



# COMMUNITY PROFILE REPORT

Susan G. Komen for the Cure®  
Knoxville, Tennessee



2009

## **Acknowledgments**

We would like to thank the organizations and community members who contributed to the development of Komen Knoxville's Community Profile.

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# **Executive Summary**

## **Introduction**

Founded in 1997, the Knoxville Affiliate of Susan G. Komen for the Cure serves a 16-county area in East Tennessee, including Anderson, Blount, Campbell, Claiborne, Cocke, Grainger, Hamblen, Jefferson, Knox, Loudon, Monroe, Morgan, Roane, Scott, Sevier and Union. Each year, the Affiliate's signature event, Komen Knoxville Race for the Cure and other fundraising efforts provide strategic funding for local breast health education and breast cancer screening and treatment programs. For fiscal year 2008-2009, \$563,052 was awarded in Community Grants to not-for-profit organizations for breast cancer education, screening and treatment support programs in the Knoxville Affiliate's service area.

The Knoxville Affiliate is run by an Executive Director and overseen by a Board of Directors. Additionally, there are six committees that handle communications, fund development, grants, human resources, mission, and volunteers.

To continue our efforts, East Tennessee relies on the Community Profile process to guide its work. The Community Profile includes an overview of demographic and breast cancer statistics that highlight target areas, groups or issues. The statistics pinpoint where efforts will have the most impact. In order to ensure effective and targeted efforts, it is important to also understand what programs and services gaps, needs, and barriers exist. The Community Profile also includes analysis of the community within, including the voices of those living in priority areas and representing priority populations.

## **Overview Demographic and Breast Cancer Statistics Key Findings**

The Knoxville Affiliate of the Susan G. Komen for the Cure includes 16 counties located in East Tennessee. The counties are Anderson, Blount, Campbell, Claiborne, Cocke, Grainger, Hamblen, Jefferson, Knox, Loudon, Monroe, Morgan, Roane, Scott, Sevier and Union.

Population estimates of 2007 reveal the adult population service area at approximately 1,147,611 persons (U.S. Census Bureau, 2007 Population Estimates). The 16-county area is predominantly Caucasian (>90%). African-Americans comprise the second largest population, with Knox County having the highest percentage of African-Americans (9%). The number of Hispanic people residing in the state of Tennessee (TN) is estimated to be 3.5%. There is an estimated 11% Hispanic population in Hamblen County, which is more than three times the state average. Hamblen County's agriculturally based economy is known to draw a growing number of Hispanic migrant workers to fulfill seasonal jobs.

It is well established that women with low educational attainment are less likely to engage in regular breast cancer screening. Educational attainment in TN and within the 16-county service area is significantly lower than national averages. In TN, only 76% and 20% of the population 25 years of age and older graduated from high school and obtained a bachelors degree or higher

respectively, versus 84% and 27% for national averages. Twelve out of the 16 counties rank below the state rates for number of high school graduates, and 14 out of the 16 counties fall below the state rates for number of people earning a bachelor's degree or higher. When considering educational attainment as a predictor of health status, the Knoxville service area as a whole is more likely to have low awareness of breast cancer risk factors, use early detection methods, or seek treatment.

Similar statistics exist for income levels, a risk factor for non-screening. The median household income in TN is \$42,389, which is less than the national average of \$50,007. Only three of our service counties meet the average state median household income (Loudon, Blount, and Knox). Nationally, about 13% of people in the US live below the poverty line. Seventy-five percent of our 16 counties have higher percentages of people living below the poverty line than the national average. With the data showing a large proportion of our service area falling into the lower income categories, this suggests that these women are at a greater risk for not being screened and not being able to afford treatment.

Incidence rates (per 100,000) are higher in Caucasian females than African-American females (116 vs. 112 respectively); however, African-American females are more likely to die from breast cancer (25 vs. 37 respectively.) The three counties with the highest breast cancer incidence rates include Grainger (147), Jefferson (126), and Knox (122) counties. The highest breast cancer mortality rates are found in Grainger (39), Morgan (29), and Scott (28). (TN Dept of Health, 2001-2005.)

## **Overview of Programs and Services Key Findings**

There are over 20 support groups in the area. In some areas there are more available support groups than providers. For example in Cocke County there are three support groups but only the health department and a major hospital as health care providers. Women who live in this area experience barriers in access to care. Because of the low education and income level in East Tennessee, traveling thirty miles or more to reach the nearest breast health provider presents a significant barrier to breast health services. Individuals with low income or people who are uninsured or underinsured may be less likely to receive an annual mammogram, which increases the likelihood that breast cancer will be diagnosed in a later, more serious stage.

Some providers in the area reported they do not accept low income patients, do not give discounts, and do not refer these individuals to medical providers who can serve them. Since many of the rural counties have very few medical providers available, low income or uninsured individuals could be denied the only local source of medical treatment due to an inability to pay. Rural medical providers need to be educated about low-cost screening and treatment options as well as breast cancer support groups available.

Komen Knoxville's future efforts include increasing early detection, education and mobile mammography units to rural areas. With the help of the East Tennessee Representatives, seven Senate Seats and 20 in the House of Representatives, the Knoxville Affiliate will build working relationships with politicians to improve the breast health of individuals in the 16-county area. The Knoxville Affiliate also sees a need to establish more partnerships with community leaders

such as churches and other organizations to promote breast health to all people living in the 16-county area.

## **Overview of Exploratory Data Key Findings**

Findings from focus groups, key informants and provider surveys suggest that though much education regarding breast health and breast cancer is being done in the 16-county area, much is still needed to be done. There are groups (such as the Hispanic/Latino and the Deaf/Hard of Hearing) that are receiving little or no breast health/breast cancer education due to communication barriers that exist in the community (lack of available interpreters, for example). Additionally, providers need to be familiar with their own breast health services, as well as others in their immediate community. Being educated about breast health services in the broader community will allow providers to better serve patients by connecting them with resources that they do not provide (breast health services for low-income/financially needy individuals, for example).

### **The following are three key findings from the Provider Surveys:**

1. Only 33% of providers surveyed reported discussing breast health with women regardless of other health issues.
2. Thirty-three percent of providers surveyed reported offering no services for low-income or financially needy patients, not even referrals to providers who do offer these services.
3. Half of the healthcare providers surveyed reported not knowing about resources in their communities who serve low-income patients.

