COMMUNITY PROFILE REPORT

Susan G. Komen for the Cure®
Tri-Cities Affiliate

2009

Acknowledgements

Tri-Cites Komen would like to acknowledge the work of the Community Profile Report Team members:

John Thompson
Brook Lambert
Toni Bounds, PhD.
Grace Ghansah, Graduate Student, ETSU
Cheryl Youland, Executive Director Komen Tri-Cities
Joy Clifton, Administrative Assistant, Komen Tri-Cities

In addition, we would like to also acknowledge the following individuals for their roles in coordinating the community focus group meetings used to collect valuable insight into our communities:

Jennifer Overbay
Kathy Visneski
Rhonda Duncan
Ann Duecing

We would like to offer special recognition to the Comprehensive Cancer Control Plans Implementation in Appalachian Communities Program grant committee for helping fund the community focus group research initiative used in this study.

We would also like to acknowledge the following organizations for their support of the Community Profile team members in their work:

Johnston Memorial Hospital
Wellmont Health System
East Tennessee State University College of Public Health

Table of Contents

Acknowledgements 2
Table of Contents 3
Executive Summary 5
- Introduction 5
- Overview Demographic and Breast Cancer Statistics Key Findings 5
- Overview of Programs and Services Key Findings 6
- Overview of Exploratory Data Key Findings 6
- Narrative of Affiliate Priorities 7
- Affiliate Action Plan 7

Introduction 9
- Affiliate History: 9
- Organizational Structure: 9
- Description of Service Area: 9
- Purpose of Report: 11

Demographic and Breast Cancer Statistics 12
- Data Source and Methodology Overview 12
- Overview of Key Demo & Breast Cancer Statistics at the State Level and County Levels 12
- Counties of Interest: What the Data Shows 13
  - Breast Cancer Incidence and Mortality 13
  - Insurance Status 13
  - Mammography Screening 13
  - Komen Tri-Cities and Appalachia 16
- Demographic and Breast Cancer Findings 18

Programs and Services 19
- Data Source and Methodology Overview 20
- Programs and Services Overview 21
- Partnerships and Grant Opportunities 22
- Promising Practices and Evidence-Based Programs 24
- Public Policy Perspectives 24
- Programs and Service Findings 26

Exploratory Data 27
- Data Sources and Methodology Overview 27
- Exploratory Data Overview 27
- Roundtable Discussion Results 28
  - Transportation to screening and treatment 28
  - Insurance and Cost of Healthcare 28
  - Lack of access to healthcare and healthcare provider 28
  - Fear 29
  - No time; too busy 29
  - Lack of knowledge about available resources 29
  - Culture 29
- Exploratory Data Findings 29

Access to Screening and Treatment ... 30
Comprehensive Breast Health Education ... 30
Access to and Knowledge of Existing Resources ... 30
Conclusions ... 31
Target Area Findings ... 31
Demographic and Breast Cancer Statistics ... 31
Programs and Services ... 31
Exploratory Data ... 31
Putting the Data Together ... 32
Selecting Affiliate Priorities ... 33
Affiliate Action Plan ... 33
Mammography Screening ... 33
Community Partnerships ... 34
Existing Grant Solutions ... 34
Needed Grant Opportunities ... 35
Fund Raising ... 35
Public Policy Efforts ... 35
Education and Outreach ... 36
References ... 37

Executive Summary

Introduction

The Komen Tri-Cities (KTC) Affiliate was officially formed in October, 2005 thanks to a cooperative effort between the two major competing health care providers in the region, Mountain States Health Alliance (MSHA) and Wellmont Health System (WHS). The cooperative spirit which helped form Komen Tri-Cities then continues today and will ensure our success in this region for years to come.

The service area for the Komen Tri-Cities Affiliate covers 22 contiguous counties 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 closely located cities: 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 897,278 people, with approximately 200,000 being women 40 years or older and 180,000 50 years or older. The racial distribution for females is 97.5% White, 1.3% Black/African American, 0.6% 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. Approximately 24% of the female population is uninsured and the median household income is $ $35,129.

There are a total of 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 cancer treatment centers. County health departments serve each of the counties in the region as well as 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.

Overview of Demographic and Breast Cancer Statistics - Key Findings

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 Thomsen Reuters and various other sources utilizing direct interpretation methodolgy, it was found that:

- Overall the KTC's regional breast cancer incidence rates are lower (115.89) and mortality rates (29.15) are higher than the states (Incidence: TN-109.30, NC-115.80, VA-121.10; Mortality: TN-25.70, NC-25.60, VA-25.40) rates and the U.S. rates (Incidence: 117.60 Mortality: 24.33).
- The rate of women without health insurance in the KTC Region is higher (23.6) compared to their counterparts in other parts of the states (TN-15.0, NC-19.0; VA-14.0) and the rest of the U.S (18.0).
- Mammography screening is low (59.2%) for the KTC Region compared to the overall screening rates in the three states and the U.S.

- All 22 KTC counties are part of the Appalachian region and all 22 counties in the KTC Region are classified as Distressed, At-risk or Transitional

The counties in our region which had the most unfavorable figures were those which 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. 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.

Overview of Programs and Services - Key Findings

The Community Profile Report serves as a periodic re-examination of our service area in order to assure that we maintain an in-depth understanding of the needs and gaps existing in our region. This, in turn, helps direct the allocation of grant, operating, and volunteer resources. 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 searching for gaps. The profile team discovered that providing a comprehensive asset analysis for this community profile would be extremely difficult for two reasons. First, no particular county or population stood out as especially problematic during the quantitative phase, so a focused effort on a small number of counties would require a rather random selection process. Second, the geography and culture of our region makes finding and defining access to particular assets a nebulous task. However, 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. Regionally, Komen Tri-Cities has many strong relationships with other organizations whose missions overlap. As part of the community profile team's strategy, we have been able to develop several new partnerships as well as cultivate some existing ones, including State Comprehensive Cancer Control Coalitions, prospective grantees, East Tennessee State University, American Cancer Society, and Public Health Departments serving the region. However, much relationship building is needed in order to reach support "micro-networks" found in the rural areas and the numerous community pockets which make up those areas. 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 rural counties 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."

Overview of Exploratory Data Key Findings

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 does provide 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 with purposive sampling and note-taking documentation 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.

