



COMMUNITY PROFILE REPORT

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2011

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Executive Summary

Susan G. Komen for the Cure's promise 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 meet this promise, the Arkansas Affiliate relies on the information obtained through the Community Profile process to guide the work needed to accomplish the promise in its communities. A quality Community Profile guarantees that local efforts backed by Susan G. Komen for the Cure are targeted to the greatest needs and non-duplicative.

The Community Profile includes an overview of demographic and breast cancer statistics that after preliminary analysis highlight target areas, groups, or issues. The statistics pinpoint where efforts are most needed. In order to ensure effective and targeted efforts, it is important to also understand what program and service gaps, needs and barriers exist, as well as what existing assets that can be looked to for partnership and collaborative interventions. The Community Profile also includes analysis of the community within, including the voices of those living in target areas and representing target populations.

Introduction

Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982, that promise became Susan G. Komen for the Cure and launched the global breast cancer movement. Today, Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists fighting to save lives, empower people, ensure quality care for all and energize science to find the cures.

In 1992 the Arkansas Affiliate of Susan G. Komen for the Cure was incorporated by Terri DeSio, Pat McClelland, and Pat Torvestad, covering 63 of the 75 Arkansas counties (Figure 1). The 12 counties that are not included in the Arkansas Affiliate service area include: Benton, Carroll, Boone, Washington, Madison, Newton, Crawford, Sebastian, Little River, Hempstead, Miller, and Lafayette. Up to 75 percent of the Affiliate's income goes toward funding grants to local hospitals and community organizations that provide breast health education and breast cancer screening and treatment programs for medically underserved women. The remaining net income (a minimum of 25 percent) supports the Komen national efforts in research to find cures for breast cancer. Over the past 17 years the Arkansas Affiliate has given \$3.7 million to research and \$10.9 million to statewide grant programs.

To aid in the understanding of where our granting efforts will have the most impact, we rely on information obtained through our bi-annual Community Profile. The Community Profile is a qualitative and quantitative assessment that aids in identifying gaps and barriers throughout the health system for breast cancer. The Community Profile includes an overview of demographic and breast cancer statistics that highlight target areas, groups, or issues. The information for the profile is gathered through policy, resource allocation, interviews, surveys and the most current, available statistics. The Affiliate takes the information gathered and uses it to strategically plan for the next two years to identify access to services.

Figure 1.
Arkansas Affiliate Service Area



The Komen Arkansas Race for the Cure® is one of the best responded to Affiliate events held each year. The Komen Arkansas Race for the Cure has been held for 17 years and has raised more than \$17 million, funding grants and educational programs which have provided support and information focused on early detection to thousands of Arkansas women and their families. The first race held in 1994, had 2,200 participants. The most recent, 17th anniversary race, had 45,952 participants.

Statistics and Demographic Review

Data was gathered from the Behavioral Risk Factor Surveillance System (BRFSS), the 2000 US Census Bureau, and the Arkansas Cancer Registry at the Arkansas Department of Health (2011) to create “The Burden of Breast Cancer in Arkansas.” The “Burden of Breast Cancer in Arkansas” is an overview of factors related to breast cancer that includes: demographics, disease status, access to care, and risk factors. The report includes information over the entire state of Arkansas.

43 percent of the population in Arkansas lives in rural areas while 57 percent of the population lives in urban areas. The total female population in Arkansas for 2009 was estimated to be 1,075,255. Counties with the largest percentage of African American residents in the population are located in the Northeast and Southeast Delta regions of the state. Phillips (62.5), Lee (56.8), and Chicot (54.3) report the highest percentage of African American residents. Counties with the highest percentage of Hispanic/Latino residents are located in the Northwest and Southwest delta regions of the state as well as Bradley and St. Francis counties. Sevier (29.5), Yell (19.2), and Benton (14.6) report the highest number of Hispanic/Latino residents. Counties with the highest percentages of white residents in 2008 are located in the north central portion of the state. Many of the counties with high percentages of white residents also have high percentages of elderly residents. Those with the largest percentage of white residents are Lawrence (96.2), Baxter (96),

and Clay (96). Counties reporting the lowest percentage of residents age 25 and older who obtained a college degree or higher include: Poinsett (6.3), Calhoun (7.3), and Lee (7.3). Counties with low average wages are dispersed throughout the state. The top three counties reporting the lowest average wages in 2007 include: Searcy (\$20,488), Newton (\$20,586), and Lincoln (\$21,006).

The majority of counties with the highest age adjusted breast cancer incidence rates from 2003-2007 are located in the Central and Northeastern regions of Arkansas. Prairie (146.9), Conway (141.4), and Clark (136.3) have the highest incidence rates in Arkansas women. Counties with the highest age-adjusted breast cancer incidence rates for white women from 1997-2007 are located in every region of Arkansas. Pulaski County (154.2) has the highest breast cancer incidence rate in white Arkansas women. Counties with the highest age adjusted breast cancer incidence rates from 1997-2007 for black women are located in the Central, Southeastern, Northeastern, and Southwestern health regions of Arkansas. Craighead (133.0) has the highest age-adjusted incidence rate for black Arkansas women. The counties with the highest age-adjusted breast cancer death rate from 2004-2007 include: Lee (27.2), Drew (26.8), and Newton (20.5).

The Arkansas Affiliate currently focuses on 20 counties in the service area who have no fixed mammography services (NFMS). In addition to these 20 counties, four counties stand out for significant need of breast health services. These include: Desha, Lee, Monroe, and St. Francis. These four counties are located in the Northeast and Southeast regions along the Delta. Desha, Lee, St. Francis, and Monroe rank in the top 10 for having the highest breast cancer burden/risk, the top 15 for the lowest percent of residents who have completed high school, the top 15 for the lowest female life expectancy, the top 15 for the lowest median household income in 2007, and the top 15 for the highest percent of the population under poverty in 2007 (Table 7).

*Table 7.
Identified Target Counties: Desha, Lee, Monroe, and St. Francis*

County:	Index Rank (1-10):	% Completed HS:	Female Life Expectancy:	Lowest Median Income (2007):	Percent of Population Under Poverty (2007):
St. Francis	1	65.1	73.1	\$28,318	32.6
Lee	2	56.2	73.1	\$24,195	31.8
Desha	7	65	74.1	\$28,119	26.6
Monroe	9	63.8	74.4	\$27,141	27.2

Health Systems Analysis

To aid in the understanding of the issues facing the targeted counties, we drew upon the expertise of key individuals in Arkansas through the methods of: surveys, key informant interviews, and questionnaires. Ninety-two surveys were completed by current and past Komen grantees, hospitals and public health clinics. The survey was used to study the service area as a whole. Responses were from nurse practitioners, case managers, managers of breast centers, and

medical directors; with the majority of respondents being women. Questionnaires were also completed by current grantees. This was done to assess the sustainability of current programs without Komen grant funds. Accurate data concerning where Komen grantee services intersected with the NFMS counties was already available from the grant committee.

32 key informant interviews were completed with individuals in leadership positions in the no fixed mammography service (NFMS) counties to ascertain viewpoints about key breast health issues as well as beliefs and attitudes about breast cancer. All key informant interviews were done by phone, and questions required about 20 minutes of the interviewee's time. Current and past grant committee members were used to conduct these interviews. The key informants included clinicians, patient navigators, and program directors from established providers within the targeted counties.

Key findings and themes.

The provider surveys showed money, including lack of insurance, was the greatest barrier to receiving treatment. Other reasons included difficulty with access, concerns about discomfort, forgetting or procrastination, and lack of information about the necessity. One fact that arose is the possibility that women think they are too old for a mammogram starting around age 65. The provider surveys also revealed that women living in poverty are not aware of the BreastCare program or possible Komen grants that could help them. 68 of the respondents noted that they address breast health issues routinely with well visits. The description of the women from this area emerges as uneducated and impoverished. Of particular note was the difficulty of accessing services for rural women.

All of the key informants, except the Lincoln County informant, felt additional Mobile Mammography Units (MMU) visits would ease the stress of these women. All informants referred to faith based education as a means to reach women in these counties.

The response from the grantee questionnaires was that programs would not continue without Komen support or could only continue with services at a greatly reduced rate.