### **The following are nine key findings from the Key Informant Surveys:**

1. There is still a need for breast health education and preventive care information in most groups, regardless of ethnicity, age, income, or other demographic factors.
2. Medical doctors are considered the most credible source of breast health information and they are perceived as the most likely place for individuals to seek breast health information.
3. Health fairs/events are considered the most effective way to disseminate breast health information.
4. The majority of key informants did not consider access to care/services as a barrier in the 16 county area of East Tennessee. Access to care/services may be a more prevalent outside of the immediate Knoxville area.
5. The most serious perceived barriers to affordability to care/services included individuals not being able to afford missing work, not being able to afford transportation, not being able to afford services, not having insurance /not having adequate insurance, and an awareness of the cost of care/services.

6. The majority of key informants saw the following problems as barriers to screening: individuals fear having cancer, fear test results, fear pain, and fear losing a breast.

7. The majority of key informants reported the following cultural/behavior barriers to seeking breast health care/services: Individuals procrastinate or forget about care/screening, distrust the medical system, have other more urgent problems and demonstrate a lack of preventive behavior (for example, they don't feel sick so they don't have screenings).

8. The majority of key informants reported that the following actions need to be taken to minimize barriers: first, the public needs to be more educated regarding preventive care. Next, more transportation needs to be provided to and from medical facilities. Finally, providers need to be trained to be more culturally sensitive regarding the topic of breast health.

9. Nearly half of all key informants reported that they perceived a large number of women are not getting mammograms. The estimated percentage of women NOT getting mammograms ranged from 20% up to 75%.

Results from the provider and key informant surveys as well as from the focus groups provide valuable insight into community perceptions of and experiences with breast health and breast cancer information. The Affiliate will use this information to inform the selection of Affiliate priorities as well as the development of outreach programs for the coming year.

## **Narrative of Affiliate Priorities**

To ensure that all necessary priorities were considered, the Knoxville Community Profile team reviewed the findings as a group to define the final priorities. As a team, problems or needs were discussed for each priority listed. After this, the complete list was used to rank the top three priorities according to each member. Each member then briefly addressed what information they had used to inform their decision. The following three priorities were determined to be of top concern for the 16-county area.

**Priority 1:** Increase the number of breast health services available to Grainger County through funding, promotion of health system partnerships, and educational outreach.

**Priority 2:** Partner with community leaders to increase awareness and access to services for women in underserved populations.

**Priority 3:** Increase access and affordability to breast health services to uninsured, underinsured and high risk communities.

## **Affiliate Action Plan**

**Priority 1: Increase the number of breast health services available to Grainger County women through grant funding, promotion of health provider partnerships, and education outreach.**

**Objective 1:** By March 31, 2011, the Knoxville Affiliate will reach out to community leaders in Grainger County to initiate community partnerships.

**Objective 2:** By March 31, 2011, the Knoxville Affiliate will have conducted an educational outreach awareness campaign in Grainger County to increase awareness of breast cancer and breast health services in this area.

**Objective 3:** By March 31, 2011, the Knoxville Affiliate will invite Grainger County health care providers to attend a grant-writing workshop at the Knoxville Affiliate office.

**Priority 2: Partner with community leaders to increase awareness and access to services for women in underserved populations.**

**Objective 1:** By March 31, 2011, the Knoxville Affiliate will establish at least one additional community faith-based lay advocate program targeting African-American and/or Latino groups in the 16-county area.

**Objective 2:** By March 31, 2011, the Knoxville Affiliate will reach out to the Deaf/Hard of Hearing community through the Knoxville Center of the Deaf and the Tennessee Association of the Deaf.

**Objective 3:** By March 31, 2011, the Knoxville Affiliate will conduct an awareness campaign to increase the cultural sensitivity of healthcare providers in the 16-county area.

**Priority 3: Increase access and affordability to breast health services to financially needy and high-risk communities.**

**Objective 1:** By March 31, 2011, the Knoxville Affiliate will recruit at least one new grant application addressing access and affordability to breast health services from each of the 16 counties.

**Objective 2:** By March 31, 2011 the Knoxville Affiliate will partner with health care providers to establish an awareness campaign to reduce access barriers to breast health services.

**Objective 3:** By March 31, 2011, the Knoxville Affiliate will build relationships with local governments within the 16-county area to raise awareness of the local impact that breast cancer has in our community.

## **Limitations**

There were several limitations in the development of this Community Profile. Any conclusions drawn from this Community Profile must be considered with regard to the following research barriers and limitations in access to various communities.

Although the exploratory data did provide important community perspectives, it is not a representative sample of the total population. For example, over 80 medical providers across the 16-county area were either mailed or emailed a Provider Survey, yet only six providers actually completed them. Letters and follow-up phone calls were made. Also, all of the Provider surveys were completed by Caucasians. Therefore the provider exploratory data does not include any perspectives from minority races. Although 37 Key Informant surveys were completed, certain populations such as the homeless, LGBT, (lesbian, gay, bisexual and transgender), may not have been represented. The paper survey was available to all participants who attended focus group sessions and to those who were mailed a copy. However, many people chose not to fill out a survey, and those who did left some questions unanswered. Online surveys were limited to those who have internet access. Two focus groups (Hispanics and young breast cancer survivors) were cancelled and could not be rescheduled in time to meet the data collection deadlines.

The demographic and breast cancer data was limited and sometimes non-existent for African-Americans and Hispanics at the state and county levels. As a result, conclusions were drawn from state or national statistics and primary data. Gaining access to Key Informants of the various communities was not always possible due to time constraints.

