COMMUNITY PROFILE REPORT 2015

SUSAN G. KOMEN®
ST. LOUIS

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Acknowledgments

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

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Executive Summary

Introduction to the Community Profile Report

Susan G. Komen® St. Louis was formed in 1999 by a passionate group of community volunteers committed to raising funds and awareness for the fight against breast cancer. The inaugural Susan G. Komen St. Louis Race for the Cure® was held in June 1999 with more than 10,200 participants, setting a record for the number of participants at an inaugural Komen Race.

Over the years, through the continued dedication of volunteers, board, and staff members – and through events including the Komen St. Louis Race for the Cure, Dine Out for the Cure and other year-round fundraising opportunities – Komen St. Louis has invested $40 million in the fight against breast cancer. Since its inception, Komen St. Louis has awarded more than $30 million in community grants to 44 organizations that deliver life-saving breast health services including breast cancer screening, breast health education, patient navigation, and support services. Komen St. Louis has also contributed over $9 million to breast cancer research. At the same time, more than $20 million in funding raised locally and nationally has come back to St. Louis area research facilities.

Komen St. Louis operates with a staff of four employees and is governed by a 10-member Board of Directors. The organization relies on the time, talents, and treasures of hundreds of committee volunteers that make it possible to be a leader in the fight against breast cancer in the greater St. Louis region.

Komen St. Louis strives to regularly educate, inform, and impact groups and individuals in the community, the region, and at the state level. Komen St. Louis not only focuses on grant-making and outreach, but it also advocates for breast health policy, research, and works to address health disparities within the service area.

Komen St. Louis serves 17 counties across two states. The service area includes the City of St. Louis and the Missouri counties of Franklin, Jefferson, Lincoln, Madison, Montgomery, Perry, St. Charles, St. Francois, Ste. Genevieve, St. Louis, Warren, and Washington, and the Illinois counties of Clinton, Madison, Monroe, and St. Clair. These counties cover over 9,300 square miles and range from urban to suburban to more rural areas. The service area's population includes approximately 1,454,710 females.

The purpose of the Community Profile is to align Komen St. Louis' strategic and operation plans by helping to establish granting priorities, education needs, and direction for marketing and outreach. It also assists Komen St. Louis in driving public policy efforts and strengthening sponsorships and community relations. 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 for Susan G. Komen St. Louis 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 was used to identify priorities within the Affiliate's service area, primarily based on estimates of how long it would take an area to achieve Healthy People 2020 national objectives for breast cancer late-stage diagnosis and death rates. The Quantitative Data Report provides data at the Affiliate and county level, as well as for the state and US averages. Overall, the breast cancer incidence rates and late-stage incidence rates and trends in Komen St. Louis' service area were higher than that observed in the US as a whole and slightly higher for death rates and trends.

Komen St. Louis selected four target communities within the 17-county service area that will be the focus of strategic efforts during the next four years: Perry County, Missouri; St. Louis City and St. Louis County, Missouri; St. Charles County, Missouri; and St. Clair County, Illinois. In selecting these communities, the Affiliate looked at Healthy People 2020 projected progress, incidence rates and trends, death rates and trends, late-stage rates and trends as well as various other demographic and socioeconomic factors.

Perry County was identified as highest priority due to the estimated amount of time needed to achieve the HP2020 target for late-stage diagnosis. Not only is the county's late-stage incidence rate higher than the US and service area averages, it is predicted to increase. Perry County also has a population with substantially lower education levels than the Affiliate as a whole and a higher percentage of the population living at or below 250 percent of the Federal Poverty Level.

St. Louis City and St. Louis County, Missouri were combined into one target community. St. Louis County is the most populous county in the Affiliate service area and is one of the more racially diverse counties, with a substantially larger Black/African-American female population than the Affiliate as a whole. Additional quantitative data exploration was conducted to examine the extent of racial disparities regarding breast cancer death rates in this target community. This data showed that Black/African-American women die at a much greater rate from breast cancer than White women in St. Louis County and St. Louis City. St. Louis County was also selected as highest priority due to the estimated amount of time needed to achieve HP2020 targets for late-stage diagnosis and breast cancer death rates.

St. Louis City also has a substantially larger Black/African-American female population than the Affiliate as whole as well as substantially lower education levels, substantially lower income levels and employment levels, and a large percentage of adults without health insurance. In St. Louis City, half of the population lives at or below 250 percent of the Federal Poverty Level. In addition to these indicators, St. Louis City was identified as highest priority due to the estimated amount of time needed to achieve HP2020 targets for late-stage diagnosis and breast cancer death.

St. Clair County, Illinois also has a substantially larger Black/African-American female population and about a third of the county lives at or below 250 percent of the Federal Poverty Level. St. Clair County has been identified as a high priority county due to the estimated amount of time needed to achieve HP2020 targets for late-stage diagnosis and breast cancer death rates.

Finally, St. Charles County, Missouri was identified as high priority due to the estimated amount of time needed to achieve HP2020 targets for late-stage diagnosis and breast cancer death rates. The county's breast cancer incidence rate and late-stage breast cancer incidence rate were higher than both the US and service area's averages.

Health Systems and Public Policy Analysis

The Health Systems and Public Policy Analysis evaluates the Breast Cancer Continuum of Care (CoC) and the delivery of health care in the community. The purpose of this section is to observe the potential strengths and gaps in the health care system that could affect a women's health as she works her way through the continuum (screening, diagnosis, treatment, and follow-up/survivorship services). These gaps were identified through asset mapping and an analysis of public policy and services available.

St. Louis County and St. Louis City have multiple hospitals with quality of care indicators that provide breast health services across the Breast Cancer Continuum of Care. Additionally, Show Me Healthy Women (SMHW), Missouri's Breast and Cervical Cancer Early Detection Program, has 24 locations in this target community that provide screening services to the uninsured. However, many of these locations only provide clinical breast exams on site. Four facilities have mobile mammography vans, which provide accessible screenings in several locations throughout parts of the service area.

While there are numerous quality providers with services throughout the CoC, major barriers still exist regarding access. More than 50.0 percent of this target community has income below 250 percent of the Federal Poverty Level, more than 30.0 percent live in medically underserved areas, and more than 20.0 percent have less than a high school education (Susan G. Komen, 2014). There are only two free clinics in this target community, and costs of care beyond screening, including diagnostic care and treatment, can be out of reach for these populations. Due to barriers including financial burdens, lack of education, and lack of transportation, many women are not accessing services.

The target community of St. Charles County, Missouri, also has numerous quality providers with breast health services throughout the CoC. There are three SMHW providers, including a free clinic. While screening services are accessible for many women, services beyond screening along the CoC may not be covered due to lack of insurance coverage and financial assistance in these areas.

Perry County has one hospital, which provides services across the Continuum of Care. There is only one SMHW provider in the county, making access to screening services for the uninsured/underinsured challenging. This could lead to delayed diagnoses and presentation with more advanced stages of breast cancer.

In St. Clair County, Illinois, there are two facilities that provide services throughout the CoC. In this target community, there is a lack of support and survivorship services beyond financial assistance and end-of-life care. St. Clair County Health Department is a lead agency for the Illinois Breast and Cervical Cancer Program (IBCCP), and it provides navigation of financial assistance and breast health services to this target community. Despite this, there are still barriers to access of care, with 55.9 percent of the population living in medically underserved areas and 32.5 percent of the population with an income below 250 percent of the Federal Poverty Level (Susan G. Komen, 2014).

Missouri's Show Me Healthy Women program and the Illinois Breast and Cervical Cancer Program are jointly funded through the Centers for Disease Control and Prevention and the state health departments. Eligibility criteria vary slightly between states, but those who qualify are eligible for free screening and diagnostic services. Women are also eligible for Medicaid-funded treatment depending on how they enter the process.

In terms of the Affordable Care Act (ACA), the biggest implications for breast health include the Essential Health Benefits and Medicaid expansion. As of 2014, the minimum coverage provision requires most US citizens and legal residents to obtain and maintain coverage for themselves and their dependents or pay a penalty. Essential Health Benefits are items and services that must be covered within a plan and include well-woman exams and mammography screenings. The ACA expands Medicaid coverage for most low-income adults to 138 percent of the Federal Poverty Level (about $32,500 for a family of four). In June 2012, the US Supreme Court ruled that states could choose whether or not to implement the Medicaid expansion. Illinois has chosen to expand Medicaid, while Missouri does not have a current plan to implement the expansion.

In 2012, approximately 14 percent, or 834,000 Missourians, were uninsured. With the insurance mandate, Missouri opted to use the federal Health Insurance Marketplace, Healthcare.gov. Illinois also had 14 percent of the population uninsured and opted for a State Partnership Marketplace, getcoveredillinois.gov. In 2014, Illinois also implemented the Medicaid expansion, making 36.0 percent of uninsured Illinoisans eligible for Medicaid coverage.

The implementation of ACA and Medicaid expansion has implications for health care providers and patients in both Missouri and Illinois. ACA provides a larger focus on preventative care, provides increased support to federally qualified health centers, and covers Essential Health Benefits with no deductible or co-pay. However, there are still numerous barriers to eligible people receiving health care coverage and utilizing services.

Komen St. Louis, along with Komen Greater Kansas City and Komen Mid-Missouri, joined together with other cancer-related organizations in the state to form the Missouri Coalition for Cancer Treatment Access (MCCTA). The MCCTA supported state legislation that would ensure cancer patients in Missouri have equal access to intravenous and oral chemotherapy. In Illinois, Komen St. Louis relies on and takes the lead from both the Komen Chicagoland and Komen Memorial Affiliates regarding Illinois public policy initiatives. Komen St. Louis also participates in Komen Advocacy webinars and events and supports national advocacy priorities.

Qualitative Data: Ensuring Community Input

Komen St. Louis relied heavily on the Quantitative Data Report (QDR) and Health System and Public Policy Analysis (HSA) in developing key assessment questions and variables for each target community when it came time for qualitative evaluation. Varying data collection methods were used depending on the feasibility in the target community, but a minimum of two methods were used for each of the four areas. Health care provider surveys were used for each target community, along with either key informant interviews or focus groups. Online provider surveys were used to get information on how the Continuum of Care works in the target communities from the perspective of those working in it. Providers of all levels were encouraged to participate.

In Perry County, key informant interviews with community members were used to investigate how issues related to socioeconomic status and geographic proximity to major cities actually affected breast cancer incidence and death. Additionally, Komen St. Louis evaluated if lack of education was a barrier, if education around breast health was present, if access was the limiting factor, or any combination thereof. Nine key informant interviews were conducted in Perry County from a wide range of individuals, including health department administrators, the Chamber of Commerce and social workers.

The main assessment variables for St. Louis City/County were evaluating the level of understanding regarding breast health, barriers to screening services and potential causes for racial disparity. Three focus groups were conducted in this target community, one with breast cancer survivors diagnosed within the last ten years; a second group that consisted of health care workers; and a third group of eight city leaders and community volunteers, all of whom had a vast knowledge of the status of breast cancer in the area.

In St. Charles County, Komen St. Louis assessed barriers to screening and possible causes for late-stage diagnosis. Six key informant interviews were conducted in St. Charles County. The Chamber of Commerce provided information about how residents get information, and other health organization executives shared their perspective on breast health and general health needs in the community.

In St. Clair County, Komen St. Louis chose to further investigate any racial gaps and causes for disparities, as well as to see how differences in state policy may affect access to care or breast health services, since St. Clair County is the only Illinois target community. Two focus groups

were organized, each with participants representing several organizations from the community. One group consisted of all Black/African-American individuals, and the second group consisted of multiple races. Each participant had a strong understanding of breast cancer, either personally or professionally.

Data were analyzed and major themes were identified from across data sources. Figure 1 shows the key findings for each target community.

Perry County, Missouri	St. Louis City/ County, Missouri	St. Charles County, Missouri	St. Clair County, Illinois
• Lack of services available • Lack of education • Lack of understanding of Komen St. Louis • Unwelcoming community dynamics	• Conflicting demands • Lack of understanding of Komen St. Louis • Need for navigation • Increased need for services for young women and minorities • Barriers related to fear and financial constraints	• Lack of focus on preventative health • Lack of understanding of Komen St. Louis	• Racial disparities • High level of fear • Lack of education • High rate of mental illness and substance abuse • Financial and insurance barriers

Figure 1. Key Findings

Mission Action Plan

After taking all of the data into consideration and thoroughly analyzing the results, Komen St. Louis selected the following needs and priorities:

Problem/Need Statement #1
According to the Quantitative Data Report (QDR), all four target communities (Perry County, St. Louis City/County, St. Charles County, and St. Clair County) have higher than desired late-stage breast cancer incidence rates and are not predicted to meet the Healthy People 2020 target of 41.0 for late-stage breast cancer incidence.

Priority
Promote activities and initiatives that improve early detection and reduce late-stage diagnosis within the four target communities of Perry County, St. Louis City/County, St. Charles County, and St. Clair County.

Objective #1
In FY17, partner with Show Me Healthy Women/Illinois Breast and Cervical Cancer Program providers as applicable, in all four target communities (Perry County, St. Louis City/County, St. Charles County, and St. Clair County) to

determine ways to facilitate communication about program availability and encourage women to seek recommended regular screening.

Objective #2
By FY17, host a working group with key volunteers, staff, and grantees from all four target communities (Perry County, St. Louis City/County, St. Charles County, and St. Clair County) to evaluate the effectiveness of breast health/breast cancer educational messaging and outreach efforts focusing on early detection.

Objective #3
In FY17, the Komen St. Louis Request for Applications (RFA) for community-based grants will provide details that give funding priority to organizations that offer mobile mammograms, after-hours appointments, or other services that increase access to screening and strive to reduce late-stage diagnosis, specifically in Perry County, where facilities are limited.

Problem/Need Statement #2
According to the Quantitative Data Report (QDR), it is predicted to take 13 years or longer for St. Louis City/County to meet the Healthy People 2020 breast cancer death-rate target. The Health Systems Analysis (HSA) and Qualitative Data Report revealed that, despite numerous quality facilities, multiple barriers still limit utilization.

Priority
Increase partnerships with community and health organizations in St. Louis City/County to decrease or remove barriers across the Breast Cancer Continuum of Care.

Objective #1
By March 2017, collaborate with at least two organizations (churches, community organizations, health care facilities, etc.) that can help promote the message of breast cancer early detection in St. Louis City/County.

Objective #2
By March 2017, hold at least three meetings with hospitals, health care providers, or clinics in St. Louis City/County to discuss promoting breast health as part of an overall preventative health approach.

Objective #3
In FY17, host a meeting with other breast cancer organizations in the community to review coordination of services, reduce overlap, and effectively communicate resources available in St. Louis City/County.

Problem/Need Statement #3
According to the Quantitative Data Report (QDR), Blacks/African-Americans in the Komen St. Louis service area, specifically St. Louis City/County and St. Clair County, have a high breast cancer death rate and high late-stage incidence rate. Findings from the Health System Analysis and Quantitative Data Report revealed that few programs target this population specifically.

Priority
Improve Breast Cancer Continuum of Care coordination in order to reduce the late-stage diagnosis rate among Black/African-American women in St. Louis City/County and St. Clair County.