Qualitative Data Overview

To gain community perspective from the women living in the 20 NFMS counties the Arkansas Affiliate sent out a letter with a survey included. The letters were sent out to identify women who would like to take on the role of a 'Community Champion.' The Arkansas Affiliate defines a 'Community Champion' as one who in an organized manner tells others about breast health, the importance of early detection, and supports those who are newly diagnosed. For the 20 NFMS counties, letters were sent out to all survivors and non-survivors who have been a part of the Arkansas Affiliate Race for the Cure, faith based organizations, community based organizations, and health clinics. Although our survey approach had a low response rate, from the surveys returned to the Arkansas Affiliate we found that the majority of women would like to become more involved in their communities, many are not able to travel to Little Rock to speak with us, and the best time to reach these women is in the early evening after work, or on Saturday mornings.

Conclusions

In 2009 the Arkansas Affiliate recognized that the assets in the service area are not evenly distributed, identifying 20 NFMS counties as target areas. These counties were identified based on a lack of access. However, as a group these counties have below median income, below median education, above state median uninsured rate, and are below the state average on usage of the BreastCare program. The key informant interviews conducted also confirmed that these women are not getting screened because they do not have access to services and if access is available, they are unable to afford the services.

Looking beyond lack of access, in 2011, the Arkansas Affiliate identified four counties of interest in the service area: Desha, Lee, Monroe, and St. Francis. The identification of these target counties was done with the available statistical and demographic information from “The Burden of Breast Cancer in Arkansas” report. To identify appropriate action plans and priorities based around this new information, the Arkansas Affiliate President of the Board of Directors, Executive Director, Missions Director, Grant Committee Chair, and Education Committee Chair came together to discuss how the Affiliate will approach these counties, and maintain the progress made with earlier grants. The priority and action plan is outlined below.

Arkansas Affiliate Priorities and Action Plan:

Priority 1: To increase the number of breast health services and providers available within our 63 county service area while maintaining and/or enhancing the quality of the programs currently in place.

Objective 1: From April 1, 2011-March 31, 2013 have grant mentors visit the grantee organization in which they were assigned to oversee one time yearly.

Objective 2: From April 1, 2011-March 31, 2013 use public policy action to assure continued funding for BreastCare- Arkansas’ Breast and Cervical Cancer Program.

Objective 3: Communicate to grantee organizations at the grants luncheon on April 1, 2011 and March 30, 2012 the four key breast self-awareness guidelines: know your risk, get screened, know what is normal for you and maintain a healthy lifestyle.

Objective 4: From April 1, 2011-March 31, 2012 have a registered nurse evaluate the educational materials placed in the Affiliate survivor kits that are provided to all the breast centers in our service area for those who are newly diagnosed with breast cancer.

Priority 2: To expand education programs in St. Francis, Desha, Lee and Monroe that address breast health and increase awareness of available services.

Objective 1: From April 1, 2011-March 31, 2013 have the education committee identify two County Coordinators in Desha, Lee, Monroe, and St. Francis counties to assist the Affiliate in developing a local network of advocates within their county who will support the promise of Susan G. Komen for the Cure.

Objective 2: From April 1, 2011-March 31, 2013 have the Affiliate education committee partner with community based organizations in Desha, Lee, Monroe, and St. Francis counties to educate the population they serve on breast health.

Priority 3: To collaborate with service area mobile mammography unit providers to increase awareness to individuals about the services they provide and when/where these services are available.

Objective 1: Have the Missions Director attend the Komen Leadership Conference Grant Forum in Ft. Worth, Texas on March 24, 2011 with a current Arkansas Affiliate grantee representative to engage in grant networking opportunities with other Komen Affiliate and grantee members.

Objective 2: Hold a mobile mammography forum in June 2012 to build cohesive collaborative efforts allowing the exchange of ideas between Baxter Regional, St. Bernards, and UAMS mobile mammography unit providers.

Introduction

Affiliate History

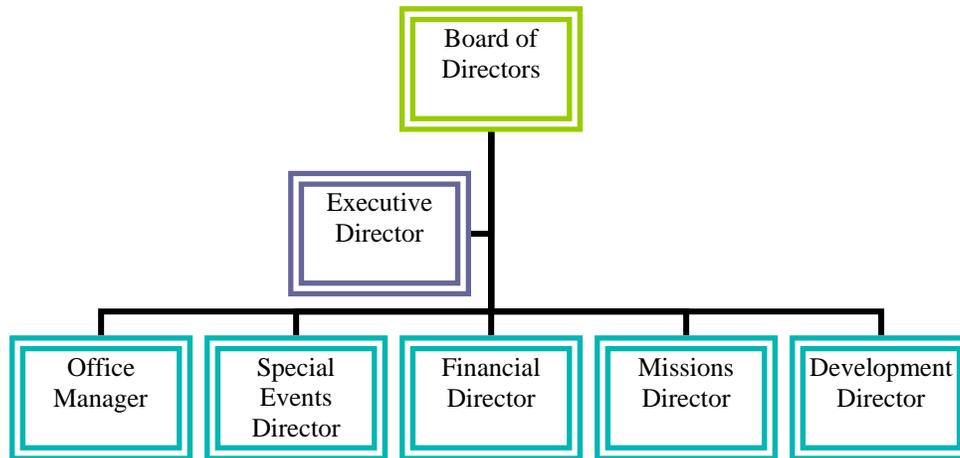
The Arkansas Affiliate of Susan G. Komen for the Cure is in one of the 125 cities and communities fighting breast cancer today. The Arkansas Affiliate follows the mission to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures. The Affiliate network is the nation's largest private funder of community-based breast health education and breast cancer screening and treatment programs. Each year the Arkansas Affiliate gives grants to local hospitals and community organizations that provide breast health education and breast cancer screening and treatment programs for medically underserved women.

The Arkansas Affiliate of Susan G. Komen for the Cure was incorporated in 1992 by Terri DeSio, Pat McClelland and Pat Torvestad. The Komen Arkansas Race for the Cure® has been held for 17 years and has raised more than \$17 million, funding grants and educational programs, which have provided support and information (focused on early detection) to thousands of Arkansas women and their families. The first race held in 1994, had 2,200 participants. The most recent, 17th anniversary race, had 45,952 participants. Of the money raised through the Race and from other Affiliate funds, 75 percent stays in Arkansas to fund educational, screening and treatment programs, while the remaining 25 percent is used for national research grants.

The Arkansas Affiliate became a powerful voice for change through the passage of the Breast Cancer Act of 1997, which provides funding for the promotion of breast cancer awareness, mammograms, and treatment. This act provides funding for BreastCare, the state's BCCCP program. A member of the Arkansas Affiliate serves on the Breast Cancer Control Advisory Board which oversees the funding provided by the legislation.

Organizational Structure

The Arkansas Affiliate continues to be a voice for the uninsured and underserved women concerning breast health. The Affiliate is incorporated in the State of Arkansas as a 501© 3 nonprofit, nonstock corporation that is organized and operated exclusively for charitable, scientific, and educational purposes. The business and affairs of the corporation are managed under the direction of its Board of Directors. The Arkansas Affiliate staff is comprised of six individuals, which includes the Executive Director who reports directly to the President of the Board, and five staff members, who are directed by the Executive Director (Chart 1).



Note: Chart 1 was created using SmartArt in Microsoft Word 2007.