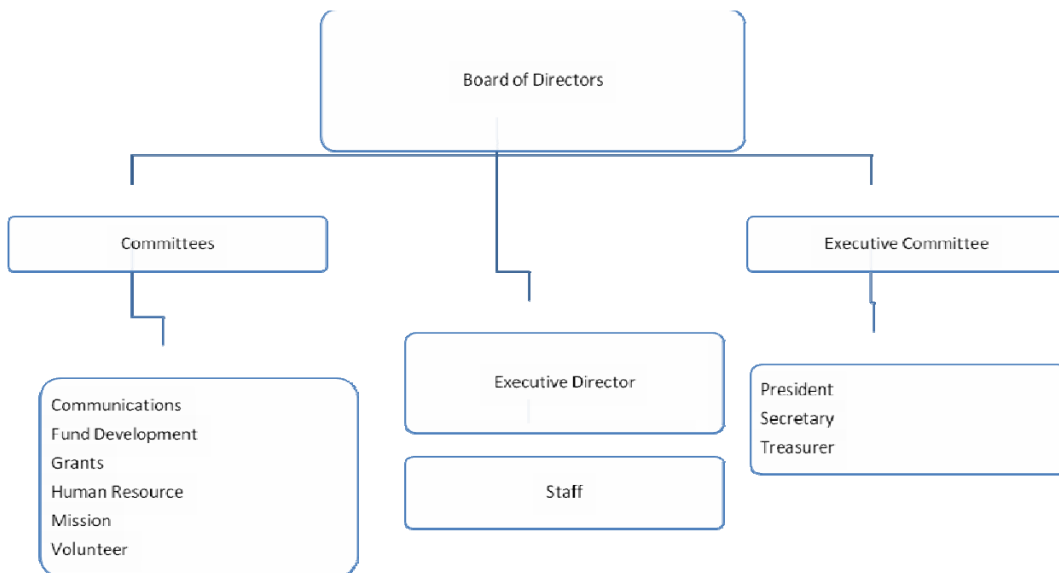
# Introduction

## *Affiliate History*

Founded in 1997, the Knoxville Affiliate of Susan G. Komen for the Cure serves a 16-county area in East Tennessee, including Anderson, Blount, Campbell, Claiborne, Cocke, Grainger, Hamblen, Jefferson, Knox, Loudon, Monroe, Morgan, Roane, Scott, Sevier and Union. Each year, the Affiliate's signature event, Komen Knoxville Race for the Cure and other fundraising efforts provide strategic funding for local breast health education and breast cancer screening and treatment programs. For fiscal year 2008-2009, \$563,052 was awarded in Community Grants to not-for-profit organizations for breast cancer education, screening and treatment support programs in the Knoxville Affiliate's service area.

## *Organizational Structure*

Susan G. Komen for the Cure Knoxville Affiliate organizational structure

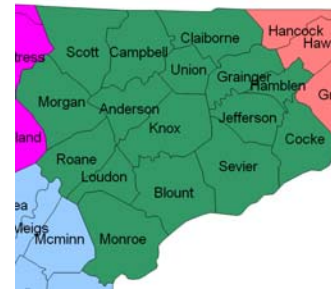


## Description of Service Area

Geographically, this Community Profile includes the Knoxville Affiliate service area which is divided into 16 counties: Anderson, Blount, Campbell, Claiborne, Cocke, Grainger, Hamblen, Jefferson, Knox, Loudon, Monroe, Morgan, Roane, Sevier, Scott and Union.



**Figure 1: Komen Tennessee Affiliates**



**Figure 2: Komen Knoxville Affiliate 16-county area**

The 16 counties are located in East Tennessee, covering 6,564 square miles. Across this area are rural communities, mountainous area and the urban city of Knoxville. The 16-county area is not a very diverse community. The population is predominantly white (~90%) with African-American being the second largest population with their largest population of 9% in Knox County. The number of Hispanics in the area is steadily rising, especially in Hamblen County where 11% of the adult population is identified as Hispanic, a number that is three times greater than the state average.

According to the 2006 Tennessee BRFSS (Behavior Risk Factor Surveillance System), the percentage of people who have had a clinical breast exam is 91% in Tennessee, 92% in East Tennessee and 87% in Knox County. The number of people who have had a mammogram is much lower at 65% in Tennessee, 64% in East Tennessee and 62% in Knox County region. The relatively lower numbers of people receiving clinical breast exams and mammograms in East Tennessee may lead to breast cancer detection at later stages, increasing mortality rates.

## Purpose of Report

The mission of Susan G. Komen for the Cure is “to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to discover the cures.” To continue to meet the organization’s mission, the Knoxville Affiliate relies on the information obtained from developing the Community Profile to guide the work needed to accomplish its mission in its communities.

The Community Profile guarantees that efforts are supported by Susan G Komen for the Cure and are targeted and non-duplicative. The Community Profile allows the organization to:

- Encourage inclusion efforts in the breast cancer community
- Tell the Komen Story and strengthen involvement of sponsors
- Establish direction for marketing and outreach
- Establish focus for granting priorities
- Establish focused breast health education needs
- Drive public policy efforts

The Community Profile includes an overview of demographics and breast cancer statistics in the Knoxville Affiliate area. A preliminary analysis of the demographics and breast cancer statistics highlight target areas, groups and/or issues. The statistics help identify where efforts will have the most impact. In order to ensure that targeted efforts are effective, it is important to identify and understand programs and services available and gaps, existing needs and barriers, as well as existing assets for partnerships and collaborative interventions. The Community Profile also includes an analysis of those living in the community through focus groups, provider and key informant surveys; giving those living in the targeted population a voice in this Community Profile.

## Demographic and Breast Cancer Statistics

### *Data Source and Methodology Overview*

To gather county level information for targeted analysis, 2007 population demographic estimates were obtained from the US Census Bureau ([www.census.gov](http://www.census.gov)). State and national breast cancer incidence and mortality rates (2001-2005) were obtained from the *Cancer in Tennessee* June 2008 publication by the Tennessee Department of Health, Office of Policy Planning and Assessment, Office of Cancer Surveillance, Tennessee Cancer Registry (<http://health.state.tn.us/Downloads/TCRAnnualReport01-05.pdf>). County breast cancer incidence and mortality was taken from the 2003 Tennessee Department of Health reports ([http://health.state.tn.us/TCR/reports/incidence/2003/2003\\_incidence.htm](http://health.state.tn.us/TCR/reports/incidence/2003/2003_incidence.htm) & [http://health.state.tn.us/TCR/reports/mortality/2003/2003\\_mortality.htm](http://health.state.tn.us/TCR/reports/mortality/2003/2003_mortality.htm).) Breast cancer incidence and mortality data was for females only. The Healthy People 2010 target breast cancer mortality rates were found on the U.S. Department of Health and Human Services website (<http://www.healthypeople.gov>). State level rates for uninsured and mammography were gathered from The Kaiser Family Foundation (<http://www.statehealthfacts.org>).

### *Demographic & Breast Cancer Statistics Overview*

Knox County and Blount County are the most populated counties with 423,874 and 119,855 people residing in these counties respectively. The remaining counties range from 18,877 to 83,527 people. The racial distribution in the 16-county area averages over 95% white, which exceeds the national average of 81%. In addition, the 16-county area has a lower ethnic minority distribution. About 2% of the population is African-American; 2% is Hispanic; and 1% other. Knox County has the highest percentage of African-Americans at 9%. Hamblen County has the highest percentage of Hispanics at 11%. In all 16 counties, race and ethnic minority distribution are not representative of the national percentage rates (US Census Bureau 2007).

The percentage of high school graduates in both the state of Tennessee (76%) and the 16-county area (68%) are lower than the national average (84%). In addition, the percent of college graduates in Tennessee (20%) and in the 16-county area (12%) are below the US average (27%) (U.S. Census Bureau, 2007.)

