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Executive Summary

Introduction

Affiliate History and Background

In 2003, discussion began to pursue the establishment of a local Komen Affiliate after a need for breast health care was seen by local health systems. In October 2005, the Komen Tri-Cities (KTC) Affiliate was officially established due to the cooperative effort between the two major competing health care providers in the region, Mountain States Health Alliance (MSHA) and Wellmont Health System (WHS). Since its beginning, the KTC Affiliate has given over $1.74 million to grantees providing breast health care to underserved and underinsured local women. Monies totaling $485 thousand have been given to national scientific research programs in hopes to find a cure. The Affiliate's objective is to provide maximum return to support Komen's mission of saving lives and ending breast cancer through education, screening, and research.

The service area for the Komen Tri-Cities Affiliate covers twenty-five communities (23 contiguous counties and 2 independent cities) nestled in the mountainous Appalachian region of Northeast Tennessee, Southwest Virginia and Northwest North Carolina. The region takes its name from the presence of three cities in close proximity: Johnson City, TN; Kingsport, TN; and Bristol, TN/VA. These three cities have developed individually, but often work collaboratively to the advantage of the region. The Tri-Cities area is economically and geographically isolated and independent of other metropolitan areas such as Knoxville, Roanoke and Asheville.

The Affiliate area covers approximately 8,861 square miles and has a total population of 948,047 people, with 258,000 being women age 40 years or older and 160,000 age 50 years or older. The racial distribution for females is 97.0% White, 1.5% Black/African-American, 0.7% Hispanic/Latino, 0.3% Asian and 0.1% American Indian. Although this naturally beautiful region is rich in history and culture, it still lags behind the U.S. in per capita income. Twenty-one percent of the female population is uninsured and the median household income is $36,232.

There are a total of thirty (30) FDA Certified Mammography sites in the Komen Tri-Cities area. Twenty of those are operated by the two major health systems, MSHA and WHS, and a majority of the sites have some type of contractual affiliation with MSHA or WHS for cancer services. MSHA and WHS also provide comprehensive oncology services to the region through eight (8) cancer treatment centers. County health departments serve each of the counties in the region and there are health clinics in each of the cities. Other outreach and educational services are provided by the health systems, American Cancer Society, health clinics and occasional civic projects.

Purpose of Report

The Community Profile Report serves as a periodic re-examination of the needs and gaps existing in our service region. The qualitative research that goes into formulating this report also serves the dual purpose of giving our affiliate an opportunity to reach out to the stakeholders and key informants in our service region, allowing us to build relationships and collaborations with the passionate people in our communities. The results of our comprehensive analysis of both qualitative and quantitative data for the report drives our strategic planning and helps direct the allocation of grant, operating, and volunteer resources to best meet the evolving needs of our communities.

Statistics Methods and Target Communities

Komen Tri-Cities (KTC) partnered with East Tennessee State University College of Public Health to research and analyze demographic and breast cancer statistics for this report. When assessing the data provided by Thomson Reuters and various other sources, it was found that:

- Overall the KTC's regional breast cancer incidence rate is lower than the rate for each state represented in our service region (Tennessee, Virginia and North Carolina) and the nation; however, the breast cancer mortality rate in our service region is much higher than the mortality rate in all of the three states and the nation.
- The rate of women without health insurance in the KTC Region is higher compared to their counterparts in other parts Tennessee, Virginia and North Carolina and the rest of the nation.
- Mammography screening is low for the KTC Region compared to the overall screening rates in the three states and the nation.
- All twenty-five KTC communities are part of the Appalachian region and all twenty-five communities in the KTC Region are classified as Distressed, At-risk or Transitional.
- Data indicate disparities exist for our Black/African-American communities; diagnoses are made at later stages and mortality rates are much higher for Black/African-American women in our region.

The communities in our region which had the most unfavorable figures were those which are rural and/or economically depressed and the majority of our communities fit that classification. A high-level summation of these statistics indicate that low screening rates may drive unfavorable incidence and death rates and the lack of insurance is contributing to the low screening rates.

Health Systems Analysis

Komen Tri-Cities utilizes the Community Profile Report preparation process as an opportunity to conduct a comprehensive review of the breast health assets in our service region. Aspects of the entire continuum of breast health are studied: early detection & education, diagnosis, treatment, and survivorship. We publish our regional asset listing

on our website, www.komentricities.org, with prominent visibility, intuitive categorization, extensive linking, and specific contact information.

Formulating the Community Profile Report also provides an opportunity to review our relationships with our wide range of breast health partners throughout the service region. As we are preparing the report, we reach out to new partners in the region, reaffirm existing relationships, and identify potential relationships that will further our mission going forward.

Community Data

In formulating the 2009 Community Profile, the community profile team decided to weave several objectives together when planning our exploratory data collection stage. Acknowledging the fact that we have three states represented in our service area and that each state provides a differing portfolio of services, we divided our counties by state. Then we acknowledged evidence of "ruralness" as a major factor influencing breast health issues and subdivided our counties into "rural" and "more populated" and decided to target one representative "rural" and "more populated" county from each of the three states. The counties chosen were: Wise and Washington Counties in Virginia, Hawkins and Sullivan Counties in Tennessee, and Madison and Avery Counties in North Carolina. Additional objectives were to begin developing relationships with each of the states' Comprehensive Cancer Control initiatives as well as passionate stakeholders in each of the counties in order to spur creative solutions and future Komen grant applicants.

We used a focus group methodology to conduct roundtable discussions with various breast cancer stakeholders and other key informants from each of the communities. The objective of these discussions was to dig deep into the factors influencing breast health by seeking to understand the breast health needs of the communities, the factors that limit the fulfillment of those needs and how the barriers can be surmounted. The discussions also helped to explore the priorities of the communities in meeting their breast health needs. Some of the most prominent barriers discussed were insurance, transportation, information, education and awareness. But even more was gleaned from the deeper dialogue surrounding solutions – like the idea that cultural issues and attitudes can often defeat well-intended initiatives. Women in our region are very strong and self-reliant with tight-knit family and church-associated support networks and we concluded that the true barriers to the women of our region are far from simple or one-dimensional.

In keeping with our focus group methodology and recognizing the power of roundtable discussions as a tool for building relationships as well as collecting data, for the 2011 Community Profile, the community profile team hosted a focused roundtable discussion with key informants from the Black/African-American community supplemented by a survey of key informants. Both the roundtable discussion and the survey revealed that while there are many similarities in the breast health needs of all women in our service area, there are also important challenges that need to be addressed which are specific to the Black/African-American community. Most notably, we found there is a need to provide education that is culturally relevant to the Black/African-American community and outreach is needed to engage members of the Black/African-American community in delivering breast health messages in the community.

Conclusions

Overview of Final Findings

Ultimately the overriding conclusion was that our region's screening rates are too low and the barriers influencing those rates are multi-dimensional and variable by communities, and heavily influenced by families, cultural attitudes, and tight social networks. We believe that if we can move women to have their screening mammograms within standard guidelines, lives will be saved. In order to move women in all of our communities, we must reach out in a way that is relevant to the diverse cultures in our communities and build relationships within the individual communities to foster grassroots mobilization.

Affiliate Priorities

Our primary strategic objective needs to be directed at increasing the number of women receiving screening mammograms and a measure of success for programs we support can be the number of screening mammograms derived from those efforts. In addition, it is imperative that we focus on developing and supporting programs along the entire continuum of care from education and diagnosis through treatment and survivorship. The programs may address a variety of specific barriers:

- Providing culturally relevant education and awareness
- Building grassroots mobilization in communities
- Mitigating risk factors
- Empowering survivorship
- Addressing the need for low/no-cost screenings
- Increasing awareness of affordable screening programs
- Offering resource awareness initiatives for physician offices
- Addressing access issues in remote regions
- Overcoming fear by incorporating entertainment
- Incorporating social, religious or other culturally relevant elements into screening recruitment initiatives
- Capitalizing on family and social network "peer" pressure to encourage women to seek screenings
- Addressing familial history variables to overcome unsubstantiated concerns

Every initiative should have a key objective of raising breast health awareness and improving the quality of women's lives before, during and/or after encountering breast health issues.