Objective #1
By March 2016, meet with at least three community organizations in St. Louis City/County and St. Clair County that work with the Black/African-American population to discuss breast health outreach.

Objective #2
By March 2017, identify and connect with at least three Black/African-American Ambassadors per community in St. Louis City/County and St. Clair County who can help link women with breast health services.

Objective #3
By March 2017, revise the Request for Applications (RFA) to include a funding priority directed at improving the Breast Cancer Continuum of Care for Black/African-American women in St. Louis City/County and St. Clair County.

Problem/Need Statement #4
Among the target communities of Perry County, St. Louis City/County, St. Charles County, and St. Clair County, the Qualitative Data Report showed a lack of understanding about Susan G. Komen St. Louis in terms of what the organization does and the organization's role in the community.

Priority
Work with the four target communities (Perry County, St. Louis City/County, St. Charles County, and St. Clair County) to promote understanding of Susan G. Komen St. Louis, helping to clarify how events such as the Susan G. Komen St. Louis Race for the Cure raise funds to benefit local breast health programs and breast cancer services through community grants.

Objective #1
By March 2017, conduct an in-house communications audit to analyze current communications efforts and identify opportunities for more effective communication about Komen St. Louis' community grants program.

Objective #2
By March 2017, create a new communication vehicle (such as an annual report) that helps illustrate how Komen St. Louis funding is utilized in the community as well as services available. The report will be made public on the Komen St. Louis website and distributed to constituents, community partners, donors, and potential supporters.

Objective #3
By March 2018, update grantee contracts for FY18 and following to include guidelines on proper acknowledgement of Susan G. Komen St. Louis in outreach efforts and on distributed materials.

The Mission Action Plan was approved by the Susan G. Komen St. Louis Board of Directors and will serve as the main reference for priorities in the coming years.

Disclaimer: Comprehensive data for the Executive Summary can be found in the 2015 Susan G. Komen St. Louis Community Profile Report.

Introduction

Affiliate History

Susan G. Komen® St. Louis was formed in 1999 by a group of motivated and hardworking community volunteers committed to raising funds to increase breast health awareness and to eradicate breast cancer. That same passion, carried on throughout the years by thousands of volunteers and dedicated board and staff members, has sustained Komen St. Louis and enabled the Affiliate to invest more than $39 million in the fight against breast cancer.

From the beginning, strong support from the community has been integral to the Affiliate's impact in the St. Louis region. More than 10,200 people participated in the inaugural Susan G. Komen St. Louis Race for the Cure® in June 1999, which set the record for number of participants at an inaugural Komen Race; this record still stands for inaugural Komen Race events.

Komen St. Louis' community grants program is made possible through the support of the Komen St. Louis Race for the Cure, other events throughout the year, individual donations and the generous support of corporate sponsors.

Since its inception, Komen St. Louis has awarded more than $29 million through more than 250 community grants. These grants have supported 44 local organizations that deliver life-saving breast health services – including free mammograms, breast health education and navigation through the health care system – to underserved women and men who may not otherwise have access due to low income, lack of insurance or other barriers.

Komen St. Louis has contributed more than $9 million to national breast cancer research since 1999. At the same time, more than $20 million in funding raised locally and nationally has come back to St. Louis area research facilities. Therefore, more than 100 percent of the dollars raised by Komen St. Louis has remained in and returned to the St. Louis region.

As a breast cancer leader and expert, Komen St. Louis' strives to regularly educate, inform and impact groups and individuals in the community, the region and at the state level. The Affiliate has hosted, sponsored and participated in events including a Clinical Research Education Day, a panel on breast cancer genomics and a Black/African-American Women and Breast Cancer conference. Komen St. Louis is a member of the Show Me Healthy Women Advisory Board and the Breast Cancer Community Partnership. The Affiliate also is part of the Missouri Coalition for Cancer Treatment Access and the Missouri Coalition for Chronic Care.

Komen St. Louis has received awards including the Quality of Life Award from the Mayor of the City of St. Louis, the Illuminator Award for outstanding leadership in the battle to eradicate breast cancer, and the Chairman's Award of Excellence from St. Mary's Health Center Foundation.

Affiliate Organizational Structure

Komen St. Louis is part of Susan G. Komen's Affiliate Network that serves more than 115 communities in the United States plus international locations. Komen St. Louis operates with a staff of four employees and is governed by a 10-member volunteer Board of Directors (see Figure 1.1). Committees, including Race, Grants, Public Relations and Marketing, Research Advocacy, and Special Events, report to respective staff members. The organization relies on the time, talents, and treasures of hundreds of committed volunteers to make it possible to be a leader in the fight against breast cancer in the greater St. Louis region.

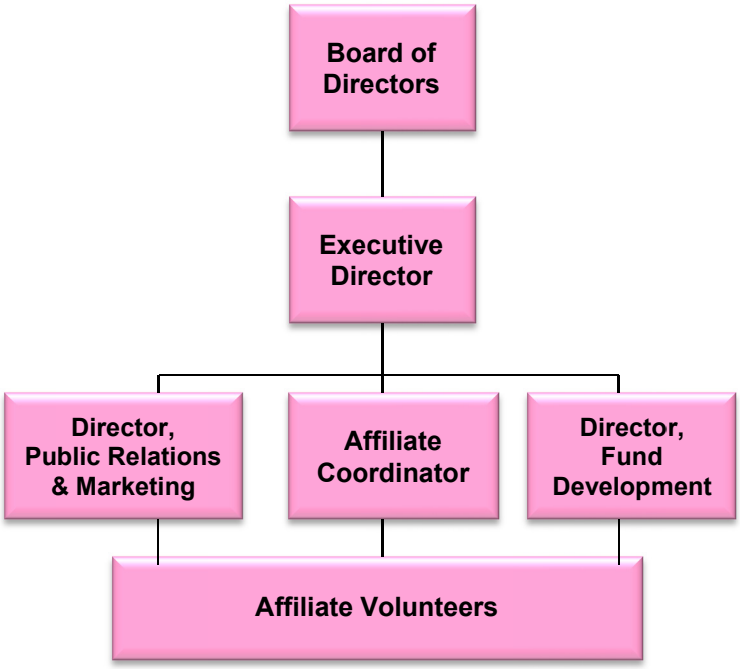


Figure 1.1. Komen St. Louis Organizational Structure

Affiliate Service Area

Komen St. Louis serves 17 counties in Missouri and Illinois (see Figure 1.2). The service area is a large and diverse geographic area that straddles the Mississippi River to include the City of St. Louis and the Missouri counties of Franklin, Jefferson, Lincoln, Madison, Montgomery, Perry, St. Charles, St. Francois, Ste. Genevieve, St. Louis, Warren and Washington and the Illinois counties of Clinton, Madison, Monroe and St. Clair. These counties cover over 9,300 square miles and range from urban to suburban to more rural areas. The service area's population includes approximately 1,454,710 females. Tables 1.1 and 1.2 display key population demographics.

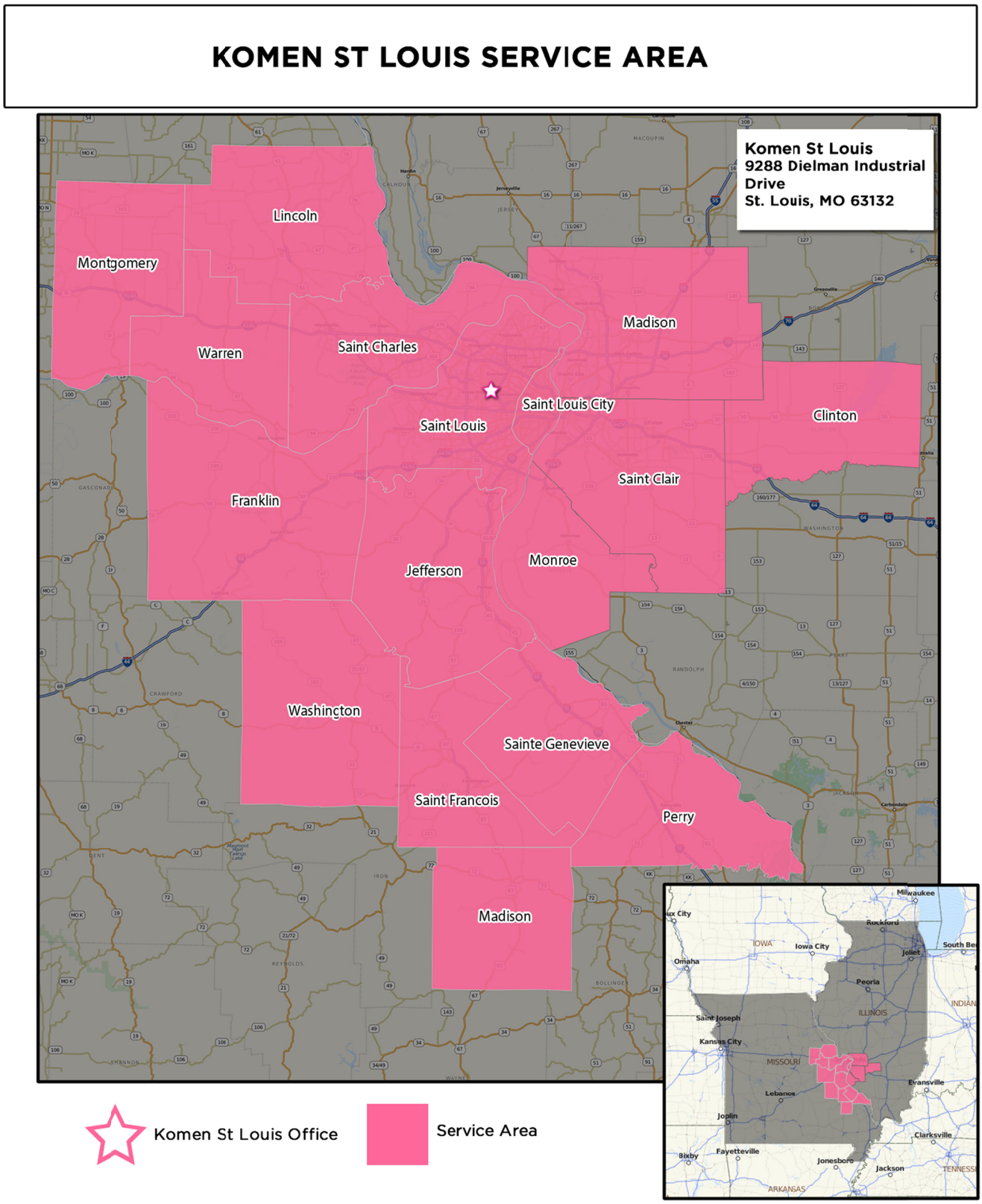


Figure 1.2. Komen St. Louis Service Area Map

Table 1.1. Service Area Demographics

Population Group	White	Black	AIAN	API	Hispanic/ Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
Komen STL Service Area	77.5%	19.6%	0.4%	2.5%	2.5%	49.7%	35.9%	15.2%

Table 1.2. Service Area Characteristics

Population Group	Less than High School 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 STL Service Area	11.4%	12.4%	28.9%	8.6%	14.0%	12.4%	12.8%

Female breast cancer rates in the Komen St. Louis service area are higher than both the US average and the Healthy People 2020 goal (see Table 1.3). However, several of the counties individually have already achieved the goal, allowing the Affiliate to give priority to those counties that are predicted to take longer to achieve the goal.

Table 1.3. Breast Cancer Statistics

Population Group	# of Deaths (Annual Average)	Age-Adjusted Rate/100,000	# of New Late-Stage Cases	Age-Adjusted Late-Stage Rate/100,000
Komen STL Service Area	426	24.4	798	48.4
US	40,736	22.6	70,218	43.7
HP2020		20.6		41.0

Purpose of the Community Profile Report

The purpose of the Community Profile Report is to:

- Align Komen St. Louis' strategic and operational plans
- Drive inclusion efforts in Komen St. Louis' 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 St. Louis retains all publication and presenting rights of the Community Profile, it is the Affiliate's desire that it be shared with the community at large, specifically with grantees, donors, sponsors, legislators and other breast cancer-focused organizations. Komen St. Louis will provide several entities with a copy of the report, post a digital copy on the Affiliate's website, and will share major findings through email, media outreach and additional presentation and communication opportunities.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Quantitative Data Report

Introduction

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

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

The following is a summary of Komen St. Louis' 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

		Incidence Rates and Trends			Death Rates and Trends			Late-stage Rates and Trends		
Population Group	**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	198,602	122.1	-0.2%	40,736	22.6	-1.9%	70,218	43.7	-1.2%
HP2020	.	-	-	-	-	20.6*	-	-	41.0*	-
Illinois	6,492,949	9,039	126.4	-0.1%	1,763	23.6	-2.4%	3,341	47.1	0.1%
Missouri	3,024,156	4,264	121.5	0.0%	890	24.2	-1.5%	1,574	45.7	-0.1%
Komen St. Louis Service Area	1,454,710	2,181	130.5	1.5%	426	24.4	NA	798	48.4	1.4%
White	1,131,232	1,800	130.6	2.0%	338	23.0	NA	624	46.3	1.2%
Black/African-American	284,601	346	131.1	1.2%	85	33.2	NA	162	61.1	3.5%
American Indian/Alaska Native (AIAN)	5,223	SN	SN	SN	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	33,653	19	70.9	-5.5%	SN	SN	SN	6	20.7	-4.6%
Non-Hispanic/ Latina	1,422,727	2,165	131.1	1.6%	424	24.5	NA	793	48.7	1.4%
Hispanic/ Latina	31,983	15	76.7	-1.6%	SN	SN	SN	5	24.6	-1.9%
Clinton County - IL	18,032	29	131.1	1.8%	4	17.4	-2.3%	10	47.7	-10.4%
Madison County - IL	137,241	202	125.2	2.3%	39	22.1	-2.1%	70	44.9	2.3%
Monroe County - IL	16,378	23	116.1	-0.4%	5	23.2	-1.2%	8	43.9	7.8%
St. Clair County - IL	138,519	197	129.2	-1.0%	40	25.3	-2.3%	73	48.2	0.9%
Franklin County - MO	50,832	74	125.0	0.1%	13	21.2	-2.5%	27	45.5	1.1%
Jefferson County - MO	108,574	129	111.4	3.9%	25	23.8	-2.4%	46	39.5	2.5%
Lincoln County - MO	25,720	26	102.9	-3.5%	5	19.3	-1.3%	9	36.1	-6.8%
Madison County - MO	6,228	10	127.3	-10.5%	SN	SN	SN	3	46.1	-12.6%
Montgomery County - MO	6,112	10	120.0	2.3%	SN	SN	SN	3	36.9	-14.9%
Perry County - MO	9,500	14	129.9	7.0%	SN	SN	SN	5	48.7	14.5%
St. Charles County - MO	178,397	245	131.1	3.4%	43	23.4	-1.2%	93	49.9	1.7%
St. Francois County - MO	30,109	43	117.3	0.1%	7	19.7	-3.7%	15	44.1	6.9%
St. Louis City - MO	165,616	215	123.6	2.5%	50	27.2	-1.9%	90	52.1	3.0%
St. Louis County - MO	526,436	921	143.1	1.4%	176	25.6	-1.0%	329	52.1	1.1%
Ste. Genevieve County - MO	9,032	9	84.5	-0.3%	SN	SN	SN	3	28.1	-20.0%
Warren County - MO	15,870	21	113.6	0.6%	3	18.5	-3.1%	8	44.4	8.7%
Washington County - MO	12,112	12	87.4	-6.0%	4	30.1	NA	5	35.0	-11.7%

*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) death 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 and trend in the Komen St. Louis service area were higher than that observed in the US as a whole. The incidence rate of the Affiliate service area was **significantly higher** than that observed for the State of Illinois and the incidence trend was not significantly different than the State of Illinois. The incidence rate of the Affiliate service area was **significantly higher** than that observed for the State of Missouri and the incidence trend was not significantly different than the State of Missouri.