Narrative of Affiliate Priorities

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 with an emphasis on all component of breast self-awareness, *lives will be saved.* Our primary strategic objective needs to be directed at increasing the number of women receiving screening mammograms. A critical measurement of success for each program we support should be the number of screening mammograms derived from those efforts or equivalent. Non-provider based programs may be measured utilizing surveys and other indirect evaluation methods. The programs may address a variety of specific barriers:

- 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
- social, or religious 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

However every initiative should have a *key objective of increasing the number of women who receive screening mammograms* within the recommended timeframe.

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 is to increase the number of screening mammograms performed in our region by 10% in the next two years 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 2 years to 70% in all of the counties in our region.

Our action plan includes:

- Implementing a major communication initiative to promote this strategic objective
- Development of a multi-partner awareness collaboration to build awareness around overcoming barriers and increase screenings throughout the region
- Using metrics relating to capacity to increase screening rates when evaluating programs and resource allocations
- Encouraging and supporting grassroots initiatives designed to increase screenings
- Establishing outreach relationships with community contacts from within every county in our service region
- Extending fundraising efforts to all counties in the region through Race for the Cure team building, sponsorships, third-party fundraising, and outright donations
- Monitoring public policy activities and help keep public representatives from throughout our region aware of the impact on breast health for our region
- Build a presence in every county in our region within the next two years.

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 15 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:

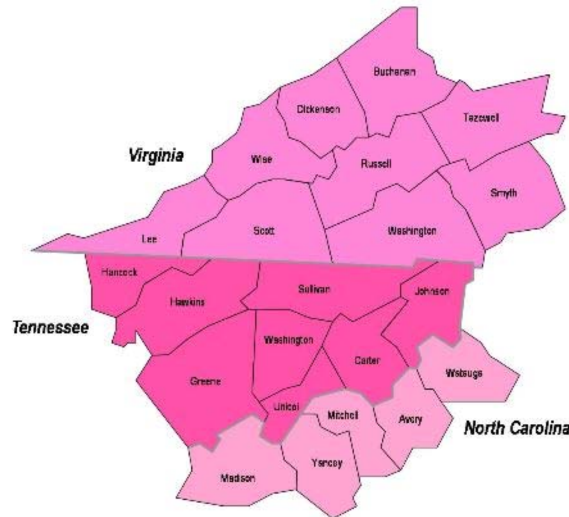
Komen Tri-Cities is led by a diverse 15 member volunteer Board of Directors representing the major regional health organizations, private companies, businesses, survivors, activists, volunteers and oncology health professionals in the region. Komen Tri-Cities is managed by a full-time Executive Director, Cheryl Youland and a part-time Administrative Assistant. 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.

Description of Service Area:

The service area for the Tri-Cities Affiliate of the Susan G. Komen for the Cure® covers 22 counties 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 272,539 (US Census 2008 estimate). 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.

This service area encompasses 22 counties in the region which includes the following counties:

Tennessee: Carter, Greene, Hancock, Hawkins, Johnson, Sullivan, Unicoi, Washington
Virginia: Buchanan, Dickenson, Lee, Russell, Scott, Smyth, Tazewell, Washington, Wise
North Carolina: Avery, Madison, Mitchell, Watauga, Yancey



The Tri-Cities Tennessee-Virginia region is an area of natural beauty and rich in history. The region takes it name from the presence of three closely located cities: 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 Knoxville, this region is unique because of its location in the mountains of the Blue Ridge and Appalachian chains.

Unlike Knoxville, Roanoke and Asheville, which are the closest metropolitan areas, the Greater Tri-Cities Region has a medical college at East Tennessee State University, Quillen College of Medicine, which creates a distinct medical community, patient relationships and service relationships. Instead of patients leaving the region to gain specialized care, patients come to the Tri-Cities to receive specialized acute services. For the 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 one of the largest industrial employers in the state, Eastman Chemical Company. In the other metropolitan areas the economies are driven by a different mix of industry and smaller-sized employers.

Johnson City is home for 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 System include the College of Public Health and the Gatton College of Pharmacy. From these beginnings, Johnson City has become the medical and education center of the area. Kingsport has attracted several industries such as Eastman Chemical Company, Domtar Paper Company, and AFG Corporation. The success of these early manufacturers created an atmosphere that resulted in the attraction of industry to Northeast Tennessee. With employers of this magnitude, 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 Jonesborough, the oldest town in Tennessee and home of the International Storytelling Center. Many other small towns are located in the area and are considered a valuable part of the Tri-Cities TN-VA region. As a result of the collaborative nature of their citizens, Tri-Cities TN-VA was the first region to be designated as an "All-America City" by the National Civic League.

The affiliate recognizes this is a geographically expansive area which is largely rural and may take many years to grow an organization that is able to fully address the needs of this 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 health needs. The affiliate realizes, however, that the participation of and service to outlying counties requires careful planning and attention to ensure that each organization serving these counties is included and has access to funding.

Purpose of Report

The Community Profile Report serves as a periodic re-examination of our service area in order to assure that we maintain an in-depth understanding of the needs and gaps existing in our region. This, in turn, helps direct the allocation of grant, operating, and volunteer resources. The information gleaned from 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.

Demographic and Breast Cancer Statistics

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 was 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 is working on a doctoral degree in Public Health and would work under the supervision of Dr. Bounds.

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 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. These data were evaluated for each county in the KTC Region to determine which of the counties would be chosen for additional assessment. From this process, six counties were chosen for further assessment; and by way of community roundtable discussions, qualitative data were gathered from local communities to enhance the quantitative data. The objective was to better understand community opinions on breast cancer issues in the KTC Region.

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

There are similarities as well as differences in breast cancer incidence and mortality trends and rates at the state level and among counties within the three KTC states. Breast cancer is the most common cancer among women, and the second leading cause of cancer death among women in the three states which is similar to U.S. Compared to other states in the U.S., the incidence rate of breast cancer for the State of Tennessee falls within the top 25 of the U.S. states. Virginia and North Carolina had relatively lower incidence rates. In 2005, 4,838 Virginia women were diagnosed with breast cancer and the age-adjusted incidence rate was 115.6 per 100,000 population; lower than the U.S. rate of 117.7 per 100,000. With 4,130 new cases diagnosed in 2005, the age-adjusted incidence rate in Tennessee was 120.7 per 100,000; higher than U.S. rate.

