the state, regaining state funding for this program is at the top of the Affiliate's legislative agenda. Because the majority of the target counties are also the counties with the lowest average income and highest unemployment rates, the women in these counties need this funding reinstated. The SC Affiliates will work together with the American Cancer Society and the South Carolina Cancer Alliance in 2011 to put together a grassroots effort to have constituents contact their legislators, plan legislative breakfasts, and meetings to inform decision makers of the severity of these cuts and the importance of reinstated funding, and continue to be in contact with the lawmakers to influence their decisions. Another issue rising on the legislative agenda of the SC Affiliates is the oral chemotherapy access legislation. Currently, health insurance companies in SC are not covering oral chemotherapy the same as IV chemotherapy, although oral chemotherapy is quickly becoming the standard of care for patients. The Affiliates, along with the SCCA, ACS, and Leukemia and Lymphoma Society, will be advocating for oral chemotherapy access for patients in the new fiscal year.

The South Carolina Cancer Alliance, a coalition healthcare organizations concerned about the burden of cancer in the state, creates and implements the state's comprehensive cancer plan. The first plan was created in 2003 with the purpose of 'coordinating and promoting partnerships to address cancer prevention and control strategies that will reduce the impact of cancer on all South Carolinians'. Currently, the cancer plan is under review and will be updated in early 2011. The updates will include progress made on existing goals as well as a strategic plan on how to continue momentum on reducing the burden of cancer in South Carolina through prevention, early detection, research, advocacy, and patient care priority areas.

Conclusions

From the asset map, it is clear that three of the target counties (Edgefield, Cherokee, and Greenwood) are lacking resources. This makes the burden that much greater and creates a need for newly available programs for these populations to reduce the barriers that keep them from receiving appropriate education and screening. The other two target counties (Richland and Spartanburg) have a wealth of resources available, but there are clear breakdowns in the continuum.

Analysis of health systems in the SC Mountains to Midlands Affiliate service area with a specific focus on the counties identified as most burdened by breast cancer in the Quantitative Data section of this Profile reveal several gaps, needs, and barriers that prevent women from transitioning successfully through the Continuum of Care. Access to care isn't equally available to all women. Because of structural barriers such as financial cost and the State's cuts to the Best Chance Network, women aren't receiving the care and screenings needed.

Breast Cancer Perspectives in the Target Communities

Methodology

As part of the exploratory data section of the Community Profile that probes deeper and fills in the gaps where statistics leave questions unanswered, the Affiliate conducted focus group, surveys, and interviews.

Three focus groups were completed, two of which were in the target areas identified in the previous sections (Cherokee and Greenwood). There were a total of sixteen attendees, ranging from current patients, survivors, and family members. These participants were located through references from the Cancer Association of Spartanburg and Cherokee Counties, Inc. and Self Regional Healthcare. During each focus group, the facilitator guided discussion to determine the needs for each of the breast cancer patients during their treatments. Obstacles regarding screening, treatment, recovery, and support were identified and the survivors expressed their greatest needs that weren't met. The third focus group was in Greenville County. While this is not a target county, the participant group was readily available and it presented as an additional opportunity to learn more the service area. The information gained from the Greenville focus group will be considered, but not highlighted as it is not from a target area.

The participants from the Cherokee and Greenwood focus groups were an equal mix of African American and Caucasian. One male participated in the Greenwood group as a family member or co-survivor; the other participants were all female. The majority of the participants did identify themselves in an anonymous survey as low-income and underinsured. Eight were breast cancer survivors, while three were current patients undergoing treatment. The entirety of the Greenville focus group was made up of breast cancer survivors not currently receiving treatment.

The questions asked in the focus groups followed the same script for each. The women were asked (in low health literacy appropriate words) about their experiences with the breast health continuum of care, barriers that kept them from entering or continuing in the cycle, and what services would keep women from falling out of the cycle. Each focus group lasted forty-five minutes to an hour. After each initial answer given, the moderator would use probing and clarification questions as necessary.

A brief key informant survey completed by sixteen local residents highlighted areas of greatest need for the service area. In addition to the survey, eleven key informants were formally interviewed. By getting this first hand information, themes were discovered that showed the beliefs and perceived needs about breast health issues in the area. The key informants surveyed are knowledgeable of the needs in the area, work in and around breast cancer patients on a daily basis, and have first-hand experience with trying to meet needs to reduce the burden of the disease. These people were asked to participate based on experience, frequency of time spent with underserved women and breast cancer survivors, and existing relationship with the Affiliate. These individuals represent highly respectable organizations in the community and their responses helped

supplement the statistics, focus groups, and interviews completed. The questions asked in the interviews and surveys were targeted to health providers, community leaders, and breast health educators.