For the United States, breast cancer incidence in Blacks/African-Americans is lower than in Whites overall. The most recent estimated breast cancer incidence rates for APIs and AIANs were lower than for Non-Hispanic Whites and Blacks/African-Americans. The most recent estimated incidence rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the incidence rate was about the same among Blacks/African-Americans and 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. The incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

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

- St. Louis County, MO

The incidence rate was significantly lower in the following counties:

- Jefferson County, MO
- Lincoln County, MO
- Ste. Genevieve County, MO
- Washington County, MO

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 St. Louis service area was slightly higher 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 Illinois. The death rate of the Affiliate service area was not significantly different than that observed for the State of Missouri.

For the United States, breast cancer death rates in Blacks/African-Americans are substantially higher than in Whites overall. The most recent estimated breast cancer death rates for APIs and AIANs were lower than for Non-Hispanic Whites and Blacks/African-Americans. The most recent estimated death rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African-Americans. 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.

Significantly more favorable trends in breast cancer death rates were observed in the following county:

- St. Francois County, MO

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 and trend in the Komen St. Louis service area were higher than that observed in 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 Illinois. The late-stage incidence rate of the Affiliate service area was **significantly higher** than that observed for the State of Missouri and the late-stage incidence trend was not significantly different than the State of Missouri.

For the United States, late-stage incidence rates in Blacks/African-Americans are higher than among Whites. Hispanics/Latinas tend to be diagnosed with late-stage breast cancers more often than Whites. For the Affiliate service area as a whole, the late-stage 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. The late-stage incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

The late-stage incidence rate was significantly lower in the following counties:

- Jefferson County, MO
- Ste. Genevieve County, MO

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

Mammography Screening

Getting regular screening mammograms (and treatment if diagnosed) lowers the risk of dying from breast cancer. Screening mammography can find breast cancer early, when the chances

of survival are highest. Table 2.2 shows some screening recommendations among major organizations for women at average risk.

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

American Cancer Society	National Comprehensive Cancer Network	US Preventive Services Task Force
Informed decision-making with a health care provider at age 40 Mammography every year starting at age 45 Mammography every other year beginning at age 55	Mammography every year starting at age 40	Informed decision-making with a health care provider ages 40-49 Mammography every 2 years ages 50-74

*As of October 2015

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

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

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

- The number of women living in an area that 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 that 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%
Illinois	2,253	1,703	76.4%	74.0%-78.6%
Missouri	2,778	2,055	77.0%	74.9%-79.0%
Komen St. Louis Service Area	841	672	81.3%	77.8%-84.4%
White	592	467	80.0%	75.8%-83.6%
Black/African-American	227	190	87.4%	80.3%-92.1%
AIAN	SN	SN	SN	SN
API	SN	SN	SN	SN
Hispanic/ Latina	SN	SN	SN	SN
Non-Hispanic/ Latina	829	662	81.3%	77.7%-84.3%
Clinton County - IL	SN	SN	SN	SN
Madison County - IL	59	46	73.0%	57.1%-84.5%
Monroe County - IL	SN	SN	SN	SN
St. Clair County - IL	36	25	73.0%	54.3%-86.1%
Franklin County - MO	26	18	77.9%	55.5%-90.9%
Jefferson County - MO	40	30	81.5%	63.5%-91.8%
Lincoln County - MO	SN	SN	SN	SN
Madison County - MO	SN	SN	SN	SN
Montgomery County - MO	SN	SN	SN	SN

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
Perry County - MO	SN	SN	SN	SN
St. Charles County - MO	58	49	85.9%	72.6%-93.4%
St. Francois County - MO	38	24	63.4%	43.6%-79.5%
St. Louis City - MO	129	107	79.0%	66.4%-87.7%
St. Louis County - MO	400	332	85.5%	80.8%-89.3%
Ste. Genevieve County - MO	18	13	82.0%	53.1%-94.8%
Warren County - MO	SN	SN	SN	SN
Washington County - MO	SN	SN	SN	SN

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 St. Louis service area was significantly higher 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 Illinois and was not significantly different than the State of Missouri.

For the United States, breast cancer screening proportions among Blacks/African-Americans are similar to those among Whites overall. APIs have somewhat lower screening proportions than Whites and Blacks/African-Americans. Although data are limited, screening proportions among AIANs are similar to those among Whites. Screening proportions among Hispanics/Latinas are similar to those among Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the screening proportion was not significantly different among 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 %
Illinois	78.2 %	16.0 %	0.7 %	5.2 %	84.7 %	15.3 %	47.6 %	33.9 %	14.4 %
Missouri	84.6 %	12.7 %	0.6 %	2.1 %	96.5 %	3.5 %	49.3 %	36.0 %	15.8 %
Komen St. Louis Service Area	77.5 %	19.6 %	0.4 %	2.5 %	97.5 %	2.5 %	49.7 %	35.9 %	15.2 %
Clinton County - IL	97.4 %	1.5 %	0.3 %	0.8 %	97.8 %	2.2 %	51.5 %	37.0 %	17.0 %
Madison County - IL	89.6 %	8.8 %	0.4 %	1.2 %	97.3 %	2.7 %	50.2 %	36.8 %	16.3 %
Monroe County - IL	98.6 %	0.5 %	0.2 %	0.7 %	98.5 %	1.5 %	53.9 %	37.8 %	16.2 %
St. Clair County - IL	65.3 %	32.3 %	0.4 %	1.9 %	96.8 %	3.2 %	48.2 %	34.3 %	14.3 %
Franklin County - MO	97.8 %	1.1 %	0.4 %	0.7 %	98.6 %	1.4 %	51.2 %	36.7 %	15.7 %
Jefferson County - MO	97.5 %	1.2 %	0.4 %	0.9 %	98.4 %	1.6 %	48.7 %	33.6 %	12.7 %
Lincoln County - MO	96.5 %	2.3 %	0.5 %	0.7 %	97.9 %	2.1 %	45.7 %	30.9 %	11.9 %
Madison County - MO	98.5 %	0.5 %	0.4 %	0.6 %	98.2 %	1.8 %	53.0 %	39.7 %	18.8 %
Montgomery County - MO	97.2 %	1.9 %	0.3 %	0.5 %	98.7 %	1.3 %	55.5 %	42.4 %	21.2 %
Perry County - MO	98.5 %	0.6 %	0.4 %	0.6 %	98.4 %	1.6 %	50.8 %	37.7 %	17.7 %
St. Charles County - MO	92.2 %	4.9 %	0.3 %	2.6 %	97.3 %	2.7 %	47.9 %	32.9 %	12.9 %
Ste. Genevieve County - MO	98.3 %	0.9 %	0.4 %	0.4 %	99.0 %	1.0 %	54.5 %	40.5 %	18.0 %
St. Francois County - MO	97.6 %	1.3 %	0.5 %	0.6 %	98.8 %	1.2 %	50.2 %	37.2 %	17.3 %
St. Louis City - MO	44.9 %	51.5 %	0.5 %	3.1 %	96.8 %	3.2 %	43.4 %	31.4 %	12.9 %
St. Louis County - MO	70.7 %	25.1 %	0.3 %	3.8 %	97.6 %	2.4 %	52.4 %	38.6 %	17.0 %
Warren County - MO	96.3 %	2.4 %	0.6 %	0.8 %	97.3 %	2.7 %	50.8 %	36.9 %	16.1 %
Washington County - MO	98.2 %	1.0 %	0.5 %	0.3 %	98.9 %	1.1 %	50.0 %	36.2 %	14.9 %

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	Linguistic-ally 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 %
Illinois	13.4 %	13.1 %	30.1 %	9.3 %	13.7 %	5.3 %	11.5 %	16.2 %	15.2 %
Missouri	13.2 %	14.3 %	34.4 %	8.1 %	3.8 %	1.3 %	29.6 %	22.9 %	15.4 %
Komen St. Louis Service Area	11.4 %	12.4 %	28.9 %	8.6 %	4.3 %	1.3 %	14.0 %	12.4 %	12.8 %
Clinton County - IL	11.9 %	8.0 %	24.8 %	5.5 %	1.1 %	0.1 %	48.8 %	2.7 %	11.6 %
Madison County - IL	10.2 %	13.3 %	28.7 %	8.0 %	2.3 %	0.7 %	13.3 %	1.7 %	10.8 %
Monroe County - IL	8.5 %	5.6 %	16.9 %	5.4 %	0.8 %	0.4 %	41.4 %	10.0 %	8.4 %
St. Clair County - IL	11.7 %	16.3 %	32.5 %	9.2 %	2.8 %	0.6 %	9.8 %	55.9 %	12.0 %
Franklin County - MO	15.1 %	11.1 %	32.2 %	8.0 %	1.1 %	0.3 %	55.6 %	0.0 %	15.0 %
Jefferson County - MO	13.3 %	10.3 %	28.5 %	8.2 %	1.8 %	0.5 %	30.2 %	2.7 %	12.8 %
Lincoln County - MO	16.0 %	12.6 %	33.0 %	11.1 %	1.4 %	0.3 %	74.8 %	0.0 %	15.4 %
Madison County - MO	23.2 %	20.8 %	51.1 %	11.4 %	1.8 %	1.0 %	65.5 %	100.0 %	19.7 %
Montgomery County - MO	20.8 %	15.9 %	42.4 %	10.1 %	0.6 %	0.0 %	78.5 %	15.4 %	19.1 %
Perry County - MO	18.8 %	12.3 %	35.3 %	4.7 %	1.7 %	0.6 %	55.6 %	16.6 %	14.7 %
St. Charles County - MO	7.2 %	4.9 %	17.7 %	6.0 %	3.5 %	0.8 %	5.8 %	0.0 %	9.3 %
Ste. Genevieve County - MO	18.9 %	11.9 %	32.7 %	6.5 %	0.2 %	0.3 %	76.1 %	0.0 %	14.6 %
St. Francois County - MO	19.6 %	17.5 %	44.2 %	10.7 %	1.1 %	0.2 %	39.8 %	0.0 %	15.1 %
St. Louis City - MO	18.1 %	26.0 %	50.5 %	13.8 %	6.9 %	2.8 %	0.0 %	36.3 %	20.5 %
St. Louis County - MO	8.5 %	9.7 %	24.0 %	7.8 %	6.5 %	1.9 %	1.1 %	2.9 %	11.9 %
Warren County - MO	15.8 %	12.5 %	30.6 %	9.7 %	1.8 %	0.7 %	63.0 %	0.0 %	13.8 %
Washington County - MO	29.6 %	22.9 %	52.4 %	14.3 %	0.8 %	0.4 %	80.5 %	100.0 %	18.0 %

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 St. Louis service area has a slightly smaller White female population than the US as a whole, a substantially larger 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 higher than and income level is slightly higher 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 smaller percentage of people living in rural areas, a slightly smaller percentage of people without health insurance, and a substantially smaller percentage of people living in medically underserved areas.

The following counties have substantially larger Black/African-American female population percentages than that of the Affiliate service area as a whole:

- St. Clair County, IL
- St. Louis City, MO
- St. Louis County, MO

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

- Montgomery County, MO

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

- Madison County, MO
- Montgomery County, MO
- Perry County, MO
- Ste. Genevieve County, MO
- St. Francois County, MO
- St. Louis City, MO
- Washington County, MO

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

- Madison County, MO
- St. Francois County, MO
- St. Louis City, MO
- Washington County, MO

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

- St. Louis City, MO
- Washington County, MO

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

- Madison County, MO
- Montgomery County, MO
- St. Louis City, MO

- Washington County, MO

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 St. Louis 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				
Time to Achieve Death Rate Reduction Target		13 years or longer	7-12 yrs.	0 – 6 yrs.	Currently meets target	Unknown
	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 proportions and key breast cancer death determinants such as poverty and linguistic isolation.

Table 2.7. Intervention priorities for Komen St. Louis 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
Perry County - MO	Highest	SN	13 years or longer	Education, rural
St. Louis City - MO	Highest	13 years or longer	13 years or longer	%Black/African-American, education, poverty, employment, insurance, medically underserved
St. Louis County - MO	Highest	13 years or longer	13 years or longer	%Black/African-American
Monroe County - IL	High	10 years	13 years or longer	Rural
St. Clair County - IL	High	9 years	13 years or longer	%Black/African-American, medically underserved
St. Charles County - MO	High	11 years	13 years or longer	
Madison County - IL	Medium High	4 years	13 years or longer	
Franklin County - MO	Medium High	2 years	13 years or longer	Rural
Jefferson County - MO	Medium High	6 years	13 years or longer	Rural
St. Francois County - MO	Medium	Currently meets target	13 years or longer	Education, poverty, rural
Warren County - MO	Medium	Currently meets target	13 years or longer	Rural
Madison County - MO	Medium Low	SN	1 year	Education, poverty, rural, insurance, medically underserved
Clinton County - IL	Low	Currently meets target	2 years	Rural
Lincoln County - MO	Lowest	Currently meets target	Currently meets target	Rural
Montgomery County - MO	Lowest	SN	Currently meets target	Older, education, rural, insurance
Ste. Genevieve County - MO	Lowest	SN	Currently meets target	Education, rural
Washington County - MO	Lowest	NA	Currently meets target	Education, poverty, employment, rural, insurance, 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.

