COMMUNITY PROFILE REPORT

Susan G. Komen for the Cure®
NC Triangle Affiliate

2011

Disclaimer

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

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I. Executive Summary

A. Introduction

This report is the fifth edition of the Susan G. Komen for the Cure, NC Triangle Affiliate's bi-annual community assessment. Each edition of this report has built upon prior quantitative and qualitative data and has expanded both the topics covered and the level of data analysis.

The NC Triangle Affiliate of Susan G. Komen for the Cure was founded in 1997 and incorporated in 2000 when the first board of directors identified a service area encompassing 13 counties around the Research Triangle region of North Carolina. In 15 years, the Komen NC Triangle Affiliate ("Affiliate") has raised more than $12 million dollars through events like the Komen NC Triangle Race for the Cure®, individual donations and corporate philanthropy. Beginning in 2009, the Affiliate embarked on a multi-year expansion effort; six counties were added prior to the 2011-2012 Community Health Grants Cycle, and a seventh was added early in calendar year 2011. This Community Profile includes data from 20 counties.

For the 2011 grant cycle the Affiliate has invested in 18 community projects totaling $1 million, providing financial assistance for breast health services to underserved women and men and funding everything from mammograms to mastectomies, patient navigation and outreach. Additionally, the Affiliate invests heavily in community mobilizing and provider capacity-building activities, including networking events, workshops and site visits that focus on several key principles: program development, program evaluation, evidence-based strategies, continuum of care, cultural competency and collaboration among organizations.

The Affiliate hosts the largest 5K Race in the Carolinas and is managing two national Komen grants: The "Edgecombe County & 'Area L' Breast Cancer Initiative" is a multi-year effort focused on reducing breast health disparities in a 5-county region, and the "Latino/Hispanic Community Advisory Group: A Plan for NC Triangle and Beyond" project is funded by a grant from the Yoplait Fondo Para la Mujer and focuses on building a targeted community action plan.

The purpose of the 2011 Community Profile is to provide current and comprehensive information on the status of breast health, breast cancer and delivery of related services within the Affiliate's 20 counties and in adjacent regions that interact with these counties. This assessment establishes a framework for further assessment that will be taking place on an ongoing basis through the Affiliate. By continuing to learn about the regions, counties, towns and individuals in our service area, we remain focused on outcomes and impact that support our vision of a world without breast cancer.

B. Statistics and Demographic Review

The Komen NC Triangle Affiliate's 20-county service area is diverse demographically and geographically, comprised of metropolitan areas, suburbs, small towns and rural communities. The Affiliate area currently covers roughly 1,304 square miles and has total population of just

under 2.5 million, with great variation across counties from the smallest, Warren County with a population of approximately 19,000 people, to Wake County with about 890,000 people.
The quantitative data in this report come from federal, state and local sources, and the qualitative findings represent diverse perspectives from within the Affiliate service area. This study includes:

- breast health program and service inventories and mapping,
- key informant interviews to explore community, provider, survivor and patient experiences,
- socio-economic, geographic and racial/ethnic demographics,
- the epidemiology of breast cancer at the Affiliate, state and national levels,
- summary of needs related to breast health services,
- identification of gaps between needs and resources,
- focused study of communities with unique challenges.

1. Key Demographics

Key demographic characteristics of the service area include:

- The median income is $42,579 compared to the state at $46,574 and national average which is $52,029; however, median household income ranges from $28,351 in Warren County to $64,527 in Wake.
- Educational attainment is similar to state and national figures; however this varies widely by region. In Northampton, Halifax, and Vance Counties a high percentage of the population didn’t graduate from high school, where as Wake, Durham and Orange have particularly high percentages of PhDs.
- The Hispanic /Latino population in NC has grown 300% in 10 years.
- Minority populations range from a low of 25% in Moore County to a over 60% in Edgecombe County.
- While the service area has several regions that are classified as metropolitan, it also has many “micropolitan” and rural areas with unique public health challenges.

2. Key Statistics

Key breast cancer statistics include:

- The female breast cancer incidence rates for counties in the Affiliate service area are higher than both the North Carolina and national rates.
- Three rural counties, Edgecombe, Halifax and Northampton, have the highest breast cancer mortality rates within the service area.
- White women experience higher incidence rates of breast cancer, but minority women have higher mortality rates from the disease in every county except Lee and Moore.
- Almost 40% of women age 40 and older in the service area had not received a mammogram in the last 12 months—regardless of insurance status.
- The presence, or lack thereof, of Breast and Cervical Cancer Control Program (BCCCP) funded services in a community appears to have no correlation to mammography rates.

C. Health Systems Analysis

This community profile takes an in-depth look into the status of breast health programs in one specific cluster of communities in the southwestern region of the service area: Lee, Moore,

Chatham, Scotland and Harnett Counties. This region is home to some of the poorest citizens in the state and one of the wealthiest golf/retirement destination communities (Pinehurst). County hospitals and local healthcare providers compete with the massive University of North Carolina Hospitals and Duke Medicine systems located just an hour away. Each of these counties has at least one public transportation system, hospitals and clinics offer transportation services, yet key informant discussions pointed to a lack of awareness about these and other important support services for patients both pre- and post-diagnosis.

D. Qualitative Data Overview

Qualitative data collection involved interviews with providers and focus groups with county residents, including several survivors and current breast cancer patients. Primary themes that emerged included:

- access, cost and distance of transportation to treatment,
- challenges for non-English speakers,
- screening and treatment resources,
- financial burden of treatment and prescription for all residents,
- importance of having a breast health navigator.

E. Conclusions

The Komen NC Triangle Affiliate has annual set goals that focus on maximizing the impact and outcomes of our mission program. The data gathered and reported here will add a new layer of focus to our mission investment strategies. As we learn more about our service area, and as we continue to expand our service area over the next few years, the complexity of issues demands almost continual study. This community assessment has also introduced new questions that we must address in order to continue building excellence in mission delivery.

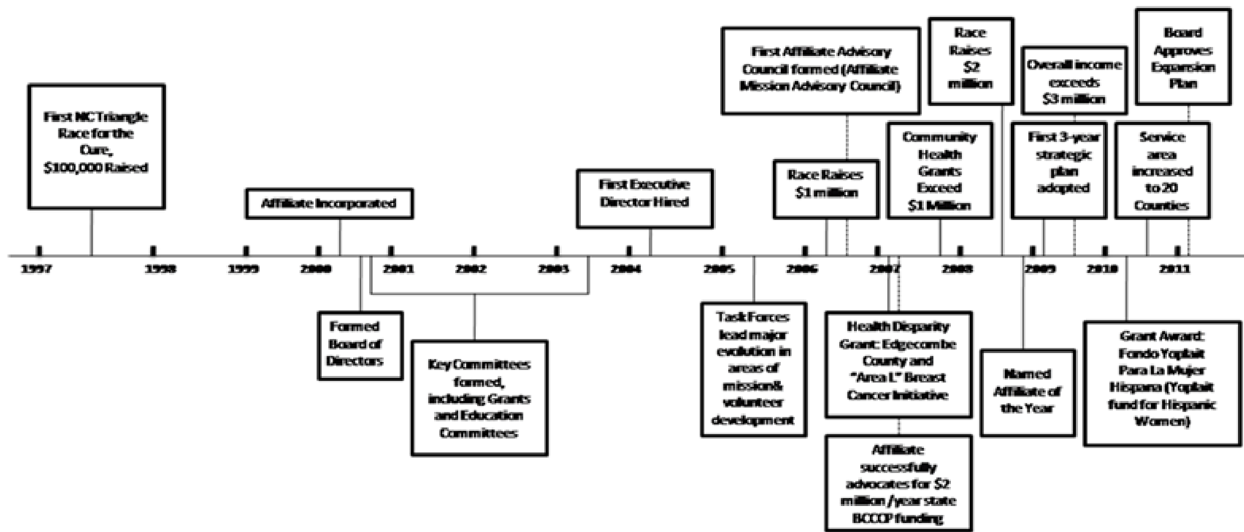
The Affiliate's action plan based on this 2011 Community Profile will be a multi-faceted investment in the mission activities that we do best: community assessment, community health grant funding, community mobilizing activities and provider education and support. The plan will focus on target areas identified by this community assessment, including access issues, financial and social support for patients and language barriers. The plan will also create processes and infrastructure that will support ongoing community assessment and responsive, community-based activity to address challenges in a targeted way, and not with generic solutions.

II. Introduction

A. Affiliate History

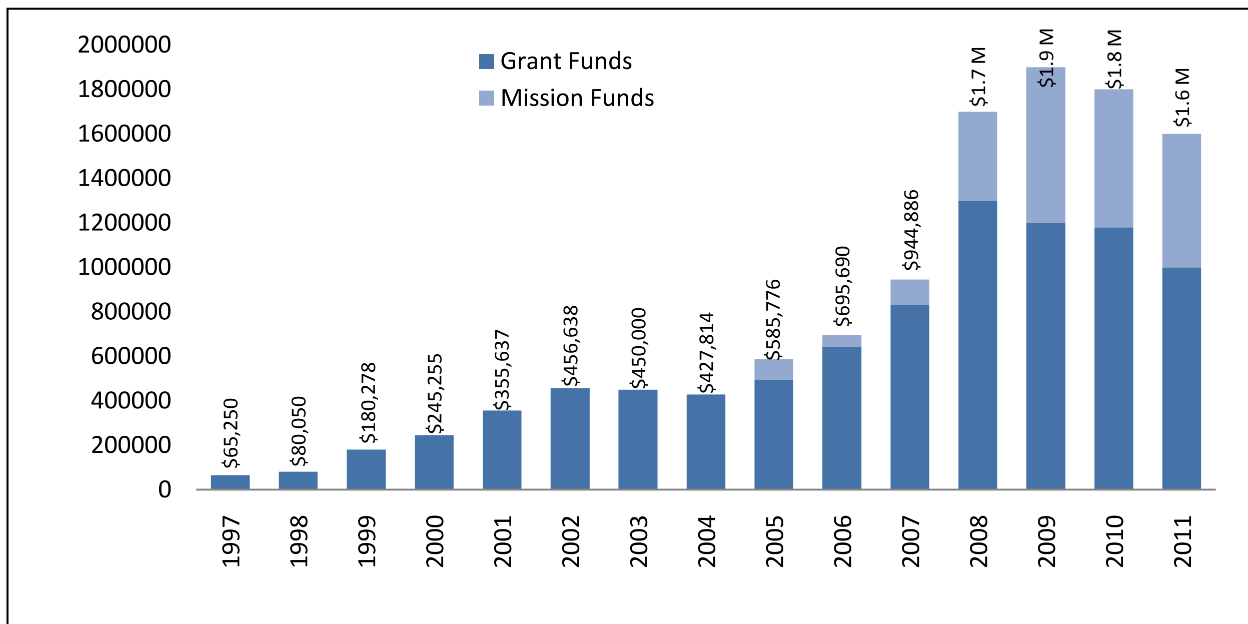
Having recently celebrated its 15th Anniversary, the Komen NC Triangle Affiliate has created a culture focused on bringing the Komen mission to as many individuals in North Carolina as possible (*Figure 1*).

Figure 1: Timeline of NC Triangle Affiliate History 1996-2010



In 1996, the Susan G. Komen Breast Cancer Foundation granted the right to host a Race for the Cure® in Raleigh, North Carolina, and the late Jeanne Peck gathered a few friends to organize the first Komen NC Triangle Race for the Cure. Twenty-five hundred individuals raised about $100,000 at that Race on June 10, 1997; by contrast, the 2011 Race raised close to $2 million and attracted about 25,000 participants. By diversifying income sources in recent years, the Affiliate has raised the annual mission investment to between $1.5 and 1.9 million (*Figure 2*).