The Community Profile process has allowed the Affiliate Board to outline the strategic plan. The current strategic plan was developed around the 2009 community profile findings. The 2011 findings further support the developed plan in place. From the 2009 findings the Affiliate developed a result (goal) of increasing the screening mammography rate in the 20 NFMS counties from 58% to 63%. The actions (tactics) around this goal include:

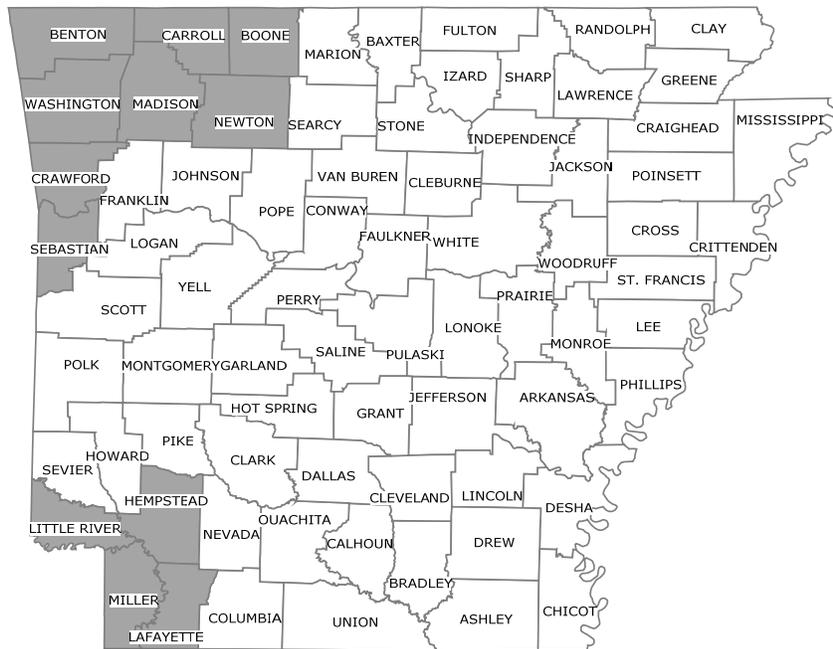
- a) Develop a liaison in each of the targeted counties for the purposes of education
- b) Facilitate coordination and support efforts of all mobile mammography units (MMU)
- c) Develop and provide a directory of sources that pay for mammograms
- d) Prioritize the 20 underserved counties by need and potential impact for increasing mammography rate and develop/implement a plan of Action specific to each county.

Description of Service Area

The Arkansas Affiliate's service area is comprised of 63 of the 75 counties in the state of Arkansas (Figure 1). Of the twelve remaining counties, eight are part of the Ozark Affiliate service area and four are in the Texarkana Affiliate service area.

Figure 1.
Arkansas Affiliate Service Area

Arkansas



Note: The counties with no shading represent the 63 counties in the service area of the Arkansas Affiliate.

The 63 counties are bordered by Missouri on the north, formed by the Mississippi River on the east to Tennessee and Mississippi; border Louisiana on the south and Oklahoma to the west. Within these counties, one can dig for diamonds in the only diamond mine in the United States, explore limestone caves in the Ozark Mountains in the north, float the country's first National River; the Buffalo River, soak in the thermal waters of our country's first National Park; Hot Springs, hike trails through the 2.67 million acres of national forest, fish the 600,000 acres of lakes and 9,700 miles of streams and rivers, and hunt ducks along the fly way of the Mississippi Delta. While traveling through the Affiliate service area, one can visit Nashville, Moscow, London, Paris, England, Palestine, and also stop by Pickles Gap or Toad Suck Lock and Dam. Stopping in Little Rock, a visit can be made to the William J. Clinton Presidential Center and Park with its museum, archival collection and educational and research facilities. From the North Western Mountains, through the timberlands, prairies and central river valley to the Oxbow Lakes and bayous of the South and Eastern Delta, the 63 counties within the Arkansas Affiliate definitely demonstrate why Arkansas slogan is "The Natural State."

Purpose of the Report

Susan G. Komen for the Cure's promise 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 meet this promise, the Arkansas Affiliate relies on the information obtained through the Community Profile process to guide the work needed to accomplish the promise in its

communities. A quality Community Profile guarantees that local efforts backed by Susan G. Komen for the Cure are targeted to the greatest needs and non-duplicative.

The Community Profile is a qualitative and quantitative assessment that aids in identifying gaps and barriers throughout the health system for breast cancer. It includes an overview of demographic and breast cancer statistics that after preliminary analysis highlight target areas, groups, or issues. The statistics pinpoint where efforts are most needed. In order to ensure effective and targeted efforts, it is important to also understand what program and service gaps, needs and barriers exist, as well as what existing assets that can be looked to for partnership and collaborative interventions. The information for the profile is gathered through policy, resource allocation, interviews, surveys and the most current, available statistics. The Affiliate takes the information gathered and uses it to strategically plan for the next two years to identify access to services.

Breast Cancer Impact in Affiliate Service Area

Methodology

Data was gathered from the Behavioral Risk Factor Surveillance System (BRFSS), the 2000 US Census Bureau, and the Arkansas Cancer Registry at the Arkansas Department of Health (2011) to create “The Burden of Breast Cancer in Arkansas.” The “Burden of Breast Cancer in Arkansas” is an overview of factors related to breast cancer including: demographics, disease status, access to care, and risk factors. The report includes information from the entire state of Arkansas. The two primary purposes of the burden report are to inform individuals on the significant impact of breast cancer in Arkansas, and allow the Arkansas Affiliate to identify opportunities to get involved.

Overview of the Affiliate Service Area

In order to better serve the population of Arkansas, the Arkansas Department of Health has divided the state into 5 distinct public health regions (Map 1). Public health includes the prevention, detection, and control of disease to promote the health of a population. The 5 public health regions include: Northeast (green), Southeast (yellow), Central (gray), Northwest (blue), and Southwest (pink).

Map 1.

5 Distinct Public Health Regions of Arkansas



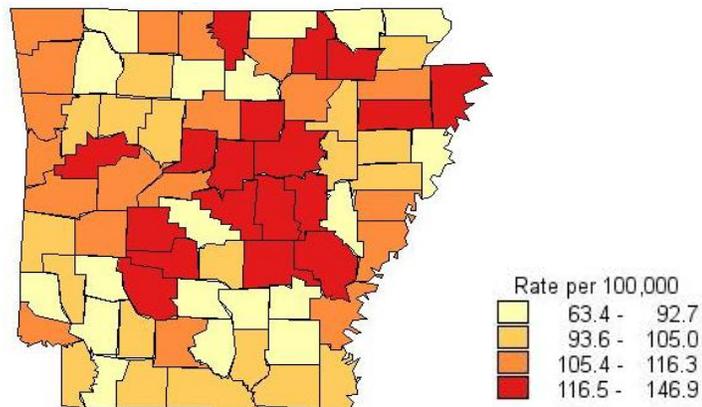
University for Medical Sciences Public Health in Arkansas Communities Search. (2011).
Note: Map 1 shows the 5 Public Health Regions of Arkansas divided by the Arkansas Department of Health.

Four key variables regarding disease status were looked at for females within these 5 public health regions. These variables include: incidence, stage of diagnosis, mortality, and screening rates.

1. Incidence: The majority of counties with the highest age-adjusted female invasive breast cancer incidence rates from 2003-2007 are located in the Central and Northeastern regions of the state (Map 2). Of these counties, the 18 with the highest incidence rates all fall in the Arkansas Affiliate Service Area. The county with the highest female invasive breast cancer incidence rate is Prairie, with a rate of 146.9. When looking at age-adjusted female invasive breast cancer incidence rate by race/ethnicity, the county with the highest incidence for white women is Pulaski County (154.2), which is located in the central region of the state. The county with the highest incidence rate for black women is Craighead (133.0), which is located in the Northeastern part of the state.

Map 2.

Age-Adjusted Female Invasive Breast Cancer Incidence Rates



Cancer Registry, Arkansas Department of Health. (2011).

Note. Map 2 shows the Age-Adjusted Female Invasive Breast Cancer Incidence Rates in Arkansas.

2. Stage of Diagnosis: The majority of breast cancer cases diagnosed in Arkansas are Stage I (64.4%). As with incidence, the counties with the highest percentage of Stage III and Stage IV diagnosis are in the Arkansas Affiliate service area. The counties with the highest percentage of Stage III diagnosis include: Phillips, Lee, Chicot, Jefferson, and Crittenden (Table 2). The counties with the highest percentage of Stage IV diagnosis include: Phillips, Lee, and Chicot (Table 3). In Arkansas there are greater percentages of African American women diagnosed at Stage II, III, and IV, compared to white women (Table 4).

Table 2.
Breast Cancer Incidence by Stage III Diagnosis

Rank	County	Stage III (%)
1	Phillips	4.5
2	Lee & Chicot	4.4
3	Jefferson & Crittenden	4.3

Thomson Reuters® 2010

Note: Breast Cancer Incidence Rate by Stage III, Area: Arkansas Affiliate, Ranked by 2009 Female per 100,000 population rate.