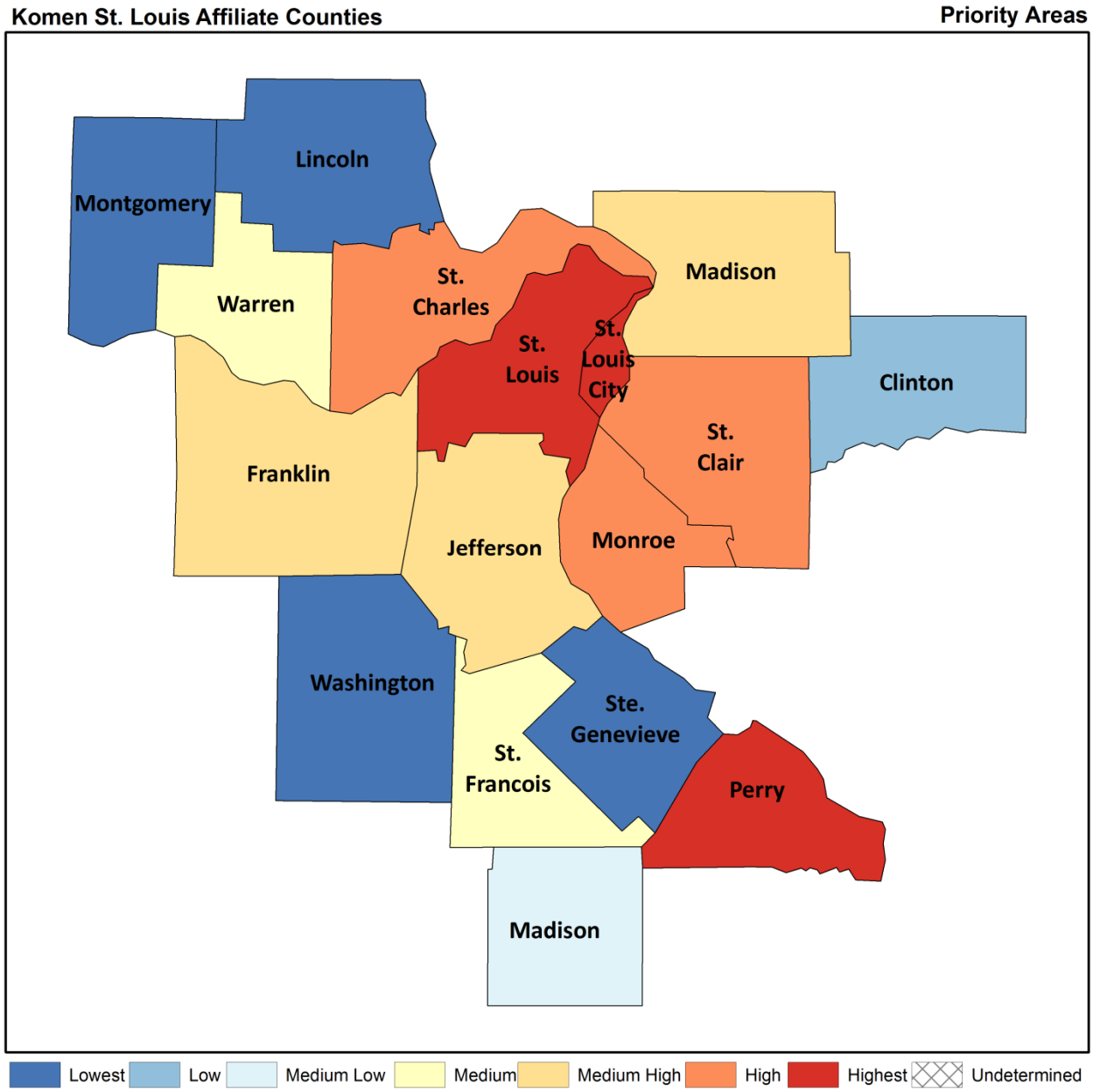


Figure 2.1. Intervention priorities

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 St. Louis service area are in the highest priority category. Two of the three, St. Louis City, MO and St. Louis County, MO, are not likely to meet either the death rate or late-stage incidence rate HP2020 targets. One of the three, Perry County, MO, is not likely to meet the late-stage incidence rate HP2020 target.

The incidence rates in St. Louis County, MO (143.1 per 100,000) are significantly higher than the Affiliate service area as a whole (130.5 per 100,000).

Perry County, MO has low education levels. St. Louis City, MO has a relatively large Black/African-American population, low education levels, high poverty level and high unemployment. St. Louis County, MO has a relatively large Black/African-American population.

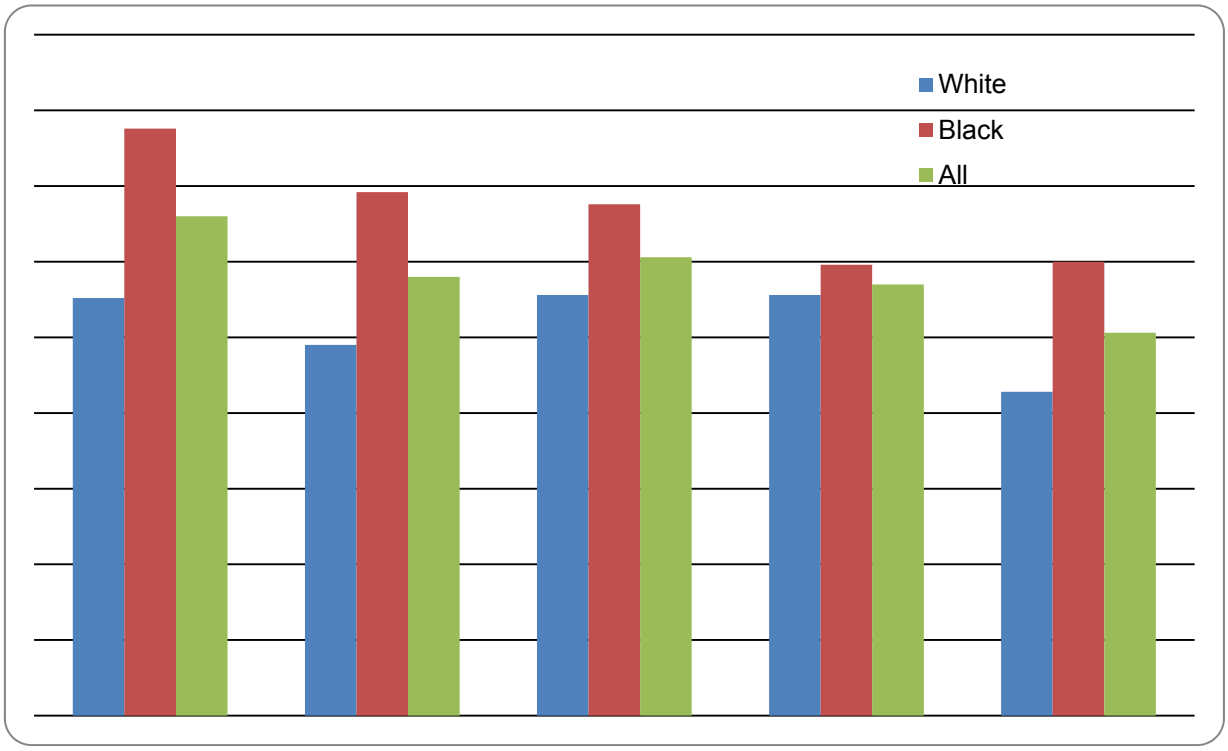
High priority areas

Three counties in the Komen St. Louis service area are in the high priority category. All of the three, Monroe County, IL, St. Clair County, IL and St. Charles County, MO, are not likely to meet the late-stage incidence rate HP2020 target.

St. Clair County, IL has a relatively large Black/African-American population.

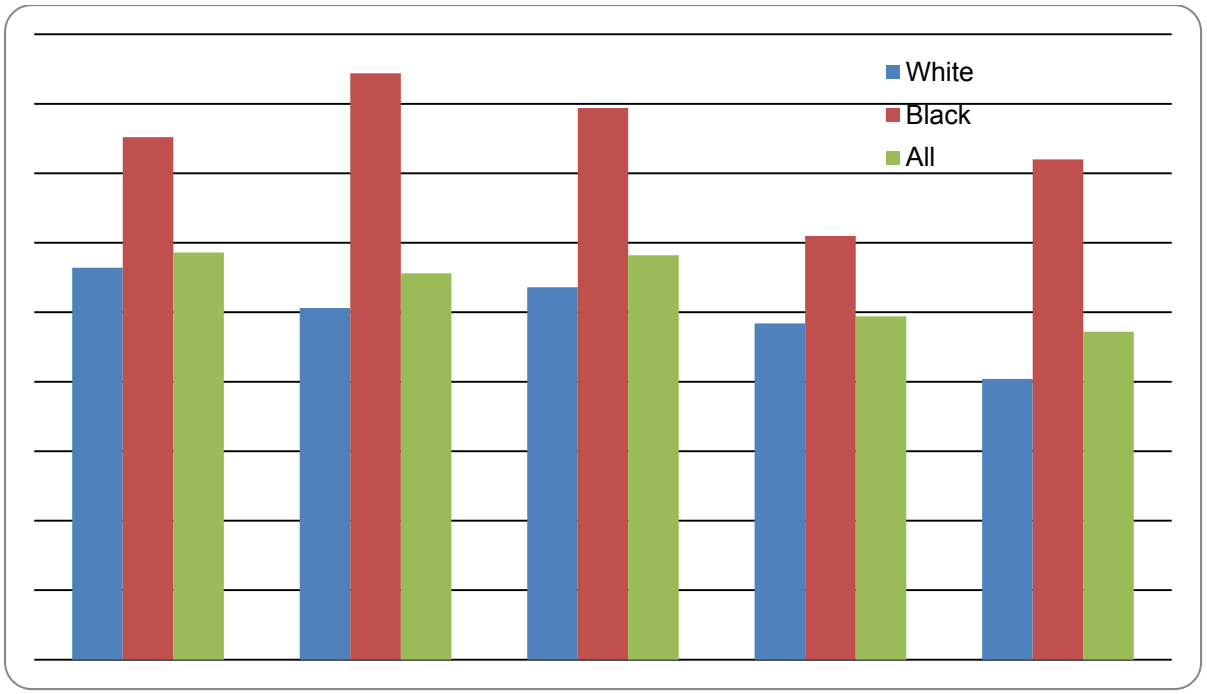
Additional Quantitative Data Exploration

In the US, Black/African-American women are more likely to die from breast cancer than White women, and their five-year survival rate for breast cancer is lower (79.0 percent) compared to White women (92.0 percent) (Susan G. Komen, 2014). These breast cancer disparities have been found to be true in the Affiliate service area as well. Therefore, Susan G. Komen St. Louis sought additional data to determine the extent of racial disparities in regard to breast cancer death. Data were obtained for the two counties with the highest populations of Black/African-American females – St. Louis County and St. Louis City. The source of the data was the Missouri Information for Community Assessment (MICA) website, maintained by the Missouri Department of Health and Senior Services. Unfortunately, publicly available breast cancer death data were not available by Race for St. Clair County, IL, another county with a high population of Black/African-American women. Figures 2.2 and 2.3 below show the extent of breast cancer disparities in St. Louis City and St. Louis County.



*Rates are age-adjusted and are figured per 100,000 women

Figure 2.2. City of St. Louis Breast Cancer Death Rate by Race



*Rates are age-adjusted and are figured per 100,000 women

Figure 2.3. St. Louis County Breast Cancer Death Rate by Race

Selection of Target Communities

Komen St. Louis has selected four target communities within the 17-county Missouri/Illinois service area. Komen St. Louis will focus its strategic efforts on these target communities during the next four years in order to be a good steward of resources while focusing on the mission of saving lives and ending breast cancer forever.

When identifying target communities, Komen St. Louis reviewed Healthy People 2020, a major federal government initiative that provides specific health objectives for communities and the United States as a whole. Komen St. Louis analyzed goals related to reducing women's death rates from breast cancer and reducing the number of breast cancers found at a late-stage. Through this review, the Affiliate identified priority areas based on the estimated time needed to meet Healthy People 2020 (HP2020) breast cancer targets.

The Affiliate reviewed additional key indicators when selecting target communities; this review included, but was not limited to:

- Incidence rates and trends
- Death rates and trends
- Late-stage rates and trends
- Below average screening percentages
- Residents living below poverty level
- Residents living without health insurance
- Unemployment percentages

The selected target communities are:

- Perry County, Missouri
- St. Louis County and St. Louis City, Missouri
- St. Clair County, Illinois
- St. Charles County, Missouri

Perry County, Missouri

Perry County is a rural county in southeast Missouri located adjacent to the Illinois border. The county's population is 98.5 percent White, which is a higher percentage than the state of Missouri as a whole.

Perry County's population has substantially lower education levels (18.8 percent with less than a high school degree) than the Affiliate as a whole (11.4 percent). The county's population includes 35.3 percent with income at or below 250 percent of the Federal Poverty Level, which is substantially higher than the Affiliate as a whole.

Perry County has been identified as a highest priority county due to the estimated amount of time needed to achieve the HP2020 target for late-stage diagnosis. The county's late-stage rate of breast cancer incidence was 48.7 per 100,000 women (Table 2.8). This is higher than the US rate (43.7) as well as the service area's rate (48.4). In addition, the late-stage incidence trend is rising (14.5 percent).

Table 2.8. Perry County Data

	Perry County, MO	**Service Area Rate**	**US Rate**
Incidence Rates*	129.9	130.5	122.1
Death Rates*	SN	24.4	22.6
Late-stage Rates*	48.7	48.4	43.7

*Rates are age-adjusted and are figured per 100,000 women
SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period)

St. Louis County & St. Louis City, Missouri

The Affiliate chose to combine the St. Louis City and County into one target community for a number of reasons. There is no distinguishable border between the two, and its residents flow freely between the two for work, study, worship, recreation, and to seek health care. In addition, another shared feature, as shown in Figures 2.2 and 2.3, is that Black/African-American women die at greater rates in both St. Louis City and County than White women. Therefore, a special focus will be placed on targeting Black/African-American women in these communities.

St. Louis County

St. Louis County is the most populous county in the Affiliate's service area. It is one of the more racially diverse counties in the service area, with 70.7 percent of the population White, 25.1 percent Black/African-American, 3.8 percent Asian/Pacific Islander, and 2.4 percent Hispanic/Latino. Of the county's population, 24.0 percent lives at or below 250 percent of the Federal Poverty Level.

St. Louis County has a substantially larger Black/African-American female population than the Affiliate as a whole. Figure 2.3 shows that Black/African-American women die at a much greater rate from breast cancer than White women in St. Louis County.

St. Louis County has been identified as a highest priority county due to the estimated amount of time needed to achieve HP2020 targets for late-stage diagnosis and breast cancer death. St. Louis County's breast cancer death rate and late-stage breast cancer incidence rate also are higher than both the service area's rates and the US rates. In addition, the county's breast cancer incidence rate was 143.1 per 100,000 women (Table 2.9). This is markedly higher than the US rate (122.1) as well as the service area's rate (130.5).

Table 2.9. St. Louis County Data

	St. Louis County, MO	**Service Area Rate**	**US Rate**
Incidence Rates*	143.1	130.5	122.1
Death Rates*	25.6	24.4	22.6
Late-stage Rates*	52.1	48.4	43.7

*Rates are age-adjusted and are figured per 100,000 women

St. Louis City

St. Louis City is primarily urban. St. Louis City has a substantially larger Black/African-American female population than the Affiliate as a whole; 51.5 percent of the city's population is Black/African-American, 44.9 percent is White, 3.2 percent is Hispanic/Latino, and 3.1 percent is Asian/Pacific Islander. Figure 2.2 shows that Black/African-American women in St. Louis City die at greater rates from breast cancer than White women.

St. Louis City's population has substantially lower education levels, substantially lower income levels, substantially lower employment levels and a larger percentage of adults without health insurance than the Affiliate as a whole. In St. Louis City, 50.5 percent of the population lives at or below 250 percent of the Federal Poverty Level.

St. Louis City has been identified as a highest priority county due to the estimated amount of time needed to achieve HP2020 targets for late-stage diagnosis and breast cancer death. For instance, St. Louis City's breast cancer death rate was 27.2 per 100,000 women, which is higher than the service area's rate (24.4) and US rate (22.6) (Table 2.10). St. Louis City's late-stage breast cancer incidence rate was 52.1 per 100,000 women, which also is higher than the service area's rate (48.4) and the US rate (43.7).

