



# COMMUNITY PROFILE REPORT

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## Acknowledgements

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### **Central and Western Oklahoma Community Profile Team Members:**

Amanda Janitz, MPH  
Project Coordinator  
Department of Biostatistics and Epidemiology  
OU College of Public Health

Becky Lawson, RN BSN  
Quality Improvement Coordinator  
Mercy Health Center

Janis Campbell, PhD  
Assistant Professor  
Department of Biostatistics and Epidemiology  
OU College of Public Health

Kathleen Johnson, MPH  
Graduate Research Assistant  
Department of Biostatistics and Epidemiology  
OU College of Public Health

Linda Cowan, MPH, PhD  
Professor  
Department of Biostatistics and Epidemiology  
OU College of Public Health

Aaron Wendelboe, PhD  
Assistant Professor  
Department of Biostatistics and Epidemiology  
OU College of Public Health

Eleni Tolma, MPH, PhD  
Assistant Professor  
Dept. of Health Promotion Services  
OU College of Public Health

David M. Thompson, PhD  
Associate Professor  
Department of Biostatistics and Epidemiology  
OU College of Public Health

Brandi Brown  
Mission and Programs Coordinator  
Central and Western Oklahoma Affiliate

Lorna Palmer  
Executive Director  
Central and Western Oklahoma Affiliate

### **University of Oklahoma Health Sciences Center, Biostatistics and Epidemiology**

**Student Association:** Anayeli Herrera Morales, Paul Rogers, Oleksandr Zeziulin, Qadir Assemy, Shirley James, Mohammad Siddiki, Thanh Nguyen, Shontelle Dixon, Erin Davis, Sarfaraz Hyder, Cynthia Harry, Summer Frank, Ann Norris, Angela Watkins, and MaKaya Saulsberry.

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## Executive Summary

### Introduction

This 2011 bi-annual Community Profile identifies key breast health issues in the 47 counties served by the Central and Western Oklahoma Affiliate of Susan G. Komen for the Cure® in order to establish priorities for improving breast health services. Five major findings were identified: (1) Women living in poverty are more likely to be diagnosed at late stage, receive treatment later and to die from breast cancer; (2) About 40 percent of women did not have a mammogram in the last 12 months; (3) Over 30 percent of women in the Affiliate service area are diagnosed at late stage; (4) There are high numbers of women in central Oklahoma still in need of breast cancer screening, diagnosis and treatment; (5) Additional services to screening, diagnosis and treatment such as transportation, prostheses, child care and nutrition programs are still needed by women diagnosed with breast cancer.

Two service provision issues were emphasized: (1) There is a need for an increase in breast health providers for women in rural and high poverty areas; (2) Gaps and barriers unique to Oklahoma are present at each stage of the continuum of care, from screening through follow-up care.

The Affiliate service area had over 1 million women in 2009. Seventy-one percent of population in the area was White, seven percent African American, ten percent American Indian, one percent Asian, and seven percent Hispanic. Sixteen percent of the area households had incomes below \$15,000 as compared to 12 percent in the US overall.

Oklahoma's overall breast cancer incidence rate in 2007 was higher than the US overall at 125.0 compared to 120.4. The age-adjusted death rate in 2007 was higher as well with 24.9 deaths compared to 22.8 for every 100,000 women. Overall, the Years of Potential Life Lost (YPLL) before the age of 65 in Oklahoma for 2007 alone was 2,400 years. In the Affiliate service area in 2007, 1,365 years of potential life before the age of 65 was lost.

Over 30 percent of women in Oklahoma and in the Affiliate service area were diagnosed at late stage.

In Fiscal Year 2010 the Oklahoma Breast and Cervical Cancer Early Detection Program (Take Charge!) served 7,009 women in Oklahoma, only 21 percent of the eligible women. Of the 7,009 women screened 10.3 percent were African American, 24.7 percent were Hispanic and 2.4 percent were American Indian.

From the inception of the Oklahoma Breast and Cervical Cancer Treatment Program on January 1, 2005 to September 2010, 24,414 women were enrolled in the program. Over 2,500 women are enrolled each month with an average of over 300 new women enrolled each. A quality assessment and performance improvement study of the

program in Oklahoma showed the top cost for diagnosis was for Breast Cancer with almost 8 million dollars from July 2007 through June 2008.

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

Data was collected from the Oklahoma State Department of Health (OSDH) and the Susan G. Komen for the Cure® Community Profile Analysis provided by Thomson Reuters© 2010 for 2009 for all 47 counties in the Affiliate area. For this report, breast cancer incidence, mortality, Years of Potential Life Lost (YPLL) from breast cancer in women under 65 years, and stage at diagnosis were collected from OSDH. Estimates of poverty, insurance, income, screening, and breast cancer prevalence for 2009 were obtained from the Thomson Reuters© 2010 data.

Review of the breast cancer data in Oklahoma helped to determine the target geographic and demographic areas in the Affiliate service area that need enhanced services. Several counties were identified as target areas based on incidence, stage at diagnosis, mortality, or screening. However, when analyzing the Affiliate service area as a whole, more focused target areas emerged. Geographic targets are Oklahoma County, Southwestern Oklahoma counties (Washita, Caddo, Harmon, Greer, Kiowa, Jackson, and Comanche Counties), and several Eastern counties in the Affiliate area (Pontotoc, Pottawatomie, and Seminole Counties). The demographic targets are African American women and women living in areas of high poverty. Several target counties were determined separately due to low incidence, high late stage diagnoses, high mortality rates, or a high percentage of women who have not had a mammogram in the last 12 months.

- Incidence Targets
  - Blaine, Carter, Ellis, Garfield, Harmon, Pontotoc, and Seminole Counties
  - American Indian women in Lincoln County and African American women in Cleveland County
  - Women 40-64 years in Logan County
- Staging Targets
  - Alfalfa, Beaver, Caddo, Carter, Cimarron, Dewey, Garfield, Garvin, Grant, Greer, Jackson, Kiowa, Love, Oklahoma, Payne, Pottawatomie, Roger Mills, Seminole, Texas, Washita, and Woodward Counties
- Mortality Targets
  - Comanche and Oklahoma Counties
- Screening Targets
  - Canadian and Harper Counties
- Small Area Analysis Targets
  - Central Oklahoma City and Southwest region of Oklahoma
  - Beaver County and parts of Texas, Harper, and Ellis Counties in Northwestern Oklahoma

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

In order to understand the areas and groups of women that needed enhanced services, data was collected from the Oklahoma Central Cancer Registry (OCCR) on geographic region, area poverty level, payer source, race/ethnicity, residential area and days to treatment from diagnosis. Also, a survey was conducted of the Affiliate service area breast health facilities to better understand services provided such as education, financial support, and their relationship with Komen.

Identified were several targeted communities based on the percentage of women who began treatment for breast cancer more than 30 days after diagnosis. Women living in census tracts with more than 20 percent of the population below the federal poverty level were more likely to begin treatment late. There was also a difference by insurance, with Indian Health Service (IHS), Medicaid, and uninsured women being more likely to begin treatment late. Also, African American, American Indian, and Hispanic women were more likely to begin treatment late.

In the provider survey, it was found that 25 percent of the responding providers provide mammography services in their clinic and they see a varying number of patients each year. The majority of providers (47 percent) reported that more than 75 percent of their clientele were women over the age of 40. Seventy-two percent of providers discuss breast health at every well-woman visit. The most common form of educational material provided was brochures (71 percent). Providers had many accepted methods of payment and 62 percent provided financial assistance to those who qualify, most frequently using the Take Charge! Program guidelines. Finally, the majority of respondents (72 percent) had heard of Komen, but had never interacted with them.

Finally, it must be noted that Oklahoma City ranked 50<sup>th</sup> (worst) of 50 major cities in a 2008 a metropolitan transportation ridership survey of US cities (<http://www.sustainlane.com/us-city-rankings/cities/oklahoma-city>). The “SustainLane US City Rankings is a proprietary, peer-reviewed, national survey that ranks the most populous US cities in terms of their sustainability practices.”<sup>1</sup> In recognition of this issue Oklahoma City residents in 2010 voted a major funding program that includes plans to improve the public transportation systems – funded by a one-penny sales tax.

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

Focus Groups were conducted to better understand the experiences of women in the community regarding breast health. Questions were asked about barriers, experiences with providers, knowledge of breast cancer and Komen, and where women seek information and medical care regarding breast health. Three focus groups were held; one with American Indian women at the Oklahoma City Indian Clinic (OKCIC), one with Latina women at the Latino Community Development Agency (LCDA), and one with African American women at the Urban League of Greater Oklahoma City Senior

Community Cottages (UL). Results were analyzed by questions and themes were recognized as being present in two out of three groups.

The first question asked where women were most likely to go for breast health information. Themes identified were the internet and the doctor's office, both reported by OKCIC and UL women. Other sources mentioned were the LCDA by Latina women, the women's daughters and Komen by OKCIC women, and the Health Department or 211 by UL women. The second question was about the barriers that prevent women from seeking or getting breast health in their community. Cost, fear, and bad experiences were themes identified from this question. All groups discussed costs, both monetary and non-monetary, as barriers. Monetary costs included the expenses of seeking care which were primarily attributed to transportation and lost wages due to missing work or losing a job. Non-monetary costs included stress related to costs of healthcare. Also, identified were three types of fear: fear of the results, fear of pain from the exams, and fear of going to the clinic due to domestic situations and language barriers. Women also reported negative experiences at clinics and not getting their test results as barriers to receiving follow-up care.

Next, women were asked what providers in their community could do differently to ensure those who really need messages and services receive them. Four themes were identified from this question: patient-provider relationship, using TV/media, lack of knowledge regarding breast self-exam, and education. LCDA and OKCIC women expressed a desire for better communication and kindness from providers. UL and LCDA women felt that advertising during commercials, particularly culturally-appropriate ads, would benefit their communities. LCDA women discussed the use of telenovelas (Latin soap operas) to communicate the importance of breast health through the story line. UL and LCDA women also felt they had a lack of knowledge about breast self-exam. Finally, women want more education about breast health, but not necessarily through brochures. LCDA women reported that they did not like to read written education materials and would throw them away. OKCIC women mentioned that women often did not pick up brochures at the clinic.

When asked what barriers American Indian, Latina, and African American women face in seeking mammography services, responses varied by group. LCDA women mentioned, as stated previously, that Latina women do not read materials given to them and oral or hands-on education is more beneficial. UL women discussed the use of home-remedies and "putting themselves in God's hands" to treat health problems. OKCIC women stated that women were raised to be quiet and not discuss personal problems.

