



## Susan G. Komen® Knoxville

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# Executive Summary

## Introduction to the Community Profile Report

Susan G. Komen® Knoxville began with a promise of one woman: Renee J. Repka. During the years of watching her mother, Beatrice, battle breast cancer, Renee began participating in races around the country. She witnessed the power of one other woman, Nancy Goodman Brinker, in making a difference in the lives of women diagnosed with breast cancer. Sadly, while Renee was completing her coursework for a doctorate in clinical psychology at the University of Tennessee-Knoxville, Beatrice Repka passed away.

Fueled by grief and the need to “do something,” Renee took charge and convinced a group of her friends and colleagues to “bring Race for the Cure®” to Knoxville. Their first Race was held on September 27, 1997, at World’s Fair Park with a 5K run/walk for women only and a one mile co-ed fun run/walk. One thousand participants were expected; 2,038 showed up and Komen Knoxville Race for the Cure was off and (literally) running!

After two successful Races, the volunteer group applied to Komen’s Headquarters in Dallas for Affiliate status. On November 12, 1999, the Knoxville Affiliate of Susan G. Komen Breast Cancer Foundation, Inc. was incorporated as a 501c3 nonprofit.

Today, Susan G. Komen Knoxville continues to provide breast health education and funding for screening and patient support. Its first Community Grants Program began in 1998, awarding a total of \$100,000 to five organizations. Since then, the Affiliate has awarded over \$6.6 million dollars to the East Tennessee community and has funded over \$2.3 million dollars to breast cancer research.

Through the years, Komen Knoxville employees have served on various Komen Headquarters’ committees including: the inaugural Affiliate Leadership Council, the Komen Headquarters Scholarship Committee, the Incentive Prize Task Force, and the Corporate Partnership Task Force. In addition, Komen Knoxville was invited to participate in the “Komen on the Go” pilot program and participate in a panel discussion “Community Health Programs Have the Biggest Impact” at the 2014 Susan G. Komen Leadership Conference.

In 2014, Komen Knoxville was awarded a two-year national Walgreen’s grant to implement a Rural Ambassador Education Program. The program is designed to engage local volunteers in four rural counties to promote breast health education within their communities.

Komen Knoxville serves 16 counties in East Tennessee: Anderson, Blount, Campbell, Claiborne, Cocke, Grainger, Hamblen, Jefferson, Knox, Loudon, Monroe, Morgan, Roane, Sevier, Scott, and Union. While four are considered urban, 12 of the 16 counties are considered rural and medically underserved.

The female population of the service area is approximately 591,862. Tables 1 and 2 display key population demographics and characteristics.

**Table 1. Service Area Demographics**

Population Group	White	Black/ African-American	AIAN*	API**	Hispanic/ Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
Komen Knoxville’s Service Area	93.0%	5.2%	0.4%	1.3%	3.2%	52.3%	38.4%	17.2%

\*AIAN – American Indians and Alaska Natives;

\*\*API – Asians and Pacific Islanders

**Table 2. Service Area Characteristics**

Population Group	Less than HS Education	Income <100% Poverty	Income <250% Poverty (Age 40-64)	Un-employed	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age 40-64)
Komen Knoxville's Service Area	17.2%	16.1%	39.5%	8.4%	37.5%	47.0%	17.1%

**Table 3. Breast Cancer Statistics**

Population Group	# of Deaths (Annual Average)	Age-Adjusted Death Rate/100,000	# of New Late-Stage Cases (Annual Average)	Age-Adjusted Late-Stage Rate/100,000
Komen Knoxville's Service Area	164	21.5	306	42.6
US	40,736	22.6	64,590	43.8

The Purpose of the Community Profile Report is to:

- Align the Affiliate's strategic and operational plans
- Drive inclusion efforts in the Affiliate community
- Drive public policy efforts
- Establish focused granting priorities
- Establish focused education needs
- Establish directions for marketing and outreach
- Strengthen sponsorship efforts

The Community Profile is the Affiliate's main mission communication tool and will be used to educate and inform stakeholders regarding the state of breast cancer in the service area, the Affiliate's current mission priorities, and the plan to address the identified breast health and breast cancer needs within the target communities.

### **Quantitative Data: Measuring Breast Cancer Impact in Local Communities**

The purpose of the quantitative data report (QDR) for Susan G. Komen Knoxville is to combine evidence from 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 mortality (<http://www.healthypeople.gov/2020/default.aspx>).

Susan G. Komen Knoxville has selected four target communities within the service area to be the focus of strategic intervention over the next three years. Target communities were identified based on the data provided from the QDR; no additional quantitative data exploration was conducted. The Affiliate took all indicators into consideration when selecting target communities, but gave specific attention to how communities lined up with the Healthy People 2020 Objectives. Healthy People 2020 (HP2020) sets national, evidence-based goals to improve the health of Americans. Released in 2010, these objectives are aggressive but attainable with appropriate intervention within the 10-year period. Two objectives are specifically related to improvements in breast cancer outcomes: first, to reduce the female breast cancer death rate by 10 percent (From 23.0 deaths per 100,000 to 20.6), and second, to reduce cases of late-stage female breast cancer from

43.2 per 100,000 to 41.0. Given that these objectives are consistent with Susan G. Komen's mission "to save lives and end breast cancer forever," they served as the basis for selecting priority counties.

Additional indicators the Affiliate reviewed included:

- Incidence rates and trends
- Below average screening rates
- Population and race distribution

Given the discrepancies among researchers on how socioeconomic factors affect breast cancer screening and survival, those indicators were given secondary consideration. Qualitative data and health systems analysis were used to further investigate issues such as education, income, health insurance, and access to care within the service area.

The selected target communities are:

- Claiborne County
- Roane County
- Union County
- Morgan County

**Claiborne County** was identified as the highest priority in terms of Affiliate intervention based on its predicted time to achieve the HP2020 breast cancer targets. It is predicted that it will take 13 years or longer for Claiborne County to achieve each of the goals, meaning they are unlikely to meet the HP2020 deadline. Other data from the QDR confirmed their risk. Claiborne County incidence rates are around 117.2 per 100,000 females, which is lower than the US and state average, but death rate and late-stage diagnosis rates are remarkably higher (28.0 and 49.6, respectively). Claiborne was also one of the few counties predicted to show an increasing trend in late-stage rates, something that is alarming. The Affiliate assumes that given these statistics a below average incidence rate is more reflective of gaps in the continuum of care and not a result of fewer women actually being diagnosed. Claiborne County also has a lower percentage of women with self-reported screening mammograms in the last two years at 61.8 percent (although, it was noted the small sample size of only 11 women interviewed).

Claiborne County was also selected on the basis of its socioeconomic characteristics: 29.3 percent of the population has less than a high school education, 22.6 percent has income below 100 percent of the poverty level, and 51.9 percent below 250 percent, (all of which are greatly above the Tennessee and Komen Knoxville service area average). Data also show that 71.6 percent of the population lives in rural areas and 100 percent are in areas considered medically underserved. These are two indicators that can significantly affect access to care.

**Roane County** was also ranked as a high priority for Affiliate intervention. It is predicted it will take the county 13 years or more to achieve both Healthy People 2020 breast cancer targets - female breast cancer death rate as well as female breast cancer late-stage incidence rate. While not one of the HP2020 targets, Roane County's incidence rate was also of concern at 128.9 with a 3.3 percent increase trending annually. Roane County also appears to have an older female population as compared to the Affiliate service area average. Given that the two main risk factors for developing breast cancer are being female and getting older, this certainly could contribute to the population's risk. Roane County also has 51 percent of its population living in rural areas and 100 percent of the population living in areas that are medically underserved.

**Union County** was the third and final county to be identified as a high priority for Affiliate interventions. It is predicted that it will take 13 years or longer to achieve the late-stage incidence target. Data needed to predict the length of time to achieve the death rate target were suppressed due to small numbers (having 15 cases or fewer for the five-year data period). Union County has the smallest female population of any county in the service area, with a female population of 9,585. However, data available on late-stage diagnosis is alarming

with an age-adjusted rate of 55.1 per 100,000 and an increasing trend of 13.1 percent, the largest increase of any county. Union County is similar to Claiborne in that it has a seemingly low incidence rate as well as a low self-reported screening rate at 54.8 percent. However, it should be noted that this data is subject to error due to the small sample size and large confidence interval.

Union County was also similar to Claiborne County in that it had a number of concerning socioeconomic indicators, including 30 percent having less than a high school education, 21.8 percent of the population living below 100 percent of the poverty level and 55.1 percent living below 250 percent. 100 percent of the population lives in rural, medically underserved areas.

**Morgan County** was ranked as Medium-Low Priority for Affiliate intervention. However, the Affiliate has decided to include it as a target due to the lack of data available regarding death rate trends. Data show that Morgan has the highest age-adjusted death rate in the service area (40.1), but trending data is not available, resulting in no prediction for how long it may take to achieve the HP2020 goal. The death rate is significantly higher in Morgan County compared to the Affiliate service area as a whole, which is of concern. The age-adjusted rate for late-stage diagnosis is also the highest in the service area, but with an optimistic downward trend of 19.6 percent annually. This corresponds to a predicted time of two years to meet the Healthy People 2020 target for late-stage incidence. Morgan County has a similar female population size as that of Union County, so data may be limited to a smaller sample size. Data are unavailable due to small numbers for self-reported mammogram screening.

As with the previous counties, Morgan County has undesirable socioeconomic indicators; specifically, having 99.9 percent of the population living in rural areas and 100 percent in medically underserved areas. As aforementioned, there is some debate as to which population indicators increase breast cancer susceptibility and at what point. However, research around women in rural areas has been more definitive in showing that even when adjusting for factors including education, income, and race/ethnicity, timely mammography was still significantly lower in rural areas compared to urban (Doescher, 2008).

**Table 4.** Summary of target counties incidence, death, and late-stage diagnosis rates compared to US and Komen Knoxville Service Area rates and Healthy People 2020 targets

<b>Target Communities Incidence, Death, and Late-Stage Diagnosis Rates</b>			
<b>Population Group</b>	<b>Age-Adjusted Incidence Rate/100,000</b>	<b>Age-Adjusted Death Rate/ 100,000</b>	<b>Age-Adjusted Late-stage Rate/100,000</b>
US	122.1	22.6	43.8
Komen Knoxville Service Area	119.2	21.5	42.6
Claiborne	117.2	28.0	49.6
Roane	128.9	23.2	43.4
Union	111.1	SN	55.1
Morgan	125.2	40.1	55.6
<i>Healthy People 2020 Target</i>	<i>NA</i>	<i>20.6</i>	<i>41.0</i>



## **Health System and Public Policy Analysis**

The Health System Analysis (HSA) was completed first by listing known organizations in the priority counties (grantees, sponsors, major hospitals, health departments, etc.). Next, a web search was conducted to add additional programs and services. Food and Drug Administration (FDA), National Association of County and City Health Officials (NACCHO), and Health Resources and Services Administration (HRSA) websites were utilized for mammography facilities, local health departments, and community health centers, respectively. Follow-up phone calls were used to confirm contact information and services provided. Once the HSA template was complete, services were compared within the continuum of care to notice major gaps in services.

The Health System's Analysis (HSA) revealed that there are major gaps in access to care within the target communities. While there are several screening facilities in each county, the vast majority of them only performs clinical breast exams (with the exception of the mobile mammography unit) and must refer patients to neighboring counties for additional screening. A clinical breast exam is a vital part of the screening process but leaves those needing additional services in a bind. For example, in Union County, the mobile unit serves as the only access to screening mammograms, and it does not have the capability to screen women that present with a problem. Neither Union nor Morgan County has diagnostic or treatment services available, creating a barrier for individuals that require these services. While Claiborne County and Roane County both have hospitals, only Claiborne County offers full diagnostic and treatment services at its hospital. Residents of the other three counties must travel across county lines to access appropriate breast screening (mammography/ultrasound) and treatment services. The presence of a mobile mammography program serving all four counties does allow some women easier access to regular screening.

While Komen Knoxville funds screening services through local health departments in each of these counties, along with a mobile mammography unit, residents are often unaware that assistance is available. Their rural location also excludes them from many survivorship/support activities, given the burden of the drive. Patients often acquire financial assistance for expenses during treatment but are unable to participate in support groups or other survivorship activities that can be so encouraging.

The NBCCEDP (National Breast and Cervical Cancer Early Detection Program) continues to be a major strength in the state of Tennessee. The Tennessee Breast and Cervical Cancer Early Detection Program (TBCCEDP) receives over \$2 million in federal funding annually to offer screening to lower income uninsured or underinsured women in Tennessee, allowing numerous women to have access to screening who otherwise would not be able to afford it. However, the program runs out of funding before the end of their fiscal year, at times forcing women to wait months in order to receive screening. Barriers to care may still exist in terms of eligibility gaps and transportation to facilities as well. Another downfall of the NBCCEDP is that it does not extend coverage to men. While it is rare for men to be diagnosed with breast cancer, in the event it does occur and the individual is uninsured, they face a major challenge in accessing treatment. In addition, the State of Tennessee chose not to expand Medicaid coverage or develop a State Health Insurance Exchange. While there is debate as to how not expanding Medicaid coverage will affect Tennesseans, it appears that a high percentage of citizens will remain uninsured due to high costs of purchasing insurance on the Marketplace without a provision for financial assistance. The implementation of the ACA does, however, provide a greater focus on preventive care services and insurance plans cover Essential Health Benefits, which include breast cancer screening.

While the Tennessee Cancer Coalition covers the entire gamut of cancer control with its statewide plan (2013-17), the East Tennessee Region does not have an active membership at this time. Komen Knoxville plans engage other Tennessee Affiliates to increase advocacy collaboration statewide, knowing that this will be key in producing change.



## **Qualitative Data: Ensuring Community Input**

Qualitative data were utilized to supplement findings from the QDR and HSA. The Affiliate's goal in qualitative analysis was to take the information that identified each county as a target community and assess how factors such as being medically underserved and rural play into the continuum of care, reveal possible explanations for the high incidence rates and death rates, and develop recommendations for the Affiliate moving forward.

The Affiliate utilized the Health Belief Model to develop qualitative questions and assessment variables. For qualitative data collection, the Affiliate utilized focus groups, provider surveys, and key informant interviews to gain community insight. The Affiliate combined the priority counties into two target areas to collect this data: Northeast (Claiborne County and Union County) and Southwest (Morgan County and Roane County). Two main questions arose:

1. How do the population characteristics of education and poverty levels affect breast health?
2. How does being medically underserved and having limited access to services across the continuum of care affect breast health?

In the Northeast, data showed that friends/family were the predominate source of breast health information. Breast cancer was strongly associated with death, and there was significant fear related to screening and a possible diagnosis. Furthermore, the population in the Northeast does not go to the doctor unless the condition is very serious, explaining in part the high late-stage diagnosis rate. Health Care providers surveyed specifically noted that the population in this target area does not place a high priority on preventive health in general, but when compared to other preventive services, breast health ranked higher than most.

The Southwest counties produced similar results, including a fear of a breast cancer diagnosis and a culture that was unlikely to seek preventive services, even though most were aware of general health screening recommendations. Other barriers to breast health care in the Southwest included lack of available transportation, financial limitations, multiple health issues, and confusion over resources available.

Both target areas related overall frustration with health insurance regulations and navigating the health care system. Consistent across counties was the idea that breast health information was most effective when given by someone they know and trust; if it was personal they were more likely to take it seriously.

## **Mission Action Plan**

The Mission Action Plan's problem statements, priorities, and objectives were developed after examining results across all data sources. The problems originated from the summary of the data and identified the major needs present in the target communities. For each problem, one or more priorities outline the goals the Affiliate hopes to achieve in addressing the need. For Problems 1 and 2, priorities were chosen to address the need for early breast cancer detection in the four target counties. For Problem 3, priorities were selected based on the need for increased access to breast health service information along with access to breast health services in all four medically underserved target counties. Finally, priorities for Problem 4 were chosen based on the need to increase awareness of the importance of screening and early detection in the four target counties. Objectives for each priority detail how the Affiliate plans to accomplish these goals.

**PROBLEM 1:** In the Quantitative Data Report, the time predicted for Claiborne, Roane, and Union Counties to meet the Healthy People 2020 late-stage incidence rate was 13 years or longer. The time predicted for Claiborne and Roane Counties to meet the Healthy People 2020 death rate target was 13 years or longer. Based on these findings, Claiborne and Roane Counties are unlikely to meet Healthy People targets for both breast cancer mortality and late-stage incidence and Union County is unlikely to meet the late-stage incidence target by 2020. Qualitative Data also showed that women in Claiborne, Roane, and Union Counties fear breast cancer diagnosis, do not go to the doctor unless their health condition is serious, and do not place a high priority on preventive and screening services, all contributing to late-stage diagnoses and increased mortality rates.