Table 2.10. St. Louis City Data

	St. Louis City, MO	**Service Area Rate**	**US Rate**
Incidence Rates*	123.6	130.5	122.1
Death Rates*	27.2	24.4	22.6
Late-stage Rates*	52.1	48.4	43.7

*Rates are age-adjusted and are figured per 100,000 women

St. Clair County, Illinois
St. Clair County is located in southwest Illinois adjacent to the Missouri border.

St. Clair County has a substantially larger Black/African-American female population than the Affiliate as a whole. The county's population is 65.3 percent White, 32.3 percent Black/African-American, 3.2 percent Hispanic, and 1.9 percent Asian/Pacific Islander. In St. Clair County, 32.5 percent of the population lives at or below 250 percent of the Federal Poverty Level.

St. Clair County has been identified as a high priority county due to the estimated amount of time needed to achieve HP2020 targets for late-stage diagnosis and breast cancer death. The county's breast cancer death rate of 25.3 per 100,000 women is higher than the US rate (22.6). Additionally, St. Clair County's late-stage breast cancer incidence rate is 48.2 per 100,000 women, which is higher than the US rate of 43.7.

Table 2.11. St. Clair Data

	St. Clair County, IL	Service Area Rate	US Rate
Incidence Rates*	129.2	130.5	122.1
Death Rates*	25.3	24.4	22.6
Late-stage Rates*	48.2	48.4	43.7

*Rates are age-adjusted and are figured per 100,000 women

St. Charles County, Missouri
St. Charles County is adjacent to St. Louis County, bordering it on the north and northwest. The county's population is 92.2 percent White, 4.9 percent Black/African-American, 2.7 percent Hispanic/Latino, and 2.6 percent Asian/Pacific Islander.

In St. Charles County, 17.7 percent of the population is at or below 250 percent of the Federal Poverty Level, which is substantially lower than the Affiliate service area.

St. Charles County has been identified as a high priority county due to the estimated amount of time needed to achieve HP2020 targets for late-stage diagnosis and breast cancer death. The county's late-stage breast cancer incidence rate of 49.9 per 100,000 women is higher than both the service area's rate (48.4) and the US rate (43.7). Also, the county's breast cancer incidence rate of 131.1 per 100,000 women is higher than both the service area's rate (130.5) and the US rate (122.1).

Table 2.12. St. Charles Data

	St. Charles County, MO	Service Area Rate	US Rate
Incidence Rates*	131.1	130.5	122.1
Death Rates*	23.4	24.4	22.6
Late-stage Rates*	49.9	48.4	43.7

*Rates are age-adjusted and are figured per 100,000 women

Conclusions

These target communities' key indicators suggest residents may be at risk for experiencing gaps in breast health services and/or experience barriers to access to quality care. The Health Systems Analysis will include a review of available breast health services in each of these counties as well as the ability of individuals to receive no-cost services through the Missouri Show Me Healthy Women program and the Illinois Breast and Cervical Cancer Program.

Health Systems Analysis Data Sources

To gain a comprehensive understanding of programs and services in each of the four target counties, data were collected primarily from the following resources:

- American College of Radiology Centers of Excellence
- American College of Surgeons Commission on Cancer
- American College of Surgeons National Accreditation Program for Breast Centers
- Food and Drug Administration
- Health Resources and Services Administration
- Medicare
- National Cancer Institute Designated Cancer Centers
- The National Association of County and City Health Officials
- The National Association of Free and Charitable Clinics

Komen St. Louis collected and analyzed data from these sources, as well as each health care provider's website and an online search using the Google search engine, and compiled a listing of all breast health care providers in the service area. Analysis included identifying the provider location, services provided along the continuum of care, and quality of care indicators. Electronic surveys, emails, and/or phone interviews were used as needed to clarify and identify missing data. For a full list and citation of sources, please see the Reference page.

Health Systems Overview

Breast Cancer Continuum of Care

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.

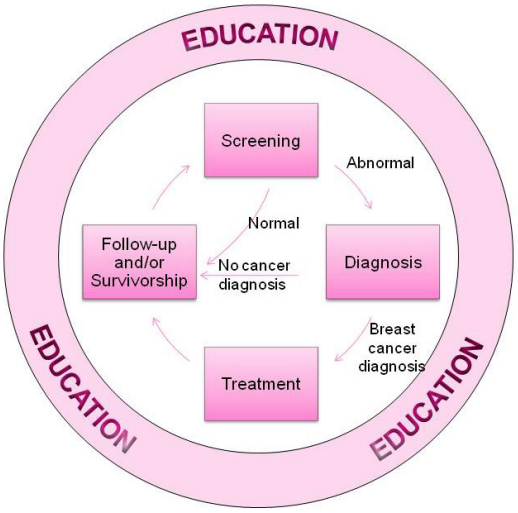


Figure 3.1. Breast Cancer Continuum of Care (CoC)

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 report 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 health care 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.

Summary of Health Systems in Targeted Communities

St. Louis County and St. Louis City have multiple hospitals with quality of care indicators that provide breast health services across the Breast Cancer Continuum of Care (Figure 3.2). Seven facilities are recognized by the American College of Surgeons Commission on Cancer, nine facilities are recognized as American College of Radiology Centers of Excellence, and four facilities are recognized as American College of Surgeons National Accreditation Program for Breast Centers (NAPBC). Siteman Cancer Center is a National Cancer Institute Designated Cancer Center. Additionally, there are 24 Show Me Healthy Women (SMHW) providers within this target community providing screening services to the uninsured, though many of these only provide clinical breast exams onsite. Mercy Hospital Saint Louis, Missouri Baptist Medical

Center, St. Anthony's Hospital and Siteman Cancer Center have mobile mammography vans, which provide screenings in several locations throughout St. Louis County and St. Louis City. In this target community, Komen St. Louis has partnerships with Barnes-Jewish Hospital, SSM Health Care, Mercy Hospital and Missouri Baptist Medical Center.

While there are numerous quality providers with services throughout the continuum of care, major barriers still exist regarding access. More than 50.0 percent of this target community has income below 250 percent of the Federal Poverty Level, more than 30.0 percent live in medically underserved areas, and more than 20.0 percent have less than a high school education (Susan G. Komen, 2014). There are only two free clinics in this target community, and costs of care beyond screening including diagnostic care and treatment can be out of reach for these populations. Because of barriers including financial burdens, lack of education, and lack of transportation, many women are not accessing services.

The target community of St. Charles County, Missouri also has numerous quality providers with breast health services throughout the continuum of care (Figure 3.3). Siteman Cancer Center and Barnes-Jewish Hospital have satellite locations in the city of St. Peters. SSM Health Care has three providers throughout the county including St. Joseph Medical Park and St. Joseph Health Center, all of which are recognized by the American College of Surgeons Commission on Cancer. There are three SMHW providers in this target community, including a free clinic, North East Community Action Corporation (NECAC) Health Services, and two hospitals, Barnes-Jewish and SSM St. Joseph Health Center. While screening services are accessible for many women, services beyond screening along the Continuum of Care may not be covered due to lack of insurance coverage and financial assistance in these areas. In St. Charles County, Komen St. Louis has partnerships with Barnes-Jewish Hospital and SSM Health Care.

The target community of Perry County, Missouri has one hospital, Perry County Memorial, which provides services across the Continuum of Care (Figure 3.4). This is the only facility in the county to have screening and diagnostic mammography and to provide treatment and survivorship services. Perry County Memorial is not a SMHW provider, making Cross Trails Medical Center the only SMHW provider in the county. A lack of screening services for the uninsured and underinsured in this area indicates that women may have a harder time getting screened, which could lead to delayed diagnoses and presentation with more advanced stages of breast cancer. For services or choice in services, women must travel to surrounding counties such as Cape Girardeau or Ste. Genevieve.

Currently, Komen does not have partnerships with providers in Perry County. Future collaborative efforts with Perry County Memorial Hospital and SMHW to identify barriers to making Perry County's only hospital a SMHW provider, and working with Cross Trails Medical Center to expand the number of people served would provide more opportunities for screening and financial assistance for women in this community.

In St. Clair County, Illinois, Memorial Hospital is recognized as an American College of Radiology Breast Imaging Center of Excellence and is the only hospital in the county with a

quality of care indicator (Figure 3.5). Memorial Hospital and St. Elizabeth's Hospital are the only facilities in St. Clair County that provide services throughout the continuum of care. In this target community, there is a lack of support and survivorship services beyond financial assistance and end-of-life care. Support and survivorship services aid cancer survivors by both preventing secondary diseases and the recurrence of cancer and by improving quality of life for each survivor (Centers for Disease Control, 2004). St. Clair County Health Department is a lead agency for the Illinois Breast and Cervical Cancer Program (IBCCP) and provides navigation of financial assistance and breast health services to this target community. Despite this, there are still barriers to access of care, with 55.9 percent of the population living in medically underserved areas and 32.5 percent of the population with an income below 250 percent of the federal poverty level (Susan G. Komen, 2014). Komen St. Louis has partnerships with Southern Illinois Healthcare Foundation for screening services at Touchette Regional Hospital in East Saint Louis, IL.