Affiliate Action Plan

The information from the demographic and breast cancer statistical analysis, program and services findings, and exploratory data garnered from the community focus group meeting were presented to representatives of the Komen Tri-Cities board of directors at a special community profile culmination and strategic planning meeting.

Our primary goal, stated in our 2009 Community Profile, was to increase the number of screening mammograms performed in our region by 20% in the next 12 months and to meet or exceed Healthy People 2010 objective of increasing the proportion of women aged 40 years and older who have had a mammogram within the past 12 months to 56.9 – 61.0% in all of the counties in our region. Current data indicate that 59.3% of women over age 40 in our service area received a mammogram in the last twelve (12) months. We are still working to make further progress in ensuring that all women over age 40 receive annual mammograms; we believe that expanding our focus to include more community-based and culturally relevant outreach will support attaining our goal.

Our action plan includes:

- Continuing a major communication initiative to promote awareness
- Developing a multi-partner awareness collaboration to build awareness around overcoming barriers and increasing screenings throughout the region
- Establishing a Pink Ambassador in each community to build grassroots mobilization and outreach relationships with community contacts from within every community in our service region
- Using metrics relating to capacity to increase screening rates when evaluating programs and resource allocations
- Extending fundraising efforts to all communities in the region through Race for the Cure team building, sponsorships, third-party fundraising, and outright donations
- Monitoring public policy activities and helping keep public representatives from throughout our region aware of the importance of breast health for our region
- Building a presence in every community in our region within the next two years
- Supporting activities that impact the quality of life for women in our service region including those that empower survivorship and mitigate risk factors

Introduction

Affiliate History

Efforts to establish a Komen Affiliate to address the breast health gaps in our region began in 2002 when two major hospital systems, Wellmont Health System and Mountain States Health Alliance, along with a group of community volunteers, identified the need and began looking for a solution. Work began immediately to prepare the application and community profile report to identify the critical gaps. The two hospital systems, along with the region's largest employer, Eastman Chemical Company, took the lead role as founders with both in-kind and financial support.

In October 2005, the Komen Tri-Cities Affiliate was officially formed, with a working Board of Directors with fifteen members. Each year, through these efforts and the generous support of our corporate, individual, and foundation donors, third party event fundraising, hundreds of volunteers, survivors, activists and the Annual Tri-Cities Susan G. Komen Race for Cure® event, the Affiliate is able to raise funds to provide grants to hospitals, health organizations and non-profit community organizations. These organizations are our partners in providing breast health education and breast cancer screening and treatment options for medically under-served women throughout the service area.

Organizational Structure

Komen Tri-Cities is led by a diverse nine (9) member volunteer Board of Directors representing the major regional health organizations, private companies, businesses, survivors, activists, volunteers and oncology health professionals in the region. Komen Tri-Cities is managed by a full-time Executive Director, Cheryl Youland, an Affiliate Coordinator, Joy Clifton, and a Mission Coordinator, Katie Skelton. Major operational tasks such as treasury, grant management, and race coordination are performed by assigned board members, while a strong team of additional volunteers help meet education, outreach, awareness, and other supporting activities.

Board of Directors

Toni Bounds, Board President

Lynn Krutak, Treasurer

Martha Chill, Member at Large

Stephanie Dominy Werner, Member at Large

Curt Rose, Member at Large, Chair Governance Committee

Stacey Ely, Board Vice President

Sara Diamond, Member at Large

Beth Cox, Member at Large

Brook Lambert, Member at Large

Description of Service Area

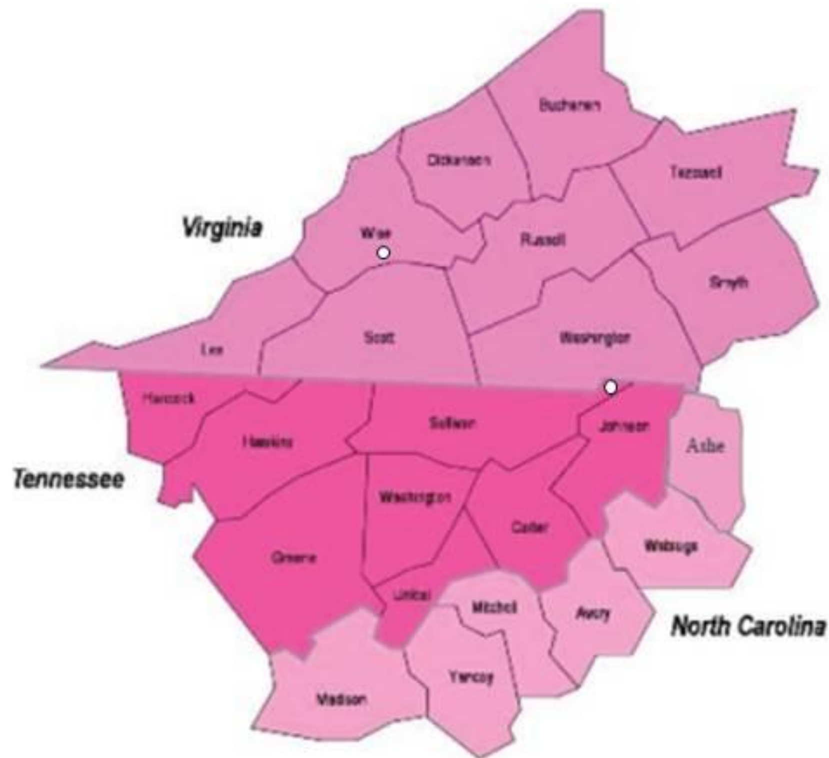
The service area for the Tri-Cities Affiliate of the Susan G. Komen for the Cure® covers twenty-five (25) communities nestled in the mountainous Appalachian region of Northeast Tennessee, Southwest Virginia and Northwest North Carolina. The economic and service hub for this service area consists of two contiguous counties, Sullivan (TN) and Washington (TN) with a total combined population of 298,282 (Thomson Rueters). The State of Tennessee's 7th largest industrial employer, Eastman Chemical Company, is an international Fortune 200 company headquartered in Sullivan County. Eastman employs more than 13,000 people who reside throughout the service area. The two major health systems, Mountain States Health Alliance and Wellmont Health System, are also headquartered in this economic/service hub and provide health care to this service area through facilities and services located in or near these population areas.

Komen Tri-Cities Service Region

North Carolina
Ashe, Avery, Madison, Mitchell, Watauga, and Yancey Counties

Tennessee
Carter, Greene, Hancock, Hawkins, Johnson, Sullivan, Unicoi, and Washington Counties

Virginia
Buchanan, Dickenson, Lee, Russell, Scott, Smyth, Tazewell, Washington, and Wise Counties and the cities of Bristol and Norton.



The Tri-Cities Tennessee-Virginia region is an area of natural beauty and rich in history. The region takes its name from the presence of three cities in close proximity: Johnson City, TN, Kingsport, TN and Bristol, TN-VA. These three cities have developed individually, but often work collaboratively to the advantage of the region. The Greater Tri-Cities Region is integrated through common culture, economies, industries, regional governmental bodies and social/retail services. Recognized as a distinct metropolitan area by the federal government and agencies, and located more than 100 miles from the nearest neighboring metropolitan area, this region is unique because of its location in the mountains of the Blue Ridge and Appalachian chains.

Unlike Knoxville and Asheville, which are the closest metropolitan areas, the Greater Tri-Cities Region has a medical school which creates a distinct medical community and patient and service relationships. Instead of patients leaving the region to gain specialized care, patients come to the Tri-Cities from throughout the region to receive specialized acute services. For cancer related services, the region has formal relationships with Vanderbilt University, Harvard University, Massachusetts General Hospital, and Bowman Gray School of Medicine. Finally, the region differs from Knoxville, Roanoke and Asheville because of the dominance of large industrial employers. In nearby metropolitan areas the economies are driven by a different mix of industry and smaller-sized employers.

Johnson City is home to the main campus of East Tennessee State University and the James H. Quillen College of Medicine, as well as Mountain Home, a large Veterans' Administration Hospital. Recent health-related additions to the university include the formation of a College of Public Health, the first in the state, and the Gatton College of Pharmacy. Johnson City has become the medical and education center of the area.