The median household income in the US (\$50,007) exceeds the Tennessee (\$42,389) and 16-county average income (\$37,630). The percentage of people living in poverty in Tennessee (16%) is significantly higher than national averages (13%). With the exception of Blount, Knox, Loudon, and Sevier counties, all remaining counties' poverty levels are worse than national averages (US Census Bureau, 2007). An estimated 16% of women 19-64 years of age are uninsured in the state of Tennessee. Although 67% of those uninsured are white, 49% of the total Hispanic population is uninsured. This is a large contrast to the Caucasian and African-American populations' uninsured rates (14% and 15% respectively) (CPS, 2007). For women who are uninsured and for those whose insurance does not cover breast screening and treatment in Tennessee, coverage could be received through the TennCare Medicaid program. To be eligible one must be under 250% of the federal poverty level (BCCSP).

Overview Demographics for US, State, and 16-County area

	2007 Population Estimates				Education		Income		% Living below the poverty line
	All Races	% Caucasian	% African-American	% Hispanic/Latino	% American /AK Native, Asian/Pac Islanders	% High School graduates	% Bachelors or higher	Median household income in US dollars	
US	281,424,602	81.1	12.7	12.5	4.9	84	27	50,007	13
TN	6,156,719	80.4	16.9	3.5	1.7	75.9	19.6	42,389	15.8
Anderson	73,471	93.1	4.1	1.7	0.4	78.9	20.8	42,059	16.1
Blount	119,855	94.5	3.2	1.7	1.3	78.4	17.9	47,466	12
Campbell	40,771	98	0.5	1.1	0.6	58.7	7	31,535	23.9
<b>Claiborne</b>	<b>31,270</b>	<b>97.4</b>	<b>1</b>	<b>0.8</b>	<b>0.8</b>	<b>60.3</b>	<b>8.9</b>	<b>29,822</b>	<b>22.3</b>
Cocke	35,337	96	2.1	1.3	0.8	61.2	6.2	29,637	26.6
<b>Grainger</b>	<b>22,546</b>	<b>98.4</b>	<b>0.7</b>	<b>1.6</b>	<b>0.2</b>	<b>60.1</b>	<b>7.8</b>	<b>34,148</b>	<b>19.4</b>
Hamblen	61,829	93.7	4	10.5	1.3	69.3	13.3	37,147	16.9
Jefferson	50,221	95.8	2.4	2.4	1	71	12.8	39,580	17.4
Knox	423,874	87.8	9	2.2	2.1	82.5	29	45,157	12.8
Loudon	45,448	96.8	1.5	4.2	0.7	75.6	17	48,355	11.1
Monroe	44,848	95.5	2.3	2.8	1.8	66.7	10.1	37,823	17.2
<b>Morgan</b>	<b>20,365</b>	<b>96.4</b>	<b>2.6</b>	<b>1.1</b>	<b>0.4</b>	<b>63.8</b>	<b>6</b>	<b>35,026</b>	<b>21.4</b>
Roane	53,399	95.2	2.8	0.9	0.8	74.8	14.8	41,897	16
<b>Scott</b>	<b>21,973</b>	<b>98.4</b>	<b>0.3</b>	<b>0.6</b>	<b>0.4</b>	<b>60.7</b>	<b>7.5</b>	<b>30,340</b>	<b>21.1</b>
Sevier	83,527	97.1	1.2	2.1	1	74.6	13.5	40,312	12.7
Union	18,877	98.2	0.6	1	0.4	56.3	5.8	31,779	21.7
16-County Average	71,726	95.77	2.39	2.25	0.88	68.31	12.40	37,630	18.04

Figure 3

Source:

U.S. Census Bureau, 2007 Population Estimates, Census 2000, 1990 Census

*Target Areas: What the Data Shows*

According to the Tennessee Breast Cancer Registry, breast cancer is the most commonly reported cancer among women in Tennessee. Between 2001 and 2005, the number of new cases of invasive breast cancer was reported to be around 4,000 each year.

Although the incidence rate of breast cancer in Tennessee is below the overall U.S. rate, the mortality rate is higher making breast cancer the second leading cause of cancer death for women in Tennessee. Incidence rates (per 100,000) are higher in white females than black females (115.7 vs. 111.6 respectively); however, African American females are more likely to die from breast cancer (24.5 vs. 37.2 respectively.) Additionally, in Tennessee 29.7% of those diagnosed were in advanced stages of breast cancer progression at the time of screening which indicates a need for community education (Li, 2008).

According to the CDC, the leading cause of death for Hispanic women in the US is breast cancer (16.1/100,000). Currently there are no data available for Hispanic breast cancer incidence and mortality in Tennessee.

The average incidence rate for the 16-county area is 112.4, which is below both the Tennessee and US incidence rates of 115.6 and 117.7 respectively. The average mortality rate in the 16-county area is 24.38/100,000, which is slightly better than the Tennessee and US mortality rates of 26.1 and 24.4 respectively. However, the East Tennessee mortality rates are still lagging behind the Healthy People 2010 goals of 22.3/100,000 people. The 16-county area on average has lower breast cancer incidence yet higher mortality compared to national averages.

The three counties with the highest breast cancer incidence rates include Grainger (146.9), Jefferson (125.6), and Knox (122.4) counties. The highest breast cancer mortality rates are found in Grainger (38.8), Morgan (28.7), and Scott (28.4). (TN Dept of Health, 2001-2005.)

Women living in Grainger County are acutely impacted by breast cancer, having the highest incidence and mortality rates in all of the 16-counties. Grainger County has an education attainment rate lower than national, state, and 16-county averages. Also, there are more people living in poverty in Grainger County compared to national and state averages.

Jefferson county ranks second highest in breast cancer incidence, yet it has lower mortality rates than national and state averages. Educational attainment is above the 16-county averages, yet the percentage of people living in poverty is greater than county averages.

In contrast to Jefferson County, Blount County has a lower incidence and higher mortality rates. Blount County has the second highest median income.

Loudon County has the highest median income and lowest poverty rates. Educational attainment exceeds the 16-county area averages in both high school and college education, yet remains lower than national and state averages. Mortality rates are lower than national and state rates. In addition, mortality rates are better than Healthy People 2010 goals. Loudon County is known for drawing a large retirement community from all over the US, a factor that may help explain the higher levels of income and education.

Knox County has a higher incidence rate and lower mortality rate than state, yet they are higher than national and Healthy People 2010 goals. Knox County has the highest rates of educational attainments. Relatively few are living in poverty compared to national and state averages. Knox County is the most racially diverse, with 9% blacks, 2% Hispanics, and 2% other. Knox County is the only county with data available for incidence (89/100,000) and mortality (27/100,000) for African Americans.