The information gathered was compiled, organized, and categorized by theme. Detailed notes were recorded during the focus groups and were then color coded to find repetitive themes or similar threads running throughout. The survey answers were compiled and organized by category. The analysis began by categorizing the data and themes found, then using them to answer the questions presented in the previous sections.

Qualitative data gathering is as much a science as it is an art. There are several limitations to each of the methods chosen. Limitations to key information interviews can include selection bias and difficulty generalizing across populations. The same limitations are true of focus groups. Surveys present other possible limitations such as low response rates and limited sample sizes. However, the advantages of these tools far outweigh the limitations presented. Very detailed and rich data can be gathered using these methods. In interviews and focus groups, there are numerous opportunities for clarification to ensure that the leader indeed understands the comments made by the participants. These methods are also important in future relationship building. The statistics can only take the community needs assessment so far. The qualitative data gathered using interviews, focus groups, and surveys add depth to the numbers and really emphasize the felt needs in the community.

Review of Qualitative Findings

Reliance on Best Chance Network – Provider Knowledge

The majority of the community leaders participating in the key informant interviews indicated a heavy reliance on the Best Chance Network for free screening mammograms for underinsured women in their service areas. As presented in the previous section, Best Chance Network funding has been cut and there are no longer services available for women under forty-seven, or women of any age who are not symptomatic. This speaks to the lack of provider knowledge about the public policy surrounding the program, as well as an unhealthy reliance on Best Chance Network to meet needs it is not equipped to meet. Possible avenues of alleviating this situation are provider education about resources available (or not as widely available as once thought, in this specific case) and increased resources for free mammograms outside of the BCN program. One of the participants interviewed noted, “There needs to be programs in place that meet gaps coming up with all of the Medicaid cuts.”

Transportation

Survey results indicate that transportation assistance is a major barrier to accessing breast health care for the underserved populations in certain communities. The counties with the biggest concern for transportation were Edgefield, Cherokee, and Spartanburg. It is no longer enough to have reduced price or free breast health services. If the women that need these services the most cannot get to them, the program is not truly filling the

gap and meeting the needs. Figure J illustrates the key informants' opinions about transportation being a barrier that is not being adequately addressed.



Figure J. Is transportation an issue for women in your community when trying to get to screenings and/or treatment?

Awareness of Resources Available

A growing concern of the individuals surveyed was community awareness about program availability in their areas. Similar to transportation, the existence of a program is not enough. If community members do not know that the program exists or that they are eligible to participate, the program will continue to be underutilized. The participants from both focus groups and interviews made the following statements about this particular need area:

“Many people are not aware of assistance programs.”

“People are not aware of the resources that are available”

“A lot of these women don’t even know we have what they need.”

“Resource availability isn’t the problem - women don’t know they can get this mammogram for free if they would just call.”

When asked what types of programs would help improve the current system:

“Advertising!”

Survivor Support

Another major issue that the survey probed into was survivor support. There is little being done in the SC Mountains to Midlands area to proactively and specifically support breast cancer survivors and their families. Figure K shows that support groups are currently the main way organizations provide support to survivors. Survivor School and educational classes are also available for survivors.

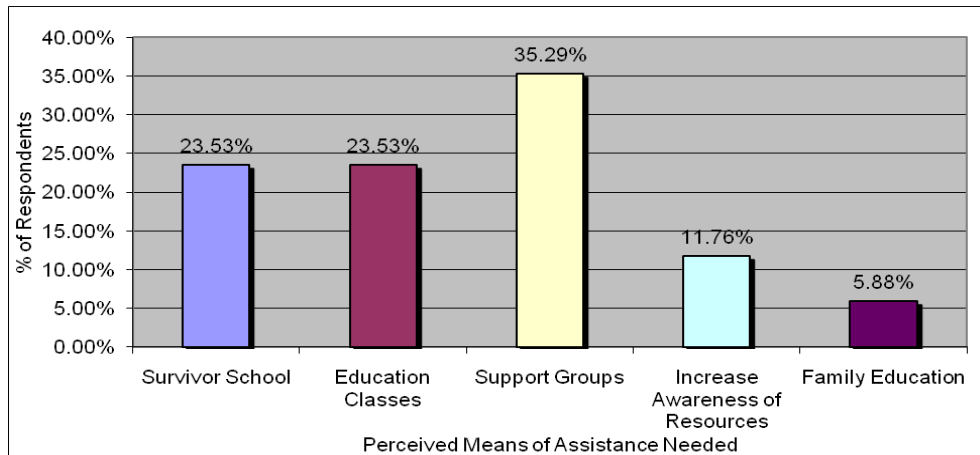


Figure K. What else could be done to assist and/or support breast cancer survivors in your community?