With approximately 7,000 new cases of breast cancer each year in North Carolina, the age-adjusted incidence rate for 2001-2005 was 120.3 per 100,000; lower than U.S. rate of 123.0 per 100,000 for that period (CDC, 2008).

Incidence rates for all three KTC states are higher among white women than black women, yet the mortality rate is higher among black women than white women (CDC, 2008). This variance is likely associated with lower screening rates and cultural influences. This trend is also true among states and counties within the U.S. Generally, the county level data for KTC Region show low incidence and high death rates compared to national and state rates (Thomsen Reuters, 2007).

The death rates are higher for each of the states compared to other states in the U.S. Breast cancer death rates for Tennessee and Virginia are among the highest within the U.S. and North Carolina's rates falls within the top 25 of the U.S. rates (CDC, 2008). In Virginia, 5,370 women died of breast cancer from 2001 to 2005, which is approximately 1,000 deaths per year. There are approximately 900 breast cancer deaths per year in Tennessee and approximately 1,200 breast cancer deaths each year in North Carolina. Virginia's age-adjusted, breast cancer death rate for 2001-2005 was 26.5 per 100,000. For the same period, Tennessee's rate was 26.2 per 100,000, and North Carolina's death rate for 2005 was 25.4 per 100,000. These rates are higher than the U.S. rate of 25 .0 per 100,000 for 2005 (CDC, 2008).

Counties of Interest: What the Data Show

Breast Cancer Incidence and Mortality

When assessing the data provided by Thomsen Reuters (2007) (Tables 1-3), the KTC's 2007 regional breast cancer incidence rate (115.89 per100,000) was lower than the U.S. (117.60 per 100,000) and the state of Virginia (121.10 per100,000) rates. However, the regional rate was equivalent to the rate of the state of North Carolina (115.80 per 100,000) and was higher than the state of Tennessee rate (109.30 per 100,000). Twelve of the 22 KTC counties had higher incidence rates than their state, the region, and the U.S. Sixteen counties had higher incidence rates than their state.

Tables 1-3 shows mortality data from Thomsen Reuters (2007). The mortality rate for the KTC region was 29.15 per 100,000 and was higher than both the U.S. rate of 24.33 per 100,000 and all three states: Virginia, 25.40 per 100,000; Tennessee, 25.70 per 100,000; North Carolina, 25.60 per 100,000. Eighteen of the KTC counties had higher mortality rates than their state.

Insurance Status

The rate of women without health insurance in the KTC Region is higher compared to their states and the rest of the U.S. (Kaiser Foundation, 2007) For the years 2005- 2006, the percentages of females 18-64 years who were uninsured was 18% for the U.S, 14% for Virginia, 15% for Tennessee, and 19% for North Carolina (Kaiser Foundation, 2007). For the KTC counties the percent uninsured females 18-64 years in 2007 was estimated to range from 17.2% to 43.5%, while the overall KTC average was 23.6% (Thomsen Reuters, 2007).

Mammography Screening

The Healthy People 2010 objective for mammography screening is to increase the proportion of women aged 40 years and older who have had a mammogram within the past 2 years to 70 % by 2010. (Healthy People 2010) Thomson Reuters mammography screening data estimates that the women in the KTC counties are below the Healthy People 2010 objective when it comes to obtaining their mammograms. (Tables 1-3) (Thomson Reuters, 2007) These data estimate that the percent of women with no mammogram within the last year ranged between 39.1% -42.7%. (Thomson Reuters, 2007)

Table 1: **KTC-VIRGINIA COUNTIES 2007**

COUNTIES	INCIDENCE	MORTALITY	%UNINSURED FEMALES (18-64)	% NO MAMMO LAST 12 MONTHS
Buchanan	130.53	39.10	43.5	42.2
Dickenson	129.67	33.88	43.5	42.7
Lee	121.60	29.26	42.5	41.7
Russell	119.76	23.69	31.9	41.5
Scott	135.13	33.67	29.2	40.8
Smyth	129.10	34.95	24.2	40.5
Tazewell	141.44	32.82	30.4	41.5
Washington	120.68	30.68	22.0	40.3
Wise	126.19	30.75	35.6	42.6
Total (KTC)	**115.89**	**29.15**	**23.6**	**40.8**
Virginia	**121.10**	**25.40**	**14.0***	
U.S.	**117.60**	**24.33**	**18.0***	

Source: Healthcare Business of Thomson Reuters © 2007. Rates are per 100,000
*Kaiser Foundation, 2007

Table 1 indicates that overall, the nine KTC Virginia counties have higher breast cancer incidence and mortality rates than the KTC region, the state of Virginia and the U.S. Also, women 18-64 years old in these counties are uninsured at a higher proportion than women in the region, the state and the U.S. In addition, overall, the percent of women who have not had a mammogram in the past 12 months exceeds that of the KTC region and also the Health People 2010 extrapolation of 30% (70% of women who have had a mammogram within 24 months). (Healthy People 2010).

Table 2: **KTC-TENNESSEE COUNTIES 2007**

COUNTIES	INCIDENCE	MORTALITY	% UNINSURED FEMALES 18-64	% NO MAMMO LAST 12 MONTHS
Carter	105.27	30.46	21.6	42.1
Greene	125.43	28.36	17.2	41.0
Hancock	111.04	26.30	32.5	42.5
Hawkins	111.74	31.19	19.1	42.2
Johnson	111.57	27.73	23.2	42.4
Sullivan	105.33	28.83	17.2	39.1
Unicoi	117.40	39.96	14.9	41.3
Washington	98.74	24.34	17.6	39.4
Total (KTC)	**115.89**	**29.15**	**23.6**	**40.8**
Tennessee	**109.30**	**25.70**	**15.0***	
U.S.	**117.60**	**24.33**	**18.0***	

Source: Healthcare Business of Thomson Reuters © 2007. Rates are per 100,000
* Kaiser Foundation, 2007

In Table 2, overall, the breast cancer incidence rates for the eight KTC Tennessee counties are higher when compared to the state of Tennessee rate but they are lower when compared to the KTC region and the U.S. rates. The mortality rates are also higher, with seven of the nine county mortality rates higher than the state and the U.S. rates. Women 18-64 years old in these Tennessee counties are uninsured at a higher proportion than women in the state and the U.S. but the county proportions are lower than that of the KTC region. Also, the overall percent of women who have not had a mammogram in the past 12 months exceeds that of the KTC region and also the Health People 2010 extrapolation of 30% (70% of women who have had a mammogram within 24 months). (Healthy People 2010).