Table 3.
Breast Cancer Incidence Rate by Stage IV Diagnosis

Rank	County	Stage IV (%)
1	Phillips	6.3
2	Lee & Chicot	6.1
3	Jefferson	5.9

Thomson Reuters® 2010

Note: Breast Cancer Incidence Rate by Stage IV, Area: Arkansas Affiliate, Ranked by 2009 Female per 100,000 population rate.

Table 4.
Breast Cancer Incidence Rate by Ethnicity and Stage

Stage of Diagnosis	% White	% Black
Stage 1	65.6	54.8
Stage 2	26.9	31.3
Stage 3	3.3	5.8
Stage 4	4.2	8.1

Thomson Reuters® 2010

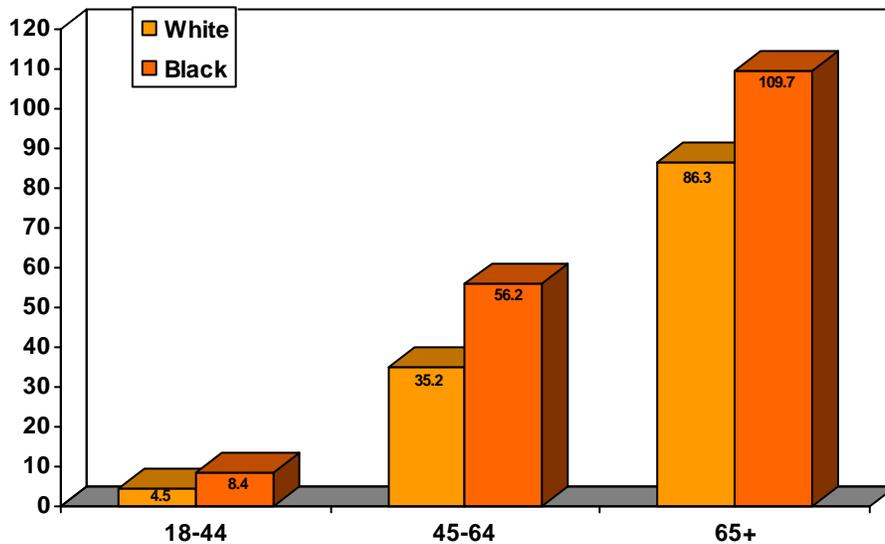
Note. Breast Cancer Incidence Rate by Ethnicity and Stage, Ranked by 2009 Female per 100,000 population rate.

3. Mortality: 14 of the 15 counties for highest breast cancer deaths (age adjusted rate 2004-2007) lie within the Arkansas Affiliate service area. A majority of these counties represent areas

with a rural population and several that experience other disparities such as economic or racial disparities. The top three counties with the highest age-adjusted breast cancer death rates are Lee (27.2), Drew (26.8), and Newton (20.5). Of the top three Lee and Drew fall within the Arkansas Affiliate service area.

Breast cancer mortality rates based on race/ethnicity and age group indicate that African American women living in Arkansas are at increased risk of dying from breast cancer at each age group (Figure 2). Yell County, having the highest mortality rate for black women (40.8) and Marion County, having the highest mortality rate for white women (48.5), are both within our service area.

*Figure 2.
Breast Cancer Mortality Rates Based on Race/Ethnicity and Age Group*



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Note. Breast Cancer Mortality Rate by Ethnicity and Age Group, Ranked by 2009 Female per 100,000 population rate.

4. Screening Rates: Counties with the highest percent of women with no recent mammogram in 2008 are distributed throughout all of Arkansas. The majority of those counties are located in the Northeast region. As with incidence 14 of the top 15 counties reporting the highest rates for no recent mammogram in 2008 lie within the Arkansas Affiliate service area. The top three counties include: Independence, Chicot, and Jackson (Table 5).

Table 5.
Highest Percent of Women with No Recent Mammogram in 2008

County	% of Women with No Recent Mammogram (2008)
Independence	40.9
Chicot	39.5
Jackson	38.5

University for Medical Sciences Public Health in Arkansas Communities Search. (2011).

Retrieved January 2001

Note: Top 3 Counties with the Highest Percentage of Women with No Recent Mammogram in 2008.

Communities of Interest

It is a fact that receiving quality breast health care can depend on where you live in Arkansas. 20 counties within the Arkansas Affiliate service area do not have a health care facility with fixed mammography services. These counties include: Calhoun, Cleveland, Dallas, Franklin, Fulton, Lee, Lincoln, Logan, Marion, Monroe, Montgomery, Nevada, Perry, Pike, Poinsett, Prairie, Scott, Searcy, Woodruff, and Yell. This group of counties has been chosen as a targeted area for the Arkansas Affiliate efforts. The median average income of the 20 counties is \$32,358 compared to a state median average income of \$37, 555. Four counties within the service area had particularly low median incomes. These include: Lee at \$24,411; Monroe at \$26,478; Searcy at \$26, 635; and Woodruff at \$25,278. NFMS counties also have a higher percentage of uninsured females. NFMS counties have a 26.6 percent rate of uninsured females compared to the state average of 22.7 percent. Lee County at 45 percent and Woodruff County at 39.1 percent have the two highest percentages of uninsured females throughout the NFMS counties. Another measure looked at was the utilization of Arkansas’ BreastCare program. NFMS counties had an average BreastCare utilization rate of 20.57 percent while the state average is 25.3 percent. Females diagnosed at Stage IV for all races equal the state average. However, Perry County, Nevada County and Dallas County had significantly higher percentages of Stage IV cancers than the rest of the counties. As well, all of the NFMS counties except Yell County are totally or partially designated as health professional shortage areas (HPSAs).

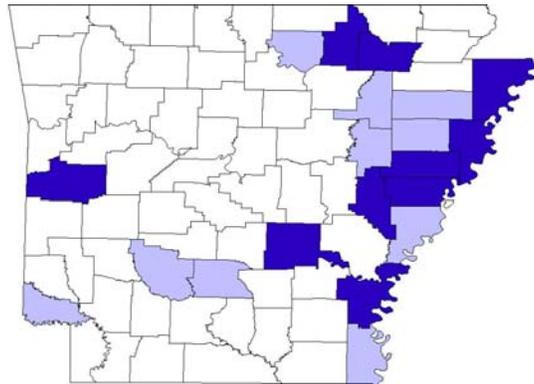
To identify counties of interest within our service area an index score was created using data from ‘The Burden of Breast Cancer in Arkansas’ report. By creating and utilizing an index score, counties can be compared based on the female population’s overall risk. The factors chosen for inclusion in the index consist of the following: incidence, mortality, percent of women with no recent mammogram, percent of adults with no health insurance, percent of adults with no personal doctor, percent of population living under poverty, percent of African American population, and percent of female residents age 40 years and older. Looking at all factors combined, the top ten counties ranking the highest for breast cancer burden/risk fall in the Arkansas Affiliate service area (Table 6 and Map 3).

Table 6.
Top 10 Breast Cancer Burden Index Scores:

Rank	County
1	St. Francis
2	Lee
3	Mississippi
4	Sharp
5	Crittenden
6	Lawrence
7	Desha
8	Jefferson
9	Monroe
10	Scott

Note. Top 10 Breast Cancer Burden Index Scores: Mortality, Incidence, Screening, Poverty, No Health Insurance, No Personal Doctor, Women age 40 and older, and Percent African American Population Combined.

Map 3.
Breast Cancer Burden Index Scores



Note: The dark blue shading indicates the top 10 counties with the highest breast cancer burden index scores for Mortality, Incidence, Screening, Poverty, No Health Insurance, No Personal Doctor, Women Age 40 and Older, and Percent African American. The light blue indicates the next 10 counties in summed rank order.