Figure 2: NC Triangle Affiliate Community Health Grant & Mission Funding 1997-2011



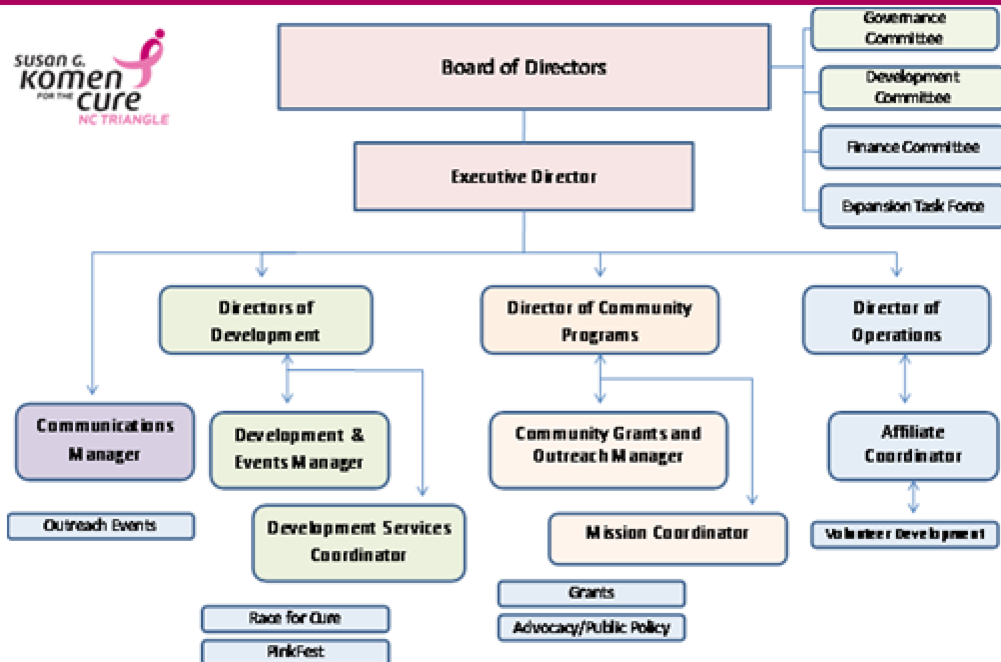
In 2000, the NC Triangle Affiliate board of directors incorporated the organization and opted to reduce the service area from more than 50 counties to a more manageable 13 counties. Once the first executive director was hired in 2004, staff size began to grow by one or two key positions a year to its current size of eight full-time and three part time employees, including experts in development, volunteer management and community health programs (*Figure 3*).

The Affiliate has been awarded two national Komen grants. The "Edgecombe County & 'Area L' Breast Cancer Initiative" is a multi-year effort focused on reducing breast health disparities in a five-county region, and the project is in Phase III after several years of community mobilizing and literature review work. The "Latino/Hispanic Community Advisory Group: A Plan for NC Triangle and Beyond" is funded by a grant from the Yoplait Fondo Para la Mujer and will build on previous Affiliate work with Hispanic and Latino leaders focused on creating a targeted community action plan. These funds are not included in totals shown in Figure 2.

In 2008, the Affiliate was recognized as the Komen National Affiliate of the year as a result a focused effort to maximize the impact of mission spending, Affiliate-facilitated community mobilizing and provider capacity building, and organizational development designed to create a strong staff and volunteer network. Rankings of 125 Komen Affiliates in 2009 placed the NC Triangle Affiliate 20th based on overall income and investment in mission programs.

The NC Triangle Affiliate has begun a strategic expansion that will, ultimately, allow us to serve more than 3 million individuals from the current Triangle region to the coast of North Carolina. To prepare for this expansion, the Affiliate will invest in ongoing community assessments, with multiple goals each year focusing on current and future counties. Hence, this Community Profile has, by design, become a working, ever-changing body of research that will help to guide our mission priorities, expansion strategies and organizational development.

Figure 3: NC Triangle Affiliate Organizational Chart



B. Organizational Structure

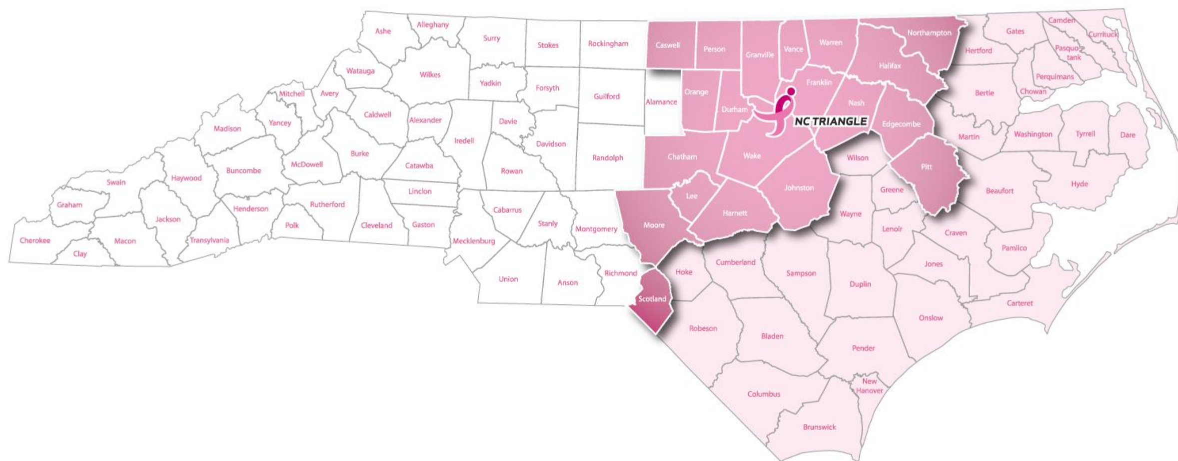
The evolution, growth and vision of the Affiliate are evident both in the structure of the organization (*Figure 3*) and in the mutually-dependent roles and responsibilities of staff and volunteer leaders. A high-level, strategic and diverse Board of Directors includes senior executives, breast cancer survivors, advocates, medical practitioners, service providers and community leaders. The staff is led by the executive director whose primary role is to work with Affiliate leadership, volunteers, partners, constituents and stakeholders to operationalize the vision as articulated by the Board. Staff directors and managers have expertise in public health, development, communications, program development and organizational operations. And as staff roles have evolved, volunteer and committee roles have become more strategic: advising and consulting on fundraising, communications, fiscal management, organizational development and strategic growth.

C. Description of Service Area

1. Counties

The Affiliate service area has changed several times over 15 years. Ironically, current expansion goals aim to bring the service area back to its 1997 size: 53 counties. Deemed too large when the Affiliate was incorporated in 2000, the Affiliate reduced to 13 counties from 2000-2010.

Figure 4: Map of NC Triangle Affiliate Service Area and Prospective Expansion Area



In 2010, the Affiliate created a strategic plan that includes a 3- to 5-year goal to expand the service area to 53 counties (*Figure 4*). The first expansion counties were added during 2010, bringing the total to 20 (dark pink in *Figure 4*). These include Pitt County, home of East Carolina University and University Health Systems which serves much of the prospective new region. The Affiliate is planning carefully for a growth in infrastructure, staff, development and volunteer capacity to responsibly support the additional mission burden in these new counties.

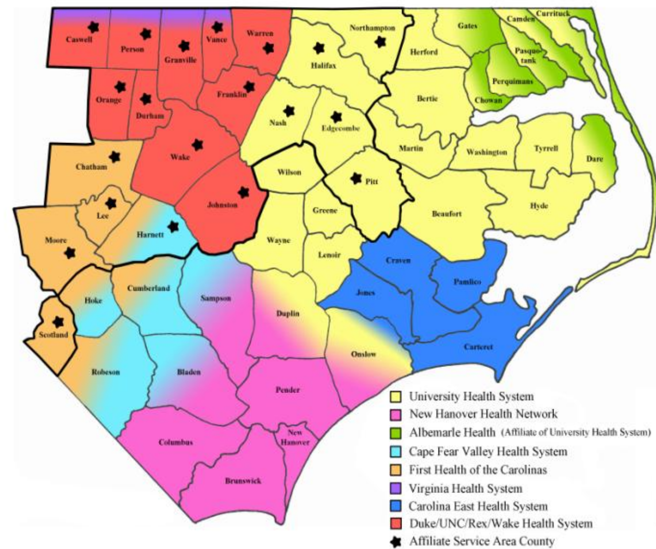
2. Health Care Systems

Previous Affiliate Community Profiles explored referral patterns among care providers and revealed that the Affiliate's original 13-county service area created challenges for maximizing the impact of grant-funded programs in a few specific counties. The original 13 counties actually included portions of three different healthcare systems, but not an entire system (see Figure 5).

Hence, certain counties (Warren, for example) were unable to benefit from either direct grants or partnerships on Affiliate grants. The first new counties added by the Affiliate in 2010 were targeted to round out a few of the health systems, thereby immediately offering grant award opportunities for existing grantees to serve these individuals who were already in their own service areas and for providers in these new counties to apply for funds.

Between the 2009 and 2011 Community Profiles, the Affiliate commissioned additional research into the referral patterns in the eastern half of North Carolina, and the results appear as Figure 5. The health systems vary in size, depth and breadth of services, but future modeling of Affiliate growth, funding and mission activity will be designed with these regions as a backdrop to maximize the impact of Community Health Grants, partnerships and community mobilizing activities (*Figure 5*).

Figure 5: Health Systems in Affiliate Service Area and Prospective Expansion Area (* indicates current service area county)



The 2011 Community Profile includes a health systems analysis on a small cluster of counties, designated on this map as the "First Health of the Carolinas" health system and consisting of two "original" Affiliate counties and three counties added in 2010.

The in depth analysis revealed that, in fact, these fairly rural and very diverse counties represent a considerable overlap in "primary service areas" for several hospital systems, including Chatham Hospital (part of the UNC Health Care system) and Duke Oncology (Duke Medicine) the two primary health systems in the NC Triangle region (shaded red in Figure 5). These major health care providers share a significant presence in this region with the private Betsy Johnson Hospital, Central Carolina Hospital, Moore Regional Hospital, the flagship facility for First Health of the Carolinas System in Pinehurst, NC. This scenario of major health system sharing territory with smaller, regional hospitals, is characteristic of the entire eastern half of North Carolina, and there is evidence that the larger systems (Duke, UNC, University Health Systems, New Hanover Health Network) will continue to expand their geographic reach in the coming years.

3. Demographic Highlights

The Affiliate service area is both demographically and geographically diverse; spanning from predominantly metropolitan, high-density communities such as Raleigh (Wake), Durham and Chapel Hill (Orange), to largely rural, low-density regions such as Caswell, Edgecombe and Vance counties (*Table 1*). Additionally, several regions are characterized by mid-sized towns with above-average wealth surrounded by low-density, less affluent regions. These include: Greenville, the Pitt County home of East Carolina University; Pinehurst, the Moore County golf

and retirement resort; and Seymour Johnson Airforce Base in Johnston County. The economic profile and racial/ethnic composition of these North Carolina communities have undergone significant challenges and changes that have influenced access to and availability of services.

- A ten-year, 300% increase in the documented Hispanic and Latino populations was potentially compounded by increases among the undocumented populations.
- As elsewhere in the U.S., an increase in unemployment correlates to increasing ranks of uninsured residents.
- The state's Breast and Cervical Cancer Control Program (BCCCP) remains in the most restrictive, Option 1 category, and health centers in high-need counties are electing not to continue their affiliation with BCCCP. While the state's FY2012 budget preserved $1.5 million in state funding for BCCCP, the instability of the budget creates uncertainty.
- Focus group discussions reflected high levels of frustration due to the financial burden for breast cancer patients, transportation challenges and multiple co-payments for doctor's visits.

Table 1. Population Characteristics of Affiliate Service Area (Source 4)
NOTE ON TABLES: High measures indicated in dark pink, low measures in light pink throughout

County	X = Added in 2010	Total Population 2010	Square Miles	Population Density People/sq mile
Caswell		23,228	428	54
Chatham		61,444	709	87
Durham		256,296	298	860
Edgecombe		52,586	507	103
Franklin		57,201	495	115
Granville		55,670	266	209
Halifax	X	55,118	731	75
Harnett		108,885	601	181
Johnston		156,888	796	197
Lee	X	57,919	259	224
Moore	X	84,280	706	119
Nash		92,814	543	171
Northampton	X	20,611	551	37
Orange		124,503	401	310
Person		37,301	404	92
Pitt	X	151,931	655	231
Scotland	X	36,394	321	113
Vance		42,987	270	159
Wake		828,759	857	967
Warren	X	19,545	444	44
Total		**2,324,360**	**10,242 sq miles**	**227 sq mi**
North Carolina		**9,535,483**	**53,819 sq miles**	**165 sq mi**

D. Purpose of the Report

The purpose of the Affiliate Community Profile is to provide current and comprehensive information on the status of breast health and breast cancer and on the delivery of related services within the Affiliate's 20 counties and adjacent regions that impact these counties. This report is the fifth edition of the Komen NC Triangle Affiliate's bi-annual assessment. Each edition of this report has built upon prior quantitative and qualitative data and has expanded both the topics covered and the level of data analysis.