Conducting focus groups with African American, American Indian, and Latina women produced a better understanding of the knowledge and perceptions of breast cancer and Komen. One finding that stands out is that women are not likely to read written material, such as brochures, that providers give them. Verbal or hands-on education is more likely to be effective. Since most clinics provide written educational material, it is

important to work with providers to use educational methods that are going to be most effective in women seeking services.

### **Narrative of Affiliate Priorities**

This report's recommendations include: increasing the number of health services and providers available in the target counties and zip codes by funding health system partnerships to increase access to services, improving educational outreach activities concerning risk factors and preventive measures including internet and provider educational resources, and investing in organizations providing ancillary services such as transportation, wigs, prosthetics, child care and the like to segments of population unable to procure those services and materials.

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

- Education – Programs in place for the general population
- Screening – Medicaid eligible recipients, Medicare eligible recipients, Ethnic specific groups (American Indian, African American, and Hispanic), low income, uninsured women over 40 years.
- Diagnosis and Treatment – Further diagnosis program for low-income, uninsured women of all ages. Treatment programs in place at local medical facilities.
- Support Services – General population support groups concentrated in Oklahoma City Metropolitan area, support group for children whose loved one has a life threatening illness, and African American support groups.

### **Affiliate Action Plan**

**Priority 1:** Increase the number of health services and providers available in the target counties and zip codes by funding health system partnerships to increase access to services.

**Priority 2:** Improve educational outreach activities concerning risk factors and preventive measures including internet and provider educational resources.

**Priority 3:** Invest in organizations providing ancillary services such as transportation, wigs, prosthetics, child care and the like to segments of population unable to procure those services and materials.

## **Introduction**

### **Affiliate History**

Dr. Glenna Young and several female healthcare professionals whose work involved the treatment of cancer were active in getting an affiliate of the Susan G. Komen for the Cure® started in Oklahoma City. This group approached Project Woman in 1993, showed the board a video of the Dallas Race for the Cure®, and explained that they wanted to start one here.

Ann Hoover was asked to co-chair the first race because she had been involved with the Aspen Race for the Cure® and because she was a close, personal friend of Nancy Brinker, the founder of Komen for the Cure. Approximately 1,200 people participated in the first race. The next year it came close to doubling and has continued to grow since. This year about 18,000 participants are expected. Revenue generated by Race, corporate and individual contributions and fees for other events generated total revenue of \$1,288,486.13 in the fiscal year ending March 31, 2010. These revenues enabled the Affiliate to help fund national research and provide education, screening, and treatment for those affected by breast cancer in the Central and now Western Oklahoma service area.

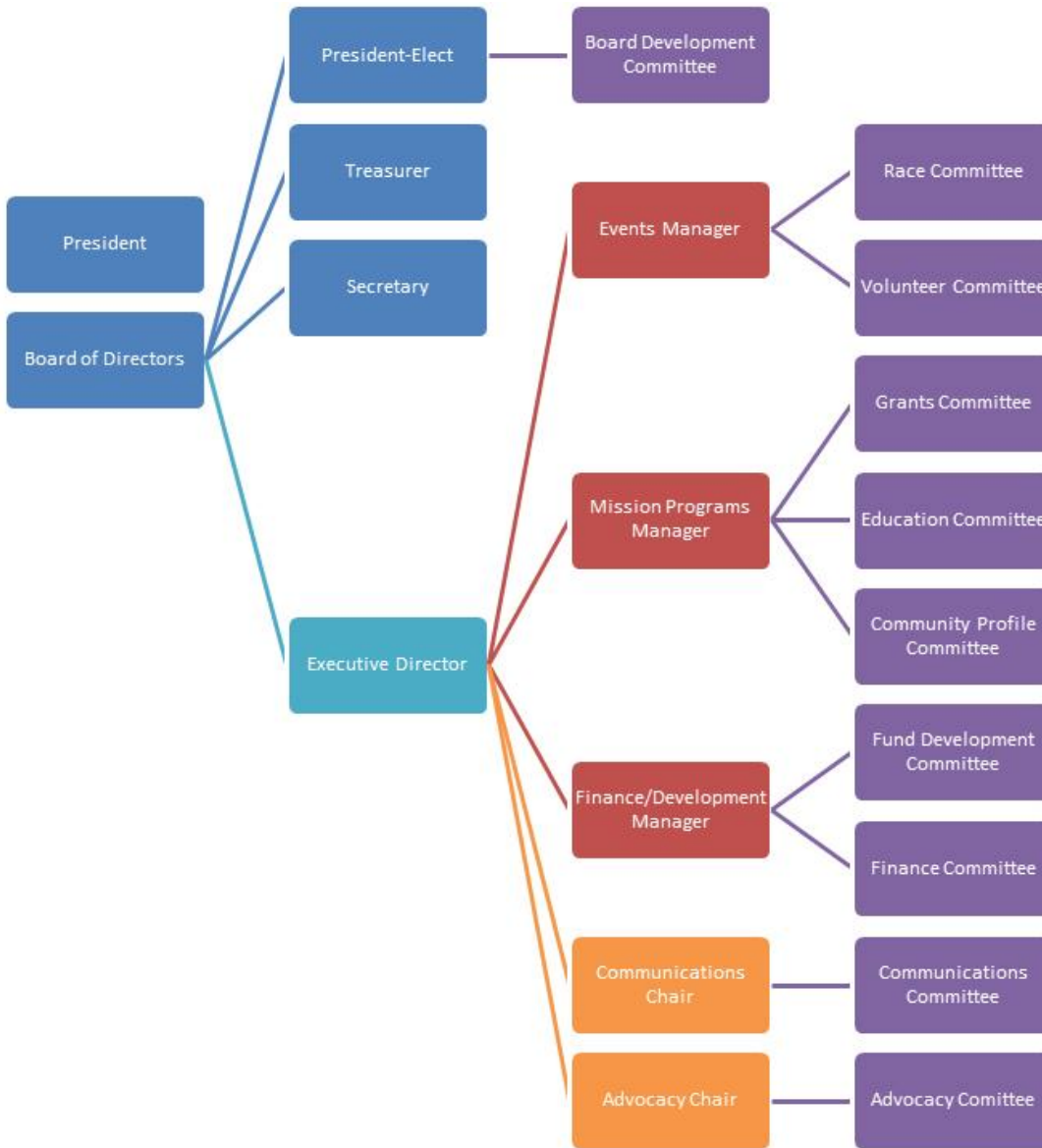
Funds raised from the Central Oklahoma Komen Race for the Cure are granted to local programs that support Susan G. Komen for the Cure's promise to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find cures. Since inception, the Affiliate has granted over 5 million dollars to local organizations providing breast health research and services. For the past sixteen years, the Affiliate service area has included the ten central Oklahoma counties. As a result of findings from the 2009 Community Profile, the Affiliate saw the need to expand much needed services to women in the western half of Oklahoma. In 2010, the Affiliate applied for and received approval for expansion thus adding thirty-seven counties to the service area and officially changing the Affiliate name from the Central Oklahoma Affiliate of Susan G. Komen for the Cure to the Central and Western Oklahoma Affiliate of Susan G. Komen for the Cure®. Another wonderful effect of expanding the service area is the upcoming addition of a second Race for the Cure to be held in May 2012 in Oklahoma's fifth largest city, Lawton, Oklahoma.

### **Organizational Structure**

The Affiliate has a staff of four fulltime employees. The organizational chart shown below provides titles and functions filled by board members, staff and volunteers. Oversight of the Affiliate is the responsibility of the Board of Directors. The primary duties of the Board include appointment and oversight of the Executive Director, the establishment and annual revision of the organization's strategic plan, fiscal oversight, adoption of an annual budget, and the establishment of policies and procedures, as may be needed. Board members are drawn from the Affiliate service area and include a diverse group of individuals with backgrounds in healthcare, other non-profits or

business. Most Board members actively participate in one of these committees: Executive, Screening, Grants, Education, Medical Advisory, Advocacy, Development and Communications, Board Development or Finance. There are currently nine Board members.