Table 3: **KTC-NORTH CAROLINA COUNTIES 2007**

COUNTIES	INCIDENCE	MORTALITY	% UNINSURED FEMALES (18- 64)	% NOMAMMO LAST 12 MONTHS
Avery	128.81	20.37	26.0	42.2
Madison	123.19	35.94	24.4	41.8
Mitchell	128.48	30.22	22.3	40.5
Watauga	109.53	18.50	27.6	40.7
Yancey	126.56	33.95	23.0	41.2
Total (KTC)	**115.89**	**29.15**	**23.6**	**40.8**
North Carolina	**115.80**	**25.60**	**19.0***	
U.S.	**117.60**	**24.33**	**18.0***	

Source: Healthcare Business of Thomson Reuters © 2007. Rates are per 100,000
* Kaiser Foundation, 2007

Table 3 shows that four of the five KTC North Carolina KTC counties have higher breast cancer incidence rates than the KTC region, the state of North Carolina and the U.S. Three of the five counties have higher mortality rates than the region, the state and the U.S. Women 18-64 years old in these counties are uninsured at a higher proportion than women in the region, the state and the U.S. In addition, overall, the percent of women who have not had a mammogram in the past 12 months exceeds that of the KTC region and also the Health People 2010 extrapolation of 30% (70% of women who have had a mammogram within 24 months). (Healthy People 2010).

Komen Tri-Cities and Appalachia

All 22 KTC counties are part of the Appalachian region. (ARC 2009) This region is characterized by many geographically isolated counties. There is also history of shortage of health care professionals, limited access to cancer care and long distance 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 ARC uses a county economic classification system to target counties in need of special economic assistance. (ARC 2009) 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 22 counties in the KTC Region are classified as Distressed, At-risk or Transitional. (Table 4) 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. (ARC 2009)

Table 4 shows the economic status designations for Komen Tri-Cities counties from 2004 to 2009.

Table 4: **Economic Status Designations for Komen Tri-Cities Counties**

Designation	2004	2005	2006	2007	2008	2009
Distressed	Hancock (TN) Johnson (TN) Dickenson (VA) Buchanan (VA) Wise (VA)	Hancock (TN) Johnson (TN) Dickenson (VA) Buchanan (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		Yancey (NC) Russell (VA)	Buchanan (VA) Lee (VA) Smyth (VA) Wise (VA) Mitchell (NC) Yancey (NC)			
Transitional		Wise (VA)	Avery (NC) Watauga (NC) Carter (TN) Hawkins(TN) Sullivan(TN) Washington(TN) Russell (VA) Scott (VA) Tazewell (VA) Washington (VA) Unicoi (TN) Greene (TN) Madison (NC)			

Source: h

Demographic and Breast Cancer Findings

Overall the data indicate that the KTC Region is lacking in terms of breast cancer incidence and death rates, insurance status, and mammography screening. When comparing counties to the KTC region:

- 18 counties had higher incidence
- 14 counties had higher mortality
- 12 counties had higher % uninsured females
- 15 counties had higher % no mammograms within last 12 months
- All counties were ARC transitional, at risk or distressed counties

The KTC counties were ranked (Table 5) to determine the top 10 counties for highest Incidence, Mortality, % Uninsured and % No Mammogram. Table 5 shows that when the counties were ranked without respect to state, Virginia counties were over-represented. If we used this method to select counties for additional assessment, Tennessee and North Carolina counties would be under-represented.

Table 5: **Overall County Ranking for Incidence, Mortality, % Uninsured (18-64) and % No Mammogram in Last 12 Months**

Rank	INCIDENCE	MORTALITY	% UNINSURED FEMALES (18-64)	% NO MAMMO LAST 12 MONTHS
1	Tazewell V	Unicoi T	Buchanan V	Dickenson V
2	Scott V	Buchanan V	Dickenson V	Wise V
3	Buchanan V	Madison N	Lee V	Hancock T
4	Dickenson V	Smyth V	Wise V	Johnson T
5	Smyth V	Yancey N	Hancock T	Hawkins T
6	Avery N	Dickenson V	Russell V	Avery N
7	Mitchell N	Scott V	Tazewell V	Buchanan N
8	Yancey N	Tazewell V	Scott V	Carter T
9	Wise V	Hawkins T	Watauga N	Madison N
10	Greene T	Wise V	Avery N	Lee V

Source: Healthcare Business of Thomson Reuters © 2007

Ranking the top two counties for each state by Incidence, Mortality, % Uninsured, % No Mammogram and ARC Designation, Table 6 shows that five Virginia counties, five Tennessee counties and five North Carolina counties are possible selections for additional assessment. These criteria, and the availability of local community resources to conduct focus groups, the Research Team chose two counties from each state. The Team decided to choose one county that was less populated or "rural" and one county that was more populated or "less rural." The

counties chosen for further assessment were Wise and Washington Counties in Virginia, Hawkins and Sullivan Counties in Tennessee and Avery and Madison Counties in North Carolina.

Table 6: KTC Counties by State and Selection Criteria for Community Discussions

State	Incidence Rates	Death Rates	% uninsured females (18-64)	% no mammogram last 12 months	ARC Economic Status Designation
VA	Tazewell	Buchanan	Dickenson	Dickenson	Dickenson
VA	Scott	Smyth	Buchanan	Buchanan	Buchanan
TN	Greene	Unicoi	Hancock	Hancock	Hancock
TN	Unicoi	Hawkins	Johnson	Johnson	Johnson
NC	Avery	Madison	Watauga	Avery	Yancey
NC	Mitchell	Yancey	Avery	Madison	Mitchell

Sources: Thomsen Reuters (Incidence rates, death rates, percent no mammogram, percent uninsured), ARC (Economic Status Designation)

Programs and Services

Data Source and Methodology Overview

After extensive analysis of the qualitative 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.