The information contained in this report comes from local, state, and federal sources, including community and national organizations and individuals to provide an accurate portrayal of the service area. The use of key informant interviews in the target communities allows the Affiliate to include diverse voices of survivors and community members to get a well-rounded perspective of breast health and cancer services in our communities. The demographic and statistical breast cancer data will assist the Affiliate in identifying where the mission efforts will be most effective and to expand the reach of our existing programs (*Table 2*).

Table 2. 2011-12 Affiliate Grantee Program Reach by County
NOTE Throughout: ^ indicates county added in 2010, * indicates county in Section IV focus area
★★Pitt County was added late in 2010 and did not qualify to apply for Community Health Grants

Komen-Funded Programs>> County	# Education Programs Serving County	# Screening Programs Serving County	# Treatment Programs Serving County	# Post-Diagnosis Programs Serving County
Caswell	4	4	1	2
^Chatham	3	5	1	4
Durham	6	7	4	5
Edgecombe	2	4	1	2
Franklin	3	4	2	3
Granville	2	3	1	1
*Halifax	1	1	0	1
^Harnett	1	2	1	2
Johnston	3	4	1	3
*^Lee	1	1	0	1
*^Moore	1	1	0	2
Nash	3	4	1	2
*Northampton	0	0	0	0
Orange	5	5	2	4
Person	1	1	0	1
*Pitt★★	0	0	0	0
*^Scotland	0	0	0	0
Vance	4	5	2	3
Wake	5	7	3	5
*Warren	1	1	0	1

Now in its 15th year, the Affiliate Community Health Grant program has realized considerable success, particularly since the Affiliate started requiring that each application: address the continuum of care, include collaborations/partnerships, use evidence-based strategies, include an evaluation component and demonstrate cultural competency. As the Affiliate seeks to maximize the impact and outcomes of our mission investment, we will use this report as a springboard for additional research and as a foundation for targeting mission dollars through Community Health Grants, community mobilizing activities, provider program support and strategic planning. Findings from the 2011 Community Profile will point to future directions for Affiliate grant programs, public policy initiatives, community mobilizing activities, and development of strong collaborations and partnerships throughout the service area. Following a discussion of quantitative/demographic data and qualitative/exploratory data, a summary offers key findings and recommended action items as we continue to evolve and expand the organization.

III. Breast Cancer Impact in the Affiliate Service Area

A. Methodology

The data sources for the breast cancer impact in our Affiliate service area include demographic, incidence and mortality information from the 20-counties we serve (*Table 3*).

- All incidence data are five year (2004-2008) as are mortality data (2005-2009). All rates are per 100,000 population.
- Census and most surveillance data only account for persons who are citizens of the United States. Consequently, undocumented persons are not included in these data.

Table 3. Key References

References throughout this report are numbered as follows:

1. North Carolina Central Cancer Registry. (2011). *2004 – 2008 Cancer Incidence Rates*.
2. North Carolina Central Cancer Registry. (2011). *2005 – 2009 Cancer Mortality Rates*.
3. North Carolina Central Cancer Registry. (2008). *2002 – 2006 Cancer Incidence Rates*.
4. Thomson Reuters 2010 –Susan G. Komen Community Profile Analysis Data Pack.
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6. US Census Bureau 2005-2009 American Community Survey 5-year Estimate. Retrieved February 2011, from: http://www.census.gov
7. U.S. Bureau of Labor Statistics. Local Area Unemployment Statistics, January 2011
8. Health Insurance Coverage Status for All Counties (2007)
9. American Cancer Society (2009). Cancer Facts & Figures 2009.

B. Overview of the Affiliate Service Area

1. Population Wealth & Education

The following indicators illustrate some interesting correlations and paradoxes within the Affiliate service area (*Table 4*). As illustrated by the high (dark pink) and low (light pink) highlights in data tables, several counties are characterized by a combination of at least three or four strong indicators. ***Note these indicators tables: *County added in 2010, ^is focus county in Health Systems Analysis (Section IV).***

Table 4: Population description by County and SES indicators (Sources 6, 7, 8)

County	Median Household Income	% Families Below Poverty Level	% Age >25, No High School Grad.	%Unemploy-ment	% Uninsured
Caswell	$37,788	14.3	22.8	11.6	16.5
^Chatham	**$54,874**	9.7	16.5	**7.0**	**20.3**
Durham	$49,958	10.5	14.2	7.6	13.7
Edgecombe	$31,775	18.9	26.7	**14.9**	11.4
Franklin	$43,508	11.3	19.9	9.7	17.1
Granville	$47,855	7.3	19.9	10.1	15.9
*Halifax	$29,393	19.2	**27.4**	12.2	**11.3**
^Harnett	$41,933	11.8	20.1	10.5	19.1
Johnston	$49,502	9.2	20.8	9.1	**19.6**
*^Lee	$43,046	10.5	22.3	12.4	19.5
*^Moore	$48,748	**6.4**	12.4	9.0	16.4
Nash	$47,726	11.8	18.1	12	14.5
*Northampton	**$28,493**	16.6	**31.3**	10.7	12.3
Orange	$53,558	7.8	**10.3**	**6.0**	15.9
Person	$45,321	13.8	19.2	10.5	14.5
*Pitt	$38,780	15.8	14.2	9.8	14.1
*^Scotland	$30,755	**25.8**	23.3	**16.1**	**9.5**
Vance	$35,686	**19.6**	27.3	12.0	13.2
Wake	**$64,527**	**5.5**	**8.9**	8.1	13.3
*Warren	**$28,351**	15.7	26.5	11.7	17.8
North Carolina	**$43,754**	**14**	**17.0**	**7.7**	**15.7**

- Edgecombe County, one of the focus counties for the Komen "Area L" grant, is characterized by low median income and high percentages of the population who are unemployed, below poverty level and/or did not receive a high school degree. Conversely, the county has an unusually low percentage of individuals who have no insurance.
- Counties in the region selected for the Health Systems Analysis (Section IV) include these with notable statistics below:
  - Chatham and Moor have higher-than-average median income and education levels combined with lower-than average unemployment.
  - Conversely, Scotland, Lee and Harnett all have indicators of "high need" including high proportions of at least two of these indicators: unemployment, % uninsured and/or % of families below poverty level.

2. Ethnicity

The Affiliate service area is racially and ethnically diverse, both at the macro level and within specific regions and communities. The high level of diversity and fairly large populations of

specific ethnic groups offers opportunity to examine healthcare data at a fairly local level with some degree of statistical significance.

- While there is no clear correlation between race and higher-than-average income on a county level (*Tables 4, 5*), counties with lower average income, lower average education and higher average unemployment rates do correlate more closely with counties that have higher minority populations, including Edgecombe, Halifax, Northampton and Vance—contiguous counties served by University Health Systems (*Figure 5*).
- Higher than average documented Hispanic populations in Chatham, Durham, Harnett, Johnston and Lee Counties make them targets of interest for more in depth research as part of the Yoplait Fondo Para La Mujer project.
- Warren (Haliwa Saponi Tribe) and Scotland (Lumbee Tribe) Counties are both homes of Native American Tribes, populations with unique public health challenges that will require more research and planning.

Table 5: Population by County and Ethnicity (Source 6)

County	% White	% Black	% Hispanic	% American Indian	% Asian/Pacific Islander	% All Other
Caswell	61.2	24.7	8.8	0.4	3.3	1.6
^Chatham	67.9	**14.1**	**15.1**	0.3	1.5	1.2
Durham	43.7	37.2	12.7	0.3	**4.3**	**1.8**
Edgecombe	**39.2**	55.5	4.2	**0.2**	**0.3**	**0.7**
Franklin	64.5	26.5	7.3	0.3	0.5	0.9
Granville	54.8	35.9	6.9	0.5	0.7	1.3
*Halifax	42.1	51.6	**1.2**	3.6	0.7	0.9
^Harnett	63.3	23.6	9.2	0.9	1.2	**1.8**
Johnston	69.6	16.7	11.7	0.3	0.6	1.0
*^Lee	61.4	20.6	**15.3**	0.4	1.1	1.2
*^Moore	**75.9**	15.0	6.4	0.8	0.8	1.0
Nash	54.2	38.7	4.8	0.4	0.8	1.1
*Northampton	39.5	**57.8**	**1.1**	0.3	**0.3**	1.0
Orange	**73.0**	**12.2**	6.1	0.4	**6.3**	**2.0**
Person	68.6	26.3	3.2	0.5	**0.2**	1.2
*Pitt	59.4	33.1	4.7	**0.3**	1.1	1.4
*^Scotland	49.2	38.2	1.3	**9.2**	0.6	1.5
Vance	43.6	48.5	6.2	**0.2**	0.7	**0.8**
Wake	65.0	19.7	8.8	0.4	**4.3**	1.7
*Warren	**33.2**	**58.7**	2.7	**4.1**	**0.3**	1.0
North Carolina	**61.2**	**24.7**	**8.8**	*	**3.3**	**2.0**
United States	**65.0**	**12.2**	**15.5**	*	**4.5**	**2.8**

- Even though North Carolina has one of the fastest-growing populations of Latinos and Hispanics in the nation, the relative proportion (8%) is lower than the national average of 16%. It is important to note that the number of Hispanics may be under-counted because of immigration, documentation status, and the difficulty in locating some members of this population. Some sources estimate this population to be up to three to five times higher than the U.S. Census indicates, especially due to the large migrant populations working for North Carolina farms and wineries.

3. Other Relevant Demographics & Observations

a. Breast & Cervical Cancer Control Program (BCCCP) Services

The Komen NC Triangle Affiliate 2009 Community Profile included an in depth study of the BCCCP program in North Carolina. Use of BCCCP support varies dramatically across the service area; compared to a statewide average of eight percent utilization among eligible residents, Nash, Northampton and Person counties have very high rates of utilization. Conversely, Lee County, one of the smallest in our service area, joins the two largest counties, Wake and Durham, at the low end of the utilization scale (*Table 6*).

Table 6: BCCCP Availability and % Usage by Eligible Populations, By County (Source 5, 8)

County	Caswell	Chatham	Durham	Edgecombe	Franklin	Granville	Halifax	Harnett	Johnston	Lee	Moore	Nash	Northampton	Orange	Person	Pitt	Scotland	Vance	Wake	Warren	North Carolina
BCCCP Services Available	X	√	√	√	X	X	√	X	√	√	√	√	√	X	√	√	X	X	√	√	
% Usage		**5**	3	7			7		9	3	9	**16**	**32**		**15**	6			2	**18**	**8**

b. Transportation Systems

As part of our baseline research, we gathered crude data on public transportation systems across the service area. Every one of the 20 counties has at least one public transportation system. The larger counties like Wake, Durham, Orange and Pitt Counties have multiple transportation systems, in part because they are heavily populated and in part because they each house one or more college and/or university.

C. Breast Cancer Statistics

Breast Cancer incidence and mortality rates within the 20-county Affiliate service area illustrate correlations between high disparity rates and certain other factors (*Table 7*). However, while correlations may suggest causal relationships, further research may be necessary in some instances. As is true elsewhere in the U.S., throughout most of the service area, white women generally experience higher incidence rates of breast cancer but minority women have generally higher mortality rates from the disease. Additionally, minorities have higher rates of distant staging (cancer that has metastasized) compared to their white counterparts. In Lee County minority women have higher rates at the regional stage than white women, and in Scotland County minority women have the second highest rates of breast cancer diagnosis at the distant stage (*Table 8*).