Figure 1. 2011 Central and Western Oklahoma Affiliate Organizational Chart

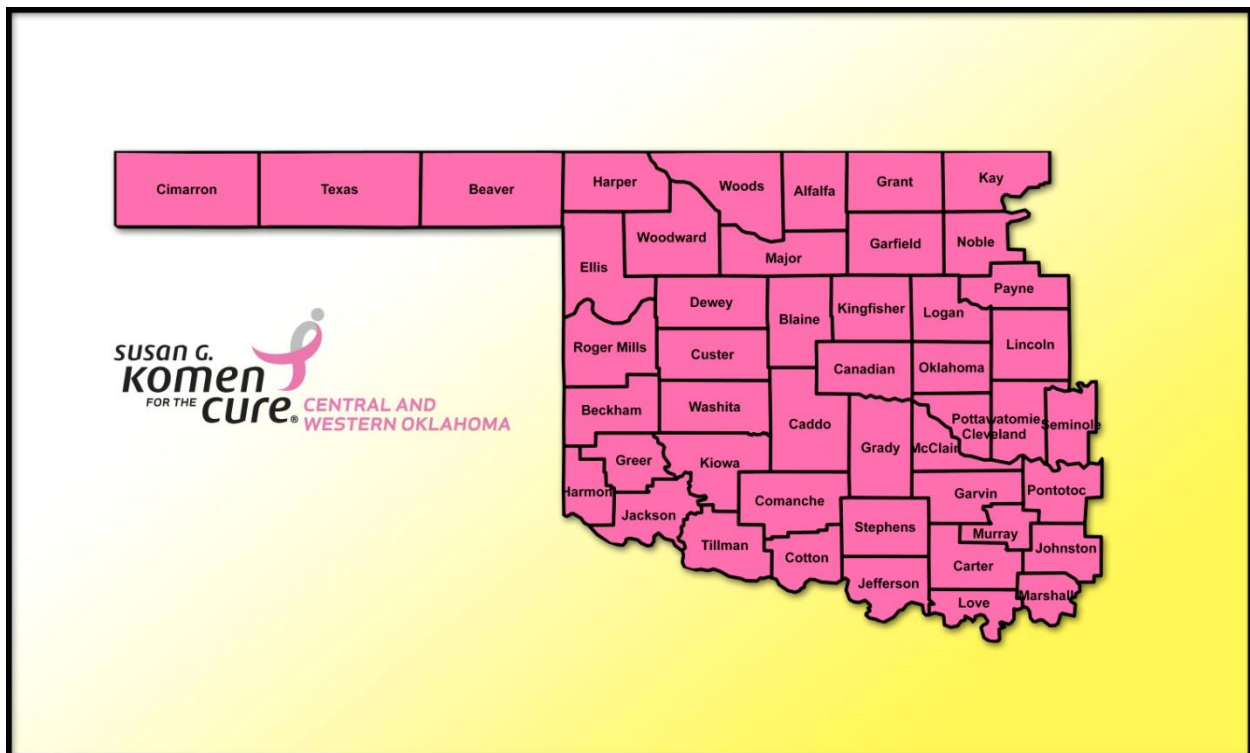


## Description of Service Area

The Affiliate serves 47 of the 77 counties in the State of Oklahoma. Our service area includes both densely populated urban counties as well as sparsely populated rural counties. The rural areas are primarily west of the central core of the service area which includes densely populated urban counties, located primarily along the Interstate 35 and Interstate 40 corridors. This urbanization begins north of Oklahoma City, Oklahoma (Oklahoma County) south to Norman, Oklahoma (Cleveland County) east to Midwest City, Oklahoma (Oklahoma County) and west to Yukon, Oklahoma (Canadian County). Even the densely populated counties also have rural areas with low population densities and some agricultural economies. Since the Affiliate expansion now encompasses such a large area, work is in progress to divide the service area into regions: Central, North Central, South Central, Western, Northwestern and Southwestern Oklahoma. The regions are not equal in size or population, but rather are drawn to closely parallel where people may access breast cancer services.

Oklahoma is the home of 39 federally recognized tribes. In the Affiliate service area, 21 of the 39 tribes have tribal land. Moreover, the service area includes Oklahoma City, which includes the third largest urban American Indian population in the US.

Figure 2. Central and Western Oklahoma Komen Service Area



## **Purpose of the Community Profile**

The purpose of the Community Profile is to provide a thorough assessment of breast health in the Central and Western Oklahoma Affiliate service area. Identified were service gaps, established priorities for improving breast health services and evaluated the impact of public health programs and policies on the community. This report serves as the basis for goals included in the Affiliate's Strategic Plan and the strategies to reach those goals. Work on the Community Profile started in September 2010 and was completed in March 2011. All of the research and writing was completed with the help of the Komen staff and those partners listed in the Acknowledgment Section.

## Demographic and Breast Cancer Statistics



### Data Source and Methodology Overview

In order to understand the impact of breast cancer in the Central and Western Oklahoma Affiliate area, data was collected from several sources. Demographics, income, information on screening, and breast cancer prevalence estimates from 2009 were reported for all 47 counties by the Susan G. Komen Community Profile Analysis provided by Thomson Reuters© 2010.

The purpose of screening for breast cancer by mammography is to identify early disease, thereby improving survival. Understanding the uptake of screening by mammography in different populations is important in knowing where to target screening and education programs. Percentages of women who have not been screened within the last 12 months in each the 47 counties were collected by Thomson Reuters© 2010.

Data on breast cancer incidence, mortality, YPLL due to breast cancer deaths in women younger than 65, stage at diagnosis, and insurance status was also collected from the Oklahoma Central Cancer Registry (OCCR) from 1997-2007 and are indicated by charts and graphs.

For this report, breast cancer incidence was defined as the number of new invasive cases in women diagnosed in each of the 47 Affiliate counties. OCCR data was available from 1997 to 2007. This report uses those years unless otherwise noted. Incidence rates were calculated by dividing the number of new cases by the number of females in the population and represents the average annual incidence rate over this 11-year period. Incidence reflects both the underlying risk of breast cancer in a population and the ability to identify the disease through screening and diagnosis. In

summarizing this data, the assumption was made that counties or groups with lower than expected incidence rates might benefit from additional screening efforts, rather than that they have an inherently lower risk of breast cancer.

In order to understand the distribution of breast cancer and the impact of screening, it is important to analyze the staging of breast cancer at diagnosis. For this report, the four stages of *in situ*, local, regional, and distant are displayed for each county. *In situ* tumors are contained within the cells where the tumor began and have not spread beyond this point. Local tumors are those that are completely contained within the breast. Regional tumors are those that have spread beyond the breast to nearby lymph nodes, organs, and/or tissues. Distant tumors are those that have spread to distant lymph nodes, organs, or tissues.<sup>2</sup> An important reason to understand staging at diagnosis is to know the proportion of women who are diagnosed at distant stage. Populations with high levels of distant stage breast cancer have likely not been screened previously; else the cancer should have been detected before it progressed to distant stage.

Breast cancer mortality was determined using OSDH data using OK2SHARE (Oklahoma's online vital statistics database), which provided the number of deaths, crude mortality rate, and age-adjusted mortality rate overall and by race, ethnicity, and age. Crude mortality rates were calculated by dividing the number of deaths in women by the total population of women from 1999 to 2003 in each of the 47 counties. Age-adjusted mortality rates remove age differences from the rate, allowing for comparison across counties. Years of Potential Life Lost (YPLL) before the age of 65 is a measure of premature death due to breast cancer and calculated for each county. YPLL was determined by subtracting the age at death from 65, then summing all of these years from all residents living in the respective county. Mortality data is important for understanding the impact of screening as well as treatment patterns.

In this report, cases diagnosed as *in situ* were excluded from the incidence data. In the staging data, cases diagnosed only through the death certificate were also excluded because stage is not classified for these cases. Rates were not calculated for any of the groups (overall, by age or by race/ethnicity) if there were fewer than five cases or deaths due to confidentiality and the higher variability of the estimates when sample sizes are too small. In the incidence section, age and race/ethnicity-specific rates were not calculated in counties with fewer than 50 cases. Instead, the overall age-adjusted incidence rate for the entire 47-county Affiliate service area was compared to the age-adjusted incidence rate for the entire county. In counties this small, it is important to interpret the results of all sections with caution due to the variability of the data. In the demographics section, the age distribution by county was not determined for race/ethnicity groups with fewer than three age groups. A limitation of the demographic and screening data from Thompson Reuters ©2010 is that these data are estimates of proportions and rates instead of exact data. Thus OCCR data was used.

In order to conduct small area analysis, a geostatistical technique, called Kriging, was used to interpolate the value of field or areas based on observations of its nearby

location. This allows visual focus on high (or low) areas and smoothes the rates so sharp boundaries are not seen. Thus efforts can be focused in the highest areas of need.

## **Overview of Key Demographic and Breast Cancer Statistics at State and County Levels**

### **Demographics**

The Affiliate service area had over 1 million women in 2009. Seventy-one percent of population in the area was White, seven percent African American, ten percent American Indian, one percent Asian, and seven percent Hispanic. In the Affiliate service area, the female population ranged from an estimated 1,259 to 380,720 in each county in 2009, with Cimarron being the smallest and Oklahoma being the largest county. In each county, the highest proportions of women were White, ranging from 58 percent to 98 percent.

### **Income/Poverty**

Sixteen percent of the area households had incomes below \$15,000 as compared to 12 percent in the US overall. The estimated median number of families in the Affiliate service area in 2009 was 4,404. The number of families ranged from 717 to 183,974 per county, with Harmon County having the smallest number and Oklahoma County having the largest number. An estimated average of 12 percent of families had income below the federal poverty line, ranging from five percent in Canadian County to 23 percent in Harmon County. The estimated median income for the Affiliate service area in 2009 was \$38,870, ranging from \$28,269 in Harmon County to \$56,929 in Canadian County.

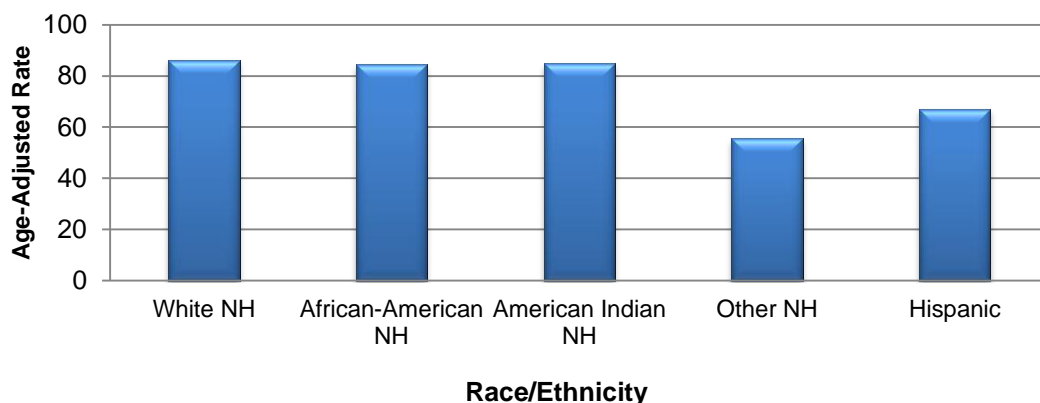
### **Breast Cancer Prevalence**

In 2009, the estimated median number of women living with breast cancer was 562 cases per 100,000 women. The prevalence proportion ranged from 354 cases per 100,000 women in Texas County to 754 cases per 100,000 women in Alfalfa County. The estimated average age of these cases was 60.5 years, ranging from 57.1 years in Cleveland County to 62.4 years in Alfalfa County. However, these numbers should be interpreted with caution due to the small number of cases, particularly in the highly rural northwestern portion of the Affiliate service area.

### **Breast Cancer Incidence**

Oklahoma's overall breast cancer incidence rate in 2007 was higher than the US overall at 125.0 compared to 120.4. In the Affiliate service area the rate was even higher at 136.7. There was no difference in the Affiliate service area by race; however, Hispanics were somewhat lower than other racial groups (Figure 2).

Figure 2. Central and Western Oklahoma Age-Adjusted Incidence Rate by Race/Ethnicity 2000-2007



Overall, differences were observed in age-adjusted incidence rates across counties, with Blaine, Carter, Ellis, Garfield, Grady, Harmon, Pontotoc, and Seminole having lower rates than the overall age-adjusted incidence rate for the Affiliate service area as a whole. Grady County continues to have a lower than average incidence. Grady County also has a lower than expected mortality rate and a low proportion of breast cancer diagnosed at a distant stage indicating that this county may be at lower risk. American Indian women in Lincoln County are still a target for additional screening efforts, as are African American women in Cleveland County. Women ages 40-49 and 50-64 years in Logan County should also be a focus of additional screening efforts.