Kingsport is largely dominated by major industrial and manufacturing employers such as Eastman Chemical Company, Domtar Paper Company, and AFG Corporation. The success of early manufacturers in the city created an atmosphere that resulted in the attraction of industry throughout Northeast Tennessee. With many large employers, it is quite common for employees working in Tennessee to live in Virginia or North Carolina.

Bristol is one community that lies in two states, Tennessee and Virginia. In 1998, Bristol was designated the Birthplace of Country Music by the United States Congress. Bristol is a rail center for the south and is also home of two NASCAR races per year at the Bristol Motor Speedway. In addition, the region encompasses many other small towns considered a valuable part of the Tri-Cities TN-VA region. As a result of the collaborative nature of the citizens, Tri-Cities TN-VA was the first region to be designated as an "All-America City" by the National Civic League. The table below lists small towns and communities throughout the service area by county:

Table 1: Small Towns and Communities within the Service Region

County	State	Towns and Communities
Watauga	NC	Beech Mountain, Blowing Rock, Boone, Deep Gap, Foscoe, Seven Devils, Sugar Grove, Valle Crucis, Zionville
Ashe	NC	Jefferson, Lansing, West Jefferson
Madison	NC	Hot Springs, Mars Hills, Marshall
Yancey	NC	Brush Creek, Burnsville, Cane River, Crabtree, Egypt, Green Mountain, Jacks Creek, Pensacola, Price's Creek, Ramseytown, South Toe
Mitchell	NC	Bakersville, Spruce Pine
Avery	NC	Banner Elk, Crossnore, Elk Park, Gragg, Grandfather Mountain, Linville, Minneapolis, Newland, Pineola, Sugar Mountain
Sullivan	TN	Bloomingdale, Blountville, Bluff City, Colonial Heights, Piney Flats, Spurgeon, Sullivan Gardens, Walnut Hill
Washington	TN	Fall Branch, Gray, Jonesborough, Limestone, Midway, Oak Grove, Telford, Watauga
Greene	TN	Afton, Baileyton, Chuckey, Greeneville, Mohawk, Moshiem, Tusculum
Carter	TN	Elizabethton, Hampton, Hunter, Milligan, Pine Crest, Roan Mountain

Hawkins	TN	Bulls Gap, Church Hill, Mount Carmel, Rogersville, Surgoinsville
Unicoi	TN	Banner Hill, Erwin, Flag Pond, Town of Unicoi
Johnson	TN	Butler, Laurel Bloomery, Mountain City, Shady Valley, Trade
Hancock	TN	Kyles Ford, Sneedville, Treadway
Washington	VA	Abingdon, Damascus, Emory-Meadowview, Glade Spring, Mendota, Saltville
Tazewell	VA	Bluefield, Cedar Bluff, Pocahontas, Richlands, Tazewell
Wise	VA	Norton (independent city), Appalachia, Big Stone Gap, Coeburn, Pound, Wise, St. Paul
Smyth	VA	Chilhowie, Marion, Adwolf, Atkins, Seven Mile Ford, Sugar Grove
Russell	VA	Cleveland, Honaker, Lebanon, Castlewood, Dante, Rosedale, Willis, Belfast, Swords Creek
Scott	VA	Clinchport, Duffield, Dungannon, Gate City, Nickelsville, Weber City
Buchanan	VA	Grundy, Big Rock, Council, Davenport, Harman, Harman Junction, Hurley, Keen Mountain, Mavisdale, Maxie, Oakwood, Prater, Shortt Gap, Stacy, Vansant, Royal City, Whitewood
Lee	VA	Jonesville, Pennington Gap, St. Charles, Ben Hur, Dryden, Ewing, Keokee
Dickenson	VA	Clinchco, Clintwood, Haysi

The affiliate recognizes this is a geographically expansive area which is largely rural and that it may take many years to grow an organization that is able to fully address the needs of such a vast region; however, because the region is integrated both economically and in services, it is appropriate to pursue this region. It is also important to note that the people in this region rely primarily on the two major health systems for their medical needs.

The affiliate realizes that the participation of and service to outlying communities requires careful planning and attention to ensure that each organization serving these areas is included and has access to funding. Increased emphasis is being placed on ensuring equitable participation of remote communities and relationship building throughout the entire twenty-five community service area.

Purpose of Report

The Community Profile Report serves as a periodic re-examination of our service area to assure that we maintain an in-depth understanding of the needs and gaps existing in our region. Re-examination helps direct the allocation of grant, operating and volunteer resources. The research invested into each Community Profile Report is presented to the Komen Tri-Cities Board of Directors who, upon extensive examination and deliberation, develops the affiliate's strategic plan based on those results.

The issue of breast cancer has many, many intertwining variables needing to be addressed in the quest to eliminate it altogether and the Komen Tri-Cities service area is geographically very large and rural. These factors, combined with the finite funding available each year, illustrate the need to carefully evaluate our funding priorities in order to ensure the greatest impact for our region. *The process of researching, evaluating, examining, and producing the Community Profile Report is the most important strategic initiative made by the affiliate.* Therefore, by utilizing the results of this report to direct how our resources are allocated in the upcoming years, we will be able to maximize both our efforts and the financial contributions in which we have been entrusted.

Quantitative Data: Measuring Breast Cancer Impact in Our Local Communities

Data Source and Methodology Overview

Komen Tri-Cities Affiliate representatives approached East Tennessee State University in Johnson City regarding the possibility of creating a partnership by providing the expertise necessary to thoroughly analyze the statistical information associated with the community profile. The University offered their wholehearted support and granted the expertise of Toni Herring Bounds, PhD, MPH, College of Public Health to guide us in that analysis. Additionally, we contracted with ETSU for the services of a graduate student, Grace Ekua Ghansah, MPH, CHES, who completed her doctoral degree in Public Health while working under the supervision of Dr. Bounds. Our ETSU partners conducted the comprehensive analysis for our 2009 Community Profile Report and provided valuable consultation in updating the report for 2011.

To better understand the needs of the Komen Tri-Cities Affiliate (KTC) service area, available breast cancer data were evaluated. Variables of interest included breast cancer incidence and mortality, demographics of the service area, mammography screening rates, breast cancer control programs, insurance rates, and available breast cancer resources. Both quantitative and qualitative data were used for this assessment.

Quantitative data sources for the 2009 analysis included: Thomson Reuters: 2007 county-level demographic estimates; the National Cancer Institute's State Cancer Profile: national and state level breast cancer incidence and death rates; the Cancer Control P.L.A.N.E.T: information about breast cancer screening and risk factors; the Behavioral Risk Factor Surveillance System (BRFSS): state-level mammography screening data; the Surveillance Epidemiology and End Results (SEER): state-level incidence and mortality data; the U.S. Census Bureau: information on population statistics and density data by county; Appalachian Regional Commission: data on the economic status of the KTC counties; Virginia, Tennessee, North Carolina state cancer registries: data on breast cancer incidence and temporal and spatial patterns; the Centers for Disease Control and Prevention's State Comprehensive Cancer Control Program: state-level information about breast cancer programs and activities in the region; Kaiser Family Foundation: state-level data related to uninsured women.

For the 2011 Community Profile Report, Thomson Reuters data (2009) was reviewed and references to these data are up-to-date throughout this report.

The focus of the 2011 Community Profile team's work has been to better assess the needs of the Black/African-American community. For this purpose, special attention has been paid to disparities in data relative to the Black/African-American community and a focused roundtable discussion with key informants from the Black/African-American community was conducted and supplemented by a survey of key informants to collect qualitative data.

Overview of Key Demographic & Breast Cancer Statistics at the State Level and County Levels

General Demographic Data for the Service Region

All twenty-five (25) communities (23 counties and 2 independent cities) in the Komen Tri-Cities service region are geographically located in Appalachia. The table below defines general demographic characteristics of the residents within the service region.