1. Incidence and Mortality by Race

Similar to breast cancer incidence statistics for the U.S. (124 cases per 100,000), North Carolina rates for white women (152.2) are generally higher than rates for minority women (145.6). Conversely, breast cancer mortality rates for minority women (30.9 deaths per 100,000) are generally higher than for white women (22.3) throughout NC. Some noteworthy observations:

- Incidence rates within most counties in our service area are higher than national rates.
- Pitt County has the highest mortality rate among minority women in our service area. The reverse is true for Edgecombe County, which sits immediately adjacent to Pitt County, where the highest mortality rate is among white women.
- Lee, Moore and Orange Counties, all located in the same general region, have higher mortality rates among white women than their minority counterparts.

Table 7: Female Breast Cancer Incidence & Mortality Rates for Affiliate Service Area
NOTE: Rates are # per 100,000. (Sources 2 & 3)

	Incidence Rates			Mortality Rates		
County	**White**	**Minority**	**Total**	**White**	**Minority**	**Total**
Caswell	116.4	152.7	129.9	18.6	38.5	22.1
^Chatham	97.9	163.3	109.5	16.1	34.2	16.5
Durham	155.0	160.9	157.7	24.0	32.4	26.9
Edgecombe	182.0	150.1	165.3	36.7	37.3	39.6
Franklin	137.4	168.0	146.7	20.6	27.3	24.2
Granville	115.7	169.0	133.6	30.9	34.2	27.8
*Halifax	178.2	153.1	165.8	30.2	34.8	35.1
^Harnett	116.1	120.2	118.2	23.7	27.3	24.2
Johnston	123.0	150.8	127.7	22.0	28.6	21.4
*^Lee	180.6	150.8	175.5	15.0	8.0	17.4
*^Moore	177.0	159.9	173.1	23.3	22.3	20.6
Nash	158.3	150.0	157.6	22.5	35.1	27.6
*Northampton	158.2	127.3	138.0	23.0	39.6	31.9
Orange	192.8	176.9	190.3	22.5	37.8	22.8
Person	115.0	123.4	118.1	21.8	35.7	27.3
*Pitt	173.6	166.9	172.5	21.9	42.4	27.9
*^Scotland	138.0	133.8	136.5	16.5	36.7	24.1
Vance	147.1	123.9	140.6	15.2	16.2	16.2
Wake	170.3	160.2	169.6	20.8	28.2	21.9
*Warren	151.4	169.1	160.3	12.1	38.7	27.7
Service Area	**157.1**	**145.1**	**155.0**	**32.4**	**40.5**	**33.1**
NC	**152.2**	**145.6**	**151.7**	**22.3**	**30.9**	**23.5**
US			**124.0**			**24.0**

- There are several counties that have higher incidence rates among minority women than white women, including Caswell, Chatham, Durham, Franklin, Granville, Harnett, Johnston, Person, and Warren. All of these counties have a higher minority population than white (Table 5), and several of these counties do not provide BCCCP to their residents (Table 6).

Table 8: Female Breast Cancer Incidence and Mortality Rates by Age Groups
NOTE: Rates are # per 100,000, rounded to the nearest digit (Source 1, 2, 3)

County || Age >	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total	
Caswell	*	86	232	410	**391**	405	**483**	129	Incidence
^Chatham	*	97	203	**225**	**374**	355	292	**109**	
Durham	10	118	280	377	591	510	**251**	157	
Edgecombe	*	**175**	**197**	441	611	547	**248**	165	
Franklin	49	110	257	335	489	492	286	147	
Granville	19	103	217	**462**	**359**	**329**	421	134	
*Halifax	48	94	**338**	412	517	500	394	166	
^Harnett	14	**67**	**174**	357	406	428	293	**118**	
Johnston	20	127	212	337	**347**	420	**258**	128	
*^Lee	41	152	276	455	**626**	479	372	176	
*^Moore	33	106	312	441	**610**	548	460	173	
Nash	22	143	285	372	582	411	285	158	
*Northampton	**	122	211	446	438	348	*	138	
Orange	39	152	**322**	447	566	**709**	**484**	**190**	
Person	**	**64**	224	**333**	440	**304**	430	**118**	
*Pitt	27	124	262	**466**	**642**	550	339	173	
*^Scotland	45	87	230	372	490	**314**	419	137	
Vance	**	144	261	349	428	449	*	141	
Wake	18	126	304	404	599	530	445	170	
*Warren	**	**163**	302	353	499	**315**	**502**	160	
North Carolina	21.0	119	256	383	514	489	371	152	
Caswell	0.0	25.3	31.7	49.4	57.2	81.0	152.9	22.1	Mortality
^Chatham	0.0	4.1	**12.5**	**35.1**	83.4	98.5	86.1	**16.5**	
Durham	0.8	11.5	35.1	49.2	97.4	**161.4**	144.5	26.9	
Edgecombe	6.4	**41.2**	44.0	57.1	**111.9**	**226.1**	**250.2**	**39.6**	
Franklin	0.0	**0.0**	22.4	57.7	100.6	118.0	**238.8**	24.2	
Granville	0.0	24.4	35.1	45.6	72.1	128.6	**288.1**	27.8	
*Halifax	7.0	26.9	**55.2**	**75.8**	**110.0**	**152.1**	118.5	**35.1**	
^Harnett	2.3	**2.4**	35.9	62.4	79.0	136.5	120.2	24.2	
Johnston	3.7	15.0	29.1	49.5	63.5	99.8	106.4	21.4	
*^Lee	0.0	10.2	**14.2**	**35.1**	90.9	**68.9**	117.0	**17.4**	
*^Moore	0.0	7.3	23.7	**33.3**	86.0	89.9	**256.3**	20.6	
Nash	0.0	**27.3**	46.1	61.5	72.1	120.4	107.0	27.6	
*Northampton	0.0	**0.0**	**58.5**	**77.1**	**174.6**	**43.9**	**265.5**	31.9	
Orange	0.0	20.2	21.4	45.7	68.5	121.6	163.6	22.8	
Person	0.0	21.6	44.0	**88.1**	**37.9**	133.7	138.9	27.3	
*Pitt	4.2	12.0	38.9	59.4	97.3	**157.6**	98.7	27.9	
*^Scotland	18.3	8.0	21.7	66.9	73.7	106.2	90.6	24.1	
Vance	0.0	13.3	23.8	50.9	**22.6**	**79.0**	83.4	**16.2**	
Wake	0.3	10.0	26.2	50.9	70.6	107.8	173.7	21.9	
*Warren	0.0	17.0	26.3	42.5	**119.2**	**209.3**	**69.3**	27.7	
North Carolina	1.8	11.6	29.7	53.2	76.9	115.2	161.5	23.5	

***Rate not calculated because counts less than 5 are suppressed*

- Wake County is interesting as the incidence rates are above the NC rate for both white and minority women, while the mortality rates are below NC rate for both white and minority women. Wake County is the home of State Capital, Raleigh, and has numerous hospitals, research facilities, breast health programs and services; the outcomes for this county may be explained by residents' utilization of these resources.

2. Incidence & Mortality by Age Group

Table 8 illustrates female breast cancer incidence and mortality rates by age groups for the Affiliate service area. Noteworthy observations include:

- Within the 25-34 age group, Franklin, Halifax, Lee, Moore and Orange have incidence rates that are higher than the NC state average and are close to double the state average in several instances; yet the mortality rates are significantly lower than the NC average.
- Edgecombe, Halifax and Northampton have disproportionately high mortality rates for most age groups over age 45. Previous studies of Edgecombe County and the surrounding area highlight several modifiable risk factors that may contribute to the high rates including knowledge deficit surrounding breast health issues; cultural and behavioral challenges relating to breast cancer risks; and limited access to utilization of breast health and cancer services. These three counties are part of the Area L grant mentioned above.

3. Breast Cancer Stage at Diagnosis

The stage at which breast cancer is diagnosed has an enormous impact on 5-year survival rates. Cancer stages include:

- ***in situ:*** cancer is confined to the site of origin: duct or lobule without invasion of neighboring tissues,
- ***local:*** cancer has invaded fatty tissue, but is confined to the breast,
- ***regional:*** cancer has spread to tissue or lymph nodes surrounding the breast, and
- ***distant:*** cancer has metastasized to distant organs.

Chances for 5-year survival post-diagnosis are increased when cancer is found at an early stage. If cancer is found at a later stage, survival post-diagnosis increases when large tumors are discovered and removed. Table 9 shows the breast cancer stage at diagnosis (5-year) by race and county.

In general, minorities have higher rates of distant staging compared to their white counterparts. This pattern follows true in counties such as Chatham, Franklin, and Lee, where high percentages are reflected in the *regional* stage for minority women. In counties including Franklin, Granville, Scotland and Warren, there are higher percentages of *distant* stage diagnosis for minority women than their white counterparts throughout the 20-county Affiliate.

These data suggest that interventions to promote early screenings in these areas could improve outcomes for women in these counties. With early detection, breast cancer treatment is far less invasive and more successful.

Table 9: Female Breast Cancer Stage at Diagnosis (5-year) by Race for Affiliate Service Area (Source 1)

Stage at Diagnosis >>	In Situ		Local		Regional		Distant		Unstaged		Total±
County/Race	**Cases**	**%**	**Cases**	**%**	**Cases**	**%**	**Cases**	**%**	**Cases**	**%**	
Caswell/White	10	17.2	29	50.0	14	24.1	5	8.6	< 5	*	58
Caswell/Minority	11	27.5	17	42.5	12	30.0	< 5	*	< 5	*	40
Chatham/White	18	12.2	89	60.1	36	24.3	5	3.4	< 5	*	148
Chatham/Minority	11	22.9	18	37.5	19	39.6	< 5	*	< 5	*	48
Durham/White	110	19.4	265	46.8	150	26.5	32	5.7	9	1.6	566
Durham/Minority	83	21.5	174	45.1	107	27.7	22	5.7	< 5	*	386
Edgecombe/White	23	17.3	74	55.6	29	21.8	7	5.3	< 5	*	133
Edgecombe/Minority	13	10.0	62	47.7	42	32.3	8	6.2	5	3.8	130
Franklin/White	35	23.3	62	41.3	40	26.7	8	5.3	5	3.3	150
Franklin/Minority	15	20.3	26	35.1	26	35.1	7	9.5	< 5	*	74
Granville/White	18	16.5	64	58.7	27	24.8	< 5	*	< 5	*	109
Granville/Minority	22	26.2	36	42.9	18	21.4	8	9.5	< 5	*	84
Halifax/White	22	13.7	94	58.4	33	20.5	7	4.3	5	3.1	161
Halifax/Minority	31	21.8	59	41.5	42	29.6	6	4.2	4	2.8	142
Harnett/White	50	21.2	108	45.8	46	19.5	18	7.6	14	5.9	236
Harnett/Minority	19	29.2	32	49.2	14	21.5	< 5	*	< 5	*	65
Johnston/White	79	20.1	200	50.9	91	23.2	17	4.3	6	1.5	393
Johnston/Minority	26	28.0	42	45.2	17	18.3	8	8.6	< 5	*	93
Lee/White	46	19.0	121	50.0	61	25.2	7	2.9	7	2.9	242
Lee/Minority	8	17.0	22	46.8	17	36.2	< 5	*	< 5	*	47
Moore/White	97	20.5	250	52.9	95	20.1	16	3.4	15	3.2	473
Moore/Minority	14	21.5	29	44.6	22	33.8	< 5	*	< 5	*	65
Nash/White	48	15.6	160	51.9	83	26.9	7	2.3	10	3.2	308
Nash/Minority	20	14.9	67	50.0	40	29.9	7	5.2	< 5	*	134
Northampton/White	8	15.7	27	52.9	10	19.6	2	3.9	4	7.8	51
Northampton/Minority	5	9.6	28	53.8	14	26.9	< 5	*	5	9.6	52
Orange/White	99	21.2	246	52.7	110	23.6	12	2.6	< 5	*	467
Orange/Minority	14	15.1	52	55.9	27	29.0	< 5	*	< 5	*	93
Person/White	17	17.2	49	49.5	33	33.3	< 5	*	< 5	*	99
Person/Minority	5	13.5	24	64.9	8	21.6	< 5	*	< 5	*	37
Pitt/White	70	17.2	196	48.0	114	27.9	11	2.7	17	4.2	408
Pitt/Minority	29	13.9	95	45.5	59	28.2	14	6.7	12	5.7	209
Scotland/White	20	23.8	42	50.0	22	26.2	< 5	*	< 5	*	84
Scotland/Minority	17	28.3	21	35.0	16	26.7	6	10.0	< 5	*	60
Vance/White	22	20.8	48	45.3	31	29.2	< 5	*	5	4.7	106
Vance/Minority	10	14.7	35	51.5	23	33.8	< 5	*	< 5	*	68
Wake/White	526	22.1	1,162	48.7	567	23.8	86	3.6	44	1.8	2385
Wake/Minority	132	19.5	285	42.0	207	30.5	38	5.6	16	2.4	678
Warren/White	7	16.7	22	52.4	13	31.0	< 5	*	< 5	*	42
Warren/Minority	9	15.3	25	42.4	16	27.1	9	15.3	< 5	*	59

± Total of known values (cells with less than five are unknown)

C. Communities of Interest

The continuum of care model involves an integrated breast health system that includes a comprehensive cycle of services including varying levels of education, screening, diagnosis, treatment, post-diagnosis, and follow-up. Challenges within this model can be correlated to many regional characteristics including, but not limited to population density, existing programs and services, and access barriers. As a result of these challenges, certain populations appear to be disproportionately affected as evidenced by higher-than-average incidence and mortality rates and/or diagnoses at a later stage.