### Breast Cancer Stage at Diagnosis

Overall, for the state of Oklahoma, 17.6 percent of diagnosed cases were *in situ*, 48.1 percent local, 24.1 percent regional, and five percent distant. For the entire 47county Affiliate service area, 16.2 percent of diagnosed cases were *in situ*, 53.3 percent local, 25.5 percent regional, and five percent distant. In the Affiliate service area, African American are more likely to be diagnosed with breast cancer at a regional or distant stage (Table 1).

Table 1. Central and Western Oklahoma Komen Affiliate Percent at Stage of Diagnosis by Race/Ethnicity, 2000-2007

Stage at Diagnosis	White NH (Percent)	African-American NH (Percent)	American Indian NH (Percent)	Hispanic (Percent)
<i>in situ</i>	16.2	18.4	17.8	18.1
Localized	49.1	38.3	43.4	42.5
Regional	22.9	29.6	25.5	28.9
Distant	4.5	7.3	5.8	4.2
Unknown	7.3	6.4	7.5	6.2

NH Non-Hispanic; Source: OK2SHARE March 10, 2011

When compared to the overall percentage of distant tumors, there are several counties with a higher percentage of distant tumors and may be targets for additional screening. These counties include Alfalfa, Beaver, Caddo, Carter, Cimarron, Dewey, Garfield, Garvin, Grant, Greer, Jackson, Kiowa, Love, Oklahoma, Payne, Pottawatomie, Roger Mills, Seminole, Texas, Washita, and Woodward. In 2009, Oklahoma and Logan Counties were identified as counties with high proportions of distant stage tumors. Oklahoma is still considered a target county for additional screening efforts.

### **Breast Cancer Mortality**

The age-adjusted death rate for Oklahoma in 2007 was higher as well with 24.9 deaths compared to 22.8 for every 100,000 women. Overall, the Years of Potential Life Lost (YPLL) before the age of 65 in Oklahoma for 2007 alone was 2,400 years. In the Affiliate area in 2007, 1,365 years of potential life before the age of 65 was lost.

In this report from 1999 to 2007, Cleveland, Grady, and McClain Counties have lower than expected mortality rates. Both Comanche and Oklahoma Counties have higher than expected mortality rates, indicating there may be a need for enhanced screening. Regarding YPLL, all of the counties except for Cleveland and Oklahoma Counties had fewer than 1,000 YPLL. Cleveland County had 1,094 YPLL and Oklahoma County had 4,984 YPLL. Of note, if there were fewer than five deaths in a county, neither mortality rates nor YPLL were calculated for that county. Cleveland and Oklahoma Counties are targets for additional screening efforts.

### **Mammography**

Approximately 40 percent of women did not have a mammogram in the last 12 months. Both Canadian and Harper counties had slightly fewer women who did not receive a mammogram in the last 12 months. However, this difference of a few percentage points was minimal.

### **Small Area Analysis**

Upon analyzing geographical distribution of distant stage, late stage (regional and distant stage), incidence rates, high proportions of uninsured women, and delayed treatment across the Affiliate service area (Figure 3). Identified was the most of the distant stage cancers and lower incidence rates are in the central Oklahoma City area with a smaller concentration in the Southwest region of the state (Figure 4).

Figure 4 Regarding the proportion of women diagnosed at late stage, the highest proportion was in Beaver County and parts of Texas, Harper, and Ellis Counties in Northwestern Oklahoma. Other areas with a high proportion were in the Western region of the Affiliate service area (Dewey, Custer, Washita, Blaine, and Caddo Counties) and the Northeastern region of the Affiliate service area (Noble and Payne Counties). A higher proportion of women who began treatment more than 30 days after diagnosis were in the far Western region of the Affiliate service area (Harper, Ellis, Woodward, Roger Mills, and Beckham Counties). There were also pockets in Caddo, Canadian,

and Oklahoma Counties. The highest proportion of uninsured women with breast cancer resided in the Southwest region and Central Oklahoma.

When analyzing the Central Oklahoma Counties, the target areas include Western Oklahoma County (73128, 73108, and 73179), Southwestern Oklahoma and Northwestern Cleveland Counties (73119, 73159, 73169, and 73139), and Central Oklahoma County (73118, 73105, 73106, 73109, 73111, 73121 and 73117) (Figure 4). Emerging is a consistent pattern of increased late stage, delayed treatment, high proportion of uninsured and low incidence rates.

Figure 3. Number of Late Stage Tumors (Regional and Distant Combined) at Diagnosis for Central and Western Oklahoma by County, 1997-2007

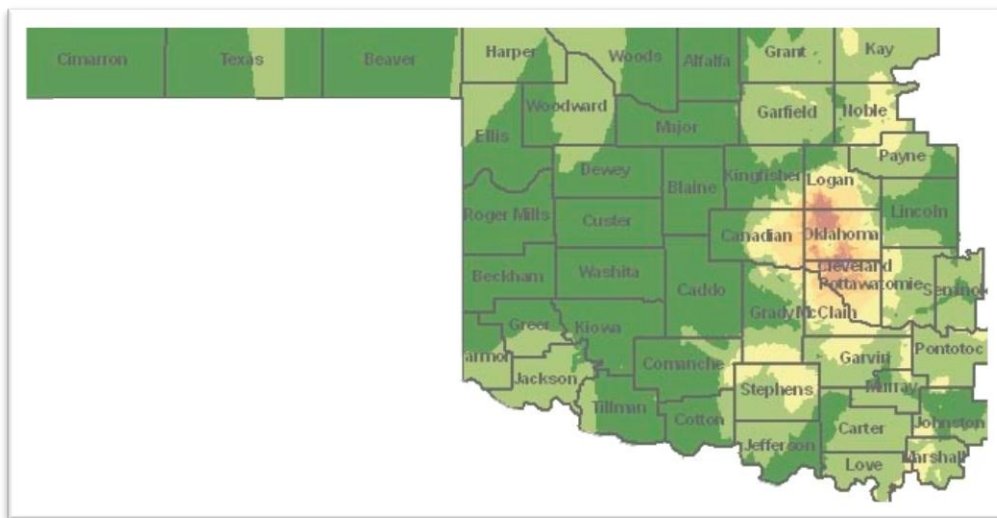
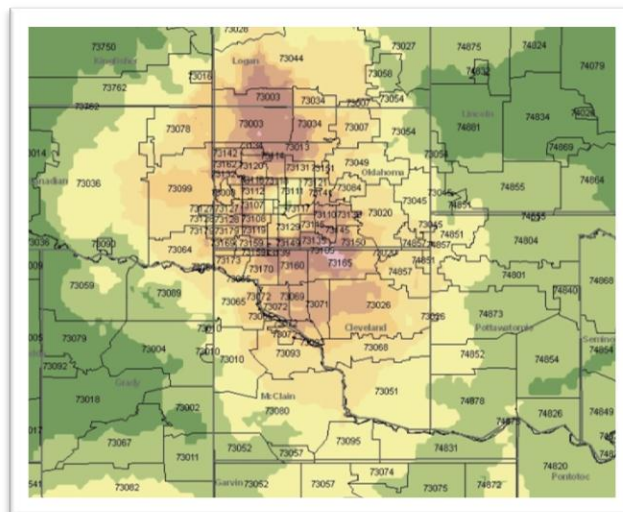


Figure 4. Number of Late Stage Tumors (Regional and Distant Combined) at Diagnosis by Zip Code in Central Oklahoma, 1997-2007



## County/Counties of Interest: What the Data Shows

After analyzing data on breast cancer for the entire Affiliate service area, identified are several target areas. Geographically, Oklahoma County, Southwestern Oklahoma (Washita, Caddo, Harmon, Greer, Kiowa, Jackson, and Comanche Counties), and three counties in the Eastern region of the Affiliate service area (Pontotoc, Pottawatomie, and Seminole Counties) are target areas. Demographic target areas are African American women and those living in high poverty areas.

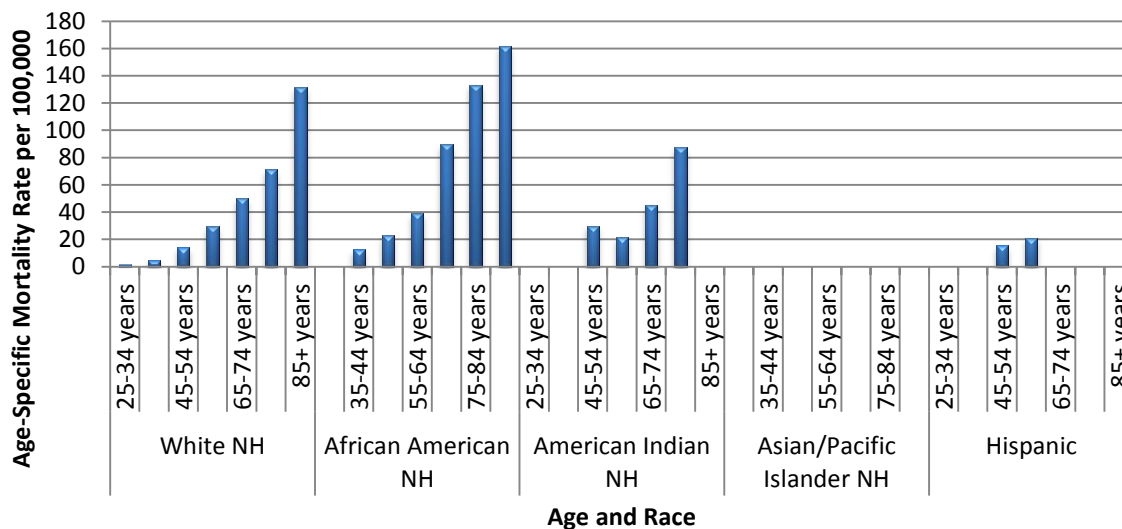
Table 2. Census Tract Areas with Percentage of the Population below the Federal Poverty Level in those Diagnosed at Distant Stage compared to *in situ*, Local, and Regional Stages Combined, 1997-2007

Federal Poverty Level	<5 Percent	5-9 Percent	10-20 Percent	>20 Percent
Percent Distant Stage	10.45	22.53	42.97	24.04
Percent <i>in situ</i> , Local, and Regional Stages Combined	13.28	24.88	43.08	18.76

Oklahoma County had a higher proportion of distant stage tumors at diagnosis than the overall proportion for the Affiliate service area and a higher mortality rate than the overall rate. The Southwestern region had a higher proportion of late stage diagnoses, higher mortality (particularly in Comanche County), and lower incidence (particularly Harmon County) than the overall rates for the Affiliate service area. The counties in the Eastern region of the state had higher distant stage and lower incidence than the overall Affiliate service area rates.