**Priority:** Promote early detection in order to reduce the number of late-stage breast cancer diagnoses and reduce mortality rates from breast cancer among women in Claiborne, Roane, and Union Counties.

- **Objective 1:** In FY-16 and 17, work with Komen Knoxville's Community Ambassadors in Claiborne, Roane, and Union Counties to conduct at least two group educational presentations per year in each county on the importance of screening and early detection.
- **Objective 2:** In FY-16 and 17, work with Komen Knoxville's Community Ambassadors in Claiborne, Roane, and Union Counties to conduct at least one outreach activity per month in each of their counties to promote the message of early detection.
- **Objective 3:** In FY-18, meet with at least two religious/community organizations in Claiborne, Roane, and Union Counties that will help promote the importance of screening and early detection.
- **Objective 4:** In FY-18, partner with at least two other Tennessee Affiliates to develop advocacy plans for protection of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) funding at the federal level.

**PROBLEM 2:** The Quantitative Data Report showed that Morgan County has the highest age-adjusted rate for late-stage diagnosis in the 16-county service area and a death rate that is significantly higher than the Affiliate's service area as a whole. Qualitative Data also showed that women in Morgan County fear breast cancer diagnosis, do not go to the doctor unless their health condition is serious, and do not place a high priority on preventive and screening services, all contributing to late-stage diagnoses and increased mortality rates.

**Priority:** Promote early detection in order to reduce the number of late-stage breast cancer diagnoses and reduce mortality rates from breast cancer among women in Morgan County.

- **Objective 1:** In FY-16 and 17, work with the Komen Knoxville's Community Ambassadors to hold at least two group educational presentations per year in Morgan County on the importance of screening and early detection.
- **Objective 2:** In FY -16 and 17, work with Komen Knoxville's Community Ambassadors to conduct at least one outreach activity per month in Morgan County to promote the message of early detection.
- **Objective 3:** In FY-18, meet with at least two religious/community organizations in Morgan County that will help promote the importance of screening and early detection.

**PROBLEM 3:** The Quantitative Data Report showed that 100 percent of the population in Claiborne, Morgan, Roane, and Union Counties is in medically underserved areas. In addition, the Health Systems Analysis found that residents of Morgan, Roane, and Union Counties do not have full diagnostic and treatment services available in their counties making access to breast health services more difficult. Furthermore, the Qualitative Data showed that residents of Claiborne, Morgan, Roane, and Union Counties have poor access to credible breast health information as they obtain the majority of their information from family and friends.

**Priority:** Increase access to breast health service information in Claiborne, Morgan, Roane, and Union Counties.

- **Objective 1:** In FY-16 and 17, utilize Komen Knoxville's Community Ambassadors to hold at least two educational events per year in Claiborne, Morgan, Roane, and Union Counties to discuss available breast health services and provide culturally appropriate breast health educational materials.
- **Objective 2:** By FY-17, develop a comprehensive listing of breast health resources available to residents of Claiborne, Morgan, Roane, and Union Counties and provide the listing to health councils, health departments, health care providers, and other community organizations for distribution within their counties.
- **Objective 3:** By FY-17, begin to plan for ways to continue funding for Komen Knoxville's Community Ambassador Program past the 2-year funded grant period.

**Priority:** Improve access to breast health services among women in Claiborne, Morgan, Roane, and Union Counties.

- **Objective 1:** In FY-17 and 18, give Community Grant funding priority to organizations that provide mobile mammograms, after-hours appointments, or other services that increase access to screening in Claiborne, Morgan, Roane, and Union Counties.
- **Objective 2:** By FY-18, hold at least one collaborative meeting in Claiborne, Morgan, Roane, and Union Counties aimed at hospitals, primary care providers, and other community organizations to discuss methods to decrease barriers and improve continuity of care between referral, screening, diagnosis, treatment, and support services.
- **Objective 3:** By FY-18, in collaboration with other community health care organizations, hold a community education event in Claiborne, Morgan, Roane, and Union Counties aimed at education on health insurance and navigating the health care system.
- **Objective 4:** In FY-17, invite eligible organizations in Claiborne, Morgan, Roane, and Union Counties to participate in the 2016 Komen Knoxville Community Grant Writing Workshop.

**PROBLEM 4:** Qualitative data showed that there is a lack of importance placed on breast health services by women in Claiborne, Morgan, Roane, and Union Counties. All four counties have a culture that makes seeking preventive and screening services unlikely.

**Priority:** Increase partnerships with community and health organizations to promote screenings in Claiborne, Morgan, Roane, and Union Counties.

- **Objective 1:** In FY-17, provide information to family care and women's health providers in Claiborne, Morgan, Roane, and Union Counties through face-to-face meetings and presentations, emails, and mailings on the most current recommendations, resources available, and other evidence-based programs that would increase their patients' screening rates.
- **Objective 2:** By FY-18, hold at least two meetings with hospitals, providers, or clinics in Claiborne, Morgan, Roane, and Union Counties to discuss how to promote breast health as a part of an overall health approach.

**Priority:** Increase Komen's health messaging to encourage screenings.

- **Objective 1:** In FY-16, develop an Affiliate social media campaign that focuses on moving people toward screening action.
- **Objective 2:** In FY-17, develop a plan for incorporating personal stories and first-person perspectives into health messaging and activities.
- **Objective 3:** By FY-18, partner with health departments and other health care organizations in Claiborne, Morgan, Roane, and Union Counties to promote screening messages during Public Health Week and during other health-focused time periods.

**Disclaimer:** Comprehensive data for the Executive Summary can be found in the 2015 Komen Knoxville Community Profile Report.

# Introduction

## **Affiliate History**

Susan G. Komen® Knoxville began with a promise of one woman: Renee J. Repka. During the years of watching her mother, Beatrice, battle breast cancer, Renee began participating in races around the country. She witnessed the power of one other woman, Nancy Goodman Brinker, in making a difference in the lives of women diagnosed with breast cancer. Sadly, while Renee was completing her coursework for a doctorate in clinical psychology at the University of Tennessee-Knoxville, Beatrice Repka passed away.

Fueled by grief and the need to “do something,” Renee took charge and convinced a group of her friends and colleagues to “bring Race for the Cure®” to Knoxville. Their first Race was held on September 27, 1997 at World’s Fair Park with a 5K run/walk for women only and a one mile co-ed fun run/walk. One thousand participants were expected; 2,038 showed up and Komen Knoxville Race for the Cure® was off and (literally) running!

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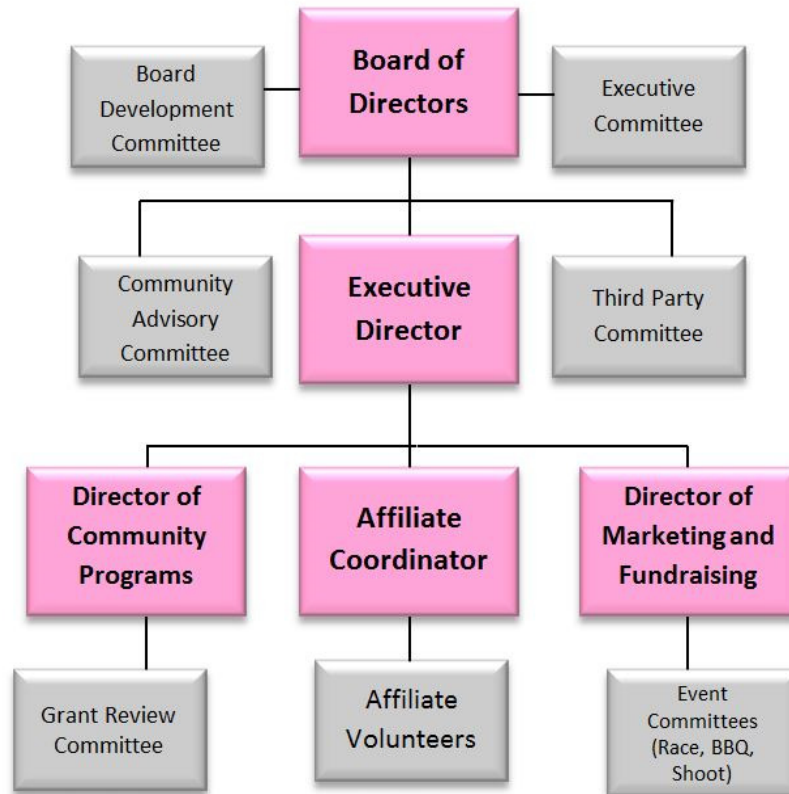
Today, Komen® Knoxville continues to provide breast health education, screening, and patient support. Its first Community Grants Program began in 1998, awarding a total of \$100,000 to five organizations. Since then, the Affiliate has awarded over \$6.6 million to the East Tennessee community and has funded over \$2.3 million dollars to breast cancer research.

Through the years, Komen Knoxville employees have served on various Komen Headquarters’ committees including: the inaugural Affiliate Leadership Council, the Komen Headquarters Scholarship Committee, the Incentive Prize Task Force, and the Corporate Partnership Task Force. In addition, Komen Knoxville was invited to participate in the “Komen on the Go” pilot program and participate in a panel discussion “Community Health Programs Have the Biggest Impact” at the 2014 Susan G. Komen Leadership Conference.

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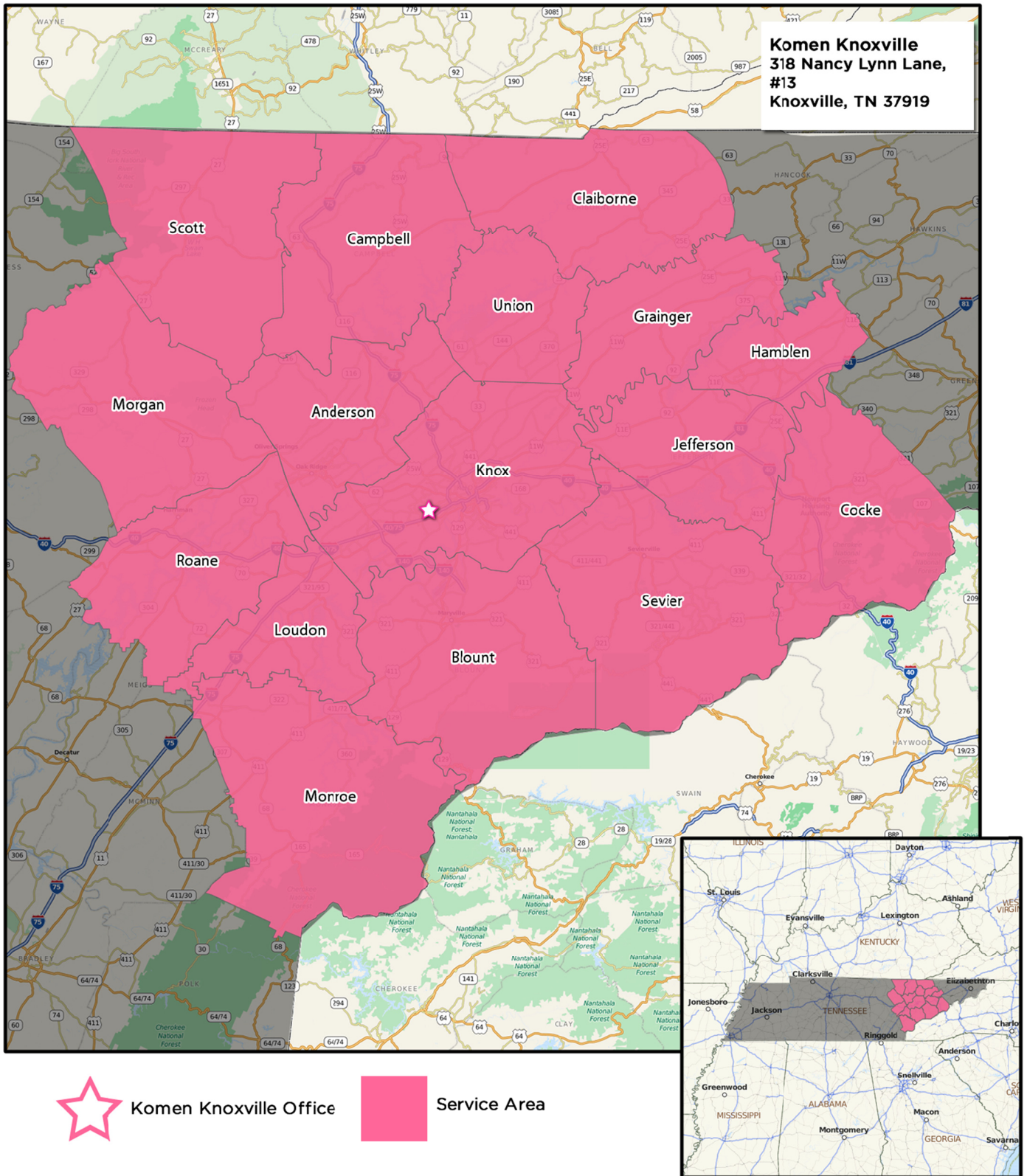
## Affiliate Organizational Structure

Komen Knoxville is part of an Affiliate Network of Susan G. Komen that consists of over 100 domestic and international Affiliates. The Affiliate operates with a staff of four employees and is governed by an eleven member volunteer Board of Directors. Six standing committees guide the Affiliate and include: Board Development Committee, Executive Committee, Community Advisory Committee, Third Party Committee, Event Committees (Race for the Cure®, Boob-B-Que, and Shoot for a Cure), and Grant Review Committee. Komen Knoxville relies on the time, talents, and gifts of hundreds of committed volunteers to accomplish its mission.



**Figure 1.1.** Affiliate Organizational Structure

# KOMEN KNOXVILLE SERVICE AREA



 Komen Knoxville Office  Service Area

Figure 1.2. Susan G. Komen Knoxville Service Area

**Affiliate Service Area**

Komen Knoxville serves 16 counties in East Tennessee: Anderson, Blount, Campbell, Claiborne, Cocke, Grainger, Hamblen, Jefferson, Knox, Loudon, Monroe, Morgan, Roane, Sevier, Scott, and Union. While four are considered urban, 12 of the 16 counties are considered rural or medically underserved.

The female population of the service area is approximately 591,862. Tables 1.1 and 1.2 display key population demographics and characteristics.

**Table 1.1. Service Area Demographics**

Population Group	White	Black/ African American	AIAN *	API* *	Hispanic/ Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
<b>Komen Knoxville's Service Area</b>	93.0%	5.2%	0.4%	1.3%	3.2%	52.3%	38.4%	17.2%

\*AIAN – American Indians and Alaska Natives

\*\*API – Asians and Pacific Islanders

**Table 1.2. Service Area Characteristics**

Population Group	Less than HS Education	Income <100% Poverty	Income <250% Poverty (Age 40-64)	Un-employed	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age:40-64)
<b>Komen Knoxville's Service Area</b>	17.2%	16.1%	39.5%	8.4%	37.5%	47.0%	17.1%

**Purpose of the Community Profile Report**

The Purpose of the Community Profile Report is to:

- Align the Affiliate strategic and operational plans
- Drive inclusion efforts in the community
- Drive public policy efforts
- Establish focused granting priorities
- Establish focused education needs
- Establish directions for marketing and outreach
- Strengthen sponsorship efforts

The Community Profile is the Affiliate’s main mission communication tool and will be used to educate and inform stakeholders regarding the state of breast cancer in the service area, the Affiliate’s current mission priorities, and the plan to address the identified breast health and breast cancer needs within the target communities.

While Komen Knoxville retains all the publication and presenting rights of the Community Profile, it is the desire of the Affiliate that it be shared with the community at large, specifically grantees, donors, sponsors, legislators, and other breast cancer focused organizations. Additionally, it will be posted on the Affiliate’s website ([www.komenknoxville.org](http://www.komenknoxville.org)) and publicized through the Affiliate’s e-newsletter (PinkLink), Facebook page, other social media, and newspaper press releases.



# Quantitative Data: Measuring Breast Cancer Impact in Local Communities

## Quantitative Data Report

### Introduction

The purpose of the quantitative data report for Susan G. Komen® Knoxville 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 mortality (<http://www.healthypeople.gov/2020/default.aspx>).

The following is a summary of Komen® Knoxville'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.