We decided to begin weaving several objectives together into a comprehensive plan of attack. Acknowledging the fact that we have three states represented in our service area and that each state does provide differing portfolio of services due to how they each manage public health departments, Medicare/Medicaid, outreach resources, etc., we divided our counties by state. Then we acknowledged the fact that "ruralness" was a major factor, and subdivided our counties into "rural" and "more populated." From there we decided to target one representative "rural" and "more populated" county from each of the three states. In the end, these counties were chosen: Wise and Washington Counties in Virginia, Hawkins and Sullivan Counties in Tennessee, and Madison and Avery Counties in North Carolina. These six representative counties were to be studied via community focus groups to dig deep into the factors influencing breast health. An added objective was to begin developing relationships with each of the states' Comprehensive Cancer Control initiatives both to capitalize on their understanding of cancer issues and to assure that both of our organizations strategic plans complement each other.

Finally, a third objective layered on the others to develop relationships with passionate stakeholders in each of the counties in order to spur creative solutions and future Komen grant applicants.

Programs and Services Overview

The profile team discovered that a comprehensive asset analysis for this community profile would be extremely difficult for two reasons. First, no particular county or population stood out as especially problematic during the quantitative phase, so a focused effort on a small number of counties would require a rather random selection process. Yet previous and current research of our region indicates that lack of knowledge/awareness of available resources in the region is a universal problem for all of our counties. Second, the geography and culture of our region makes finding and defining access to particular assets a nebulous task. Our "mountain people" rely closely on extended family and tight church relationships for support, so while those types of assets exist, they are not easily inventoried. Likewise most people, accustomed to journeying distances on mountain roads to the larger cities for a variety of needs, don't necessarily equate the lack of an asset in their particular county to be the same as lack of that asset altogether. But on the other hand residents are also just as likely to consider an asset a relatively short distance away as being external to their perceived local area.

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 counties 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.

Several references to specific gaps are discussed further in the Exploratory Data section which follows. But the community profile team found much difficulty in pinpointing gaps which were directly and specifically related to inadequate assets.

- Transportation is an issue in almost any rural county in the country. However, that issue is clouded in our region due to the fact that every region offers access to some type of public transportation, but because their routes are so large and disbursed the passenger often must spend the entire day traveling. Family and church often provide transportation but financial assistance/gas money for these supporters is either unknown – the ACS program is available but underutilized - or the request must be driven from within the small rural communities.
- Access to screening equipment was discussed in several focus groups. The Komen Tri-Cities region has 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. Actual access to the units is again plagued with issues relating to the rural topography – even a unit only 20 miles away can take an hour of travel in many of our rural settings. This, in turn causes problems relating to time off work, cost, lack of free time, etc. and lead to less utilization. Mammography unit managers were generally receptive to extended operation hours to encourage screenings, but their experience was that this alone did not change behavior. Mobile units were suggested by some participants, but discouraged by some technicians.

- Women lacking insurance or high deductible costs were referenced as problems 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 which 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. This process helped us develop a strategy to cultivate relationships through coalition membership between Komen Tri-Cities and our region's three 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 we had included a presentation from that state's Plan representative, serving to both build

awareness and encourage participation. Our particular 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 in several of our more rural, outlying counties and by recruiting local group coordinators to arrange for broad-based focus group participant mixes, we were 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 included information about Komen Tri-Cities and its grant program. The moderators encouraged and coached participants to be catalysts for change by partnering with Komen via the grant programs. In just a short time period we were able to develop very close ties with some great advocates in some of our counties and we believe this may be a great way to continue building bridges with our counties 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 new board member. Our new relationship with the University has provided new contacts that will allow us to reach out to the Latino population 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 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 were able to attend the focus group meeting and lend to the discussion their knowledge of the issues in the communities. Several 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 screens/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.

Focus groups discussions also revealed two key organizations that KTC would like to establish partnerships with in order to further our cause.

- **Mountain Laurel Cancer Coalition:** This is a work group of the VA Comprehensive Cancer program who focuses on improving the state of cancer in portions of Southwest Virginia. It is based out of Wise County, VA and consists of individuals who are passionate about fighting cancer from healthcare organizations, churches, universities, advocacy programs, senior centers, the community at large, etc. This group works to implement strategies from the state's Comprehensive Cancer Control Plan designed to improve the state of cancer in the region, and ultimately across the state. By establish

membership in this organization, KTC can become engaged in these activities while also sharing Komen goals, strategies, education, etc with the group.

- **Churches:** Multiple times during our focus groups discussions, participants said they often rely on their pastor and/or church family for medical information and counseling. In response to this feedback, KTC will seek to establish relationships/partnerships with the religious leaders throughout our services area particularly within the rural counties where our focus groups were conducted. This could be accomplished by reaching out to local ministerial associations. By making these contacts, we hope to provide religion leaders with information related to best breast care practices in hopes that the info will reach congregations. For example, over the past two years, KTC has worked with several local predominately African-American churches, conducting education seminars, recruited volunteers for general fundraising and race participation. As a result of these relationships, we are anticipating their submission of one or more grant proposals for the upcoming grant cycle.

Promising Practices and Evidence-Based Programs

The format and strategic participant makeup of our focus groups helped us identify several promising practices for which other communities could benefit. In particular the 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 and which 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.

Public Policy Perspectives

Breast and Cervical Cancer Control Program (BCCCP)

The Tri-Cities Affiliate encompasses counties 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 state, regional and county health department staff who oversees this program. The relationship has developed over the past three years through our funding of grants to the State of TN 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 woman 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 who are below the 250% federal poverty level.

This program has been very successful in helping to increase the number of women who have breast cancer, 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 screen 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 3 years and have recently added the Mt. Rogers Health District. The three districts cover all of our service area in VA. 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 this year with Roundtable Meetings in two counties in NC: Mitchell and Watauga. We have begun dialog with regional/state staff and have become involved in the NC 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 two years. Recently, 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 (NC, VA & TN) in counties that fall within the Tri-Cities 22 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, TN 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 Rick Boucher
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.

Exploratory Data

Data Sources and Methodology Overview

Roundtable discussions were conducted to collect information from Breast Cancer stakeholders and other key informants from the community. We used a focus group methodology with purposive sampling and note-taking documentation 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 discover 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. Communities were chosen within the selected six counties to represent the Komen Tri-Cities (KTC) region.