African American women have a higher mortality rate than other racial groups in the Affiliate service area. Compared to White women, African American women have higher mortality rates at each age group except 25-34 years (Figure 5). Women diagnosed with breast cancer living in census tract areas with more than 20 percent of the population below the federal poverty level were more likely to be diagnosed at distant stage compared to *in situ*, local, and regional stages combined (Table 1).

Figure 5. Age-Specific Mortality Rates by Race/Ethnicity for Komen Central and Western Oklahoma Affiliate, 1999-2003



NH Non-Hispanic; Source: OK2SHARE

### Demographic and Breast Cancer Findings

In sum, there are several counties with either low incidence, high proportions of distant stage, high mortality rates, or higher proportion that have not received a mammogram in the last 12 months. Furthermore, there are still counties that should be considered as focus areas from the previous report that only included the ten Central Oklahoma Counties. Certain demographic groups in Lincoln, Logan, and Cleveland Counties are still target areas due to lower than expected incidence rates. Oklahoma County still has a high proportion of distant stage diagnoses and Cleveland and Oklahoma Counties are still targets due to high mortality rates.

When taking all three measures into consideration, Oklahoma County, Southwestern Oklahoma, and the Eastern region of the Affiliate service area were identified as targets for additional screening efforts. African American women and women living in areas with more than 20 percent of the population below the federal poverty level are also targets for enhanced screening efforts.

## Programs and Services



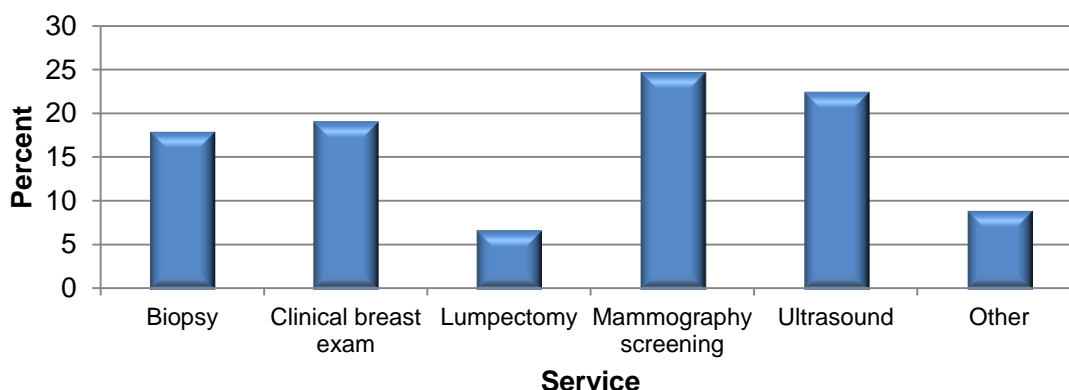
### Data Source and Methodology Overview

To understand the structure and needs of breast health facilities in the Affiliate service area, surveys were sent to all facilities. Of the 165 surveys mailed, 41 responded (25 percent). The purpose of the survey was to understand breast cancer services provided, educational materials, financial support for breast health services, and knowledge of Komen. Only those providers who responded that they provided breast cancer screening or diagnostic tests were included in the analysis. Each survey was completed by a clinic staff member either by paper or online. In surveying the Affiliate service area providers, 83 percent of those who responded provided breast cancer screening or diagnostic tests and were included in the analysis. It is important to remember when interpreting these findings that the majority of the Affiliate service area was recently added.

### Programs and Services Overview

Thirty-four percent of respondents were in management positions. Although providers could choose multiple answers for the types of services they provided, the most common was mammography at 25 percent (Figure 6). Of those who provide diagnostic services (18 percent), the most frequent type was ultrasound (28 percent), followed by stereotactic biopsy (22 percent), and needle localization (19 percent). Among the providers that provide other services, the most common response was diagnostic mammography (25 percent). The median number of patients seen in the clinics that responded was 5,000, ranging from 525 to 49,553 and the median number of mammograms per year was 1,050, ranging from 0 to 36,826 (this includes facilities that do not perform mammograms). The majority of providers (47 percent) reported that 75 percent or more of their patients were women over the age of 40.

Figure 6. Breast Cancer-Related Services Provided by Clinic



When asked how the clinic conducts breast cancer screening and education, 72 percent of providers reported that they address breast health at every well-woman visit. However, 72 percent of respondents reported that they did not have formal policies regarding Clinical Breast Exams (CBE). Regarding screening and diagnostic services for women with disabilities, 85 percent of providers are able to provide services for these women.

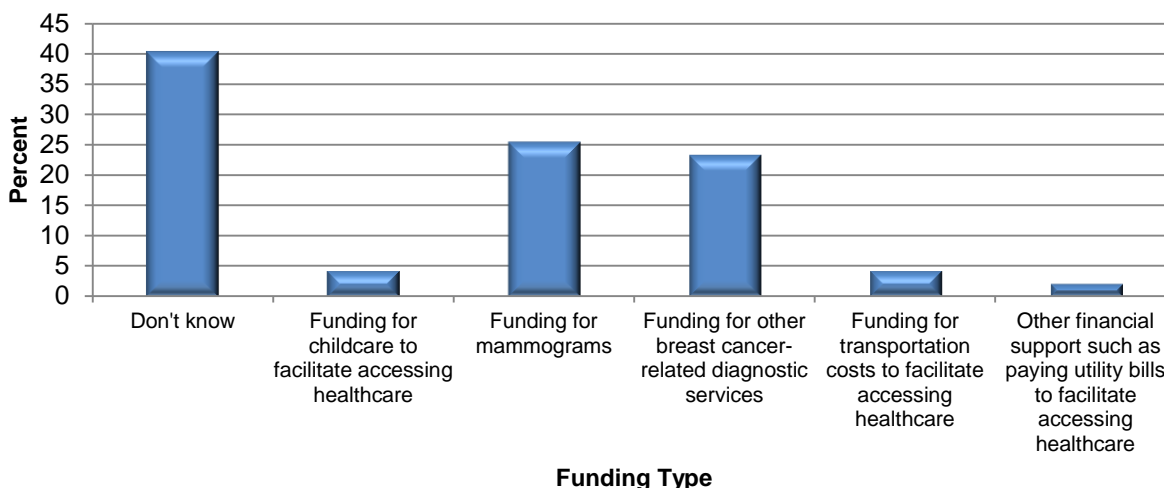
Next, providers were asked about educational materials. Ninety-four percent of the providers that responded provide breast health education materials to patients. Among all of the responses, the most common form of material was brochures (71 percent). The most common source of the educational materials that the clinics provided was American Cancer Society (46 percent), followed by Komen (19 percent). Eighty-one percent of respondents serve a non-English speaking population. Of these clinics, 87 percent serve Spanish-speaking patients and seven percent serve Vietnamese-speaking patients. Sixty-two percent of these clinics provide educational materials in these languages. Those that do not provide materials in these languages (35 percent) reported a lack of resources and that these materials were not available. Of those that provide these materials, sources include American Cancer Society Spanish materials and instructions for biopsies and other procedures and educational material in Spanish. All but three of the responding clinics reported that they would benefit from educational opportunities from Komen. The most common response was brochures for lobby display (20 percent).

Providers were then asked about the financial support available for breast health services at the clinics. The most common methods of payment accepted were Medicare (22 percent) and private health insurance (22 percent), followed by Medicaid (21 percent) and out of pocket (21 percent). Sixty-two percent provided financial assistance for uninsured, underinsured, or low-income clients for breast health service. Of these, 43 percent provided reduced price mammograms or clinical breast exams. Clinics used several different methods to determine the income threshold for eligibility including Take Charge! guidelines (28 percent) of 185 percent of the federal poverty level, up to 200 percent of the poverty level (17 percent), and up to the federal poverty level (11

percent). Of the responders, one-half of the clinics were aware of other organizations in their community offering financial assistance to income eligible women for breast health services. The most common organization was the Health Department or the Take Charge! Program.

Finally, clinics were asked about their knowledge of Komen. Fifty-five percent of respondents had heard of Komen, but never interacted with them and 32 percent received educational materials from Komen in the past. Only four respondents (13 percent) interact with Komen on a regular basis. The majority of respondents did not know what forms of financial assistance Komen could provide (40 percent; Figure 7). Another question for providers was if they have ever applied for Komen funding, of which five (16 percent) had. Among those who have applied, three were successful in obtaining funding. Among those who have never applied for funding, the majority were not aware of the availability of funding (82 percent). The majority of clinics (53 percent) stated that they were not-for-profit agencies. Three reported that they were government agencies and eight were for-profit.

Figure 7. Knowledge of Forms of Financial Assistance Provided by Susan G. Komen for the Cure to Women at Risk for or Already Diagnosed with Breast Cancer



Time to treatment has been shown to be an important factor in survival from breast cancer.<sup>3-5</sup> Only the Central and Eastern regions of Oklahoma differed regarding the proportion beginning treatment more than 30 days after diagnosis, with Central Oklahoma having a higher proportion than Eastern Oklahoma (Table 3). Regarding poverty level, those living in census tracts with more than 20 percent of the population below the federal poverty level were significantly more likely to begin treatment more than 30 days after diagnosis compared to those areas with less poverty. There was also a difference among the proportion that began treatment late by insurance status (Table 3). Those with Indian Health Services (IHS), Medicaid, and uninsured were significantly more likely to begin treatment late (Table 3). Furthermore, African American, American Indian, and Hispanic women were more likely to begin treatment more than 30 days

after diagnosis (Table 3). However, there were no differences between rural and metropolitan women.

Table 3. Percentage of women diagnosed with breast cancer in Central and Western Oklahoma Affiliate who began treatment more than 30 days after diagnosis, 2000-2007.