**Overview Breast Cancer Incidence & Mortality Rates (Females only)**

Breast Cancer	Incidence Rates					Mortality Rates				
	All races	Caucasion	African-American	Hispanic/Latino	American/AK Native, Asian/Pac Islander	All races	Caucasion	African-American	Hispanic/Latino	American/AK Native, Asian/Pac Islander
Healthy People 2010 Goal	-	-	-	-	-	22.3	22.3	22.3	22.3	22.3
US	117.7	132.5	118.3	89.9	158.8	24.4	23.8	32.3	16.1	27.6
TN	115.6	115.7	111.6	*	151.4	26.1	24.5	37.2	*	*
Anderson	122.1	121.9	*	*	*	19	15.7	*	*	*
Blount	107.4	91.7	*	*	*	<b>27.5</b>	31	*	*	*
Campbell	107.5	83.1	*	*	*	<b>26.9</b>	*	*	*	*
<b>Claiborne</b>	<b>116</b>	<b>131.2</b>	*	*	*	<b>25.3</b>	<b>41.8</b>	*	*	*
Cocke	94.4	107.8	*	*	*	21.5	27.5	*	*	*
<b>Grainger</b>	<b>146.9</b>	<b>185.5</b>	*	*	*	<b>38.8</b>	*	*	*	*
Hamblen	112.7	121.9	*	*	*	19.5	29.4	*	*	*
Jefferson	125.6	95.6	*	*	*	22.5	30.6	*	*	*
Knox	122.4	114.9	88.9	*	*	24.7	23.4	27.2	*	*
Loudon	139	123.3	*	*	*	20	21.7	*	*	*
Monroe	94.8	125.5	*	*	*	22.9	30.8	*	*	*
<b>Morgan</b>	<b>90.7</b>	<b>94.9</b>	*	*	*	<b>28.7</b>	*	*	*	*
Roane	113.4	116.7	*	*	*	24.2	26.6	*	*	*
<b>Scott</b>	<b>119.1</b>	<b>167.2</b>	*	*	*	<b>28.4</b>	*	*	*	*
Sevier	117.8	99.7	*	*	*	22	17	*	*	*
Union	67.9	81.1	*	*	*	18.1	*	*	*	*
16-County Average	112.4	116.4	88.9	*	*	24.4	26.9	27.2	*	*

**Figure 4**

Sources:

Tennessee Department of Health, Office of Health Statistics, 2001-2005 & 2003

Healthy People 2010, 2<sup>nd</sup> ed., U.S. Department of Health and Human Services

- Rates are per 100,000 and are age adjusted using 2000 U.S. population standard
- Rates are suppressed when fewer than six deaths were reported

*Demographic and Breast Cancer Findings*

Preliminary 16-county area analysis based on breast cancer and demographic data revealed three areas of need for breast cancer services: Grainger, Morgan, and Scott County. Grainger has the highest incidence and mortality rates. Morgan County has a low incidence rate yet the second highest mortality rate. Scott County has incidence and mortality rates above national and state levels.

Additionally, Claiborne County is one of the poorest counties and has a low educational attainment rate. These socioeconomic challenges may contribute to disparities in access to screening and treatment.

## Programs and Services



### *Data Source and Methodology Overview*

The Komen Knoxville Affiliate providers, programs and services assessment included the collection and mapping of provider and key organizational data. Inventory data was collected using the Tennessee Health Department website ([www.health.state.tn.us](http://www.health.state.tn.us)), Tennessee Breast Cancer Coalition ([www.tbcc.org](http://www.tbcc.org)), Internet provider searches and an internal Komen Knoxville database of grant applicants and recipients.

Google Mapping System was used to display 89 providers and partners in the 16-county area. The East Tennessee asset map displays local providers, grantees, breast cancer support groups, and other breast health services within the community. The asset map will be used to direct the selection of providers for further data collection.

### *Programs and Services Overview*

#### **Medical Providers**

There are multiple cancer related health care facilities and providers in the East Tennessee region, but they are not equally distributed. Knox County has more than twice the amount of providers as the surrounding counties. The lack of facilities in the more rural areas may prevent equal access to care. Cancer care in this region is provided to those with access and without barriers. However, individuals from underserved populations experience disparities in every aspect of care including screening, early detection, incidence, treatment, quality of care and survival.

Knox County has the most breast health providers. Examples include: The Free Medical Clinic of America, Knox County Health Department, Interfaith Health Clinic, Mercy Health Systems,

Covenant Health/Thompson Cancer Survival Center, The University of Tennessee Cancer Institute, etc. In contrast, surrounding counties may only have a single health clinic, which means individuals would likely need to travel to Knox County for breast cancer treatment. The Grainger County Health Department, for example, is located 33 miles away from Knox County. This distance may be a barrier for some people living in rural counties. Also, there are no cancer support groups or programs that support women living in Grainger County and some of the other more rural counties. Individuals living in counties such as Hamblen County are not solely limited to health department services. Hamblen County has a range of medical providers and services from Lakeway Regional Hospital, Morristown-Hamblen Healthcare System, Amedysis Hospice of Knoxville, and several more.

### **Community Support Groups**

Community support groups in the area provide financial and emotional support. One example is the Celebrate Life Cancer Support Group, which reaches out to rural patients to assist them during their lowest point in battling breast cancer. Hope for Today Cancer Support Group “Project H. O. P. E.” (Helping Oncology Patients Endure) helps breast cancer patients endure their diagnosis with travel expenses to treatment centers, physical aids (prostheses, bras, etc.), utility payments, housing expenses and medication as needed. Project C.L.E.A.R (Celebrate Life Enriching and Renewing) provides direct financial aid to patients when treatment expenses conflict with daily living needs. Reducing Breast Health Disparities is a program by the Rural Medical Services, Inc. which targets low income women in Cocke and Jefferson counties as well as the Hamblen County Hispanic population.

### **Komen Grantees**

The Knoxville Affiliate of Susan G. Komen for the Cure currently has 11 grantees located in several counties, but clustered in Knox County. Grantees include the American Cancer Society, Cathy L. Hodges Memorial Foundation, Celebrate Life Cancer Support Group, Hope for Today Cancer Support Group, Pastoral Care Department of the University of Tennessee Medical Center, People Empowering People Project, Inc. (PEPP), Rural Medical Service, Inc., Tennessee Department of Health Breast and Cervical Screening Program, The Wellness Community, Thompson Cancer Survival Center, and the University of Tennessee Cancer Institute.