Taking the index score information and looking at four significant variables in addition; percent of residents who have completed high school, lowest female life expectancy (2000), lowest median household income in 2007, and the highest percent of population under poverty in 2007, four target counties have been identified: St. Francis, Lee, Desha, and Monroe (Table 7). These four counties can be found in the Northeast and Southeast regions along the Delta

Table 7.
Identified Target Counties: Desha, Lee, Monroe, and St. Francis

County:	Index Rank (1-10):	% Completed HS:	Female Life Expectancy:	Lowest Median Income (2007):	Percent of Population Under Poverty (2007):
St. Francis	1	65.1	73.1	\$28,318	32.6
Lee	2	56.2	73.1	\$24,195	31.8
Desha	7	65	74.1	\$28,119	26.6
Monroe	9	63.8	74.4	\$27,141	27.2

Note: Index Score (1 being the highest for breast cancer burden/risk), Percent of Residents who Have Completed High School, Lowest Female Life Expectancy (2000), Lowest Median Household Income in 2007, and Highest Percent of Population Under Poverty in 2007

Desha, Lee, Monroe, and St. Francis counties all rank in the:

- Top 10 for having the highest breast cancer burden/risk
- Top 15 for the lowest percent of residents who have completed high school
- Top 15 for the lowest female life expectancy
- Top 15 for the lowest median household income in 2007
- Top 15 for the highest percent of the population under poverty in 2007

Conclusions:

Looking at all of the factors combined to obtain information used to identify the communities of interest the Affiliate has recognized that there is a significant need for breast health services in these target areas.

Health Systems Analysis of Target Communities

Overview of Continuum of Care

The continuum of care provides a framework for health communication and understanding a woman's experience when moving through the health care system for breast cancer. To identify the gaps and barriers that exist throughout the continuum, it is important to talk with key stakeholders, breast cancer survivors, and community members. Advocacy efforts and partnerships can be formed with the information obtained from these individuals.

The four phases of the continuum of care for breast cancer include: screening, diagnosis, treatment and follow-up (Figure 3).

Screening: Getting regular screening tests is the best tool for lowering a woman's risk of dying from breast cancer. Susan G. Komen for the Cure® recommends: clinical breast exams at least every three years for women age 20-39, clinical breast exam every year beginning at age 40 and mammograms every year beginning at age 40. Women with special risk factors should discuss screening recommendations with their health care providers. There is however barriers to

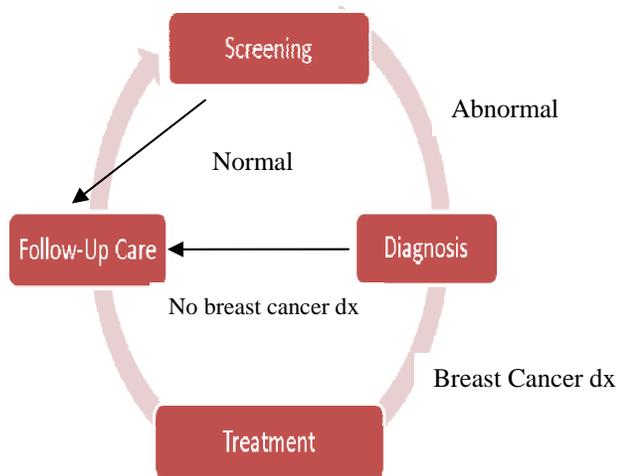
screening services that a woman may face. Examples of barriers may include: knowledge of screening services available, transportation to services, or not having insurance coverage.

Diagnosis: Once a woman has been screened she will either have a normal or abnormal finding on her mammogram. If the finding is normal the woman will move directly into follow-up care (described below). If the screening is abnormal she will move into the diagnosis stage. During the diagnosis stage a woman will undergo one or more diagnostic procedures such as: a diagnostic mammogram, ultrasound, or biopsy. While in the diagnosis stage a woman will need to be guided as to where she is able to access these procedures, what each procedure entails, and what to do if the diagnosis is breast cancer.

Treatment: If a diagnosis of breast cancer is found a woman will enter into treatment. If no breast cancer is detected she will proceed to follow-up (described below). The best course of treatment is decided by the patient and provider. Difficulties that may occur during the treatment phase can include: having the proper insurance coverage, having a mode of transportation to and from treatment, knowledge of possible side effects- short and long term or child care (if needed) while undergoing treatments.

Follow Up-Care: Improving quality of life after treatment. Follow-up care may include: regular screening as recommended by health care providers, short and long term side-effect management, long-term treatment, end-of-life care, or support services.

Figure 3.
Continuum of Care



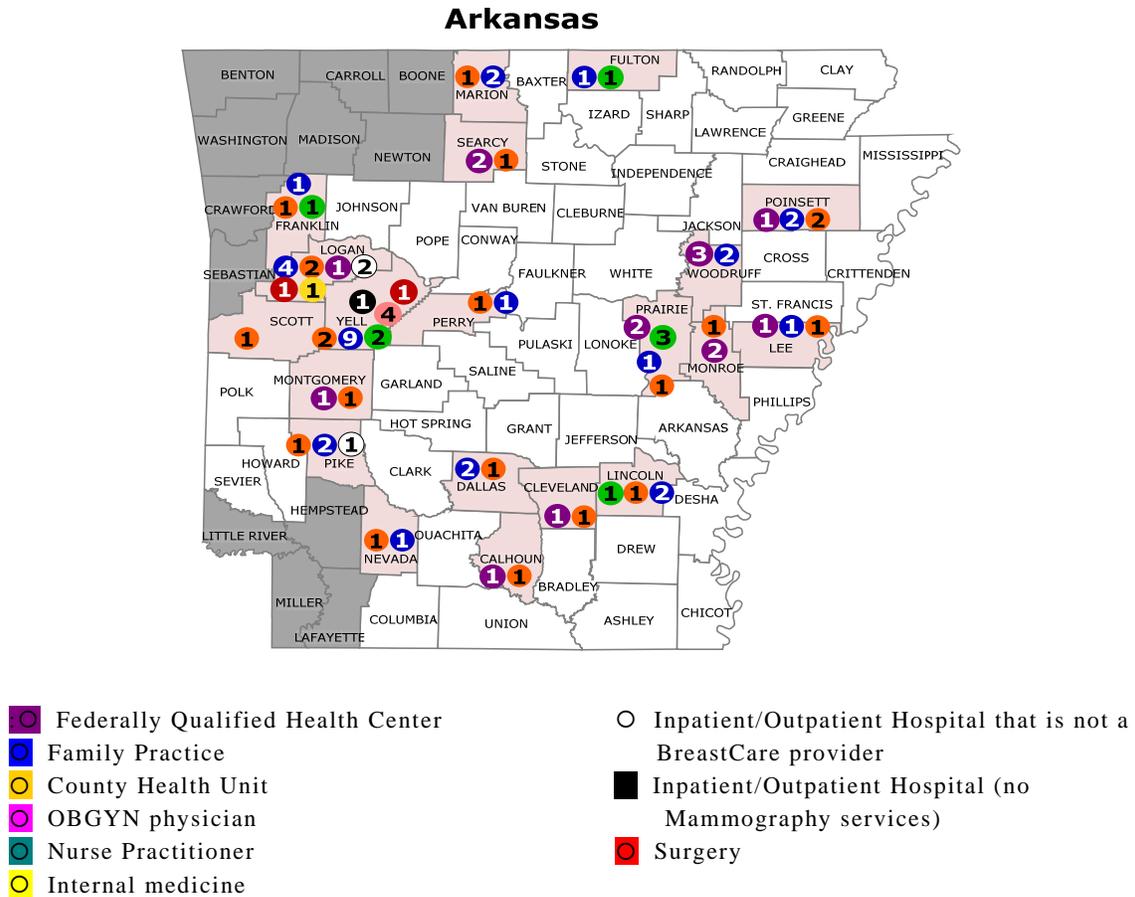
Note: Figure 3 created using Microsoft Word 2007, shows that the continuum of care is a continuous cycle.