Table 2: General Demographic Characteristics			
Total Population:	948,047	Income:	65.9% <=$50K (US: 48.8%)
Women:	482,476 (50.9%)		Median HH Income: $36,232
Men:	465,571 (49.1%)	Education:	HSD: 32.6% (US: 28.3%)
Age:	32.6% > 55 yo (US: 24.2%)		BS: 15.0% (US: 24.7%)
Race:	White: 94.5% (Female: 97.0%) Black: 2.4% (Female: 1.5%)	Uninsured Females:	29.4% (Ages 18-64: Pop: 87,790)

The Appalachian region is characterized by many geographically isolated communities. The region has a history of shortages of health care professionals, limited access to cancer care and long distances to referral centers from rural areas (Wingo et al, 2005). "Residents of Appalachia, especially those in rural Appalachia, are generally considered to be medically underserved. In fact, cancer mortality in Appalachia, especially in rural Appalachia, is higher than it is in the remainder of the United States" (Lengerich et al, 2004). Most women are uninsured or underinsured and are less likely to get screened for breast cancer regularly (Hall et al, 2002).

The Appalachian Regional Commission (ARC) uses a county economic classification system to target counties in need of special economic assistance. The system classifies counties into five economic status designations—Distressed, At-risk, Transitional, Competitive, and Attainment—based on a comparison of county and national averages for three economic indicators: three-year average unemployment rate, per capita market income, and poverty rate. Each fiscal year, using the most current data available, ARC determines each Appalachian county's economic status designation based on thresholds established for each level (ARC, 2009).

All twenty-five (25) communities in the KTC service region are classified as Distressed, At-risk or Transitional. Distressed counties are the most economically depressed counties; At-Risk counties are counties that are at risk of becoming economically distressed; and Transitional counties have rates worse than the national average for one or more of the three economic indicators. The vast majority of the counties in our service region are Distressed or At-Risk; only eleven (11) of our counties are Transitional.

Table 3: Economic Status Designations for Counties within the Service Region

Designation	2006	2007	2008	2009	2010	2011
Distressed	Hancock (TN) Johnson (TN) Dickenson (VA)	Hancock (TN) Johnson (TN) Dickenson (VA)	Hancock (TN) Johnson (TN) Dickenson (VA)	Hancock (TN) Johnson (TN) Dickenson (VA)	Hancock (TN) Johnson (TN) Dickenson (VA)	Hancock (TN) Johnson (TN) Dickenson (VA)
At-Risk	Buchanan (VA) Lee (VA) Smyth (VA) Wise (VA) Mitchell (NC) Yancey (NC)	Buchanan (VA) Carter (TN) Lee (VA) Mitchell (NC) Russell (VA) Wise (VA) Yancey (NC)	Buchanan (VA) Carter (TN) Lee (VA) Mitchell (NC) Russell (VA) Wise (VA) Yancey (NC)	Buchanan (VA) Carter (TN) Lee (VA) Mitchell (NC) Russell (VA) Scott (VA) Wise (VA) Yancey (NC)	Buchanan (VA) Carter (TN) Lee (VA) Mitchell (NC) Russell (VA) Scott (VA) Wise (VA) Yancey (NC)	Buchanan (VA) Carter (TN) Greene (TN) Lee (VA) Mitchell (NC) Russell (VA) Scott (VA) Wise (VA) Yancey (NC)
Transitional	Ashe (NC) Avery (NC) Watauga (NC) Carter (TN) Greene (TN) Hawkins (TN) Madison (NC) Sullivan (TN) Washington (TN) Russell (VA) Scott (VA) Tazewell (VA) Unicoi (TN) Washington (VA)	Ashe (NC) Avery (NC) Watauga (NC) Greene (TN) Hawkins (TN) Madison (NC) Sullivan (TN) Washington (TN) Scott (VA) Smyth (VA) Tazewell (VA) Unicoi (TN) Washington (VA)	Ashe (NC) Avery (NC) Watauga (NC) Greene (TN) Hawkins (TN) Madison (NC) Sullivan (TN) Washington (TN) Scott (VA) Smyth (VA) Tazewell (VA) Unicoi (TN) Washington (VA)	Ashe (NC) Avery (NC) Watauga (NC) Greene (TN) Hawkins (TN) Madison (NC) Sullivan (TN) Washington (TN) Smyth (VA) Tazewell (VA) Unicoi (TN) Washington (VA)	Ashe (NC) Avery (NC) Watauga (NC) Greene (TN) Hawkins (TN) Madison (NC) Sullivan (TN) Washington (TN) Smyth (VA) Tazewell (VA) Unicoi (TN) Washington (VA)	Ashe (NC) Avery (NC) Watauga (NC) Hawkins (TN) Madison (NC) Sullivan (TN) Washington (TN) Smyth (VA) Tazewell (VA) Unicoi (TN) Washington (VA)

Breast Cancer Statistics

There are similarities as well as differences in breast cancer incidence and mortality trends and rates for each state and among counties within the three states in our service region. Breast cancer is the most common cancer among women and the second leading cause of cancer death among women in the three states (CDC, 2008). The incidence rate per 100,000 women in Tennessee (117.2) is lower than the national incidence rate (118.69). In Virginia (119.8) and North Carolina (124.0) the incidence rate per 100,000 women is higher than the national rate. The incidence rate per 100,000 women in our service region is 114.36, lower than each state's and the national rate (Thomson Reuters, 2009).

The mortality rate per 100,000 women in each state in our service region (TN: 27.34, VA: 27.39, NC: 25.96) is higher than the national mortality rate (23.61). The mortality rate per 100,000 women in our service region (31.05) is higher than the mortality rate for women in each state and nationally (Thomson Reuters, 2009).

The prevalence rate for our service region (60.3) is higher than the national rate (59.1) and higher than the rate in each state (TN: 59.1, VA: 58.5, NC: 58.9). In our service area, 40.7% of women over 40 were reported as not having had a mammography in the last twelve (12) months (Thomson Reuters, 2009).

Table 4:	Incidence Rate	Mortality Rate	Prevalence Rate
Tennessee	117.2	27.34	59.1
Virginia	119.8	27.39	58.5
North Carolina	124	25.96	58.9
United States	118.69	23.61	59.1
KTC Service Region	114.36	31.05	60.3

While mammography rates have improved in our service region since the 2009 Community Profile Report, there is still progress to be made:

Table 5: Mammography Statistics	
Female Population Age 40+	258,631
Without a Mammogram	40.7%
Chose Not To	7.2%
Didn't Have Time	10.0%
Don't Need	3.6%
Have Scheduled	3.6%
Other Reasons	16.1%

Communities of Interest: What the Data Show

Data reveal a number of disparities for the Black/African-American community with regard to breast health and breast cancer outcomes in our service region.

Table 6: Breast Health Data by Race				
Incidence Rate per 100,000 population		**Mortality Rate per 100,000 population**		
White	115.85	White	31.32	
Black	70.54	Black	30.28	
Breast Cancer Cases by Stage	**1**	**2**	**3**	**4**
White	65.8%	26.7%	3.3%	4.2%
Black	55.3%	30.8%	5.7%	8.1%

While incidence is markedly lower for Black/African-American women, mortality is not proportionately lower. The high mortality rate for Black/African-American women is reflective of significantly later stage diagnosis. These data, local to our service region, are

reflective of national breast health data for the Black/African-American community (SEER, 2005).

Research has not pinpointed a definitive cause for higher breast cancer mortality among Black/African-American women. The National Cancer Institute Black/White Cancer Survival Study (1994) found, "After controlling for geographic site and age, the risk of dying was 2.2 times (95% confidence interval [CI], 1.8 to 2.8) greater for blacks than whites. Adjustment for stage reduced the risk from 2.2 to 1.7; further adjustment for sociodemographic variables had no effect. Treatment was not a contributing factor once stage and tumor pathology were in the model. After adjusting for stage, treatment, comorbid illness, and pathologic and sociodemographic variables, blacks continued to demonstrate a slightly increased, but not statistically significant, risk of death (hazard ratio=1.3; 95% CI, 1.0 to 1.8). Results were similar for all-cause mortality and breast cancer—specific mortality." The study concluded, "Approximately 75% of the racial difference in survival was explained by the prognostic factors studied. Sociodemographic variables appeared to act largely through racial differences in stage at diagnosis, which may be amenable to change through improved access to and use of screening for black women" (JAMA, 1994).

Section Findings

Based on these findings, the community profile team found it imperative to solicit input from key informants in the Black/African-American community to determine how best to address the unique needs of Black/African-American women. In order to eliminate barriers specific to the Black/African-American community, our efforts need to be informed by local experiences and activities must be relevant to the cultural influences impacting the disparity in breast cancer outcomes for Black/African-American women.