	<b>≤30 Days to Treatment</b>	<b>≥31 Days to Treatment</b>	<b>Percent Late Treatment (LCI-UCI)</b>
<b>State of Oklahoma</b>	2063	11595	15.1 (14.5-15.7)
Central	1295	6622	16.4 (15.5-17.2)
Eastern	722	4702	13.3 (15.5-17.2)
Ozarks	46	269	14.6 (10.7-18.5)
Unknown	0	2	0.0
<b>Poverty</b>			
<5 percent	191	1102	14.8 (12.3-16.7)
5 percent-9 percent	270	1663	14.0 (12.4-15.5)
10 percent-19 percent	523	2642	16.5 (15.2-17.8)
≥20 percent	290	1166	19.9 (17.9-22.0)
Unknown	21	49	30.0 (19.3-40.7)
<b>Payer Source</b>			
IHS	25	75	25.0 (16.5-33.5)
Insured	861	4999	14.7 (13.8-15.6)
Medicaid	157	495	24.1 (20.8-27.4)
Medicare	54	290	15.7 (11.9-19.5)
Medicare/Medicaid	14	47	23.0 (12.4-33.5)
Military	58	241	19.4 (14.9-23.9)
Uninsured	114	396	22.4 (18.7-26.0)
Unknown	12	79	13.2 (6.2-20.1)
<b>Race</b>			
African American NH	152	478	24.1 (20.8-27.5)
American Indian NH	91	330	21.6 (17.7-25.5)
Hispanic	78	231	25.2 (20.4-30.1)
Other	17	87	16.3 (9.2-23.5)
Unknown NH	1	15	6.3 (-5.6-18.1)
White NH	956	5481	14.9 (14.0-15.7)

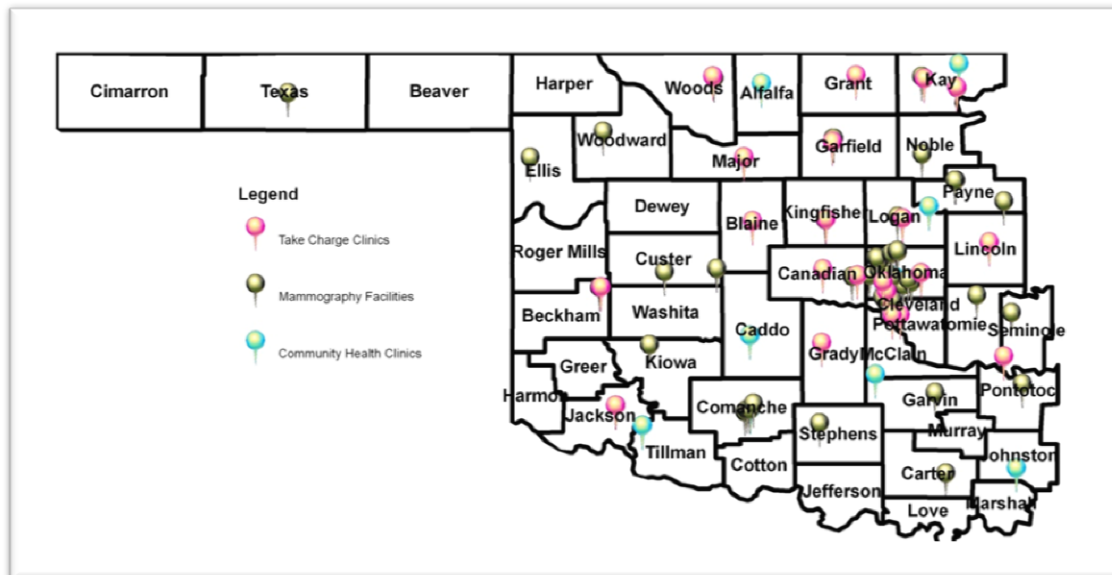
NH-Non-Hispanic; Source: OCCR 2010

## Partnerships and Grant Opportunities

The Affiliate works with a variety of partners to encourage breast health education and outreach and there are many educational programs offered independently by health systems throughout the area. Komen Affiliate staff travel throughout the service area providing breast health information, attending community health fairs and offering “train the trainer” type programs to empower local programs to begin teaching breast health education on their own.

A review of the assets available in central and western Oklahoma shows that there are Take Charge! Clinics in central Oklahoma, but none in northwestern or southern part of the Affiliate area (Figure 8). Moreover, there are no community health clinics in the northwestern part of the state, however, there are mammography facilities located sporadically throughout the area (Figure 8).

Figure 8. Location of Take Charge! Clinics, Community Health Clinics and Mammography Facilities in Central and Western Oklahoma 2010



## Promising and Evidence Based Programs

There are several examples of successful programs within the Affiliate service area which not only used previously created evidence based models but also developed programs that became evidence based models of success. Mercy Health Center began their program, *Project Early Detection*, based upon the already successful *Friend to Friend* model to implement education and outreach. This program provides education, outreach, screening and treatment for uninsured, underinsured and medically

underserved women of all ages. The use of this model has been so successful for Mercy that in the last fiscal year grant cycle, they exceeded their Komen funding with three months remaining on the calendar. Another especially promising program is *the Pink Glory Breast Care* program at the Oklahoma City Indian Clinic (OKCIC). This program provides education and outreach along with patient navigation to American Indian women in the Central Oklahoma service area. As a result of their efforts, the mammography rate has increased more than 50 percent since its inception, their no-show rate was reduced from more than 60 percent to 16 percent and the wait time for follow up services has reduced from more than 60 days to less than 20 days. The proven success of this program in reaching and effectively serving American Indian women has become a model of success. Its success has been recognized by Komen Headquarters and has received the honor of being asked to present its program at the 2011 Affiliate Leadership and Development Conference.

### **Public Policy Perspectives**

In Fiscal Year 2010 the Oklahoma Breast and Cervical Cancer Early Detection Program (Take Charge!) served 7,009 women in Oklahoma, only 21 percent of the eligible women. Of the 7,009 women screened 10.3 percent were African American, 24.7 percent were Hispanic and 2.4 percent were American Indian. The Komen Affiliate has a very good relationship with the Take Charge! program. An example of this relationship was the planning and assistance provided women and agencies in Oklahoma City when the University of Oklahoma College of Nursing contract (the largest contractor in the Oklahoma City area) was suddenly ended in May of 2010. Komen staff, as well as those Komen partner staff worked together to assure that all 3000 women seen in by this contract were placed with a new breast cancer screening home depending on the needs of the individual woman. As seen in Figure 8 above there are large gaps in service particularly in the western Affiliate service area.

Another important relationship for the Affiliate in Oklahoma is with the Oklahoma Health Care Authority (OHCA) the state's Medicaid agency. The state of Oklahoma began providing Medicaid benefits to uninsured women under 65, who are identified through Take Charge! and are in need of treatment for breast or cervical cancer on January 1, 2005. Oklahoma was the last state to implement the program but implemented the program in the broadest way. The national program allowed states to choose among options for implementation. Oklahoma chose screening options 1, 2 and 3. Meaning that women are considered screened under the Take Charge! program if their clinical services were provided all or in part by the program, or women were considered screened under the program if their clinic service was rendered by a provider and/or an entity funded at least in part by program fund, and the service was within the scope of a grant, sub-grant or contract under that state program and the state elects to make these services eligible, or women who are screened by any other provider and/or entity and the Oklahoma BCCEDP has elected to include screening activities by that provider.

Once screened by means of clinical breast exam, mammogram, or Pap smear and found to be in need of further diagnosis and treatment, a woman is eligible for the

program provided she meets the remaining qualifications. These qualifications include: have qualifying low income (less than 185 percent of the Federal Poverty level for the general population in Oklahoma and 250 percent for those women eligible for IHS Services and screened through a provider deemed by one of the two tribal programs in Oklahoma – Cherokee Nation or Kaw Nation Breast and Cervical Cancer Early Detection Program); having no other insurance covering Breast and Cervical Cancer diagnosis or treatment (medical care programs of the Indian Health Services (IHS) or tribal organizations are not considered creditable insurance); be under the age of 65; be an Oklahoma resident who is a U.S. citizen or eligible qualified alien; declare a Social Security number; assign her rights to third party liability if she has insurance that is not creditable; declare her income for the purpose of determining that she is not otherwise eligible for Medicaid. She is eligible for Medicaid services until the woman is no longer in need of breast or cervical cancer treatment. Finally, women who have been previously diagnosed with breast or cervical cancer and are still undergoing treatment and meet all of the other eligibility criteria are eligible as well.

Once an eligible woman is screened by a deemed provider and found to be in need of treatment, she then completes an application for the treatment program. The Oklahoma Health Care Authority, the Oklahoma Agency responsible for providing services for the Medicaid eligible population. OHCA providers provide diagnosis and treatment beyond the initial screen. Women in this program, who receive further diagnostic testing and are found to not have cancer or pre-cancerous conditions, will lose their Medicaid eligibility. However, if a woman does receive a diagnosis of cancer or a pre-cancerous condition, she will be enrolled in full Medicaid, the state's partially capitated, managed care Medicaid program. The woman will choose a primary care provider and receive needed specialty referrals through the primary care provider. In addition, she will have available care management services, transportation as well as Helpline and Nurse Advice Line. A woman has 60 days from the time she is eligible for services to receive care if she does not received a definitive diagnosis she is no longer eligible for services. Additionally, a woman will no longer meet eligibility criteria for this program when her health care provider deems she is cancer free and will not require continued cancer treatment and/or therapy.

From the inception of the program up to September 2010, 24,414 women have been enrolled in the program. Over 2,500 women are enrolled each month with an average of over 300 new women enrolled each. A quality assessment and performance improvement study of the program in Oklahoma showed the top cost for diagnosis was for Breast Cancer with almost 8 million dollars from July 2007 through June 2008.

A study in progress by one of the authors of this report, is reviewing the impact of the program on women throughout Oklahoma. The key results of this study show that the Take Charge! Program as implemented in Oklahoma is effective at reaching the target population and, even in the early stages of implementation, showing some promising results in improving cancer treatment in Oklahoma. Women and their providers are using the program, as nearly double the number of women were enrolled in the Medicaid program and diagnosed with breast cancer in the three years after

implementation of the treatment act. In particular we see that the women enrolling in the program were uninsured women across all racial or ethnic groups, all geographic areas, all poverty levels, age groups, marital status and whether she has had a previous diagnosis of cancer. More importantly, we do not see substantial changes in these distributions of these general demographic characteristics among women diagnosed with breast cancer in the three years after implementation of the treatment act in Oklahoma. The proportion in each age group, by marital status, previous diagnosis of cancer and urban or rural residence, and area poverty levels are all virtually identical. In short poor women in all social and demographic groups or areas across Oklahoma are being enrolled in this program.