While the community leaders and providers surveyed felt that there was survivor support available, the questions and probing done during the focus groups proved otherwise.

The women believed that they were not as informed by physicians as they should have been, and as a result they worried about many things they felt could have been avoided. They believe that providers should deliver more comprehensive care that includes thoroughly explaining the things they will go through as well as the symptoms and side-effects they will experience. In the times that the patients did experience strange symptoms or side effects, they felt it was hard to get in touch with a doctor or nurse to ask about their condition and also felt that many of their questions were stupid or silly and were afraid to bother the doctors and nurses with them. As a result of both of these things, the survivors felt that all breast cancer patients should have access to a 24/7 nurse navigator service where they can call someone who has access to their medical file and ask them any types of questions they have related to their treatment or recovery.

The women also suggested that having a breast cancer survivor mentor similar to them would be a great tool so that they could be assured that they were experiencing the same things many breast cancer patients go through. They had a strong desire to know that how they were feeling wasn't abnormal and wanted this reassurance from other breast cancer survivors. The women all expressed a great need for contact with other patients or survivors, but it was discovered that many of these women weren't attending support groups because of inconvenience of meeting times or lack of child care. As a result of this strong desire for contact, it was suggested that child care be provided at the support groups or that groups be scheduled during school hours so child care was not an obstacle to getting much needed support. In addition, the women who could not attend the support groups or get these types of support, expressed feelings of abandonment once treatment was over. For so long the women had been relying on their routine treatments as a source of stability, and once treatment was abruptly finished, they felt they were thrown back into their lives as a survivor with no source of

support. As a result, they thought that there should be a program linking them to support throughout their recovery, not just during their treatments. The mentor, when paired with a parent organization linking survivors to other community support programs, is a great way to begin filling this void. Cancer Survivor Plans are a way to fulfill this need.

Key Informant Interview Findings

Key informant interview results indicate that in most areas, services and programs are available but the large majority of the targeted population is unaware. For programs that are advertised, the population's lack of self-efficacy keeps them from seeking out ways to get involved. Other themes that emerged during the interviews were transportation, lack of financial assistance or 'discount' mammogram programs, and lack of education about breast health.

When asked about moving uninsured women through the continuum of care, every single interviewee answered by mentioning a referral to the Best Chance Network program. Most were unaware of any other programs providing access to low-cost or free screenings to women without insurance. Each interviewee also mentioned lack of education about existing resources or breast health screening recommendations in their area. Interviewees expressed praise for the existing health care systems and resources available to women, but were unsure how women get connected into these programs if they aren't current patients. Specific to Cherokee County, the interviewee said that newspaper advertisements with a clip-out coupon using the word 'free' are hugely successful; news stories and advertisements without coupons are not effective. A few of the interviewees did have organizations in mind that would be ideal for future partnerships (i.e. Local Area Transits providing transportation to and from appointments at a discounted rate or churches providing education material to congregations) but didn't know where to start or how to begin a partnership relationship to move forward.

Conclusions

Transportation assistance, reduced-cost or free breast health procedures, increased survivor support, and community awareness about resource availability are defined needs among the underserved, uninsured, and low-income female population in the SC Mountains to Midlands service area. Increased transportation assistance programs could translate into women being more likely to seek treatment and keep appointments. The financial barriers and providers' heavy reliance on Best Chance Network for free or reduced price mammograms can also be eliminated with the implementation of free screening programs using Komen grant dollars. Programs that address this barrier are crucial to filling gaps, meeting needs, and reducing mortality rates in this area.

As evidenced in the key informant interviews, structural barriers are not the only variables affecting access for women; a lack of both patient and provider education about available programs breaks the continuum of care cycle. It is evident that community education about available resources and the importance of early detection is an important factor in reducing breast cancer burdens in each of these target counties.

To improve life for breast cancer survivors, it was determined that women need more comprehensive care from providers, which could be achieved through provider education, letting physicians know of these desires and how to address them. The need for better support after treatment was expressed and is very suitably addressed by implementing a support program that links patients to a survivor mentor and other community support programs available during treatment as well as recovery. The survey and the focus groups show that convenient support group times and child care provision are also steps in the right direction to eliminating barriers to support. A nurse navigator program that allows all breast cancer patients continuous access to medical support is needed to answer all questions for women going through treatment who may be feeling that they are experiencing abnormal side effects or experiences.

