# Table of Contents

**Table of Contents** ........................................................................................................................ 2

**Acknowledgments** ...................................................................................................................... 3

**Executive Summary** .................................................................................................................... 6

  - Introduction to the Community Profile Report ............................................................................ 6
  - Quantitative Data: Measuring Breast Cancer Impact in Local Communities ......................... 7
  - Health Systems and Public Policy Analysis .............................................................................. 9
  - Qualitative Data: Ensuring Community Input .......................................................................... 11
  - Mission Action Plan ................................................................................................................. 11

**Introduction** ............................................................................................................................... 15

  - Affiliate History ....................................................................................................................... 15
  - Affiliate Organizational Structure .......................................................................................... 16
  - Affiliate Service Area .............................................................................................................. 18
  - Purpose of the Community Profile Report ............................................................................ 19

**Quantitative Data: Measuring Breast Cancer Impact in Local Communities** ....................... 21

  - Quantitative Data Report ....................................................................................................... 21
  - Additional Quantitative Data Exploration ............................................................................. 36
  - Selection of Target Communities ............................................................................................ 37

**Health Systems and Public Policy Analysis** .............................................................................. 42

  - Health Systems Analysis Data Sources .................................................................................. 42
  - Health Systems Overview ....................................................................................................... 43
  - Public Policy Overview .......................................................................................................... 52
  - Health Systems and Public Policy Analysis Findings .............................................................. 59

**Qualitative Data: Ensuring Community Input** ........................................................................ 61

  - Qualitative Data Sources and Methodology Overview ............................................................ 61
  - Qualitative Data Overview ..................................................................................................... 65
  - Qualitative Data Findings ....................................................................................................... 71

**Mission Action Plan** .................................................................................................................. 87

  - Breast Health and Breast Cancer Findings of the Target Communities .................................. 87
  - Mission Action Plan ................................................................................................................. 88

**References** ................................................................................................................................... 91

**Appendices** .................................................................................................................................. 92
The Community Profile Report could not have been accomplished without the exceptional work, effort, time and commitment from many people involved in the process.

Susan G. Komen® Ozark would like to extend its deepest gratitude to the Board of Directors and the following individuals who participated on the 2015 Community Profile Team:

Heather Schneller, Ph.D.
Director of Housing and Residence Life
University of Arkansas

Lauren Marquette, LMSW
Executive Director
Susan G. Komen Ozark

Sarah Faitak, RN
Director, The Breast Center
Grants Chair for Susan G. Komen Ozark

Tyler Clark
Community Development Director
Community Clinic

Vicki Cowling
Director of Mission Services
Susan G. Komen Ozark

In appreciation for leadership and contribution to the Komen Ozark Affiliate

Mary Alfrey
(1956-2015)
Executive Director
Susan G. Komen Ozark

A special thank you to the following entities for their assistance with data collection and analyses, as well as providing information included in this report:

Deborah Henderson, RN
Academic Advising, Eleanor Mann School of Nursing
University of Arkansas

Gloria Flores Passmore
Director, Sponsored Student Programs
University of Arkansas
Silke Spiesshoefer, Ph.D.
Adjunct Professor, Electrical Engineering
University of Arkansas

Madeline Marquette
Komen Ozark Volunteer

Drenda Pinkleton
Operations Manager
Susan G. Komen Ozark

Polly Gocke
Volunteer Coordinator
Susan G. Komen Ozark

Lindsay Dixon
Development Officer
Susan G. Komen Ozark

Teresa Jones
Outreach/Communications Coordinator
Susan G. Komen Ozark

Holly Gillies
Program Coordinator
North Arkansas Partnership for Health Education

Heather Zoromski, MPH, CGW
Grants Administrator
Skaggs Foundation

Donna Graham, RN
Breast Health Nurse Navigator
Madison County Health Coalition

Merlin Leach, Ph.D.
President
The Merlin Foundation

Ede Zuniga
Patient Advocate
Community Clinic
Introduction to the Community Profile Report

Komen Ozark was established in 1998 by a group of dedicated community volunteers who wanted to increase awareness of breast cancer and raise funds to support the promise of saving lives and ending breast cancer forever. The Affiliate initially served six counties covering Benton, Carroll, Crawford, Madison, Sebastian and Washington Counties in Arkansas. In order to support the Affiliate, the first Race for the Cure was held on April 17, 1999 at the Northwest Arkansas Mall in Fayetteville, Arkansas. The first Race raised $120,000. Since 1999 Komen Ozark has funded over $9 million in local breast health programs through fundraising events like the Race for the Cure.

In order to support more communities, Komen Ozark first expanded the service area in 2009. Two additional counties-Boone and Newton were annexed into the service area for a total of eight counties. In 2011, the second expansion occurred when the Affiliate annexed Stone and Taney Counties located in Missouri. Currently, Komen Ozark covers 10 counties including eight counties in the Northwest and River Valley area in Arkansas and two counties in Southwest Missouri (Figure 1).

Key Activities
Since 1998, the Affiliate has awarded over $9 million to local organizations to provide life-saving breast health services. Additionally, Komen Ozark has funded nearly $3 million to the scientific research program. In the most current granting cycle, Komen Ozark (FY 2015-2016) awarded $725,000 to 10 local organizations throughout the Affiliate service area. Grantees provided services including; screening, diagnostics, treatment assistance, navigation, education, gas cards, mobile mammography, and survivorship support.

Komen Ozark provides speakers for educational events, representatives at health fairs, events and advocates for breast health programs and services at the local, state and national levels throughout the year.

Purpose of the Community Profile Report
The Purpose of the 2015 Community Profile report is to provide an updated and comprehensive assessment of the Affiliate’s 10 county service area. The profile can be used by grantees and donors to gain insight to the communities served. The Community Profile describes the state of breast cancer and the availability of services in the community. It provides the foundation to make the best decisions about how Komen Ozark can use available resources to make the greatest impact. The Community Profile also provides the Affiliate insight priority setting, marketing strategies and guiding public policy initiatives. Another key outcome of a comprehensive assessment is a portrait of community needs that will be used to strengthen education, outreach and specific fundraising efforts.
**Quantitative Data: Measuring Breast Cancer Impact in Local Communities**

The Community Profile Team utilized quantitative data from many credible sources and use the data to identify the highest priority areas for evidence-based breast cancer programs. The data provided are used to identify priorities within the Affiliate’s service area based on estimates of how long it would take an area to achieve Healthy People 2020 objectives for breast cancer late-stage diagnosis and death rates. These indicators are assessed for each county within the Affiliate’s service area and then measured against state and national data.

Key indicators the Affiliate examined included incidence rates and trends for death, late-stage and screening. Analysis also included demographics of residents, rural and medically underserved areas, education level, health insurance, language barriers and poverty levels.

Target communities selected for further exploration for Komen Ozark include:
- North Arkansas (Boone, Madison and Newton Counties)
- Hispanic/Latina Women (Benton, Carroll, Sebastian and Washington Counties)
- South Missouri Region (Stone and Taney Counties)

**About the target communities:**

**North Arkansas (Boone, Madison, and Newton Counties)**

Due to the population size, geographic location and lack of data provided for smaller counties, Boone, Newton and Madison counties have been combined to make up the North Arkansas region of the targeted selected communities. These three counties have been selected as a target area for the Komen Ozark service area because of low screening percentages, late-stage diagnosis, breast cancer death rate, demographic data and having been identified as medically underserved with high poverty rates. The North Arkansas region has a series of commonalities that, when combined, concern the Affiliate.

**Socioeconomic statistics and affordable health care:** All three counties have a significantly higher percentage of people living in the income bracket that is 250 percent below the poverty line. Newton County has the highest percentage living in poverty. The counties are rural. Madison and Newton have 100 percent of the population living in rural areas with Boone County is 62.2 percent rural. The North Arkansas region is considered medically underserved. Access to services continues to be an issue. The population of Madison and Newton Counties has almost five times the rate of people living in medically underserved areas as the United States. Additionally, the North Arkansas region is significantly higher than the United States for rates of people age 40-64 without health insurance. The uninsured percentage in each of these counties is an issue of concern that prevents men and women from seeking services.

**Age:** Boone, Madison and Newton Counties have older populations than the Komen Ozark service area and the United States. In all three age category breakdowns (Female Age 40+, Female Age 50+ and Female Age 65+) Boone, Madison and Newton counties are significantly higher than the United States average. This is important because age is a risk factor for breast cancer.
**Education:** Education levels are low in this region. Newton, Madison and Boone Counties all have a higher percentage of the population with less than a high school education than the United States. Madison County has the highest percentage of the population with less than a high school education than any other county in the entire Affiliate.

**Healthy People 2020:** Due to the rural population, it is difficult to predict if the North Arkansas region will meet targets outlined for screening, late-stage incidence rate and female death rate due to breast cancer. Newton and Boone are not likely to meet target numbers. Madison County may meet the target for one criteria; late-stage incidence rate.

**Hispanic/Latina Women (Benton, Washington, Sebastian and Carroll Counties)**
These four counties have been identified as a select target community due to the percentage of the population that is Hispanic/Latina and linguistically isolated. Breast cancer is the most common cancer among Hispanic/Latina women and it also remains the leading cause of cancer death in Hispanic/Latina women. Hispanic/Latina women tend to be diagnosed with later stage breast cancer than white women and they may be less likely to receive prompt follow-up after an abnormal mammogram.

**Linguistic isolation:** Language barriers can block access to quality care and can affect all stages of the Continuum of Care. The language barrier with the Hispanic/Latina population is a concern for health care providers.

The linguistically isolated average for the State of Arkansas is 1.7 percent and the percentage of the Komen Ozark service area is significantly higher at 3.2 percent. The highest counties include:
- Washington= 5.4 percent
- Sebastian= 4.2 percent
- Benton= 3.1 percent
- Carroll= 2.5 percent

Washington and Benton Counties have the largest percentage of immigrants. This population often has difficulty accessing or being eligible for insurance or other government assistance programs like the Arkansas Department of Health’s BreastCare. Those who are not US residents and/or undocumented are not eligible for health insurance.

**South Missouri (Stone and Taney Counties)**
Due to population size, geographic location and statistical similarities, two counties (Stone and Taney) have been combined in this report in order for Komen Ozark to address the needs of this targeted area. Stone and Taney Counties are located in the southwest corner of Missouri and border Arkansas. The population of women in Stone and Taney Counties is 16,295 and 25,334 respectively. The demographic makeup is almost entirely White in both counties.
Socioeconomic statistics and affordable health care: The socioeconomic statistics of Stone and Taney Counties can negatively impact access to quality, affordable health care. Stone and Taney County have a significantly higher percentage of people living in the income bracket that is 250 percent below the poverty line than the Affiliate service area and the United States. Unemployment percentages of Stone County are higher than the United States and Komen Ozark service area. Taney County is equal to the United States rate of unemployment and higher than the Affiliate service area.

The population of Stone County is considered to be 100 percent medically underserved. Additionally, both Stone and Taney Counties have significantly higher rates of people with no health insurance than the United States.

Age: Stone and Taney Counties both have a greater percentage of older residents than the Komen Ozark service area and the United States. As a woman ages, her risk of getting breast cancer increases.

Incidence rate, late-stage diagnosis trend and Healthy People 2020: Stone and Taney Counties have a rising incidence rate trend and late-stage diagnosis trend for breast cancer compared to the Affiliate service area.

When examining incidence trend confidence intervals, Stone and Taney Counties are the only counties in the Affiliate service area that have an incidence rate trend that is rising. This means that there is an increase in occurrence of breast cancer among women.

Additionally, Stone and Taney Counties have a late-stage rate trend direction that is rising compared to the Affiliate service area. This rise is a predictor of an increase in late-stage diagnosis. Due to this increase, Stone and Taney Counties are likely to miss the HP2020 late-stage incidence rate target unless the late-stage incidence rate falls faster than estimated. Late-stage diagnosis is concerning because of the poorer prognosis given to women who are diagnosed with a later stage.

Health Systems and Public Policy Analysis

An analysis of the health system in each Komen Ozark target community was conducted. This work gives insight into the strengths and weaknesses of the Breast Cancer Continuum of Care (CoC) within each target community. The Breast Cancer Continuum of Care is a model that shows how a woman typically moves through the health care system for breast care. A woman would ideally move through the CoC quickly and seamlessly, receiving timely, quality care in order to have the best outcomes. The Community Profile Team identified reasons why women in the Komen Ozark service areas do not enter or continue in the CoC.

A few themes carry throughout all target communities including: transportation, bilingual services and survivorship support. All communities have a need for transportation, whether it is
public transportation, transportation to breast cancer screenings, access to a mobile unit or transportation to and from breast cancer treatment. There needs to be a focus on providing services, especially follow-up care, to the Hispanic/Latina community. Offering bilingual navigators and staff, translated materials and culturally competent practices is a need that has been identified for much of the service area. Survivorship support is also lacking in many of the selected target communities. Breast cancer survivors in rural areas may not have transportation to support groups or the distance may limit participation. Professionals with the skills to meet the multifaceted needs of those living with and beyond the cancer diagnosis are scarce in rural areas. While many oncologists and nurses understand the psychosocial aspects, body images, cognitive changes, distress, fear, socioeconomic issues and anxiety these issues may not be addressed. Group or individual support for survivorship issues is minimal or limited in the Affiliate’s target communities.

There is a lack of medical services and access to breast health screening, diagnostic and treatment services in Madison and Newton Counties. In these two counties, the only breast health screening available to patients is for clinical breast exams. The only access to screening or diagnostic mammograms is through a mobile unit. In the Affiliate’s two counties in Missouri (Stone and Taney) no mobile unit is available.

In 1993, Arkansas Health Department (ADH) received a grant to study how many Arkansas women had breast cancer and to assess the available of health care workers across the State able to test, diagnose and treat their breast cancer. This grant was the foundation for the Arkansas BreastCare program. Two years later and based on the study findings, the ADH received federal funds to provide eligible women with breast cancer screening and diagnostic services. BreastCare combined with the Affordable Care Act have made access to health care more attainable. Between the two programs, much of the focus on financial barriers for screening mammograms has been shifted to diagnostic and follow-up costs.

As the number of those insured increases, the Komen Ozark priorities will be adjusted to identify and fill emerging gaps and barriers. Financial barriers like out of pocket or deductible costs for follow-up diagnostics after abnormal screening results are currently being analyzed. How to navigate through the complexities of the health care system to reduce breast cancer death disparities is just another example of one of the barriers. The focus will remain on screening; however, the landscape of breast care services must emphasize the entire continuum of care, including survivorship.

Komen Ozark will advocate for the state of Arkansas to continue the private option and Medicaid exchange to low-income adults. The Affiliate will also continue to educate on the importance for legislative support to continue funding programs like Arkansas BreastCare and Missouri Show Me Healthy Women.
Qualitative Data: Ensuring Community Input

The key focus of the qualitative analysis was to understand how women living in rural communities access and utilize breast care. Provider surveys and focus groups were used to gather information.

In-depth analysis of 83 individuals’ experiences were used to critically examine existing barriers to health care and develop action plans to address key findings. Over the course of four months, nine focus groups were conducted. One was conducted in Spanish.

The questions derived for the evaluation were selected from the Komen Qualitative Question bank and were arranged under the following topical areas: general health, access to care and breast cancer—screening and outreach. The following served as guiding questions for the respective topical areas:

- What factors do low income women consider when thinking about personal health care?
- What factors affect accessibility to (preventive/diagnostic/active treatment/post-treatment/follow-up) care in the community?
- What factors increase educational opportunities within these selected communities?
- What is the most important message you would send to breast cancer treatment providers?

The questions used for the qualitative study are directly linked to the findings from the quantitative and public policy analysis.

The target areas dealt with a higher number of deaths from cancer in addition to late-stage diagnosis. Furthermore, because of geographic barriers, the access to health care is limited for this population. Lastly, the analysis indicated there were inconsistent resources and information in these communities. Outreach is necessary to assist in ameliorating the barriers existing for women in the target areas.

Many focus group participants told their personal experiences of trying to receive the best health care possible within the culture of a small town. Many participants felt as if they were given mixed messages about their personal health. Whether it was misinformation, lack of transportation or financial resources, these barriers created confusion for participants. Additionally, cultural issues surrounding the rural areas contributed to barriers related to care. Getting information about financial resources and screening services to key community leaders could help women in being diagnosed earlier and getting treatment.

Mission Action Plan

Komen Ozark developed a Mission Action Plan to address the needs identified through the Community Profile process. This plan is the culmination of more than one year’s effort by the Affiliate. The Community Profile Team reviewed the findings from the Quantitative Data Report, Health Systems and Public Policy Analysis and the Qualitative Data Report.
statements, priorities and objectives were created. Many individuals outside of the Community Profile Team were consulted and the Mission Action Plan was presented to the Komen Ozark Board of Directors for approval.

**Problem Statement:** The Community Profile Team reviewed the findings from the data and has determined that Boone, Madison and Newton Counties in Arkansas have a low understanding of the availability for screening services and knowledge of breast health.

**Priority:** Increase understanding of topics centered on availability of breast health and screening services.

- **Objective 1:** By October 2016, implement the Worship in Pink program in at least one church in Boone, Madison and Newton counties.
- **Objective 2:** By October 2016, develop, implement and evaluate three workshops on breast health aimed at women organizations in Boone, Madison and Newton counties. The Affiliate will use a pre and post questionnaire to measure understanding of breast health and available screening services.
- **Objective 3:** By December 2016, visit with two providers in Boone, Madison and Newton Counties to discuss client motivation intervention in order to increase screening percentages overall by five percent.

**Problem Statement:** According to the information learned from the focus groups with Hispanic/Latina population in Benton, Carroll, Sebastian and Washington Counties in Arkansas face more barriers to care access and need culturally competent information about breast health.

**Priority:** Partner with community-based outreach/health organizations to effectively promote breast health education and services including breaking down cultural and language barriers for Hispanic/Latina women.

- **Objective 1:** By June 2016, partner with community-based health organizations to arrange small group education classes on breast self-awareness in at least four clinics serving Hispanic/Latina women.
- **Objective 2:** By June 2016, reach out to at least three predominantly-Hispanic/Latino schools and/or faith-based organizations in the service area counties to hold breast cancer community outreach presentations.
- **Objective 3:** For FY 2016, boost funding to patient navigator programs aimed specifically at working with Hispanic/Latina residents in the Benton, Carroll, Sebastian and Washington counties.
- **Objective 4:** By August 2016, meet with at least three community organizations and/or faith communities that work with the Hispanic/Latina community to discuss breast health outreach.
- **Objective 5:** By August 2017, partner with at least one organization and a health care institution to provide a culturally appropriate breast health event where women aged
40+ can sign up for a mammography appointment. Breast self-awareness materials in Spanish will also be distributed.

**Problem Statement:** The Community Profile Team reviewed the findings from the data and has determined that in Stone and Taney, Missouri there is a shortage of health services and providers.

**Priority:** Increase the number of health services and providers by funding health system partnerships to increase access to services.

- **Objective 1:** By May 2016, hold at least two meetings with breast health providers to discuss the availability of grant funding.
- **Objective 2:** By December 2016, visit with two providers in Stone and Taney Counties to discuss client motivation intervention to increase screening percentages overall by five percent.

**Priority:** Increase understanding of topics centered on survivorship knowledge.

- **Objective 1:** By December 2016, collaborate with local providers and community partners to coordinate and sponsor a survivorship conference.
- **Objective 2:** By December 2016, implement quarterly webinars addressing survivorship topics with a pre and post questionnaire to measure increased knowledge.

**Problem Statement:** The Community Profile Team reviewed the findings from the data and has determined that there is a lack of knowledge about breast health by public policy decision makers.

**Priority:** Increase state legislators’ education and understanding of breast health issues.

- **Objective 1:** In FY 2016, hold quarterly conference calls with the two other Komen Affiliates in Arkansas to discuss joint public policy efforts and any pending breast cancer legislation, including advocating for maintaining state Breast and Cervical Cancer Program (BCCP) funding.
- **Objective 2:** In FY 2017, conduct a bi-annual mailing to all legislators to increase Komen’s visibility as a trusted local resource on breast cancer.

**Priority:** Develop and utilize partnerships to enhance Affiliate public policy efforts in order to improve breast health outcomes of women in the Affiliate service area.

- **Objective 1:** By December 2015, identify and train at least six key volunteers to serve on the public policy committee to carry out the Affiliate public policy efforts.
- **Objective 2:** In FY16 and FY17, partner with at least one other Affiliate within Arkansas on advocacy and public policy efforts.
**Problem Statement:** The Community Profile Team reviewed the findings from the data and determined that Affiliate-wide there is a need to improve the quality of life for survivors as they transition from treatment to recover.

**Priority:** Increase understanding of topics centered on survivorship knowledge.

- **Objective 1:** By December 2016, collaborate with local providers and community partners to coordinate and sponsor a conference focusing on survivorship.
- **Objective 2:** By December 2016, implement quarterly webinars addressing survivorship topics with a pre and post questionnaire to measure increased knowledge.

**Disclaimer:** Comprehensive data for the Executive Summary can be found in the 2015 Susan G. Komen® Ozark Community Profile Report.
Affiliate History

Susan G. Komen® Ozark was established in 1998 by a group of dedicated community volunteers who wanted to help increase awareness of breast cancer and raise funds to support the promise of saving lives. Shortly after the Affiliate founding, the first Race for the Cure® was held on April 17, 1999 at the Northwest Arkansas Mall in Fayetteville, Arkansas. The 5K Run/Walk and 2K Family Walk raised $120,000 and has grown to raising nearly $875,000 in 2014.

Since 1998, Komen Ozark has brought a local focus to an important public health concern. The Affiliate continues to grow to meet the ever increasing need for breast health services, education, treatment assistance, support and navigation for those underinsured and uninsured members of the community. Through the hard work of volunteers and staff, Komen Ozark continues to look for ways to grow and support more communities. The first expansion of the service area happened in 2009, when two additional counties-Boone and Newton were annexed into the service area for a total of eight counties. The second expansion was in 2011, when the Affiliate annexed Stone and Taney Counties located in Missouri. As of July 2011, Komen Ozark service area includes; Benton, Boone, Carroll, Crawford, Madison, Newton, Sebastian and Washington Counties in Arkansas and Stone and Taney Counties in Missouri.

Komen Ozark is a proven leader in breast health and fundraising efforts in the region. Komen Ozark Race for the Cure® is the signature event of the Affiliate and has won consecutive awards as the Best of the Best local Charity Challenge by CitiScapes magazine.