1. Non-Metropolitan Counties

Using data from the North Carolina Demographic and Economic Profile from the Rural Policy Research Institute, the Affiliate has identified ten counties within our service area that are non-metropolitan. Non-metropolitan counties/areas are split into two categories:

- ***Non-Core Areas*** are counties that have no urban cluster of at least 10,000 population. In our Affiliate service area, Non-Core counties are: Caswell, Granville and Warren.
- ***Micropolitan Areas*** are counties that have at least one urban cluster of 10,000-49,999 inhabitants and are these counties: Vance, Halifax, Northampton, Lee, Harnett, Moore and Scotland.

The socio-economic variables in Table 4 allow us to broaden our understanding of the non-metropolitan population. Statistics show that since 2001, overall breast cancer incidence rates have fallen substantially, but the reductions have been in urban and low-poverty, affluent counties opposed to rural or high-poverty counties (Hausauer, A.K., et al., 2009).

The dominant industries in non-metropolitan counties are farming and manufacturing. As with other industries these are suffering due to the economic status. The 2008 Rural America at a Glance reports that the unemployment rate for nonmetropolitan communities corresponds with the trend of metropolitan unemployment but at a higher level. Lee, Scotland, and Vance counties fall within the top five for the highest rate of unemployment in the Affiliate service area.

Within the Affiliate's non-metropolitan counties, the median household income ranges from $28,351 in Warren County to $48,748 in Moore County. Similarly Halifax, Northampton, Warren, and Scotland counties have the lowest median income in the Affiliate area.

Just as employment options are limited in non-metropolitan areas so are the services and facilities available:

- The majority of the non-metropolitan counties in our service area have one local daily/weekly newspaper for the whole county compared to the metropolitan counties that have three or more newspapers.
- Other limited resources in these counties include number of libraries, bus/transportation services, and free wi-fi internet access.
- The NC Department of Health and Human Services identifies several rural health clinics in the non-metropolitan area as being located in "health profession shortage areas," having shortages in primary medical care institutions. These limitations serve as barriers to health care screening and treatment and contribute to the rise of health disparities in rural populations.

Statistics show that only 51.2 percent of uninsured rural women had a mammogram in 2008 (Bennett, K.J., et al, June 2008). Among the metropolitan counties in our service area, Caswell, Granville, Harnett, Lee, Moore, and Warren are above the NC state average for percentage of population that is uninsured (*Table 4*).

In the Non-Core counties Caswell and Granville, minorities account for less than half of the population, whereas the population in Warren County is predominantly minority. Interestingly these counties do not follow the overall trend of incidence rates in whites vs. minorities. Conversely in Lee and Moore, both Micropolitan counties, white women have a higher mortality rate than minorities, which may be reflective of the fact that in these counties, the white populations are disproportionately larger than in other counties. Studies continue to show that African American and Hispanic/Latina women are more likely to be diagnosed with large tumor and late stage breast cancer than white women (ACS, Cancer Facts & Figures for African Americans 2009-2010 and ACS, Cancer Facts & Figures for Hispanics/Latinos 2009-2011).

2. Examination of Unscreened Women Age 40+ by County

Table 10 illustrates that the lowest relative rates of women 40+ who have not gotten mammograms in the last 12 months are in Durham, Wake and Orange Counties, the homes of the largest hospital and medical systems in the current Affiliate service area and three of the most densely populated areas. Conversely, while Pitt County is home of the large University Health Systems, this hospital serves a more rural population, suggesting a strong correlation between physical access to care and proportions of individual who actually get screened.

Table 10. Percentage of Females 40+ Years of Age Without Mammography, by County (Source 4)

County	% No Mammo Last 12 months	% Chose Not to	% Didn't Have Time	% Didn't Need	% Have Scheduled	% Other Reasons
Caswell	40.2	7.2	10.0	3.5	3.3	15.9
Chatham	38.6	6.7	9.9	3.2	3.7	14.8
Durham	**36.2**	5.9	9.4	2.6	3.1	14.8
Edgecombe	41.4	7.1	10.1	3.2	3.9	16.9
Franklin	40.7	7.1	9.5	3.3	4.7	16.0
Granville	38.7	6.6	10.1	3.1	4.1	14.5
Halifax	**42.9**	7.1	10.8	3.8	4.1	17.0
Harnett	41.6	7.5	9.3	3.5	4.3	16.9
Johnston	39.6	7.0	9.6	2.9	4.3	15.7
Lee	40.0	7.2	9.9	3.3	3.8	15.5
Moore	37.2	6.6	9.4	3.4	4.0	13.5
Nash	38.6	6.5	9.9	3.2	3.9	14.9
Northampton	41.6	7.5	10.4	3.7	3.4	16.3
Orange	**34.9**	5.8	9.9	2.3	3.3	13.4
Person	40.6	6.8	10.4	3.3	4.0	15.9
Pitt	40.5	7.0	9.9	3.1	3.5	16.7
Scotland	41.3	7.0	10.5	3.4	3.8	16.5
Vance	**43.5**	7.7	10.4	3.6	4.0	17.5
Wake	**34.3**	5.2	9.5	2.4	3.3	13.7
Warren	41.0	7.4	9.9	3.5	4.0	15.9
NC Total	**38.5%**	**6.5%**	**9.8%**	**3.0%**	**3.7%**	**15.2%**

There are 13 counties within our service area where the percentage of women 40+ without a mammogram in the past year is above the state average of 38.5%. In 16 counties, the percentage of women who chose not to have a mammogram exceeds the state average of 6.5%.

An examination of these trends relative to availability of BCCCP programs offers few definitive conclusions and, in fact, show a distinct lack of correlation. With the North Carolina average usage of the BCCCP program at 8% statewide, Lee, Durham and Wake counties fall well below this average (*Table 5*), yet the proportions of women 40+ who have been screened in the last 12 months are higher in Wake and Durham, lower in Lee. Likewise, the counties with highest BCCCP utilization rates like Nash, Northampton, Person, and Warren counties show a similar lack of consistency in mammography behaviors.

D. Conclusions

While the Affiliate service area is diverse demographically and geographically, these data focus attention on several areas that merit further research and targeted attention from the Affiliate. The characteristics of several specific counties led us to select a cluster of counties in the southwest region of our service area as the subject of our Health Systems Analysis.

1. BCCCP Program Utilization

Data reflect varied BCCCP support and usage across our service area, BCCCP is not available in some counties, other counties have low usage among the eligible population. Furthermore, the impact of BCCCP on rates of mammography utilization is unclear.

- Collaboration with county coordinators and the state BCCCP director to discuss the challenges they are facing may help to increase the number of counties utilizing this program.
- Increasing awareness of the program and educating eligible county residents on the benefits of BCCCP could increase enrollment and utilization of the program.

2. Non-Metropolitan Areas

Data and background on non-metropolitan counties reveal challenges that are unique and must be addressed with solutions that may not apply to more densely populated regions.

- As the Affiliate continues to gather data, we will look carefully at Non-Core and Micropolitan areas and study the access issues with a focus on identifying potential solutions that are reasonable within these communities that have unique challenges.
- Mammography utilization data may be a strong measure of impact against which to benchmark Affiliate grant-funded programs in these areas.

3. Affiliate-Funded Program Reach

Figure 6 and Table 10 reflect the extent of the Affiliate reach within and across the current counties 20 by organizations funded through the Community Health Grants that have been awarded this cycle. The Affiliate will work toward strengthening our presence within the counties we serve by increasing the number of grant preparation workshops, enhancing the technical assistance available to organizations, and assisting in building capacity in priority areas in order to decrease the incidence and mortality rates throughout the 20-county service area.

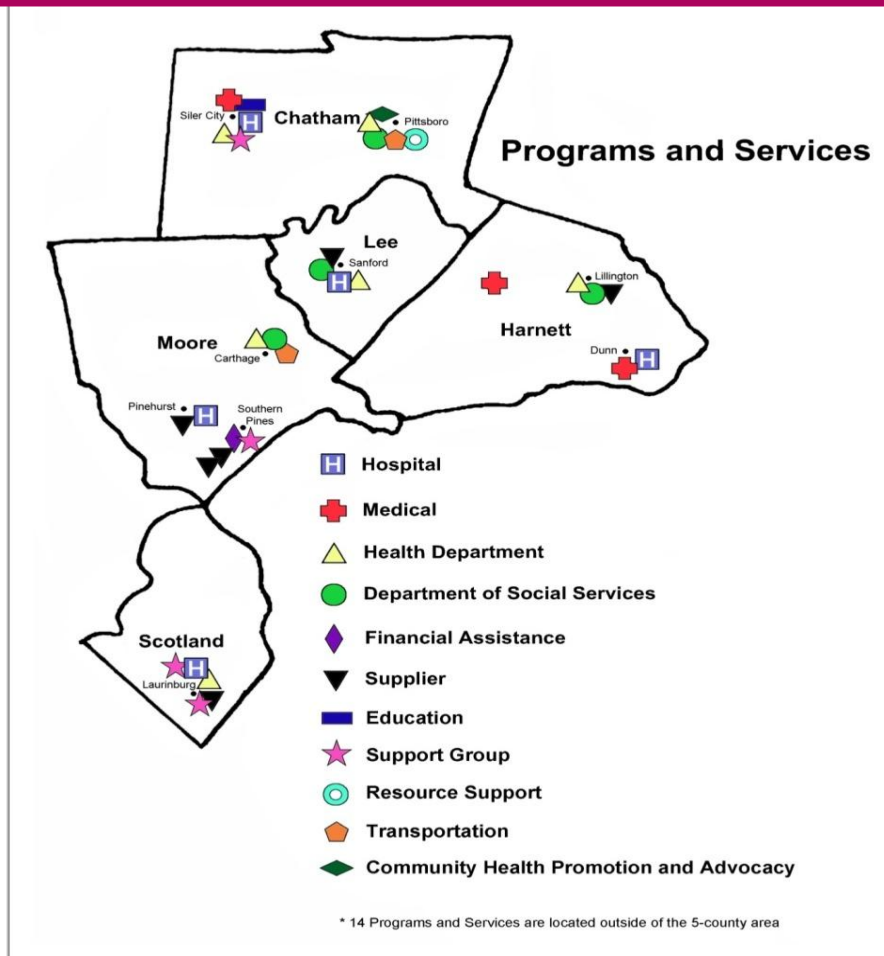
IV. Health Systems Analysis of Target Communities

A. Overview of Continuum of Care

The comprehensive cycle of services known as the continuum of care is an integrated system of breast health programs and services including varying levels of education, screening, diagnosis, treatment, post-diagnosis, and follow-up. After reviewing the breast health statistics, programs, and services in the NC Triangle Affiliate service area, we selected five counties in the southwest region of our service area to be the focus of our health system analysis: Chatham, Harnett, Lee, Moore, and Scotland. A Health Systems Analysis was conducted to better understand the gaps, needs and barriers throughout the continuum of care. Three of these counties, Moore, Lee and Scotland were new additions to the Affiliate area in 2010.