Methodology

Key informant interviews were conducted to identify the issue of having no mammography services available in the 20 NFMS counties. To aid in the identification of key individuals in the 20 NFMS counties for the interviews, two maps were developed from information gathered by the Arkansas Affiliate Task Force (Map 4 and Map 5). The Arkansas Affiliate Task Force was comprised of eight women from different counties in the service area. The volunteer

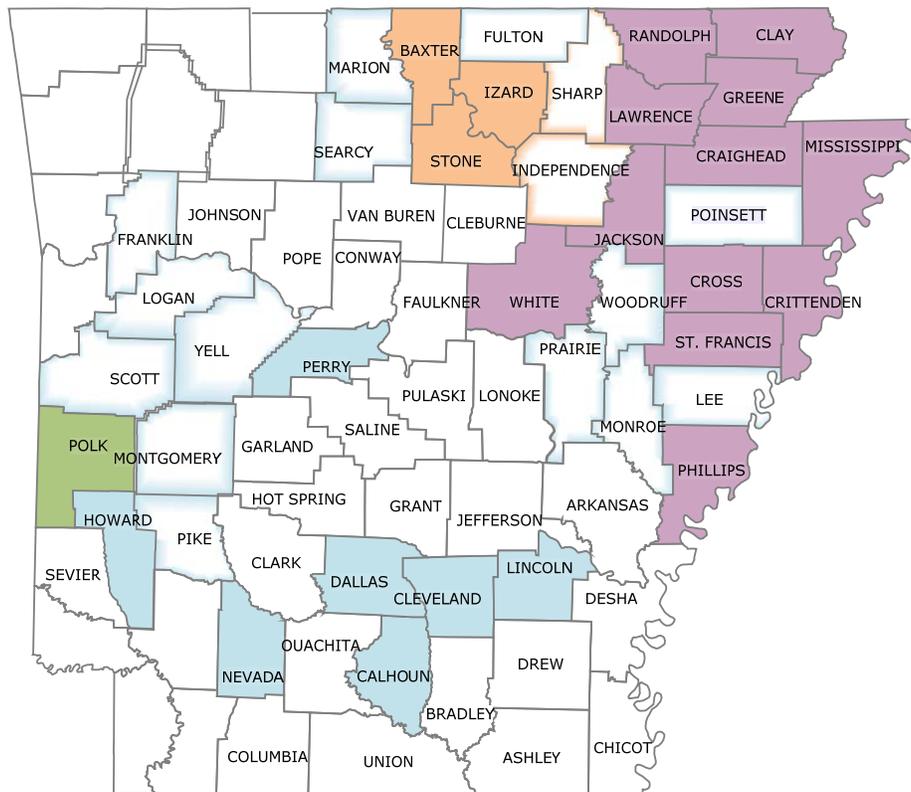
responsibilities of the Task Force included: researching and gathering information on the 20 NFMS counties. Map 4 provides a snapshot of the limited services that are available in these 20 counties. Map 5 depicts the mobile mammography units from four Arkansas hospitals that travel within the Arkansas Affiliate service area. One of the hospitals St. Edwards is not in the Arkansas Affiliate service area but does provide mammography services to three of the NFMS counties.

*Map 4.
Snapshot of Limited Services Available in NFMS counties*



Note. Map 4 shows the number of limited services available in the 20 NFMS counties in 2009.

Map 5.
Mobile Mammography Unit Coverage



 Baxter Regional Medical Center	 St. Bernards Medical Center
 UAMS	 St. Edwards Mercy Medical Center

Note: Map 5 shows the coverage by county of the mobile mammography units currently on the road throughout the Arkansas Affiliate service area.

Using these two maps the Arkansas Affiliate Task Force was able to identify 32 key leaders from established healthcare providers within the targeted counties to conduct key informant interviews. The key informants included: clinicians, patient navigators and program directors. Of the 20 NFMS counties, key informant interviews were conducted with individuals from 13. The counties represented include: Calhoun, Cleveland, Dallas, Franklin, Grant, Lincoln, Lee, Logan, Montgomery, Nevada, Paris, Pike, and, Scott. Although a large source of useful information has been obtained from the 32 key informants in the 20 NFMS counties, a limitation of the qualitative data collection process was not identifying current services available or key informants from the entire 63 county service area. Having information on all 63 counties would have provided an understanding of the breast health services that already exist and the quality of those services in the areas surrounding the 20 NFMS counties.

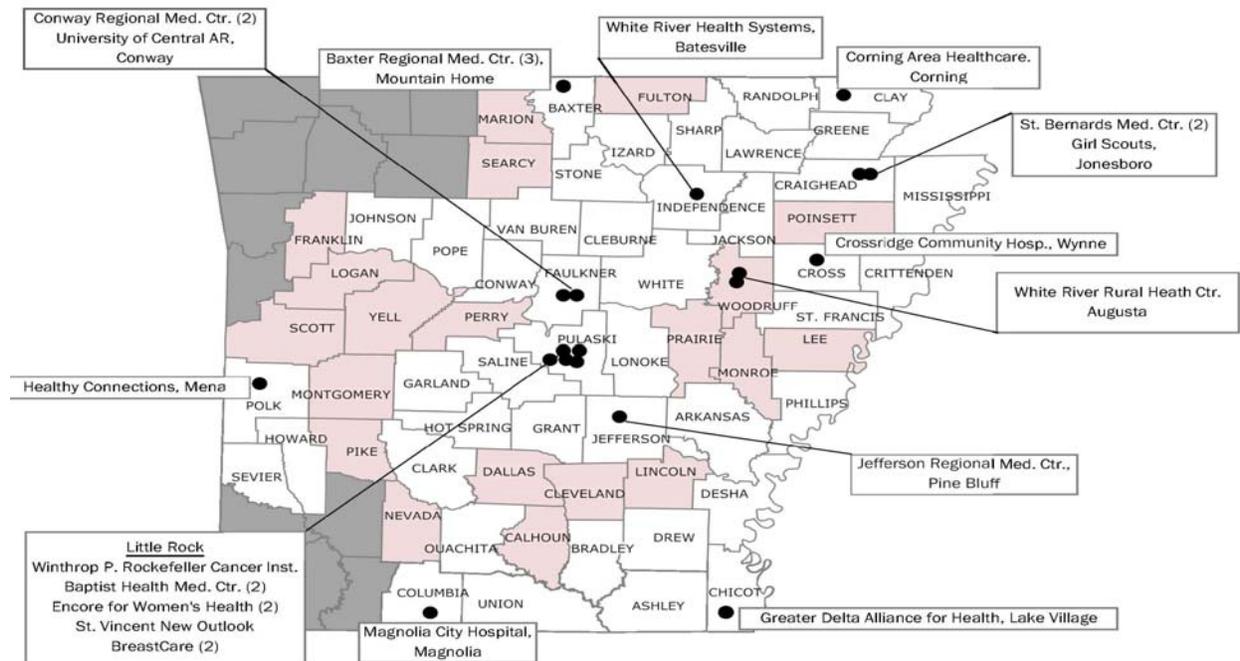
The Arkansas Affiliate conducted key informant interviews with leaders throughout the NFMS counties but unfortunately not the additional four counties of need identified in the ‘Breast

Cancer Impact in Affiliate Service Area' section (Desha, St. Francis, Lee, and Monroe). This was due to the 2011 Community Profile being built upon from the 2009 Community Profile. The 2011 Community Profile includes the data that was gathered from the key informant interviews conducted in 2009 as well as new data included in the 'Breast Cancer Impact in Affiliate Service Area and Breast Cancer Perspectives in the Target Communities' sections.

Overview of Community Assets

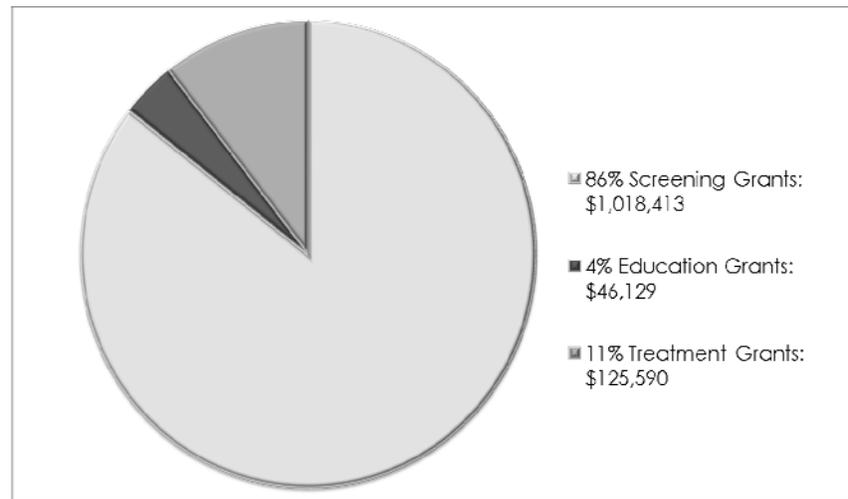
Currently, the Arkansas Affiliate has 24 grants in its 63 county service area (Figure 4) totaling \$1,190,132. The distribution of spending between screening, treatment and education throughout the service area is shown in Figure 5. One can see that currently the distribution of spending dollars is predominately in screening.