Other Affiliate awards include:

- 2003 – The Eagle Award for Outstanding Health Care Leadership presented by Washington Regional Medical Center Foundation
- 2004 – The Outstanding Philanthropic Organization Award presented by the Association of Fundraising Professionals
- 2004 – The Josetta Wilkins Award presented by Arkansas BreastCare
- 2005 – The Education Outreach Honor Roll Award presented by the Susan G. Komen Foundation
- 2008 – The Amethyst Award presented by Washington Regional Medical Center
- 2010 – The Spirit Award presented by Rogers-Lowell Chamber of Commerce
- 2012 – The Partner of the Year Award presented by the Arkansas Cancer Coalition
- 2014 – The Readers Favorite Nonprofit Event Award presented by Entertainment Fort Smith

Since the inception in 1998, Komen Ozark has awarded over $9 million through the local granting process to provide breast health services to uninsured and underinsured men and women in the 10 county service area. In addition, nearly $3 million has supported Komen Headquarters’ Research and Awards program. The most current granting cycle of Komen Ozark FY2015-2016 awarded $725,000 to 10 local organizations located throughout the Affiliate service area. Grantees provide much needed services including: screening, diagnostics,
treatment assistance, navigation, education, mobile mammography, gas cards, supplies and support groups. This brings Komen Ozark’s financial contribution to save lives and end breast cancer forever to over $12 million.

Komen Ozark continues to identify barriers to care and addresses them through grant funding. Breast health navigators are a critical service the Affiliate has funded for several years. In 2014, four nurse navigators provided guidance to patients and their families to help them understand diagnosis and treatment options, to navigate them through the health care system and to connect patients to available resources.

Mobile mammography units and screening events are other examples of how Komen Ozark funds overcome barriers in care within the service area. Mobile units travel to rural communities and major employers’ locations to provide screenings and education. In 2014, Affiliate funding detected 36 cases of breast cancer.

The Affiliate has provided quality education in the community and, for seven years, held a Provider Conference for local health care professionals, with the last conference being held in 2012. In 2008, the Affiliate partnered with area cancer agencies to conduct a Cancer Conference.

Komen Ozark partnered with the Walmart corporate headquarters in 2013 to host a local Cancer Survivor Celebration and served as a core team planning member with Walmart & Sam’s Club in launching breast cancer support groups for the corporate team members. This support group model will be used to launch subsequent groups across the nation in multiple Walmart locations. Additionally, several senior leaders and volunteers of the Affiliate have served through the years on a Governor appointed Breast Cancer Control Advisory Board.

Komen Ozark is also a member of the Arkansas Cancer Coalition (ACC). The Coalition formed to support and monitor the state’s breast cancer control plan and joined forces with the Arkansas Department of Health’s Breast and Cervical Cancer Control Program to initiate an agreement with the Centers for Disease Control and Prevention to provide services for early detection of breast and cervical cancer. Arkansans were given access to early detection in 1995. ACC has provided support to the Affiliate through competitive grant funding and numerous mini-grant opportunities. Also, the Director of Mission Services serves on the Breast Cancer Workgroup to help provide a breast cancer specific outline to the Arkansas Cancer Plan Steering Committee for the Arkansas Cancer Plan.

**Affiliate Organizational Structure**

Komen Ozark staff consists of six (6) employees including five full-time and one part-time staff members. The full-time positions include an: Executive Director, Director of Mission Services, Operations Manager, Development Officer, and Outreach/Communications Coordinator (Figure 1.1). A part-time Volunteer Coordinator position was added in 2014.
Komen Ozark has a central office, located in Springdale, Arkansas which is staffed by five employees. The Affiliate has a satellite office in Fort Smith, Arkansas staffed by the Outreach/Communications Coordinator. Originally funded by the Arkansas Cancer Coalition, the focus of the position was to specifically serve the counties of Sebastian and Crawford located in the southern region of the service area, but will continue to adapt to Affiliate needs and priorities.

Komen Ozark is governed by a 14 member volunteer Board of Directors that meets monthly to guide the Affiliate. Volunteers are vital to Affiliate activities with over 200 volunteers serving on committees, acting as ambassadors and volunteering for the numerous Affiliate community events and fundraisers. There are two mission focused committees which include the Grants/Mission Committee and the Breast Health Initiative (BHI) Committee. Both committees are supervised by the Director of Mission Services. The Grants/Mission Committee exists to develop, implement and offer support in the area of grantmaking at the Affiliate. The BHI Committee advocates and educates local, state and national lawmakers for breast cancer related issues. In order to achieve the mission of Susan G. Komen, scientific progress must be complemented by sound public policy. Through government action, broad, systemic, lasting change can be made in the fight against breast cancer. This means that Komen—as a patient advocacy organization with first-hand knowledge of how breast cancer touches local communities—must engage policymakers and government as partners in the effort to end breast cancer forever. Priorities that the BHI Committee will focus on in the future include: continued funding for the BCCEDP state funding, oral parity and continued support of Medicaid expansion.

Outside of the mission focused committees, the Affiliate also has committees that help with fundraising events. These steering committees are supervised by the development staff and include: Komen Ozark Race for the Cure, Paint the Park Pink, Pink Ribbon Luncheon, Swing for the Cure and Football 101.

**Figure 1.1.** Komen Ozark organizational chart
Figure 1.2. Susan G. Komen Ozark service area
Through two different expansions, Komen Ozark has increased services and outreach to include ten counties—eight counties located in the Northwest corner of Arkansas and two counties in Missouri, located on the Southwest border of Missouri and Arkansas.

The Komen Ozark service area has a substantially larger White female population than the US as a whole, a substantially smaller Black/African-American female population, a slightly smaller Asian and Pacific Islander female population, a slightly larger American Indian and Alaska Native female population and a slightly smaller Hispanic/Latina female population. The Affiliate’s female population is about the same age as that of the US as a whole. The Affiliate’s education and income levels are slightly lower than those of the US as a whole. There are a slightly smaller percentage of people who are unemployed in the Affiliate service area. The Affiliate service area has a slightly smaller percentage of people who are foreign born and a slightly smaller percentage of people who are linguistically isolated. There are a substantially larger percentage of people living in rural areas, a slightly larger percentage of people without health insurance and a substantially larger percentage of people living in medically underserved areas.

Of the current population in the service area, women comprise 384,648 of that total. Major employers of this area include the world headquarters of Walmart, Sam’s Club, Tyson Foods and J.B. Hunt. Additionally, numerous national suppliers have offices in the region to serve Walmart and Sam’s Club. These industries thrive alongside tourism and agriculture.

**Purpose of the Community Profile Report**

In order to make the most informed decisions about how the Affiliate can make the greatest impact through resources, Komen Ozark creates a Community Profile. The Community Profile is a project to assess the state of breast health in and around the 10 county service area and will be a vital tool in guiding the Affiliate priorities for educational outreach and funding.

The purpose of the Community Profile Report for Komen Ozark is to:

- Include a broad range of people and stakeholders in the Affiliate’s work and become more diverse
- Fund, educate and build awareness in the areas of greatest need
- Make data-driven decisions about how to use its resources in the best way- to make the greatest impact
- Strengthen relationships with sponsors by clearly communicating the breast health and breast cancer needs of the community
- Provide information to public policymakers to assist focusing their work
- Strategize direction to marketing and outreach programs toward areas of greatest need
- Create synergy between Mission-related strategic plans and operational activities

The Community Profile will serve as a targeted approach to address breast health in the 10 county service area. The data and findings of the report will set the funding priorities of the Affiliate. The Community Profile will identify target communities that have the highest needs.
Once the target communities are identified, the data and specifics of why they are a selected community will help the Affiliate establish the necessary community partnerships needed to address barriers to quality breast health care. Community outreach will be strategic and data driven.

Additionally, by identifying priorities in breast health care, the specific information is vital to the development side of the Affiliate. The data driven approach to a community health problem allows Development staff to use the Community Profile to demonstrate the local impact of Komen Ozark on the service area. The Affiliate service area includes the International Headquarters of Walmart, Sam’s Club, Tyson and J.B. Hunt. These companies are generous to the community but their support, both financial and otherwise, is in high demand. The Development staff is able to use the Community Profile to demonstrate the local impact the Affiliate is making on the region these headquarters have made their home. Likewise, when seeking involvement from the numerous corporations for employee engagement and partnerships, the Community Profile is a useful tool to exemplify how Komen Ozark is invested in the community. The Community Profile is included in presentations for fundraising and participation support for the many Affiliate events, including the annual Komen Ozark Race for the Cure.

The Community Profile will be disseminated in a variety of ways. The Profile will be available to view on the Affiliate’s website, www.komenozark.org. Once the Profile is available electronically, Affiliate staff will include information about the Profile and where to access it through the Affiliate’s social media sites (Facebook, Twitter, LinkedIn and YouTube) as well as on the Affiliate blog. Information about the report and information that the report revealed will also be provided through the Affiliate newsletter. An article announcing the Community Profile and how to access the Profile will be sent to community partners, key stakeholders, Affiliate grantees and media partners. The information released by the Affiliate will be tailored for specific audiences in order to ensure a more targeted approach.
Quantitative Data Report

Introduction
The purpose of the quantitative data report for the Ozark Affiliate of Susan G. Komen® is to combine evidence from many credible sources and use the data to identify the highest priority areas for evidence-based breast cancer programs.

The data provided in the report are used to identify priorities within the Affiliate’s service area based on estimates of how long it would take an area to achieve Healthy People 2020 objectives for breast cancer late-stage diagnosis and death rates (http://www.healthypeople.gov/2020/default.aspx).

The following is a summary of the Komen Ozark Affiliate’s Quantitative Data Report. For a full report please contact the Affiliate.

Breast Cancer Statistics

Incidence rates
The breast cancer incidence rate shows the frequency of new cases of breast cancer among women living in an area during a certain time period (Table 2.1). Incidence rates may be calculated for all women or for specific groups of women (e.g. for Asian/Pacific Islander women living in the area).

The female breast cancer incidence rate is calculated as the number of females in an area who were diagnosed with breast cancer divided by the total number of females living in that area. Incidence rates are usually expressed in terms of 100,000 people. For example, suppose there are 50,000 females living in an area and 60 of them are diagnosed with breast cancer during a certain time period. Sixty out of 50,000 is the same as 120 out of 100,000. So the female breast cancer incidence rate would be reported as 120 per 100,000 for that time period.

When comparing breast cancer rates for an area where many older people live to rates for an area where younger people live, it’s hard to know whether the differences are due to age or whether other factors might also be involved. To account for age, breast cancer rates are usually adjusted to a common standard age distribution. Using age-adjusted rates makes it possible to spot differences in breast cancer rates caused by factors other than differences in age between groups of women.

To show trends (changes over time) in cancer incidence, data for the annual percent change in the incidence rate over a five-year period were included in the report. The annual percent change is the average year-to-year change of the incidence rate. It may be either a positive or negative number.

- A negative value means that the rates are getting lower.
- A positive value means that the rates are getting higher.
• A positive value (rates getting higher) may seem undesirable—and it generally is. However, it's important to remember that an increase in breast cancer incidence could also mean that more breast cancers are being found because more women are getting mammograms. So higher rates don’t necessarily mean that there has been an increase in the occurrence of breast cancer.

**Death rates**
The breast cancer death rate shows the frequency of death from breast cancer among women living in a given area during a certain time period (Table 2.1). Like incidence rates, death rates may be calculated for all women or for specific groups of women (e.g. Black/African-American women).

The death rate is calculated as the number of women from a particular geographic area who died from breast cancer divided by the total number of women living in that area. Death rates are shown in terms of 100,000 women and adjusted for age.

Data are included for the annual percent change in the death rate over a five-year period.

The meanings of these data are the same as for incidence rates, with one exception. Changes in screening don’t affect death rates in the way that they affect incidence rates. So a negative value, which means that death rates are getting lower, is always desirable. A positive value, which means that death rates are getting higher, is always undesirable.

**Late-stage incidence rates**
For this report, late-stage breast cancer is defined as regional or distant stage using the Surveillance, Epidemiology and End Results (SEER) Summary Stage definitions (http://seer.cancer.gov/tools/ssm/). State and national reporting usually uses the SEER Summary Stage. It provides a consistent set of definitions of stages for historical comparisons.

The late-stage breast cancer incidence rate is calculated as the number of women with regional or distant breast cancer in a particular geographic area divided by the number of women living in that area (Table 2.1). Late-stage incidence rates are shown in terms of 100,000 women and adjusted for age.
Table 2.1. Female breast cancer incidence rates and trends, death rates and trends, and late-stage rates and trends

<table>
<thead>
<tr>
<th>Population Group</th>
<th>Incidence Rates and Trends</th>
<th>Death Rates and Trends</th>
<th>Late-stage Rates and Trends</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female Population (Annual Average)</td>
<td># of New Cases (Annual Average)</td>
<td>Age-adjusted Rate/100,000</td>
</tr>
<tr>
<td>US</td>
<td>154,540,194</td>
<td>198,602</td>
<td>122.1</td>
</tr>
<tr>
<td>HP2020</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Arkansas</td>
<td>1,463,198</td>
<td>1,804</td>
<td>109.5</td>
</tr>
<tr>
<td>Missouri</td>
<td>3,024,156</td>
<td>4,264</td>
<td>121.5</td>
</tr>
<tr>
<td>Komen Ozark Affiliate Service Area</td>
<td>384,648</td>
<td>429</td>
<td>107.1</td>
</tr>
<tr>
<td>US White</td>
<td>356,156</td>
<td>413</td>
<td>107.3</td>
</tr>
<tr>
<td>US Black/African-American</td>
<td>10,145</td>
<td>4</td>
<td>65.5</td>
</tr>
<tr>
<td>US American Indian and Alaska Native (AIAN)</td>
<td>6,994</td>
<td>4</td>
<td>85.2</td>
</tr>
<tr>
<td>US Asian and Pacific Islander (API)</td>
<td>11,353</td>
<td>SN</td>
<td>SN</td>
</tr>
<tr>
<td>US Non-Hispanic/Latina</td>
<td>344,085</td>
<td>421</td>
<td>108.7</td>
</tr>
<tr>
<td>US Hispanic/Latina</td>
<td>40,562</td>
<td>8</td>
<td>48.3</td>
</tr>
<tr>
<td>Benton County - AR</td>
<td>106,285</td>
<td>110</td>
<td>107.5</td>
</tr>
<tr>
<td>Boone County - AR</td>
<td>18,759</td>
<td>27</td>
<td>106.7</td>
</tr>
<tr>
<td>Carroll County - AR</td>
<td>13,654</td>
<td>17</td>
<td>92.9</td>
</tr>
<tr>
<td>Crawford County - AR</td>
<td>30,790</td>
<td>36</td>
<td>110.1</td>
</tr>
<tr>
<td>Madison County - AR</td>
<td>7,726</td>
<td>10</td>
<td>107.3</td>
</tr>
<tr>
<td>Newton County - AR</td>
<td>4,139</td>
<td>4</td>
<td>75.4</td>
</tr>
<tr>
<td>Sebastian County - AR</td>
<td>63,119</td>
<td>73</td>
<td>105.8</td>
</tr>
<tr>
<td>Washington County - AR</td>
<td>98,547</td>
<td>94</td>
<td>110.3</td>
</tr>
<tr>
<td>Stone County - MO</td>
<td>16,295</td>
<td>27</td>
<td>105.7</td>
</tr>
<tr>
<td>Taney County - MO</td>
<td>25,334</td>
<td>38</td>
<td>114.3</td>
</tr>
</tbody>
</table>

NA – data not available  
SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period).  
Data are for years 2006-2010 except for the incidence and late-stage data for Arkansas and the Affiliate as a whole which are from 2004-2008.  
Rates are in cases or deaths per 100,000.  
Age-adjusted rates are adjusted to the 2000 US standard population.  
Source of incidence and late-stage data: NAACCR – CINA Deluxe Analytic File.  
Source of death trend data: NCI/CDC State Cancer Profiles.

Incidence rates and trends summary
Overall, the breast cancer incidence rate in the Komen Ozark Affiliate service area was lower than that observed in the US as a whole and the incidence trend was higher than the US as a whole. The incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of Arkansas. The incidence rate of the Affiliate service area was significantly lower than that observed for the State of Missouri and the incidence trend was not significantly different than the State of Missouri.

For the United States, breast cancer incidence in Blacks/African-Americans is lower than in Whites overall. The most recent estimated breast cancer incidence rates for Asians and Pacific Islanders (APIs) and AIANs were lower than for Non-Hispanic Whites and Blacks/African-Americans. The most recent estimated incidence rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the incidence rate was lower among Blacks/African-Americans than Whites and lower among AIANs than Whites. There were not enough data available within the Affiliate service area to report on APIs so comparisons cannot be made for this racial group. The incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

None of the counties in the Affiliate service area had substantially different incidence rates than the Affiliate service area as a whole.

It's important to remember that an increase in breast cancer incidence could also mean that more breast cancers are being found because more women are getting mammograms.

**Death rates and trends summary**

Overall, the breast cancer death rate in the Komen Ozark Affiliate service area was similar to that observed in the US as a whole and the death rate trend was not available for comparison with the US as a whole. The death rate of the Affiliate service area was not significantly different than that observed for the State of Arkansas. The death rate of the Affiliate service area was not significantly different than that observed for the State of Missouri.

For the United States, breast cancer death rates in Blacks/African-Americans are substantially higher than in Whites overall. The most recent estimated breast cancer death rates for APIs and AIANs were lower than for Non-Hispanic Whites and Blacks/African-Americans. The most recent estimated death rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African-Americans. There were not enough data available within the Affiliate service area to report on Blacks/African-Americans, APIs and AIANs so comparisons cannot be made for these racial groups. Also, there were not enough data available within the Affiliate service area to report on Hispanics/Latinas so comparisons cannot be made for this group.

None of the counties in the Affiliate service area had substantially different death rates than the Affiliate service area as a whole or did not have enough data available.
**Late-stage incidence rates and trends summary**

Overall, the breast cancer late-stage incidence rate in the Komen Ozark Affiliate service area was lower than that observed in the US as a whole and the late-stage incidence trend was higher than the US as a whole. The late-stage incidence rate of the Affiliate service area was significantly lower than that observed for the State of Arkansas and the late-stage incidence trend was not significantly different than the State of Arkansas. The late-stage incidence rate of the Affiliate service area was significantly lower than that observed for the State of Missouri and the late-stage incidence trend was not significantly different than the State of Missouri.

For the United States, late-stage incidence rates in Blacks/African-Americans are higher than among Whites. Hispanics/Latinas tend to be diagnosed with late-stage breast cancers more often than Whites. There were not enough data available within the Affiliate service area to report on Blacks/African-Americans, APIs and AIANs so comparisons cannot be made for these racial groups. The late-stage incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

None of the counties in the Affiliate service area had substantially different late-stage incidence rates than the Affiliate service area as a whole or did not have enough data available.

**Mammography Screening**

Getting regular screening mammograms (and treatment if diagnosed) lowers the risk of dying from breast cancer. Screening mammography can find breast cancer early, when the chances of survival are highest. Table 2.2 shows some screening recommendations among major organizations for women at average risk.

<table>
<thead>
<tr>
<th><strong>American Cancer Society</strong></th>
<th><strong>National Comprehensive Cancer Network</strong></th>
<th><strong>US Preventive Services Task Force</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Informed decision-making with a health care provider at age 40</td>
<td>Mammography every year starting at age 40</td>
<td>Informed decision-making with a health care provider ages 40-49</td>
</tr>
<tr>
<td>Mammography every year starting at age 45</td>
<td></td>
<td>Mammography every 2 years ages 50-74</td>
</tr>
<tr>
<td>Mammography every other year beginning at age 55</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*As of October 2015

Because having regular mammograms lowers the chances of dying from breast cancer, it’s important to know whether women are having mammograms when they should. This information can be used to identify groups of women who should be screened who need help in
meeting the current recommendations for screening mammography. The Centers for Disease Control and Prevention’s (CDC) Behavioral Risk Factors Surveillance System (BRFSS) collected the data on mammograms that are used in this report. The data come from interviews with women age 50 to 74 from across the United States. During the interviews, each woman was asked how long it has been since she has had a mammogram. The proportions in Table 2.3 are based on the number of women age 50 to 74 who reported in 2012 having had a mammogram in the last two years.

The data have been weighted to account for differences between the women who were interviewed and all the women in the area. For example, if 20.0 percent of the women interviewed are Hispanic/Latina, but only 10.0 percent of the total women in the area are Hispanic/Latina, weighting is used to account for this difference.

The report uses the mammography screening proportion to show whether the women in an area are getting screening mammograms when they should. Mammography screening proportion is calculated from two pieces of information:

- The number of women living in an area whom the BRFSS determines should have mammograms (i.e. women age 50 to 74).
- The number of these women who actually had a mammogram during the past two years.

The number of women who had a mammogram is divided by the number who should have had one. For example, if there are 500 women in an area who should have had mammograms and 250 of those women actually had a mammogram in the past two years, the mammography screening proportion is 50.0 percent.

Because the screening proportions come from samples of women in an area and are not exact, Table 2.3 includes confidence intervals. A confidence interval is a range of values that gives an idea of how uncertain a value may be. It’s shown as two numbers—a lower value and a higher one. It is very unlikely that the true rate is less than the lower value or more than the higher value.

For example, if screening proportion was reported as 50.0 percent, with a confidence interval of 35.0 to 65.0 percent, the real rate might not be exactly 50.0 percent, but it’s very unlikely that it’s less than 35.0 or more than 65.0 percent.