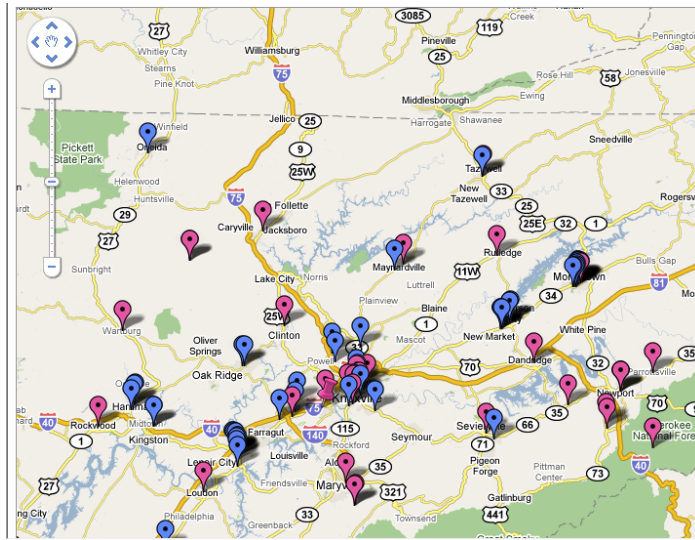
### *Target Areas: What the Data Shows*

Knox County is a resource rich community that consists of an abundance of hospitals and support groups. Knox County sits in the center of the 16-county region. Knox County is the major resource of East Tennessee breast health services. According to the last Census report in 2007, Knox County has a population of 423, 874 with 752 people per mile compared to the state average of only 138 people per mile. Knox County has several health department locations and over thirteen hospitals. Other counties in the 16-county region vary from having three or four hospitals to none at all. These communities such as Grainger County have shown a higher incidence of breast cancer and would benefit greatly from having a treatment facility in the area.

## Asset Map

A Google Map of breast health service providers and Komen Affiliate grant recipients appears below. The list of breast health providers is not comprehensive; however it is intended to illustrate the general clusters of services.

Komen Knoxville Affiliate grantees appear in pink, and medical providers appear in blue. The Komen Knoxville office is indicated by the pink thumb tack icon. Location and contact information can be accessed by pressing control+click over the map to open a new window.



**Figure 1: Breast Service Providers & Komen Affiliate Grant Recipients**

### *Promising Practices: Meeting People Where They Are*

The Komen Knoxville Affiliate has found that for any program to be successful the service providers must incorporate the strategy of “meeting the people where they are.” This includes providing patient navigation, being non-judgmental, going the extra mile to provide information, and helping bridge the gap in language barriers, regional dialects, and cultural differences. Other considerations in “meeting the people where they are” include accounting for differences in standards of living, family dynamics, and basic needs; and sometimes giving the extra emotional support that medical providers may not. When unexpected challenges arise for individuals, it should not preclude them from receiving the support and care they deserve. Ultimately, service providers are accountable to help equalize the access to medical and community services for all. This is the guiding principle in Komen Knoxville's community outreach and service provision.

Both UT Cancer Institute and the Thompson Cancer Survival Center are examples of meeting people where they are, allowing the underserved to be served. Cancer outreach services provide free or low-cost mammograms and educate women in target groups on prevention, early

detection, risk factors and types of screening. To reach the underserved populations, they provide mobile mammography at numerous churches, businesses, industrial sites and indigent clinics.

### *Public Policy Perspectives*

The Breast and Cervical Cancer Prevention (BCCP) program in Tennessee is operated by the Tennessee Department of Health (DOH). This is done through the county health departments', "TN Breast and Cervical Screening Program." This is a government funded program that changes with government perspective. Those eligible are under 65 years of age; uninsured or their insurance does not cover treatment for breast cancer; are at or below 250 percent of the federal poverty level; and have been determined by the county to need treatment (BCCSP). Many eligible people are unaware of this program and need a link to provide this knowledge. With more knowledgeable providers these women can be connected with the right resources to receive this free treatment.

The 16-county area of East Tennessee is represented by 7 Senate seats and 20 representatives in the House. Senators Rand McNally (R-Oak Ridge) and Doug Overbey (R-Maryville) both sit on the General Welfare, Health & Human Resources Committee. Other Senate members representing the area are not associated with health related committees (Tennessee General Assembly).

In the House of Representatives, Joe E. Armstrong (D-Knoxville) is Chairman of the Health & Human Resources Committee along with fellow committee member Representative Bob Ramsey (R-Maryville). The remaining representatives in the area are not associated with health related committees (Tennessee General Assembly).

Currently, the Knoxville Affiliate does not have an active role or relationship with the local governments within the 16 counties. However, building an active relationship with these community leaders could prove beneficial in increasing community access and addressing affordability issues. In the next two years, the Knoxville Affiliate will work to build relationships with local government within the 16-county area to raise awareness on the local impact breast cancer has in our community. These efforts will work towards addressing breast cancer policy related needs that will help reduce access barriers.

### *Programs and Service Findings*

There are over 20 support groups in the area. In some areas there are more available support groups than providers. For example, in Cocke County there are three support groups but only the health department and a major hospital as health care providers. Women who live in this area experience barriers in access to care. Because of the low education and income level in East Tennessee, traveling thirty miles or more to reach the nearest breast health provider presents a significant barrier to breast health services. Individuals with low income or people who are uninsured or underinsured may be less likely to receive an annual mammogram, which increases the likelihood that breast cancer will be diagnosed in a later, more serious stage.

Some providers in the area reported they do not accept low income patients, do not give discounts, and do not refer these individuals to medical providers who can serve them. Since many of the rural counties have very few medical providers available, low income or uninsured individuals could be denied the only local source of medical treatment due to an inability to pay. Rural medical providers need to be educated about low-cost screening and treatment options as well as breast cancer support groups available.

Komen Knoxville's future efforts include increasing early detection, education and mobile mammography to rural areas. With the help of our East Tennessee legislators, (seven senators and 20 representatives), the Knoxville Affiliate will build working relationships with politicians to improve the breast health of individuals in the 16-county area. The Knoxville Affiliate also sees a need to establish more partnerships with community leaders such as churches and other organizations.

## Exploratory Data



### *Data Sources and Methodology Overview*

To further understand the issues facing the intended population, the Community Profile assessment draws on the experiences and perspectives of providers of breast health services and community members in the 16 counties of East Tennessee.