- Each county has a major hospital and there are cancer centers located in Moore, Harnett and Scotland Counties.
- Harnett and Scotland Counties do not have NC BCCCP (Breast and Cervical Cancer Program) providers and Harnett County has the highest percent of uninsured females in the service area.
- Even though hospitals and health care suppliers are represented throughout the 5-county area, data reveal that many breast cancer patients travel to Wake, Durham, and Orange counties in order to consolidate their health services and keep their medical records unified – despite the distance and commute.

Figure 6. Programs and Services: Continuum of Care in Chatham, Lee, Moore, Harnett and Scotland Counties



B. Methodology

After reviewing and analyzing the breast cancer impact in our Affiliate, several data sources were used to assess the continuum of care and complete the health system analysis for our target community.

- Demographic data in this section were collected from the U.S. Census Bureau and the North Carolina Central Cancer Registry. Table 11 illustrates detailed demographic information about the women in these five counties.
- Secondary Data were collected from county websites, North Carolina Association of Free Clinics, U.S. Department of Health and Human Services, and the Breast Cancer Resource Directory of North Carolina. This information includes programs and services i.e. health departments, transportation, imaging, and treatment within the target community.
- Google Earth was used for geo-locating and then Adobe Creative Suite was used for plotting key area assets reflecting care in these communities.
- Key informant interviews were conducted via phone and provider surveys were sent to health departments, imaging centers, and non-profit organizations to collect qualitative data in this section.

Table 11. Female Population by Ethnicity, Age Group, Percentage Uninsured and County within the Health Systems Analysis Communities (Source 4)

County Female population & Female % uninsured	Age range	% White	% Hispanic	% Black	% Asian/Pacific Islander	% American Indian	% All other
Chatham 24,964 (21.3% uninsured)	30-39	14.1	21.0	13.4	21.6	4.1	10.4
	40-49	**15.3**	**9.3**	**13.7**	**15.0**	**20.4**	**11.4**
	50-64	20.7	5.5	19.7	14.7	12.2	12.4
	65+	17.3	1.8	17.8	5.4	2.0	3.5
Harnett 60,573 (32% uninsured)	30-39	14.9	17.3	15.0	15.9	19.2	10.8
	40-49	**14.3**	**8.2**	**14.3**	**17.2**	**15.0**	**13.4**
	50-64	18.6	7.6	13.5	20.3	19.9	9.8
	65+	13.2	2.7	10.8	13.2	4.4	4.1
Moore 43,888 (20.3% uninsured)	30-39	10.8	18.3	13.8	16.4	13.3	10.2
	40-49	**13.0**	**10.1**	**13.9**	**14.3**	**17.3**	**14.2**
	50-64	20.6	4.5	13.2	18.2	12.4	9.6
	65+	26.4	1.9	13.3	5.0	7.6	5.0
Lee 35,090 (23.2% uninsured)	30-39	11.5	16.9	12.9	12.8	16.8	11.2
	40-49	**14.7**	**10.0**	**15.1**	**19.6**	**8.4**	**14.9**
	50-64	21.7	6.9	15.7	23.6	13.7	8.2
	65+	18.2	3.1	14.0	8.1	2.1	3.2
Scotland 18,891 (29.4% uninsured)	30-39	10.7	6.2	12.0	16.3	11.6	12.0
	40-49	**13.2**	**9.6**	**14.2**	**19.8**	**12.0**	**15.4**
	50-64	23.6	12.3	16.8	14.0	15.9	15.4
	65+	19.3	2.1	13.4	1.2	12.9	8.3

C. Overview of Community Assets

Figure 6 illustrates the general location of programs and services within the 5-county area. The symbols represent the variety of support service options each county has to offer.

1. Hospital Systems

There are three hospital systems represented in these five counties, the First Health of Carolinas, UNC Health System and Duke Health System. The variety of options for patients can be seen as a positive, offering many options. Conversely, it may create more of a challenge for patients to navigate across systems and not just within a single system.

Each county has a public hospital except for Harnett Health's Betsy Johnson Hospital, located in Dunn, NC. Moore County, one of the newly added counties in 2010, is home to Moore Regional Hospital which is the flagship hospital for First Health of the Carolinas. Other county hospitals are affiliated with Duke and UNC.

There is no cancer facility at Chatham Hospital so patients are referred to UNC's Lineberger Comprehensive Cancer Center in Orange County for breast health care. Similarly Central Carolina Hospital (Lee County) is without a cancer center but has a Certified Quality Breast Center with a certified Breast Health Navigator and MammaCare® Specialist.

2. Clinics and Breast Health Imaging Facilities

In all five counties, there are health clinics and health departments that provide breast health services; however some counties have more limited resources than others.

- The hospitals in Lee, Moore, and Harnett counties offer low-cost mammograms, chemotherapy, and have a breast surgeon on staff.
- In Moore and Scotland Counties, radiation is available at the hospital.
- Genetic risk counseling is offered through Central Carolina Hospital (Lee County) and Scotland Memorial Hospital (Scotland County).
- There are free clinics with limited hours in Lee and Moore County, while Chatham has a non-profit pharmacy that accepts donations only.

3. Transportation

a. Public Transportation

Each county has at least one public transportation system. Scotland County is the only county in which there is a fixed route throughout city limits. In the others, residents must call to schedule pick up to medical facilities and other resources located in the county. All of the transportation systems travel anywhere within county limits except for the Chatham County transit system which currently serves Siler City and Pittsboro but will provide county wide service beginning August 2011. For residents needing to go across county lines to receive services, the counties do offer transportation to neighboring counties; however residents need to plan and make arrangements days in advance. Each county sets fares according to route or distance, generally there is a limited no-cost option for Medicaid patients and seniors 60+, and this alternative varies across the 5-county region.

b. Travel Time

Each county in the target area has at least one health care facility for their residents. According to hospital affiliation, or additional patient needs, often breast cancer patients need to travel out of

county to receive additional services that are not offered locally. Occasionally patients are referred to, or choose health facilities in Orange, Durham or Wake Counties post-diagnosis where travel times can be substantial (*Table 12*).

For individuals who are ill, having to make arrangements for transportation whether public transit or personal vehicle, can become a challenge. The time and cost for travel to multiple appointments is substantial in the current economy and may cause individuals to make choices that conflict with their health priorities.

Table 12. Approximate Driving Time (one-way) to Treatment Centers by County (Source: Google Maps)

County (health department)	**REX- UNC Health (Raleigh/Wake)**	**Duke University Hospital (Durham)**	**UNC Lineberger Comprehensive Cancer Center (Chapel Hill/Orange)**	**First Health of the Carolinas (Pinehurst/Moore)**
Chatham	42 min	38 min	22 min	1 hour 8 min
Harnett	57 min	1 hour 15 min	1 hour 18 min	1 hour 21 min
Lee	45 min	1 hour 5 min	55 min	43 min
Moore	1 hour 18 min	1 hour 35 min	1 hour 25 min	(local)
Scotland	1 hour 51 min	2 hours 8 min	1 hour 59 min	47 min

4. Non-Profit Agencies & Organizations

Non-profit agencies often fill in the gaps with services not commonly found in each county. The Affiliate requires that Community Health Grant programs include community partnerships to address critical issues including the continuum of care, transportation and other access issues, education and social support. The following agencies provide services to breast health clients:

a. Community Health Services

- Piedmont Health Services
- Hispanic Liaison of Chatham County
- Johnston -Lee-Harnett Community Action
- Harnett County Coharie Indian Association
- Woman's Club of Dunn Inc.
- Coalition for Families in Lee County
- Helping Hand Free Clinic
- Highway to Healing
- Sandhills Coalition for Human Care

b. Places of Worship

- The following congregations participated in Hat's off to Breast Health: Johnsonville AME Zion, Mt. Olive United Methodist, and Lillington Star RFWB.
- The following congregations participate in Pink Sunday: McLean Chapel Free Will Baptist Church, Smith Grove, Burning Bush Non Denominational Church, Lillington Star Reformed Free Will Baptist Church, Healing Center Ministry's, Inc., Dunn Chapel, Mt. Zion Pentecostal, James Matthew Memorial Church, Rising Son Church of Christ, Mt. Olive United Methodist Church, Paradise AME Zion, Johnsonville AME Zion, Mt Pisgah, and Dunn Chapel.
- Christians United Outreach Center of Lee County

c. Organizations

Based on interviews with providers in these five counties, several relevant observations are germane to this study.

- Known partnerships with local organizations in providing breast health services to women in the community that providers are aware of include: the Lee County Enrichment Center, Rex Hospital Mobile mammography van, Helping Hands, the Breast Cancer Navigator at Central Carolina Hospital, the Lee County Health Department Director and their BCCCP program, physicians in Harnett County through First Choice.
- The American Cancer Society has a strong presence in this Community; many organizations participate in Relay for Life annually. Due to this commitment, community organizations may decide not to any additional involvements beyond this partnership.
- The American Breast Cancer Directory is another organization that some providers join. Many community organizations are overwhelmed with current priorities and have no real interest in building coalitions alone or in partnership with others, even if funding were to be provided. In addition, providers are not interested in working with Komen on public policy initiatives in the near future, or find this type of partnership may be in conflict with the mission of their organization.

d. Support Groups

Participating in a support group can be a powerful source of encouragement for those going through treatment, survivors and their family members. Our research revealed formalized support groups in each county. Chatham County has one cancer support group; both Harnett and Lee have one breast cancer support group each. Moore County has two cancer support groups and one breast cancer support group; and Scotland County has one breast cancer and one cancer support group.

D. Legislative Issues in the Target Communities

The 2011 North Carolina budget is complete and the $1.5 million dollars for the states BCCCP funding remains intact. The Senate is proposing a new branch for men's health within the NC Department of Health and Human Services. This new branch will be tasked with obtaining funding for prostate cancer screenings and treatment and may end up competing with BCCCP state funding. Meetings are ongoing to find a strategy to address this concern.

The Komen Advocacy Alliance is the arm of Susan G. Komen for the Cure that focuses on public policy. All of four of the North Carolina Affiliates participate in the Komen Advocacy Alliance including Charlotte, NC Foothills, NC Triad, and the NC Triangle Affiliate.

Table 5 illustrates that NC BCCCP serves three of the five counties identified in the health system analysis. Presently Harnett and Scotland counties do not participate in the statewide program; hence, their low income, un- and underinsured residents have to look to alternative options for breast health care. On average, only eight percent of women eligible for BCCCP services are being screened.

E. Key informant Findings

Our survey results offer provider perspective on breast health services in these counties, including breast health education, screening and diagnostics, financial support, and partnerships within our service area. We received survey responses from nine providers from the five target counties. Respondents included health educators, nurses, BCCCP coordinators and breast health navigators representing hospital oncology departments, a senior center, medical supplier and county health departments.

1. Local Services and Clients

a. Characteristics of the Women Served

Providers described women in the community who are least likely to get regular breast cancer screening as uninsured or underinsured, older, without financial support, new to the area, and often minorities. Providers indicated that Latina women were more likely to seek breast health care, but that they had low rates of follow-up care.

b. Screening Facilities

Some providers in this region offer both screening and diagnostic mammography, while some offer breast cancer screening only, referring patients who need diagnostic services to other facilities.

Women with disabilities and those with special physical requirements have access to health facilities throughout the county. In order to provide adequate breast cancer services to these groups, providers described facilities that provide such amenities as larger room sizes, lower exam tables, ramps for wheelchair access and elevators.

Providers confirmed use of the Rex Hospital mobile mammography van (based in Raleigh/Wake County) in their area two times a year, and stated that many women prefer going to the "Mobile" than going to the hospital. The Rex unit is accessible for women with special physical needs.

c. Communication and Education

Outreach to women who do not access mammography services is a challenge. Providers describe alternate methods of disseminating information including: announcements in church programs and during services, articles in the newspaper, use of media and collaboration with nearby counties. Outreach efforts including public speaking events in the community and through the foundation at the hospital are common. Hospitals do some advertising to promote mammography screening, but some do not offer free or alternative payment options at their facilities.