In general, screening proportions at the county level have fairly wide confidence intervals. The confidence interval should always be considered before concluding that the screening proportion in one county is higher or lower than that in another county.
### Table 2.3. Proportion of women ages 50-74 with screening mammography in the last two years, self-report

<table>
<thead>
<tr>
<th>Population Group</th>
<th># of Women Interviewed (Sample Size)</th>
<th># w/ Self-Reported Mammogram</th>
<th>Proportion Screened (Weighted Average)</th>
<th>Confidence Interval of Proportion Screened</th>
</tr>
</thead>
<tbody>
<tr>
<td>US</td>
<td>174,796</td>
<td>133,399</td>
<td>77.5%</td>
<td>77.2%-77.7%</td>
</tr>
<tr>
<td>Arkansas</td>
<td>2,179</td>
<td>1,513</td>
<td>69.2%</td>
<td>66.5%-71.7%</td>
</tr>
<tr>
<td>Missouri</td>
<td>2,778</td>
<td>2,055</td>
<td>77.0%</td>
<td>74.9%-79.0%</td>
</tr>
<tr>
<td>Komen Ozark Affiliate Service Area</td>
<td>449</td>
<td>300</td>
<td>65.3%</td>
<td>59.1%-71.0%</td>
</tr>
<tr>
<td>White</td>
<td>424</td>
<td>282</td>
<td>65.1%</td>
<td>58.8%-71.0%</td>
</tr>
<tr>
<td>Black/African-American</td>
<td>SN</td>
<td>SN</td>
<td>SN</td>
<td>SN</td>
</tr>
<tr>
<td>AIAN</td>
<td>12</td>
<td>9</td>
<td>78.6%</td>
<td>30.0%-96.9%</td>
</tr>
<tr>
<td>API</td>
<td>SN</td>
<td>SN</td>
<td>SN</td>
<td>SN</td>
</tr>
<tr>
<td>Hispanic/ Latina</td>
<td>SN</td>
<td>SN</td>
<td>SN</td>
<td>SN</td>
</tr>
<tr>
<td>Non-Hispanic/ Latina</td>
<td>443</td>
<td>295</td>
<td>65.4%</td>
<td>59.2%-71.1%</td>
</tr>
<tr>
<td>Benton County - AR</td>
<td>148</td>
<td>105</td>
<td>70.3%</td>
<td>59.3%-79.3%</td>
</tr>
<tr>
<td>Boone County - AR</td>
<td>30</td>
<td>20</td>
<td>71.8%</td>
<td>50.8%-86.3%</td>
</tr>
<tr>
<td>Carroll County - AR</td>
<td>21</td>
<td>12</td>
<td>64.9%</td>
<td>40.3%-83.6%</td>
</tr>
<tr>
<td>Crawford County - AR</td>
<td>23</td>
<td>15</td>
<td>58.1%</td>
<td>31.8%-80.5%</td>
</tr>
<tr>
<td>Madison County - AR</td>
<td>11</td>
<td>4</td>
<td>34.3%</td>
<td>10.4%-70.1%</td>
</tr>
<tr>
<td>Newton County - AR</td>
<td>SN</td>
<td>SN</td>
<td>SN</td>
<td>SN</td>
</tr>
<tr>
<td>Sebastian County - AR</td>
<td>58</td>
<td>43</td>
<td>73.2%</td>
<td>54.4%-86.2%</td>
</tr>
<tr>
<td>Washington County - AR</td>
<td>133</td>
<td>84</td>
<td>56.7%</td>
<td>45.0%-67.7%</td>
</tr>
<tr>
<td>Stone County - MO</td>
<td>14</td>
<td>10</td>
<td>76.9%</td>
<td>43.7%-93.5%</td>
</tr>
<tr>
<td>Taney County - MO</td>
<td>11</td>
<td>7</td>
<td>63.5%</td>
<td>25.7%-89.8%</td>
</tr>
</tbody>
</table>

SN – data suppressed due to small numbers (fewer than 10 samples).

Data are for 2012.

Source: CDC – Behavioral Risk Factor Surveillance System (BRFSS).

**Breast cancer screening proportions summary**

The breast cancer screening proportion in the Komen Ozark Affiliate service area was **significantly lower** than that observed in the US as a whole. The screening proportion of the Affiliate service area was not significantly different than the State of Arkansas and was **significantly lower** than the State of Missouri.

For the United States, breast cancer screening proportions among Blacks/African-Americans are similar to those among Whites overall. APIs have somewhat lower screening proportions than Whites and Blacks/African-Americans. Although data are limited, screening proportions among AIANs are similar to those among Whites. Screening proportions among Hispanics/Latinas are similar to those among Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the screening proportion was not
significantly different among AIANs than Whites. There were not enough data available within the Affiliate service area to report on Blacks/African-Americans and APIs so comparisons cannot be made for these racial groups. Also, there were not enough data available within the Affiliate service area to report on Hispanics/Latinas so comparisons cannot be made for this group.

None of the counties in the Affiliate service area had substantially different screening proportions than the Affiliate service area as a whole.

**Population Characteristics**

The report includes basic information about the women in each area (demographic measures) and about factors like education, income, and unemployment (socioeconomic measures) in the areas where they live (Tables 2.4 and 2.5). Demographic and socioeconomic data can be used to identify which groups of women are most in need of help and to figure out the best ways to help them.

It is important to note that the report uses the race and ethnicity categories used by the US Census Bureau, and that race and ethnicity are separate and independent categories. This means that everyone is classified as both a member of one of the four race groups as well as either Hispanic/Latina or Non-Hispanic/Latina.

The demographic and socioeconomic data in this report are the most recent data available for US counties. All the data are shown as percentages. However, the percentages weren’t all calculated in the same way.

- The race, ethnicity, and age data are based on the total female population in the area (e.g. the percent of females over the age of 40).
- The socioeconomic data are based on all the people in the area, not just women.
- Income, education and unemployment data don’t include children. They’re based on people age 15 and older for income and unemployment and age 25 and older for education.
- The data on the use of English, called “linguistic isolation”, are based on the total number of households in the area. The Census Bureau defines a linguistically isolated household as one in which all the adults have difficulty with English.
### Table 2.4. Population characteristics – demographics

<table>
<thead>
<tr>
<th>Population Group</th>
<th>White</th>
<th>Black/African-American</th>
<th>AIAN</th>
<th>API</th>
<th>Non-Hispanic/Latina</th>
<th>Hispanic/Latina</th>
<th>Female Age 40 Plus</th>
<th>Female Age 50 Plus</th>
<th>Female Age 65 Plus</th>
</tr>
</thead>
<tbody>
<tr>
<td>US</td>
<td>78.8 %</td>
<td>14.1 %</td>
<td>1.4 %</td>
<td>5.8 %</td>
<td>83.8 %</td>
<td>16.2 %</td>
<td>48.3 %</td>
<td>34.5 %</td>
<td>14.8 %</td>
</tr>
<tr>
<td>Arkansas</td>
<td>80.8 %</td>
<td>16.5 %</td>
<td>1.0 %</td>
<td>1.7 %</td>
<td>93.9 %</td>
<td>6.1 %</td>
<td>48.6 %</td>
<td>35.7 %</td>
<td>16.1 %</td>
</tr>
<tr>
<td>Missouri</td>
<td>84.6 %</td>
<td>12.7 %</td>
<td>0.6 %</td>
<td>2.1 %</td>
<td>96.5 %</td>
<td>3.5 %</td>
<td>49.3 %</td>
<td>36.0 %</td>
<td>15.8 %</td>
</tr>
<tr>
<td>Komen Ozark Affiliate Service Area</td>
<td>91.9 %</td>
<td>3.0 %</td>
<td>1.9 %</td>
<td>3.2 %</td>
<td>88.4 %</td>
<td>11.6 %</td>
<td>46.4 %</td>
<td>33.4 %</td>
<td>14.8 %</td>
</tr>
<tr>
<td>Benton County - AR</td>
<td>92.3 %</td>
<td>2.0 %</td>
<td>2.1 %</td>
<td>3.5 %</td>
<td>85.0 %</td>
<td>15.0 %</td>
<td>43.9 %</td>
<td>30.3 %</td>
<td>13.4 %</td>
</tr>
<tr>
<td>Boone County - AR</td>
<td>97.7 %</td>
<td>0.7 %</td>
<td>1.0 %</td>
<td>0.6 %</td>
<td>98.1 %</td>
<td>1.9 %</td>
<td>54.2 %</td>
<td>40.9 %</td>
<td>19.9 %</td>
</tr>
<tr>
<td>Carroll County - AR</td>
<td>96.7 %</td>
<td>0.8 %</td>
<td>1.3 %</td>
<td>1.2 %</td>
<td>87.8 %</td>
<td>12.2 %</td>
<td>56.7 %</td>
<td>44.6 %</td>
<td>20.7 %</td>
</tr>
<tr>
<td>Crawford County - AR</td>
<td>93.6 %</td>
<td>2.0 %</td>
<td>2.6 %</td>
<td>1.8 %</td>
<td>93.9 %</td>
<td>6.1 %</td>
<td>48.6 %</td>
<td>34.6 %</td>
<td>14.9 %</td>
</tr>
<tr>
<td>Madison County - AR</td>
<td>96.8 %</td>
<td>0.9 %</td>
<td>1.5 %</td>
<td>0.7 %</td>
<td>95.5 %</td>
<td>4.5 %</td>
<td>52.6 %</td>
<td>39.6 %</td>
<td>17.4 %</td>
</tr>
<tr>
<td>Newton County - AR</td>
<td>97.2 %</td>
<td>0.6 %</td>
<td>1.6 %</td>
<td>0.6 %</td>
<td>98.0 %</td>
<td>2.0 %</td>
<td>59.4 %</td>
<td>47.1 %</td>
<td>23.0 %</td>
</tr>
<tr>
<td>Sebastian County - AR</td>
<td>85.6 %</td>
<td>7.5 %</td>
<td>2.3 %</td>
<td>4.6 %</td>
<td>88.1 %</td>
<td>11.9 %</td>
<td>47.8 %</td>
<td>34.5 %</td>
<td>15.0 %</td>
</tr>
<tr>
<td>Washington County - AR</td>
<td>90.3 %</td>
<td>3.5 %</td>
<td>1.6 %</td>
<td>4.5 %</td>
<td>84.9 %</td>
<td>15.1 %</td>
<td>39.3 %</td>
<td>27.3 %</td>
<td>11.3 %</td>
</tr>
<tr>
<td>Stone County - MO</td>
<td>98.0 %</td>
<td>0.6 %</td>
<td>0.8 %</td>
<td>0.6 %</td>
<td>98.2 %</td>
<td>1.8 %</td>
<td>64.3 %</td>
<td>51.8 %</td>
<td>25.6 %</td>
</tr>
<tr>
<td>Taney County - MO</td>
<td>96.2 %</td>
<td>1.5 %</td>
<td>1.2 %</td>
<td>1.1 %</td>
<td>95.1 %</td>
<td>4.9 %</td>
<td>52.5 %</td>
<td>39.9 %</td>
<td>18.9 %</td>
</tr>
</tbody>
</table>

Data are for 2011.
Data are in the percentage of women in the population.
Source: US Census Bureau – Population Estimates
### Table 2.5. Population characteristics – socioeconomics

<table>
<thead>
<tr>
<th>Population Group</th>
<th>Less than HS Education</th>
<th>Income Below 100% Poverty</th>
<th>Income Below 250% Poverty (Age: 40-64)</th>
<th>Unemployed</th>
<th>Foreign Born</th>
<th>Linguistically Isolated</th>
<th>In Rural Areas</th>
<th>In Medically Underserved Areas</th>
<th>No Health Insurance (Age: 40-64)</th>
</tr>
</thead>
<tbody>
<tr>
<td>US</td>
<td>14.6 %</td>
<td>14.3 %</td>
<td>33.3 %</td>
<td>8.7 %</td>
<td>12.8 %</td>
<td>4.7 %</td>
<td>19.3 %</td>
<td>23.3 %</td>
<td>16.6 %</td>
</tr>
<tr>
<td>Arkansas</td>
<td>17.3 %</td>
<td>18.4 %</td>
<td>42.1 %</td>
<td>8.4 %</td>
<td>4.4 %</td>
<td>1.7 %</td>
<td>43.8 %</td>
<td>58.7 %</td>
<td>19.5 %</td>
</tr>
<tr>
<td>Missouri</td>
<td>13.2 %</td>
<td>14.3 %</td>
<td>34.4 %</td>
<td>8.1 %</td>
<td>3.8 %</td>
<td>1.3 %</td>
<td>29.6 %</td>
<td>22.9 %</td>
<td>15.4 %</td>
</tr>
<tr>
<td>Komen Ozark Affiliate Service Area</td>
<td>17.1 %</td>
<td>16.6 %</td>
<td>40.2 %</td>
<td>6.7 %</td>
<td>8.2 %</td>
<td>3.2 %</td>
<td>36.2 %</td>
<td>31.1 %</td>
<td>21.0 %</td>
</tr>
<tr>
<td>Benton County - AR</td>
<td>15.0 %</td>
<td>11.8 %</td>
<td>33.1 %</td>
<td>5.5 %</td>
<td>10.2 %</td>
<td>3.1 %</td>
<td>25.2 %</td>
<td>37.9 %</td>
<td>18.8 %</td>
</tr>
<tr>
<td>Boone County - AR</td>
<td>15.3 %</td>
<td>15.8 %</td>
<td>45.4 %</td>
<td>6.3 %</td>
<td>1.1 %</td>
<td>0.1 %</td>
<td>62.2 %</td>
<td>0.0 %</td>
<td>20.7 %</td>
</tr>
<tr>
<td>Carroll County - AR</td>
<td>19.6 %</td>
<td>17.0 %</td>
<td>51.6 %</td>
<td>8.1 %</td>
<td>7.7 %</td>
<td>2.5 %</td>
<td>72.8 %</td>
<td>100.0 %</td>
<td>27.3 %</td>
</tr>
<tr>
<td>Crawford County - AR</td>
<td>21.1 %</td>
<td>17.6 %</td>
<td>44.6 %</td>
<td>6.7 %</td>
<td>3.9 %</td>
<td>1.7 %</td>
<td>52.0 %</td>
<td>70.2 %</td>
<td>20.0 %</td>
</tr>
<tr>
<td>Madison County - AR</td>
<td>24.7 %</td>
<td>20.8 %</td>
<td>48.1 %</td>
<td>6.5 %</td>
<td>2.3 %</td>
<td>1.5 %</td>
<td>100.0 %</td>
<td>100.0 %</td>
<td>24.8 %</td>
</tr>
<tr>
<td>Newton County - AR</td>
<td>20.2 %</td>
<td>21.6 %</td>
<td>57.6 %</td>
<td>3.8 %</td>
<td>1.0 %</td>
<td>0.0 %</td>
<td>100.0 %</td>
<td>100.0 %</td>
<td>25.0 %</td>
</tr>
<tr>
<td>Sebastian County - AR</td>
<td>17.8 %</td>
<td>19.5 %</td>
<td>41.2 %</td>
<td>6.6 %</td>
<td>9.3 %</td>
<td>4.2 %</td>
<td>20.8 %</td>
<td>20.7 %</td>
<td>21.3 %</td>
</tr>
<tr>
<td>Washington County - AR</td>
<td>17.9 %</td>
<td>18.9 %</td>
<td>38.5 %</td>
<td>6.9 %</td>
<td>11.1 %</td>
<td>5.4 %</td>
<td>25.5 %</td>
<td>3.4 %</td>
<td>21.9 %</td>
</tr>
<tr>
<td>Stone County - MO</td>
<td>16.2 %</td>
<td>19.1 %</td>
<td>44.8 %</td>
<td>10.6 %</td>
<td>1.2 %</td>
<td>0.2 %</td>
<td>88.7 %</td>
<td>100.0 %</td>
<td>19.8 %</td>
</tr>
<tr>
<td>Taney County - MO</td>
<td>14.3 %</td>
<td>16.3 %</td>
<td>47.2 %</td>
<td>8.7 %</td>
<td>3.9 %</td>
<td>0.7 %</td>
<td>43.9 %</td>
<td>0.0 %</td>
<td>22.1 %</td>
</tr>
</tbody>
</table>

Data are in the percentage of people (men and women) in the population.
Source of health insurance data: US Census Bureau – Small Area Health Insurance Estimates (SAHIE) for 2011.
Source of medically underserved data: Health Resources and Services Administration (HRSA) for 2013.
Source of other data: US Census Bureau – American Community Survey (ACS) for 2007-2011.

**Population characteristics summary**

Proportionately, the Komen Ozark Affiliate service area has a substantially larger White female population than the US as a whole, a substantially smaller Black female population, a slightly smaller Asian and Pacific Islander (API) female population, a slightly larger American Indian and Alaska Native (AIAN) female population, and a slightly smaller Hispanic/Latina female population. The Affiliate’s female population is about the same age as that of the US as a whole. The Affiliate’s education level is slightly lower than and income level is slightly lower than those of the US as a whole. There are a slightly smaller percentage of people who are unemployed in the Affiliate service area. The Affiliate service area has a slightly smaller percentage of people who are foreign born and a slightly smaller percentage of people who are linguistically isolated. There are a substantially larger percentage of people living in rural areas, a slightly larger percentage of people without health insurance, and a substantially larger percentage of people living in medically underserved areas.
The following counties have substantially older female population percentages than that of the Affiliate service area as a whole:
- Boone County, AR
- Carroll County, AR
- Newton County, AR
- Stone County, MO

The following county has a substantially lower education level than that of the Affiliate service area as a whole:
- Madison County, AR

The following county has a substantially lower income level than that of the Affiliate service area as a whole:
- Newton County, AR

The following county has a substantially lower employment level than that of the Affiliate service area as a whole:
- Stone County, MO

The following county has a substantially larger percentage of adults without health insurance than does the Affiliate service area as a whole:
- Carroll County, AR

**Priority Areas**

**Healthy People 2020 forecasts**

Healthy People 2020 (HP2020) is a major federal government initiative that provides specific health objectives for communities and for the country as a whole. Many national health organizations use HP2020 targets to monitor progress in reducing the burden of disease and improve the health of the nation. Likewise, Komen believes it is important to refer to HP2020 to see how areas across the country are progressing towards reducing the burden of breast cancer.

HP2020 has several cancer-related objectives, including:
- Reducing women’s death rate from breast cancer (Target as of the writing of this report: 20.6 cases per 100,000 women).
- Reducing the number of breast cancers that are found at a late-stage (Target as of the writing of this report: 41.0 cases per 100,000 women).

To see how well counties in the Komen Ozark service area are progressing toward these targets, the report uses the following information:
- County breast cancer death rate and late-stage diagnosis data for years 2006 to 2010.
- Estimates for the trend (annual percent change) in county breast cancer death rates and late-stage diagnoses for years 2006 to 2010.
- Both the data and the HP2020 target are age-adjusted.
These data are used to estimate how many years it will take for each county to meet the HP2020 objectives. Because the target date for meeting the objective is 2020, and 2008 (the middle of the 2006-2010 period) was used as a starting point, a county has 12 years to meet the target.

Death rate and late-stage diagnosis data and trends are used to calculate whether an area will meet the HP2020 target, assuming that the trend seen in years 2006 to 2010 continues for 2011 and beyond.

**Identification of priority areas**
The purpose of this report is to combine evidence from many credible sources and use the data to identify the highest priority areas for breast cancer programs (i.e. the areas of greatest need). Classification of priority areas are based on the time needed to achieve HP2020 targets in each area. These time projections depend on both the starting point and the trends in death rates and late-stage incidence.

Late-stage incidence reflects both the overall breast cancer incidence rate in the population and the mammography screening coverage. The breast cancer death rate reflects the access to care and the quality of care in the health care delivery area, as well as cancer stage at diagnosis.

There has not been any indication that either one of the two HP2020 targets is more important than the other. Therefore, the report considers them equally important.

Counties are classified as follows (Table 2.6):
- Counties that are not likely to achieve either of the HP2020 targets are considered to have the highest needs.
- Counties that have already achieved both targets are considered to have the lowest needs.
- Other counties are classified based on the number of years needed to achieve the two targets.
Table 2.6. Needs/priority classification based on the projected time to achieve HP2020 breast cancer targets

<table>
<thead>
<tr>
<th>Time to Achieve Death Rate Reduction Target</th>
<th>Time to Achieve Late-stage Incidence Reduction Target</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>13 years or longer</td>
</tr>
<tr>
<td>13 years or longer</td>
<td>Highest</td>
</tr>
<tr>
<td>7-12 yrs.</td>
<td>High</td>
</tr>
<tr>
<td>0 – 6 yrs.</td>
<td>Medium High</td>
</tr>
<tr>
<td>Currently meets target</td>
<td>Medium Low</td>
</tr>
<tr>
<td>Unknown</td>
<td>Highest</td>
</tr>
</tbody>
</table>

If the time to achieve a target cannot be calculated for one of the HP2020 indicators, then the county is classified based on the other indicator. If both indicators are missing, then the county is not classified. This doesn't mean that the county may not have high needs; it only means that sufficient data are not available to classify the county.

**Affiliate Service Area Healthy People 2020 Forecasts and Priority Areas**

The results presented in Table 2.7 help identify which counties have the greatest needs when it comes to meeting the HP2020 breast cancer targets.

- For counties in the “13 years or longer” category, current trends would need to change to achieve the target.
- Some counties may currently meet the target but their rates are increasing and they could fail to meet the target if the trend is not reversed.

Trends can change for a number of reasons, including:

- Improved screening programs could lead to breast cancers being diagnosed earlier, resulting in a decrease in both late-stage incidence rates and death rates.
- Improved socioeconomic conditions, such as reductions in poverty and linguistic isolation could lead to more timely treatment of breast cancer, causing a decrease in death rates.

The data in this table should be considered together with other information on factors that affect breast cancer death rates such as screening percentages and key breast cancer death determinants such as poverty and linguistic isolation.
### Table 2.7. Intervention priorities for Komen Ozark service area with predicted time to achieve the HP2020 breast cancer targets and key population characteristics

<table>
<thead>
<tr>
<th>County</th>
<th>Priority</th>
<th>Predicted Time to Achieve Death Rate Target</th>
<th>Predicted Time to Achieve Late-stage Incidence Target</th>
<th>Key Population Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boone County - AR</td>
<td>Highest</td>
<td>13 years or longer</td>
<td>13 years or longer</td>
<td>Older, rural</td>
</tr>
<tr>
<td>Madison County - AR</td>
<td>Medium High</td>
<td>SN</td>
<td>7 years</td>
<td>Education, rural, medically underserved</td>
</tr>
<tr>
<td>Taney County - MO</td>
<td>Medium High</td>
<td>5 years</td>
<td>13 years or longer</td>
<td>Rural</td>
</tr>
<tr>
<td>Crawford County - AR</td>
<td>Medium</td>
<td>Currently meets target</td>
<td>13 years or longer</td>
<td>Rural, medically underserved</td>
</tr>
<tr>
<td>Sebastian County - AR</td>
<td>Medium</td>
<td>13 years or longer</td>
<td>Currently meets target</td>
<td></td>
</tr>
<tr>
<td>Washington County - AR</td>
<td>Medium</td>
<td>13 years or longer</td>
<td>Currently meets target</td>
<td></td>
</tr>
<tr>
<td>Stone County - MO</td>
<td>Medium</td>
<td>Currently meets target</td>
<td>13 years or longer</td>
<td>Older, employment, rural, medically underserved</td>
</tr>
<tr>
<td>Benton County - AR</td>
<td>Lowest</td>
<td>Currently meets target</td>
<td>Currently meets target</td>
<td>Medically underserved</td>
</tr>
<tr>
<td>Carroll County - AR</td>
<td>Lowest</td>
<td>Currently meets target</td>
<td>Currently meets target</td>
<td>Older, rural, insurance, medically underserved</td>
</tr>
<tr>
<td>Newton County - AR</td>
<td>Undetermined</td>
<td>SN</td>
<td>SN</td>
<td>Older, poverty, rural, medically underserved</td>
</tr>
</tbody>
</table>

NA – data not available.
SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period).
Map of Intervention Priority Areas

Figure 2.1 shows a map of the intervention priorities for the counties in the Affiliate service area. When both of the indicators used to establish a priority for a county are not available, the priority is shown as “undetermined” on the map.