*Figure 4.
Arkansas Affiliate Grant Slate by Headquarter Location*



Note. Figure 4 shows where the 24 grantees are headquartered, and how many grants each organization received for the 2010-2011 grant cycle. Please note that this does not reflect the counties served by each grant, only the headquarter location.

Figure 5.
Distribution of Spending Dollars throughout Arkansas Affiliate Service Area



Note. Figure 5 shows how the grant money is distributed throughout the Arkansas Affiliate service area in regards to screening, education, and treatment for the 2010-2011 grant cycle.

With the 24 grants currently in place, all 63 counties in the service area are covered by at least one of these grants. The screening grants target low socio-economic, minority and medically underserved/uninsured women, some of which do not qualify for BreastCare. The education grants target a range of audiences which includes: high school seniors, their moms, school teachers, and staff; women 40+ years attending faith-based services, girl scouts ages 5-17 and girl scout adult volunteers. Like education, the treatment grants target a range of audiences which includes: underserved, uninsured breast cancer patients ages 20-65, uninsured and underinsured breast cancer survivors, women diagnosed with breast cancer who are undergoing radiation or chemotherapy treatment, and breast cancer survivors and patients who would benefit from therapeutic massage.

Partnerships.

One well known and established partnership that currently exists within the Arkansas Affiliate is BreastCare, which is Arkansas' Breast and Cervical Cancer program. The BreastCare Program administered by the Arkansas Department of Health, is guided by an eight member Breast Cancer Control Advisory Board who has been appointed by the Governor of Arkansas. The program was created by the passage in the Arkansas General Assembly of the Breast Cancer Act of 1997. The Arkansas Affiliate was instrumental in the passage of the act that established BreastCare. A Komen representative has a permanent position on the Breast Cancer Control Advisory Board. This position is recommended by the Arkansas Affiliate. The Arkansas Affiliate and BreastCare have a contractual agreement, defining a partnership to serve the women of Arkansas.

The Arkansas BreastCare program targets Arkansas women 40 years of age and older, with incomes at or below 200 percent of the federal poverty level, who do not have health insurance and whose insurance does not cover mammograms. Women who qualify for BreastCare and are

diagnosed with breast cancer are automatically enrolled in Medicaid for their treatment. Under the Breast and Cervical Cancer Prevention and Treatment Act of 2000, states have the option to provide full Medicaid benefits to uninsured women under age 65 who are diagnosed with cervical or breast cancer through the National Breast and Cervical Cancer Early Detection Program. Coverage extends throughout the duration of treatment. There are three options that a state can choose from. Arkansas has chosen Option 3, which means that any woman screened by a provider the state decides to consider part of the CDC screening network is eligible for treatment. Presumptive eligibility allows women who appear to be eligible for Medicaid to enroll in the program on a temporary basis and receive services while their Medicaid applications are processed (Kaiser State Health Facts, 2002).

Now entering its second decade of service, BreastCare is an effective and well managed state program, exceeding the minimum CDC reporting standards. For the first time in 2008, this program was unable to provide mammograms for the last six weeks of its fiscal year. The passage of HB1204 will provide an additional \$2.5 million for treatment costs in FY 2010 and FY 2011.

BreastCare facts/statistics for 2010:

- 9,749 women were served while 48,140 were eligible
- 2,121 women were screened (October-December 2010)
- 1,303 screening mammograms provided (October-December 2010)
- \$3,315,423 was spent on direct services to women enrolled in the program. These services consist of: recruitment, screening, diagnostic, and case management services.

The Arkansas Affiliate also has a sound partnership with the American Cancer Society and the Arkansas Cancer Coalition.

Additional partnership opportunities suggested by participants from Star City as well as from the Susan G. Komen for the Cure Coastal Georgia Affiliate included:

- **StarDaze:** StarDaze is a festival that is put on by the Chamber of Commerce in Star City on April 15th and 16th. The festival includes: entertainment, rides, games, arts and crafts, a car show, food, and exhibits. This year represents the 8th annual event.
- **Relay for Life:** Relay for Life will be held June 3rd at the Star City Town Square. A survivors team has been formed, and the Arkansas Affiliate has been invited to set up an educational table with them for the event.
- **Mammovan visits:** The Arkansas Affiliate has teamed up with the Patient Navigator from the Winthrop P. Rockefeller Cancer Institute to receive the mammovan schedule and updates as they are available for the UAMS mobile mammography unit.
- **County Coordinator:** The Missions Director recently spoke with a representative from the Susan G. Komen for the Cure Coastal Georgia Affiliate, whose Affiliate also serves a large county area, to ask for recommendations on how to reach the women. After discussion the Arkansas Affiliate has decided to shift from identifying 'Community Champions' to 'County Coordinators.' The primary role of each County Coordinator will be to help the Affiliate in developing a network of advocates who are willing to reach out to the women in their local communities, while supporting the promise of Susan G. Komen for the Cure. The Arkansas Affiliate Education Committee will develop the

Legislative Issues Affecting the Target Communities

BreastCare, which is a major provider for the women in our target counties, has recently been faced with funding difficulty. BreastCare funding currently comes from a tobacco product excise tax. Besides the downturn in the economy, two other factors have also contributed to the balance of this program over the past two years. A new head of the Department of Health had a different viewpoint on the role that the advisory board should have in the financial decisions of this program. In addition, a new federal excise tax of 63 cents per package of cigarettes and a 55 cent state tax per package were approved at the same time. Of this increase, BreastCare received \$2.5 million of additional treatment money. The two taxes combined made a package of cigarettes cost \$1.18 more. Although the increase in cigarette cost per package is a positive aspect, a significant drop in the purchase of tobacco products has occurred, which means there is less money for screening in the BreastCare program. The number of women served by this program went from 14,000 to 8,000 in just two years.

A coalition of organizations who are the stakeholders for BreastCare, are working to restore BreastCare to its prior position. The coalition is named Restore BreastCare. Through the work of many stakeholders, Restore BreastCare has demonstrated leadership and supported others to demonstrate leadership to save the integrity of the legislation passed to establish BreastCare and the Advisory Board of BreastCare. The Komen presence has been before legislators, legislative committees and elected officials all the way to the governor. The Arkansas Affiliate has worked with the governor, the BreastCare staff, the Director of the Health Department and his staff, legislators and legislative committees. Education of this issue has been made possible through luncheons, letters, emails, legislative committee presentations, and video.

Findings from Key Informant Interviews

From the key informant interviews, the Arkansas Affiliate was able to assess the experience of a woman moving through the continuum of care. 15 questions based around the continuum were asked in each interview. Nine questions were based around screening, two around diagnosis, two around treatment, and two around follow-up. The responses, as expected varied from county to county.

Key informant findings around the 20 NFMS counties.

Screening: The three main barriers reported in the key informant interviews in regards to receiving a screening mammogram were price, fear, and transportation. Most women travel 30-60 miles on two lane highways with twists and curves to receive a mammogram. Some of the NFMS counties have access to services in a county adjoining them and feel that it is not a hindrance to their women, while the others feel that this is a big issue. Many informants referred to faith based education as a means to reach women in these counties, and felt that more mobile mammography visits would ease their stress.

“No. Most women do not get an annual mammogram due to a lack of health insurance, transportation issues, and ignorance.”

Diagnosis: If a woman needs further diagnostic testing, the health clinic will refer her to BreastCare if she qualifies, or to the nearest hospital. Often times if the women do not qualify for BreastCare, they are sent to the University of Arkansas for Medical Sciences, where services are provided at low or no cost. Providers also noted that they felt having educational materials available in the waiting areas would be beneficial to the women coming in for further testing.

Treatment: The key informants reported that many women do not get mammograms because they fear that they would not have the means to treat the breast cancer if found, and are unaware of the financial services available to help with these costs. It was noted that many providers try to educate the women on the financial services available through BreastCare. BreastCare is Arkansas' Breast and Cervical Cancer Program (BCCP). If you qualify and are screened in BreastCare they will automatically cover a women's treatment cost through the state Medicare program.

Follow-Up: The two most common responses in regards to follow-up care from the key informants were counseling and education. Many women are unaware of the support services available to them after their treatment ends. Education is needed to inform the women about follow-up visits, how to handle long-term side effects, and maintaining a healthy lifestyle after their treatments end.