Providers feel that breast health education speakers and awareness programs could help to improve the delivery of services in the current system. Finding strategies to eliminate breast cancer myths would be helpful. Providers stressed that programs providing financial alternatives are needed so breast health patients are not hassled for payment by the hospital in these difficult economic times.

d. Incentive challenges

The common practice of providing incentives in order to encourage women to seek mammography/ diagnostic services is a challenge as providers acknowledge this strategy is cost

prohibitive for many organizations where funds are not budgeted for this purpose. When extra materials are available, the health department offers bags of giveaways like pens or water bottles along with educational materials. Providers would like to do more for the clients they serve; the bags are distributed to all women who are served as far as possible, until the supply is depleted.

2. Financial Support

a. Funds for Screening

Providers described barriers that prevent women from seeking or obtaining breast health services include the lack of money or insurance (ability to pay), procrastination, financial issues, fear of knowing their breast health status, other issues to deal with, lack of education on the importance of breast exams, and lack of transportation. Residents face serious challenges when BCCCP funds are cut or depleted at the County level. Generally women can set up a payment program with the hospital, but providers confirm that there is minimal flexibility when the women cannot meet a payment. The hospital sends the patient to collections almost immediately; this issue can contribute to an already difficult and stressful situation.

Providers described several local programs that they use to refer patients for financial assistance:

- Central Carolina Hospital has a sliding scale program.
- The Lee County Primary Care Clinic charges $45.00 for all clients.
- If there is a positive diagnosis post-screening, BCCCP of the Anderson Creek Federal Grant program will absorb the costs.
- For women with screening needs, the Scotland Memorial Hospital offers free mammograms as long as funding is available.
- The Rex Mobile Mammography van is utilized for screenings needs of county residents.
- Providers also indicated that the Lee County Enrichment Senior Center, the Helping Hands program, and Moncure Health Clinic have limited financial services locally.

b. Post-diagnosis Challenges

Medicare, insurance and private pay seem to be the most common options women use to pay for breast health services. Providers desire several grants programs to ease the financial burden on residents in need of breast health services. Uninsured women in the area seem to fall through the cracks as there are no real options for these women beyond Family Planning, BCCCP, and the Helping Hands programs that assist clients in filling prescriptions and screening resources. Some providers in Lee County direct their clients to Harnett County, or encourage patients to visit the First Choice Federal Program. Clients received a voucher for health care through this program, but the First Choice Federal program ended early 2011 once the funds were depleted.

Many women are referred by providers to the Breast Health Navigator at Central Carolina Hospital. The navigator can direct breast cancer patients to post-diagnosis services such as bras/prosthesis which are quality of living (cosmetic) services; generally grants and financial support are not applicable to these items, but donated, used items are available.

F. Conclusions

- A major challenge within the five Health Services Analysis counties includes limited breast health resources locally. Partnerships could provide opportunities for better dissemination strategies.

- In Lee, Chatham, and Scotland Counties, women who are 40 and older and chose not to have mammography have higher distant stage diagnoses. Variables contributing to this behavior may include lack of access to, awareness of, or education about BCCCP services. Possible barriers for these women may include cost of transportation, and long commutes to facilities.
- Within the five county areas, there is a higher breast cancer incidence rate among white women versus their minority counterparts, with the exception of Chatham County, where the reverse is true. Late stage diagnosis is reflected among minority women in this same region resulting in higher mortality rates.
- Options are needed to lessen the financial burden on patients. Access and adherence to treatment plans post-diagnosis are directly impacted by the patient's ability to participate in recovery strategies. Availability of transportation and the cost of co-pays for multiple doctors' visits can be prohibitive for some breast cancer patients.

V. Breast Cancer Perspectives in Target Communities

A. Methodology

The qualitative data-gathering for this report focused specifically on Lee County. Focus groups sought to ascertain providers', community members' and patients' perspectives on breast health services, the role of community and organizational relationships, socio-cultural factors that influence access, utilization and availability of services. Each focus group was conducted using a reflective process that enabled all parties to share their perspectives and collaboratively identify key issues and directions to improve availability, access and utilization of breast health services in the community.

Participants were recruited using multiple methods including referral from providers in the community, direct contact with the county enrichment center, and reaching out to the faith based community. Participants included male and female survivors, co-survivors, providers, patients undergoing treatment, and health educators residing in Lee and Moore Counties. The ethnicities of the participants included Caucasian, African American and American Indians ranging in age from under 25 to 65+ years old.

The focus groups were held in convenient, "neutral" locations and included a meal and Komen gifts and materials for each participant. Each focus group lasted no more than 90 minutes, focused on safe and constructive discussion, and was conducted with a facilitator and a note taker. Upon conclusion key themes were discussed and participants were able to add, adjust or correct the information as deemed necessary. Note takers and the facilitator held debriefing sessions after each session and notes of the meetings were transcribed. At least two community profile team members independently analyzed the data for emerging themes. Upon completion, team members compared their findings, examined, discussed and refined themes.

B. Review of Qualitative Findings

The following are findings from our exploratory data focusing mainly on residents of Lee County. Focus group participants were highly engaged and willing to share positive and negative perspectives.

1. Access, Cost and Distance of Transportation to Treatment

a. Transportation

Transportation is a big expense when treatment requires travel outside of the county. An organization called Highway to Healing provides free transportation to appointments inside and outside of the county for patients with cancer diagnoses. Several participants mentioned the strong transportation network within their church congregations, as well as committed family members and friends willing to drive at a moment's notice. Another option discussed was the County of Lee Transportation (COLT); however there are limitations to this choice, including having to make arrangements to travel at least 24 hours in advance.

b. Travel Vouchers

Travel vouchers are provided for patients at some health facilities and organization, but not at others. Unfortunately, many participants did not know about these resources for travel, and were unaware that gas vouchers are not offered unless specifically requested by the patient.

c. Access to Treatment

There are no radiation facilities in Lee County; the closest facility is in Moore County. Many patients traveled to Chapel Hill, Durham or Raleigh for treatment, a significant challenge for women needing to commute daily, up to an hour and a half, feeling ill and/or in pain to receive chemotherapy or radiation treatments. Because of challenges within the Lee County public transportation system, participants worried about women who have no knowledge of alternate resources being able to successfully navigate treatment.

1. Screening and Diagnosis

When the focus group discussion turned to availability of resources, it is noteworthy that many participants were surprised to hear of certain local services, even though they had been diagnosed for a year or longer.

a. Breast Health Knowledge

Support group members in attendance seemed to be the most well-informed about resources. The support group allows for a sense of unity and true understanding of what each individual cancer journey. The importance of breast health is common knowledge to the participants of our focus group. Many participants started getting regular mammograms after turning 40 years old; they understand the importance of early detection and that participating in screening empowers a woman to take charge of her personal health.

b. Education Materials

Focus group participants obtain breast health education from sources including the Central Carolina Hospital breast health navigator, the Lee County Health Department, Lee County Senior Services as well as directly from their primary care physician. The breast health educational materials and services focus group participants are aware off come from local sources including BCCCP, Lee County Health Department, the Family Planning Clinic and Lee County Social Services. Resourceful participants mentioned requesting information from internet and national resources including National Cancer Institutes, the Centers for Disease Control, American Cancer Society, *EduCare* teaching sheets, American Breast Cancer Foundation, and Susan G. Komen for the Cure.

c. Regular Screening

At least two focus group participants mentioned that they had skipped one or more annual mammogram appointments, and then found breast cancer at their next mammogram screening. Barriers to screening within the group included common themes such as cost, fear of results, pain during the procedure, breast health not being a priority in their busy schedules, and women thinking that they would not get breast cancer until they were old.

d. Self-Awareness

Several women mentioned finding their own lump. One individual mentioned that her lump did not show up on the digital mammogram, and it was not until she went to specialist that she learned she had breast cancer. One individual noticed discoloration on her skin, her husband encouraged her to go and get it checked out her mammogram revealed that she had breast cancer.

e. Provider Challenges

There were at least two focus group participants who found their own breast cancer lump in their 30s. They found it difficult to located doctors willing to diagnose their breast cancers. One individual changed doctors repeatedly for five years trying to get a doctor to take action and start treating the lump in her breast. Finally, a physician took a syringe and deflated the lump in his exam room—he did not send the fluid to the lab, nor did the biopsy the lump until years later, when cancer was found.

f. Availability of Resources

One individual diagnosed with a rare form of breast cancer had doctors who were unwilling to discuss genetic testing. Other participants desperately tried to access any literature and resources they could find about genetic testing, BRCA1 and BRCA2, as well as double- and triple negative information. Patients in the focus group wanted to learn more about genetic testing to fully understand their diagnoses.

g. Misinformation

Focus group participants shared experiences of well-meaning individuals who offered home remedies or personal businesses (i.e., vitamins or herbal products) to cure cancer.

2. Post-Diagnosis

Patients in the group indicated that after diagnosis, the path to treatment was extremely fast.

a. Trust

Patients discussed having to fully trust their physicians and the resources and recommendations that were being provided. Most focus group participants traveled to UNC or Duke for treatment because they trusted these places after recommendation from family and friends.

b. Transition

Many focus group members admitted that they were not prepared or expected too much of themselves after treatment. Treatment side effects making them feel ill, having a lack of energy or being bedridden meant that they could not maintain household duties, take care of their families or go back to work. It was difficult to transition back to what they perceived should be

their normal life. Knowing about resources like *Look Good Feel Better* in participating hair salons was helpful during this transition, but it was interesting to note that they did not have the appropriate wigs for African-American women in Lee County.

c. Co-Survivor Support

The support group at the Lee County Hospital welcomes co-survivors and family members to attend the monthly meetings, but many area women are not aware of this resource.

d. Clinical Trials

Focus group participants were not aware of insurance carriers that offer coverage for clinical trial participation, nor were they aware of a clinical trial program or patient information in their county. All participants were open to more information about clinical trials.

3. Language Barriers

Participants shared that many providers find it challenging to get breast health materials for the various populations they serve.

a. Education Materials

The majority of Spanish language information and materials utilized by providers in Lee County come from Social Services and the health department. The *EduCare* company provides Spanish Language worksheets, and many providers get Spanish language material from the American Cancer Society. Non-English speaking clients they serve include Hmong, various Hispanic/Latino communities, Asian populations, Vietnamese women, and a few women from India. On many occasions community members will take the English language breast health literature and translate these items for patients, family and friends.

b. Translation Resources

As breast health materials for all of these groups are not readily available, these women generally have an English-speaker accompanying them on visits to health facilities. There are many bilingual Spanish language speakers onsite at the hospital, but when an onsite interpreter is not available, the hospital utilizes the AT&T language line where a 3rd party call is placed with a person who speaks any language needed. Many participants were unaware of a translation service provided by the NC Department of Health and Human Services that could also help to alleviate translation concerns when the onsite interpreter is not available.

4. Financial Burden of Treatment

The focus group discussion of finances was especially robust; it was abundantly clear that health care bills can quickly become overwhelming. The patients stressed how difficult it was to be sick and constantly being asked for money.

a. Billing Challenges

Participants found billing statements tough to understand: expenses come from the lab, hospital, doctor's visits, insurance and other vendors. Many participants worked with a breast health navigator or social worker to understand multiple statements. Having limited options for patients with no insurance, the financial burden of co-payments for multiple doctor visits were issues

patients had to deal with regularly. Focus group participants even gave suggestions to alleviate the financial burden:

- If payment can be deferred for a little while after first treatment and diagnosis.
- Avoid harassing phone calls immediately after treatment, it feels like request for payment beats you home from the hospital.
- It's frustrating when the hospital asks for payment upfront, then sends a refund check because insurance covered the costs.

b. Financial Support

Other focus group members mentioned the difficulty in receiving financial services unless you have been fully diagnosed with cancer. For patients with other medical and health issues beside cancer the financial challenges seem to be greater. Several individuals mentioned that when you feel ill from the treatment, and you are unable to go back to work, the other financial burdens like your mortgage, utilities, car note, start to fall behind. Financial support from family members was welcomed, but everyone is not fortunate enough to have family members who can be helpful in this way.