Table 6: Roundtable Discussions: Communities, Number of Participants and Dates

County	Community	Number of Participants	Session Date (2009)
Wise	Big Stone Gap	14	Jan 14
Washington	Abingdon	13	Jan 15
Hawkins	Rogersville	11	Jan 21
Sullivan	Blountville	15	Jan 22
Madison	Marshall	13	Feb 10
Avery	Linville	16	Feb 11

Exploratory Data Overview

There were 82 participants in the six roundtable discussions consisting of breast cancer survivors, representatives from state cancer registries and state cancer control programs, American Cancer Society, local health departments, and other community-based organizations that fund or provide breast cancer services.
The discussions were organized into three broad topics: barriers to accessing breast cancer services, solutions to those barriers, and priorities among the solutions. The discussions were facilitated and recorded on flip charts by members of the Komen support team. After the discussions, 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

There were many common themes expressed across the six community discussion groups. Major themes that were consistently mentioned among the discussions groups included:

Transportation to screening and treatment

Lack of transportation support to screening and treatment facilities was a priority issue among participants. They mentioned that women are required to travel long distances to get mammograms or for treatment after positive diagnosis, as there are no local mammography units or treatment centers in most of these counties. Additionally, many people do not have any or limited means of transportation.

> "One study has shown that 55% of Madison County residents over 55 years do not own cars" said one participant from Madison County, NC.

In counties where there are transportation systems in place, the system does not work as well as women need it to and using the services is often very arduous.

> "We use their services to get free rides to screening and treatment appointments but we all have different schedules so sometimes it can take the whole day just to go to one appointment."

Insurance and Cost of Healthcare

Participants expressed concern about the lack of insurance coverage and the high cost of healthcare for women. Many women in these communities are uninsured or under-insured. If they are insured, they are unable to afford the high insurance deductibles. These issues keep women from routinely seeing a health care provider or getting screened. In addition, those who do not have adequate insurance prefer not to know whether or not they have breast cancer because if they are diagnosed with cancer, they cannot afford the cost of treatment.

Lack of access to healthcare and healthcare provider

Many participants expressed concern about the limited number of health care providers in their area.

> "We have fifteen physicians and two nurse practitioners in the whole county; and there is no hospital."
>
> "We used to have a mobile unit but they stopped coming. When we asked, the reason they gave was that there was no oncologist to travel with it due to the schedule."
>
> "It depends on where you live in this county. Most people go to Asheville (NC) or Greenville (TN) for care."

Fear

Fear hinders some women from getting mammograms. According to the participants, women fear having a mammogram because it might hurt. Also, they fear they might receive a positive breast cancer diagnosis and they fear not being able to afford treatment if they do receive a positive diagnosis. Fear keeps them immobile.

> "Women never get over the fear after diagnosis."

No time; too busy

Lack of time was also mentioned by participants as a barrier to seeking breast health care. Breast health care is often not considered an urgent issue. Many women therefore tend to put off getting mammograms. The lack of time coupled with transportation issues impact negatively on the need to seek breast health care. Long travel time also conflicts with the need for women to work to support their families.

> "Some people simply cannot afford to take time off to go for screening. They would rather work to put food on the table than worry about breast health care."
>
> "Sometimes they have to go for treatments three times a week and that is just impossible for some people."
>
> "Some people are afraid to travel long distances or bother others for rides to appointments."

Lack of knowledge about available resources

There is a general lack of knowledge among participants about available breast health resources and services in the communities. Many participants did not know where to go for breast cancer services. Others were not aware of the Breast and Cervical Cancer Early Detection Program in the county health department which provides free mammograms to low-income, uninsured women. Familiarity with breast cancer programs and services tended to increase with the availability of health care providers and other breast cancer services in the discussion group areas. Avery County had a strong support/resources system; therefore, women from Avery County were more likely to have heard about the Breast and Cervical Cancer Early Detection program than women living in other counties with fewer resources.

Culture

Culture determines how cancer care is accessed; some aspects of the Appalachian culture do not encourage women to seek health care.

> "Appalachians do not talk openly about their issues, health issues are thought to be private affairs"
>
> "Madison County has four different cultures…four different mind sets…"

Capitalizing on the good parts of the Appalachian culture, for example through volunteerism, can expand breast health service provision in the communities.

> "People here are down to earth; they are ready to give their souls to help anybody who needs it"

Other issues that were discussed included lack of support groups, misinformation about breast health issues, denial, discomfort, lack of patient education by physicians, and lack of primary care providers' education about mammography guidelines.

Exploratory Data Findings

The six roundtable discussions enumerated a number of issues pertaining to breast health care in which KTC may focus. From the community discussions in all six communities, the following emerged as issues that could be addressed by funding from KTC.

Access to Screening and Treatment

Most Appalachian communities are rural and therefore access to screening and treatment is very difficult. Lack of transportation, public or private, makes it seemingly impossible for women to receive mammograms and/or treatment. Most screening and treatment facilities are located long distances away in larger urban areas and are out of reach for those living in smaller rural areas. Many of the women either do not have an automobile, or do not have relatives/friends to provide transportation, or do not have access to public transportation. Even if transportation is provided, many women in rural Appalachia are uninsured or under-insured and need financial assistance to pay for a mammogram or treatment. Providing free or low-cost mammograms and locating satellite treatment clinics within the local communities would provide access.

Comprehensive Breast Health Education

Providing comprehensive breast health education to women, the community, healthcare providers and physicians will reduce fear and misconceptions about breast cancer, improve breast cancer awareness and increase mammography screening rates. In addition, community events that allow survivors to tell their stories can help put a face on breast cancer and educate women about how others have gone through the process of screening and/or treatment. Other possibilities include education through the school system, the churches, and community centers. Also, education of physicians and other health care providers with attached incentives to include continuing medical education credit would be helpful.

Access to and Knowledge of Existing Resources

Despite the fact that programs exist to assist low-income, uninsured, or underinsured women in receiving breast cancer screening and treatment services, many women lack knowledge and awareness of them. Increased awareness related to programs that provide support to women who need access to existing resources would provide a mechanism of support for screening, treatment, patient navigator services, etc. Supporting community storytelling events would also provide information about available resources in local communities. Also, existing services could be expanded to provide additional outreach to the community.

Future Analysis

Because our analysis revealed that the rural counties in our coverage area tend to have increased incidents of cancer, few screenings, and increased mortality rates, we plan to hone in on these localities during our next Community Profile update to further examine the barrier to breast care. Possible strategies to accomplish this included conducting multiple focus groups and exploring disparities related to race, ethnicity, social economic status, etc.