Health Systems Analysis

Data Source and Methodology Overview

After extensive analysis of the quantitative information coupled with further exploration of the influence of the Appalachian culture we found there to be an "abundance of generalities." While all counties in the region might be considered rural, the "most rural" with natural access issues had less desirable indicators while the "more populated" counties with better access had only slightly better indicators. State to state variations weren't particularly impacting as much as the degree to which the counties, towns, or regions were geographically and economically challenged.

Because of our geography being mountainous and rural, moving from any one point of service outward one encounters physical and cultural barriers in a relatively short distance. In the end, particular counties or population "pockets" did not float up as definitive target areas for further study. Instead, we chose to focus on the disparity in the breast health data and breast cancer outcomes for the Black/African-American community which showed statistical significance.

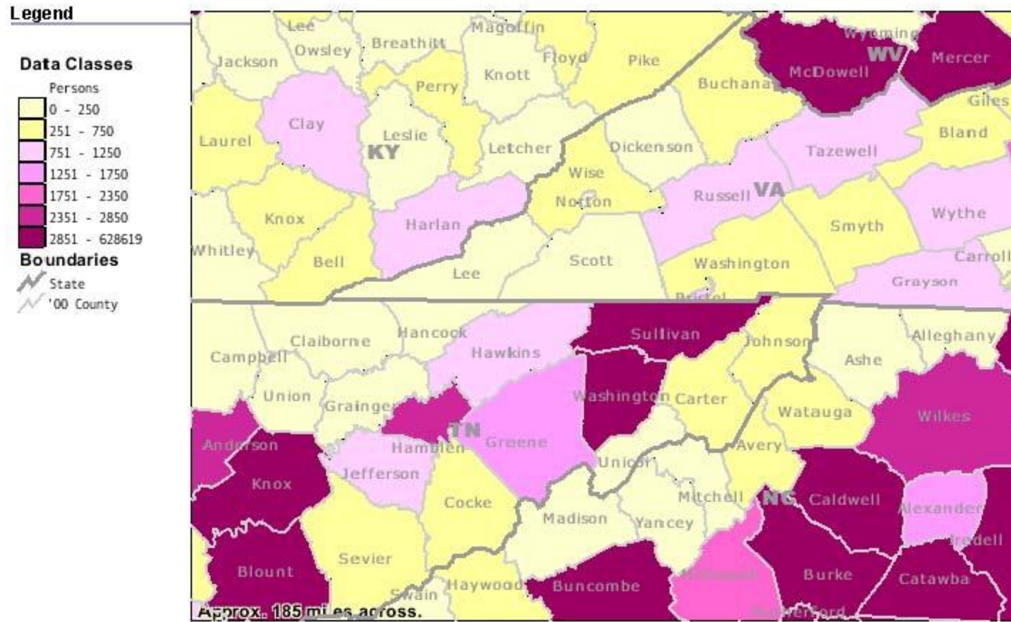
Based on the geographical challenges in our service region and in order to assess access to health systems, we began by identifying where, geographically, our Black/African-American population is located within the service area. Utilizing the American FactFinder mapping utility from the U.S. Census Bureau, we were able to ascertain which counties and communities have the largest population of Black/African-American residents (see Figure 1).

Next, we utilized a similar program to map the various types of breast health resources available in the service region (see Figure 2). These resources were grouped into six (6) categories: Mammography and Diagnostic Centers, County Health Departments, Regional Breast Cancer Treatment Centers, Aftercare Products and Services, Financial and Other Assistance Programs, and Support Groups and Other Local Resources.

It is important to note that this fully interactive map, with descriptions of each resource and links to the resource's website, is available online. The map is being made publicly available via a link on our website and will serve as a valuable resource in itself for women in our service region.

Ultimately, we compared the two maps to determine if issues of geographical access are creating a barrier for Black/African-American women in our service region.

Figure 1: American FactFinder, U.S. Census Map, Persons Who are Black or African-American Alone



Source: U.S. Census Bureau, Census 2000 Summary File 1, Matrix P7.

Figure 2: Google Map, Breast Health Resources in the Komen Tri-Cities Service Region

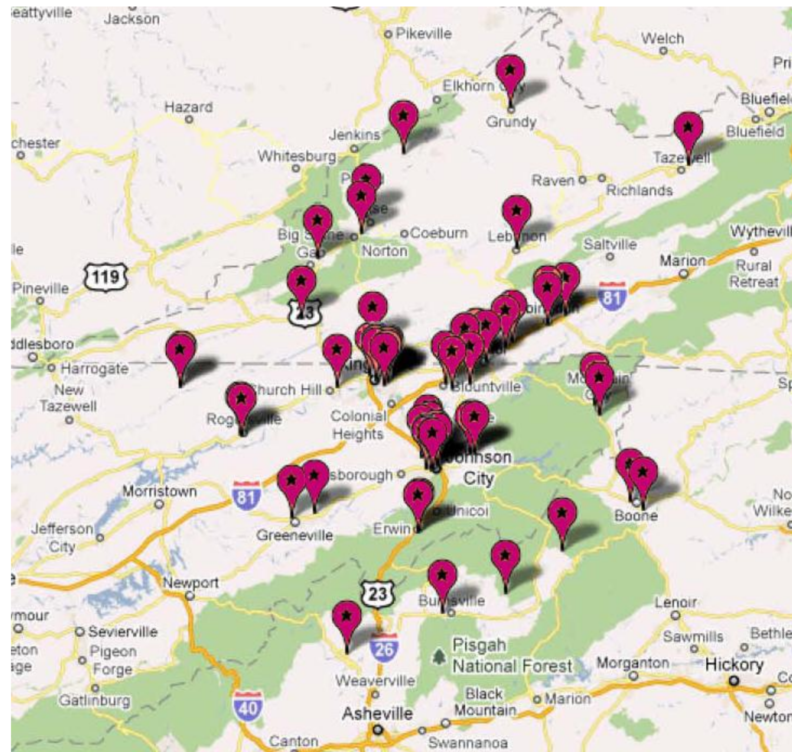


Table 7: Breast Health Assets in the Komen Tri-Cities Service Region

Mammography & Diagnostic	
Holston Valley Medical Center	Wellmont Bristol Regional Medical Center
Lonesome Pine Hospital	Hawkins County Memorial Hospital
Kingsport Hematology-Oncology	Women's Health & Imaging Center
Indian Path Medical Center, Women's Diagnostic Center	Mountain States Health Alliance: Sycamore Shoals Hospital
Johnston Memorial Hospital: Women's Imaging Center	Johnston Memorial Hospital: Bristol East Diagnostic Center
Seasons at Kingsport	Seasons At Bristol
Seasons At Abingdon	Holston Medical Group
East Tennessee State University: Johnson City Downtown Clinic	East Tennessee State University: Mountain City Extended Hours Health Center
Public Health Departments	
ETSU Student Health Services	Carter County Health Department
County of Hancock: Health Dept	Hawkins County Health Department
Greene County Health Department	Johnson County Health Department
Sullivan County Health Department	Unicoi County Health Department
Washington County Health Center	Northeast Tennessee Regional Health Office
Wise County Health Department	Scott County Health Department
Washington County Health Department	Buchanan County Health Department
Dickenson County Health Department	Russell County Health Department
Tazewell County Health Department	Avery County Health Department
Mitchell County Health Department	Yancey County Health Department
Watauga County Health Department	Hot Springs Health Program Inc
Breast Cancer Treatment Centers	
Holston Valley Medical Center	Wellmont Bristol Regional Medical Center
Southwest Virginia Cancer Center	Seby B. Jones Cancer Center
Kingsport Hematology-Oncology	Regional Cancer Center
ETSU Cancer Center	McLeod Cancer & Blood Center of East Tennessee: Hematology-Oncology Associates
Johnston Memorial Cancer Center	
Aftercare Products & Services	
Chic Boutique	Finer Things for Her
Unique Boutique	International Wigs
Jellybeans Wig Boutique	McGlothlin Wig & Hair Replacement Center
Queen Sheba Hair	
Financial & Other Assistance Programs	
Patient Advocate Foundation	Virginia Health Care Foundation
Virginia Breast Cancer Foundation	Cancer Outreach Foundation
Tennsessee Breast Cancer Coalition	Sullivan County Human Services Department
Washington County Social Services	Greene County Human Service Department
Carter County Human Service Department	Hawkins County Human Services Department
Unicoi County Human Service Department	Hancock County Human Services Department