Population Group	Incidence Rates and Trends				Death Rates and Trends			Late-stage Rates and Trends		
	Female Population (Annual Average)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of Deaths (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)
US	154,540,194	182,234	122.1	-0.2%	40,736	22.6	-1.9%	64,590	43.8	-1.2%
HP2020	.	-	-	-	-	20.6*	-	-	41.0*	-
Tennessee	3,195,539	4,363	118.8	0.0%	880	23.3	-1.6%	1,605	44.1	-3.0%
Komen Knoxville Service Area	591,862	872	119.2	0.3%	164	21.5	NA	306	42.6	-3.3%
White	553,129	828	118.6	0.1%	155	21.4	NA	288	42.2	-3.7%
Black/African-American	29,327	37	138.5	6.4%	8	30.6	NA	14	52.3	6.6%
American Indian/Alaska Native (AIAN)	2,216	SN	SN	SN	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	7,191	4	68.7	9.2%	SN	SN	SN	SN	SN	SN
Non-Hispanic/ Latina	575,409	869	120.2	0.3%	163	21.7	NA	304	42.9	-3.2%
Hispanic/ Latina	16,453	SN	SN	SN	SN	SN	SN	SN	SN	SN

Population Group	Female Population (Annual Average)	Incidence Rates and Trends			Death Rates and Trends			Late-stage Rates and Trends		
		# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of Deaths (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)
Anderson County - TN	38,393	61	118.7	5.6%	12	20.1	-1.3%	21	41.2	11.8%
Blount County - TN	62,532	100	123.4	-2.2%	16	19.5	-2.0%	34	42.6	-8.9%
Campbell County - TN	20,806	32	119.0	-1.4%	6	21.5	-1.8%	12	45.6	-1.6%
Claiborne County - TN	16,276	24	117.2	5.5%	6	28.0	-0.7%	10	49.6	2.4%
Cocke County - TN	18,237	22	93.2	0.4%	5	22.7	-1.2%	9	40.5	-10.7%
Grainger County - TN	11,269	16	114.9	-5.6%	5	33.2	1.5%	5	39.0	-15.1%
Hamblen County - TN	31,675	43	105.8	3.7%	11	25.0	-0.9%	13	32.6	-4.6%
Jefferson County - TN	25,731	33	102.7	-0.7%	6	18.1	-2.4%	12	39.0	4.2%
Knox County - TN	218,022	320	129.6	-0.9%	52	20.2	-1.8%	111	45.3	-4.1%
Loudon County - TN	23,975	40	109.4	3.7%	6	18.9	-2.3%	12	33.0	-10.7%
Monroe County - TN	22,241	34	120.4	3.4%	6	21.8	-0.3%	12	42.9	-8.1%
Morgan County - TN	9,795	15	125.2	-1.3%	5	40.1	NA	7	55.6	-19.6%
Roane County - TN	27,578	50	128.9	3.3%	10	23.2	-0.6%	16	43.4	6.4%
Scott County - TN	11,274	14	109.7	-4.3%	SN	SN	SN	5	41.4	-20.3%
Sevier County - TN	44,473	57	102.8	-1.5%	14	23.2	-1.7%	21	39.4	-0.6%
Union County - TN	9,585	12	111.1	1.5%	SN	SN	SN	6	55.1	13.4%

\*Target as of the writing of this report.

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.

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: North American Association of Central Cancer Registries (NAACCR) – Cancer in North America (CINA) Deluxe Analytic File.

Source of death rate data: Centers for Disease Control and Prevention (CDC) – National Center for Health Statistics (NCHS) mortality data in SEER\*Stat.

Source of death trend data: National Cancer Institute (NCI)/CDC State Cancer Profiles.

### ***Incidence rates and trends summary***

Overall, the breast cancer incidence rate in the Komen Knoxville service area was slightly 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 Tennessee.

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 Asian and Pacific Islanders (APIs) and American Indians and Alaskan Natives (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 higher among Blacks/African-Americans than Whites and lower among APIs than Whites. There were not enough data available within the Affiliate service area to report on AIANs so comparisons cannot be made for this racial group. 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.

The following county had an incidence rate **significantly higher** than the Affiliate service area as a whole:

- Knox County

The incidence rate was significantly lower in the following county:

- Cocke County

The rest of the counties had incidence rates and trends that were not significantly different than the Affiliate service area as a whole or did not have enough data available.

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 Knoxville service area was slightly lower than 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 Tennessee.

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. For the Affiliate service area as a whole, the death rate was higher among Blacks/African-Americans than Whites. There were not enough data available within the Affiliate service area to report on 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.

The following county had a death rate **significantly higher** than the Affiliate service area as a whole:

- Morgan County

The rest of the counties had death rates and trends that were not significantly different 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 Knoxville service area was slightly lower than that observed in the US as a whole and the late-stage incidence trend was lower than the US as a whole. The late-stage incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of Tennessee.

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. For the Affiliate service area as a whole, the late-stage incidence rate was higher among Blacks/African-Americans than Whites. There were not enough data available within the Affiliate service area to report on 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 significantly different late-stage incidence rates than the Affiliate service area as a whole.

## 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 2.2.** Breast cancer screening recommendations for women at average risk.

American Cancer Society	National Cancer Institute	National Comprehensive Cancer Network	US Preventive Services Task Force
Mammography every year starting at age 40	Mammography every 1-2 years starting at age 40	Mammography every year starting at age 40	<p>Informed decision-making with a health care provider ages 40-49</p> <p>Mammography every 2 years ages 50-74</p>

Because having 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. BRFSS is the best and most widely used source available for information on mammography usage among women in the United States, although it does not collect data matching Komen screening recommendations (i.e. from women age 40 and older). 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 Latina, but only 10.0 percent of the total women in the area are 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 who 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.

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
US	174,796	133,399	77.5%	77.2%-77.7%
Tennessee	2,882	2,209	76.6%	74.5%-78.5%
Komen Knoxville Service Area	475	380	79.6%	74.7%-83.7%
White	442	356	79.7%	74.7%-83.9%
Black/African-American	23	18	77.7%	50.3%-92.3%
AIAN	SN	SN	SN	SN
API	SN	SN	SN	SN
Hispanic/ Latina	SN	SN	SN	SN
Non-Hispanic/ Latina	473	378	79.4%	74.5%-83.5%
Anderson County - TN	24	19	86.0%	61.1%-96.0%
Blount County – TN	40	32	78.1%	57.7%-90.4%
Campbell County - TN	SN	SN	SN	SN
Claiborne County - TN	11	7	61.8%	30.0%-85.9%
Cocke County – TN	19	16	80.3%	57.8%-92.4%
Grainger County - TN	11	8	80.3%	42.6%-95.7%
Hamblen County - TN	17	13	77.1%	52.2%-91.2%
Jefferson County - TN	18	12	65.7%	34.6%-87.4%
Knox County – TN	206	170	80.3%	72.4%-86.3%
Loudon County - TN	20	17	86.7%	58.6%-96.8%
Monroe County - TN	27	20	80.1%	59.6%-91.7%
Morgan County - TN	SN	SN	SN	SN
Roane County – TN	15	12	77.5%	44.9%-93.6%

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
Scott County – TN	SN	SN	SN	SN
Sevier County – TN	37	30	80.1%	58.8%-91.9%
Union County – TN	11	6	54.8%	25.6%-81.1%

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 Knoxville service area was not significantly different 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 Tennessee.

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 Blacks/African-Americans than Whites. There were not enough data available within the Affiliate service area to report on 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 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.

Population Group	White	Black /African-American	AIAN	API	Non-Hispanic /Latina	Hispanic /Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
US	78.8 %	14.1 %	1.4 %	5.8 %	83.8 %	16.2 %	48.3 %	34.5 %	14.8 %
Tennessee	79.9 %	17.9 %	0.4 %	1.8 %	95.8 %	4.2 %	49.3 %	35.5 %	15.2 %
Komen Knoxville Service Area	93.0 %	5.2 %	0.4 %	1.3 %	96.8 %	3.2 %	52.3 %	38.4 %	17.2 %
Anderson County – TN	93.8 %	4.5 %	0.4 %	1.3 %	97.9 %	2.1 %	55.9 %	41.9 %	19.5 %
Blount County – TN	95.4 %	3.2 %	0.4 %	1.0 %	97.4 %	2.6 %	54.5 %	39.9 %	18.1 %
Campbell County – TN	98.7 %	0.6 %	0.3 %	0.4 %	99.0 %	1.0 %	54.6 %	40.5 %	19.0 %
Claiborne County – TN	97.8 %	1.2 %	0.3 %	0.7 %	99.1 %	0.9 %	53.5 %	39.7 %	18.0 %
Cocke County – TN	96.7 %	2.4 %	0.5 %	0.4 %	98.4 %	1.6 %	55.8 %	41.4 %	17.9 %
Grainger County – TN	98.7 %	0.9 %	0.2 %	0.3 %	97.9 %	2.1 %	55.3 %	40.2 %	17.5 %
Hamblen County – TN	93.2 %	5.1 %	0.7 %	1.0 %	90.6 %	9.4 %	51.8 %	38.3 %	18.1 %
Jefferson County – TN	96.4 %	2.5 %	0.4 %	0.7 %	97.2 %	2.8 %	53.0 %	38.9 %	17.7 %
Knox County – TN	87.6 %	9.8 %	0.4 %	2.2 %	96.7 %	3.3 %	48.2 %	34.8 %	15.0 %
Loudon County – TN	97.2 %	1.5 %	0.3 %	0.9 %	93.8 %	6.2 %	59.9 %	47.3 %	23.6 %
Monroe County – TN	96.2 %	2.6 %	0.6 %	0.6 %	96.8 %	3.2 %	54.3 %	40.7 %	18.2 %
Morgan County – TN	98.5 %	0.7 %	0.4 %	0.4 %	99.1 %	0.9 %	53.4 %	38.8 %	16.7 %
Roane County – TN	95.7 %	3.2 %	0.3 %	0.7 %	98.6 %	1.4 %	58.8 %	44.8 %	20.9 %
Scott County – TN	99.0 %	0.4 %	0.3 %	0.2 %	99.5 %	0.5 %	49.2 %	35.3 %	15.8 %
Sevier County – TN	97.2 %	1.3 %	0.5 %	1.0 %	95.4 %	4.6 %	54.0 %	39.5 %	17.1 %
Union County – TN	98.7 %	0.7 %	0.4 %	0.2 %	98.7 %	1.3 %	52.1 %	37.5 %	15.5 %

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.**

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistically Isolated	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age: 40-64)
US	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
Tennessee	16.8 %	16.9 %	38.9 %	9.2 %	4.5 %	1.5 %	33.6 %	47.7 %	17.6 %
Komen Knoxville Service Area	17.2 %	16.1 %	39.5 %	8.4 %	3.4 %	1.0 %	37.5 %	47.0 %	17.1 %
Anderson County - TN	16.1 %	16.8 %	37.3 %	8.0 %	2.7 %	0.4 %	34.7 %	30.5 %	15.8 %
Blount County - TN	14.1 %	12.3 %	34.4 %	8.3 %	2.7 %	0.9 %	32.6 %	34.8 %	16.2 %
Campbell County - TN	30.2 %	23.1 %	55.4 %	11.5 %	0.8 %	0.3 %	55.0 %	100.0 %	18.8 %
Claiborne County - TN	29.3 %	22.6 %	51.9 %	8.4 %	0.9 %	0.2 %	71.6 %	100.0 %	16.5 %
Cocke County - TN	27.2 %	26.9 %	56.5 %	13.1 %	1.6 %	0.0 %	67.5 %	100.0 %	20.4 %
Grainger County - TN	31.4 %	19.8 %	53.3 %	11.4 %	1.1 %	0.0 %	100.0 %	100.0 %	19.8 %
Hamblen County - TN	21.5 %	17.7 %	43.7 %	11.6 %	7.3 %	3.3 %	21.9 %	8.7 %	19.3 %
Jefferson County - TN	21.2 %	18.9 %	45.8 %	10.9 %	1.9 %	0.6 %	59.5 %	52.9 %	18.3 %
Knox County - TN	11.0 %	13.7 %	31.6 %	6.0 %	4.3 %	1.3 %	10.9 %	14.5 %	14.7 %
Loudon County - TN	15.2 %	14.0 %	32.8 %	10.1 %	5.6 %	1.6 %	40.6 %	100.0 %	17.3 %
Monroe County - TN	25.6 %	20.9 %	50.6 %	12.1 %	2.1 %	0.9 %	76.1 %	100.0 %	20.1 %
Morgan County - TN	20.9 %	20.7 %	47.1 %	8.1 %	0.6 %	0.1 %	99.9 %	100.0 %	17.3 %
Roane County - TN	17.9 %	15.2 %	37.3 %	9.0 %	1.7 %	0.2 %	51.0 %	100.0 %	15.1 %
Scott County - TN	26.0 %	26.0 %	56.3 %	12.2 %	0.6 %	0.1 %	80.6 %	100.0 %	19.7 %
Sevier County - TN	18.9 %	13.5 %	45.4 %	8.4 %	4.5 %	1.4 %	56.6 %	55.3 %	23.0 %
Union County - TN	30.0 %	21.8 %	55.1 %	8.6 %	0.9 %	0.0 %	100.0 %	100.0 %	20.4 %

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 rural population data: US Census Bureau – Census 2010.

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 Knoxville service area has a substantially larger White female population than the US as a whole, a substantially smaller Black/African-American female population, a substantially smaller Asian and Pacific Islander (API) female population, a slightly smaller American Indian and Alaska Native (AIAN) female population, and a substantially smaller Hispanic/Latina female population. The Affiliate's female population is slightly older than 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 is a slightly smaller percentage of people who are unemployed in the Affiliate service area. The Affiliate service area has a substantially smaller percentage of people who are foreign born and a substantially smaller percentage of people who are linguistically isolated. There is 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 county has substantially larger Hispanic/Latina female population percentages than that of the Affiliate service area as a whole:

- Hamblen County

The following county has substantially older female population percentages than that of the Affiliate service area as a whole:

- Loudon County

The following counties have substantially lower education levels than that of the Affiliate service area as a whole:

- Campbell County
- Claiborne County
- Cocke County
- Grainger County
- Monroe County
- Scott County
- Union County

The following counties have substantially lower income levels than that of the Affiliate service area as a whole:

- Campbell County
- Claiborne County
- Cocke County
- Scott County
- Union County

The following counties have substantially lower employment levels than that of the Affiliate service area as a whole:

- Campbell County
- Cocke County
- Grainger County
- Hamblen County
- Monroe County
- Scott County

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

- Sevier County

## **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 Knoxville 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.

		Time to Achieve Late-stage Incidence Reduction Target				
		13 years or longer	7-12 yrs.	0 – 6 yrs.	Currently meets target	Unknown
Time to Achieve Death Rate Reduction Target	13 years or longer	Highest	High	Medium High	Medium	Highest
	7-12 yrs.	High	Medium High	Medium	Medium Low	Medium High
	0 – 6 yrs.	Medium High	Medium	Medium Low	Low	Medium Low
	Currently meets target	Medium	Medium Low	Low	Lowest	Lowest
	Unknown	Highest	Medium High	Medium Low	Lowest	Unknown

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 rates and key breast cancer death determinants such as poverty and linguistic isolation.

**Table 2.7.** Intervention priorities for Komen Knoxville service area with predicted time to achieve the HP2020 breast cancer targets and key population characteristics.