Conclusions

Target Area 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 which had the most unfavorable figures were those which 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. A high-level summation of these statistics indicate that low screening rates may drive unfavorable incident/incidence and death rates and the lack of insurance or financial resources is contributing to the low screening rates.

Programs and Services

Our programs and services inventory analysis was tailored to address factors such as the identified target area was very large, and asset identification for a given rural community was nebulous. 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 and the community profile process 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 the numerous community pockets which make up those areas. 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 rural counties 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."

Exploratory Data

Community focus group meetings representing rural and more populated counties in each of the three states comprising our region were a very effective tool for identifying barriers, solutions, and need prioritization regarding breast health in the representative communities. In addition, the focus group input helped clarify our understanding of cultural influences and allowed us to develop relationships with grassroots advocates in the communities as well as Cancer Control Plan leaders from the states. Some of the most prominent barriers discussed were insurance, transportations, 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.

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 **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.**

Our primary strategic objective needs to be directed at increasing the number of women receiving screening mammograms and internalizing breast self awareness. A critical measurement of success for each program we support should be the number of screening mammograms derived from those efforts, or equivalent. Non-provider based programs may be measured utilizing surveys and other indirect evaluation methods. The programs may address a variety of specific barriers

- 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, social, or religious 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.

However, *every initiative* should have increasing the number of women who have received a screening mammogram within the recommended timeframe *as a key objective*.

A multi-year strategic focus on screening mammograms should be reflected in an increase in the raw number of screening mammograms in this area as well as increase the Behavioral Risk Factor Surveillance System statistics reported earlier in this profile and Healthy People 2010 objectives should be met or exceeded for the region. This strategy is supported by the Comprehensive Control Plan objectives relating to breast cancer in all three states. However, the Affiliate's leadership does recognize that some current grantees and future grant applicants could be subject to decreased prioritization or outright decline with such a marked change in strategy. But we feel that by having a clear and concise strategy, capitalizing on our strong capacity for communicating what types of initiatives we are seeking, cultivating our relationships with our outlying communities, supporting grassroots ideas with networking and grant-writing training,

and having a unified belief that this strategy will save lives, we will overcome any initial pushback.

Selecting Affiliate Priorities

Our strategic priority is to increase the number of women who have received a screening mammogram within their recommended timeframe among women in our region - a simple and clear directive. The way we plan to achieve this objective, however, is going to be more organic and flexible. We seek to embrace the cultural mindset of our women which is rooted in their strength and self-reliance but with the added challenge of stepping up to overcome resistance to obtaining mammograms. The initiatives which will work to overcome barriers in the depths of our region must begin from within the tight family and social networks in which they live, not from any broad-based, far-reaching initiatives from the outside, in order to truly break through the barriers. This strategy will require a lot of small ideas and initiatives to be implemented in each micro-community rather than a few broad-scope initiatives; though larger scale ideas would also be supported. We seek to encourage our health care providers to develop programs which will help reduce financial hardships which can stand in the way of women seeking the mammograms they know they need, whether it is through low- or no-cost programs, modified business hours for working women, or awareness initiatives targeting these women. Rather than dictating specific solutions, we want to encourage creative, grassroots initiatives derived from passionate volunteers who want to make a difference by empowering them with the support needed to be successful. Many of our action plans, therefore, must revolve around pulling solutions out of our region rather than pushing solutions into the region. The Affiliate recognizes that the Grants Process will need to focus on screening; however, we recognize that this can take many shapes, not just granting service providers for screens. The needs of the region include the need to educate the populace on the criticality of early screens, to motivate them to get the screens, and to remove existing barriers (childcare, transportation, accessibility, affordability). The Board feels strongly that we must change the profile of the region prior to the next data review/community profile.

Affiliate Action Plan

Mammography Screening

Goal:
Our primary goal is to increase the number of screening mammograms performed in our region by 10% in the next two years 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 2 years to 70% in all of the counties in our region. The Board recognizes that this is an ambitious goal but after much debate agreed that it is doable if all mission efforts (education, outreach, grants, etc) focus on screening. Certainly the women of our 22 county service area should be at the national average within 5 years.

Actions:

- Establish baseline screening measurements for prior two years.
- Deliberately evaluate/measure all major initiatives by its expected capacity to increase screening rates.

- Communicate strategic plan to concentrate resources on increasing screening rates to all of the Affiliate's major stakeholders within first quarter.
- Develop and implement a strategy to build awareness around overcoming barriers and increase screenings throughout the region.
- Encourage and support grassroots initiatives designed to increase screenings through relationship development, sharing of best practice ideas, and timely communication - targeting at least one such initiatives in each county throughout the region.

Community Partnerships

Goal:
Partnerships are a key element to impacting the geographically expansive area which we serve with our limited resources. One goal is for our Affiliate to initiate a multi-partner awareness collaboration which drives awareness initiatives to every corner of our region.
Actions:

- Develop a concise targeted message.
- Seek supportive partners to develop awareness initiatives.
- Execute awareness campaign.

Goal:
Another goal is for our Affiliate to become integrated with the Cancer Control Plan organizations in each of the states, resulting in an extensive partnership network throughout the region and access to additional resources as opportunities arise.
Actions:

- Affiliate becomes supporting member of each organization.
- Affiliate representatives join communication network for coalitions and monitor activities on a continual basis.
- Coalition representatives in the region should be invited to make presentations to Affiliate Board of Directors annually.

Goal:
Another important goal is to establish new and grow existing outreach relationships with community contacts from within every county in our service region.
Actions:

- Review volunteer and team captain lists to identify existing contacts in strategic geographic locations.
- Contact these individuals with communications regarding Affiliate strategic plans and objectives.
- Consider developing an ad hoc outreach committee to further identify, cultivate, and support community partners.

Existing Grant Solutions

Goal:
Our current slate of funded grant programs all support a strategy of intense concentration on increasing mammograms. However, all current grantees will be included in our communication plan to inform our stakeholders of our strategic direction. This change may affect the design of their programs or applications. Our next grant cycle information will be revised to reflect a strategic emphasis on increasing mammography rates including specific metrics associated with the application and status reports.

Actions:

- Update all grant-related communication devices.
- Communicate changes with existing grantees.
- Integrate grant program with communication and outreach efforts described previously.