Forty-three surveys were completed by current and past Komen grantees, hospitals, community members, breast cancer survivors, and providers of breast health services. Two surveys were developed; *East Tennessee Community Profile Key Informant Survey* and *East Tennessee Community Profile Provider Survey* which included a mixture of 31 and 23 open and closed ended questions respectively. The two surveys were built and distributed using the online survey tool Survey Monkey. The questions on the survey aimed at better understanding community needs for breast health services in the 16-county area. Additionally, the questions allowed participants to provide perspectives on access barriers for residents of the intended population, perspectives on high risk groups as well as ideas on approaches to address disparities in the targeted population.

Two focus groups were completed. One focus group was conducted with African-American Survivors, the other was conducted with a Deaf/Hard of Hearing senior citizens group who have never had breast cancer. The focus groups ranged from 35-45 minutes in length and were completed by members of the Community Profile Team. Both focus groups were scheduled based on the availability of those individuals participating in the focus groups. Potential discussion questions were established to be used during the focus groups. Participants received an educational key chain that brought forth awareness of the various size of lumps detected with and without mammograms.

Attendance ranged from 12 to 20 people. Both focus groups were conducted in Knox County. One group was a survivor group consisting of African-American women. Another group was the Deaf/Hard of Hearing which consisted of senior citizens and was conducted by a trained culturally competent sign language facilitator. The same script was used for both groups. The women were asked questions to assess their breast cancer, screening and resource knowledge and to discover barriers to screening and treatment services. Due to scheduling conflicts among the Community Profile Team, a note taker was only present at the African-American group. For analysis, the notes were reviewed after the group with the facilitator to fill in any gaps and determined themes. For the Deaf/Hard of Hearing group, notes were taken by the facilitator and were discussed with the Community Profile Team.

### *Exploratory Data Overview*

Findings from focus groups, key informant and provider surveys suggest that although much education regarding breast health and breast cancer is being done in the 16-county area, much remains to be done. There are groups (such as Hispanic/Latinos and the Deaf/Hard of Hearing) that are receiving little or no breast health/breast cancer education due to communication barriers that exist in the community (difficulty of obtaining interpreters, for example). Additionally, providers need to be familiar with their own breast health services, as well as others in their immediate community. Being educated about breast health services in the broader community will allow providers to better serve patients by connecting them with resources that they do not provide (breast health services for low-income/financially needy individuals, for example).

### *Exploratory Data Findings*

#### **The following are three key findings from the Provider Surveys:**

1. Only 33% of providers surveyed reported discussing breast health with women regardless of other health issues.
2. Thirty-three percent of providers surveyed reported offering no services for low-income or financially needy patients, not even referrals to providers who do offer these services.
3. Half of the health care providers surveyed reported not knowing about providers in their communities who serve low-income patients.

#### **The following are nine key findings from the Key Informant Surveys:**

1. There is still a need for breast health education and preventive care information in most groups, regardless of ethnicity, age, income, or other demographic factors.
2. Medical doctors are considered the most credible source of breast health information and they are perceived as the most likely place for individuals to seek breast health information.
3. Health fairs/events are considered the most effective way to disseminate breast health information.

4. The majority of key informants did not consider access to care/services as a barrier in the 16-county area of East Tennessee; however, since most key informants were from the Knoxville area, access to care/services may be an issue that is more prevalent outside of the immediate Knoxville area.

5. The most serious perceived barriers to affordability to care/services included individuals not being able to afford missing work, not being able to afford transportation, not being able to afford services, not having insurance /not having adequate insurance, and an awareness of the cost of care/services.

6. The majority of key informants saw the following problems as barriers to screening: individuals fear having cancer, fear test results, fear pain, and fear losing a breast.

7. The majority of key informants reported the following cultural/behavior barriers to seeking breast health care/services: Individuals procrastinate or forget about care/screening, distrust the medical system, have other more urgent problems and demonstrate a lack of preventive behavior (for example, they don't feel sick so they don't have screenings).

8. The majority of key informants reported that the following actions need to be taken to minimize barriers: first, the public needs to be more educated regarding preventive care. Next, more transportation needs to be provided to and from medical facilities. Finally, providers need to be trained to be more culturally sensitive regarding the topic of breast health.

9. Nearly half of all key informants reported that they perceived a large number of women not receiving mammograms. The estimated percentage of women NOT getting mammograms ranged from 20% up to 75%.

**The following are key findings from the African-American Survivors focus group:**

1. The overarching theme from this focus group was that more breast health education and information regarding preventive care is needed for young women. One participant suggested talking to women beginning at a young age; "middle school and high school is not too early."

2. This group also expressed a concern regarding limited services for low-income and financially needy individuals. When asked what causes gaps in treatment services for women in their communities, the participants cited a lack of money or lack of health insurance most often.

**The following are key findings from the Deaf/Hard of Hearing Senior Citizen focus group:**

1. For the deaf/hard of hearing senior citizen community, friends, family and television were the most commonly cited sources of breast health and breast cancer information.

2. Medical doctors were not cited as a common source of breast health and breast cancer information, possibly due to communication barriers. Many participants reported that doctors have refused to pay for an interpreter and that some medical appointments get canceled because an interpreter is not scheduled.

3. Due to various communication barriers, it is likely that this group is getting misleading or incomplete information about breast health and breast cancer. For example, one participant reported that at age 65 her doctor told her she no longer needed mammograms because she was too old. Another woman was in her 60's and had never had a mammogram.

4. Deaf/hard of hearing senior citizens seem eager for more information about breast health and breast cancer. The major finding of this focus group was that more education services are needed for the Deaf/Hard of Hearing (in American Sign Language and through other channels such as videos) to ensure that this group gets accurate information regarding breast health and breast cancer.

Results from the provider and key informant surveys as well as from the focus groups provide valuable insight into community perceptions of and experiences with breast health and breast cancer information. The Affiliate will use this information to inform the selection of Affiliate priorities as well as the development of outreach programs for the coming year.

## Conclusions

### *Putting the Data Together*

The Knoxville Affiliate 2009 Community Profile reflects a combination of primary and secondary data. Secondary data such as demographics and breast cancer incidence and mortality rates were cross-referenced with existing breast health providers and breast cancer survivor support groups. Demographics such as population numbers, race, education level, median income, percentage of people living in poverty, and amount of uninsured individuals were all considered. Primary data from surveys and focus groups were gathered to better understand breast health priorities from a program and services perspective as well as a community perspective. Although the primary data may not be representative of all targeted demographic groups, it did suggest needs and findings compatible with the secondary data.