Data Limitations

The following data limitations need to be considered when utilizing the data of the Quantitative Data Report:

- The most recent data available were used but, for cancer incidence and deaths, these data are still several years behind.
- For some areas, data might not be available or might be of varying quality.
• Areas with small populations might not have enough breast cancer cases or breast cancer deaths each year to support the generation of reliable statistics.
• There are often several sources of cancer statistics for a given population and geographic area; therefore, other sources of cancer data may result in minor differences in the values even in the same time period.
• Data on cancer rates for specific racial and ethnic subgroups such as Somali, Hmong, or Ethiopian are not generally available.
• The various types of breast cancer data in this report are inter-dependent.
• There are many factors that impact breast cancer risk and survival for which quantitative data are not available. Some examples include family history, genetic markers like HER2 and BRCA, other medical conditions that can complicate treatment, and the level of family and community support available to the patient.
• The calculation of the years needed to meet the HP2020 objectives assume that the current trends will continue until 2020. However, the trends can change for a number of reasons.
• Not all breast cancer cases have a stage indication.

Quantitative Data Report Conclusions

Highest priority areas

One county in the Komen Ozark Affiliate service area is in the highest priority category. Boone County, AR is not likely to meet either the death rate or late-stage incidence rate HP2020 targets.

Boone County, AR has an older population.

Medium high priority areas

Two counties in the Komen Ozark Affiliate service area are in the medium high priority category. One of the two, Taney County, MO is not likely to meet the late-stage incidence rate HP2020 target. The other, Madison County, AR is expected to take seven years to reach the late-stage incidence rate HP2020 target.

Madison County, AR has low education levels.

Additional Quantitative Data Exploration

Komen Ozark had several counties within the service area that had suppressed data due to the population size. Additionally, the data provided regarding the behavior of women who received a screening mammogram surveyed only a small group in some counties, which resulted in over a 50 percent difference in confidence intervals of some portions screened. The width of the confidence interval may indicate the uncertainty of the data collected. Due to the difference within the confidence intervals, the Affiliate decided to supplement the data provided with data from the University of Arkansas Medical Services.
The Affiliate obtained the additional data from the University of Arkansas Medical Services Public Health in Arkansas’ Communities Search database, which is available from Arkansas Behavioral Risk Factor Surveillance Survey. The health ranking is for all 75 counties in Arkansas. The rankings are assigned by placing the counties into five equal groups by the occurrence of the health indicator. If a county value exists in two adjacent groups, then the county is moved to the quintile group with the most favorable rating.

The data shows some of the counties increasing in the percentage of women with no recent mammogram (Table 2.8).

<table>
<thead>
<tr>
<th>County</th>
<th>2008</th>
<th>2010</th>
<th>% increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boone</td>
<td>32.8%</td>
<td>35.2%</td>
<td>2.4%</td>
</tr>
<tr>
<td>Madison</td>
<td>31.9%</td>
<td>34.6%</td>
<td>2.7%</td>
</tr>
<tr>
<td>Newton</td>
<td>28.7%</td>
<td>37.7%</td>
<td>9.0%</td>
</tr>
</tbody>
</table>

Additionally, data show Newton County in the lowest favorable health ranking for breast cancer deaths. It is important to note that data were suppressed in the Quantitative Data Report due to fewer than 15 deaths over the five year period of 2004-2008. Data pulled from the University of Arkansas for Medical Services is a limitation based on the few number of deaths reported. The data enhances the Quantitative Data Report by providing more information about and a more complete picture of the selected target communities.

Selection of Target Communities

The purpose of this report is to use the Quantitative data to identify the Affiliate’s highest priority areas to help develop effective, targeted breast cancer programs to meet the Healthy People 2020 (HP2020) targets for breast cancer. HP2020 provides national objectives for improving the health of all Americans. The cancer objectives for Healthy People 2020 support monitoring trends in cancer incidence, deaths and survival to better assess the progress made toward decreasing the burden of cancer in the United States.

Key indicators the Affiliate considered and examined when selecting the target communities included, but were not limited to:

- Incidence rates and trends
- Death rates and trends
- Late-stage rates and trends
- Below average screening percentages
- Breakdown of demographics of residents
- Residents living in rural, medically underserved areas
- High school education rates of residents
- Residents living with no health insurance
- Residents living below the poverty level
- Residents who are linguistically isolated and/or foreign born
**Regional Target Communities:** Although the service area is divided by the 10 counties, the counties are linked through medical care hubs in five main regions:

- Region 1- Benton and Washington Counties, AR
- Region 2- Madison and Carroll Counties, AR
- Region 3- Taney and Stone Counties, MO
- Region 4- Crawford and Sebastian Counties, AR
- Region 5- Boone and Newton Counties, AR

Therefore, when considering health disparities and access to care, a regional division can be more effective for targeted breast cancer programs. Screening, diagnostic and treatment support programs would be concentrated around the medical hubs in each region, whereas, education and awareness programs would be provided in each county.

The Selected Target Communities are:

- North Arkansas (Boone, Madison and Newton Counties)
- Hispanic/Latina Women (Benton, Carroll, Sebastian and Washington Counties)
- South Missouri Region (Stone and Taney Counties)

**North Arkansas (Boone, Madison, and Newton Counties)**

Due to the population size, geographic location and lack of data provided for smaller counties, Boone, Newton and Madison counties have been combined to make up the North Arkansas region of the targeted selected communities.

These three counties have been selected as a target area for the Komen Ozark Service Area because of screening percentages, late-stage diagnosis, breast cancer death rate, demographic data and having been identified as medically underserved with high poverty rates.

Due to the size of the counties, reported screening percentages for Newton County were not available and some counties had a very small number of women surveyed. (Boone= 30, Madison=11) The screening proportion of the Affiliate service area was not significantly different than the state of Arkansas, but is significantly lower than that observed in the United States as a whole. Additional screening percentages from the University of Arkansas Medical Sciences Public Health in Arkansas’ Communities Search shows some of the counties increasing in the percentage of women with no recent mammogram (Table 2.8).

Boone County is likely to miss the HP2020 late-stage incidence rate target with an 11.3 percent increase. Since data were not available due to the small numbers of people, it cannot be predicted whether Newton County will reach the late-stage incidence rate target of 41.0 per 100,000. Madison County is likely to achieve the target by 2020.

Additionally, death rate trend data are not available for the Affiliate service area, so it cannot be predicted whether the target region will meet the HP2020 target of 20.6 female breast cancer deaths per 100,000. Boone County is likely to miss the HP2020 target for female breast cancer death rates. Since data from the Quantitative Data Report were not available due to the small numbers of people, it cannot be predicted whether Newton or Madison Counties are likely to
achieve the target by 2020. The breast cancer age-adjusted death rate from 2004-2007 were obtained from the University of Arkansas for Medical Sciences Public Health in Arkansas Communities Search and shows Newton County ranking in the lowest favorable health ranking for breast cancer deaths.

It is important to note that in order to determine each county’s estimated time to reach the HP2020 target, late-stage diagnosis and death rates were compared and then each county was categorized into seven priority levels. Boone County was the only county ranked in the highest priority level. Two counties in the Komen Ozark service area were ranked in the medium high priority category, one being Madison County.

Boone, Madison and Newton Counties all have older populations than the Komen Ozark service area and the United States. In all three age category breakdowns within the data (Female Age 40+, Female Age 50+ and Female Age 65+) Boone, Madison and Newton counties are significantly higher than the United States average. This is important because age is a risk factor for breast cancer. The older a woman is, the greater her risk of getting breast cancer increases. Rates begin to increase after age 40 and are highest in women over age 70. (Susan G. Komen, 2014)

The socioeconomic statistics of the North Arkansas region (Boone, Madison, Newton) are concerning to the Affiliate in terms of access to quality, affordable health care. All three counties have a significantly higher percentage of people living in the income bracket that is 250 percent below the poverty line. Newton County has the highest percentage of people living 250 percent below the poverty line in the Komen Ozark Service Area. All three counties have a significantly greater percentage of the population living in rural areas than the Komen Ozark service area and United States. Madison and Newton have 100 percent of the population living in rural areas with Boone County having 62.2 percent. The North Arkansas region is also considered as medically underserved. The population of Madison and Newton Counties has almost five times the rate of people living in medically underserved areas as the United States.

Education levels are also low in this region. As a whole, the Komen Ozark service area has a higher percentage of the population with less than a high school education than the United States. Newton, Madison and Boone Counties all have a higher percentage of the population with less than a high school education than the United States. Madison County has the highest percentage of the population with less than a high school education than any other county in the entire Affiliate. Additionally, the North Arkansas region is significantly higher than the United States for rates of people age 40-64 without health insurance.

The socioeconomic characteristics outlined above concern the Affiliate. Income levels can affect access to care and living in rural and medically underserved communities often creates issues with transportation. The Health System Analysis report will research further any health disparities that may result from lack of access to quality breast health care.
Hispanic/Latina Women Specifically in Benton, Washington, Sebastian and Carroll Counties

Although the Komen Ozark service area is lower than the national average in regards to the Hispanic/Latina population, some counties have a significantly higher percentage of Hispanics/Latinas than the Affiliate service area average. Four counties (Benton, Carroll, Sebastian and Washington) have been combined for the purpose of this report and for the Affiliate’s targeted efforts.

These four counties have been identified as a select target community due to the percentage of the population that is Hispanic/Latina and linguistically isolated. Breast cancer is the most common cancer among Hispanic/Latina women and it also remains the leading cause of cancer death in Hispanic/Latina women. Hispanic/Latina women tend to be diagnosed with later stage breast cancer than white women and they may be less likely to get prompt follow-up after an abnormal mammogram. (Susan G. Komen, 2014)

Linguistic isolation is another barrier to access to quality care. Linguistic isolation can affect all stages of the Continuum of Care. The linguistically isolated average for the State of Arkansas is 1.7 percent and the percentage of the Komen Ozark service area is 3.2 percent. The highest counties include:

- Washington = 5.4 percent
- Sebastian = 4.2 percent
- Benton = 3.1 percent
- Carroll = 2.5 percent

The counties with the highest percentage of those who are linguistically isolated also have the highest percentage of those who are foreign born. Washington and Benton Counties have the largest percentage of immigrants. This population often has difficulty accessing or being eligible for insurance or other government assistance programs like the Arkansas Department of Health’s BreastCare. Those who are not US residents and/or undocumented are not eligible for health insurance.

The Health Systems Analysis will provide a more in-depth look at what health care services are available for the Hispanic/Latina women in these counties and if these providers offer no-cost or reduced cost care, are culturally sensitive and are easily accessible. The language barrier with the Hispanic/Latina population is a concern for health care providers and will also be analyzed during the Health Systems Analysis process.

South Missouri (Stone and Taney Counties)

Due to population size, geographic location and statistical similarities, two counties (Stone and Taney) have been combined in this report in order for Komen Ozark to address the needs of this targeted area. Stone and Taney Counties are located in the southwest corner of Missouri and borders Arkansas. The population of women in Stone and Taney Counties is 16,295 and 25,334 respectively. The demographic makeup is almost entirely White in both counties.
The South Missouri Region (Stone and Taney Counties) has been identified as a selected target community because of the rising incidence rate trend, late-stage diagnosis trend compared to the Affiliate service area, income levels, unemployment percentages, lack of health insurance and being identified as rural and medically underserved.

When examining incidence trend confidence intervals, Stone and Taney Counties are the only counties in the Affiliate service area that have an Incidence Rate Trend that is rising. (Susan G. Komen, 2014). This means that there is an increase in occurrence of breast cancer among women.

Additionally, Stone and Taney Counties have a Late-Stage Rate Trend direction that is rising compared to the Affiliate service area. This translates as that there is a significant increase in late-stage diagnosis. Due to this increase, Stone and Taney Counties are likely to miss the HP2020 late-stage incidence rate target unless the late-stage incidence rate falls faster than estimated. Late-stage diagnosis is concerning because of the poorer prognosis given to women who are diagnosed with a later stage.

Based upon the estimated time to reach the HP2020 targets for late-stage diagnosis and death rates, Taney County was one of two counties in the Komen Ozark service area ranked in the medium high priority category.

Stone and Taney Counties both have a greater percentage of older residents than the Komen Ozark service area and the United States. As mentioned previously, as a woman ages, her risk of getting breast cancer increases.

The socioeconomic statistics of Stone and Taney Counties are a concern in terms of access to quality, affordable health care. Stone and Taney County have a significantly higher percentage of people living in the income bracket that is 250 percent below the poverty line than the Affiliate service area and the United States. Unemployment percentages of Stone County are higher than the United States and Komen Ozark service area. Taney County is equal to the United States rate of unemployment and higher than the Affiliate service area. Stone and Taney Counties both have significantly higher percentages of people living in rural areas than in the United States and the service area, with Taney County doubling the United States rates and Stone County quadrupling the United States rates. The population of Stone County (100 percent) is considered to be medically underserved. Additionally, both Stone and Taney Counties have significantly higher rates of people with no health insurance than the United States.

Through the Health Systems Analysis, the Affiliate will examine available breast health services in the region and how women in these two counties access these services. The socioeconomic statistics described previously (poor, rural and medically underserved) can greatly effect access to affordable, quality care.
Health Systems Analysis Data Sources

In order to gain a comprehensive understanding of programs and services data, Komen Ozark utilized numerous sources to compile information. This information compiled for the Health Systems Analysis will offer the Affiliate a more complete picture of existing services and providers that impact the breast health services in the selected target communities.

The Affiliate utilized the following sources:

- **Mammography Centers**: US Food and Drug Administration

- **Hospitals**: Medicare
  [https://data.medicare.gov/Hospital-Compare/Hospital-General-Information/v287-28n3](https://data.medicare.gov/Hospital-Compare/Hospital-General-Information/v287-28n3)

- **Health Departments**: National Association of County and City Health Officials
  [http://www.naccho.org/about/lhd/](http://www.naccho.org/about/lhd/)

- **Community Health Centers**: Health Resources and Services Administrations

- **Free Clinics**: National Association of Free and Charitable Clinics
  [http://www.nafcclinics.org/clinics/search](http://www.nafcclinics.org/clinics/search)

- **Missouri Primary Care Association**:

- **Community Health Centers of Arkansas**:
  [http://www.chc-ar.org](http://www.chc-ar.org)

The following sources were utilized to identify any certified or accredited providers in the ten county service area:

- **American College of Surgeons Commission on Cancer**
  [http://datalinks.facs.org/cpm/CPMAccreditedHospitals_Search.htm](http://datalinks.facs.org/cpm/CPMAccreditedHospitals_Search.htm)

- **American College of Radiology Centers of Excellence**
  [http://www.acr.org/Quality-Safety/Accreditation/Accredited-Facility-Search](http://www.acr.org/Quality-Safety/Accreditation/Accredited-Facility-Search)

- **American College of Surgeons National Accreditation Program for Breast Centers (NAPBC)**
  [http://napbc-breast.org/resources/find.html](http://napbc-breast.org/resources/find.html)

- **National Cancer Institute Designated Cancer Centers**
The Grants/Mission Committee members assisted in analyzing each selected target community by working through online resources. Local grantees and community members also assisted in providing information and names of providers. Once all of the information was collected for each selected target community, Affiliate staff then combined all information into one spreadsheet in order to analyze access to care in each selected target community.

**Health Systems Overview**

The Breast Cancer Continuum of Care (CoC) is a model that shows how a woman typically moves through the health care system for breast care (Figure 3.1). A woman would ideally move through the CoC quickly and seamlessly, receiving timely, quality care in order to have the best outcomes. Education can play an important role throughout the entire CoC.

While a woman may enter the continuum at any point, ideally, a woman would enter the CoC by getting screened for breast cancer – with a clinical breast exam or a screening mammogram. If the screening test results are normal, she would loop back into follow-up care, where she would get another screening exam at the recommended interval. Education plays a role in both providing education to encourage women to get screened and reinforcing the need to continue to get screened routinely thereafter.

If a screening exam resulted in abnormal results, diagnostic tests would be needed, possibly several, to determine if the abnormal finding is in fact breast cancer. These tests might include a diagnostic mammogram, breast ultrasound or biopsy. If the tests were negative (or benign) and breast cancer was not found, she would go into the follow-up loop, and return for screening at the recommended interval. The recommended intervals may range from three to six months for some women to 12 months for most women. Education plays a role in communicating the importance of proactively getting test results, keeping follow-up appointments and understanding what it all means. Education can empower a woman and help manage anxiety and fear.

If breast cancer is diagnosed, she would proceed to treatment. Education can cover such topics as treatment options, how a pathology reports determines the best options for treatment, understanding side effects and how to manage them, and helping to formulate questions a woman may have for her providers.

---

**Figure 3.1. Breast Cancer Continuum of Care (CoC)**
For some breast cancer patients, treatment may last a few months and for others, it may last years. While the CoC model shows that follow up and survivorship come after treatment ends, they actually may occur at the same time. Follow up and survivorship may include things like navigating insurance issues, locating financial assistance, symptom management, such as pain, fatigue, sexual issues, bone health, etc. Education may address topics such as making healthy lifestyle choices, long term effects of treatment, managing side effects, the importance of follow-up appointments and communication with their providers. Most women will return to screening at a recommended interval after treatment ends, or for some, during treatment (such as those taking long term hormone therapy).

There are often delays in moving from one point of the continuum to another – at the point of follow-up of abnormal screening exam results, starting treatment, and completing treatment – that can all contribute to poorer outcomes. There are also many reasons why a woman does not enter or continue in the breast cancer CoC. These barriers can include things such as lack of transportation, system issues including long waits for appointments and inconvenient clinic hours, language barriers, fear, and lack of information - or the wrong information (myths and misconceptions). Education can address some of these barriers and help a woman progress through the CoC more quickly.

**Boone, Newton and Madison Counties, AR**

The first selected target community includes Boone, Newton and Madison Counties (Figure 3.2). These counties were selected as a target community for the Affiliate service area because of screening percentages, late-stage diagnosis, breast cancer death rate, demographic data and having been identified as medically underserved with high poverty rates. The Health Systems strengths of this area include a hospital and radiation therapy institute in Boone County. Each area has a county health unit to enroll women into the Arkansas BreastCare program and to disseminate information.

The weaknesses of the target selected community include the lack of medical services and access to breast health screening, diagnostic and treatment services. In Madison and Newton Counties, the only breast health screening that is available to patients are for clinical breast exams. There is no access to screening or diagnostic mammograms other than what the mobile unit offers. Also, there is a lack in support/survivorship services in the area. There are support groups, side effect management and financial assistance offered in Madison and Boone Counties, but no counseling or complementary therapies are offered.

Currently, the Affiliate has two community grant programs located in this priority area. The first program is through the North Arkansas Partnership for Health Education Community Health Center and offers screening and diagnostic testing to residents in Boone and Newton counties. The program also partners with University of Arkansas Medical Sciences (UAMS) to bring the mobile mammography unit to serve women in both counties. In Newton County, receiving services on the mobile unit is the only time some women receive breast health screenings.
Women who do not have insurance are covered by Affiliate funds, but the mobile unit addresses the barrier of access to care.

The second program to address health care barriers is the Affiliate funded breast health navigator through the Madison County Health Coalition and located in the Madison County Health Unit. Women in Madison County are able to receive breast health navigation services by a nurse navigator. The navigator also works with other Affiliate funded programs to help women who are uninsured receive screening and/or diagnostic services. The program also includes the distribution of gas cards to help with transportation issues of living in a rural, medically underserved county. The gas cards help patients afford to drive to another county for care and services. The nurse navigator also coordinates with UAMS to bring mobile mammography to different locations of the county.

The Affiliate will continue to work with the health department in the three counties. County health coalitions also exist and partnering with the coalitions will help keep the need of breast health care on the forefront of local health organizations. In the past, the Affiliate created an advisory group in Boone County to address outreach concerns, but the group has not met due to lack of Affiliate staff capacity to manage the group. The Affiliate will research and consider the possibility of starting up the advisory group once again.
Figure 3.2. Breast cancer services available in Boone, Newton and Madison Counties
Stone and Taney Counties, MO

The second selected target community includes the counties of Stone and Taney in Southwest Missouri (Figure 3.3). These counties have been identified as a selected target community because of the rising incidence rate trend, late-stage diagnosis trend compared to the Affiliate service area, income levels, unemployment percentages, lack of health insurance and being identified as rural and medically underserved.

The strengths of this selected community are the presence of a hospital and cancer center. CoxHealth is located in Taney County and offers screening, diagnostic and treatment services. CoxHealth Cancer Center is also an important asset to Stone and Taney Counties and offers quality cancer treatment. In each county, there are two local health units with a total of four in the two county areas. These local units offer clinical breast exams and refer women to the Show Me Healthy Women program (the Missouri State Breast and Cervical Cancer Control Program).

Although screening, diagnostic and treatment services for breast cancer are offered at CoxHealth, the two counties are considered rural and medically underserved. There is no mobile unit that serves this area, so if a patient does not or cannot travel to Branson in Taney County they will not receive screening for breast cancer. Also, there are few support/survivorship programs offered in the two counties. There are a couple support groups, but side effect management, individual counseling, exercise/nutrition programs, complementary therapies and legal services are not offered.

The Affiliate funds programs through Skaggs Foundation at CoxHealth Branson. The program includes a nurse navigator to help patients navigate a breast cancer diagnosis and services for women who are uninsured/underinsured to receive screening and diagnostic testing. In addition to the community grant, the Affiliate has funded outreach programs that include partnerships between local organizations, homeless shelters and CoxHealth.

A representative from the American Cancer Society (ACS) has an office in the CoxHealth Cancer Center. At this location, numerous services are offered to breast cancer patients. The programs include; Reach to Recovery-program matching breast cancer patients to newly diagnosed survivors; Road to Recovery-transportation to and from treatment; Hope Lodges and Guest Room Housing- housing for patients and families; and wigs, head coverings and scarves. Another organization called Breast Cancer Foundation of the Ozarks (BCFO) provides services to women needing breast health care. Although located in Springfield, Missouri the organization covers both Stone and Taney counties. The organization offers support groups, free mammograms, financial assistance, lymphedema garments and education.

Through work on the Community Profile, the Affiliate has made contact with both the Stone and Taney County’s health departments with plans to discuss future collaborations. The Affiliate is also a member of the local Branson/Lakes Area Chamber of Commerce and would like to get more involved with the chamber and their nonprofit/community organization committee.
Figure 3.3. Breast cancer services available in Stone and Taney Counties
Hispanic/Latina Population in Benton, Washington, Carroll and Sebastian Counties
The four counties in this selected community have been identified as a select target community due to the percentage of the population that is Hispanic/Latina and linguistically isolated (Figure 3.4). Breast cancer is the most common cancer among Hispanic/Latina women and it also remains the leading cause of cancer death in Hispanic/Latina women. Hispanic/Latina women tend to be diagnosed with later stage breast cancer than white women and they may be less likely to get prompt follow-up after an abnormal mammogram.