5. Breast Health Navigation

Being newly diagnosed, focus group participants described having to trust and embrace a tremendous amount of information quickly, and make decisions about their treatment and health in short order. During this period patient navigators were a tremendous resource for the patient and the family members trying to understand the new circumstances, and family members. A book provided by the patient navigator and hailed as an invaluable tool by the majority of participants was, "*Breast Cancer Treatment Handbook: Understanding the Disease, Treatments, Emotions, and Recovery from Breast Cancer"* by Judy C. Kneece. The women who were desperate for information after being newly diagnosed expressed over and over how this book answered so many of the questions they had, and was extremely helpful in preparing them with questions to ask at their next doctors visit. The women learned to come to their doctor's visit prepared with questions or information in order to get the doctors to give them information, otherwise the doctor would simply treat them and the patient would leave and head home.

C. Conclusions

a. Health Communications

The focus group participants stated their frustration with the lack of access to screening information and services provided to breast cancer patients. Use of church program inserts, church clerk announcements, and access to a patient navigator are commons ways women in treatment and breast cancer survivors acknowledged receiving breast health information. Provider education about marketing their services and health communication strategies could be helpful in this region.

b. Support Groups

The focus groups revealed the need for support groups, as well as establishing groups to provide emotional support to caregivers and family members.

c. Patient Navigation

It is important for breast cancer patients to know how to make the most of their doctor's visit. Many focus group participants were frustrated that their doctor's did not volunteer information about clinical trials and genetic testing. Patient navigators and social workers are tremendous resources in assisting patients to prepare for their doctor's visit. The Affiliate could connect organizations to resources to train local Lay Health Advisors and health promotores to work with residents on various breast health concerns.

c. Hispanic/Latina Assistance

Table 4 reflects the increasing rates of Hispanic residents within the 20-county service area. In the past 10 years, this population has grown 300% statewide. The Affiliate could connect local organizations to resources in order to effectively reach Latina women. Utilizing state organizations like El Pueblo to assist in developing culturally appropriate information for the Latino community could be an effective strategy.

d. Financial Support

Many focus group participants were frustrated by the financial burden they experienced with breast cancer treatments and diagnosis. Special effort should be made to address the cost of transportation, and insured having to pay multiple co-payments for doctor's visits. Develop resources to keep providers aware of resources for financial support is an important strategy. Assisting community groups explore opportunities to decrease the financial burden to patients through local partnerships and participation in the Affiliate's Community Health Grant program.

VI. Conclusions: What We Learned, What We Will Do

A. Review of the Findings

The data collected and analyzed in this assessment point to several key areas that are crucial to breast health services across the Affiliate service area. Some findings are not new, while others offer new perspectives and new layers to ongoing challenges. This research has revealed opportunities for developing the Affiliate's framework for investing in community mobilizing, community health grants and provider program support. Several themes in our current service area will also be applicable as we continue to grow the Affiliate's footprint.

- Metropolitan, Micropolitan and Non-Core areas (Section III.C.1.) have distinctive characteristics that will provide an important foundation for additional research into health behaviors and outcomes for various demographic groups. For example, rural women are less likely to have had a mammogram in the last 12 months. Why?
- Breast Cancer incidence and mortality disparities among races and ethnicities vary from region to region within our Service area, supporting the need for more localized research to identify causality in some regions (Section III.B.). For example, what are the unique characteristics of geographic areas where incidence rates for white vs. minority women are the opposite of other locations in the state?
- BCCCP may or may not be having a real impact in our state. Within our data sets, there is no evidence that the presence of BCCCP in a community clearly influences the incidence, mortality and/or mammography rates in that community (Section III.C.2.).

- Gaps in breast health education suggest that targeted interventions may have a greater impact than broad-based education strategies. For example, there are regions characterized by greater-than-average proportions of late-state diagnoses perhaps pointing to a need for education about the importance of early detection (Section III.B.3.). Focus groups pointed to a distinct lack of awareness in certain counties about transportation options for cancer patients (Section V.).
- Asset mapping offers a useful tool in assessing specific regions, and adding several components to those maps will help us to target our strategies. These components include transportation systems (as gathered for our Health Systems Analysis, Section IV.), for-profit cancer centers, radiology facilities, community and senior centers, and large places of worship (especially those with health ministries). Grantee partnerships that include some of these organizations, even those that are "for profit," may offer successful and replicable solutions to access and education issues.
- Support groups can serve not only as sources of encouragement for patients, but as crucial sources of information for patients' networks of supporters and co-survivors. Additionally, support groups may have the potential to become patient advocacy groups, particularly when managed by a patient navigator (Section V.B.).
- Substantial Native American populations in at least three counties have unique public health challenges that must be addressed with targeted strategies (Section III.B.2).
- Secondary needs are not being addressed, including financial support, education about post-diagnosis challenges, and access to resources like wigs and prostheses (Section V).

B. Conclusions

1. We are Many Communities, Not Just One Community

Our Affiliate serves healthcare communities that connect to several different "hubs" and often overlap, especially with the major systems based at UNC in Chapel Hill (Orange County), Duke in Durham and University Health Systems in Greenville (Pitt County). Within each of these systems, there are communities defined demographically that often have special needs. We often study the low-income, un- and under-insured "population" as a single entity, but that status combined with a number of other factors can create a more unique set of challenges. For example, Latino/Hispanic communities may have basic transportation challenges, but those can be compounded by language and documentation issues. Or African-American women in a place like Lee or Moore County, where their relative population is considerably lower than it is elsewhere in the state, may find that the hospital's supply of free wigs for cancer patients doesn't include any wigs that are racially appropriate/comfortable.

Each cluster of counties shown on Figure 5 represents the potential to target Affiliate funding to specific issues in the continuum of care—issues that will strengthen the entire system of education, screening, treatment and survivor services.

2. Access to Care Remains a Crucial Issue

Transportation, language and cultural barriers, and an absence of accessible information about breast health continue to be recurring themes. In some communities, these programs exist but are unknown; in others, they don't exist at all. Partnerships with other cancer, health and/or community organizations may offer opportunities to address some of these barriers; consolidating resources, particularly in small communities during times of economic stress, may have considerable potential for impact.

3. Education About Breast Health Resources is Only Marginally Successful

Mammography rates for all women aged 40+ are very low, indicating a fundamental disconnect in the continuum of care—for ALL women and not just for the under-insured. However, community characteristics and demographics appear to offer opportunity for creative communication strategies. For example, in more rural communities (Micropolitan and Non-Core areas), opportunities for delivering health messages may be found in churches, community centers and senior centers. While these strategies may also work in more urban communities, so might broad-based media exposure on billboards, for example.

4. BCCCP is Impacting Fewer People

Until the details of healthcare reform are clear and have been implemented, BCCCP remains our most important safety-net program for breast health in North Carolina. However, data about the impact of the program are not compelling, and in the last year, several counties have dropped BCCCP because of the administrative burden associated with managing the funds.

5. Providers Have Limited Resources & Capacity

As the economy continues to stress individuals and organizations, healthcare providers, especially small providers in resource-poor areas, are making tough decisions on a daily basis. For a provider that is making budget cuts just to keep basic services available, public education, hiring a translator or handing out gas vouchers may no longer be feasible. The increasing administrative burden of BCCCP has led some providers to drop the program altogether, leaving even fewer options for women in those communities. This sort of financial and programmatic stress creates an environment where the continuum of care can break down at any juncture: no marketing budget can mean less public outreach, no salary budget for patient navigators can lead to missed follow-ups and even missed diagnoses, smaller clinic staffs mean less time to spend discussing screening and treatment options with patients, and so on.

C. Action Plan

1. Target Community Health Assessments

Goal: Create an ongoing strategy for continually adding depth to the quantitative and qualitative assessments of the many communities served by our Affiliate.

The Affiliate has made a commitment to changing our model for community health assessments, and this Community Profile has offered additional insights into how the new model will look. We are currently experimenting with a permanent staff position dedicated primarily to executing ongoing information and data gathering for our Affiliate. Every 3-4 months, we will set targeted community health assessment goals that will allow us to learn about specific "communities"—whether it is a specific geographic region, a specific demographic group, or specific health behaviors. It is our intention to continually add depth and richness to our knowledge of our service area and of the unique combinations of demographics, characteristics and behaviors that lead to certain outcomes.

2. Focus Funding Opportunities

Goal: Create a transparent and manageable strategy and process for delivery of community health grants and small grants that target issues at a regional and/or "community" level.

As we learn more about how outcomes are connected to community characteristics, it is our intention to develop mechanisms that allow us to target community health funding where it will

have the greatest impact for each community. We will continue to explore successful models for targeting funds to specific needs while preserving the integrity of the granting process and Komen's commitment to transparency. For the 2012 Community Health Grant RFA, we will add a published scoring "bonus" during the review for grant applications that address "priority areas" including access to care, impactful and appropriate outreach/education for under-insured populations, and patient navigation for certain geographic areas. We will model the grant process on the system used by Komen National for the National Capital Area Community Health Grants, and we intend to develop a process that is flexible enough to accommodate priorities based on geography, demographics or any other parameter that may create a unique set of needs that require targeted solutions.

3. Support Community Mobilizing and Provider Capacity Building

Goal: Invest small grants (up to $10,000) in targeted providers to build their capacity to address specific issues identified for their communities.

To maximize our return on mission investment, it is our intention to actively participate in creating community partnerships and programs to address specific issues. We have created the framework for invitation-only small grants for this purpose and will be inviting our first applicants this Fall to apply for support. For example, we discovered in our Health Systems Analysis that while transportation options are available for cancer patients in those five counties, many don't know about them. Small grants will give us the flexibility to encourage one or more of the providers in that region to get together and collaborate to create an information network that would allow them to promote these services. Or in Caswell County, where the family clinic brings a mobile mammography unit to the county several times a year, this small grant program could allow us to work with the clinic to create outreach strategies for groups that are under-represented among the clients who utilize the unit.

4. Target Education/Outreach Funding for Maximum Impact

Goal: Create a strategy to maximize the outcomes of Affiliate-funded breast health outreach/education efforts, and modify the 2013 Community Health Grants RFA to target "education" funds based on that strategy.

We must increase our understanding, both locally and nationally, of how to create the biggest "bang for the buck" on education investment. In depth community assessments, particularly additional focus groups, will allow us to identify targeted strategies and/or communities and to establish affordable priorities for education about the importance of early detection, mammography after age 40, and basic breast health. We will also study evidence-based strategies for education/outreach programs that might work for our targeted communities and will look for opportunities to encourage small-grant applicants to develop such strategies locally.

5. Create a Strategy for Supporting BCCCP

Goal: Work with other NC Affiliates to (1) research the true impact of BCCCP funds (2) create a strategy for investing mission funds to enhance that impact, either directly or indirectly, and (3) continue to advocate for state budget allocation of funds AND for responsible and transparent investment of those funds by the BCCCP program.

The coalition of Komen advocates working on supporting BCCCP funding in the state budget is motivated and well-organized. However, our support of BCCCP cannot be limited to supporting a line-item in the budget. We must ensure that the program is well-managed, insofar as that is

possible, and that they communicate and interact responsively with service providers in the regions we serve. Our Affiliate will also be collecting qualitative and some additional quantitative data on the availability and usage of BCCCP so that we can identify targeted priorities for our own mission funding to fill gaps and potentially reinforce any weaknesses in the program at the provider level.

6. Develop Strong Relationships

Goal: Continue to develop relationships with academia, other non-profits and community and state leaders as a way of supporting program development and bringing much-needed resources and solutions to communities—particularly to non-metropolitan communities.
In a troubled economic environment, it is our responsibility to seek out potential partners to help address issues that are common across communities and regardless of the "disease." Such partnerships can offer communities collaborative approaches to transportation challenges, patient navigation and lay-health training, public health information campaigns and even program development and evaluation. We will also broaden our program of community networking/education events and training workshops.

The Komen model of investing in the community offers a robust framework for making a considerable impact in the Affiliate service area, not just as a single community, but as a collection of many distinct communities with equally distinct needs. Our vision is to learn as much about our communities as we can so that we can target our funds for maximum impact. To realize this vision, we will build on what we do best: mobilize communities, nurture relationships, support and empower organizations, and invest in the very best breast health programs in our state.

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