The key informant and provider surveys focused on the patient services in rural counties of East Tennessee and the impacts on breast cancer diagnosis and treatment. After gathering information from providers, gaps appeared that were later explained by key informants. Perceived gaps included lack of access and affordability to breast health services. These gaps were also reported as problematic by key informants. For example, key informants reported several barriers such as lack of financial resources and lack of services that would prevent individuals from visiting the doctor or seeking other breast health services. Barriers that were revealed in both secondary and primary data influenced the selection of Affiliate priorities and objectives.

Findings from the key informant and provider surveys support the idea of a lack of services in some communities resulting in later diagnosis and treatment. The questionnaire revealed several areas where services were not provided and need funding to provide more services.

### *Target Area Findings*

Breast cancer mortality rates are alarmingly high in Grainger, Morgan, Scott, Campbell, and Claiborne counties (all above 25/100,000 people). Grainger County is particularly concerning with a 39/100,000 mortality rate. Demographics of these counties suggest barriers to screening and treatment may stem from a lack of financial resources, lack of insurance, and lower education levels. Asset mapping reveals fewer breast health providers and breast cancer support groups in all counties aside from Knox, Blount, Anderson, and Hamblen counties. Key informant surveys suggest barriers can be removed by providing transportation (from rural counties to city treatment centers), by offering public health education on prevention (especially at health fairs), and by educating medical providers to be more culturally sensitive.

Lack of resources (financial, transportation, insurance, etc) presents a major barrier to treatment. Since the average breast cancer incidence rates in the 16-county area are *below* state and national levels, the mortality rates should be as well. The fact that mortality rates are *higher* than state and national rates is a serious discrepancy. This discrepancy points to inadequate early detection and insufficient breast cancer treatment. Lack of resources is undoubtedly a barrier to treatment for many living in the 16-county area.

Underserved populations include minorities such as African-Americans, Hispanics/Latinos, Deaf/Hard of Hearing people, individuals living in poverty, and individuals without adequate insurance. These groups are especially at-risk. In fact, findings from the focus groups and key informant surveys indicated a resounding need for more affordable services as well as greater educational outreach to underserved populations. The fact that African-Americans have a lower breast cancer incidence, but a significantly higher mortality rate, echoes this request for more education and screening. Almost half of Hispanics are uninsured and may have language barriers to accessing education, screening, and treatment.

Fear and misconceptions were frequently reported as perceived barriers in key informant surveys and focus groups. These findings also underscore the need for more education, not just on the part of individuals, but also on the part of providers. Providers should be able to connect patients with the services they need (uninsured individuals and individuals who need interpreter services, for example). Additionally, there is a need for more providers of breast health services in counties where breast cancer rates are higher.

### *Selecting Affiliate Priorities*

To ensure that all necessary priorities were considered, the Knoxville Community Profile team reviewed the findings as a group to define the final priorities. As a team, problems or needs were discussed for each priority listed. After this, the complete list was used to rank the top three priorities according to each member. Each member then briefly addressed what information they had used to inform their decision. A final ranking was then done to determine the three priorities of top concern for the 16-county area. Based on the primary and secondary data findings, the following priorities were established:

**Priority 1:** Increase the number of breast health services available to Grainger County through grant funding, promotion of health provider partnerships, and educational outreach.

**Priority 2:** Partner with community leaders to increase awareness and access to services for women in under-served populations.

**Priority 3:** Increase access and affordability to breast health services to uninsured or under-insured and high-risk communities.

### *Knoxville Affiliate Action Plan*

To ensure that the priorities established by the Community Profile Team are met in a timely manner, the following objectives are proposed according to priority.

**Priority 1: Increase the number of breast health services available to Grainger County women through grant funding, promotion of health provider partnerships, and educational outreach.**

**Objective 1:** By March 31, 2011, the Knoxville Affiliate will reach out to community leaders in Grainger County to initiate community partnerships.

**Objective 2:** By March 31, 2011, the Knoxville Affiliate will have conducted an educational outreach awareness campaign in Grainger County to increase awareness of breast cancer and breast health services in this area.

**Objective 3:** By March 31, 2011, the Knoxville Affiliate will invite Grainger County health care providers to attend a grant-writing workshop at the Knoxville Affiliate office.

**Priority 2: Partner with community leaders to increase awareness and access to services for women in underserved populations.**

**Objective 1:** By March 31, 2011, the Knoxville Affiliate will establish at least one community faith based lay advocate program targeting African-American and/or Latino groups in the 16-county area.

**Objective 2:** By March 31, 2011, the Knoxville Affiliate will reach out to the Deaf/Hard of Hearing community through the Knoxville Center of the Deaf and the Tennessee Association of the Deaf.

**Objective 3:** By March 31, 2011, the Knoxville Affiliate will conduct an awareness campaign to increase the cultural sensitivity and atmosphere of inclusion by providers in the 16-county area.

**Priority 3: Increase access and affordability to breast health services to financially needy and high-risk communities.**

**Objective 1:** By March 31, 2011, the Knoxville Affiliate will recruit at least one new grant application addressing access and affordability to breast health services from each of the 16 counties.

**Objective 2:** By March 31, 2011, the Knoxville Affiliate will fund at least two grants featuring outreach campaigns that address access and affordability to breast health services.

**Objective 3:** By March 31, 2011, the Knoxville Affiliate will partner with providers to establish a campaign to reduce access barriers to breast health services.

**Objective 4:** By March 31, 2011, the Knoxville Affiliate will build relationships with local governments within the 16-county area to raise awareness on the local impact breast cancer has in our community.

## *Limitations*

There were several limitations in the development of this Community Profile. Any conclusions drawn from this Community Profile must be considered with regard to the following research barriers and limitations in access to various communities.

Time constraints led to limitations in exploratory data. Although the exploratory data did provide important community perspectives, it is not a representative sample of the population. For example, over 80 medical providers across the 16-county area were either mailed or emailed a Provider Survey, yet only six providers actually completed them. Letters and follow-up phone calls were made, however time constraints prevented further follow-up. Also, all of the Provider surveys were completed by Caucasians. Therefore the provider exploratory data does not include any perspectives from minority races. Although 37 Key Informant surveys were completed, certain populations such as the homeless, LGBT, (lesbian, gay, bisexual and transgender), and many others may not have been represented. The paper survey was available to all participants who attended focus group sessions and to those who were mailed a copy, however many people chose not to fill out a survey and those who did left some questions unanswered. Online surveys were limited to those who have internet access. Two focus groups (Hispanics and young breast cancer survivors) were cancelled and could not be rescheduled in time to meet the data collection deadlines.

The demographic and breast cancer data was limited and sometimes non-existent for African-Americans and Hispanics at the state and county levels. As a result, conclusions were drawn from state or national statistics and primary data. Gaining access to Key Informants of the various communities was not always possible due to time constraints.

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