The number of hospitals, health centers and health departments are a strength in this target area. In Carroll County, there is a local hospital located in Eureka Springs and Mercy Hospital in Berryville. In addition to the two hospitals, there is a health department and a community health center. In the Northwest Arkansas counties of Benton and Washington there are seven hospitals, three community health centers, five health departments, five imaging centers, two oncology clinics and one free health center. In Sebastian County, there are two hospitals that serve residents in and around the county. There are two community health centers that offer clinical breast exams as well as a clinic that offers services on a sliding scale payment plan. There are two oncology centers located in Sebastian County that offer treatment. Mobile mammography units also visit Carroll, Benton, Washington and Sebastian Counties with mobile services.

The weaknesses of the area are the lack of specific programs and services that directly address the Hispanic/Latina population. Some hospitals offer a translator if available, but most rely on a special telephone service to translate medical information to a patient. The Affiliate previously funded a breast health navigator that specifically worked with the Hispanic/Latina population, but the program no longer exists. There are no bilingual navigators in this target community. The Community Clinic offers bilingual services at the three medical locations and Hope Cancer Resources does provide bilingual social workers in the two locations of Highlands Oncology Group. In addition to specific programs of outreach, in Carroll County there is a lack of diagnostic testing and no access in the county to breast cancer treatment. Support/survivorship also plays a factor in the continuum of care in this selected community.

In Carroll County there is no access to support groups, side effect management, individual counseling/psychotherapy, exercise/nutrition programs or complementary therapies. In Sebastian County, the Donald W. Reynolds Cancer Support House provides a full range of support/survivorship programs, but outside of the house only the two local hospitals provide side effect management and the Area Agency for Aging provides Exercise/Nutrition programs. In Benton County, support groups are only offered by the Washington Regional Cancer Support Home. The cancer support home also provides side effect management, financial assistance and individual counseling/psychotherapy. The two locations of Community Clinic provide financial assistance; the Highlands Oncology Group provides side effect management and complementary therapies, Sister’s Women’s Health Boutique offers side effect management and the Mercy YMCA offers exercise/nutrition programs. In Washington County, Washington Regional Cancer Support Home, Highlands Oncology, Hope Cancer Resources and Circle of Life all offer support groups. Side effect management is offered by Washington Regional
Cancer Support Home, Hope Cancer Resources, Highlands Oncology Group and Breast Treatment Associates. Washington Regional Cancer Support Home and Hope Cancer Resources provides individual counseling/psychotherapy and financial assistance. Lastly, Highlands Oncology Group and Hope Cancer Resources provide complementary therapies.

In this target area, the Affiliate funds two breast health nurse navigators through Washington Regional Cancer Support Home and Mercy Breast Center in Benton and Washington Counties to help a patient navigate a breast cancer diagnosis. Screening, diagnostic and treatment services are provided through Affiliate grant funds in all three Community Clinic locations in Benton and Washington County, the Washington Regional Cancer Support Home in Benton and Washington County, Mercy Breast Center in Benton County, The Merlin Foundation in Carroll County and The Women’s Center at Sparks in Sebastian County. In addition to the organizations that the Affiliate funds, the Affiliate also has a satellite office located in Sebastian County. The satellite office staff partners with numerous local organizations to provide breast health education and training. The Coordinator also works with the Donald W. Reynolds Cancer Support Home to ensure continuum of care for residents in and around Sebastian County.

The Affiliate will continue to work with existing partnerships and establish new ones to ensure that the Hispanic/Latina community is getting access to quality health care and is not lost in the continuum of care cycle. The Hispanic Organization for Women is a partnership the Affiliate would like to cultivate as well as the other largely Hispanic/Latina organizations, churches and leaders. The Affiliate will work with existing grantees to address this population through Affiliate funding, as well as the Arkansas BreastCare program for outreach and the UAMS program Esperanza y Vida.
Figure 3.4. Breast cancer services available in Benton, Washington, Carroll and Sebastian Counties
Public Policy Overview

National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

Arkansas

In 1993, the Arkansas Department of Health (ADH) received grant funding from the Center for Disease Control and Prevention to create the Arkansas BreastCare program. The grant included studying how many Arkansas women had breast and cervical cancer; finding health care workers across the state able to test, diagnose and treat these cancers; and developing public and professional education materials. Two years later in 1995, Arkansas Department of Health received federal funds to provide eligible women with breast and cervical cancer screening and diagnostic services.

The BreastCare program’s goal is to reduce breast and cervical cancer related morbidity/mortality through early detection by providing timely screening, follow-up and treatment. BreastCare utilizes an online patient enrollment and slot management system to implement the program through local providers, Departments of Health and Community Health Centers. The online patient eligibility survey determines the likelihood for eligibility into the BreastCare program if they fit the criteria:

- Age 40-64 years old
- Are under 40 years old but have breast symptoms
- Do not have health insurance (including Medicaid or Medicare)
- Have a household income at/or below 250 percent of the Federal Poverty Line (FPL)
- Live in Arkansas

The Federally-facilitated Marketplace (FFM) offers health insurance coverage in Arkansas beginning in 2014 through a plan management partnership model. The state Medicaid agency has delegated authority to the Marketplace to make determinations of eligibility for Medicaid and the Children’s Health Insurance Program (CHIP). Arkansas expanded Medicaid coverage to low-income adults that was effective as of January 1, 2014.

The Affordable Care Act established a streamlined enrollment process through which individuals can gain access to affordable insurance coverage for which they are eligible. The law directs the Secretary of Health and Human Services (HHS) to develop a model application that will be used to apply for coverage through the Marketplace, Medicaid and CHIP. States have the option to adopt the Secretary of HHS’s model application form for affordable insurance programs or to adopt an alternative application that meets federal requirements. There is variation across states in the degree to which the alternative applications resemble the Secretary’s model and some states are continuing to modify their applications, but every state is offering a single application for the Marketplace, Medicaid and CHIP that will enable consumers to enroll in the coverage program that is appropriate for them.

New, modernized rules regarding verification of State Medicaid and CHIP eligibility will rely primarily on information available through data sources (e.g., the Social Security Administration,
the Departments of Homeland Security and Labor) rather than paper documentation from families.

In 2001, Arkansas Department of Health partnered with the Department of Human Services to provide treatment services for women diagnosed with breast cancer through a special category of Medicaid. The Affordable Care Act changed the partnership and the special category no longer exists. BreastCare still has a relationship at the Department of Human Services that helps the patient with the initial enrollment online.

The BreastCare program currently receives funding from the Affiliate to provide breast health services to women in Boone, Carroll, Crawford, Madison, Newton, and Sebastian Counties. In addition to grant funding, the Affiliate has made it a mandatory requirement that all grantees enroll women through the BreastCare program before Komen funds are used. The Affiliate also works closely with BreastCare staff helping to promote and educate about the program. The Affiliate's Public Policy Committee, called the Breast Health Initiative Committee (BHI), works with the Arkansas and Texarkana Affiliates to ensure that state funding is not cut from the BreastCare budget. The Breast Health Initiative (BHI) Committee advocates and educates the Governor and state legislators to ensure awareness of the need and importance for continued monetary support for breast services. In addition to funding and advocacy, the Affiliate partners with BreastCare program staff to visit local providers to educate them on the BreastCare program and what resources exist for their patients.

Even though there has been an increase in access to health insurance to those who are qualified there is still a need for the BreastCare program. The Community Profile will be shared with the community and BreastCare staff to ensure inclusivity and enhance public education, outreach, and screening efforts, especially in disparate and under-served populations.

**Missouri**

Show Me Healthy Women (SMHW) began in 1992 and is Missouri’s implementation of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). SMHW is funded by the Centers for Disease Control and Prevention (CDC) and several national, regional and local partner organizations.

There are 188 provider locations throughout the state, including local public health agencies, federally qualified health centers, hospitals, private physician offices and not-for-profit health centers. A full list of providers can be found on the SMHW website: [www.health.mo.gov/showmehealthwomen.org](http://www.health.mo.gov/showmehealthwomen.org)

In Stone County, there are two providers of SMHW located at the Stone County Health Department in Galena and Stone County Health Department-Branson West. In Taney County, the SMHW providers are located at Jordan Valley Community Health Center in Hollister and Taney County Health Department in Forsyth, MO.
To be eligible for SMHW services, women must meet all of the following guidelines:
- Income at or below 200 percent of the Federal Poverty Level for household income, and
- Age 35-64, or older if they do not receive Medicare Part B, and
- No insurance to cover program services

The Federally-facilitated Marketplace (FFM) will be offering health insurance coverage in Missouri in 2014. The FFM will make assessments of Medicaid/CHIP eligibility and then transfer the applicant’s account to the state agency for a final eligibility determination. Missouri is not expanding Medicaid coverage to low-income adults.

The SMHW program has worked closely with the Missouri HealthNet program since August 2001, when legislation was passed in Missouri to participate in the Missouri Medicaid program. Eligible women receiving SMHW funded screenings and/or diagnostic services that are diagnosed and need treatment for breast cancer or precancerous conditions could be eligible for Breast and Cervical Cancer Treatment (BCCT) in Missouri. Once enrolled in BCCT, women are qualified for full Missouri HealthNet benefits along with medical services for cancer care. The date of presumptive eligibility and the date when treatment is completed is covered by BCCT and is determined by Missouri HealthNet.

Currently, the Affiliate requires any grantee from Stone and Taney Counties to screen for eligibility for the SMHW program before Komen funding is used. The Affiliate annexed Stone and Taney in 2011 and is working on relationship building in the two counties.

During the Community Profile process, the Affiliate will be communicating with local SMHW providers to gather information on breast health services and access to care. The Affiliate will contact SMHW staff to discuss future collaboration opportunities and will also share the Community Profile information.

**State Comprehensive Cancer Control Coalition**

**Arkansas**

In 1992, Arkansas’ breast cancer control program began, and one year later, the Arkansas Cancer Control Coalition formed to support and monitor the state’s breast cancer control plan. This coalition joined forces with the Arkansas Department of Health’s Breast and Cervical Cancer Control Program to initiate a five-year agreement with the Centers for Disease Control (CDC) and Prevention to provide services for early detection of breast and cervical cancer.

The coalition led the way for the passage of The Breast Cancer Act of 1997. This act appropriated $4 million in state general revenue with a back fill funding from a tobacco tax. This funding provided breast cancer screening, diagnosis, treatment and research and complemented CDC funds to ensure timely diagnosis and treatment for eligible Arkansas women.

In 1998, Arkansas was selected to participate in a case study of cancer prevention and control conducted by Battelle Centers for Health Research and Evaluation, a contractor of CDC.
Arkansas was selected based on previous attempts at comprehensive cancer planning, the degree of centralization of public health functions, presence of a cancer registry and resources available to support cancer planning activities. Later that year, Arkansas submitted a Comprehensive Cancer Control grant application and was designated a CDC planning state but did not receive funding. Following the release of the Battelle report in September 1998, ADH formed an internal taskforce for comprehensive cancer planning.

The first comprehensive cancer conference, the Arkansas Cancer Summit, took place in September 2000 and later that year the framework for a statewide comprehensive cancer control plan began to emerge. By the end of 2000, the Arkansas Cancer Control Coalition and ADH’s comprehensive cancer planning taskforce merged to form the Arkansas Cancer Coalition. In November 2001, the Arkansas Cancer Plan: A Framework for Action was published and led the way for implementation funding from CDC.

According to information in the Arkansas Cancer Coalition’s Cancer Plan:

**Priorities for Change**
- Reduce deaths from female breast cancer
- Increase proportion of women aged 40 and older who have received a mammogram within the preceding two years
- Follow-up care
- Quality Assurance of breast cancer screening and follow-up

**Breast Cancer Screening and Detection**

**Goal A:** Promote and Increase the Appropriate Utilization of High-Quality Breast Cancer Screening and Follow-up Services
- Objective 1: Public Education for Breast Cancer Screening- Increase knowledge and improve attitudes of all women with regards to the importance of breast cancer screening.
- Objective 2: Provider Referral/Promotion for Breast Cancer Screening- Increase the proportion of primary care providers who recommend regular mammograms to their patients.
- Objective 3: Access to Services for Breast Cancer Screening- Increase the availability of breast cancer screening to populations facing geographic, economic or cultural barriers
- Objective 4: Access to Follow-up Care- Educate women about their risk of breast cancer and the need to return routinely for appropriate re-screening and/or diagnostic testing.

Currently, the Affiliate serves on the Arkansas Cancer Coalition. The coalition offers insight, expertise, opportunities and resources in order to collaborate on ideas to work together with other agencies towards the mission of the ACC. In the past, the Affiliate has received grant funding for various projects and programs for a Providers Conference and a Rural Outreach Coordinator to improve breast health literacy and screening percentages. The Director of
Mission Services also takes part in a workgroup dedicated to breast cancer. Affiliate staff also follows information provided by the ACC and attends quarterly meetings when time permits.

The Affiliate will continue to work with the ACC and their Call to Action to:

- Provide cancer awareness information to constituents
- Promote cancer screening among clients
- Encourage participation in clinical trials
- Collaborate to provide community prevention programs

**Missouri**

The Missouri Comprehensive Cancer Control Plan, “The Burden of Cancer in Missouri: A Comprehensive Analysis and Plan 2010-2015,” was created through the partnership of the Missouri Department of Health and Senior Services and the Missouri Cancer Consortium. The goal and objectives addressing breast cancer include:

*Goal:* Increase early detection and appropriate screening for cancer using evidence-based guidelines.

- **Objective 1:** Increase the percentage of women who receive regular breast cancer screenings.

Currently, the Affiliate does not have a relationship with the Missouri Cancer Consortium. The Affiliate’s two counties located in Southwestern Missouri were not annexed into the Affiliate service area until 2010 and the Affiliate is still trying to build capacity to effectively impact the two counties.

The Affiliate will contact the Missouri Cancer Consortium staff and become educated on the programs and strategies the consortium conducts.

**Affordable Care Act**

**Arkansas**

In April 2013, Arkansas chose to implement the Affordable Care Act through a waiver request to Centers for Medicare/Medicaid Services (CMS) in a model called the “Arkansas Health Care Independence Program”. The program, called the Private Option, is an innovative way under the Affordable Care Act to fund Medicaid expansion. The Private Option allows people up to 138 percent of the Federal Poverty Level (FPL) to receive health care benefits not from Medicaid, but though private insurance coverage.

The Private Option is funded with federal Medicaid dollars and patients at 138 percent or below the FPL receive insurance coverage from commercial insurance companies and may choose their provider. The Private Option provides subsidies to private health insurers to assist low-income Arkansans with the costs of premiums. Under this legislation, participants choose a qualified plan on the Insure Arkansas Portal. To be eligible, one must be between the ages of 19 and 65 and have an income of no more than 138 percent of the FPL. For an individual, 138 percent of FPL is $15,856; for a four-person family, it is $32,500. The Medicaid expansion targets adults below 138 percent of FPL. Adults over age 65 qualify for Medicare. Children 18
and under in Arkansas are generally covered by the ARKids programs. Arkansas’ Traditional Medicaid program was one of the most stringent programs in the US and covered adults from 0-17 percent FPL or who were pregnant or disabled. For individuals above 138 percent of FPL there is a graduated subsidy scale to assist with the purchase of insurance up to 400 percent of FPL or around $45,960 annually for an individual.

As many as 250,000 Arkansans were estimated to be eligible for Private Option coverage. Enrollment in the program began on October 1, 2013. According to the Arkansas Department of Human Services, 170,033 people statewide through the end of April 2014 have been deemed eligible and gained coverage under the Private Option. Because the Arkansas Constitution requires all fiscal measures of this magnitude to be voted on annually, in the 2014 fiscal session the Private Option was at risk of being defunded by the State Legislature due to the fear that in three years there would not be enough state funds to meet the ten-percent state share for the Private Option. This argument was used to advocate for defunding the Private Option. After several votes, the State Legislature voted to keep the Private Option in place. They did, however, eliminate the funding for all Assisters (573) who were in place to help enroll many Arkansans for the Private Option. The elimination of state funding for Assisters has created a gap in navigation and enrollment of the new health insurance system.

According to the US Census Bureau, 16.9 percent of Arkansans have no form of health insurance.

In 2001, Arkansas Department of Health partnered with the Department of Human Services to provide treatment services for women diagnosed with breast cancer through a special category of Medicaid. The Affordable Care Act changed the partnership and the special category no longer exists. BreastCare still has a contact at the Department of Human Services that helps the patient with the initial enrollment online.

Most of the implications of the Affordable Care Act and the Private option are largely unknown at this time. Rural hospitals, large hospital systems, private providers and community health centers have prepared for increased demand for services. With only seven months since full enrollment, data are inconclusive at this time.

The continuing changes in health care have kept the Affiliate constantly seeking training for Affiliate staff and grantees on how this will impact programs and clients. There will always be a need for screening and diagnostic services in the Affiliate service area; however as the number of people gaining access to health care due to the Affordable Care Act increases, the Affiliate will not only continue to analyze the statistics and situation, but also adjust funding priorities accordingly. In the future, the Affiliate anticipates a funding shift to breast health navigation, programs to address direct barriers to care like transportation and survivorship programs.
Missouri
The Affordable Care Act originally would cover those making less than 138 percent of poverty through the expansion of Medicaid, the public insurance program for the poor. When the US Supreme Court ruled that Medicaid expansion was optional for states, Missouri opted out of the Medicaid expansion.

Despite the Governor of Missouri Jay Nixon’s push for the Medicaid expansion during the legislative session, the General Assembly rejected the plan stating that the current Medicaid program was flawed and adding more participants was financially unsustainable.

The Affordable Care Act has the potential to reach over 800,000 Missourians who lack insurance coverage. The marketplace in Missouri is federally facilitated, as the state opted not to run its own. Missouri did not expand its Medicaid program, leaving many uninsured adults below poverty in Missouri who would have been newly-eligible for Medicaid without a coverage option. Prior to implementation of the ACA, 834,000 Missourians-16 percent of the state’s nonelderly population-were without health insurance coverage.

A large segment of the uninsured in Missouri has little or no connection to the health care system. Only 55 percent of uninsured adults report that they have a usual source of care, or a place to go when they are sick or need advice about their health, and only 36 percent of uninsured adults say they have a regular doctor, about half of the rate of insured adults in Missouri. This lack of a connection to the health care system leads many uninsured adults to go without care.

As of January 2014, about 54,000 Missourians had enrolled in coverage, and about 83 percent of these people were eligible for financial assistance. However, this only represents about eight percent of the population eligible for marketplace coverage.

Since Missouri chose not to expand Medicaid, there are a large number of women who fall in the gap of not being insured for their health care coverage. These women could turn to SMHW to cover screening services, thus the decrease in numbers the program services could be minimal.

Affiliate’s Public Policy Activities
Komen Ozark currently has a committee that addresses public policy concerns called Breast Health Initiative (BHI). The BHI is made up of Komen mission staff, grantees, board members and community advocates. BHI has participated in state lobby days, the most recent being 2012. The Affiliate also invites local dignitaries to site visits and Affiliate events and partners with other Affiliates in the state of Arkansas for a Governor’s proclamation in the month of October. The Affiliate has also participated in collecting signatures for petitions involving reauthorizing the breast cancer awareness stamp and has often lobbied the Arkansas Delegation for the sequester and funding for breast cancer research. The Affiliate meets with local representatives and senators to educate them on the impact local Komen Ozark grantees are having in the community.
The BHI Committee also works with the Arkansas and Texarkana Affiliates to ensure that state funding is not cut from the BreastCare budget. The BHI Committee advocates and educates the Governor and state legislators to ensure of awareness of the need and importance for continued monetary support for breast services.

The BHI committee will continue to reach out to local representatives and senators to educate them on the needs in the community and what the Affiliate and grantees are doing to address those needs. The Affiliate will be working with other cancer organizations, patient advocacy organizations and the Arkansas Affiliate to pass Oral Chemotherapy Parity legislation. It is critical that patients who are prescribed an orally administered cancer medication receive as much coverage by their insurance as they would for IV administered cancer medications. BHI will also send copies of findings from the Community Profile to local legislators.

Arkansas has been fortunate to expand Medicaid, but upcoming elections in November of 2014 could threaten the state of health care coverage in Arkansas. BHI will possibly need to advocate for continuing the expansion and educate lawmakers on the need for continuing to fund BreastCare at the level committed.

The Affiliate also encourages grantees to contact local, state and federal governmental officials on breast cancer/breast care issues. Grantees and the Affiliate work together to invite local dignitaries and lawmakers to site visits to see the impact Komen funding has in their community. The Affiliate also extends invitations to lawmakers to attend Affiliate events (i.e.; Race for the Cure, Pink Ribbon Luncheon, Promise Circle Luncheon, etc.).

**Health Systems and Public Policy Analysis Findings**

The Affiliate’s three selected target communities all have a need for transportation, whether it is public transportation, transportation to breast cancer screenings, access to a mobile unit or transportation to and from breast cancer treatment. In some communities that have screening, diagnosis and/or treatment services, hours of business could be examined to see if there could be a policy change. There also needs to be a focus on providing services, especially follow-up care, to the Hispanic/Latina community. Offering bilingual navigators/staff, translated materials and culturally competent practices is a need that has been identified through the Health Systems Analysis. Education needs have also been identified through the Health Systems Analysis process. Whether it is education on how to get signed-up for health insurance coverage, education on the Arkansas BreastCare or Show Me Healthy Woman programs, education on screening guidelines or education on where services are located and what resources exist to obtain the services, lack of education is a barrier to care. Support/Survivorship is also lacking in many of the selected target communities as well.

In the first selected community of Boone, Newton and Madison Counties, the Affiliate will focus on continuing work with the local health departments and county health coalitions. In the second selected community of Stone and Taney Counties, the Affiliate will establish relationships with the local health departments and the area chamber of commerce. In the third
selected community of the Hispanic/Latina population in Benton, Washington, Carroll and Sebastian Counties, the Affiliate will continue to work with local Affiliate grantees and will contact additional Hispanic/Latina groups like the Hispanic Women’s Organization and other nonprofits, churches and community leaders. The Affiliate will continue work with the Arkansas BreastCare program and will work on contacts within in the Show Me Healthy Women program to address local concerns on a statewide level.

Public policy directly impacts the access to quality breast health. The ACA has already benefited breast cancer patients by not allowing a pre-existing condition, like breast cancer, be the reason why a person is denied insurance. Also, there is no lifetime maximum cap on insurance costs that would affect future coverage and eligibility. The ACA also established a streamlined enrollment process through which individuals can gain access to affordable insurance coverage for which they are eligible. The state of Arkansas voted to expand Medicaid coverage to low-income adults, but Missouri voted to not expand Medicaid. This decision directly impacts whether or not a certain population group will be able to access health insurance coverage.