Support Groups & Other Local Resources
Kingsport Hematology-Oncology Support group for high-risk BRCA positive women, meets twice annually. **Holston Valley Medical Center** *Survive and Thrive Support Group* Meets each Tuesday from 6:30 - 8 p.m. in the Oncology Library on the third floor of Wilcox Hall *SISTERS Breast Cancer Support Group of Survive and Thrive* Meets the first Thursday of each month from 6:30 - 8 p.m. at the Wellmont Outpatient Center in Kingsport, TN **Indian Path Medical Center** Breast Cancer Education & Survivorship Support Group Meets the fourth Tuesday of each month from 6:00 - 7 p.m. **Bristol Breast Cancer Support Group** Meets the third Tuesday of each month from 6:30 - 8 p.m.at Euclid Avenue Baptist Church in Bristol, VA

Programs and Services Overview

Recognizing the need for a comprehensive inventory of breast health related assets in our region, not only for the purpose of the community profile study but for the benefit of all of the people in our service area, the Komen Tri-Cities executive director launched an initiative to collect, categorize, and publish a comprehensive asset listing. It is published on www.komentricities.org with prominent visibility, intuitive categorization, extensive linking, and specific contact information. The director and her assistant are able to make changes to the published information at any time and have developed a strategy for periodically testing the information for accuracy.

This asset listing applies to all communities within our service area and any additional assets discovered or developed will be added over time. The internet penetration for the region is actually quite significant, in the 75% range due to several forward-thinking statesmen's efforts to secure funding for high-speed information technology infrastructure to the area's rural counties. To be sure this information is available to everyone in the region who needs it, when it is needed, our strategic plans include efforts to support broader distribution initiatives.

A comparison of the current asset map and the U.S. Census map illustrating the geographical distribution of Black/African-American residents in our service region indicates that both the Black/African-American community and the majority of our breast health assets are clustered in the same areas. The clusters correlate with urban and more densely populated areas. It does not appear that rurality is a major factor creating a barrier to breast health services for the Black/African-American community in our service region.

The Komen Tri-Cities region has thirty (30) FDA registered mammography sites spread throughout the region, many of which are digital units. While most mammography unit managers certainly acknowledge "busy" periods, universally they indicate that they could handle additional capacity. When approached about the issue of women having difficulty scheduling time away from work, especially low-wage earners, mammography unit

managers were generally receptive to extending hours of operation to encourage screenings, but their experience was that this alone did not change behavior.

For many women, lacking insurance or having high deductible costs is a barrier problem and with depressed economic conditions, this is worsening. However, many of the community representatives were generally unaware of BCCCP initiatives in the health departments and of current Komen Tri-Cities grant-funded programs available in their own communities that could help such women. The BCCCP managers did indicate that program funding has been slashed by the states and they fully anticipated running out of support before the end of the year.

Partnerships and Grant Opportunities

As part of the community profile team's strategy, we have been able to develop several new partnerships in the collection and analysis process as well as cultivate some existing ones.

State Comprehensive Cancer Control Coalitions: East Tennessee State University presented an opportunity for Komen Tri-Cities to respond to a request for proposal to the Office of Rural and Community Health & Community Partnerships at ETSU for a Comprehensive Control Program grant to help us defer/defray some of the costs of our focus groups for the 2009 Community Profile Report. This process helped us develop a strategy to cultivate relationships through coalition membership between Komen Tri-Cities and our region's three (3) State Cancer Control Program representatives. This allows us to reinforce each other's efforts to fight cancer and assure that all of our resources are maximized. Each focus group meeting included a presentation from that state's Plan representative, serving to both build awareness and encourage participation. Our effort to relate three different states cancer initiatives was considered unique and our executive director was asked to share her experiences at the Tennessee Coalition's state-wide conference.

Prospective Grantees: By conducting focus groups for each Community Profile Report and by recruiting community-based coordinators to arrange for broad-based focus group participant mixes, we are able to reach some of the most passionate advocates in areas we did not previously have deep involvement. The format of the focus group discussions includes information about Komen Tri-Cities and its grant program. The moderators encourage and coach participants to be catalysts for change by partnering with Komen via the grant programs. In just a short time period we have been able to develop very close ties with some great advocates in some of our communities and we believe this may be a great way to continue building bridges with our communities year by year.

East Tennessee State University: Through the community profile process, Komen Tri-Cites has been able to develop a very close relationship with East Tennessee State University, forged some great friendships, and gained a valuable board member. Our new relationship with the University has provided new contacts that will allow us to reach out to special populations and provide breast health education. This partnership has the potential to generate not only technical assistance relating to community profile compilation and analysis from the School of Public Health, but in deeper understanding

of our region via the Office of Rural and Community Health & Community Partnerships as well as volunteer and educational opportunities relating to their student body.

American Cancer Society: Komen Tri-Cities has enjoyed a strong relationship with our American Cancer Society representatives. Each of our 2009 focus group meetings included representatives from the ACS so they could lend their own expertise and understanding of breast health issues in the region and this has helped deepen our organizational relationships.

Public Health Departments: Several of our current grantees include public health departments within the partnerships. Representatives from each public health district have attended focus group meetings and added to the discussion their knowledge of the issues in the communities. Several 2009 focus groups included an impromptu explanation/promotion of that area's BCCCP and their contributions to the meetings were extremely valuable. The current grant programs relating to the public health departments focus primarily on screenings for women who would normally fall through the cracks for one reason or another and are quite important to the Komen Tri-Cities mission.

Promising Practices and Evidence-Based Programs

The format and strategic participant makeup of our focus groups helps us identify several promising practices from which other communities could benefit. In particular the 2009 group in Avery County, North Carolina seemed to have simple yet easily adaptable ideas. In conjunction with the mammography center at Cannon Memorial Hospital, they offer a program in which transporters go out to pick up women and give them free mammograms. They also have a very nice breast cancer resource center manned by volunteers that offers everything from information and an empathetic ear to wigs when you need them. They also have a very successful Pink Nails day program at the schools in which, after learning about the importance of breast screenings, both boys and girls have their nails painted pink to encourage them to go home and have a discussion with their mothers.

The 2011 focus group participants primarily represented faith-based organizations from the Black/African-American community. Their participation in the focus group opened a dialogue and made a connection with the churches; establishing relationships with these organizations will be invaluable in reaching the Black/African-American community throughout our region.

Public Policy Perspectives

Breast and Cervical Cancer Control Program (BCCCP)

The Tri-Cities Affiliate encompasses communities in three states and interestingly each of those three states have a different option level policy for enrolling women as identified by Susan G. Komen for the Cure. Virginia is Option 1, the most restrictive; North Carolina is Option 2, moderately restrictive; and Tennessee is Option 3, least restrictive as defined in its publication *The State of Breast Cancer*.

KTC has a strong relationship with the Tennessee BCCCP program and state, regional and county health department staff who oversee this program. The relationship has developed over the past five years through our funding of grants to the State of Tennessee Department of Health. The grants seek to target women in Carter, Greene, Hancock, Hawkins, Johnson, Sullivan, Unicoi and Washington counties for breast screening, diagnostic and treatment services that are not covered under other federally funded programs. The focus is on reaching and educating women who have never had a mammogram or have not had one in two or more years. The goal of the project/grant “The BeST for Tennessee Women Project” (FY 09-10) is to reach and serve at least 270 women whose incomes are below 250% of the federal poverty level.

This program has been very successful in helping to increase the number of women who have breast cancer who are diagnosed, thus decreasing the overall mortality rate. For example in the FY08-09 grant, of the 1,231 women screened, 105 received a mammogram for the first time and of these, 40 met the definition for never or rarely screened. Stated a different way, 38.1 percent of the new women met the “never” or “rarely screened” definitions. Of the 1,231 women screened, 412 were referred for diagnostic services and 17 of those were diagnosed with breast cancer.