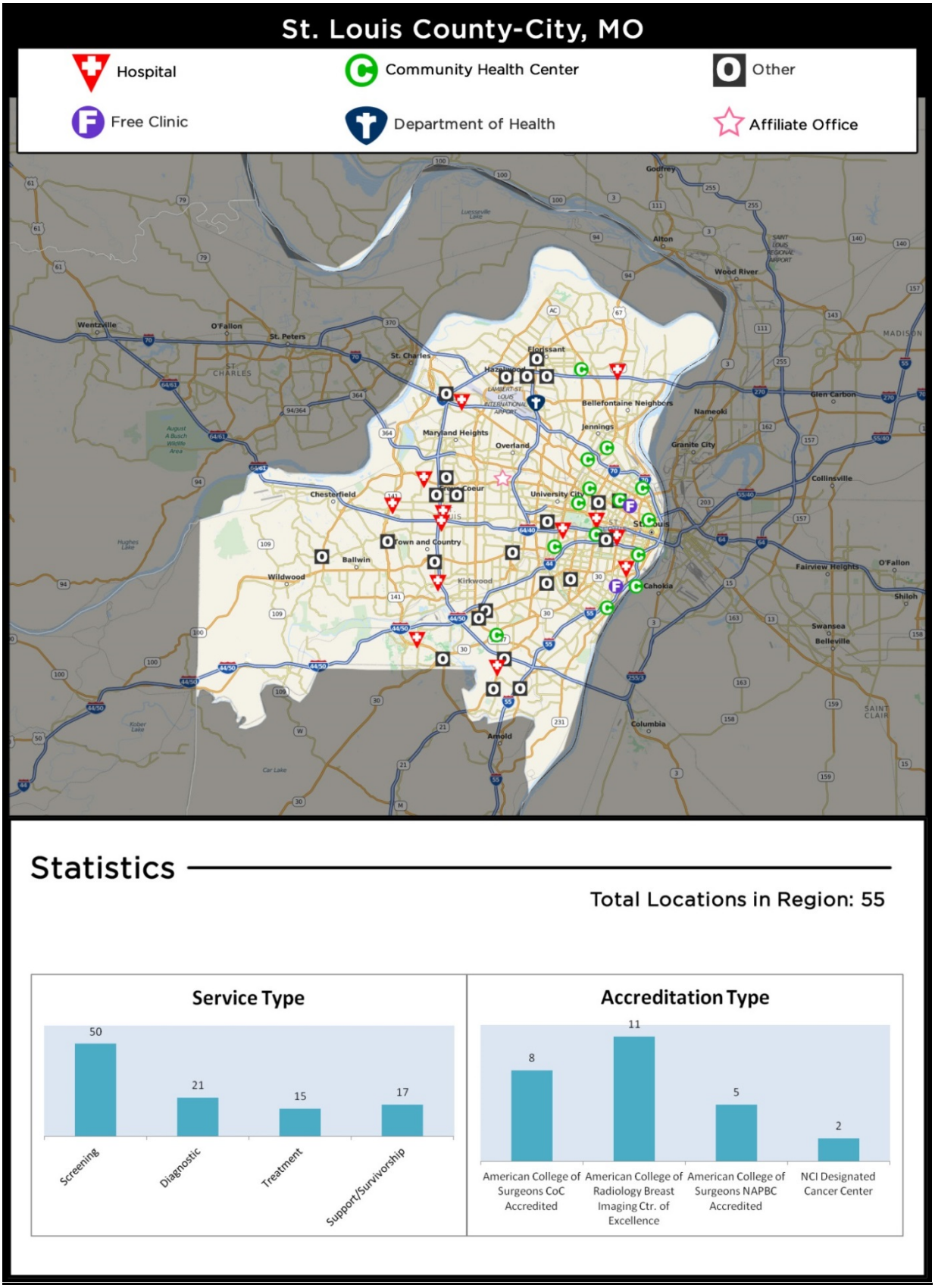


Figure 3.2. Breast Cancer Services Available in St. Louis County and City, MO

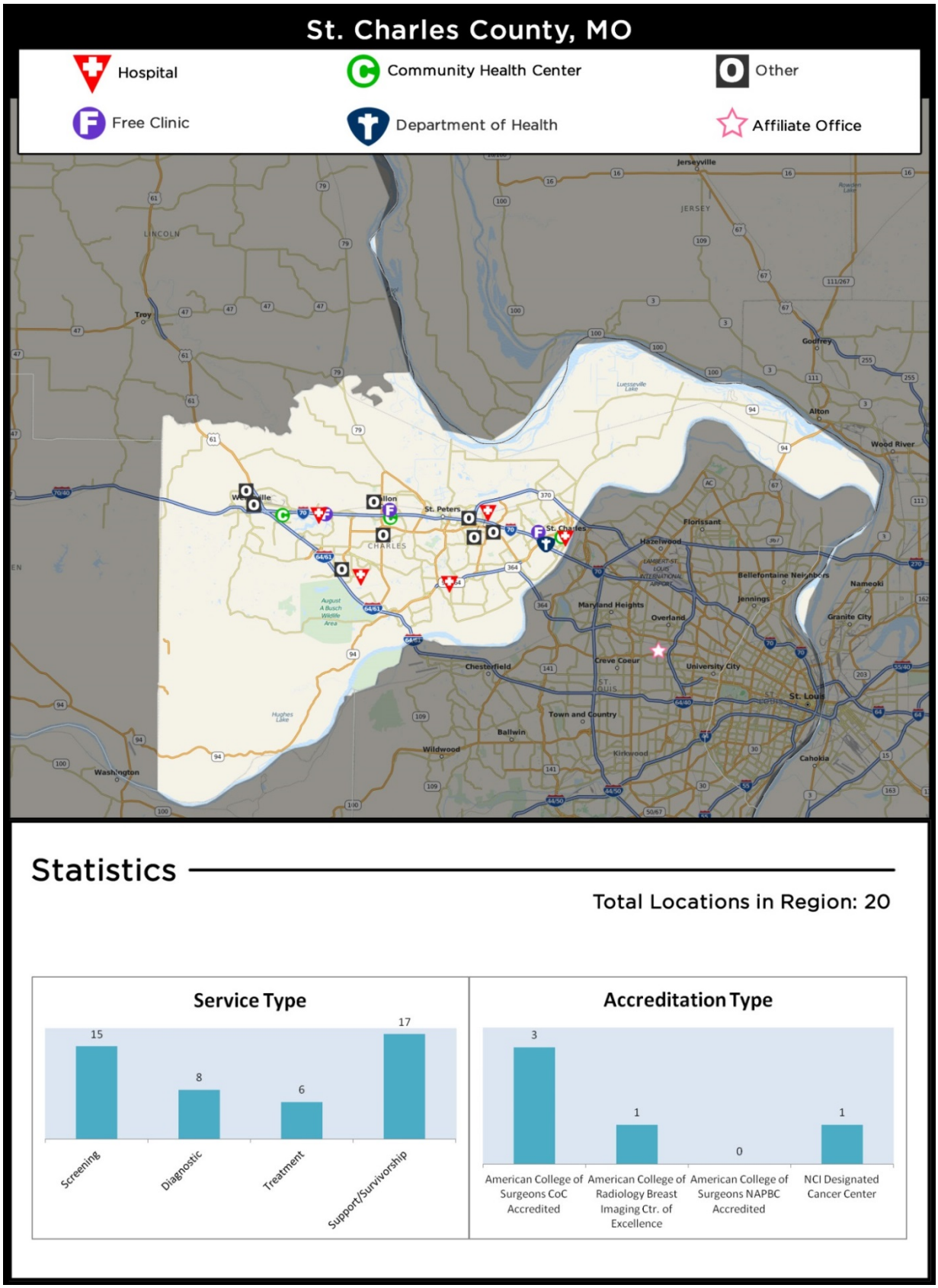


Figure 3.3. Breast Cancer Services Available in St. Charles County, MO

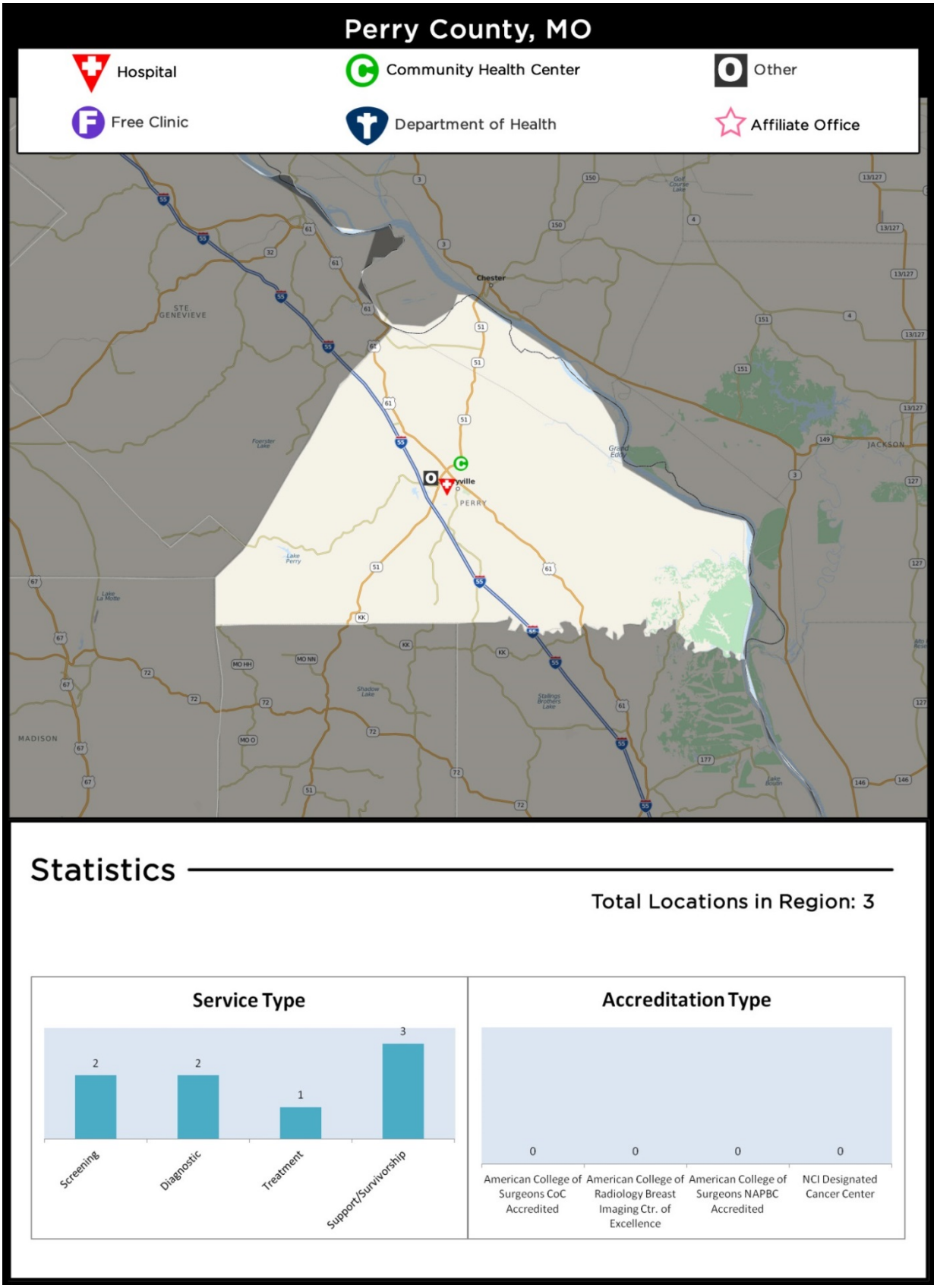


Figure 3.4. Breast Cancer Services Available in Perry County, MO

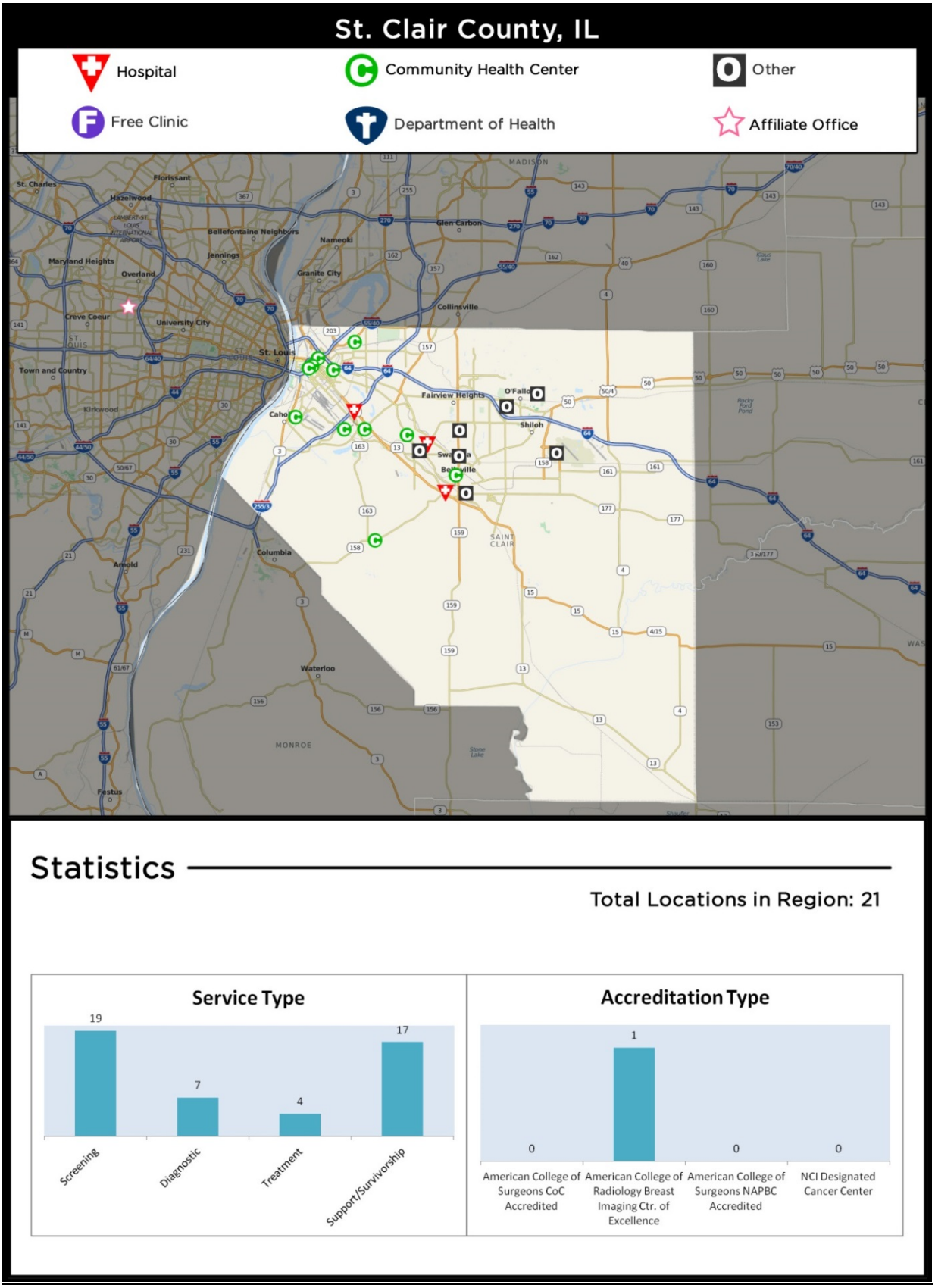


Figure 3.5. Breast Cancer Services Available in St. Clair County, IL

Public Policy Overview

National Breast and Cervical Cancer Early Detection Program

The Centers for Disease Control and Prevention (CDC) provides low-income, uninsured, and underserved women access to timely, high-quality screening and diagnostic services through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). Through the NBCCEDP, uninsured women under age 65 who are diagnosed with cervical or breast cancer may have access to full Medicaid benefits under the Breast and Cervical Cancer Prevention and Treatment Act of 2000.

Missouri: Show Me Healthy Women

Show Me Healthy Women (SMHW) is the name of Missouri's Breast and Cervical Cancer Early Detection Program. It is federally funded through the Centers for Disease Control and Prevention (CDC) and state funded through the Missouri Department of Health and Senior Services. Through SMHW, eligible women receive free screening and diagnostic services. Eligibility criteria include household income at or below 200 percent of the Federal Poverty Level for ages 35 to 64, or older if they do not receive Medicare Part B, and no insurance to cover program services. In order for a woman to receive treatment and Medicaid services through SMHW, she must be screened under the program and NBCCEDP funds must pay for all or part of the costs of her screening services (Option 1). This means the door a woman in Missouri enters for the diagnosis of breast cancer matters, especially if she is uninsured or low income. If a woman is not diagnosed through a SMHW provider, she cannot access coverage through the Breast and Cervical Cancer Treatment (BCCT) program, which offers Medicaid-funded breast cancer treatment. Throughout the State of Missouri there are 188 provider locations, which include local public health agencies, federally qualified health centers, hospitals, private physician offices, and not-for-profit health centers.

Komen St. Louis is an identified partner for the Show Me Healthy Women program, as are the other two Komen Affiliates in Missouri, Komen Greater Kansas City and Komen Mid-Missouri. The three Komen Affiliates in Missouri will continue to work together to maintain the positive relationship with the Show Me Healthy Women program.

Illinois: Illinois Breast and Cervical Cancer Program

The Illinois Breast and Cervical Cancer Program (IBCCP) is funded through the CDC and the Illinois Department of Public Health. To receive services through IBCCP, a woman must be 30 to 64 years old and living without insurance in Illinois. Free screening and diagnostic services are provided through local IBCCP lead agencies, which include 34 county health departments, hospitals, and federally qualified health centers located throughout the state. Regarding treatment, a woman can receive Medicaid services through IBCCP regardless of where she was originally screened, as long as she would otherwise meet the other eligibility requirements (Option 3). This means that women not diagnosed through the program can still qualify for treatment through IBCCP.

With the 2014 Medicaid expansion, many women who currently receive services through IBCCP are now eligible for Medicaid. IBCCP has arranged with the Illinois Department of Human Services that even if a client is approved for Medicaid during the course of being served by IBCCP, then IBCCP can pay for her services through the end of the screening cycle so that her services will not be interrupted or delayed. Despite a large number of women served being eligible for Medicaid or insurance through the Health Insurance Marketplace, the IBCCP still plays an integral role in providing screening and diagnostic services to the uninsured.

Komen St. Louis has an established relationship with the Illinois Breast and Cervical Cancer Program. Komen St. Louis will continue to strengthen this relationship, as opportunities allow, for the benefit of the women served by the Affiliate.

State Cancer Control Programs

Breast Cancer Objectives in Missouri

The Missouri Comprehensive Cancer Control Plan, written by the Missouri Department of Health and Senior Services and Missouri Cancer Consortium, addresses cancer control across the continuum of care including cancer prevention, early detection, diagnosis, treatment, survivorship and end of life (2010-2015). The following goals and objectives are provided as a framework of action to address the control of breast cancer in Missouri.

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

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

Goal: *Healthier Missourians through evidence-based treatment of cancer that is accessible to everyone*

Objective 1: Eliminate barriers and increase access to evidence-based treatment services and appropriate follow-up

Objective 2: Increase participation in Clinical Trials

Objective 3: Increase the percentage of patients with cancer who receive evidence-based treatment and follow-up based on acceptable standards of care

Goal: *Improve the quality of life for cancer survivors and their families*

Objective 1: Increase education and awareness of survivorship issues and resources

Objective 2: Increase the availability of effective services, programs and policies addressing cancer survivorship

Objective 3: Increase access to quality care and services for cancer survivors in Missouri

Komen St. Louis is a member of the Missouri Cancer Consortium, which is a contributor to the Missouri Comprehensive Cancer Control Plan. The plan's goals and objectives, particularly those related to breast cancer, are in line with the Komen mission of saving lives and ending breast cancer forever. The Affiliate, in partnership with Komen Greater Kansas City and Komen Mid-Missouri, will continue to work, as opportunities allow, in support of fulfilling the Missouri Comprehensive Cancer Control Plan's goals and objectives to address the control of breast cancer in Missouri.

Breast Cancer Objectives in Illinois

Prepared by the Illinois Comprehensive Cancer Control Program of the Illinois Department of Public Health, the Illinois Comprehensive Cancer Control Plan provides a framework of action to reduce the burden of cancer in the state. This plan serves to mobilize individuals, organizations, institutions and communities across the continuum of care that are committed to fighting cancer (Illinois Comprehensive Cancer Control Program, 2010-2015). The following goals and objects are provided to address the control of breast cancer in Illinois.

Goal 1*: Increase the knowledge of the general public to include all diverse groups and health care providers regarding early detection guidelines and the importance of screenings for breast, cervical, colorectal, oral, prostate, skin and testicular cancers.*

Objective 1: Increase early stage cancer detection, diagnosis and treatment while in the organ of origin before metastasis

Goal 2*: Increase access to cancer resources and services, especially among diverse, underserved, and underinsured populations.*

Objective 1: Increase access to cancer treatment and supportive care.