County	Priority	Predicted Time to Achieve Death Rate Target	Predicted Time to Achieve Late-stage Incidence Target	Key Population Characteristics
Claiborne County - TN	Highest	13 years or longer	13 years or longer	Education, poverty, rural, medically underserved
Roane County - TN	Highest	13 years or longer	13 years or longer	Rural, medically underserved

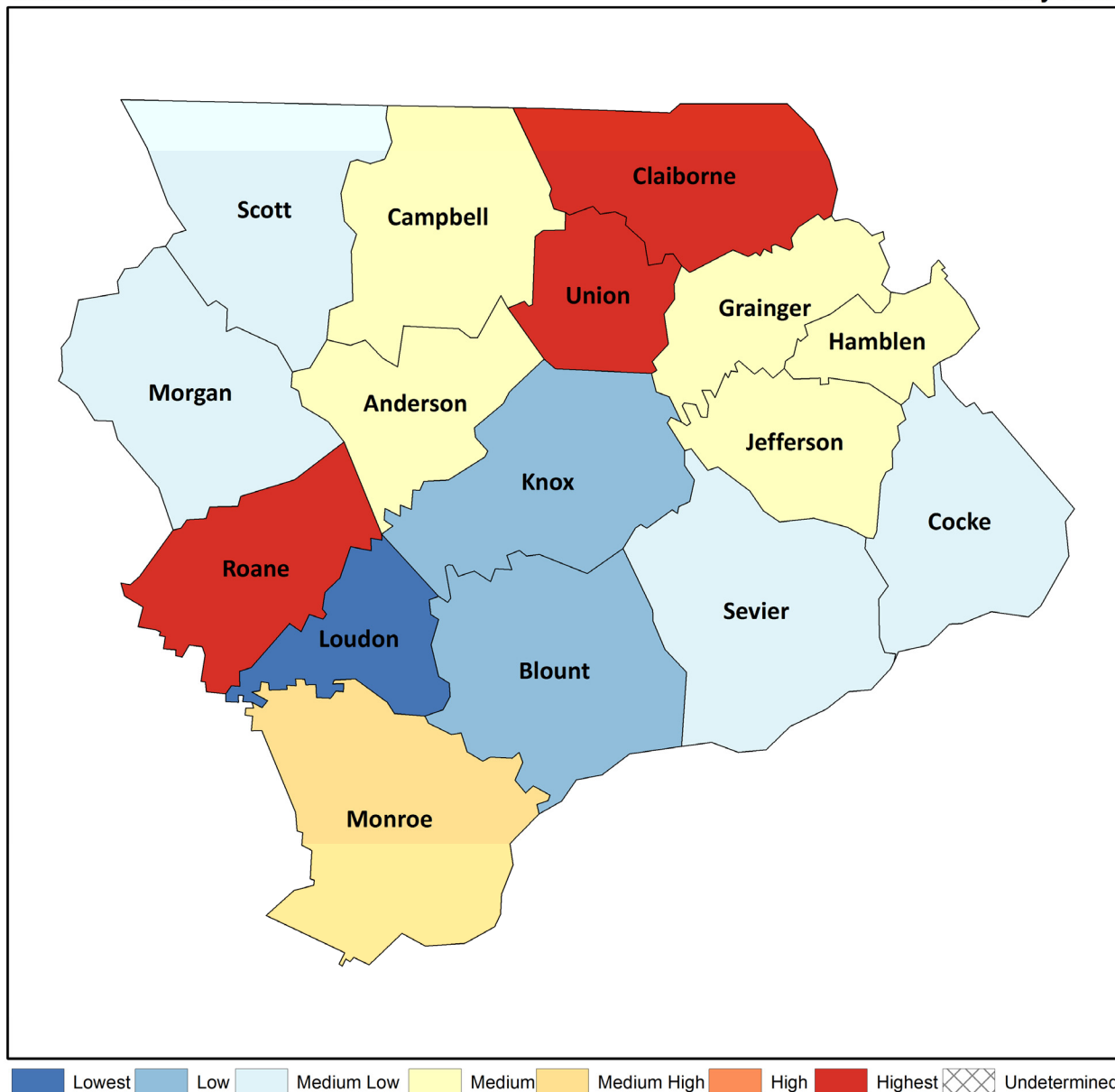
County	Priority	Predicted Time to Achieve Death Rate Target	Predicted Time to Achieve Late-stage Incidence Target	Key Population Characteristics
Union County - TN	Highest	SN	13 years or longer	Education, poverty, rural, medically underserved
Monroe County - TN	Medium High	13 years or longer	1 year	Education, employment, rural, medically underserved
Anderson County - TN	Medium	Currently meets target	13 years or longer	
Campbell County - TN	Medium	3 years	7 years	Education, poverty, employment, rural, medically underserved
Grainger County - TN	Medium	13 years or longer	Currently meets target	Education, employment, rural, medically underserved
Hamblen County - TN	Medium	13 years or longer	Currently meets target	%Hispanic, employment
Jefferson County - TN	Medium	Currently meets target	13 years or longer	Rural, medically underserved
Cocke County - TN	Medium Low	9 years	Currently meets target	Education, poverty, employment, rural, medically underserved
Morgan County - TN	Medium Low	NA	2 years	Rural, medically underserved
Scott County - TN	Medium Low	SN	1 year	Education, poverty, employment, rural, medically underserved
Sevier County - TN	Medium Low	7 years	Currently meets target	Rural, insurance, medically underserved
Blount County - TN	Low	Currently meets target	1 year	
Knox County - TN	Low	Currently meets target	3 years	
Loudon County - TN	Lowest	Currently meets target	Currently meets target	Older, medically underserved

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.



**Figure 2.1.** Intervention priorities.

**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***

Three counties in the Komen Knoxville service area are in the highest priority category. Two of the three, Claiborne County and Roane County, are not likely to meet either the death rate or late-stage incidence rate HP2020 targets. One of the three, Union County is not likely to meet the late-stage incidence rate HP2020 target.

Claiborne County has relatively low education levels and high poverty rates. Union County has relatively low education levels and high poverty rates.

### ***Medium high priority areas***

One county in the Komen Knoxville service area is in the medium high priority category. Monroe County is not likely to meet the death rate HP2020 target. Monroe County has relatively low education levels and high unemployment.

## **Selection of Target Communities**

Susan G. Komen Knoxville has selected four target communities within the service area to be the focus of strategic intervention over the next three years. Target communities were identified based on the data provided from the Quantitative Data Report (QDR); no additional quantitative data exploration was conducted. The Affiliate took all indicators into consideration when selecting target communities, but gave specific attention to how communities lined up with the Healthy People 2020 Objectives. Healthy People 2020 (HP2020) sets national, evidence-based goals to improve the health of Americans. Released in 2010, these objectives are aggressive, but attainable with appropriate intervention within the 10 year period. Two objectives are specifically related to improvements in breast cancer outcomes: first, to reduce the female breast cancer death rate by 10 percent (From 23.0 deaths per 100,000 to 20.6), and second, to reduce cases of late-stage female breast cancer from 43.2 per 100,000 to 41.0. Given that these objectives are consistent with Susan G. Komen's mission "to save lives and end breast cancer forever," they served as the basis for selecting priority counties.

Additional indicators the Affiliate reviewed included:

- Incidence rates and trends
- Below average screening rates
- Population and race distribution

Given the discrepancies among researchers on how socioeconomic factors affect breast cancer screening and survival, those indicators were given secondary consideration. Qualitative data and health systems analysis

will be used to further investigate issues such as education, income, health insurance, and access to care within the service area.

The selected target communities are:

- Claiborne County
- Roane County
- Union County
- Morgan County

**Table 2.8.** Target Communities Incidence, Death and Late-Stage Diagnosis Rates

Population Group	Age-Adjusted Incidence Rate/100,000	Age-Adjusted Death Rate/ 100,000	Age-Adjusted Late-stage Rate/100,000
US	122.1	22.6	43.8
Komen Knoxville Service Area	119.2	21.5	42.6
Claiborne	117.2	28.0	49.6
Roane	128.9	23.2	43.4
Union	111.1	SN	55.1
Morgan	125.2	40.1	55.6
<i>Healthy People 2020 Target</i>	<i>NA</i>	<i>20.6</i>	<i>41.0</i>

**Claiborne County** was identified as the highest priority in terms of Affiliate intervention based on Table 2.7 which shows predicted time to achieve the HP2020 breast cancer targets. It is predicted that it will take 13 years or longer for Claiborne County to achieve each of the goals, meaning they are unlikely to meet the HP2020 deadline; other data from the QDR confirmed their risk. Claiborne County incidence rates are around 117.2 per 100,000 females, which is lower than the US and state average, but death rate and late-stage diagnosis rates are remarkably higher (28.0 and 49.6, respectively). Table 2.1 shows that Claiborne was also one of the few counties predicted to show an increasing trend in late-stage rates, something that is alarming. The Affiliate assumes that given these statistics a below average incidence rate is more reflective of gaps in the continuum of care and not a result of fewer women actually being diagnosed. Table 2.3 furthers this thought, showing that Claiborne County has a lower percentage of women with self-reported screening mammograms in the last two years at 61.8 percent (although, it was noted the small sample size of only 11 women interviewed). Qualitative data will investigate this further.

Claiborne County was also selected on the basis of its socioeconomic characteristics: 29.3 percent of the population had less than a high school education, 22.6 percent had income below 100 percent of the poverty level, and 51.9 percent below 250 percent, (all of which are greatly above the Tennessee and Komen Knoxville service area average). Data also show that 71.6 percent of the population lives in rural areas and 100 percent are in areas considered medically underserved. These are two indicators that can affect access to care.

**Roane County** was also ranked as a high priority for Affiliate intervention, according to Table 2.7. It is predicted it will take the county 13 years or more to achieve both Healthy People 2020 breast cancer targets - female breast cancer death rate as well as female breast cancer late-stage incidence rate. While not one of the

HP 2020 targets, Roane County's incidence rate was also of concern at 128.9 with a 3.3 percent increase trending annually. Roane County also appears to have an older female population as compared to the Affiliate service area average. Given that the two main risk factors for developing breast cancer are being female and getting older, this certainly could contribute to the population's risk.

**Table 2.9.** Roane County Demographics

Population Group	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
Komen Knoxville Service area	52.3%	38.4%	17.2%
Roane County	58.8%	44.8%	20.9%

Roane County also has 51 percent of its population living in rural areas and 100 percent of the population living in areas that are medically underserved, something seen with the last target community, Morgan County.

**Union County** was the third and final county to be identified as a high priority for Affiliate interventions. It is predicted that it will take 13 years or longer to achieve the late-stage incidence target. Data needed to predict the length of time to achieve the death rate target were suppressed due to small numbers (having 15 cases or fewer for the 5-year data period). Union County has the smallest female population of any county in the service area, with a female population of 9,585. However, data available on late-stage diagnosis is alarming with an age-adjusted rate of 55.1 per 100,000 and an increasing trend of 13.1 percent, the largest increase of any county, as evident in Table 2.1. Union County is similar to Claiborne in that it has a seemingly low incidence rate as well as a low self-reported screening rate at 54.8 percent. However, it should be noted that this data is subject to error due to the small sample size and large confidence interval.

**Table 2.10.** Union County Demographics

Population Group	#Women Interviewed	# w/Self-Reported Mammogram	Proportion Screened (weighted average)	Confidence Interval of Proportion Screened
Union Co.	11	6	54.8%	25.6%-81.1%

Union County was also similar to Claiborne County in that it had a number of concerning socioeconomic indicators, including 30 percent having less than a high school education, 21.8 percent of the population living below 100 percent of the poverty level and 55.1 percent living below 250 percent. 100 percent of the population lives in rural, medically underserved areas.

**Morgan County** was ranked as Medium-Low Priority for Affiliate intervention in Table 2.7. However, the Affiliate has decided to include it as a target due to the lack of data available regarding death rate trends. Data provided in Table 2.1 show that Morgan has the highest age-adjusted death rate in the service area (40.1), but trending data is not available, resulting in no prediction for how long it may take to achieve the HP2020 goal. The death rate is significantly higher in Morgan County compared to the Affiliate service area as a whole, which is of concern (Komen Knoxville Quantitative Data Report, 2015). The age-adjusted rate for late-stage diagnosis is also the highest in the service area, but with an optimistic downward trend of 19.6 percent annually, this corresponds with a predicted time of two years to meet the Healthy People 2020 target for late-stage incidence. Morgan County has a similar female population size as that of Union County, so data may be

limited to a smaller sample size. This is evident in Table 3 where data is unavailable due to small numbers for self-reported mammogram screening.

As with the previous counties, Morgan County has undesirable socioeconomic indicators; specifically, having 99.9 percent of the population living in rural areas and 100 percent in medically underserved. As aforementioned, there is some debate as to which population indicators increase breast cancer susceptibility and at what point. However, research around women in rural areas has been more definitive in showing that even when adjusting for factors including education, income, and race/ethnicity, that timely mammography was still significantly lower in rural areas compared to urban (Doescher, 2008).

# Health Systems and Public Policy Analysis

## **Health Systems Analysis Data Sources**

The Health System Analysis (HSA) was completed first by listing known organizations in the priority counties (grantees, sponsors, major hospitals, health departments, etc.). Next, a web search was conducted to add additional programs or service. Food and Drug Administration (FDA), National Association of County and City Health Officials (NACCHO), and Health Resources and Services Administration (HRSA) websites were utilized for mammography facilities, local health departments, and community health centers respectively. Follow-up phone calls were used to confirm contact information and services provided.

Once the HSA template was complete, services were compared within the continuum of care to notice major gaps in services.

## **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. 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.

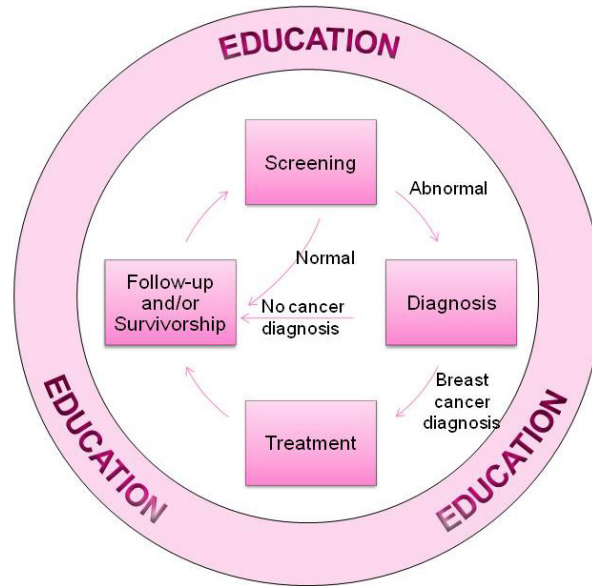
While a woman may enter the continuum at any point, ideally a woman would enter the CoC by getting screened for breast cancer – with a clinical breast exam or a screening mammogram. If the screening test results are normal, she would loop back into follow-up care, where she would get another screening 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.

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.



**Figure 3.1.** Breast Cancer Continuum of Care (CoC)

**Claiborne County**

Strengths	Weaknesses
Several Mobile Mammography Screening Sites	Geographically isolated
Claiborne County Hospital	Limited survivorship/support services
Howard H. Baker Cancer Treatment Center	

**Morgan County**

Strengths	Weaknesses
Within reasonable driving distance to facilities in surrounding counties	No diagnostic services
	No treatment services
	Limited screening services
	Limited survivorship/support services

**Roane County**

Strengths	Weaknesses
Several mobile mammography sites	No treatment services
Roane County Medical Center	Limited survivorship/support services

## Union County







Strengths	Weaknesses
Within reasonable driving distance to facilities in surrounding counties	Limited screening services
	No diagnostic services
	No treatment services
	Limited survivorship/support services