Needed Grant Opportunities

Goal:
Efforts to cultivate grassroots initiatives and develop partnerships throughout our region will increase the number of grant applicants in our region. However, with the emphasis on smaller solutions within specific communities and targeting women within tighter circles, many of the programs are expected to have relatively low funding request amounts.
Actions:
Integrate grant information into other outreach and communication initiatives.

- Offer grant writing workshop for new grantees.
- Help connect supportive non-profits and grant writing assistance from regional universities with motivated individuals and small groups who want to submit a funding proposal

Fund Raising

Goal:
Making deliberate efforts to expand our relationships to include every county in the region and encouraging grassroots initiatives will likely increase the total funds recommended by the grant committee for funding. This will increase the demand for fundraising in order to succeed in supporting these additional initiatives. However, by the same token, relationships developed through solution-driven connections should bring with them fundraising opportunities both through the Race for the Cure teams and sponsorships as well as supporting donations to the Affiliate.
Actions:

- Integrate fundraising/Race information into other outreach and communication initiatives.
- Leverage focus group participant and community outreach contacts by encouraging team recruitment and sponsor recommendations.
- Target some of the prominent coal industry-related companies in the rural Virginia counties for fundraising and team recruitment.

Public Policy Efforts

Goal:
Having three separate states within our region makes keeping on top of state-level policy challenging, but also allows us connection to several key leaders on the federal level. Some important public policy concerns affecting our strategic initiatives are state funding for mammograms and women's health programs. Decreased funding for screening mammogram programs administered through the public health departments will have an offsetting effect on increasing mammography screenings as women fall behind due to lack of funding. Our goal is to monitor public policy activities and help keep public representatives from throughout our region aware of the impact on/of breast health for our region.
Actions:

- Maintain vigilance of women's health funding activities.
- Mobilize supporters, stakeholders, and partners to help enact positive change.

Education and Outreach

Goal:
Education and outreach efforts are crucial to fulfilling our strategic objectives. Our goal regarding education is to maximize our volunteer educators by carefully choosing educational opportunities which support our strategic effort to increase mammogram screening rates throughout the region. We would like to have an educational presence in 80% of our counties within the next two years.
Actions:

- Integrate educational efforts with communication and outreach initiatives.
- Leverage grant, outreach, and new program relationships to create educational opportunities. Support small group initiatives with educational materials.

Goal:
Many of our outreach efforts were discussed in the partnership development section, but an additional outreach initiative goal is for Komen to become the first place women look to find local breast cancer resources and information.
Actions:

- Encourage and support grassroots initiatives designed to provide resources information to physician groups.
- Develop resource data sheets which can be provided to offices.
- Include references to www.komentricities.org in all communication initiatives.

References

Appalachian Regional Commission: Appalachian Region Economic Overview: http://www.arc.gov/index

Cancer Control P.L.A.N.E.T. Screening Risk Factors Report: http://cancercontrolplanet.cancer.gov/breast_cancer.html

Cancer Control P.L.A.N.E.T. Breast Cancer Incidence Map: http://cancercontrolplanet.cancer.gov/breast_cancer.html

Cancer Control P.L.A.N.E.T. Breast Cancer Mortality Map: http://cancercontrolplanet.cancer.gov/breast_cancer.html

Centers for Disease Control and Prevention (CDC). *Behavioral Risk Factor Surveillance System Survey Data.* Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2008. http://www.cdc.gov/BRFSS/

Hall, H.I., Uhler, R.J., Coughlin, S.S., and Miller, D.S. (2002). Breast and cervical cancer screening among Appalachian women. *Cancer Epidemiol Biomarkers Prev* pp.137-42

Healthcare Business of Thomson Reuters © 2007, Komen Tri-Cities Demographic and Breast Cancer Data [Data File].

Healthy People 2010 (2000). Objective 3-13: http://www.healthypeople.gov/Data/midcourse/comments/faobjective.asp?id=3&subid=13

Lengerich, E.J., Wyatt, S.W., Rubio, A., Beaulieu, J.E., Coyne, C.A., Fleisher, L. et al (2004). The Appalachia Cancer Network: cancer control research among a rural, medically underserved population. *Rural Health*. Spring;20(2):181-7.

National Cancer Institute: State Cancer Profiles (2005) Death Rate/Trend Comparison by Cancer, death years through 2005 US States versus US Breast All Races, Female: http://statecancerprofiles.cancer.gov/cgi-bin/quickprofiles/profile. pl?00&055

National Cancer Institute: Surveillance Epidemiology and End Results (2005): http://seer.cancer.gov/statistics/atlas.html

North Carolina Central Cancer Registry: www.schs.state.nc.us/SCHS/CCR

North Carolina Comprehensive Cancer Program: http://www.nccancer.com/

State of Tennessee Comprehensive Cancer Control Plan 2009-2012: http://health.state.tn.us/CCCP/TCCC_Plan.pdf

Tennessee Cancer Registry: http://health.state.tn.us/TCR

Tennessee Comprehensive Cancer Control Coalition: http://health.state.tn.us/cccp/index.htm

The Henry J Kaiser Family Foundation (December, 2007). Women's health policy facts: Health Insurance Coverage of Women Ages 18 to 64, by State, 2005-2006: http://www.kff.org/womenshealth/upload/1613_07.pdf

U.S. Cancer Statistics Working Group. *U.S. Cancer Statistics: 1999–2005 Incidence and Mortality Web-based Report*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2009: www.cdc.gov/uscs.

U.S. Census Bureau: 2008 Population Estimates Retrieved December 2008 from http://factfinder.census.gov/servlet/ThematicMapFramesetServlet?_bm=y&-geo_id=01000US&-tm_name=PEP_2008_EST_M00090&-ds_name=PEP_2008_EST&-_MapEvent=displayBy&-_dBy=040&-_lang=en&-_sse=on

Virginia Department of Health Cancer Plan 2008: http://www.vahealth.org/cdpc/cancerprevention/

Virginia Cancer Registry: http://www.vahealth.org/cdpc/cancerregistry

Wingo, P.A., Howe, H.L., Thun, M.J., Ballard-Barbash, R., Ward, E., Brown M.L., et al (2005). A national framework for cancer surveillance in the United States. Cancer Causes Control.pp.151–170.