Objective 2: Increase access to cancer treatment and supportive care services provided by, or at the standard of, American College of Surgeons (ACoS) approved cancer centers.

Objective 3: Educate health care providers, caregivers, survivors, payers, and policy/decision makers about access to care issues.

Goal 3*: Increase access to survivorship and palliative care programs, especially among diverse, underserved and underinsured populations.*

Objective 1: Increase knowledge of cancer survivors and their families about survivorship, rehabilitative, psychosocial, supportive, and palliative care.

Objective 2: Increase access to and utilization of the full spectrum of supportive care (exercise, nutrition, spiritual, psychological, rehabilitative, behavioral, and social services)

Objective 3: Educate survivors, policy and decision makers to ongoing survivorship, palliative care, and quality of life issues.

Objective 4: Develop, enhance, and use survivorship surveillance data to define the scope, needs, and health behaviors of the cancer survivor population.

In a 2013 report published by the Illinois Department of Public Health, breast cancer is listed as the number one form of cancer in women and the second highest cause of cancer death. Every day in Illinois, 25 women are diagnosed with breast cancer.

The goals and objectives outlined in the Illinois Comprehensive Cancer Control Plan, particularly those related to breast cancer, are in line with the Komen mission of saving lives and ending breast cancer forever. Komen St. Louis, in partnership with the other Komen Affiliates serving Illinois, will continue to work, as opportunities allow, in support of fulfilling the Illinois Comprehensive Cancer Control Plan's goals and objectives to address the control of breast cancer in Illinois.

Affordable Care Act (ACA)

The Affordable Care Act (ACA), enacted March 2010, aims to expand access to care through insurance coverage, enhance quality of health care, improve coverage for those with health insurance, and to make health care more affordable. As of 2014, the minimum coverage provision requires most US citizens and legal residents to obtain and maintain coverage for themselves and their dependents or pay a penalty. Essential Health Benefits are items and services that must be covered within a plan and include well-woman exams and mammography screenings. Coverage can be through an employer, Medicare, Medicaid, other private insurance, or through public insurance that can be purchased through a Marketplace.

In most states, before ACA, adults without dependent children were ineligible for Medicaid, regardless of their income, and income limits for parents were often below half the Federal Poverty Level. The ACA expands Medicaid coverage for most low-income adults to 138 percent of the federal poverty level (about $32,500 for a family of four). In June 2012, the US Supreme Court ruled that states could choose whether or not to implement the Medicaid expansion. Illinois has chosen to expand Medicaid, while Missouri does not have a current plan to implement the expansion.

ACA in Missouri

According to the Kaiser Family Foundation, 50.0 percent of Missourians receive health insurance coverage through their employer, 15.0 percent through Medicare, 14.0 percent through Medicaid, 6.0 percent through other private insurance, and 1.0 percent through other public insurance. In 2012, approximately 14.0 percent or 834,000 Missourians were uninsured. With the insurance mandate, Missouri opted to use the federal Health Insurance Marketplace, Healthcare.gov. This Marketplace is currently the main method for the uninsured to obtain health insurance coverage. Under the ACA, those with incomes between 100 percent and 400.0 percent of the federal poverty level may be eligible for premium tax credits to assist with purchasing coverage. These tax credits are based on income and the cost of insurance and are only available to people who are not eligible for other coverage including Medicaid/CHIP (Children's Health Insurance Program), Medicare or employer coverage and who are citizens or lawfully present immigrants. During the open enrollment period between October 1, 2013, and March 31, 2014, 152,335 people in Missouri selected a Marketplace plan for health care coverage (Department of Health and Senior Services, 2014).

Missouri is not currently planning to implement Medicaid expansion. With this decision, Medicaid eligibility for nonelderly adults is limited to parents with incomes below 23.0 percent of the federal poverty level. Because ACA envisioned low-income people receiving coverage

through Medicaid, nonelderly adults below the federal poverty level are not eligible for Marketplace subsidies. Therefore, 23.0 percent of uninsured Missourians (193,000 people) fall into a coverage gap (Kaiser Family Foundation, 2014).

The coverage gap includes nonelderly adults without dependents with incomes below 100 percent of the Federal Poverty Level and nonelderly adults with dependents with incomes between 23.0 percent and 100 percent of the federal poverty level (Kaiser Family Foundation, 2014). These individuals have incomes above Medicaid eligibility or do not have dependents, making them ineligible for Medicaid, and do not make enough to received financial assistance to obtain health coverage under the ACA. Safety net providers such as hospitals' emergency rooms, community health clinics and free clinics will still need to provide care to these individuals. Show Me Healthy Women will also continue to play an important role in providing screening services to those who are uninsured, as many will fall into this gap in coverage.

ACA requires states to have navigators to help the public understand health insurance coverage options and eligibility. Missouri state law requires navigators to be licensed. Of the three Missouri target counties in the Komen St. Louis service area, all but one has licensed navigators available. As of 2014, Perry County does not have a licensed navigator to assist individuals in identifying coverage options and eligibility (State of Missouri Data Portal, 2014). To receive support from a licensed navigator, Perry County residents must travel to neighboring counties.

ACA in Illinois

In Illinois, 50.0 percent of the total population receives health insurance coverage through their employer, 17.0 percent through Medicaid, 13.0 percent through Medicare, 5.0 percent through other private insurance, and 1.0 percent through other public insurance. In 2012, 14.0 percent of the population was uninsured including 1.8 million nonelderly adults. Illinois opted for a State Partnership Marketplace, getcoveredillinois.gov. In 2014, Illinois implemented the Medicaid expansion, making 36.0 percent of uninsured Illinoisans eligible for Medicaid coverage. During the open enrollment period in Illinois, 217,492 people enrolled in a Marketplace plan and 38,510 people enrolled in Medicaid and CHIP (Children's Health Insurance Program).

Medicaid enrollment is open year-round; women can apply directly at the local Human and Family Services (HFS) office, can go online at www.getcoveredillinois.gov, or can go to a federally qualified health center or any local hospital or health department where there are trained In-Person Navigators to assist with the application process and enrollment. With the larger group of eligibility, HFS has a backlog of Medicaid applications, and many clients who are approved do not understand what to do to complete the process or access care. Further education and motivation is needed regarding enrollment and access to care through Medicaid.

Like Missouri, there are still questions in Illinois involving the costs to patients and providers along the continuum of care. While screening is considered an Essential Health Benefit with no co-pay, costs of diagnostic care can be overwhelming for patients. Patients who picked the lowest level of coverage through the Marketplace must pay $3,000 out of pocket for diagnostic care before insurance will pick up any cost. Additionally, there are questions about how

Medicaid will track data regarding populations and services as they relate to breast health. This data, similar to that currently collected by the IBCCP, is necessary to identify figures such as the number of women provided with breast health services and the identification of gaps in services across the continuum of care. These figures can help guide improvements in health care access and quality.

With the implementation of ACA and Medicaid expansion in 2014, many women in the IBCCP program are eligible for coverage through insurance plans on the Marketplace and Medicaid. However, gaps still remain for women who will continue to be uninsured or underinsured due to affordability and health literacy barriers. In 2014, it is estimated that 81,191 Illinois women will lack access to breast cancer screenings despite the increase in eligibility for coverage (American Cancer Society, 2014). Legislators have chosen to continue funding the IBCCP program, though funding has decreased in the past five years. Maintaining funding and eligibility for IBCCP preserves a critical safety net for thousands of Illinois women.

The implementation of ACA and Medicaid expansion has implications for health care providers in both Missouri and Illinois as well. ACA provides a larger focus on preventative care, provides increased support to federally qualified health centers, and covers Essential Health Benefits with no deductible or co-pay. Health care providers play a role in educating patients regarding their eligibility for services and identification of community resources for patients to reach out to for more information.

In both Missouri and Illinois, there are still numerous barriers to eligible people receiving health care coverage through Medicaid or through plans in the Marketplace. Some barriers include a lack of understanding regarding how to enroll, an unwillingness to enroll due to a comfort level with pathways and forms of health care they are currently using, and a hesitation to begin paying fees for services under coverage plans. Many implications of the ACA and Medicaid expansion are still unknown as the implementation of these laws is ongoing and will change and develop over upcoming years.

Affiliate's Public Policy Activities

Missouri: Komen St. Louis, along with Komen Greater Kansas City and Komen Mid-Missouri, joined together with other cancer-related organizations in the state to form the Missouri Coalition for Cancer Treatment Access (MCCTA). The MCCTA supported state legislation that would ensure cancer patients in Missouri have equal access to intravenous and oral chemotherapy. In March 2014, the Missouri legislature approved the legislation and the Missouri Governor signed the "oral chemotherapy parity bill."

In Missouri, a major issue that needs to be addressed is the need to change the State of Missouri from one of the most restrictive states for access to breast cancer treatment dollars (Option 1) to an Option 3 state that would permit full access to treatment dollars for all eligible women. In Missouri, the door you enter for the diagnosis of breast cancer matters if you are uninsured or low income. If a woman is not diagnosed through a SMHW provider, she cannot access coverage through the Breast and Cervical Cancer Treatment (BCCT) program, which

offers Medicaid-funded breast cancer treatment. This is a critical public policy issue that Komen St. Louis considers a priority for continued dialogue and attention in subsequent legislative sessions.

Illinois: In Illinois, Komen St. Louis relies on and takes the lead from both the Komen Chicagoland and Komen Memorial Affiliates regarding Illinois public policy initiatives. The Affiliate has participated in meetings and phone calls with the Illinois Komen Affiliates on public policy matters, and will continue to lend support when able.

Illinois is an Option 3 state, where women are considered eligible for Medicaid-funded treatment for breast cancer regardless of their screening provider. Also, instead of having designated providers, select health departments or hospitals manage the program and funding. Maintaining state funding for the IBCCP will be critical in future years to ensure access to screening and diagnostic services for those women still uninsured.

Health Systems and Public Policy Analysis Findings

Within Komen St. Louis' service area, the majority of people and services reside in three of the four identified target counties: St. Louis County and St. Louis City, St. Charles County, and St. Clair County in Illinois. Current partnerships in these communities include Barnes-Jewish Hospital, Mercy Hospital St. Louis, SSM Health Care facilities, and Southern Illinois Healthcare Foundation. Currently there are no partnerships within Perry County, with potential partners including Perry County Memorial Hospital and Cross Trails Medical Center. Barriers to access to services in St. Louis County and St. Louis City, St. Charles County, and St. Clair County in Illinois include education regarding services and financial assistance available, transportation/travel, and gaps in care for support and survivorship. In Perry County, a rural community, access to screening services and choices along the continuum of care are few. To access services women must travel to Perryville, where both providers are located, or to neighboring counties such as Cape Girardeau and Ste. Genevieve.

With the implementation of the Affordable Care Act and the changes in Medicaid, the implications for BBCP programs, health care providers and individuals are still unclear. While screening is now considered an Essential Health Benefit, costs for services beyond screening along the continuum of care are unknown. Assistance with navigation through the changing health care laws and education and motivation regarding eligibility of services for individuals will be vital to increasing accessibility of services in both Missouri and Illinois.

Komen St. Louis will continue to collaborate with the Komen Affiliates serving Missouri and Illinois on appropriate public policy activities, as opportunities allow, in support of the mission to save lives and end breast cancer.

Qualitative Data Sources and Methodology Overview

Methodology

Komen St. Louis relied heavily on the Quantitative Data Report (QDR) and Health Systems and Public Policy Analysis (HSA) in developing the key assessment questions and variables for each target community. Given the differences of the four communities, each was approached with a different qualitative goal.

Perry County was selected as a target community because of lower than average educational levels, being rural, having an above average percentage of the population living at or below 250 percent of the Federal Poverty Level, and a predicted time of 13 years or longer to achieve the Healthy People 2020 (HP2020) late-stage incidence target. Key informant questions in this community were directed at investigating how issues related to socioeconomic status and geographical proximity to major cities actually affected breast cancer incidence and death. Komen St. Louis wanted to evaluate if a lack of education was a barrier, if education around breast health was present, if access was the limiting factor, or any combination thereof.

St. Louis County and St. Louis City were combined into one target community and selected for several reasons, primarily because it is predicted that both of the communities will take 13 years or longer to achieve the Healthy People 2020 goals. It was also selected due to its large population and racial diversity. St. Louis County/City has a very large population in general, making up close to half of Komen St. Louis' service area, with a substantially larger Black/African-American female population than the service area as a whole. Concerns around lower education levels, lower employment rates, and lower insurance rates were also present. The main assessment variables for this community were looking at the level of understanding regarding breast health, barriers to screening services, and potential causes for the racial disparity.

St. Charles, Missouri, rated high priority in the QDR; it is predicted that it would take 11 years to achieve the death rate target and 13 years or longer to achieve the late-stage incidence target. The county didn't appear to have any key population characteristics that would contribute to these statistics. Here the Affiliate wanted to assess the barriers to screening and possible causes of late-stage diagnosis.

Finally, St. Clair County was also rated as high per the QDR, predicting nine years to achieve the death rate target and 13 years to achieve the late-stage target. Additionally, 32 percent of St. Clair's population is Black/African-American, the main factor Komen St. Louis wanted to investigate in this area. St. Clair differs from the other three target communities as this county is located in Illinois. The Affiliate was curious to see how differences in state policy may affect access to care or breast health services. The main difference discovered from the HSA was that Missouri has not implemented Medicaid expansion, while Illinois has, theoretically making 36.0 percent of uninsured Illinoisans eligible for Medicaid coverage. The two states also have differing policy in terms of their Breast and Cervical Cancer Programs.

Varying data collection methods were used depending on the feasibility in the target community. Two methods were utilized for each of the four areas (see Table 4.1). Utilizing two methods, along with building assessment questions based on the Quantitative Data Report and Health Systems Analysis, allowed for greater triangulation among findings.

Table 4.1. Data Collection Methods Used

Target Community	Method One	Method Two
Perry County, MO	Provider Surveys	Key Informant Interviews
St. Louis County/City, MO	Provider Surveys	Focus Groups
St. Charles County, MO	Provider Surveys	Key Informant Interviews
St. Clair County, IL	Provider Surveys	Focus Groups

Surveys

Provider surveys were used for each of the four target communities. Surveys were selected as a data collection method for this target group because they were cost effective and an efficient way to reach numerous providers. Surveys were completed online via Survey Monkey. The survey consisted of 13 questions, a combination of multiple choice and short answer, taking about 20 minutes to complete.

Key Informant Interviews

Telephone key informant interviews were utilized as a data collection method for Perry and St. Charles Counties because of driving distance and the uncertainty of being able to recruit participants for a focus group. 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. Key informant interviews were recorded using a recording app, Call Recorder, allowing users to save the phone call in a media format that could be emailed and saved to the computer for later transcription and analysis. The main questions from the interviews were then transcribed into a Word document for later analysis.

Focus Groups

Focus groups were selected for St. Louis County/City and for St. Clair County based on the feasibility of recruiting participants. While more expensive given the need to incentivize participants, the Affiliate felt that focus groups created an opportunity to gather in-depth data from local men/women. Two focus groups were conducted in St. Clair County, and three focus groups were conducted in St Louis County/City. Focus group audio was recorded and an abbreviated transcription was completed.