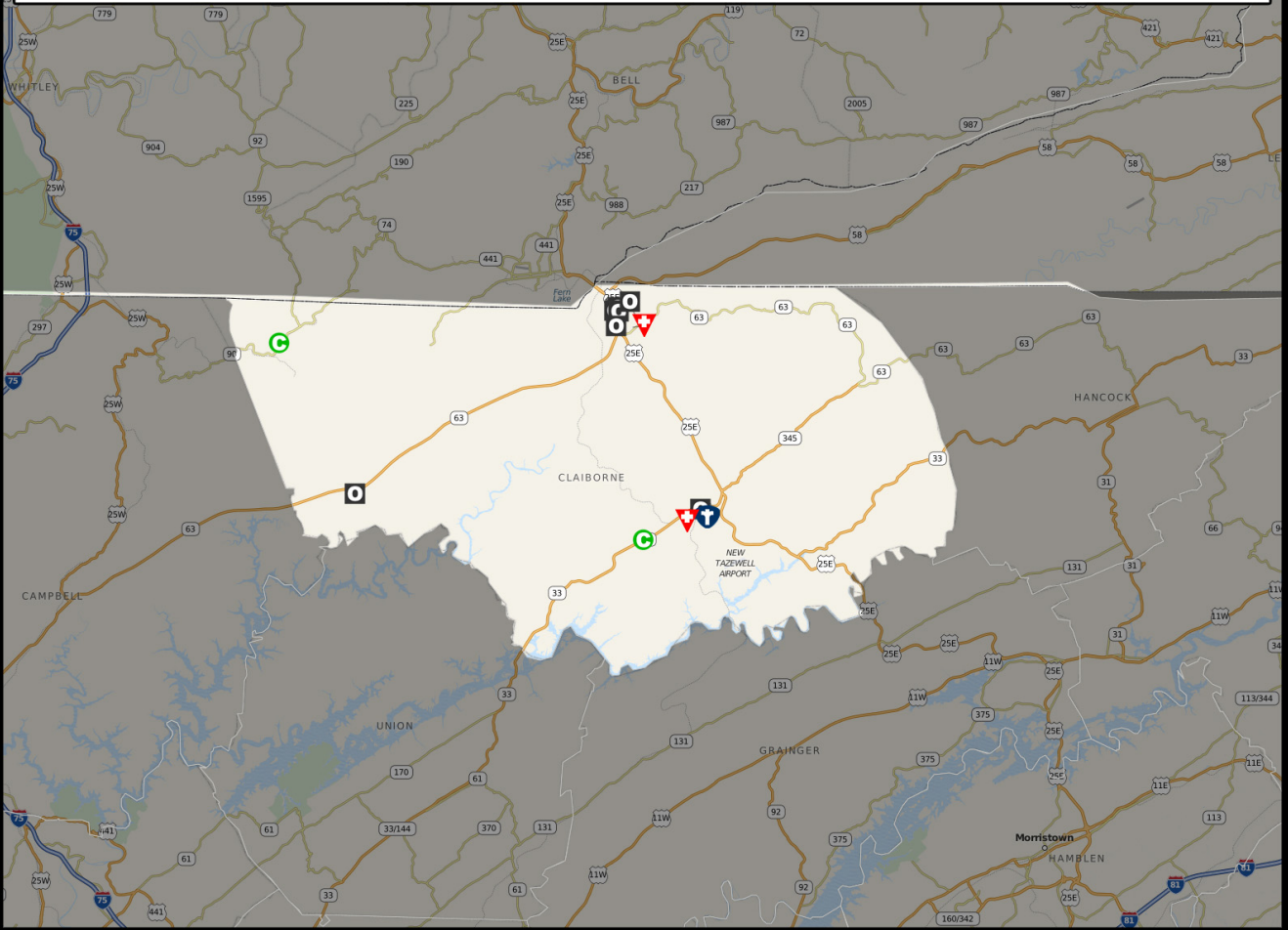
**Table 3.1.** Target Communities Health Systems Strengths & Weaknesses

The main mission related partners in each of the priority counties are the local health departments and the University of Tennessee Medical Center’s mobile mammography unit. The nurses associated with the National Breast and Cervical Cancer Early Detection Program in each county serve as a valuable resource when it comes to understanding the status of breast health in each county. In addition, the mobile mammography unit meets a great need by being the only provider of mammograms in both Morgan and Union County. Without its presence, individuals would have to travel to neighboring counties for a bricks and mortar location. Also, these two partners are often the only sources for breast health education. In the coming years, Komen Knoxville will partner with local women in these four counties by implementing an Ambassador Education Program that can help provide education and link women with resources.



# Claiborne County

 Hospital	 Community Health Center	 Other
 Free Clinic	 Department of Health	 Affiliate Office