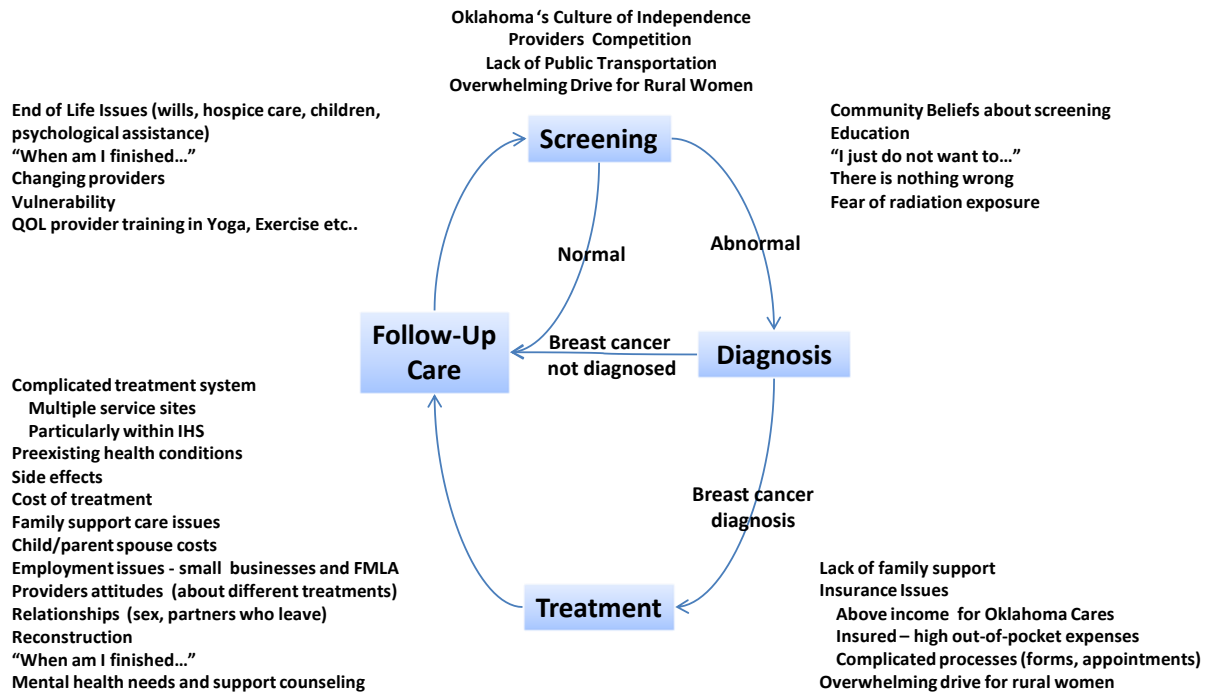
## **Program and Service Findings**

Overall, there are many aspects to the breast health systems in the Affiliate service area that can impact breast health, from understanding which groups of breast cancer patients are receiving treatment more than 30 days after diagnosis and provider understanding of breast health barriers in their communities. Race/ethnicity, income, insurance status, and geographic location impacted whether women began treatment more than 30 days after diagnosis. Many factors were identified throughout the continuum of care in Oklahoma that are barriers to women obtaining breast health services (Figure 9). Finally, there is a better understanding of the services and financial support that breast health provider's offer, methods and policies that providers use to conduct education and screening, and knowledge and relationship with Komen.

In order to better understand data findings in relation to the continuum of care and issues in Oklahoma, findings were summarized as seen in Figure 9. Gaps and barriers are present at each stage of the cycle, from screening through follow-up care. Some of the gaps and barriers throughout the continuum include Oklahoma's culture of independence, competition among providers, and transportation issues. Oklahoma has a unique culture and history. As a state initially founded by American Indian Tribal Nations that eventually became the 47<sup>th</sup> state, Oklahoma has a culture of fierce independence without want of outside interference. As a result, many Oklahomans will not ask for or seek out assistance even in dire circumstances.

In women with an abnormal screening finding, barriers include community beliefs about screening, education, and fear. In those who are diagnosed with breast cancer, barriers include a lack of family support, financial costs and burdens of insurance/appointments, and transportation. As women are completing treatment and moving into follow-up care, barriers include the complicated treatment system, side effects, other pre-existing health conditions, costs, family support, attitudes of providers, and quality of life issues. Finally, as women move from needing follow-up care back to having regular breast care, barriers include end of life issues and quality of life.

Figure 9. Central and Western Oklahoma Continuum of Care Gaps and Barriers Summary



## Exploratory Data



### Data Sources and Methodology Overview

In order to better understand areas and groups that need breast health and cancer services, a comparison of those treated within 30 days of diagnosis to those who did not begin treatment for greater than 30 days after diagnosis was used. Data for these analyses were obtained from the OCCR from 2000-2007 and compared by geographic region, poverty level, payer source, race/ethnicity, and residential area. Focus groups were conducted in the Affiliate service area. The purpose of the focus groups was to understand experiences with breast health and any perceived barriers to screening and treatment specific to their community. These services included access to mammography screening, diagnostics and treatment. Three focus groups were conducted with American Indian women at the Oklahoma City Indian Clinic (OKCIC), African American women at the Urban League Senior Cottages (UL), and Latina women at the Latino Community Development Agency (LCDA). Out of twelve women invited to each particular focus group, five women participated in each one. However, it is ideal to conduct at least three focus groups per ethnic group, thus, findings may be limited. Four people analyzed the findings from the focus groups and focused on the most important questions related to the purpose. Results were analyzed by question and themes within and across groups were determined. For this analysis, a theme was defined as being present in two out of the three groups.

### Exploratory Data Overview

It is important to understand where women are going to obtain information related to breast health in order to be able to target information to these sources. Two themes related to resources were identified. The first theme discovered was the extensive use

of the internet. In the OKCIC and UL groups, women stated that they would go online to get information on breast health. For example, one American Indian woman “Maybe get online and research it a little bit.” Another American Indian woman stated “I have a computer at home, but I’m illiterate about it...I just go to Google.” The second theme discovered was that both the OKCIC and UL groups stated that they would obtain breast health information at their doctor’s office. For example, one American Indian women stated “I’d come to my clinic, here.” And another “I’d talk to my doctor as soon as I can.”

To better target messages, education, and resources, we asked participants what were the perceived barriers in their community. Three themes were identified: costs, fear, and previous bad experiences along with several key ideas unique to each group. Of note, many of the Latina women did not know what age or conditions that breast cancer screening should begin. They asked many questions about guidelines for breast cancer screening, indicating a need for better education. Another response in the OKCIC women was that they felt like a “ping-pong ball” going to different clinics around the state to have different screening and diagnostic procedures performed. They felt that this causes a problem for women with transportation issues.

Cost, either monetary or non-monetary, was a barrier to obtaining screening. Monetary costs identified were costs of missing work (OKCIC) and transportation (UL). Missing work would make it hard to pay bills as well as fear of losing their job if they missed work (OKCIC) and stress related to costs of healthcare. One African American woman stated “Charging people \$3 a day to ride the bus!” and an American Indian woman noted “And some people might get fired if they even take off ... she was sick but she didn’t want to take off because she had bills to pay.”

The women from each group identified several different types of fear, including fear of the results, fear of pain, and fear of going to the clinic due to risk of children being taken away or the language barrier. One Latina woman stated “You know the old people...they don’t want to go anywhere that they don’t speak Spanish. They are really scared.” An African American woman reported “...once we find out what it is and we try it, then you’re fearful after that first time of going back because it’s going to be painful or something...”

The participating OKCIC and LCDA women also reported that bad experiences and not getting their test results prevented patients from seeking follow-up care. A Latina woman reported “I have always wonder(ed) what happened with my exam results because they never told me.” An American Indian woman reported that “I came for my mammogram. Next thing I know they’re telling me to go to this other place to get one done, but no reasons why.”

Another discovery included understanding what providers can do to ensure the at-risk women are receiving the breast health messages and services. The themes identified for this question were improving the patient-provider relationship, better messaging through TV/media, and a need for more education through methods other than

brochures. Latina women stated that the use of telenovelas (Latin soap operas) to intertwine breast health messages into their plots would be useful in making sure Latina women learn about breast health. Generally, women also expressed a need for more education from providers, but not through brochures. LCDA women stated that they do not read the brochures and pamphlets that providers give them. They prefer to receive education orally or by learning hands-on. OKCIC women liked the idea of a 'Welcome to 40' packet with information on what health screenings were recommended at this age. These women also felt that few women pick up pamphlets available in the clinic regarding recommended health screenings. There was not a consistent theme across all groups, but each group had their own barriers. As previously mentioned, LCDA women do not read the material providers give them and education about breast health would be more effective orally. UL women discussed the presence of home remedies to treat health problems and "putting themselves in God's hands." They also mentioned that they do not take their health seriously unless they feel bad. OKCIC women reported that in their culture, women were raised to be quiet and not discuss personal problems. "Old time remedies, keep you from having a doctor's bill."

### **Exploratory Data Findings**

Several themes were found among the women who participated in the focus groups. Also found were unique responses to questions in each focus group. Women seek information about breast health on the internet and at their doctor's office. The internet can provide useful information, but it can also contain bad and misleading information so it is important to educate women regarding trustworthy websites. Women also face many barriers to receiving breast care, including costs, fear, and previous negative experiences preventing them from returning for follow-up care. One important finding was the approach that providers take in educating patients. The women felt it was important for providers to educate them about breast health using a method that was more likely to be culturally successful, including the use of oral and hands-on education methods as opposed to written materials. Women also felt it was important to target their specific cultural communities, from advertising to African American women specifically to integrating breast health messages into telenovelas for Latina women.

## **Conclusions**

### **Target Communities Findings**

#### **Statistics**

Review of the breast cancer statistics in Oklahoma determined the target geographic and demographic areas in the Affiliate service area in need of enhanced services. Several counties were identified as target areas based on incidence, stage at diagnosis, mortality, or screening. However, when analyzing the Affiliate service area as a whole, more focused target areas emerged. Geographic targets are Oklahoma County, Southwestern Oklahoma (Washita, Caddo, Harmon, Greer, Kiowa, Jackson, and Comanche Counties), and the Eastern region of the Affiliate service area (Pontotoc, Pottawatomie, and Seminole Counties). The demographic targets are African American women and women living in areas of high poverty.