Another way that public policy effects breast health care is through the NBCCEDP. NBCCEDP provides federal funds to states to provide eligible women with breast and cervical cancer screening and diagnostic services. Without the program in place and the money to fund the program, women who are uninsured would not have access to breast health services.

The Affiliate’s BHI Committee will continue to contact local representatives and senators to educate them on the needs, what kind of impact the Affiliate has on those needs and the importance for continued legislative support to keep state programs like Arkansas BreastCare and Show Me Healthy Women funded. BHI will also continue to encourage grantees to contact local, state and federal governmental officials on breast cancer/breast care issues. Grantees and the Affiliate will also continue to work together to invite local dignitaries and lawmakers to site visits to see the impact Komen funding has in their community.
Qualitative Data Sources and Methodology Overview

Methodology
The purpose of this evaluation was to explore issues affecting women's health in the identified three target communities. Overall perceptions of general health, access to care, and factors increasing opportunities for screening and general outreach were examined utilizing focus groups and survey data. This in-depth analysis of 83 individuals’ experiences can be used to critically examine existing barriers to health care, and develop action plans to address key findings. Over the course of four months, nine focus groups were conducted with one being a Spanish only focus group.

The questions derived for the evaluation were selected from the Komen Qualitative Question bank, and were arranged under the following topical areas: general health, access to care, and breast cancer—screening and outreach. The following served as guiding questions for the respective topical areas:

- What factors do low income women consider when thinking about personal health care?
- What factors are affecting accessibility to (screening/diagnostic/active treatment/post-treatment/follow-up) care in the community?
- What factors increase educational opportunities within these selected communities?
- What is the most important message you would send to breast cancer treatment providers?

The entire list of questions for the focus groups can be found in Appendix A.

The data collection method used for this profile incorporated the use of focus groups. Focus group interviews generally involve participants between six to 12 individuals. These individuals are selected because they share similar characteristics that are relevant to the questions being asked. In the focus group interview setting, the facilitator creates an amiable environment in which pre-determined questions are asked with the goal of encouraging participant dialogue and voicing their point-of-view (Krueger, 1988). They are versatile, and good at garnering introspective responses producing rich data (Goldenkoff, 2004). The evaluation’s goals and nature of the research questions being asked generally determine the methodology used in the data collection. The rationale for utilizing focus group interviews as the source for data are derived from an approach to understand the lived experience of selected individuals, and how these multiple realities constructed from one vantage point can share similarities (Hatch, 2002). In qualitative research, divergent multiple realities are constructed by the individuals involved in the evaluation including the researcher, participants, and reviewers interpreting the evaluation (Creswell, 1994).

The researcher’s role is central to the process in that they serve as a participant observer in the focus group interview process. The researcher who moderated the focus groups has worked in higher education for over sixteen years, and has a broad range of experiences from program administration to being responsible for departmental research efforts. Since the researcher had
no prior experiences directly related to Komen operations, there was a sense of empathic
neutrality where the researcher is perceived as caring about the participants, but is neutral
regarding the findings. The focus groups were audio recorded, and were transcribed by both
the researcher and the Director of Mission Services for Komen Ozark.

There are several methods for ensuring internal validity in qualitative studies, and Creswell
(2002) explains it as the need to establish trustworthiness. The data were triangulated with
repeated observations of the same phenomenon. Participants with different backgrounds and
experiences shared similar examples within the focus group interviews. Moreover, participants
were able to clarify and offer comments when the researcher asked for member checks during
the focus group interviews. A detailed audit trail exists for this evaluation that includes raw
recordings, the staff member’s notes from each focus group, transcripts from the recordings,
and information about the coding process.

Sampling
The Community Profile Team relied on community contacts and Komen Ozark grantees when
selecting participants for the nine focus groups. Factors considered either as an influence or
barrier to participation included: when the group was held, where the group was held, the
population of interest from the target communities and incentives to participation.

Boone, Madison and Newton Counties in Arkansas
In the first selected priority area, Komen grantees assisted in securing the participants and
arranged the group logistics. The focus group conducted in Madison County (city, Huntsville)
consisted of all breast cancer survivors. The Komen Ozark grant funded breast health
navigator, through the Madison County Health Coalition, called on her clients to participate. The
focus group was conducted at the Madison County Health Department at 5:30pm. Many of the
survivors worked full time and could not take off work to participate during their work day, and
this influenced the focus group start time.

The second focus group in the first selected priority area was conducted in Boone County (city,
Harrison). A Komen Ozark grant funded Program Coordinator, through the North Arkansas
Partnership for Health Education, assisted the Community Profile Team in recruiting participants
for the focus group. The focus group consisted of women who have never been diagnosed with
breast cancer. Many of the women worked full time and were unable to take off in the middle of
their work day, so the group met in the evening.

The third focus group in the select priority area was conducted in Newton County (city, Jasper).
The Program Coordinator assisting with the focus group in Harrison helped recruit participants
for the focus group in Jasper. Jasper is a small, rural, tight knit community, so the Program
Coordinator relied on the AmeriCorps Vista staff, who lives in that particular community, to
recruit participants. The Jasper focus group was a mixture of breast cancer survivors and
women who have never been diagnosed with breast cancer. Many of the participants were
retired or not currently employed, so the focus group was held over lunch.
**Stone and Taney Counties, Missouri**

The second priority area included two of the newest counties to the Affiliate. The Affiliate has a limited number of community contacts and relied on the Program Coordinator of the Komen Ozark grant through the Skaggs Foundation. The first two focus groups in this selected target community were held in CoxHealth Branson in Stone County (city, Branson). The focus group held in the morning was a breast cancer survivor only focus group, which included one male survivor. The second focus group was held the same day with a combination of breast cancer survivors and women who have never been diagnosed.

The third focus group held in this selected target community was in Taney County (city, Reeds Spring) at the LifeSong United Methodist Church. The Program Coordinator of the Komen Ozark grant at the Skaggs Foundation relied on community contacts to secure participants. The first focus group scheduled in Taney County had to be rescheduled due to a lack of participants. Reeds Spring is a small, rural community and it was decided that the only way to ensure participation was to conduct the focus group after the work day was over so it wasn’t necessary for the participants to take off work.

**Hispanic Community in Benton, Carroll, Sebastian and Washington Counties in Arkansas**

The first focus group conducted in this target community was in Carroll County (city, Green Forest) at the Tyson Plant. The Community Profile Team worked with the Komen funded program staff through The Merlin Foundation and two nurses at the Tyson Plant to get the focus group scheduled and participants secured. Family and work constraints influenced the best time to conduct the focus groups. It was decided that the focus group would be held on the Tyson Campus over the lunch break. The Community Profile Team decided to limit the group to only women who were bilingual or spoke English. There was a participant that, at times, would step in to help women translate a word and/or sentiment to English.

The second focus group in this selected target community was conducted in Washington County (city, Springdale) and was entirely in Spanish. The Community Profile Team had to rely on a bilingual staff member of an organization that holds a grant from Komen Ozark. The Community Clinic has approximately 56 percent of staff members that are bilingual, so a Patient Advocate took the lead of scheduling, recruiting participants and conducting the focus group. The staff member had previous experience conducting focus groups, so the Community Profile Team provided all of the necessary information and education to facilitate a focus group for collecting Qualitative data. Prior to the focus group, the Community Profile Team had the questions and demographic forms translated from English to Spanish. To address the needs and possible barriers of the participants of the focus group, childcare was provided as well as dinner, a bilingual note taker and a bilingual translator.

The third and final focus group was conducted in Sebastian County (city, Fort Smith) at the Komen Ozark satellite office. The Community Profile Team relied on a longtime Komen Ozark volunteer to secure a community contact that could provide participants. The focus group was conducted in English with all participants being bilingual. Further, the focus group was conducted in the evening and dinner was provided.
**Provider Survey**

The Community Profile Team evaluated the best type of data collection methods to obtain information from breast health providers across the 10 county Affiliate service area and an online survey fit the team’s needs. Surveys are a good source of data collection when looking to:

- Gather information from providers about service delivery gaps, needs and barriers
- Support, expand or better understand data previously obtained
- Gather information from providers on behaviors, beliefs or attitudes
- Determine the level of knowledge that providers and/or the community has on a particular issue.

The first question the Community Profile Team addressed through the Provider Survey is “what do we want to glean from the survey?” The team reviewed the Quantitative data report and noted areas that should be addressed by the Provider Survey. The Provider Surveys consisted of revised questions the Community Profile Team pulled from the Komen Headquarters Community Profile Team question bank.

The question bank consisted of eight pages of examples of open-ended questions, so the questions had to be paired down significantly. Once the information was paired down and the topics to cover were outlined, the team evaluated the information and decided to use a combination of open-ended and close-ended questions, due to the scarce amount of time providers would have to participate and submit the survey.

After a rough draft of the survey was created, the Community Profile Team had two Komen Ozark board members (a local Radiologist and Oncologist) as well as the Komen Ozark Grant Chair review the survey for feedback and edits. After feedback was obtained and revisions made, the next step for the team was to plan the distribution of the survey. The Community Profile Team was concerned about participation rate, time constraints and securing enough volunteers to conduct the surveys via regular mail, telephone or face-to-face. The Convio system the Affiliate uses for the website proved to be the best platform to host the Provider Survey. The survey was entered into the system and could only be accessed by someone who had the specific link information and not by the general public.

While the survey was being submitted into the system, the Community Profile Team was busy obtaining contact information for breast health providers in the 10 county service area. This task proved to be difficult and more time consuming than the Community Profile Team had originally budgeted for in the Qualitative report completion timeline. The Community Profile Team reached out to the state NBCCEDP program, BreastCare, to pull provider contact information. Although useful, information was limited to providers that registered to be a BreastCare provider and the information did not include email addresses. A team of five volunteers were put together to help gather contact information and to pull provider information from providers who were not enrolled as BreastCare providers. Originally, the plan was to call these agencies, clinics, hospitals, etc. to get the email of each provider, specific to each
location. After the first few phone calls, the tactic to get the contact names and email addresses had to be reevaluated. Office Administrators were not comfortable giving out email address information of their providers, so the Community Profile Team had to get the email information from the Office Administrator and get them to agree to send out the information to the providers with the link to the Provider Survey. The set-up wasn’t ideal, but necessary to get information to providers.

Once the contact information was collected, the Community Profile Team and providers emailed out two emails to the Office Administrators. The first email was a general description of the Provider Survey—why it was important, who the surveys should be sent to and what information was covered by the survey questions. The second email was an email the Office Administrators would directly forward to breast health providers. This email gave breast health providers general information about the Provider Survey including; why it was important, what information would be covered, how the participants’ identity would be anonymous and how long the survey would take to complete. Additionally, the Community Profile Team sent the Provider Survey emails to various Komen Ozark grantees to send to their breast health provider contacts. A few weeks after the initial emails were sent to Office Administrator and breast health providers, a follow-up thank you/reminder card was emailed to help with the response rate.

**Ethics**

All participants were given and asked to sign a consent form (Appendix B), and were also told about the project in the explanation of the evaluation. While participants were privy to the data collected from them, they were not privy to information collected from and about other participants. Participants were also told involvement in this evaluation was voluntary, and individuals were permitted to leave at any time without penalty. Further, they were informed they did not have to answer questions they found uncomfortable. Additionally, participants were given the assurance their personal identity would not be disclosed. To maintain the confidentiality of the participants, all data were coded. Specific descriptions of events were disguised to maintain anonymity. Both the researcher and staff member informed groups if they were interested in seeing the report, how to access the copy. As stated in the consent form, all data are currently maintained in a locked office on the University of Arkansas campus.

**Qualitative Data Overview**

Focus group recordings were transcribed to present data for the typological analysis. There were also focus group observation notes to assist in the overall confirmation process. For this evaluation, there were specific areas in which the researcher focused on as outlined in methodology section. As Hatch (2002) stated this type of analysis is warranted if the researcher has clear beginning categories in mind. This evaluation centered on examining factors as related to low income women’s general health, access to care, and screening and outreach.

Focus group data were analyzed by selecting categories demonstrating similar meanings among participants. Themes were categorized under the topical areas guiding the evaluation. The researcher used interrater reliability with the Komen staff member to establish validity of
the findings. Interrater reliability was found to be consistent. Demographic data were also captured during the focus groups, and provided a broader perspective on the participants. The demographic form utilized is in Appendix C.

Focus groups were hand coded after a utilization attempt with QDI Miner Lite. The software would not export coded documents into Microsoft Word. While the statistical function of counting coded words and passages was a great feature, it was not germane to this evaluation. The focus was to confirm experiences under the topical areas not to generate theory. All hand coded transcripts were electronically scanned and added to the audit trail. Common findings are represented below in Table 4.1.

**Table 4.1. Common focus group findings**

<table>
<thead>
<tr>
<th>Typologies with Themes</th>
<th>General Health</th>
<th>Access to Care</th>
<th>Screening and Outreach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attitudes towards good health</td>
<td>Cultural barriers</td>
<td>Need for resource information</td>
<td></td>
</tr>
<tr>
<td>Health concerns</td>
<td>Rural area issues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Barriers to preventative services</td>
<td>Lack of general knowledge</td>
<td>Lack of trust with medical community</td>
<td></td>
</tr>
<tr>
<td>Misinformation issues</td>
<td>Lack of transportation</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Financial barriers</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Table 4.2. Focus Group Characteristics

<table>
<thead>
<tr>
<th>Priority Area</th>
<th>Focus Group Location</th>
<th>Participant Number</th>
<th>Breast Cancer Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boone, Madison, &amp; Newton Counties</td>
<td>Huntsville</td>
<td>10</td>
<td>Survivor</td>
</tr>
<tr>
<td>Boone, Madison, &amp; Newton Counties</td>
<td>Harrison</td>
<td>9</td>
<td>Non-survivor</td>
</tr>
<tr>
<td>Boone, Madison, &amp; Newton Counties</td>
<td>Jasper</td>
<td>10</td>
<td>Mixed</td>
</tr>
<tr>
<td>Stone &amp; Taney Counties</td>
<td>Branson</td>
<td>10</td>
<td>Survivor</td>
</tr>
<tr>
<td>Stone &amp; Taney Counties</td>
<td>Branson</td>
<td>12</td>
<td>Mixed</td>
</tr>
<tr>
<td>Stone &amp; Taney Counties</td>
<td>Reeds Spring</td>
<td>10</td>
<td>Non-survivor</td>
</tr>
<tr>
<td>Hispanic Community in Benton, Carroll, Sebastian, &amp; Washington Counties</td>
<td>Green Forest</td>
<td>9</td>
<td>Non-survivor</td>
</tr>
<tr>
<td>Hispanic Community in Benton, Carroll, Sebastian, &amp; Washington Counties</td>
<td>Springdale</td>
<td>10</td>
<td>Non-survivor</td>
</tr>
<tr>
<td>Hispanic Community in Benton, Carroll, Sebastian, &amp; Washington Counties</td>
<td>Ft. Smith</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

### Boone, Newton, and Madison Counties

**Huntsville**

The participants in Huntsville’s focus group indicated they all received a mammogram, and all but one participant had been diagnosed with breast cancer. The average age of diagnosis was 49 years of age. The majority indicated they were diagnosed with stage one breast cancer with three individuals noting they were diagnosed with stage three. There was variety within the educational level of the participants. Two participants marked they had completed master’s degrees, and only two participants had not graduated high school. The majority of participants fell between graduating high school and completing an associate’s degree. The racial makeup of the focus group was homogenous with all participants indicating they were White.

Surprisingly, the internet was the highest rated category for where they receive their health information. The second highest rated category was word of mouth from individuals, and the individuals listed were friends, doctors, and the breast health navigator. Additionally, three participants listed their household income being more than $50,000 a year. One participant preferred not to disclose. One participant chose not to mark an income. The others marked income levels that would be consistent with other data within the report. The primary occupations of this group were mixed. There were retirees, and individuals indicating they worked in office/clerical environments, educational settings, and in health care. Homemaking and working as a cook and in dietary at a nursing home were the other occupations.

Last, the majority of women indicated that private insurance (five participants) paid for their breast cancer treatment costs. Four participants indicated that Medicaid/Medicare/Government Assistance paid for their treatment costs. In addition to those two primary sources, three participants specified they also self-paid. The majority utilized more than one person as a health care provider, and they did not experience not being able to see a doctor due to cost.
**Harrison**

Harrison’s focus group did not have any participants diagnosed with breast cancer. The majority had received a mammogram, and only one participant that was over 40 years of age had not received a mammogram. The educational level was mixed, with the majority having attained more than a high school degree. The outliers included one participant not graduating high school, and one having a master’s degree. The racial makeup of this group was similar to Huntsville. In regard to ethnicity, one participant indicated they were Hispanic/Latina.

Similar to the Huntsville focus group, Harrison’s participants indicated that the internet and word of mouth were the top two sources for health information. They are getting health information from their doctors, at work, and various individuals. They looked to the newspaper and radio to find out about community events. Household income was divided evenly between $20,001-$30,000 and $30,001-$40,000, and the majority work in education or some type of office position. The participants were also evenly split between utilizing one person as a health care provider and having multiple providers. Four participants selected that on more than one occasion they did not see a doctor due to costs. One indicated this had occurred only once the past year, and four selected that cost had not been a factor for them.

**Jasper**

All of Jasper’s participants indicated they had received a mammogram, and the majority of this group were breast cancer survivors. The average age of diagnosis was 43 years of age. The majority were diagnosed with stage one breast cancer; one participant was diagnosed with stage two and another with stage three. Again, the educational distribution was similar to the other focus groups within this priority area. Only one participant had not graduated high school, and the rest had at least graduated high school. All of the participants were White.

Following how others answered in this priority area, the majority of participants receive their health information from the internet. Where this group differed from the two other focus groups was in relying on other sources. This group highly rated television, newspapers, and social media as additional outlets where they receive their health information. For community events, friends and word of mouth were the sources for information. This group has the lowest distribution of income of those who disclosed. Three participants did not choose to disclose income, and one indicated their household income was more than $50,000. The highest income indicated for this group, outside of the outlier, was $20,001-$30,001. Occupations for this group included homemaking, office work, health care non-clinical, and retirees.

For those who received breast cancer treatment, two used private insurance, and three utilized some form of government assistance. None of those that went through treatment selected self-pay as a payment option. The majority of participants only used one person as a health care provider, and did not experience being able to not see a doctor due to cost.
Stone (MO) and Taney (MO) Counties

**Branson #1**

All of the participants of this focus group had been diagnosed with breast cancer, and the average age of diagnosis was 56 years of age. The majority were diagnosed with stage two breast cancer with only three participants being diagnosed with stage one. All of the participants had at least graduated high school, and the majority had some form of educational experience beyond secondary education. All of the focus group participants were White.

Again, similar to the previous focus groups, the participants indicated they receive their health information from the internet and word of mouth. Those they talk to included friends, family, individuals at work, and health care providers. The senior centers seemed to be a hub of activity, and many indicated it was an outlet for information on community events. Data regarding income is inconclusive due to the majority of participants indicating they would prefer not to disclose. Retirees made up this group for the most part, but those still working indicated they worked in an office or an educational setting. Private insurance and government assistance were the two methods of payment for breast cancer treatment. Additionally, this group indicated they did not experience not being able to see a health care provider due to cost. The group was split between having only one person they considered as their primary health care provider and having more than one providing care.

**Branson #2**

Only four focus group participants indicated they had been diagnosed with breast cancer, and their average age of diagnosis was 38 years of age. Two participants also indicated that they had yet to receive a mammogram. As with the first Branson focus group, all of the participants had at least graduated high school, and was the most educated group in the priority area with four participants stating they had received a bachelor’s degree and two stating they had received a master’s degree. Income correlated with educational level, and more participants indicated having a household income of more than $50,000. There was one outlier for the group indicating a household income less than $10,000. For those still employed, the majority worked in a professional setting. One participant indicated being an American Indian, and the rest selected White for racial background.

Overwhelmingly, this group selected internet as being a source for health information, and second was word of mouth. Those they considered for information were friends, medical providers, and someone listed employer. This group relied on the newspaper and Facebook to get information related to community and social events.

Of those requiring breast cancer treatment, the participants selected private insurance and self-pay as the options for paying for the treatment. This group did not rely on any type of government assistance. The majority indicated they only had one primary health care provider and did not avoid seeing a health care provider due to cost.
Reeds Spring
All of the focus group participants indicated they had not received a breast cancer diagnosis, but not all had received a mammogram. Four participants indicated they had never received a mammogram although they fell within the recommended age range. The educational level varied within this group. The highest degree level attained was an associate's degree, and one participant indicated not graduating from high school. Many participants had attempted some form of college credit, but less than one year. Income was more evenly distributed within this group with one person earning less than $10,000, and one person earning more than $50,000. The majority fell within the $30,001-$40,000 range. Primary occupation varied from homemaking (three participants) to disabled veteran (one participant), but the majority worked in a professional setting. One person was Hispanic, while the rest were non-Hispanic White.

For health care information sources, this group selected first the internet and second social media. Word of mouth, while mid-ranked, was behind television. The rural nature of this community may influence how individuals receive information. Overall, this group thinks of one person as their personal health care provider, and have not needed to worry about cost and health care access.

Hispanic Community in Washington, Benton, Sebastian and Carroll Counties

Green Forest
While there were other health issues related to cancer, this group did not have anyone diagnosed with breast cancer. Of all the participants, only three indicated they had yet to receive a mammogram. Only two participants fell under the recommended screening age. Only two participants had graduated high school, and the rest indicated they had not finished high school. The most frequent language used in writing and in speaking was Spanish, and all indicated they were of Hispanic, Latina, or Spanish ethnicity.

How this group differed from all previous focus groups was in how they received their health information. The majority indicated it was through word of mouth or mail delivered to the home. Only one participant indicated they used the internet. The majority of participants’ household income was within the range of $10,001-$30,000. All of the participants worked at a poultry processing plant. For the most part, they have one person they view as their primary health provider, and have not been challenged with not being able to see a health care provider due to cost.

Springdale
All of the participants were healthy, but not all had received a mammogram. Four participants indicated they had yet to receive one. Again, only two participants fell under the recommended screening age. As in the Green Forest focus group, the Springdale participants were not highly educated. The majority had not finished high school, and the outlier for this group was someone with a bachelor’s degree. The most frequent language used in writing and in speaking was Spanish, and all indicated they were of Hispanic, Latina, or Spanish ethnicity. Again, as in the previous group, the majority received their health information through word of mouth as well as information about community and social events.
Household income levels clustered around $10,001-$20,000, and one participant preferred not to disclose. For occupation, the majority indicated they were in some type of homemaking position, and other care services whether daycare or housekeeping. Differing from the Green Forest focus group, the majority indicated they did not have a primary health care provider, and had instances of not being able to see a health care provider due to cost.