## Statistics

Total Locations in Region: 12

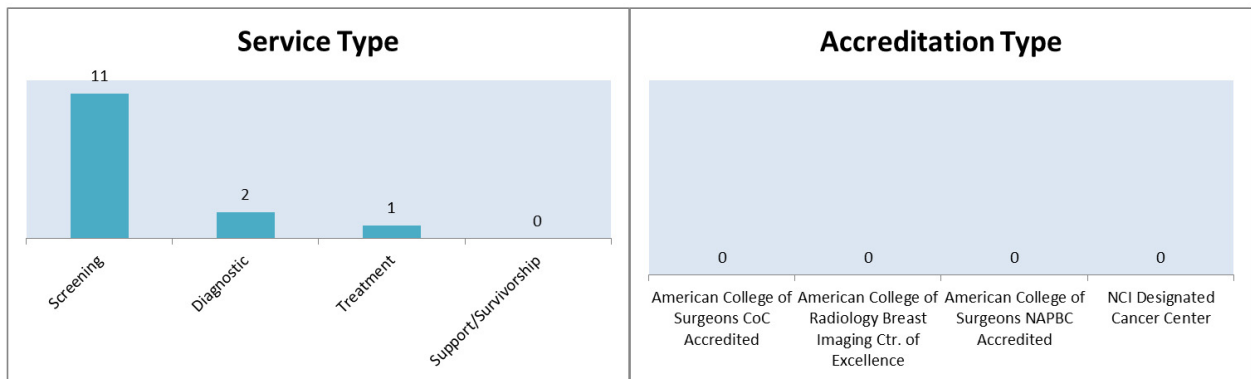


Figure 3.2. Breast Cancer Services Available in Claiborne County

# Morgan County



Hospital



Community Health Center



Other



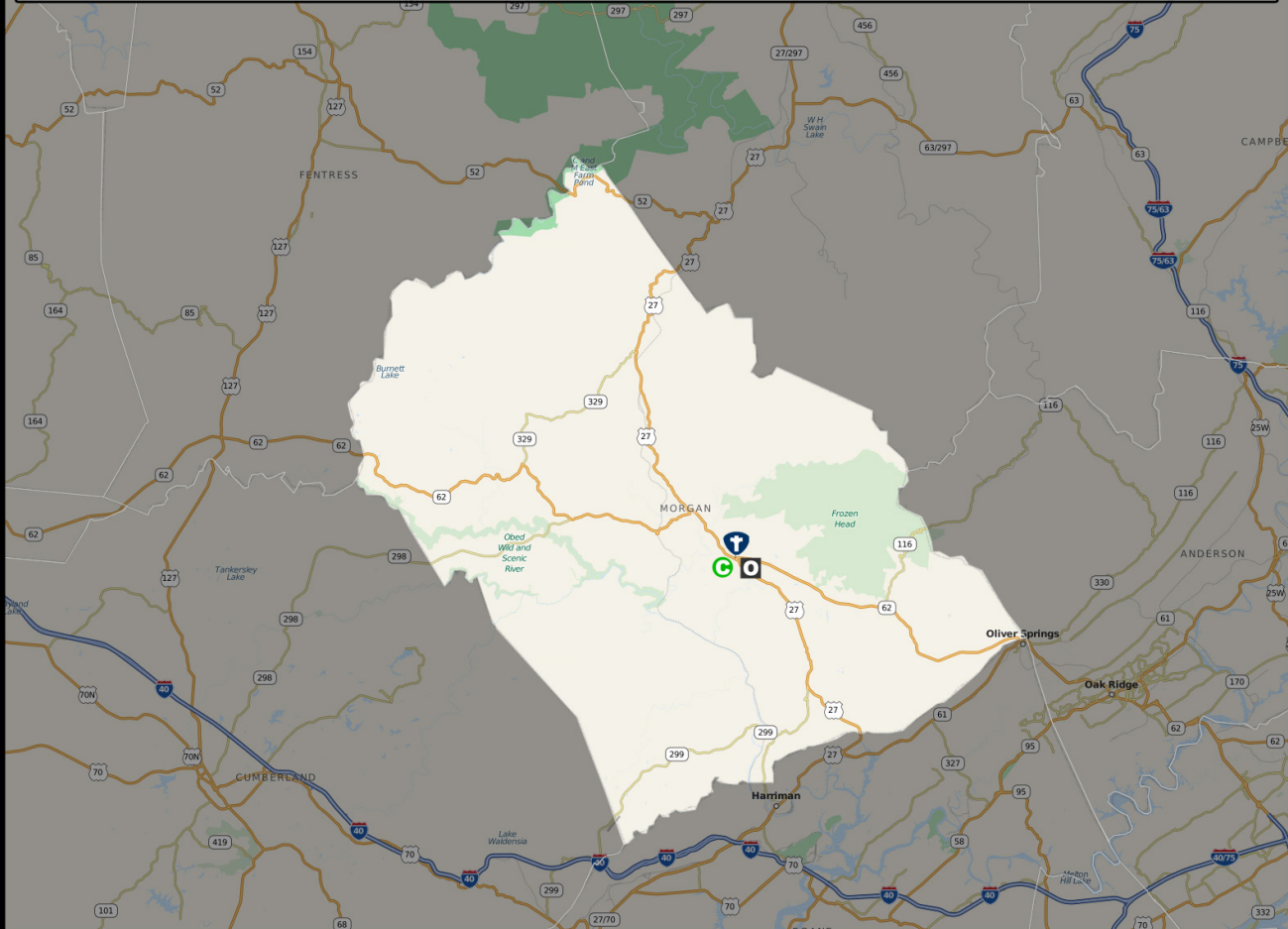
Free Clinic



Department of Health



Affiliate Office



## Statistics

Total Locations in Region: 3

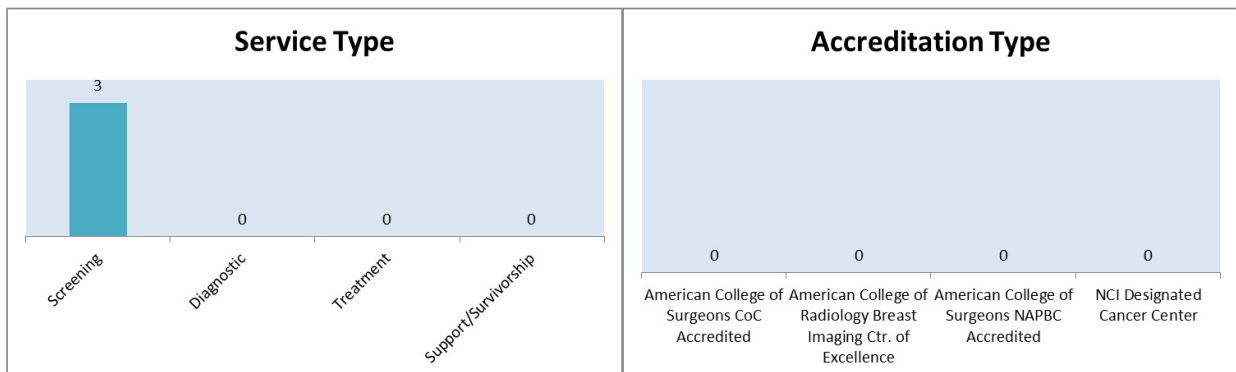






Figure 3.3. Breast Cancer Services Available in Morgan County


# Roane County


 Hospital
 

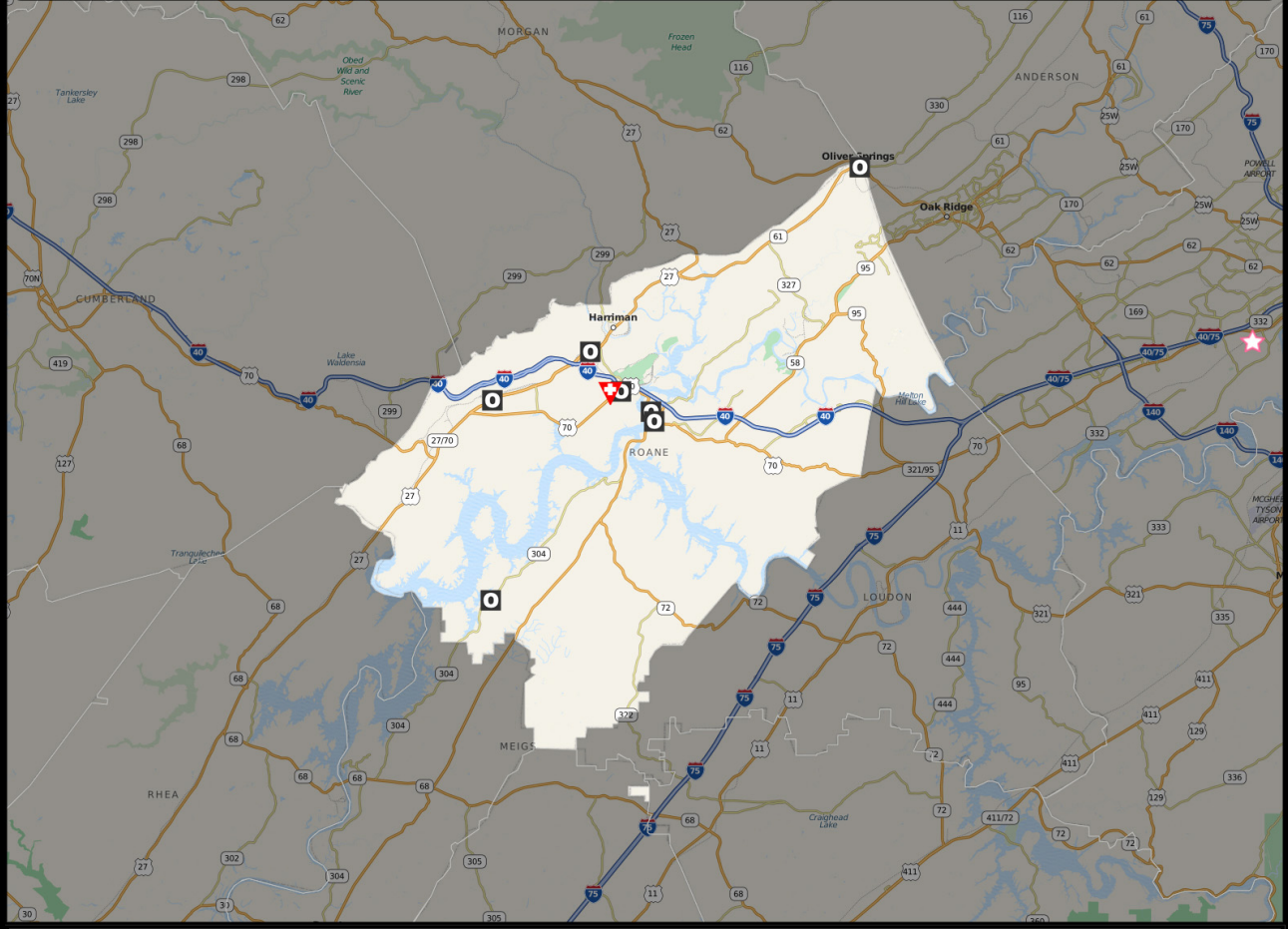
 Community Health Center
 

 Other

 Free Clinic
 

 Department of Health
 

 Affiliate Office



## Statistics

Total Locations in Region: 8

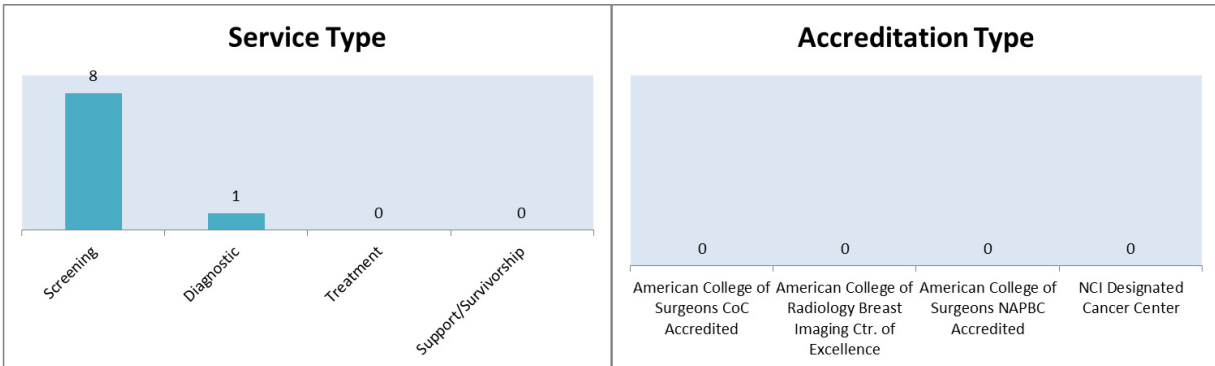


Figure 3.4. Breast Cancer Services Available in Roane County



# Union County



Hospital



Community Health Center



Other



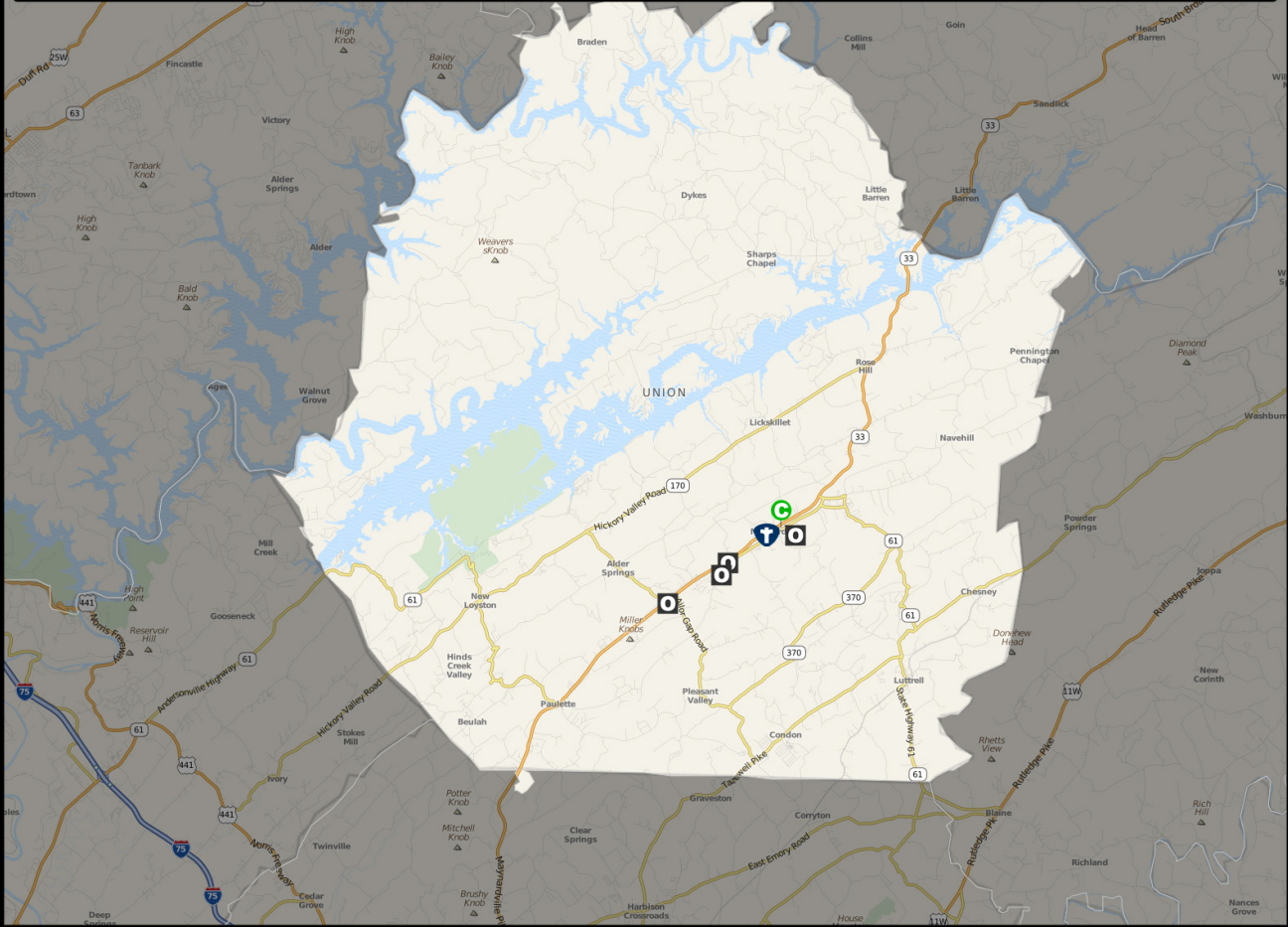
Free Clinic



Department of Health



Affiliate Office



## Statistics

Total Locations in Region: 6

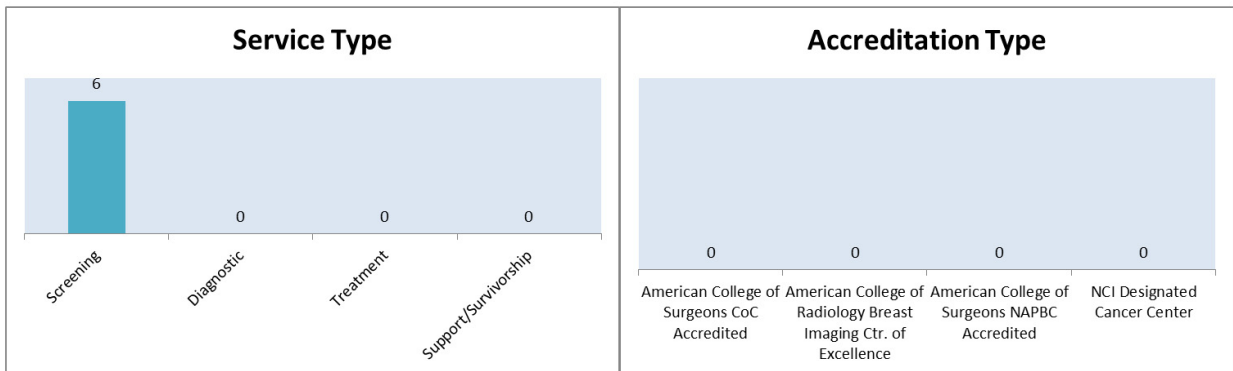


Figure 3.5. Breast Cancer Services Available in Union County

## **Public Policy Overview**

### ***National Breast and Cervical Cancer Early Detection Program (NBCCEDP)***

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP), as overseen by the Center of Disease Control and Prevention (CDC), was established in 1990 to provide free or reduced cost mammograms and Pap tests to low-income, uninsured, and underinsured women (“NBCCEDP Saves Lives”, 2014). Currently, the NBCCEDP provides funding in relation to breast health for clinical breast exams (CBEs), mammograms, diagnostic testing if needed, and treatment referrals to all 50 states, the District of Columbia, five US territories, and 11 American Indian/Alaska Native tribes (“National Breast & Cervical,” 2014). In addition to clinical services, NBCCEDP programs utilize population-based methods such as public education, community outreach, care coordination, patient navigation, and quality reassurance (NBCCEDP Fact Sheet, 2013). These proven approaches are applied to increase screening compliance while reaching underserved populations (NBCCEDP Fact Sheet, 2013).

Federal guidelines establish a baseline for breast health program eligibility nationwide while states customize the program according to these decrees (NBCCEDP Fact Sheet, 2013). Nationally, women who are at or below 250 percent of the federal poverty level and fall between the ages of 40-64 meet the federal guidelines for breast health services (“National Breast & Cervical,” 2014). Approximately nine percent of US women are eligible for NBCCEDP breast cancer screening (“National Breast & Cervical,” 2014). Unfortunately, only 11.7 percent of women eligible for breast health screening are being served (“National Breast & Cervical,” 2014). In 2000, Congress passed the Breast and Cervical Cancer Prevention Treatment Act of 2000 (Public Law 106-354) that allows states to offer women diagnosed with breast cancer the ability enroll in Medicaid for treatment coverage (“National Breast & Cervical,” 2014). The Tennessee Breast and Cervical Early Detection Program (TBCCEDP) as established in Tennessee is described below.

### ***Tennessee Breast and Cervical Early Detection Program (TBCCEDP)***

The Tennessee Breast and Cervical Cancer Early Detection Program (TBCCEDP) has a mission to reach and serve lower income uninsured, or underinsured, women in Tennessee while reducing the incidence of these diseases. TBCCEDP partners with local health departments and providers to provide breast and cervical screening services, such as clinical breast examinations (CBEs), mammograms, cervical cancer screenings, and office visits to eligible Tennessee women, as defined below. Women who receive suspicious results are provided with diagnostic testing. If a diagnosis of breast cancer, cervical cancer, or pre-cancerous cells is determined, these individuals are enrolled inTennCare, Tennessee’s Medicaid managed care program, for treatment coverage.

TBCCEDP receives both federal and state dollars as funding sources. Since 2007, the CDC has allocated approximately \$1.2 million annually to TBCCEDP while the state has remained steady with its match at \$1 million (K. Luskin, personal communication, June 24, 2015). Additionally, TBCCEDP has consistently received funding from Susan G. Komen Affiliates across the state. Since 2006, Komen Knoxville, through its Community Grant’s Program, has awarded \$826,500 to the Tennessee Department of Health Eastern Region to supplement the TBCCEDP program in its 16 county service area.

To be eligible for services, Tennessee women must meet certain criteria. An individual must be between 40 and 64, have an income at or below 250 percent of the Federal Poverty Line (FPL), and be uninsured or underinsured (TBCCEDP, 2013). Mammograms are only available to women between the ages of 50 and 64 unless a family history of breast cancer is evident (“Breast and Cervical,” 2014). If a family history can be

determined, a patient may start receiving mammograms at age 40 (“Breast and Cervical,” 2014). As in many cases, there are women who have suspicious symptoms apparent before the stated ages (“Breast and Cervical,” 2014). In this case, women younger than the age of 40 who meet the general eligibility requirements will be enrolled in TBCCEDP for screening (“Breast and Cervical,” 2014). Diagnostic testing will follow if suspicious results return from the original tests (“Breast and Cervical,” 2014).

In order to receive services, contact must be made with the county health department where residency is established. Upon determination of eligibility, an appointment will be made for breast and/or cervical screening (“Breast and Cervical,” 2014). Some community health centers throughout the state such as those in Nashville, Chattanooga, Memphis, and some in other rural areas may also provide these services (“Breast and Cervical,” 2014). Additionally, each public health region has an approved network of providers who perform screenings, diagnostic tests, and follow-up appointments (“Breast and Cervical,” 2014). To determine additional center locations and/or to find a network of providers, the TBCCEDP Central Office should be contacted at 1-877-969-6636 (“Breast and Cervical,” 2014).

### ***State Comprehensive Cancer Control Coalition***

The Tennessee Cancer Coalition (TC2) was formed in 2003 to measurably reduce the cancer burden in Tennessee by implementing a collaborative statewide plan driven by data, science, capacity and outcomes. TC2 has now grown to include over 500 members, including health care providers, researchers, cancer survivors, advocates, public health professionals, insurers and employers from seven regions across the state.

TC2 has released three state cancer plans since its inception. The latest Tennessee Comprehensive Cancer Control Plan was released in 2012 and provides a roadmap for the coalition's activities for 2013-2017. The plan includes cancer-specific chapters that identify goals, objectives and strategies to improve cancer outcomes across the state. Chapter 19 of the plan is dedicated to women's cancer with objectives related to breast cancer and strategies that increase collaboration with Tennessee Susan G. Komen Affiliates.

The State of Tennessee Cancer Plan 2013-2017 includes the following goal and objectives that include breast cancer:

#### **Goal 1**

Reduce female breast, cervical, ovarian and uterine cancer mortality through increased awareness, early detection, diagnosis and treatment. Mortality rates for 2005-2009 and reduction goal by June 2017: breast rate of 24.0, reduce to 22.0; cervical rate of 2.8, reduce to 1.8; ovarian rate of 8.1, reduce to 7.1; and uterine rate of 3.8, reduce to 2.8.

#### **Objective 1.1**

Increase awareness of these cancers, current incidence rates, current mortality rates and screening guidelines and to promote access to services and increase screenings by conducting annual updates on the rates for each of the TC2 regions.

#### **Strategies:**

- Develop and promote public information campaigns with state partners (American Cancer Society (ACS), the six Susan G. Komen Affiliates, family practice physicians, OB/GYN physicians, mammography facilities, etc.).
- Identify counties with the highest rates of breast and cervical cancer for special community-based campaigns through the work of the regional Tennessee Cancer Coalition (TC2) coalitions.
- Continue to emphasize targeted outreach to underserved groups through the University of TN Extension statewide, county-based educational delivery systems, The Witness Project of Davidson

County, Komen grantees and other local initiatives for breast and cervical cancer awareness and screening.

- Promote awareness in January (Cervical Cancer Prevention Month), September (Gynecological Cancer Awareness Month), and October (Breast Cancer Awareness Month) through TC2 regional coalitions.
- Work with medical and health care practitioner societies to encourage members to promote regular, periodic screening for breast and cervical cancer.
- Review trends in ovarian and uterine cancer, at least bi-annually, and advocate for screening if evidence-based screening methods become available before 2017.

### **Objective 1.2**

By June 2017, increase funding for breast and cervical cancer screening.

Strategies:

- Advocate for the expansion of state funding to improve TN's incidence and mortality rates for these two highly treatable cancers, if the cancers are caught early.
- Support local Susan G. Komen Affiliate's fundraising activities which in turn support local education and screening services.
- Advocate for an increased appropriation from the federal government so that all states have additional resources for their state breast and cervical screening programs.

Currently, Komen Knoxville does not have a considerable relationship with TC2, but hopes to increase collaboration in the coming years by reaching out to the East Tennessee representatives and becoming more involved on a regional level. The Affiliate sees this as a particularly great opportunity to join forces in advocacy efforts related to increased funding for NBCCEDP, one of Susan G. Komen's major policy priorities.

### ***Affordable Care Act***

According to the Kaiser Family Foundation, the 2010 Affordable Care Act (ACA) has the potential to extend coverage to many of the 47 million nonelderly uninsured people nationwide, including the 850,000 uninsured Tennesseans. The ACA establishes coverage provisions across the income spectrum by providing states the option to expand Medicaid and offering tax credits for those who purchase through the Health Insurance Marketplace (Kaiser Family Foundation, 2014).

Governor Bill Haslam announced Tennessee would not develop and administer a State Health Insurance Exchange. Therefore, in Tennessee, it is federally facilitated. He also announced that the State would not expand Medicaid. Prior to the enactment of the ACA, it was estimated there were 850,000 uninsured Tennesseans. Of the 850,000 uninsured, 305,628 were determined eligible to enroll in a marketplace plan, and, of that number, 169,470 individuals were determined eligible to enroll in a marketplace plan with financial assistance. In Tennessee, 151,352 individuals have selected a marketplace plan. (Kaiser Family Foundation, 2014; DHHS, 2014) According to a report recently issued by the Council of Economic Advisors, an additional 254,000 Tennesseans would have insurance coverage by the year 2016, if the state were to expand Medicaid (Council of Economic Advisors, 2014). The decision not to expand Medicaid has consequences, not only for the uninsured in Tennessee, but for medical providers, such as rural hospitals and disproportionate share hospitals, which serve a high number of uninsured individuals. Because the ACA was written to mandate the expansion of Medicaid in every state, there was no provision for financial assistance, such as premium tax credits, to purchase insurance through the health insurance marketplace for individuals or families whose income would make them eligible for Medicaid under the expansion.

With the Supreme Court ruling that Medicaid expansion is optional for states, hundreds of thousands of Tennesseans whose income is below 138 percent of the federal poverty level (FPL) (\$16,100 for an individual, \$27,300 for a family), find themselves eligible to purchase a plan through the marketplace, but at full cost, this is challenging. Hundreds of thousands of Tennesseans will, therefore, remain uninsured. According to The

Tennessee Justice Center, a small nonprofit law firm that provides free legal services to vulnerable Tennesseans, “Statewide, 47 percent of all uninsured Tennesseans, ages 18 to 64 have incomes below 138 percent of the federal poverty level, which would make them eligible for Medicaid under the new law. Expanding Medicaid could extend health coverage to over 300,000 Tennesseans.” (U.S. Census Bureau, 2014)

Even though the state is not expanding Medicaid eligibility, some currently uninsured people are eligible for Medicaid in 2014. Half (50 percent) of uninsured Tennesseans eligible for Medicaid are children who are already eligible but not yet enrolled in coverage. A small number of uninsured adult parents (nine percent of the uninsured in the state) are eligible for Medicaid in Tennessee under eligibility pathways in place before the ACA. Not all eligible individuals are enrolled in the program due to lack of knowledge about their eligibility and historic enrollment barriers. As the ACA expansions are implemented it is likely that broad outreach efforts and new streamlined enrollment processes will lead to increased enrollment of eligible individuals into Medicaid. (Kaiser Family Foundation Fact Sheet, 2014).

For medical providers such as rural hospitals or hospitals that serve a high number of uninsured individuals the effect of not expanding Medicaid is also detrimental. Hospitals that serve a disproportionate share of uninsured individuals receive additional funding (DSH) payments. But hospitals agreed to accept cuts in DSH along with other Medicare and Medicaid payments.

Under the provisions of the ACA all health plans in the Health Insurance Marketplace must offer “essential benefits” which include breast cancer mammography screenings every one to two years for women over 40, breast cancer genetic test counseling (BRCA) for women at higher risk for breast cancer, and breast cancer chemoprevention counseling. These services must be provided without charging a co-pay or co-insurance. However, although many more women in Tennessee may have insurance coverage through the ACA Health Insurance Marketplace, and have these benefits available to them, many barriers still exist that could prevent full utilization of these benefits. These barriers include lack of education, geographic isolation, lack of access to services/providers, lack of access to reliable transportation, misunderstanding/fear of the need for cancer screenings, and language/cultural barriers.