Conclusions

The health systems analysis completed in 2009 allowed the Arkansas Affiliate to have an understanding of how a women moves through the continuum of care for breast health and where the gaps and barriers are along the way. To begin working towards solutions to these gaps and barriers the Arkansas Affiliate came together to prioritize a plan of action for these target issues; seeking to develop a plan for each of the NFMS counties. The goals and objectives around the 20 NFMS counties will be discussed in further detail in the Conclusions section.

Breast Cancer Perspectives in the Target Communities

Methodology

An approach to reaching survivors and women in the 20 NFMS counties that the Arkansas Affiliate has taken is through a letter with a survey included. A total of 50 letters and surveys were sent out. The letters were sent out to identify women who would like to take on the role of a 'Community Champion.' The Arkansas Affiliate defines a 'Community Champion' as one who in an organized manner tells others about breast health, the importance of early detection, and supports those who are newly diagnosed.

The letter explains to the individual that they are being contacted because their community has been targeted in Arkansas as one that is lacking in resources, as well as providing an explanation to define the purpose of the survey. The surveys served as a tool for the Arkansas Affiliate to identify: if these women were interested, how they were interested (i.e. health fair events, train the trainer, speaking engagements), and the best time and method for reaching them. For the 20 NFMS counties, letters were sent out to all survivors and non-survivors who have been a part of the Arkansas Affiliate Race for the Cure, faith based organizations, community based organizations, and health clinics in hopes to receive feedback from as many individuals as possible.

The Race database was used to identify those who have been a part of the Arkansas Affiliate Race for the Cure®. The Task Force members researched and created a spreadsheet of all the church organizations, community organizations, and health clinics for the 20 NFMS counties. Provided on this spreadsheet for each was the facility name, address, and telephone number.

Review of Qualitative Findings

The survey approach used had a low response rate with only 20 being returned. The 20 surveys that were returned to the Arkansas Affiliate allowed us to see that the majority of women would like to become more involved in their communities, many are not able to travel to Little Rock to speak with us, and the best time to reach these women is in the early evening after work or on Saturday mornings.

With the highest response rate being from individuals in Lincoln County the Arkansas Affiliate has decided to start in this county to begin gaining community perspectives around the continuum of care. To gain an appropriate perspective from the women who would like to become ‘Community Champions,’ the Education Committee of the Arkansas Affiliate feels that the best approach is to travel to these counties and speak with the individuals face to face, allowing for a more personal experience. The city in Lincoln County that has been chosen is Star City. Star City has the largest population in the county, the largest school district, and is visited by the mobile van.

A day trip to Star City was made where two survivors were interviewed for two hours to identify gaps and barriers around the continuum of care. Each participant received a binder. The binder included: a copy of the educational materials Susan G. Komen for the Cure® offers, volunteer forms to be used at health fair events, a hard copy and electronic copy of the most current Breast Self-Awareness Community Outreach presentation, our contact names and numbers. In the two hours spent with the women we were able to gain insight on where women in Lincoln County go or chose to go for breast health services, their experiences with the facilities they go to, the best way to reach out to individuals in the community, educational opportunities for the Arkansas Affiliate to have a presence, and concluded with the community outreach presentation. More specifically:

- The best approach for reaching the women in Star City and Lincoln County is through word of mouth.
- There is currently no breast cancer support group in Star City
- The newspaper for Star City is the Lincoln Ledger
- Many women are actively involved in their church organizations
- Both women currently travel to Little Rock to see a doctor for their breast health.
- The nearest facility for breast health screening besides the mammovan is Jefferson Regional Medical Center, which is approximately 30 miles from Star City.

We were not only able to gain perspective around discussion but also from driving through the city. We were able to see the how the school districts are set up, the organizations that are located in and near Stay City, the development of the Town Square, the layout of the neighborhoods, and where all the churches are located. Communication with the ‘Community Champions’ continues at least on a monthly basis.

Conclusions

Reaching out to the women on a more personal basis in each of the targeted counties to identify the gaps and barriers throughout the continuum of care is a new process for the Arkansas Affiliate. Lincoln County is our model to learn new approaches we can implement throughout the NFMS counties.

Conclusions: What We Learned, What We Will Do

Conclusions

In 2009, the Arkansas Affiliate recognized that the assets in the service area were not evenly distributed, identifying 20 NFMS counties as target areas. Within these 20 counties the provider surveys showed that money, including lack of insurance was the greatest barrier to receiving treatment. The key informant interviews conducted with key stakeholders also confirmed that the women in these 20 counties are not getting screened because they do not have access to services and if access is available they are unable to afford the services.

Looking beyond lack of services, in 2011 the Arkansas Affiliate identified four counties of interest in the service area: Desha, Lee, Monroe, and St. Francis. The identification of these target counties was done with the available statistical and demographic information from “The Burden of Breast Cancer in Arkansas” report. Taking all counties in the service area into consideration; Desha, Lee, Monroe, and St. Francis ranked the highest for: breast cancer burden/risk, lowest percentage of residents who have completed high school, lowest female expectancy, lowest median household income in 2007, and highest percentage of the population under poverty in 2007.

To understand the perspectives of survivors and individuals living in the communities the Arkansas Affiliate took on the approach of a survey and letter. This survey and letter led to identifying individuals in our communities of interest who would like to become a “Community Champion.” The letter explained to the individual that they are being contacted because their community has been targeted in Arkansas as one that is lacking in resources, as well as providing an explanation to define the purpose of the survey. The surveys served as a tool for the Arkansas Affiliate to identify: if these women were interested, how they were interested (i.e. health fairs, train the trainer, speaking engagements), and the best time and method for reaching them.

Taking the information gained throughout the processes of the Community Profile the next steps for the Affiliate was to identify action plans and priorities. To identify appropriate action plans and priorities incorporating this new information, the Arkansas Affiliate President of the Board of Directors, Executive Director, Missions Director, Grant Committee Chair, and Education Committee Chair came together to discuss how the Affiliate will approach these counties, and maintaining the progress made with earlier grants. The priority and action plan is outlined below.

Arkansas Affiliate Priorities and Action Plan:

Priority 1: Increase the number of breast health services and providers available within our 63 county service area while maintaining and/or enhancing the quality of the programs currently in place.

Objective 1: From April 1, 2011-March 31, 2013 have grant mentors visit the grantee organization in which they were assigned to oversee one time yearly.

Objective 2: From April 1, 2011-March 31, 2013 use public policy action to assure continued funding for BreastCare- Arkansas' Breast and Cervical Cancer Program.

Objective 3: Communicate to grantee organizations at the grants luncheon on April 1, 2011 and March 30, 2012 the four key breast self-awareness guidelines: know your risk, get screened, know what is normal for you and maintain a healthy lifestyle.

Objective 4: From April 1, 2011-March 31, 2012 have a registered nurse evaluate the educational materials placed in the Affiliate survivor kits that are provided to all the breast centers in our service area for those who are newly diagnosed with breast cancer.

Priority 2: To expand education programs in St. Francis, Desha, Lee and Monroe that address breast health and increase awareness of available services.

Objective 1: From April 1, 2011-March 31, 2013 have the education committee identify two County Coordinators in Desha, Lee, Monroe, and St. Francis counties to assist the Affiliate in developing a local network of advocates within their county who will support the promise of Susan G. Komen for the Cure.

Objective 2: From April 1, 2011-March 31, 2013 have the Affiliate education committee partner with community based organizations in Desha, Lee, Monroe, and St. Francis counties to educate the population they serve on breast health.

Priority 3: To collaborate with service area mobile mammography unit providers to increase awareness to individuals about the services they provide and when/where these services are available.

Objective 1: Have the Missions Director attend the Komen Leadership Conference Grant Forum in Ft. Worth, Texas on March 24, 2011 with a current Arkansas Affiliate grantee representative to engage in grant networking opportunities with other Komen Affiliate and grantee members.

Objective 2: Hold a mobile mammography forum in June 2012 to build cohesive collaborative efforts allowing the exchange of ideas between Baxter Regional, St. Bernards, and UAMS mobile mammography unit providers.

From the work we have done and with our priorities laid out the Arkansas Affiliate is committed to addressing the needs as identified in the 2011 Community Profile.

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