BCCCP Program State/Regional Directors – TN

Mary Jane Dewey, Program Director/TN Breast and Cervical Screening Program
TN Department of Health
Pat Wheeler, RN, Coordinator, Eastern Regional Office
Becca Wright, RN, Maternal-Child Health Director/Assistant Director of Nursing
Sullivan County Regional Health Department

We also have a strong relationship with the BCCCP program in Virgina. We have funded the Lenowisco and Cumberland Health Districts for the past three (3) years and have recently added the Mt. Rogers Health District. The three districts cover all of our service area in Virginia. These grants augment the BCCCP program, called Every Woman’s Life in Virginia.

BCCCP – VA (Every Woman’s Life) State/Regional Directors

Kathy Rocco, Program Director for Every Woman’s Life (BCCCP)
Virginia Department of Health

Marietta Allen, Project Director Lenowisco Health District
Wise County Health Department
Anna Harris, Project Director, Cumberland Plateau Health District
Sherry Jones, Project Director, Mt. Rogers Health District

To date, the Affiliate has not developed a funding or other type of relationship with counties in North Carolina providing BCCCP services. However, the process to build awareness of our affiliate began in 2009 with Roundtable Meetings in two counties in North Carolina: Mitchell and Watauga. We have begun dialog with regional/state staff and have become involved in the North Carolina Comprehensive Cancer Control Coalition.

BCCCP – NC State/Regional Coordinators
Linda Rascoe, Director, BCCCP Program
North Carolina Department of Health
Pat Cannon Fowler, Regional Coordinator BCCCP/WISEWOMAN/Project

U.S. Elected Officials

The Tri-Cities Affiliate has developed a relationship our region's elected officials over the past four years. We met with each leader or legislative assistant at the Washington D.C. offices to encourage them to support/and or co-sponsor the Kennedy/Hutchison 21st Century Cancer ALERT Act of 2009 and the EARLY Act, which was introduced in the U.S. House of Representatives by Debbie Wasserman Shultz (D-FL), Sue Myrick (R-NC), Donna Christensen (D V.I) and Olympia Snowe (R-ME). This was through our work with the Susan G. Komen Advocacy Alliance and the annual Lobby Day efforts of all Komen affiliates.

In addition, we have a Public Policy Chair as a part of the Tri-Cities Board of Directors. The Chair is responsible for liaison activities between the Komen Advocacy Alliance and elected officials in all three states (North Carolina, Virginia and Tennessee) in counties that fall within the Tri-Cities 23 county service region.

We are planning to work with both US and State Representatives in the coming year by inviting them to participate with us in visits to our Grantees and the annual Tri-Cities Race for the Cure® in Kingsport, Tennessee in October.

Tennessee
US Senator Lamar Alexander
US Senator Bob Corker
US Representative Phil Roe

Virginia
US Senator Mark Warner
US Senator Jim Webb
Maribel Ramos, LA
US Representative Morgan Griffith
Chris Davis, LD

North Carolina
US Representative Virginia Foxx
US Representative Heath Shuler

Programs and Service Findings

The community profile team chose to approach the inventory/analysis of our region's assets in a parallel manner - in conjunction with the exploratory data collection process - rather than sequentially when we were seeking to find gaps. As such, the asset inventory step did not really drive the exploratory step as much as they served as two distinct elements of information from which our final conclusions were drawn. Our exploratory focus group initiative helped to not only reveal assets and gaps in our region but it also helped us better understand how cultural and geographic elements drive the use and perceptions of those assets. We generated a resource inventory focused on the entire region rather than honing in on a particular target region and it will provide an interactive resource for all of the women we serve. Once compiled, the results of the quantitative analysis, asset inventory, and exploratory date were all presented to the Komen Tri-Cities Board of Directors for discussion and overall conclusions were drawn from this culmination of data. Therefore our findings specifically regarding the analysis of services tend to intertwine with the next two sections of this report.

Qualitative Data: Ensuring Community Input in Our Research

Data Sources and Methodology Overview

In 2011, our qualitative data collection focused on the unique needs of the Black/African-American community in our service region. A roundtable discussion was conducted to collect information from breast cancer stakeholders and other key informants from the community. The objective of these discussions was to discover the breast health needs of the community, the factors that limit the fulfillment of those needs and how the barriers can be surmounted. The discussions also helped to explore the priorities of the community in meeting their breast health needs.

In addition to the roundtable discussion, key informants were asked to complete a survey/questionnaire. The survey questions are listed below.

1. What does Susan G. Komen for the Cure mean to you?
2. Who are the most credible people providing breast health information in our community?
3. Where are African-American women in our community most likely to go for breast health information?
4. Who are the women in our community that need breast health messages and services?
5. What do you think are the barriers that prevent women from seeking or getting breast health screening (clinical screening and mammograms) in our community?
6. What can providers do to encourage women to seek breast health services?
7. What can providers do differently in our community to make sure breast health messages and services get to the women that really need them?
8. Tell us about your experience with breast health providers?
9. How could Komen or a Komen partner best get the word out about breast health to African-American women in our community?

Qualitative Data Overview

The roundtable discussion included seven (7) Black/African-American women each representing a separate faith-based organization. Key informants were of a convenience sample from the local African American community. The discussion was organized into three broad topics: barriers to accessing breast cancer services, solutions to those barriers, and priorities among the solutions. The discussion was facilitated and recorded on flip charts by members of the Komen support team. After the discussion, the key responses were assembled according to each discussion question which allowed comparisons of group responses. Major quotes, key points, and themes that emerged were then reviewed.

Roundtable Discussion Results:
Barriers

Many common themes were expressed during the roundtable discussion. Major barriers that were consistently mentioned among the discussions groups included:

1. Uninsured/Underinsured
2. Education/Lack of Knowledge
3. Age
4. Lack of “seriousness” about health
5. Fear of the unknown
6. If it doesn’t hurt, it is not a problem.
7. Transportation
8. Lack of access/medical providers are not located within walking distance of the community
9. Psychological/mental health issues
10. Disbursement of information
11. Not enough emphasis on “at risk” groups
12. Self-esteem issues

Uninsured/Underinsured

Every participant unanimously agreed that financial barriers have a significant impact Black/African-American women’s access to breast health services. Each survey respondent made reference to expense or lack of insurance as a barrier to screening.

Education/Lack of Knowledge

All participants also agreed that a lack of education about or knowledge of breast health facts is a barrier. Common misperceptions in the community were discussed at length. An example of a common misperception was given - ”I don’t have to worry about breast cancer; it doesn’t run in my family.”

Age

Several participants lamented that older women feel they are “too old” to have to worry about breast health.

Lack of “seriousness” about health

Many parallels were drawn during the discussion of this barrier between the Black/African-American person’s denial of breast health realities and realities about

diabetes. One participant noted, “We don’t get diabetes; we get *sugar*.”

Fear of the unknown
Interchangeably, “fear of finding out.” The consensus among the group was that Black/African-American women believe that if something isn’t diagnosed, then it doesn’t exist.

If it doesn’t hurt, it is not a problem
One participant pointed out, and several agreed, that Black/African-American women have the idea that unless something is causing immediate pain and discomfort, then it isn’t serious. This statement led to a general agreement that Black/African-American women do not take their health seriously. As one woman noted, “If we fall off our horse, we just get back on, no matter whether we’ve cracked a few ribs or our skull…”

Transportation/lack of access/medical providers are not located within walking distance of the community
Although most Black/African-American residents live in more urban areas in the service region, transportation was still deemed to be a significant barrier. It was noted that many low-income residents do not own cars and travel only within walking distance of their home; doctors offices, mammography and diagnostic sites, and treatment centers typically are not located within walking distance of the lowest income areas. Participants pointed out that this is particularly problematic for those undergoing treatments that may leave them physically incapable of walking great distances.

Psychological/mental health issues
Participants felt that the Black/African-American community is less accepting of counseling or mental health supports which creates a barrier in that they will not seek counseling when needed and often fail to care for themselves or seek medical treatment for physical issues that are possibly beyond what they are psychologically equipped to handle.

Disbursement of information
Specifically, participants pointed out the need to be cognizant of reading-levels in printed materials and to take in account that not all of the target audience may be literate. Most surveys mentioned this as well, encouraging door-to-door education campaigns and other marketing that can reach a socio-economically and educationally diverse target population.