Conclusions: What We Learned, What We Will Do

Review of the Findings

By researching breast cancer and demographic statistics, analyzing health systems in the SC Mountains to Midlands Affiliate service area, and evaluating qualitative data gathered using several methods, a few common themes of unmet needs and unfilled gaps in services became evident.

The statistics of breast cancer mortality and stage at diagnosis, screening rates, and demographics of the area laid a good foundation for where to start digging deeper and examining the area more closely. These statistics produced target counties which were given more attention in the health system analysis section. By identifying resources available for the counties most burdened by breast cancer, the Affiliate can begin filling in the gaps and meeting the needs. This step of the Community Profile was eye-opening and gave great insight about what services are needed in what areas.

In keeping with the Susan G. Komen for the Cure's promise of saving lives and ending breast cancer forever by empowering people, the SC Mountains to Midlands Affiliate gathered information from key informants, breast cancer survivors, and community leaders about barriers and survival issues that keep women from receiving mammograms or hinder women from moving through the continuum of care successfully.

By combining all of the data collected, it is very clear what efforts the Affiliate needs to continue and what new efforts need to be launched to be effective in delivering our promise to the community.

Conclusions

After analyzing the breast cancer statistics and demographics for the SC Mountains to Midlands Affiliate twenty-two county service area, the counties that are experiencing the highest burden of breast cancer and the most devastating economic effects are Edgefield, Cherokee, Greenwood, Richland, and Spartanburg counties.

Edgefield County

- High mortality rates for all races (32.5 per 100,000)
- Large disparity in mortality rates between races
- High late stage diagnoses for African Americans
- Low education levels
- Low income levels
- Limited resources available
- No breast health programs specific to this community

Cherokee County

- High mortality rates for all races (30.0 per 100,000)
- High late stage diagnoses for African Americans
- Low education levels

- Programs and services available, but remain unused

Greenwood County

- High mortality rates for all races (29.9 per 100,000)
- Only county with higher mortality rates for Caucasians than African Americans
- High late stage diagnoses for Caucasians
- High percentage of Hispanic population
- Only county in service area with larger African American population than Caucasian
- Lack of breast health education programs

Richland County

- High mortality rates for all races (29.4 per 100,000)
- High late stage diagnoses for Caucasians
- Many resources available but are used as treatment options rather than preventative screening

Spartanburg County

- High mortality rates for all races (28.9 per 100,000)
- High late stage diagnoses for African Americans
- Breast health programs available that are being utilized well, but the need is great and the programs have limited funding

The SC Mountains to Midlands area is a mix of thriving, robust cities and less fortunate, destitute rural areas with everything in between. This poses a very interesting challenge for the future of the Affiliate. The areas that have the most resources, also have the most granting and partnership building opportunities, while the counties that are lacking in important resources have little to build on. By being aware of key industries, social service organizations, colleges and universities with resources and programs throughout the area, medical facilities with resources not yet tapped into, as well as public policy initiatives with the state government, the Affiliate can begin building partnerships, finding new ways to meet needs, and open doors for expanded services to the areas. There have been programs implemented in the SC Mountains to Midlands area that have shown success. Replication of these model grantee programs in other areas, coupled with an initiative to move grantees and other providers to evidence-based programs, provide a good starting point to begin reaching these communities that lack resources and access.

Transportation assistance, reduced-cost or free breast health procedures, increased survivor support, and community awareness about resource availability are defined needs among the underserved, uninsured, and low-income female population of the target areas. Increased transportation assistance programs are needed to get women into the continuum of care and facilitate their movement through the continuum. The inability to afford gas or lack of access to transportation to get to appointments or survivor services keep women from receiving adequate care and support. Another major barrier identified is cost. Uninsured, underinsured, and low-income women (especially in tough economic times) cannot afford a simple screening procedure. Programs that address this barrier are crucial in the service area to continue to fill gaps and meet needs. The providers' heavy reliance on the Best Chance Network for these