The role of Komen and the role of each Affiliate in Tennessee is as critical as it has always been. The Affiliate mission has not changed and the challenges faced by those the Affiliate has promised to help has not changed.

### ***Affiliate Public Policy Activities***

Susan G Komen Knoxville follows Komen Headquarters’ Public Policy Model guidelines in promoting the following advocacy priorities:

- Protecting federal and state funding for the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), to ensure all women have access to potentially lifesaving breast cancer screening;
- Ensuring continued federal investment in cancer research through the National Institutes of Health (NIH), National Cancer Institute (NCI) and Department of Defense (DOD), to discover and deliver the cures.
- Requiring insurance companies provide coverage for oral anti-cancer drugs on a basis that is no less favorable than what’s already provided for intravenously-administered chemotherapy, to protect patients from high out-of-pocket costs; and



- Expanding Medicaid Coverage to ensure the availability of the full-range of breast health services to low-income women, including cancer screening, diagnostics and treatment.

Members of the Komen Knoxville community (Including board members, grantees, and race participants) are encouraged to join the efforts regarding these particular priorities. Komen Knoxville plans to utilize the State Campaign Issues Toolkit in the coming years to better communicate advocacy priorities to legislators; and hopes to collaborate with other Tennessee Affiliates to schedule meetings with members of Congress whose districts correspond with the Affiliate's service area during their recess to discuss these issues.

Susan G. Komen Knoxville includes several advocacy activities in their annual mission plan. All elected officials will receive a copy of the completed community profile to inform them of the work Komen is doing in their service area. Also, local city and county mayors are invited to participate in the Race for the Cure® and are given an opportunity to say a few words to the participants before the start. Komen Knoxville continues to have great support from these political leaders, with both the Knox County and the City of Knoxville Mayors publicly recognizing Race for the Cure Day and Breast Cancer Awareness Month being endorsed state wide by Governor Bill Haslam.

The State of Tennessee has additional organizations furthering breast cancer advocacy, including the Tennessee Breast Cancer Coalition, the Tennessee Cancer Coalition, and American Cancer Society's Cancer Action Network.

### **Health Systems and Public Policy Analysis Findings**

The Health System's Analysis (HSA) reveals that there are major gaps in access to care within the target communities. While there are several screening facilities in each county, the vast majority of them only perform clinical breast exams (with the exception of the mobile mammography unit), and refer to neighboring counties for additional screening. A clinical breast exam is a vital part of the screening process, but leaves those needing additional services in a bind. For example, in Union County, the mobile unit serves as the only access to screening mammograms, and they do not have the capability to screen women that present with a problem. Neither Union nor Morgan County has diagnostic or treatment services available, creating a barrier for individuals that require these services.

With the exception of the local health departments, Komen Knoxville does not have any grantees located in these four counties. While residents are still eligible for services, they often are unaware assistance is available. This also excludes them from many survivorship/support activities, given the burden of the drive. Patients often acquire financial assistance for expenses during treatment but are unable to participate in support groups or other survivorship activities that can be so encouraging. The NBCCEDP continues to be a major strength in the state of Tennessee, so much in fact, that the program runs out of funding before the end of their fiscal year, at times forcing women to wait months in order to receive screening. Another downfall of the NBCCEDP is that it does not extend coverage to men. While it is rare for men to be diagnosed, in the event it does occur, and the individual is uninsured, they face a major challenge.

Another strength across the state is the Tennessee Cancer Coalition. While it covers the entire gamut of cancer control, it has specific objectives related to breast cancer awareness. Currently, Komen Knoxville does not have a strong relationship with the coalition, something it hopes to invest in during the coming years. Komen Knoxville also hopes to work with the other Tennessee Affiliates to increase advocacy collaboration statewide, knowing that this will be key in producing change.

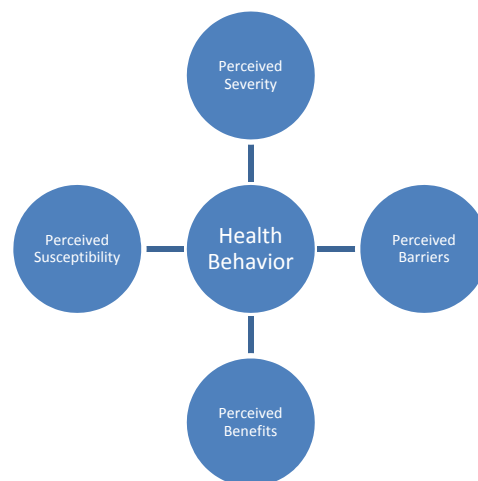
# Qualitative Data: Ensuring Community Input

## Qualitative Data Sources and Methodology Overview

### *Methodology*

Komen Knoxville utilized the Health Belief Model as a framework for developing qualitative questions and assessment variables. The Health Belief Model is often used in public health practice to understand change and maintenance in health behaviors. The model in its simplest form consists of four parts: perceived susceptibility, perceived severity, perceived benefits, and perceived barriers. The first, perceived susceptibility, looks at an individual's perception of his/her vulnerability to the health condition: do they see themselves at risk? The second, perceived severity, is the individual's thoughts of how severely it could affect his/her life or the lives of those around them. Perceived benefits examines whether or not the individual views the behavior as having a benefit: does the considered behavior change really make a difference in risk or severity of the condition? The last factor, perceived barriers, takes into account what barriers to action exist and what will have to be overcome or worked around to adopt this new behavior. Barriers can present themselves in many different ways, including financial, social, and cultural or others. This is an examination of whether the benefit is worth the cost. Komen Knoxville was interested in how these aspects played into the breast cancer Continuum of Care (CoC), primarily entering the CoC and accessing screening.

The Health Systems Analysis concluded that the state has a strong breast and cervical program, allowing women to enroll in TennCare (Tennessee's Medicare) for up to five years upon a breast cancer diagnosis. For this reason, the Affiliate focused more on the early stages of the continuum and causes of late-stage diagnosis rather than treatment and follow-up. Questions all followed this general model, but they were adapted to each specific group of participants, and supplemental questions were asked that fell outside of these categories as needed.



**Figure 4.1.** Health Belief Model

Susan G. Komen Knoxville chose to utilize three qualitative methods to collect information in the target communities: focus groups, key informant interviews, and surveys. Each method reached out to a particular group of interest in the community to gather its insight.

Komen Knoxville's Quantitative Data Report identified four priority counties: Claiborne, Roane, Union, and Morgan Counties. Given the geographical grouping of the counties and the small female population of Morgan County (9,795) and of Union County (9,585), the Affiliate decided to combine the counties into two target areas: Northeast, including Claiborne and Union and Southwest, including Morgan and Roane.

### *Focus Groups*

Komen Knoxville used focus groups in the target communities to gather rich, in-depth data from the local women. Given the barrier of random recruitment within rural communities, Komen Knoxville contracted with an independent research firm, U30, to conduct focus groups. The researcher was responsible for recruiting, developing the moderator guide, and moderating the discussions. U30 and Komen Knoxville worked together to develop the script for the focus groups. Following the outline of the Health Belief Model, the script included questions that addressed each of the four components as they relate to breast cancer screening. The focus group sessions were recorded and provided to the Affiliate on DVD for review. Susan G. Komen Knoxville's Director of Community Programs analyzed the focus group recordings for key themes.

### *Key Informant Interviews*

Key informant interviews were also conducted in the target communities by Komen Knoxville's Director of Community Programs. The goal was to collect information from a diverse group of community experts who have a thorough understanding of community thoughts, beliefs, and practices, especially pertaining to breast cancer. Phone interviews were selected as the method to reach this group in order to accommodate key informants' demanding schedules and to decrease expenses associated with travel to target communities. Key informant interviews followed a basic template, but the questions were adjusted given the direction of the conversation and the individual's knowledge of breast cancer. A few informants had a much greater knowledge of the community and health care as a whole but not specifically breast cancer.

Call Recorder, a recording app, was utilized to record most phone calls. The app allowed users to save the phone call in a media format that could be emailed and saved to the computer for later transcription and analysis.

### *Surveys*

Surveys were used to gather information from providers in the target communities. Surveys were selected as the data collection method for this target group because they were a more cost effective and efficient way to reach providers. The surveys were administered via FluidSurveys through email, and the providers were able to complete them at their convenience. The survey consisted of 17 questions that examined providers' views of accessibility to care, barriers to service, and the level of education of women in their communities. The survey also allowed providers to make suggestions for improvements to the Affiliate.

### *Triangulation*

By utilizing the three methods of qualitative data collection (focus groups, key informant interviews, and surveys), triangulation across multiple sources was obtained. The Health Belief Model served as the focal point for review and interpretation for each method. Qualitative data methods were also developed and analyzed with the results from quantitative analysis and the health systems analysis in mind. For example, in counties that were labeled as rural and medically underserved through quantitative measures, the Affiliate wanted to

assess how issues such as transportation and distance to appropriate medical care contributed to an individual's breast health.

### *Sampling*

#### *Focus Groups*

Two focus groups were conducted, one in each target area. Participants were recruited randomly by the independent research firm U30, and a list of participants was provided to the Affiliate before each group session:

Group 1: Targeted Claiborne and Union Counties and included women ages 30-50 who had never had breast cancer.

Group 2: Targeted Morgan and Roane Counties and included women ages 51-64 who had never had breast cancer.

The age segregation of the two groups was chosen based on knowledge from within the communities that women seek medical care during pregnancy but often do not continue preventive care as their children get older. Group 2 also included older women who should be getting recommended screening but are not yet old enough to receive Medicare. Ten participants were randomly recruited for each focus group. They were incentivized with a cash payment for their time.

#### *Key Informant Interviews*

The Affiliate contacted individuals with whom it has a relationship for interviews. These key informants were also asked to recommend other potential informants from their areas. Additional key informants were recruited from online research, health councils, government offices, and other nonprofits active in the area. For each county, the Chamber of Commerce was contacted to learn more about how residents get information and to identify active community partners. Additionally, health department administrators were contacted and asked about health care needs, barriers, priority of breast health, and resources available to the medically underserved. Other informants included a county mayor, ETHRA (East Tennessee Human Resource Agency) directors, senior center administrators, clinic administrators, survivors, and health council members. Twelve interviews were conducted in each area, with the average length of each interview being approximately 17 minutes.

#### *Surveys*

Survey participants were recruited from the Health Systems Analysis. The office managers or nursing managers from all of the organizations identified in the HSA were contacted to see if they would be willing to disseminate the survey to their providers. For the purpose of the survey, providers included all levels of health care workers, including LPN, RN, PA, FNP, and MD. The Affiliate included all levels of providers in order to get a range of perspectives. The survey was also given to grantees affiliated with medical offices to disseminate among their providers.

#### *Ethics*

U30 research group was responsible for obtaining consent from focus group participants and following confidentiality measures for the focus group sessions. When recruited, all participants were read a non-disclosure and consent agreement assuring them of the confidentiality of their participation. Participants were advised of the purpose of the focus group, how the information from the focus group would be utilized, and that their participation was voluntary. After giving their verbal consent, participants were again advised at the start

of the focus group that their privacy would be protected. All participant data collected by U30 were given to Komen Knoxville and were stored on a password protected Komen Knoxville computer. DVDs of the focus groups were stored in a locked file cabinet at Komen Knoxville.

Komen Knoxville acquired verbal consent to record key informant interviews. Key informants were told how the information they provided would be utilized. They were also advised that their identities and any other personal information would not be disclosed and that they could withdraw their voluntary participation at any point with no consequences. After key informant information was collected, it was stored on a password protected Komen Knoxville computer.

The survey was administered in such a way that no identifying information other than county was required. An introductory statement was included with the survey stating the purpose of the survey, how information obtained from the survey would be utilized, and that participation was voluntary.

### **Qualitative Data Overview**

Focus group video and audio data were provided to the Affiliate via DVD. Due to budget and time constraints, complete transcription was not possible. Instead, the Affiliate created a modified transcript that included the key questions but omitted introductions and small-talk. The same modified transcription process was used for recorded key informant interviews. A few key informant interviews were conducted without audio recording. In those cases, detailed notes were taken during and immediately following the call. Survey results were printed directly from FluidSurveys.com.

Komen Knoxville's Director of Community Programs was responsible for analyzing all qualitative data. With the help of the documents in the Qualitative Data Toolkit, the Affiliate followed a six-step process for data analysis.

**Step 1: Record Data:** Once data were collected, they were immediately formatted and saved. Notes were typed and organized by region and data source. This was an ongoing process throughout data collection which ensured that information was recorded promptly and accurately.

**Step 2: Begin Coding:** Once data collection was complete for a specific method, the first step of coding began.

In the first step, all data were read. Surveys were reviewed first in their complete form and codes were assigned to themes/phrases in each response. A survey spreadsheet was made with each participant, the question, and the initial codes related to their answers.

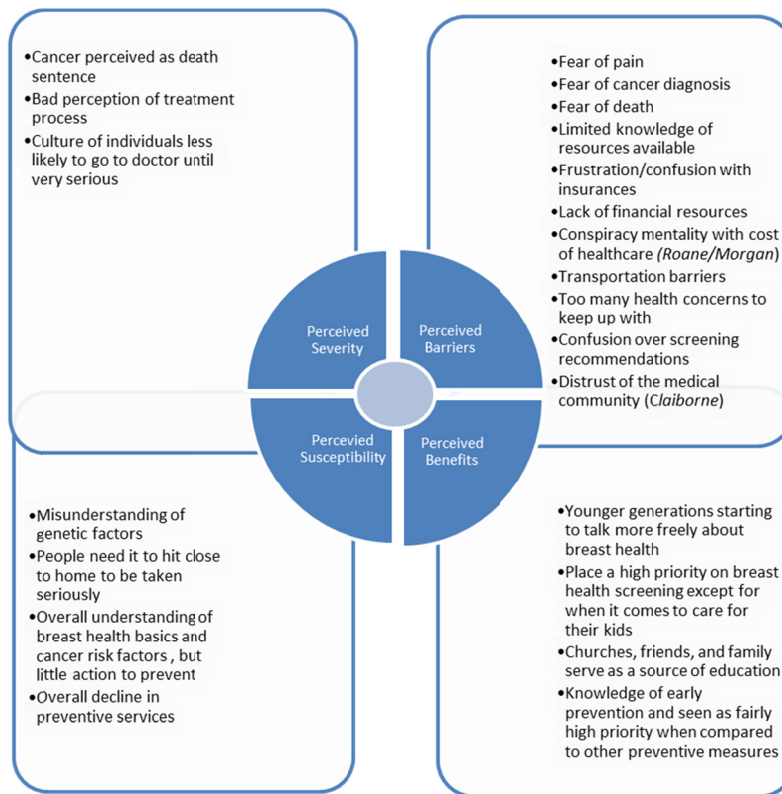
Key informant interviews and focus groups were coded in a similar manner via segments either by the question or grouping of related questions. Coding was done by hand. A master list of codes was generated throughout the process.

**Step 3: Data Reduction:** Once initial codes were assigned, the master code list was then evaluated for overlapping and redundant themes. This narrowed the list of codes to a more manageable number.

**Step 4: Identify Themes:** Remaining codes were grouped into categories based on barriers, benefits, severity, susceptibility, and other. These major categories are presented below in the findings.

**Step 5: Format the Data:** Data were formatted by inputting results in relation to the Health Belief Model (Figure 4.1). Other findings not pertaining to one of these four categories were also taken into consideration when determining overall conclusions.

**Step 6: Compare Overall:** As data were analyzed, similarities between the two target areas became apparent. Given that these communities are under the same state regulations, similar distances from Knoxville’s major medical centers and resources, and that they have similar social service agencies in their communities, results were combined into one final figure (Figure 4.2).



**Figure 4.2.** Komen Knoxville Findings

*Claiborne County & Union County*

In the Northeast, data showed that the majority of women primarily got their breast health information from friends and family. They also consulted their physicians for advice as needed. In Claiborne County, numerous sources noted that there was a culture of distrust when it came to health care providers, but residents were hopeful that the distrust would improve. Participants also felt that doctors were too rushed to provide adequate information which made them reluctant to ask additional questions.

Knowledge regarding the role of genetics and environmental factors pertaining to breast health was lacking. While there was an overall awareness of risk factors and the need for screening and early detection, there was a lack of follow through. While participants understood that early detection of breast cancer increased the likelihood of survival, they still strongly associated breast cancer with a death sentence. There was also an attitude of fear around the pain and vulnerability of a mammogram as well as a fear of the results of a mammogram. There were multiple remarks that people from Claiborne and Union Counties do not go to the doctor and will not go until their health conditions become extremely bad. Many providers confirmed this by stating that the emergency room was over-utilized and several other health conditions often go undetected for years. Providers also mentioned a decline in preventive services across the board, even when access and funding were available. It appears to be a problem not with availability, but rather utilization. It was noted that with barriers such as money and transportation, it was hard for many families to decide on which health issue to focus. Breast health care was considered important but was usually secondary to a child’s health care.