**Fort Smith**

It is important to note this group only had three participants, but this group still provided salient information. All had received a mammogram and had a relatively high educational level with all attempting college. The household level income for every member of this group was $30,001-$40,000, and they were all in a professional field. The most frequent language used in writing and in speaking was English, and all indicated they were of Hispanic, Latina, or Spanish ethnicity.

This group differed from the other two focus groups in where they sought out health information. The group rated internet and social media as the most used outlets and then word of mouth. Newspapers and radio were utilized in finding out information about social and community events. Moreover, this group did not worry about costs and access to health care, and indicated they had a primary health care provider.

**Provider Survey**

There was a low response rate for this portion of the evaluation. Only 14 providers responded, and there are several possible reasons for low turnout. Providers were not offered any incentive for completing the survey, and the launch period could also factor into the low response rate due to the holiday season. The information gained from this effort only provides the views of the 14 providers, thus is only descriptive in nature.

**Qualitative Data Findings**

**Boone, Newton, and Madison Counties**

**Huntsville**

**Good Health**

All of the participants understood the importance of maintaining good health, and working to make sure they stayed in some form of optimal health. As one participant stated,

> I think good health is a general balance, consuming, you have your energy, you have good health. You can be active, you can find the time to do the exercises, or to eat […] It isn’t just one aspect of anything. If you eat properly you are going to have better health. It is a combination of everything.
Another survivor put perspective on viewing good health in this way,

I didn’t know, you know when I had my health, and I didn’t have to take medicine how good I had it. I mean, until I got sick, I did not realize how hard it was, I guess I took that for granted.

The health concerns for this group ranged from diabetes to cancer returning, but more important issues related to the lack of information regarding health care resources came out in this group.

Well, to get the word out that this is even here to get people to come here, even if it is a family member who doesn’t have cancer. My husband didn’t know what to do. He was very supportive, but he didn’t know. But, get the community, the local community involved in it. Say, hey, it is scary to ask too. We don’t have this here in Huntsville. I didn’t know this existed, I did a self-breast exam and found mine, and took me about two weeks to tell my girlfriend, and she told me that I needed to get that checked out. And, I thought, oh no. I have lymph nodes, and milk ducts, but couldn’t help, and then my girlfriend was telling me to get it checked out. I didn’t know where to go, and in Madison County paper said, free mammograms. I thought well, someone is trying to tell me something, I find the lump, and I have the girlfriend to tell me to get it checked out, and then I read in the paper, this is in all in a week’s time to when I told somebody. I didn’t know it was there. And then, Donna is the one that loved me through all my junk. She has been awesome for me. Who would’ve else done that?

Access to Care
Participants told story after story regarding the lack of resources to allow them access to care. Whether it was misinformation, lack of transportation and financial resources, these barriers created confusion for participants. Additionally, cultural issues surrounding the rural area contributed to barriers related to care.

I don’t think we know all of the resources out there. When I was at Pink at the Park and somebody was talking about a warehouse in Bentonville. My daughter started working for Hope Cancer Resources. I never heard of that. She was telling me to tell a friend of mine who was in the midst of chemo that there was a free housekeeping service for [individuals with] breast [cancer], we don’t know those things.

Well, my sister, she is 56 and she works at the school and their insurance there is not that great, and for her to go to get a mammogram she has to pay up front or a lot of money. She doesn’t do it because she can’t afford it. And, I think that is sad, and she works at the school.

And I wouldn’t have known about getting a gas card to go to my doctor’s appointment. I went to my doctor’s appointments every two weeks. And a lot of times I would go twice a week. And I couldn’t afford to do that. And, Donna
Graham was the one that got me in here and told me she could get me a gas card. I was like, really? Because I wouldn’t have known if she hadn’t been there to tell me the stuff I could do.

All of the participants reported driving over 70 miles to receive some form of medical treatment during their breast cancer diagnosis and treatment process. Being in a rural part of the state made it harder for them to access resources and also hindered receiving additional assistance.

For me, it is a long way to go to get a prosthesis, bra, a swim suit. I just discovered there is Snell or whatever in Fayetteville, or otherwise it was the Women’s Pavilion in Rogers, and when you are working that is a long, and then they weren’t open on Saturdays. How are you supposed to get a bra? Take a day off and go. And after surgery. I didn’t know about it. There is a Liberator Medical that I started ordering from, a co-op, but you gotta get fit.

Screening and Outreach Services
Many of the participants rely on the county health units for primary care. Potential partnering with these county agencies could expand screening opportunities as well as outreach efforts.

The lady here, I had two appointments, and I could never remember to come in, and I had to cancel two times, and I found a knot and called up her and I needed a mammogram and that it was two and half weeks a month away, my daughter called and said that I found a knot and needed to get in before a month, and they got me in two weeks later and she got me set up to the cancer center in Fayetteville so the lady here that did the second exam and set me up to go the next day. I mean I went in there the next day. If it hadn’t been for her I would not have known who to go to.

Harrison
Good Health
The group discussed components of good health and how they related to current health concerns. They discussed the importance of eating healthy and exercising, but also what could go wrong if not being proactive.

Such as cancer, primarily. Heart problems. Anything, diabetes anything that could be detrimental to your health. I knew a lady that always said, I don’t think I have a 100 different things wrong with me, I think one thing wrong with me that has 100 different symptoms, and she was right. She ended up dying of a brain tumor.

I think of things that are passed down from generation to generation, so like what your mom had and your grandparents had, and you don’t know what is going to hit at any certain time.
I know, since my mom passed away, I haven’t been to the doctor since. It has been two years now. I haven’t been to any medical checkups. Haven’t done my mammogram yet. I haven’t done any of that yet.

**Access to Care**
The Harrison participants told stories as it related to their personal experiences within the culture of a small town and trying to receive the best health care possible. Many participants felt as if they were given mixed messages about their personal health.

The doctors are completely different here. So are the patients. You can go to the doctor’s office and just asking yes/no questions figure it out. Here they want to know what you had for breakfast and what you did yesterday, who you ran into last week, but not anything about what you are there for.

I don’t have a regular family physician, one of the things I have run into around here, a lot of doctors assume that you are an addict before you can present what is going on with you, and they present a cold shoulder and not want to help you. At one time, it was with one of my children because I thought they needed medical attention, and a lot of it just in the way, and in the result of people being dishonest making it harder on honest people. It comes down to good communication and honesty. I don’t know if it has to do with small town. But that could be everywhere.

Well there was that confusion two or so years ago when they decided you really don’t need those [mammograms] once a year, you only need a pelvic exam, and then I was confused. Then my OB/GYN said I didn’t need to do this on a yearly basis. All you hear is early detection if you don’t do the tests, and mixed messages are hard.

A difference of the doctors I see in [large city in the Southwest] than here, in [large city in the Southwest], he would say, who are you having sex with…he was really up front with it, and I was going through a divorce and he said, hey, how many partners do you have now. He would say it in a joking way, but he wanted to know. So that he could base his, and now here I think it is more touchy feely, now it’s why wouldn’t I? But the attitude here is different, conservative. I wish they wouldn’t do that. I grew up in a place that was very open. When I first started going to a clinic, it was a free clinic, they would ask you the most invasive questions, when I was 18 I wanted to know why they wanted to know that…all they ask for is honesty. Let’s deal with it.

**Screening and Outreach Services**
There seems to be a lack of trust with the medical providers of this community, and it has affected where participants seek out services. Additionally, participants felt like they had to personally go and research information.
I just don’t trust. I’ve seen mistakes, it is just a cold come back, and then it turns out horrible.

A lot of what I’ve seen, there is some dissention in the medical community. Not all of our doctors are Affiliated with the hospital. Doctors are affiliated with hospitals in other towns. Doctors here are affiliated with Washington Regional, and it is happening more and more.

*Jasper*
*Good Health*

Many of the participants were focused on issues related to post treatment, but others focused on current issues related to autoimmune disorders.

Mental health is important. Read the paper and keep up with the nightly news. Volunteer.

I have neuropathy in my hands from the chemo, so it’s like, I get cut on the hands I don’t know about it until they stop working. I drop a lot of stuff if I am not looking. I’ve gone through six glasses.

Peripheral neuropathy, but I had doctors tell me I had diabetes, and I don’t have diabetes, but it could be a side effect of chemo, if I stand too long or if I sit too long, I can turn to walk and the feeling is not there. So I have to be very careful.

I’m 32, I take about nine medications a day to walk. I am getting used to falling. I could only wish that I will make it to your ages. Being this age and going through it, and go through so much medication. I got to cut down on medication. I have fibro. Most people would be where I am at in their 50’s. One hip doesn’t work properly. Been through rounds and rounds of PT.

I’m 44 and I’ve been diagnosed with fibro, osteoarthritis, and degenerative disc disease, and a host of other things wrong with my spine and seems like a lot of this generation are getting more debilitating illnesses. I never heard my grandparents complain about not being able to get out of bed. So I don’t know if it is our environment or what we are eating, but they pushed so many pills to me I finally said stop. I started PT I’ve been to several specialists and they don’t know how to fix me. It has been so difficult I finally gave my notice at my job because it is so difficult to finish my day. I have enough energy to get here and get home.

*Access to Care*

There was a sense throughout the group barriers existed outside of living in a rural community. Inconsistent information from health providers, as well as general feelings of government mistrust, came out through this focus group.
The problem is they said that women don’t need them [mammograms] as often or as early now. But I think male doctors are buying into that, but the females are not they are still sending them every year. I have one friend that is 70 and her, and she was going to a male doctor and the female doctor is like oh no you still need to have mammograms. While the male doctor told her she didn’t need to. My sister sees a female doctor, and she said that she doesn’t care what they say. The female doctors are more pushy.

What is frustrating is those people you can’t help. You know that they are in those situations where they can’t get any type of help or they can be in the between the guidelines where their insurance is so expensive they can’t afford it. And they make too much for Medicaid or the private option. Those people fall through the cracks it’s just, I don’t think they fixed anything with the affordable health care because from my experience, from what I’ve seen, they’ve created a bigger problem. They’ve created a sucking hole that people that having to buy insurance, when it’s $900 a month for a family…they can’t afford that. So, they are stuck in a situation. And the people that couldn’t afford it before, I mean they are really…they will never be eligible for that. Komen has been great because there are people that have been in those situations where they don’t have insurance, can’t afford the insurance, or and then they or their insurance didn’t pay for those services, they have been able to pick them up.

I’ve had people tell me that, and I am like how do you not know. We are tucked away here. Our whole county is huge and if they don’t need those services they don’t come. And if they, we’ve added services over the years and they haven’t been good past of sharing that information outside of the Jasper area. I will be blunt that is a fact. I’ve found that since I’ve been here. I’ve worked in Boone County a couple of years, it’s almost like we are in a bubble and we haven’t reached out to other communities and considered them part of the county.

**Screening and Outreach Services**
The overall experience within the medical community was mixed for these participants. Many went through several physicians until they found someone they were comfortable with and would answer their questions.

I went to [teaching medical hospital in the South Central Region], and I saw Dr. XXX who to me is one of the finest breast cancer doctors I’ve ever met. But after the surgery I had to see another. You drive to their office to sit for xxx hours waiting for them to come in, but I can remember on two occasions having one question written on a piece of paper, and [they] walked in and said, don’t ask me a bunch of questions, I’m running late and I don’t have time, and [they] did [their] little thing and walked out the door and did not answer my question. My husband who was very upset by it told me do not go back to see [them]. I said, yes, I will go back to see [them]. [They] had been recommended, and so I figured [they] must good, and [they] was head of oncology at [teaching medical hospital in the South Central Region], and the second time I drove xxx hours and this is getting
up at xxx am and hitting the traffic at xxx in and I was at a point I would lay back in the car and cover my head because the traffic was just horrendous. And then sit there for another xxx hours. [They] walked in and said the same thing to me. And I said, you know what, I said I’ve given you two chances, I got up and drove xxx hours to get here and I sat xxx hours waiting to see you and you can’t give me an answer to one question? I quit seeing [them].

**Stone (MO) and Taney (MO) Counties**

**Branson #1**

**Good Health**

The survivor only group did not discuss much as related to good health, but focused more on the concerns related to being a breast cancer survivor. While they stressed the importance of early detection and staying on top of screenings, there were several expressing fear of finding additional cancers.

I’m very concerned about cancer. Having gone through breast cancer and when I finished the chemo on that, I had a colonoscopy and had a tumor on my colon. I’ve been through three melanomas. It just seems like it just keeps coming back. My maternal grandmother and my mother both had breast cancer. They both lived to a 100 before they died. My father’s father died of colon blockage and my father had colon cancer so that’s my biggest concern is cancer.

I could speak to that. They were saying on the television that possibly if the women don’t have no family history of breast cancer that they were maybe getting screenings too often and maybe should be going every two years. But I got a letter from a health care provider in Springfield telling me it was time to get my mammogram and I didn’t know family history of breast cancer but I went to the bus that came into Cedar Square and that’s how they found it. So if I went by what they were saying and just put it off no telling how large the cancer might have been or what I might have gone through because all I had to was 16 treatments of radiation and a lumpectomy and one lymph node taken out of my arm that was clear, so and by going so early when I had my lumpectomy I’m no different...in size. Didn’t have to go through getting extra special garments or anything just because they caught it so early. So I really recommend women get their mammograms every year.

I’ve ran into that when I first was diagnosed with the breast cancer. My friends, there was only two of them. One of them she did hers regularly every year. The other one went and got one. Everybody else said I’m too scared, I don’t want to know. And you can’t use me as an example because if you do it, you know, most likely you have nothing there.

I actually ran into an RN who works with breast cancer people every day for a surgeon and she waited. She found a tumor and she was so scared she waited
two months before she did anything about it. I just thought that was an amazing story. She works with that every day and she knew better she said that the fear just took over.

Access to Care

Financial barriers and general information about resources seemed to be central to the discussion related to access to care.

I can tell you it is an issue from personal experience. I got my mammograms right on time, on that sheet I put down 25-30 I couldn’t remember my first one until I was 51. I didn’t have insurance. I worked for a not for profit agency and we didn’t have it. So I would do my self-breast exams. In 2012 I got really sick with an infection. I had strep b and it went all though my body. While I was in the hospital they ran all kinds of tests and did get a mammogram there because they were just doing everything else and everything was good. That was in April of 2012. In May of 2013 I found the lump myself and so I started calling around because I knew. I knew what it was and I knew I was going to need help and I fell through every crack. I was too old for this, too young for this. Didn’t make enough money for this, made too much money for this. And finally I just threw caution to the wind and I said Lord it’s yours, I’m going. And I went and I got the exam in the office and of course they found the same thing I found and that was on a Wednesday or a Thursday and that following Monday I was at Hollister getting the ultrasound and they said yes, and set me up for the following Thursday for needle biopsy just boom, boom, boom. It was a stage two but it’s okay. As soon as they said stage two I’m getting a… double mastectomy I’m not going to play around with it. I applied for help and eventually I got help, but that had to be secondary to everything else and I would take care of the financial part of it later.

I listen to a lot of stories there isn’t a lot of help for people who can’t afford to get mammograms. You can get the mammogram, you know, but after that if they find something you’re up a creek. Medicaid is the only way to get it.

When she spoke to finances being the problem and stuff, well I have insurance and stuff but I know that when I did all my treatment I told you I stayed at the hospital they didn’t charge nothing to stay in those rooms at the hospital. And they even asked me if I needed help with buying my food, which I didn’t need no help but they offered. They also offered gas money because we lived in a 50 mile distance and like $50 for travel back and forth. They were just really bend over backwards to try to help you out.

Screening and Outreach Services

The group mainly concentrated on issues related to being a survivor, so information related to general information related to breast cancer education and awareness was connected to them
telling their story. The navigators contributed to them learning more about resources and general health information as well.

I spoke to Rotary yesterday about it and I tell people, I will put my big foot in the door any day any time, any place and advocate that you have to get a mammogram because my story is similar. I had not planned on getting a mammogram. I hadn’t had one in several years and I was so healthy and no history and I kind of tell people that God broke my rib and saved my life. I literally had pneumonia and coughed so hard I broke my rib and I went to see the nurse for my rib. She said while you are here we can also do a mammogram on you. It looks like you haven’t had one in several years. I said, I really don’t have time today and I have none from my sister and my mother and she said, XXX it doesn’t matter. I said, alright go ahead and do it and it was, of course like y’all know, if you have a mammogram and they do see something they call back, call back, call back.

One more thing I will say about the navigator, when it came time for me to go visit my surgeon the first time, which he came highly recommended from my nurses so I felt comfortable. She went with me and she sat in that room with me and I talked to him and I guess I should back up a little bit, I have to say when I was diagnosed, I never claimed cancer so I knew it was going to be okay. It was just a journey I was on. And so I was asking him the questions and then I got to a question that I knew he couldn’t answer so I asked him to leave the room and he did and I asked her, and my question to her was I want to have both of my breasts taken off. I don’t want to have that little devil sitting on this shoulder saying, I’m going to get the other one.

And I said will Medicaid pay for both and she said, yes it will. So she knew not only the medical answers, she knew the Medicaid answers, she knew everything. If there came a question she didn’t know, I had an answer within the day. And so I can’t praise the navigators enough.

Branson #2

Good Health

The mixed focus group was able to concentrate on more substantive issues related to health outside of survivorship, and presented a more balanced view of total health.

Aware of where your changes are coming from and what’s going on and what needs to be addressed and what normal aging stuff.

Being active and doing things that you want to do.

When I think of good health I also don’t think of the physical health, the emotional, the social, the spiritual all of what that encompasses good health.
Lack of awareness of personal health conditions. There are some people who have felt bad for so long. Some of them are just afraid to go to the doctor because they know something is wrong and they just don’t want to hear about it.

When you are trying to keep a roof over your head and keep your kids fed it is the last thing on the list and things have become so expensive. Nutrition and health wise and when you go to the store and you are on such a fixed income and prices of everything have just gone through the roof it’s like okay what do you scrimp on or where do you cut I don’t have to try to keep up with that.

Access to Care
Participants discussed the cultural aspects and how it affected access along with the traditional issues of financial and transportation barriers in addition to a general lack of knowledge.

I think also that you’ve got a problem with small town thinking. Anybody that’s lived in a big city has a different outlook. I refer to it as the real world. And it’s a whole total different outlook on everything.

Let me give you a specific for instance, this happened a number of years ago it’s relatively new to the community. We are seeing a general practitioner, kind of picked him out of the phone book. And I said oh by the way I have to buy new prosthetics. Where do I go? I’m new to town. And this man who had been and still is in practice in this community for more than 30 years said well I don’t have the slightest idea.

In the Ozarks, it is very traditional and everyone kind of has their families. The ones that, not the imports, the old families. They have their families, they stick to their families. There is not a whole lot of interaction.

We even found that with the tornado. They didn’t come looking for help. The only way they were found if we went door to door and found them ourselves. And said, we’ll help put your house back together if you need help, but they didn’t come looking for it.

The women who do hear about the breast cancer prevention services that are available have often told me, at least the ones that I serve, I don’t want to find out because if I find out I don’t have money, I don’t have insurance then I know there is something wrong and there is nothing I can do about it and I think that is a very real fear.

Screening and Outreach Services
The screening and outreach opportunities exist within this community, especially since culturally there is a lack of open dialogue about breast cancer.
Even then sometimes the mammography people can't come when we do it. We have one event where they were doing at least exams, physical exams and then making appointments for them when they sit there. This doesn't feel right, let's get you in and the women were not following up on the free appointment, so again.

Well, what we learned from that, because I volunteer there, what we learned from that was the follow-up appointment needs to happen that day because once we got to the appointment time and they're not in pain, then it wasn't an urgent matter. Like the dentist that comes to those events, if you're in pain with a tooth and they're saying yes that needs to come out and we can get you in tomorrow and pull it and your pain will be gone, then that works, so we're trying to figure out a way for the next one to have either transportation set-up to where at that moment we can bring them over here and have them do the test then, but that's got to be a coordinated effort and we're trying to figure out how to do that, but that's what happened with the mammography thing. It was a learning experience for us and we know now that yes, we can offer the breast exam, but if we are going to offer anything further we either have to transport them or we have to bring a mobile unit which I don't even know if Branson has one.

Well what's the normal lumps and what's not. It's not a big deal, it's not sexual, you've just got to know what you feel like.

And to show them. I mean to not be, I know it's become a little bit easier here lately because it's more out to actually lift your arm up and show a woman okay, this is where, you know. Check it. Be aware of what your body's doing. I did that after I had mine I had a friend who was a Girl Scout leader and she had me come in and talk to the Girl Scouts and you know what, I need to let these young girls know with their mommas and some of them with their daddies, stand up there in front of the room and say, be aware of what your body is about to go through major changes. Be aware of it, don't be-it's just you, it's not. Feel it. If something looks wrong, look in the mirror, if something looks wrong, ask mom. Don't be, it's not a shame thing. It shouldn't be a shame thing and there's still such a stigma to touching yourself.

**Reeds Spring**

**Good Health**

Ideas surrounding good health were on disease management whether it was BMI or managing pain. There was little discussion around health concerns other than heart disease and cancer, but those were mentioned in a categorical manner as something to worry about.

**Access to Care**

The answers related to access to care could be attributed to the socioeconomic status of the group. This group dealt with several barriers in trying to access basic care as well as misinformation.
I know used to, you could go to the health clinics and they would send you for a mammogram. That is what Butler County did for me. Now I went to the one here a couple of years ago and they said only if we feel like you need it. And I am 43, so that has been two years ago. I was like, really?

Because the one in Butler County, the doctor was all over that because my friend had been diagnosed with it. And she was 34, and I want to do this because I was 33ish. So, I went immediately and got one. They said you don't need one until you are over 40. So you are good.

I had a family history. After my son was born, my milk never dried so I still produce milk and I have no hormones. I did a full blown hysterectomy in March and they still can't, I'm still trying to produce. That is why I've done mammograms. They see stuff, but they don't see concern for anything.

You go by what your doctor tells you. And when a doctor tells you that you don't need it until you are 50 you think, ok.

**Screening and Outreach Services**
The community has activities that promote screenings and outreach, and these activities center around the church and the Curves fitness center. However, it seems there are limited activities related to breast cancer screening and outreach.

We had a lifeline screening and they set up in the church, but it was like $300 for the screenings they were doing, and we had a couple of ladies from the church call, but they didn't take their insurance it was cash, and I am like, they were so busy. How are these people paying for that? But it was all preventative screenings not sure what they were testing for. My aunt did it, and she said it was cheaper to do it there than to go to her doctor and do it there.

Curves really promotes breast cancer, getting your mammograms, and in October you can join without a service fee if you can provide proof of getting your mammogram.