Not enough emphasis on “at risk” groups
In discussing risk factors in general, participants pointed out that many Black/African-American women think only of family history as a risk factor and fail to recognize that other factors, some of which are more common among Black/African-American women, have also been shown to increase risk. Smoking and overweight were two examples mentioned.

Self-esteem issues
The women in the discussion group were very candid in speaking about self-esteem issues specific to the Black/African-American female community. They expressed worry that some women may undervalue themselves, as a result of very low self-esteem, to the

point that they truly do not care to take care of themselves. They also expressed that particularly older women can be very modest and self-conscious and this may inhibit some women from even conducting self breast exams.

Roundtable Discussion Results: Solutions
After identifying a wide variety of barriers, the group compiled an even longer list of possible solutions:

1. Mobile Mammography
2. Free and Reduced Mammograms
3. Partnerships with the major health care providers for women's services
4. Soliciting parish nurses to assist with access
5. Encouraging churches to share information year round
6. Educational pamphlets – 3rd to 4th grade reading-level
7. Breast models for teaching self-examination and assisting self-conscious women
8. Education: Housing Authority – take education initiatives directly into the target community
9. Age - beginning educating women about breast health when they are younger
10. Mentor/Coach
11. Transportation programs - issuing gas cards or working with public transit to ensure that patients, especially those undergoing treatment, have access to transportation to and from breast health assets and resources in the region
12. SISTER TO SISTER (door to door program) - education initiative
13. Powerful messages – messages must be strong, powerful and culturally relevant
14. Health fairs in the community
15. Communicate information, especially about support groups, in places where the target audience will be exposed (church, corner store, barber shop)

Exploratory Data Findings

The roundtable discussion enumerated a number of issues pertaining to breast health care in which KTC may focus. The roundtable participants identified the following six (6) solutions as having the highest priority:

- Free and Reduced Price Mammography
- Encouraging churches to share information year round
- Education: Housing Authority – take education initiatives directly into the target community
- Transportation programs - issuing gas cards or working with public transit to ensure that patients, especially those undergoing treatment, have access to transportation to and from breast health assets and resources in the region
- Powerful messages – messages must be strong, powerful and culturally relevant
- Health fairs in the community

Conclusions

Target Community Findings

Demographic and Breast Cancer Statistics

From our analysis of the demographic and breast cancer statistics for the Komen Tri-Cities region we determined that overall we have low incidence and high death rates, low screening rates, and high numbers of uninsured when compared to outside the region. The counties that had the most unfavorable figures were those that are rural and/or economically depressed and the majority of our counties fit that classification.

Our analysis did not identify particular counties or population "pockets" to serve as definitive target areas for further study. Instead, we focused our research on the Black/African-American community, which has a lower incidence rate but disproportionately high mortality rate and staging data that indicates that breast cancer is being diagnosed much later in Black/African-American patients.

Programs and Services

A comprehensive database of identifiable breast health related assets for the region was compiled, published, and maintained. Regionally Komen Tri-Cities has many strong relationships with other organizations whose missions overlap with ours. The community profile process has helped develop and/or strengthen those relationships. However, much relationship building is needed in order to reach support "micro-networks" found in the rural areas and diverse communities. We determined that due to cultural dispositions and geographic isolation variables, program and service gaps as well as effective solutions will have to evolve from within the specific communities throughout the service region in order for them to be successful. Our Affiliate must cultivate those solutions through grassroots relationship development efforts rather than attempting to apply any type of comprehensive solutions which would be perceived as derived from "outsiders."

Qualitative Data

A community focus group meeting with key informants from the Black/African-American community was a very effective tool for identifying barriers, solutions, and need prioritization regarding breast health in the community. In addition, the focus group input helped clarify our understanding of cultural influences and allowed us to develop relationships with grassroots advocates in the community. Some of the most prominent barriers discussed were uninsured/underinsured, education/lack of knowledge, age, lack of "seriousness" about health, fear of the unknown, "if it doesn't hurt, it is not a problem," and transportation.

But, even more was gleaned from the deeper dialogue surrounding solutions – like the idea that cultural issues and attitudes can often defeat well-intended initiatives. Women in our region are very strong and self-reliant with tight-knit family and church-associated support networks and we concluded that the true barriers to the women of our region are far from simple or one-dimensional.

Putting the Data Together

The information from the demographic and breast cancer statistical analysis, program and services findings, and exploratory data garnered from the community focus group meeting were presented to representatives of the Komen Tri-Cities board of directors at a special community profile culmination and strategic planning meeting. In addition to the research data, board members were able to add their individual experiences and understanding to the discussion as we sought to understand what all of the collective information was telling us and how we should respond to the needs which were revealed.

Ultimately the overriding conclusion was that **there are disparities in incidence and mortality rates, staging, and breast cancer outcomes for women in our Black/African-American community** and the **barriers** influencing those rates **are multi-dimensional** and **variable**, and **heavily influenced by families, cultural attitudes, and tight social networks**. We believe that if we can move women to have their screening mammograms within standard guidelines, **lives will be saved.**

Selecting Affiliate Priorities

Our primary strategic objective needs to be directed at increasing the number of women receiving screening mammograms and a critical measurement of success for each program we support should be the number of screening mammograms derived from those efforts. In addition, we need to include a focus on improving the quality of lives by mitigating risk factors, improving survival and empowering women to thrive after breast cancer. The programs may address a variety of specific barriers:

- Providing culturally relevant education and awareness
- Building grassroots mobilization in communities
- Mitigating risk factors
- Empowering survivorship
- Addressing the need for low/no-cost screenings
- Increasing awareness of affordable screening programs
- Offering resource awareness initiatives for physician offices
- Addressing access issues in remote regions
- Overcoming fear by incorporating entertainment
- Incorporating social, religious or other culturally relevant elements into screening recruitment initiatives
- Capitalizing on family and social network “peer” pressure to encourage women to seek screenings
- Addressing familial history variables to overcome unsubstantiated concerns
- Focusing upon mammograms while staying aware of the continuity of care through all phases of medical care

Every initiative should have a key objective of raising breast health awareness and improving the quality of women's lives before, during and/or after encountering breast health issues.

Affiliate Action Plan

Our primary goal, stated in our 2009 Community Profile, was to increase the number of screening mammograms performed in our region by 20% in the next 12 months and to meet or exceed Healthy People 2010 objective of increasing the proportion of women aged 40 years and older who have had a mammogram within the past 12 months to 56.9 – 61.0% in all of the counties in our region. Current data indicate that 59.3% of women over age 40 in our service area received a mammogram in the last twelve (12) months. We are still working to make further progress in ensuring that all women over age 40 receive annual mammograms; we believe that expanding our focus to include more community-based and culturally relevant outreach will support attaining our goal.

Our action plan includes:

- Continuing a major communication initiative to promote awareness by:
  - Developing multiple health fair educational/resource units to be permanently placed in area communities.
  - Extending our volunteer network throughout the rural areas to reach more young women and adults.
- Developing a multi-partner awareness collaboration to build awareness around overcoming barriers and increasing screenings throughout the region by:
  - Continually networking throughout our region in hopes of increasing grant applications
  - Purchasing culturally sensitive education and presentation materials.
  - Relationship building with different ethnic groups throughout the region.
  - Attending health fair events specifically aimed at minority groups.
- Establishing a Pink Ambassador in each community to build grassroots mobilization and outreach relationships with community contacts from within every community in our service region by:
  - Holding bi-monthly events for Pink Ambassadors to keep them engaged with Komen.
  - Training the Pink Ambassadors in breast health education & networking methods
- Extending fundraising efforts to all communities in the region through Race for the Cure team building, sponsorships, third-party fundraising, and outright donations by:
  - Holding Komen events in different parts of our region to expand our network base and awareness.

    - Organizing new fundraising events (ex. Volleyball Tournament, Gala, etc.) tailored to different age groups throughout our region.
- Monitoring public policy activities and helping keep public representatives from throughout our region aware of the importance of breast health for our region.
- Building a presence in every community in our region within the next two years by:
    - Establishing key persons in each community to assist in outreach and relationship building
    - Ensuring Komen volunteers become a 'close-knit-family' united together to promote Komen's mission.

Supporting activities that impact the quality of life for women in our service region including those that empower survivorship and mitigate risk factors

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