#### **Health Systems**

Next reviewed was the percentage of women who began treatment more than 30 days after diagnosis, gaps and barriers in the continuum of care, and services and education from Affiliate service area providers. Through this, confirmed targets were identified in the breast cancer statistics and helped to gain a better understanding of the continuum of care. In the provider survey, the most common source of education was through the use of brochures and most providers discussed breast health at every well-woman visit. When asked about their relationship with Komen, the majority of respondents had never interacted with them. Through the expansion process of the Affiliate, more providers should become aware of the services Komen provides.

#### **Focus Groups in Target Communities**

Conducting focus groups with African American, American Indian, and Latina women gave a better understanding of the knowledge and perceptions of breast cancer and Komen. One finding that stands out is that women are not likely to read the written material, such as brochures, that providers give them. Verbal or hands-on education is more likely to be effective. Since most clinics provide written educational material, it is important to work with providers to use educational methods that are going to be most effective in women seeking services.

#### **Putting the Data Together**

Specific statistics lead to targeted review of programs and services, which led to targeted and in-depth community data collection. For example when the initial finding showed that African American, American Indian and Hispanic women were shown to be diagnosed at late stage, were more likely to receive late treatment, and had higher mortality rates, the conclusion reached was that more detailed information is needed from members of these communities. Focus groups were implemented and the findings

were instructive on specific ways to provide enhanced education and outreach within the communities.

Because African American, American Indian and Hispanic women were receiving later treatment, transportation is probably an issue. From the focus groups, each group had unique transportation issues. For African American women, it is the public transportation system; Oklahoma City's well documented lack of public transportation impacts women's lives. For American Indian women, it is the "ping-ponging" between rural IHS clinics. These rural IHS clinics are often at minimum 60 miles apart and can sometimes result in traveling more than 200 miles one way for a particular service.

Finally, because of the expanded service area it was unclear if providers were aware of Komen services. Results of the provider surveys showed that most providers have heard of Komen, but never interacted with them. Thus, regional grant writing workshops were implemented and targeted media for those specific areas was developed.

### **Selecting Affiliate Priorities**

In order to ensure that the necessary key players were part of the selection process for priorities in the Central and Western Oklahoma service area, the Central and Western Oklahoma Community Profile team invited advocates to review the findings and inform the final priority decisions. Expectations were clearly defined at the beginning of the meeting as to the role of the invited guests and their continued support of the breast cancer efforts in their specific communities.

Those invited to be a part of this process included, target area key informants from the University of Oklahoma College of Public Health and Health Sciences Center. Additionally, the Affiliate's Mission and Programs Coordinator, Brandi Brown along with the Affiliate's Executive Director, Lorna Palmer participated. As a team, participants ranked the already established problem/need statements derived from the findings. Member discussed what had informed their decision. From that process three problem/need statements clearly stood out and were determined the basis for the priorities in the Central and Western Oklahoma service area. The objectives were then set for each priority.

### **Affiliate Action Plan**

**Priority 1:** Increase the number of health services and providers available in the target counties and zip codes by funding health system partnerships to increase access to services.

Objective 1: By December 2011, hold at least four grant writing workshops in each of targeted regions (Central, Southwestern Oklahoma, Northwestern Oklahoma, and the South Central regions) aimed at existing hospitals, primary care providers, mammography facilities and health clinics identified on the asset map.

Objective 2: By March 2012, reach out to at least four community health clinics or primary care providers identified on the asset map and located within high poverty areas (Western Oklahoma County-73128, 73108, and 73179, Southwestern Oklahoma County and Northwestern Cleveland County-73119, 73159, 73169, and 73139, and Central Oklahoma County-73118, 73105, 73106, 73109, 73111, 73121 and 73117).

Objective 3: By March 2012, reach out to at least four community health clinics or primary care providers identified on the asset map and located within high risk area (Southwestern Oklahoma-Comanche County, Caddo County, and Jackson County; South Central Oklahoma-Stephens County, Garvin County, Marshall County and Carter County).

**Priority 2:** Improve educational outreach activities concerning risk factors and preventive measures including internet and provider educational resources.

Objective 1: By March 2013, expand investment by two in programs focused on culturally appropriate targeted and quantifiable educational outreach that describes the risk factors, screening guidelines, treatment options and healthy lifestyle initiatives for Hispanic, African American, and American Indian (Oklahoma County, Cleveland County, Logan County, Comanche County, Lincoln County, and Payne County).

Objective 2: By December 2013, strengthen relationships with organizations that specifically serve the uninsured and medically underserved by holding at least six presentations on current screening and treatment recommendation in the region to healthcare providers, clinics, hospitals, and hospices.

Objective 3: By March 2013, partner with community based health organizations serving Latinas and African American women to arrange two small group education classes on breast self awareness

**Priority 3:** Invest in organizations providing ancillary services such as transportation, wigs, prosthetics, child care and the like to segments of population unable to procure those services and materials.

Objective 1: By March 2012, expand investment by two for programs addressing the need for transportation, child care, utilities, social services, or nutrition programs for low income individuals seeking breast cancer screening, diagnostics and treatment, specifically, service high poverty areas (Western Oklahoma County-73128, 73108, and 73179, Southwestern Oklahoma County and Northwestern Cleveland County-73119, 73159, 73169, and 73139, and Central Oklahoma County-73118, 73105, 73106, 73109, 73111, 73121 and 73117).

Objective 2: By December 2013, link current and future grantees with outside sources that provide transportation, child care, utilities, social services and nutrition programs to fully use Komen funding for women in high poverty areas (Western Oklahoma County-73128, 73108, and 73179, Southwestern Oklahoma County and Northwestern

Cleveland County-73119, 73159, 73169, and 73139, and Central Oklahoma County-73118, 73105, 73106, 73109, 73111, 73121 and 73117).

Objective 3: By March 2013, identify outside sources that provide transportation, child care, utilities, social services and nutrition programs in high risk areas in the newly expanded areas (Southwestern Oklahoma-Comanche County, Caddo County, Beckham County, and Jackson County; South Central Oklahoma-Stephens County, Garvin County, Marshall County and Carter County; Northwestern Oklahoma-Woodward County and Texas County).

### **Existing Grant Solutions**

In order to avoid an overlap in services provided, analysis was conducted about what programs were already being offered to meet identified needs. In addition to offering a grant workshop, the request for application was updated to reflect a more specific focus on meeting prioritized needs within the service area. To reflect the focus on meeting prioritized need in the new counties, the grant workshop is being developed to be offered in communities regionally. Currently, the use of incentives such as gas cards along with the incorporation of patient navigators has been implemented in response to the overwhelming needs of the targeted population. Additionally, it was determined that increased site visits as well as strategic collaboration and networking between and among grantees was needed to leverage available services in order to focus better on priorities. This was implemented when the Take Charge! Program funding was reduced and women were without services.

### **Needed Grant Opportunities**

The Central and Western Oklahoma service area would benefit from an increase in free and/or low-cost transportation services. A vast majority of the Affiliate service area is rural and along with high poverty rates, transportation to and from breast health services remains a barrier. There are current grantees offering some transportation assistance along with a focused effort on educating minority populations but there is a need to expand these services. It will be beneficial see an increase in the promotion of Komen within these organizations so that the communities they serve are more aware of services offered throughout the Affiliate service area. Based on the Community Profile findings, specific high risk areas are in need of Komen services, such as culturally appropriate education and outreach along with resources to improve screening and treatment outcomes.

### **Marketing and Fundraising**

Oklahoma would benefit greatly from a surge of culturally appropriate media and educational outreach related to risk factors and preventive health measures. Because of the large increase in service area (37 counties) a targeted media campaign introducing Komen as a breast health resource will be necessary. Increased marketing around the unique cultural heritage of Oklahoma was developed, for example Stomp for the Cure®.

Stomp was developed and introduced with the African American Community in the identified high risk areas of Cleveland and Oklahoma Counties. Culturally specific events such as Stomp are being developed with the American Indian and Hispanic communities. The focus would be on areas identified as having late stage incidence and high poverty.

Additionally through the efforts of the Affiliate, the Oklahoma Breast and Cervical Cancer Prevention and Treatment Advisory Board approved the use of new breast cancer car tag in Oklahoma. The new tags will replace the current tag. The designs were voted on at the 2010 OKC Race for the Cure and each owner will have the option of one of the two following designs. The profits from these tags are placed in a revolving fund to be allocated by the committee for breast cancer diagnoses and treatment in Oklahoma.



## Public Policy Efforts

The Central and Western Oklahoma Affiliate has been actively involved in educating and building relationships with our senators and representatives at the federal and state levels. Lobby Days have been an avenue used by the Affiliate to educate our state leaders as well as promoting Komen's mission. The Affiliate also invites our state and federal leaders to Komen events to keep them current with issues affecting breast health. In the next two years, the Affiliate will continue to strengthen these relationships through the continued use of Lobby Days and event exposure with the goal of placing the Affiliate as the "go-to" organization regarding breast health information and services.

The Executive Director of the Affiliate has been appointed to the Oklahoma Breast and Cervical Cancer Prevention and Treatment Advisory Board by the Speaker of the House, Kris Steele, for a four-year term. This legislative committee was created in 1999 by Senate Bill 741. The Mission of this committee is "...to increase the accessibility of quality Breast Cancer Prevention and Treatment Programs and Services Statewide." The objectives include promoting quality early detection and breast services, epidemiological studies which reflect trends of breast cancer incidence, prevalence and survival statewide, to promote breast cancer research studies, collaborate with other breast cancer organizations and services to provide accessible, acceptable, and available early detection services, and to translate, develop and promote public policy related to breast cancer throughout Oklahoma. As a public policy effort, Komen will

work with the Advisory Board to reduce times to treatment for women on Medicaid, uninsured women, minority women and those living in high poverty areas.

## **Education and Outreach**

There are a total of nine Komen Community Partners funded through the FY11 Grant Program. All nine partners provide education and outreach to very specific target groups including African Americans, American Indians, Hispanic women, college age men and women, undocumented women along with those who identify themselves as Lesbian/Gay/Bisexual/Transgender. These programs provide essential outreach to educate women about breast health and encourage them to practice breast self-awareness by incorporating healthy lifestyle recommendations, breast self-exams as well as getting regularly screened. When appropriate, this education also includes directing them to screening through the Oklahoma Breast and Cervical Cancer Early Detection Program (Take Charge!). In addition, five programs work with patient navigators who assist in directing and keeping women in the continuum of care. The Affiliate has a very good relationship with its community partners and is satisfied with their work.

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