**Hispanic Community in Washington, Benton, Sebastian, and Carroll Counties**

**Green Forest**

**Good Health**
It is important to note language barriers existed for this focus group, and so answers and examples will not be as descriptive as previous groups. However, the participants did contribute thoughtful answers and contributed new knowledge about the topical area. For good health, they were concerned about watching weight and exercising. One participant was diagnosed with bone cancer, and shared experiencing managing the disease.
Ah, I think you have to keep yourself healthy. Like if you have children, you have to be able to provide and look out for them. Therefore, you have to take care of yourself.

I got bone cancer. And it's, I think about it every day. Night, morning. Look at the babies wondering if you are still goin' to be here with them. It's tough.

Access to Care
Some of the barriers to access were similar to other groups with finances, transportation, and lack of information (fear). However, legal status as a barrier emerged out of this focus group discussion, as well as language abilities.

Because, for example, right now, um, my first mammogram was ok. But the second time after I get pregnant, um, I breastfeeding my daughter. They found something on my breast and I am so afraid of it. And um, but what they told me is was that my breast tissue [participant had to ask in Spanish what words to substitute] so heavy. And uh, that is what they find out, and now I have to go and see a better, uh, get a better mammogram. I'm on that way.

We are only talking about the people that work at Tyson, but there are other people out there that are not working and are not legal. They don't have what we have at work, and there is a lot, a lot of people who don't have the insurance.

I think now a lot of the clinics have Spanish speaking workers, but a lot of them still don't and if they don't have someone there to translate, right, then they don't go. Or they can't take someone to help them, then they are going to be blamed because they can't understand. That is a lot of the problem.

We need a lot of communication in Spanish.

Screening and Outreach Services
Dual language outreach materials are a must in reaching this population. Being cognizant of work and family time is also important in planning activities.

First of all, if they need to be paperwork, then it needs to be in Spanish because there are lots of Hispanics that don’t read English, and you know, they pick up the paper and don’t know what it is. We work on the weekends. But, there are a lot of times when you get off and you go by Walmart so you see the fair anyways. Ok. I think that would be good. There are constant people at Walmart.

That would be a good idea, where the health department would have a health fair for the whole community. If there are more of the health fairs, then there is more information and it would be constantly on their minds.
**Springdale**
*Good Health*

This focus group was facilitated by a native Spanish speaker, and was transcribed by the facilitator. Most ideas were presented in short sentences or phrases. In general, the women discussed mind/body concerns such as sleeping well, avoiding depression, and controlling mood. They also discussed concerns with cost as being a factor when thinking about personal health care. Concerns related to health were around weight gain, asthma, and depression.

**Access to Care**
The participants’ access to care is mostly low income/free access programs within their community. The Community Clinic, health department, Komen, and Breast Care programs were mentioned as programs that expand access to care. Not having insurance was a major barrier for them in addition to transportation. Fear is prevalent, and one participant stated “every time I go to the doctor I get worse.” Participants rely on public transportation to take them to various appointments, but lack specific information about routes/times/prices.

**Screening and Outreach Services**
The informal network existing in their community provided most of the information discussed in the focus group. It was noted that more programs are needed within their community. Participants also wanted physicians to be reassuring to patients, and to help with dissipating fear.

**Fort Smith**
*Good Health*

While there were only three participants to this group, the information relayed corresponded with what other focus groups within this priority area were saying in relation to the topical areas.

Because I’ve learned a lot now that I’ve gotten into a lot more fitness, doing the Zumba and stuff. Before, even though I’ve always been an athletic person, was in gymnastics in high school and junior high, running and everything, but I never really paid that much attention to the nutrition part of it and how both of them you definitely have to maintain both, you know, to be able to be a healthier person. Definitely that would be what comes to mind for me.

Take care of your body so it takes care of you, take care of yourself.

**Access to Care**
Cultural barriers, in addition to financial, emerged as main barriers to access care. The lack of general knowledge seemed tied to language issues as well.

Yeah, because we dealt with our parents’ health a lot. I go to all my parents’ appointments with them and I had to share the importance with my mom of how a pap smear, a yearly pap smear, was important for her and, you know, I was
doing it more than she was because she was embarrassed. And it was just her generation was like you just don't do that unless you absolutely have to and I told her, I said, if I wouldn't have done that, if I wouldn't have found what I found in me. It could have been worse for me if I wouldn't have done that since my younger years. So, you know, she could not understand in my early twenties, why on earth are going to a gynecologist! (Laughs) Because! One, my insurance paid and I wasn't feeling right and I knew something was wrong and it took them many years to finally figure it out but, yeah. You know, so, it's definitely, I think, a, education is a big, big part of our community that we need to work harder at trying to get them to understand the importance of it.

Definitely language because if you don't have translator with you or someone that is...

It's sometimes on behalf of those moms take their younger kids to translate.

And you have 10, 12 year old kids that really don't understand what they're translating, so they're really not translating to the extent that it needs to be.

**Screening and Outreach Services**

Other than my mother and I go to our family physician who is Hispanic, she does, I know, have a lot of Hispanic patients, clients, and I know she does try to make that awareness to her own patients and stuff. Basically, with word on us, I try to make that an importance, that and going to get a pap smear to a lot of women just when going into a conversation. As far as really going out there to inform them, I really don't, I'm not aware of it. There could be but I'm not aware of it.

I would say, kind of like how we do in our environment, I'm going to say English speaking, you know we do a lot of promoting and stuff. I think we need to really promote it more in the Hispanic community than what it is and I would say in the newspapers, in the church.

Give them enough information to where they understand that they have to get that done and how to at least help detect it by doing your self-examinations and stuff.

**Provider Survey**

The respondents were majority female (n=11), and most had 20+ years of experience (n=7). Further, their roles were more spread out with office assistant/office manager (n=4), nurse (n=3), and other (n=3) being the top choices for provider role. The organizations in which they were employed ranged from private practice to nonprofit organizations. Only one respondent replied that their practice did not make available breast health education materials, and only three stated there was a formal practice policy of discussing breast health with patients. For the most part, the guidelines for mammograms of average risk responses were in line with every
year starting at 40 years of age. Of the most salient questions of this survey, the answers were specific for their practice, and would be limited in creating an overall aggregate due to the low response. However, the last question asking about what factors prevent the women you service from seeking breast health services correlates with the focus group efforts. Many of the answers providers gave could be found in the vignettes taken from the various focus groups. Transportation issues, financial concerns coupled with a lack of insurance, as well as general misinformation were main answers from the providers. Additionally, as the Affiliate found in the Hispanic/Latina community focus groups, language and cultural barriers exist preventing individuals from receiving recommended screenings and follow-up care.

Limitations of the Qualitative Data
First, the participants were not selected randomly, but rather through a community contact that had some type of connection to them. Participants’ responses to questions may have been influenced by their connection to the community contact and the social desirability of a particular answer for Komen. The evaluation did not take into account other factors such as how survivorship could have influenced the discussion within the focus group. Time limitations for the focus groups as well as group dynamics may have restricted responses. The evaluation is limited to the researcher’s analysis, and as such, the findings could be subject to further interpretation. Lastly, the findings are limited to selected volunteers who chose to participate in the evaluation.

Conclusions
The questions developed for the qualitative study are directly linked to the findings from the quantitative and public policy analysis. The target areas were found to be dealing with a higher number of deaths from cancer in addition to late-stage diagnosis. Further, because of geographic barriers, the access to health care is limited for this population. Last, the analysis indicated there was inconsistent resources and information in these communities. Outreach is necessary to assist in ameliorating the barriers existing for women in the target areas. Getting information about financial resources and screening services to key community leaders could help women in being diagnosed earlier and getting treatment. Overall, the qualitative findings validated the previous analysis regarding public policy and health statistics.
Breast Health and Breast Cancer Findings of the Target Communities

Quantitative Data Report Summary
The Community Profile Quantitative data reflects the disparities in breast health services with regard to screening percentages, late-stage diagnosis and death rates in the Affiliate service area. Reviewing and analyzing the quantitative data allowed the Affiliate the ability to identify priority action items most applicable for the five county and Hispanic/Latina service areas.

In order to develop effective, targeted breast cancer programs, Komen Ozark chose six target communities within the ten county service area. Healthy People 2020 (HP2020) objectives for breast cancer incidence, deaths and survival were used to assess and analyze the communities of highest need. Additional indicators included; demographic data, medically underserved areas, population data, linguistically isolated communities, lack of health insurance, unemployment percentages, income levels and other vital statistics. Upon analysis of the statistics from the Quantitative Data Report, Komen Ozark identified and selected six communities of focus: Boone, Madison and Newton Counties in Arkansas; Stone and Taney Counties in Missouri and the Hispanic/Latina population in Benton, Carroll, Sebastian and Washington Counties in Arkansas.

Health Systems and Public Policy Analysis Summary
The analysis of health systems and public policy revealed disparities in the breast health continuum of care model in the selected target communities. In the target counties, there is a lack of medical services and access to breast health screening, diagnostic and treatment services. In Madison and Newton Counties, the only breast health screening that is available to patients are for clinical breast exams. There is no access to screening or diagnostic mammograms other than what the mobile unit offers. In Stone and Taney counties, there is no mobile unit in the area.

The Affiliate service area’s three selected target communities all have a need for transportation, whether it is public transportation, transportation to breast cancer screenings, access to a mobile unit or transportation to and from breast cancer treatment. There needs to be a focus on providing services, especially follow-up care, to the Hispanic/Latina community. Offering bilingual navigators and staff, translated materials and culturally competent practices is a need that has been identified through the Health Systems Analysis. Education also been identified. Support/Survivorship is also lacking in many of the selected target communities as well.

The importance of the Affordable Care Act and the state of Arkansas adopting a private option has made access to health care more attainable; however there are still disparities in the accessibility of the various health insurance programs. Factors like understanding options in insurance levels, English as second language, health literacy, lack of transportation, etc. all lead to a barrier in care. Komen Ozark will continue to support the state of Arkansas to continue the private option and Medicaid coverage to low-income adults. The Affiliate will also continue to educate on the importance for legislative support to keep state programs like Arkansas BreastCare and Show Me Healthy Women funded.
Qualitative Data Findings Summary
The Community Profile Team utilized focus groups and provider surveys to explore issues affecting women’s breast health in the identified target communities. Overall perceptions of general health, access to care and factors for increasing opportunities for screening and general outreach were examined utilizing focus groups and survey data. The questions developed for the qualitative study were directly linked to the findings from the quantitative and public policy analysis. The target areas were found to be dealing with a higher number of deaths from cancer in addition to late-stage diagnosis. Further, because of geographic barriers, the access to health care is limited for this population. Last, the analysis indicated there was inconsistent resources and information in these communities. Outreach is necessary to assist in ameliorating the barriers existing for women in the target areas. Many participants told stories related to their personal experiences within the culture of a small town and trying to receive the best health care possible. Many participants felt as if they were given mixed messages about their personal health. Whether it was misinformation, lack of transportation or financial resources, these barriers created confusion for participants. Additionally, cultural issues surrounding the rural areas contributed to barriers related to care. Getting information about financial resources and screening services to key community leaders could help women in being diagnosed earlier and getting treatment.

Mission Action Plan
The Community Profile data allowed the Affiliate the ability to identify priority action items most appropriate for the six target communities. Based on further data analysis, the Affiliate will continue to focus on outreach efforts targeting low socioeconomic status rural women and the Hispanic/Latina service area. The data confirmed these women are least informed about breast health and face more barriers to care.

Once the Community Profile Team reviewed the findings from the Quantitative Data Report, Health Systems and Public Policy Analysis and the Qualitative Data Report, problem statements, priorities and objectives were created. Many individuals outside of the Community Profile Team were consulted and the Mission Action Plan was presented to the Komen Ozark Board of Directors for approval.

Problem Statement: The Community Profile Team reviewed the findings from the data and has determined that Boone, Madison and Newton Counties in Arkansas have a low understanding of the availability for screening services and knowledge of breast health.

Priority: Increase understanding of topics centered on availability of breast health and screening services.

- **Objective 1:** By October 2016, implement the Worship in Pink program in at least one church in Boone, Madison and Newton counties.
- **Objective 2:** By October 2016, develop, implement and evaluate three workshops on breast health aimed at women organizations in Boone, Madison and Newton
counties. The Affiliate will use a pre and post questionnaire to measure understanding of breast health and available screening services.

- **Objective 3:** By December 2016, visit with two providers in Boone, Madison and Newton Counties to discuss client motivation intervention in order to increase screening percentages overall by five percent.

**Problem Statement:** According to the information learned from the focus groups with Hispanic/Latina population in Benton, Carroll, Sebastian and Washington Counties in Arkansas face more barriers to care access and need culturally competent information about breast health.

**Priority:** Partner with community-based outreach/health organizations to effectively promote breast health education and services including breaking down cultural and language barriers for Hispanic/Latina women.

- **Objective 1:** By June 2016, partner with community-based health organizations to arrange small group education classes on breast self-awareness in at least four clinics serving Hispanic/Latina women.
- **Objective 2:** By June 2016, reach out to at least three predominantly-Hispanic/Latino schools and/or faith-based organizations in the service area counties to hold breast cancer community outreach presentations.
- **Objective 3:** For FY 2016, boost funding to patient navigator programs aimed specifically at working with Hispanic/Latina residents in the Benton, Carroll, Sebastian and Washington counties.
- **Objective 4:** By August 2016, meet with at least three community organizations and/or faith communities that work with the Hispanic/Latina community to discuss breast health outreach.
- **Objective 5:** By August 2017, partner with at least one organization and a health care institution to provide a culturally appropriate breast health event where women age 40+ can sign up for a mammography appointment. Breast self-awareness materials in Spanish will also be distributed.

**Problem Statement:** The Community Profile Team reviewed the findings from the data and has determined that in Stone and Taney, Missouri there is a shortage of health services and providers.

**Priority:** Increase the number of health services and providers by funding health system partnerships to increase access to services.

- **Objective 1:** By May 2016, hold at least two meetings with breast health providers to discuss the availability of grant funding.
- **Objective 2:** By December 2016, visit with two providers in Stone and Taney Counties to discuss client motivation intervention to increase screening percentages overall by five percent.
**Priority:** Increase understanding of topics centered on survivorship knowledge.

- **Objective 1:** By December 2016, collaborate with local providers and community partners to coordinate and sponsor a survivorship conference.
- **Objective 2:** By December 2016, implement quarterly webinars addressing survivorship topics with a pre and post questionnaire to measure increased knowledge.

**Problem Statement:** The Community Profile Team reviewed the findings from the data and has determined that there is a lack of knowledge about breast health by public policy decision makers.

**Priority:** Increase state legislators’ education and understanding of breast health issues.

- **Objective 1:** In FY 2016, hold quarterly conference calls with the two other Komen Affiliates in Arkansas to discuss joint public policy efforts and any pending breast cancer legislation, including advocating for maintaining state Breast and Cervical Cancer Program (BCCP) funding.
- **Objective 2:** In FY 2017, conduct a bi-annual mailing to all legislators to increase Komen’s visibility as a trusted local resource on breast cancer.

**Priority:** Develop and utilize partnerships to enhance Affiliate public policy efforts in order to improve breast health outcomes of women in the Affiliate service area.

- **Objective 1:** By December 2015, identify and train at least six key volunteers to serve on the public policy committee to carry out the Affiliate public policy efforts.
- **Objective 2:** In FY16 and FY17, partner with at least one other Affiliate within Arkansas on advocacy and public policy efforts.

**Problem Statement:** The Community Profile Team reviewed the findings from the data and determined that Affiliate-wide there is a need to improve the quality of life for survivors as they transition from treatment to recover.

**Priority:** Increase understanding of topics centered on survivorship knowledge.

- **Objective 1:** By December 2016, collaborate with local providers and community partners to coordinate and sponsor a conference focusing on survivorship.
- **Objective 2:** By December 2016, implement quarterly webinars addressing survivorship topics with a pre and post questionnaire to measure increased knowledge.

APPENDIX A. Focus Group Questions

**General Health**

*Guiding Question*
What factors do low income women consider when thinking about personal health care?
- When you think about “good health” what comes to mind?
- What kinds of health problems are of greatest concern to you?
- How do you feel about catching health problems early?
- What is your source for health information?

**Access to Care**

*Guiding Question*
What factors are impacting accessibility to (preventive/diagnostic/active treatment/post-treatment/follow-up) care in the community?
- Do you know about available services for breast health and/or breast cancer?
- For women like yourself, what makes it difficult for you to seek clinical examination/mammography screening services?
- What do you think are the greatest barriers preventing women from seeking or getting breast cancer screening in your community?
- How far are you willing to travel for care?
- How do treatment costs influence health care decisions?

**Breast Cancer—Screening/Prevention Outreach**

*Guiding Question*
What factors increase educational opportunities within these selected communities?
- What is being done in your community to get breast cancer messages to women? *Is it working?*
- Where do most women in this community get health information?
- Who are the most creditable people that provide breast health information in this community?
- What can local providers do to encourage women to seek breast health services?

*Overall Question*
- What is the most important message you would send to breast cancer treatment providers?
APPENDIX B. Consent Form

Focus Group Participant Consent Form
Susan G. Komen Ozark

I understand that I was invited to participate in a focus group being conducted by Susan G. Komen Ozark. By conducting this focus group, the Affiliate assess what barriers and resources exist in the 10 county service area specifically related to breast health. I understand that I am being asked to take part because I fit the eligibility criteria.

A focus group is a discussion between 6-12 people. The facilitator will ask a few questions to gain understanding about a topic and then ask my thoughts and opinions on the topic. The discussion will last approximately 1.5 hours.

I understand that I do not have to participate in this focus group and can choose to leave at any time. My participation is voluntary, and I may change my mind at any time. There will be no penalty if I decide not to participate, nor if I start to participate and decide to stop early. I understand that my participation in the focus group will in no way affect any current or future assistance from Susan G. Komen Ozark.

I understand that all information obtained from the focus group will be kept strictly anonymous. All participants will be asked not to disclose anything said within the focus group discussion. All identifying information will be removed from the collected materials. In addition, all materials will be stored in a locked office on the University of Arkansas campus.

I understand that there are no physical risks to participating in this focus group, but I might not be completely comfortable answering some of the questions being asked. I understand that I am free not to answer any of the questions asked.

I also understand that my words may be quoted directly. With regards to being quoted, I have put my initials next to the following statement that I agree with:

_____ I agree to be quoted directly if my name is not published (I remain anonymous).
_____ I agree to be quoted directly if a made-up name is used.
Please use this name: ________________________
_____ I do not want my words quoted directly.

By signing this consent form, I indicate that I fully understand the above information and I agree to participate in the focus group.

_________________________ ____________________________ ____________
Participant Printed Name  Participant Signature   Date
**APPENDIX C.** Demographic Information Sheet

**Focus Group Participant Demographic Form**

- Please select **one of the choices** below that best represents your current age:
  
  [ ] 39 years of age and younger
  [ ] 40-49 years of age
  [ ] 50-59 years of age
  [ ] 60 years of age and older

- County/Zip Code of Residence: ____________

- Have you ever had a mammogram?  
  [ ] Yes  [ ] No

  a. If yes, at what age did you have your first mammogram? ___________years

  b. How long has it been since you had your last mammogram? **Please check one.**
     
     [ ] Within the past year (anytime less than 12 months ago)
     [ ] Within the past two years (one year but less than two years ago)
     [ ] Within the past three years (two years but less than three years ago)
     [ ] Within the past five years (three years but less than five years ago)
     [ ] 5 or more years ago
     [ ] Don't know or not sure

- Have you ever been diagnosed with breast cancer?  
  [ ] Yes  [ ] No

  a. If yes, at what age were you diagnosed? ___________years

  b. What stage of breast cancer were you diagnosed with? **Please check one.**
     
     [ ] Stage 1  [ ] Stage 2  [ ] Stage 3  [ ] Stage 4

- Has anyone else related to you been diagnosed with breast cancer? **Please check all that apply.**
  
  [ ] Grandmother  [ ] Mother  [ ] Sister  [ ] Daughter

- Currently, at what age is it recommended for women to have a mammogram once a year?

  **Please check one.**
  
  [ ] 30  [ ] 40  [ ] 50  [ ] 60
What is your primary occupation? Please check one.

- Homemaking
- Computer/Office
- Sales
- Daycare
- Beautician/Salon
- Health care- clinical
- Social Work
- Housekeeping Services
- Health care- non-clinical
- Education
- Other (please list):

What is the highest degree or level of school that you have completed? Please check one.

- Did not graduate high school
- High school graduate/GED
- Vocational certification
- Some college credit, but less than one year
- One or more years of college credit, no degree
- Associate’s degree
- Bachelor’s degree
- Master’s degree
- Professional/Doctorate degree

What language do you most frequently use in writing? _______________________

What language do you most frequently use in speaking? _______________________

What is your Race? Please check all that apply.

- White
- Black or African-American
- American Indian or Alaska Native
- Asian (e.g. Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese)
- Native Hawaiian or Other Pacific Islander (e.g. Native Hawaiian, Guamanian/Chamorro, Samoan)
- Other (please write your race): _______________________

Are you of Hispanic, Latino/a or Spanish origin? Please check all that apply.

- No, not of Hispanic, Latino/a, or Spanish origin
- Yes, Mexican, Mexican-American, Chicano/a
  - Yes, Puerto Rican
- Yes, Cuban
- Yes, another Hispanic, Latino/a, or Spanish origin
- Yes, other (please write your origin): _______________________

Where do you receive your health information? Please check all that apply.

- Church
- Mail delivered to your home
- Shopping
- Television
- Radio
- Newspapers
- Internet
- Social Media (e.g. Facebook, twitter)
- Word of mouth
  (From whom or where: _______________________)
• Where or how do you receive community/social information on events?

• What is your household income in (insert year)? Please check one.
  ____ Less than $10,000
  ____ $10,001- $20,000
  ____ $20,001-$30,000
  ____ $30,001-$40,000
  ____ $40,001-$50,000
  ____ More than $50,000
  ____ Don’t know/Not sure
  ____ Would prefer not to disclose

• If you received treatment for breast cancer, how was your treatment paid for? Please check all that apply.
  ____ Private insurance
  ____ Nonprofit assistance grant
  ____ Medicaid/Medicare/Government Assistance
  ____ Self-pay
  ____ Don’t know/Not sure
  ____ Would prefer not to disclose

• Do you have one person you think of as your personal doctor or health care provider?
  ____ Yes, only one
  ____ Yes, More than one
  ____ No

• Was there a time in the past 12 months when you needed to see a doctor, but could not because of cost?
  ____ Yes, only one
  ____ Yes, more than once
  ____ No

---

i Member checks are generally used to improve internal validity of a research project. The researcher verifies the findings, themes found in the interviews, with the participants. This technique can prevent personal bias from the researcher to be included in the report.

ii Inter-rater reliability is a method of checking reliability, and is used to check the consistency between different raters observing the same phenomenon.