free screenings increases the burden of cost on women that meet eligibility for the program but cannot be accepted due to lack of state funds and budget cuts. Additional programs to address this financial cost barrier are important to filling these gaps and reducing mortality rates. To improve life for breast cancer survivors, it was determined that women need more comprehensive care from providers, which could be achieved through provider education by informing physicians about these desires and how to address them. The need for better support after treatment is expressed and is very suitably addressed by implementing a support program that links patients to a survivor mentor and other community support programs available during treatment, as well as recovery. Convenient support group times and child care provision are also steps in the right direction for eliminating barriers to support. A nurse navigator program that allows all breast cancer patients 24/7 access to medical support is needed to answer all questions for women going through treatment and feeling that they are experiencing abnormal side effects or experiences. Another need that surfaced during the qualitative data analysis was the need for increased community awareness about breast health recommendations and programs that are available. In many cases, there were programs available; however, they remained largely underutilized because there was no method of community outreach or advertisement. One particular interview discussed the great need of using 'clipable coupons' in the local newspaper. Without proper advertising and outreach, breast health programs are not successful to their highest potential.

These findings are crucial in determining how the Affiliate should move forward toward the goal of ending breast cancer forever. It is true that breast cancer knows no boundaries and is an 'equal opportunity disease', but there are defined pockets and populations that experience greater breast cancer burdens. It is the Affiliate's hope that the findings and the Community Profile journey to the findings will guide the strategies, outreach efforts, and grant programs for the next two years, until another Community Profile is completed. The breast cancer statistics, health system analysis, and qualitative data all combine to produce several 'theme areas' from which the Affiliate's priorities were formed. Each priority is followed by several specific, measurable, and realistic objectives that serve as action items for the Affiliate. These objectives will in turn serve as the measuring stick or evaluation tool at the completion of the two years.

Action Plan

Priority 1: Reduce mortality rates by increasing breast screenings for Edgefield, Cherokee, Greenwood, Richland, and Spartanburg Counties through reduction of structural barriers and knowledge barriers. Structural barriers may include, but are not limited to, financial cost, lack of transportation, and limited access to the continuum of care. Knowledge barriers include, but are not limited to, low breast health education, limited community outreach, and lack of awareness about available programs.

- Objective 1.1: Increase investment of grant funds in non-profit organizations in these counties to provide free breast screening and diagnostic services to low-income and underinsured women by 10% each year.

- Objective 1.2: Partner with programs that can implement programs to provide access to transportation to and from screening, diagnostic, and treatment services every fiscal year.
- Objective 1.3: Unite local stakeholders in each target county to organize community breast health programs to reach and educate the underserved populations by start of fiscal year 2012-2013.
- Objective 1.4: Evaluate long-term benefits and outcomes of allowing grant funding to be used for small amounts of advertising along with the main grant program by 2012.

Priority 2: Increase survivor support services (counseling, support groups, transitional assistance, co-survivor network, children's counseling, etc.) for breast cancer survivors in all counties of the service area.

- Objective 2.1: Increase awareness among Breast Health Patient Navigators, providers, social workers, etc. about the importance of Cancer Survivor Planning to transition patients from treatment to 'normal' by 2013.
- Objective 2.2: In the coming grant cycles, fund pilot support programs for families, children, and friends of Survivors and/or a co-Survivor network.
- Objective 2.3: Initiate conversations and relationships with providers in order to educate on the need for quality follow-through with breast cancer patients and Survivors.

Priority 3: Build partnerships with key organizations and individuals in all counties for fundraising, granting, and outreach outlets.

- Objective 3.1: Meet with providers in the newly acquired eleven counties to develop partnerships for future funding and/or fundraising efforts throughout fiscal year 2011-2012.
- Objective 3.2: Seek out opportunities for grantmaking with free clinics, nonprofits, faith based organizations, etc. in the newly acquired eleven counties.
- Objective 3.3: Foster relationships with any organizations in the entire service area that may have been past recipients of grant funding and/or fundraising sponsors, but have not participated in recent years.
- Objective 3.4: Mandate that Best Practices and Evidence-Based Programs be incorporated into all grant programs by 2013.
- Objective 3.5: Using evidence-based programming, educate providers about the most current breast health recommendations, resources available in the community, and other evidence-based programs that would increase their patients' screening rates.

Priority 4: Provide increased access to breast health screening through Best Chance Network and other state policies regarding health access.

- Objective 4.1: Build and cultivate a comprehensive group of advocates in each county and legislative district in the service area to call to action when necessary.
- Objective 4.2: Continue to partner with the Lowcountry Affiliate and the South Carolina Cancer Alliance on all advocacy and public policy efforts for the state of South Carolina.
- Objective 4.3: Identify and train several key volunteers to serve on the public policy committee to carry out the majority of the public policy efforts of the Affiliate.

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