There was an overall lack of knowledge of the resources available, even to those in health care and social service roles. There was also a strong frustration with health insurance and a lack of understanding of the need for different insurance referrals, payments, etc.

Several qualitative questions focused on what it would take for women to take action when it comes to breast health. Across the board, women mentioned that it would have to “hit close to home” or be someone they loved for them to really pay attention. In the Northeast, participants reported that they would need to be motivated by loved ones to take action toward a health behavior.

*“It would take a case of being close to home, and that would make you stop and think.” – Focus Group Participant, Northeast*

*“My son would have to say, ‘What about me?’”- Focus Group Participant, Northeast*

*“If the right person that loves you and they tell you.” – Focus Group Participant, Northeast*

### *Roane County & Morgan County*

The Southwest had very similar results to that of Union and Claiborne Counties. One notable difference was that while Claiborne County participants noted lack of trust for providers, Roane and Morgan County participants noted more of an overall mistrust in the medical system related to health care costs, drug companies, and doctors’ salaries. There was also confusion and frustration around health care benefits, insurance coverage, and conflicting preventive recommendations.

The Southwest produced the same results as the Northeast in terms of fear of cancer in general. They shared the same fatalistic attitude toward breast cancer even when participants knew multiple survivors. The Southwest also represented a culture not likely to go to the doctor.

*“They weren’t raised to think about their health, they were just raised to think, whatever happens, happens.” – Focus Group Participant, Southwest*

This group also felt that awareness was most effective when shared from someone they knew. Women in the Southwest wanted more first-person, real stories of women with breast cancer. This population was also familiar with reality television and much more open to communication through television media.

*“Really, show me why they went [for screening] and how they found a lump.” – Focus Group Participant, Southwest*

*“It’s when it becomes a reality in your life that you think maybe I should get this checked.” – Focus Group Participant, Southwest*

*“If you could convince people, this is what could happen if you don’t do something and find it now, you’ve got this kind of outcome.” - Focus Group Participant, Southwest*

*“There needs to be some scare tactic.” – Focus Group Participant, Southwest*

In both areas, there was a lack of knowledge of available resources for breast cancer. Several breast cancer survivors were interviewed as key informants, and they mentioned that they didn’t know about Komen Knoxville until after they were diagnosed with breast cancer and finished with treatment. Many were also unaware of Komen Knoxville’s community grants program and local outreach.

## **Qualitative Data Findings**

### *Limitations of the Qualitative Data*

The major limiting factor to the focus group method of data collection was that only one focus group in each target community was conducted. Thus, the focus group results cannot be considered representative of women in the target communities. While the Affiliate thought better recruitment results would be obtained by contracting with an outside research group, the cost prohibited conducting additional groups. Because the two focus groups consisted of different ages, it was also hard to know if results were due to differences in ages or differences in geographical areas or both. To reduce this limitation, the Affiliate utilized three qualitative data collection methods rather than the recommended two.

Low response rate was a limitation of the survey method of data collection. Only 11 survey responses were completed within the allowed time frame. Office administrators and nurse managers were originally contacted via telephone and then sent two reminder emails to encourage participation. A better response rate may have been obtained had the Affiliate provided a shorter survey or targeted a specific group of providers. Another limitation was that a precise response rate was not known since the Affiliate did not know how many managers actually forwarded the survey and to how many individuals the survey was forwarded.

While the Affiliate conducted 12 key informant interviews in each target community, limitations included the sampling method. Given that many key informants were close associates of Komen Knoxville, this may have produced bias in their responses.

### *Conclusions*

The Affiliate's goal in qualitative analysis was to take the information that identified each county as a target community and assess how factors such as being medically underserved and rural played into the CoC, reveal possible explanations for the high incidence rates and death rates, and develop recommendations for the Affiliate moving forward.

### *Claiborne County & Union County*

As mentioned above, for the purpose of qualitative data collection, Claiborne and Union Counties were combined into one target area due to their geographical proximity and Union County's small population. Claiborne County was selected because of its below average incidence rates but above average late-stage diagnosis and death rates. This suggests a lack of screening and early diagnosis.

The Affiliate can conclude that Claiborne County has gaps in the CoC when it comes to screening, mostly related to lack of easily accessible and affordable screening and a culture that does not go to the doctor unless the health condition is perceived as serious. No data indicated that this was directly linked to a lack of services but rather to the utilization of services, with transportation being the greatest barrier.

Union County was selected as a target community given its high late-stage rate with an increasing trend. Death rate data for Union County was unavailable due to sample size, but the Affiliate hypothesized that it would be high as well.

Both Claiborne and Union Counties have low education rates, high poverty, and are considered rural and medically underserved populations. Poverty seemed to have the greatest impact on breast health in terms of making it a priority among other health concerns. The role education plays is still unclear. Given that the general education and awareness for risk reduction is present, how level of education affects a person's ability to take action needs further investigation.



### *Roane County & Morgan County*

Roane County was selected as a target community not only because of above average late-stage diagnosis and death rates, but also because of their increased incidence rate and their aging population.

Morgan County has the highest age-adjusted death rate in the service area, but like Union County, it is small in size, making quantitative data analysis challenging. They also had the highest age-adjusted rate for late-stage diagnosis but with a significant downward trend.

Morgan and Roane Counties were also both considered rural and medically underserved, something known to be a barrier in accessing care. While Roane and Morgan were statistically better in terms of education and poverty level than Claiborne and Union, the Affiliate was interested in investigating the extent to which those and other population indicators increase breast cancer susceptibility. Transportation was a major barrier for this area as well. Individuals found it difficult to make breast health a priority when they had multiple health concerns and limited resources to access care.

Roane and Morgan Counties' qualitative participants seemed to talk more about genetics, insurance, and preventive recommendations, but they also seemed to have greater confusion and frustration. While exposure to these topics among the population in Roane and Morgan Counties is encouraging, the level of uncertainty around these topics is not.

# Mission Action Plan

## **Breast Health and Breast Cancer Findings of the Target Communities**

The Quantitative Data Report (QDR) allowed the Affiliate to use reliable data to identify the highest priority areas for evidence-based breast cancer programs. In selecting target communities, the Affiliate looked primarily at the time needed for counties to meet the two Healthy People 2020 (HP2020) objectives for breast cancer.

Three counties, Claiborne, Roane, and Union, were identified as highest priority. The HP2020 report predicted that it would take 13 years or longer for these three counties to achieve the late-stage incidence target. It projected that Claiborne County and Roane County would take 13 years or longer to meet the death rate target (no data was available for Union County on this target).

Morgan County was the fourth county selected as a target community. Although Morgan County was predicted to take only two years to achieve the late-stage incidence target, other data showed that it had the highest age-adjusted death rate in the service area. The age-adjusted rate for late-stage diagnosis was also the highest in the service area.

The Affiliate also took into consideration key population characteristics in selecting target communities. All four counties were considered to be rural and medically underserved. The Health Systems Analysis (HSA) examined this further by evaluating strengths and weaknesses of each county's health systems and compared services available across the Continuum of Care to identify gaps. While Claiborne County and Roane County both have hospitals, only Claiborne County offers full diagnostic and treatment services at its hospital. Residents of the other three counties must travel across county lines to access appropriate breast screening (mammography/ultrasound) and treatment services. The presence of a mobile mammography program serving all four counties does allow some women easier access to regular screening.

Another strength identified by the HSA was the Tennessee Breast and Cervical Cancer Early Detection Program (TBCCEDP) which receives over \$2 million in federal funding annually to offer screening to lower income uninsured or underinsured women in Tennessee, allowing numerous women to have access to screening who otherwise would not be able to afford it. However, barriers to care may still exist in terms of eligibility gaps and transportation to facilities. In addition, the State of Tennessee chose to not expand Medicaid coverage or develop a State Health Insurance Exchange. While there is debate as to how not expanding Medicaid coverage will affect Tennesseans, it appears that a high percentage of citizens will remain uninsured due to high costs of purchasing insurance on the Marketplace without a provision for financial assistance. The implementation of the ACA does, however, provide a greater focus on preventive care services and insurance plans cover Essential Health Benefits, which include breast cancer screening.

Qualitative data were utilized to supplement findings from the QDR and HSA. The Affiliate utilized the Health Belief Model to develop qualitative questions and assessment variables. For qualitative data collection, the Affiliate utilized focus groups, provider surveys, and key informant interviews to gain community insight. The Affiliate combined the priority counties into two target areas to collect this data: Northeast (Claiborne County and Union County) and Southwest (Morgan County and Roane County). Two main questions arose:

1. How do the population characteristics of education and poverty levels affect breast health?
2. How does being medically underserved and having limited access to services across the continuum of care affect breast health?

In the Northeast, data showed that friends/family were the predominate source of breast health information. Breast cancer was strongly associated with death, and there was substantial fear related to screening and a possible diagnosis. Furthermore, the population in the Northeast does not go to the doctor unless the condition is very serious, explaining in part the high late-stage diagnosis rate. Health care providers surveyed

specifically noted that the population in this target area does not place a high priority on preventive health in general, but when compared to other health services, breast health ranked higher than most.

The Southwest counties produced similar results, including a fear of a breast cancer diagnosis and a culture that was unlikely to seek preventive and screening services, even though most were aware of general health screening recommendations. Other barriers to breast health care in the Southwest included lack of available transportation, financial limitations, multiple health issues, and confusion over resources available.

Both target areas related overall frustration with health insurance regulations and navigating the health care system. Consistent across counties was the idea that breast health information was most effective when given by someone they know and trust; if it was personal they were more likely to take it seriously.

The Mission Action Plan's problems, priorities, and objectives were developed after examining results across all data sources. The problems originated from the summary of the data and identified the major needs present in the target communities. The priorities refer to the goals the Affiliate hopes to achieve in addressing the problem or need. For Problems 1 and 2, priorities were chosen to address the need for early breast cancer detection in the four target counties. For Problem 3, priorities were selected based on the need for increased access to breast health service information along with access to breast health services in all four medically underserved target counties. Finally, priorities for Problem 4 were chosen based on the need to increase awareness of the importance of screening and early detection in the four target counties. The objectives for each priority are how the Affiliate plans to accomplish these goals.

## Mission Action Plan

**Problem 1:** In the Quantitative Data Report, the time predicted for Claiborne, Roane, and Union Counties to meet the Healthy People 2020 late-stage incidence rate was 13 years or longer. The time predicted for Claiborne and Roane Counties to meet the Healthy People 2020 death rate target was 13 years or longer. Based on these findings, Claiborne and Roane Counties are unlikely to meet Healthy People targets for both breast cancer mortality and late-stage incidence and Union County is unlikely to meet the late-stage incidence target by 2020. Qualitative Data also showed that women in Claiborne, Roane, and Union Counties fear breast cancer diagnosis, do not go to the doctor unless their health condition is serious, and do not place a high priority on preventive and screening services, all contributing to late-stage diagnoses and increased mortality rates.

**Priority 1:** Promote early detection in order to reduce the number of late-stage breast cancer diagnoses and reduce mortality rates from breast cancer among women in Claiborne, Roane, and Union Counties.

**Objective 1:** In FY-16 and 17, work with Komen Knoxville's Community Ambassadors in Claiborne, Roane, and Union Counties to conduct at least two group educational presentations per year in each county on the importance of screening and early detection.

**Objective 2:** In FY-16 and 17, work with Komen Knoxville's Community Ambassadors in Claiborne, Roane, and Union Counties to conduct at least one outreach activity per month in each of their counties to promote the message of early detection.

**Objective 3:** In FY-18, meet with at least two religious/community organizations in Claiborne, Roane, and Union Counties that will help promote the importance of screening and early detection.

**Objective 4:** In FY-18, partner with at least two other Tennessee Affiliates to develop advocacy plans for protection of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) funding at the federal level.

**Problem 2:** The Quantitative Data Report showed that Morgan County has the highest age-adjusted rate for late-stage diagnosis in the sixteen-county service area and a death rate that is significantly higher than the Affiliate's service area as a whole. Qualitative Data also showed that women in Morgan County fear breast cancer diagnosis, do not go to the doctor unless their health condition is serious, and do not place a high priority on preventive and screening services, all contributing to late-stage diagnoses and increased mortality rates.

**Priority 1:** Promote early detection in order to reduce the number of late-stage breast cancer diagnoses and reduce mortality rates from breast cancer among women in Morgan County.

**Objective 1:** In FY-16 and 17, work with the Komen Knoxville's Community Ambassadors to hold at least two group educational presentations per year in Morgan County on the importance of screening and early detection.

**Objective 2:** In FY -16 and 17, work with Komen Knoxville's Community Ambassadors to conduct at least one outreach activity per month in Morgan County to promote the message of early detection.

**Objective 3:** In FY-18, meet with at least two religious/community organizations in Morgan County that will help promote the importance of screening and early detection.

**Problem 3:** The Quantitative Data Report showed that 100 percent of the population in Claiborne, Morgan, Roane, and Union Counties is in medically underserved areas. In addition, the Health Systems Analysis found that residents of Morgan, Roane, and Union Counties do not have full diagnostic and treatment services available in their counties making access to breast health services more difficult. Furthermore, the Qualitative Data showed that residents of Claiborne, Morgan, Roane, and Union Counties have poor access to credible breast health information as they obtain the majority of their information from family and friends.

**Priority 1:** Increase access to breast health service information in Claiborne, Morgan, Roane, and Union Counties.

**Objective 1:** In FY-16 and 17, utilize Komen Knoxville's Community Ambassadors to hold at least two educational events per year in Claiborne, Morgan, Roane, and Union Counties to discuss available breast health services and provide culturally appropriate breast health educational materials.

**Objective 2:** By FY-17, develop a comprehensive listing of breast health resources available to residents of Claiborne, Morgan, Roane, and Union Counties and provide the listing to health councils, health departments, health care providers, and other community organizations for distribution within their counties.

**Objective 3:** By FY-17, begin to plan for ways to continue funding for Komen Knoxville's Community Ambassador Program past the 2-year funded grant period.

**Priority 2:** Improve access to breast health services among women in Claiborne, Morgan, Roane, and Union Counties.

**Objective 1:** In FY-17 and 18, give Community Grant funding priority to organizations that provide mobile mammograms, after-hours appointments, or other services that increase access to screening in Claiborne, Morgan, Roane, and Union Counties.

**Objective 2:** By FY-18, hold at least one collaborative meeting in Claiborne, Morgan, Roane, and Union Counties aimed at hospitals, primary care providers, and other community organizations to discuss methods to decrease barriers and improve continuity of care between referral, screening, diagnosis, treatment, and support services.

**Objective 3:** By FY-18, in collaboration with other community health care organizations, hold a community education event in Claiborne, Morgan, Roane, and Union Counties aimed at education on health insurance and navigating the health care system.

**Objective 4:** In FY-17, invite eligible organizations in Claiborne, Morgan, Roane, and Union Counties to participate in the 2016 Komen Knoxville Community Grant Writing Workshop.

**Problem 4: Qualitative data showed that there is a lack of importance placed on breast health services by women in Claiborne, Morgan, Roane, and Union Counties. All four counties have a culture that makes seeking preventive and screening services unlikely.**

**Priority 1:** Increase partnerships with community and health organizations to promote screenings in Claiborne, Morgan, Roane, and Union Counties.

**Objective 1:** In FY-17, provide information to family care and women's health providers in Claiborne, Morgan, Roane, and Union Counties through face-to-face meetings and presentations, emails, and mailings on the most current recommendations, resources available, and other evidence-based programs that would increase their patients' screening rates.

**Objective 2:** By FY-18, hold at least two meetings with hospitals, providers, or clinics in Claiborne, Morgan, Roane, and Union Counties to discuss how to promote breast health as a part of an overall health approach.

**Priority 2:** Increase Komen's health messaging to encourage screenings.

**Objective 1:** In FY-16, develop an Affiliate social media campaign that focuses on moving people toward screening action.

**Objective 2:** In FY-17, develop a plan for incorporating personal stories and first-person perspectives into health messaging and activities.

**Objective 3:** By FY-18, partner with health departments and other health care organizations in Claiborne, Morgan, Roane, and Union Counties to promote screening messages during Public Health Week and during other health-focused time periods.

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