Sampling

Komen St. Louis hired a public health contractor familiar with the Susan G. Komen organization to help complete the qualitative data collection. The Affiliate worked collaboratively with the contractor to develop an overall plan, but left question development, collection and analysis to the contractor.

Surveys

The Affiliate chose to survey health care providers due to their obvious understanding of the health care system. The Affiliate wanted to get the health care providers' perspective on how the Continuum of Care was at work in their community. One of the main conclusions from the HSA was that the target communities, with the exception of Perry County, had several strong medical facilities and providers in the area, but major barriers still existed regarding access.

Survey participants were gathered from the HSA spreadsheet. The office managers or development staff members 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. Up to three attempts at contacting organizations were made. Providers included all levels of health care workers in order to get a range of perspectives. The survey was also shared via newsletters, social media, and grantee dissemination to recruit participants. The Affiliate contractor developed the questions and shared the link with interested participants. Those who agreed to disseminate the survey received two reminder emails. The survey was available to complete for a four week period. Table 4.2 shows the number of surveys completed for each county.

Table 4.2. Survey Completion

County	Perry	St. Louis	St. Charles	St. Clair
Number of organizations receiving survey	2	6	2	3
Number of surveys completed	1	11	2	15

Key Informant Interviews

The goal for key informant interviews was to collect information from a diverse group of community experts who have a thorough understanding of local thoughts, beliefs, and practices, especially pertaining to breast cancer. Key informant interviews followed a basic template, but the questions were adjusted based on the direction of the conversation and the individual's knowledge of breast cancer. Several informants had a much greater knowledge of the community and health care as a whole but not specifically breast cancer.

The Affiliate contractor first contacted major organizations in the county and then used a combination of convenience and snowball sampling to gather other participants. Informants were asked to suggest individuals or organizations that could be contacted for a possible interview. Others 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. A list of 12-15 possible informants was created, and then at least three points of contact were

made with each individual for an interview. Nine key informant interviews were conducted in Perry County and six were conducted in St. Charles County.

Focus Groups

Focus group participants were recruited via convenience sampling through the Affiliate's communication channels and grantee relations. Budget constraints prohibited the Affiliate from being able to truly conduct random sampling.

In St. Clair County, a Komen St. Louis grantee was able to organize two focus groups each with seven participants representing several organizations from the community. One focus group consisted of all Black/African-American individuals, and the second group was a mix, with two White individuals. Focus group participants ranged from age 40-60, although age parameters were not indicated. Each participant had a strong understanding of breast cancer either personally or professionally and lived in St. Clair County. The contactor developed the focus group guide and moderated the discussion. Focus groups lasted 90 minutes and participants were compensated for their time.

Four focus groups were scheduled in St. Louis County/City, one of which had to be cancelled due to its proximity to ongoing protests in the community. One focus group that took place consisted of 10 breast cancer survivors ranging in age from 36-61 who had been diagnosed within the last 10 years. Two of the participants had been diagnosed within the last year, and one was currently going through treatment. A second group consisted of 15 health care workers, not necessarily providers, a few of whom were breast cancer survivors. A third focus group consisted of eight city leaders and community volunteers in the St. Louis area, all of whom had a vast knowledge of the status of breast cancer in the area.

Ethics

Focus group participants signed a consent form before beginning, which detailed the purpose of the group, informed participants that they were there voluntarily and were able to discontinue their participation at any time, and stated that personal information obtained would be kept confidential. The participants were given the option to select if they were willing to be quoted directly, in part, or not at all.

Komen St. Louis acquired verbal consent to record key informant interviews. Key informants were told how the information they provided would be utilized. They also were 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.

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.

Anonymity of the sources was protected by not utilizing any identifying information in the analysis, with the exception of key informants. Focus group participants were asked to sign in

and provide some basic demographic information, but only for the purposes of confirming the audience. Data were not transmitted outside of the Komen St. Louis or contractor network, and participants were not made public during the process.

Qualitative Data Overview

Focus group audio was recorded and then the contractor completed an abbreviated transcription of the sessions. 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 Monkey has an automatic analysis function as part of the survey membership. It generates question summaries showing the percentages of each response. The Affiliate used this as the primary analysis for multiple-choice responses, while short-answer responses were analyzed following the format below.

Komen St. Louis' contract employee was responsible for analyzing all qualitative data. With the help of the documents in the Qualitative Data Toolkit, a five-step process was used. Surveys, key informant interviews, and focus groups were all evaluated individually to begin with, and then major themes were combined across data sources.

Step 1: Record Data: Once data were collected, the data were immediately formatted and saved. Notes were typed and organized by county 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 this first step, all data were initially read in entirety. Surveys were reviewed first in their complete form to analyze short-answer responses. Liberal codes were assigned to themes/phrases in each response. Key informant interviews and focus groups were coded in a similar manner via segments either by the question or by the 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 major themes, referring to the original assessment questions and variables for guidance.

Step 5: Format the Data: Finally, data were organized via county, and this is presented in Figure 4.1. Along with the qualitative data findings, themes from the QDR and HSA were taken into consideration when making final conclusions and are presented below.

Perry County, Missouri	St. Louis County/ City, Missouri	St. Charles County, Missouri	St. Clair County, Illinois
• Lack of services available • Lack of education • Lack of understanding of Komen St. Louis • Unwelcoming community dynamics	• Conflicting demands • Lack of understanding of Komen St. Louis • Need for navigation • Increased need for services for young women and minorities • Barriers related to fear and financial constraints	• Lack of focus on preventative health • Lack of understanding of Komen St. Louis	• Racial disparities • High level of fear • Lack of education • High rate of mental illness and substance abuse • Financial and insurance barriers

Figure 4.1. Key Findings

Perry County

Of the nine key informants interviewed in Perry County only two were familiar with Komen St. Louis other than the association with Race for the Cure. Several interviewees, while in tune with the community, couldn't offer a suggestion on where to go for breast health information or who to speak to specifically. Several individuals mentioned that Relay for Life has a big presence in Perry County and that there are several fundraising events, but not education or outreach opportunities of which they were aware. A theme across respondents for Perry County was that it is often hard for outside organizations to be well received by the community, that to be accepted it can often take a great deal of time and consistency.

> *"It's very hard to get into. They are sometimes hesitant of outsiders and it can take a while to get into the community."*

> *"It takes a while to be accepted. It's going to be hard to break the ice, you might have to be escorted in, have someone that can help you get integrated into the community."*

Barriers related to Perry's rural location were confirmed. However, it was often stated that if transportation allowed, individuals would receive information or services from neighboring counties including St. Louis or Cape Girardeau. Location only seemed to be part of the problem; several services seemed to be available if needed, but convincing individuals to utilize them can be challenging. There was a lack of response from providers in Perry County; therefore, their perspective is under represented.

> *"I think there are a lot of women that have never had a mammogram and just don't think about it."*

St. Louis County/City

Themes were consistent across data sources for St. Louis except for one major point. Numerous providers mentioned that no-show rates were high – they contributed it mostly to conflicting priorities. Often, individuals would make appointments because they were prompted by their physician, but not place a high enough priority on it to follow through. It is thought that women, especially those with families, will put their health last and address the needs of their family first.

> *"We send out [reminders] for the women who came back every year, I send out personal letters myself. We call them several times and schedule them several times - no show."*

> *"Taking care of my family is more important than coming in for my mammogram."*

Major themes around access to services included not only a lack of knowledge of the services available, but more so the inability to navigate those services. Individuals seemed to know there are resources available but weren't sure how to access them. Repeated comments were made about how information was overwhelming to sort through, stating it required a good bit of time and self-motivation to find what you needed.

> *"Lots of positive things going, there are great medical systems, great support groups. In a way sometimes I wonder if there is too much, that we are too spread out."*

> *"I think they have so many competing barriers that it is tough for them to really think about health care -- competing priorities -- that's the world."*

It was also unclear as to the role of Komen St. Louis as an organization. Participants were unclear as to where the money went and how it benefited those living in St. Louis directly.

> *"Komen here is mammogram vans and the race. I would never think to call Komen for any sort of advice. I don't remember seeing anything on treatment advice or survivorship."*

> *"It's collecting money from research, and it's supposed to stay here locally, and it does, but I don't think they do a good job of spreading the word."*

A few hospitals have started employing nurse navigators to help those diagnosed navigate the system between different providers, insurance barriers, and other services needed. There was unanimous support for positions like this and requests for additional investment into this type of navigation.

Several mentioned a lack of services available for young women, be it educational programs directed at the younger population or access to screening or support groups. There also was an apparent need for culturally competent information for the various ethnic groups represented in St. Louis County/City.

"When I was first diagnosed there wasn't anything for young women."

In terms of perception and beliefs, it was encouraging to note that awareness has increased and the perception of a diagnosis appears to be evolving. Providers reported fear as the number one barrier; others noted that people were starting to see women living through the disease with a greater quality of life. The second greatest barrier reported was financial, wondering how they would pay for treatment if diagnosed, not being able to pay co-pays or deductibles associated with insurance, and not really understanding what insurance covers with the recent changes.

St. Charles County

St. Charles had the least amount of qualitative data of the four target communities. The lack of data especially after persistent pursuit highlights a lack of accessible information. Two breast cancer support groups in the area were contacted that are no longer in session; these were omitted from the Key Informant List. It also was challenging to reach the health centers to speak to either administration or someone in clinical for more information on screening. One organization was contacted nine times with no success, long wait times and unreturned phone calls.

One organization couldn't recall anything going on in the community related to breast cancer, and five out of the six key informants were not familiar with Komen St. Louis. Conflicting information was provided regarding if more education was needed or if it was greater access to services.

"You see pink things, but I don't know what it's for."

"We do some general women's health information, but nothing specifically for breast."

It was reported that many women drove to St. Louis for services and that transportation wasn't a major barrier as long as you lived in the eastern part of the county.

St. Clair County

Qualitative data from St. Clair depicts strong racial disparities in the community as one of many potential contributing factors to the disparity in breast cancer survival. Participants described tensions between East St. Louis and the neighboring city of Belleville; while in close proximity, individuals usually don't go back and forth for services, and East St. Louis is typically seen as inferior in terms of education and access.

"What we are really talking about here is a lot of racial gaps."

"It's Belleville versus East St. Louis."

"There may be collaboration between the higher levels, but not with the general population."

There also seems to be a lack of collaboration and/or communication between greater St. Louis in St. Louis County/City and East St. Louis in St. Clair County in terms of overall health and social service agencies.

> *"They are coming from St. Louis and we already have this community over here and these organizations. So I don't know if they are really coming over here and working effectively; I think they are duplicating what's already going on."*

St. Clair County was also described to have a population that was very unlikely to seek preventative care, and that high utilization of the emergency system was a concern. Many attributed this to a cultural mindset not focused on preventative health as a whole, or to barriers related to education, fear, and cost that prohibited individuals from seeking care earlier. Another barrier described was the high rates of homelessness, alcoholism, and mental illness, leaving people in a state unsuitable to take care of their basic health needs.

> *"They don't go anywhere, they don't seek out health information. They will go to the ER if it's bad enough."*

Related to breast cancer specifically, it was noted that general awareness had improved, but awareness didn't translate into education and action. There were still several misconceptions around risk factors and the recommendations. There is still a strong fear mentality associating breast cancer with a death sentence and a fatalistic mindset. There seemed to be lack of understanding of the survival rate if detected early, something possibly associated with decreased focus on preventative health.

> *"There is a lack of education, people don't take it seriously. They don't understand it could be more."*

Issues related to cost, financial instability, and confusion around insurance were consistent throughout conversations. There were numerous complaints about Illinois' managed health care plans and Medicaid options.

Qualitative Data Findings

Limitations

The major limiting factors to the focus groups in both counties were that they were not randomly recruited and only one or two groups were conducted per population group, rather than the recommended three. These factors may have prevented the information from being a good representation of the community as a whole. Also, with the reliance on convenience sampling for focus group participants, there were very little inclusion/exclusion criteria.

Low response rate was a limitation to the survey. Despite persistence in reaching the organizations, several never returned emails or phone calls, and a few were unable to disseminate the survey because of no-solicitation policies. The survey, consisting of 13 questions, may have been too lengthy for a busy practitioner. The contractor could have

shortened the survey and possibly acquired more responses or tried to reach health care professionals individually rather than going through the organizations.

The number of responses limited key informant interviews. In Perry County, the Affiliate had a hard time finding individuals who knew much about the status of breast cancer in the community. While there is crossover between Perry County and neighboring Cape Girardeau County, the Affiliate was hesitant to gather data on a community not selected as a target. Perry County has one of the smallest female populations in the service area and only has two medical facilities, one of which did not return phone calls or emails for an interview.

In St. Charles, the Affiliate had a very hard time with organizations returning phone calls and responding to emails. There was also a lot of outdated or incorrect contact information on several websites. For example, the Health Resources and Services Administration (HRSA) website lists three possible health centers in St. Charles County. One of these had an incorrect phone number, and the phone number listed and the organization seemingly associated with the clinic could not provide information; 11 unsuccessful attempts were made to reach the listed clinic. The predominant health clinic in St. Charles County did not respond to nine attempts at contact, both to administrative and the clinical staff.

Due to the small sample sizes of focus groups, surveys and interviews, responses may not be representative of providers or women in the target communities.

Conclusions

Comparing results from qualitative data collection corroborates several of the assumptions from the Quantitative Data Report and Health System and Public Policy Analysis. Perry County's lower socioeconomic statistics combined with its lack of screening facilities, especially for those who are uninsured or underinsured women, is apparent in qualitative findings. One can conclude that even if educational programs are implemented in the area, they may not be well received or be of interest to a population not highly invested in preventative health, especially from outside organizations.

St. Louis County/City will most likely continue to be a focus for the Affiliate due to the area's large and diverse population. Breast health education programs seem to be similar to breast health services in that availability isn't the limiting factor; rather, the limiting factors are utilization of the services, ability to navigate through education and support services, and ability to afford screening and diagnostic procedures. There will be a continued need for programs to accommodate large populations of young survivors and minorities.

St. Charles County had numerous quality providers with breast health services throughout the Continuum of Care according to the QDR and HSA. Despite that, St. Charles still had statistics well above the desired Healthy People 2020 goals. This may be attributed to some of its population characteristics, since high socioeconomic status (SES) has been linked to an increased risk of breast cancer. St. Charles County has the lowest percentage of people who have less than a high school education and the lowest percentage of people living below 100

percent of the Federal Poverty Level. While qualitative data on St. Charles were limited, it was noted that several residents utilize St. Louis County/City for services. More research is needed to confirm, however the Affiliate wonders if St. Charles County residents face similar challenges as those reported from St. Louis.

St. Clair County is the most racially diverse county in the Affiliate's service area, surpassed only by the City of St. Louis. The county's population is 32.3 percent Black/African-American and 32.0 percent Hispanic/Latina. Qualitative data indicated racial disparities between population groups, much of which has persisted for generations. St. Clair County also seemed to have challenges around insurance and funding for screening and diagnostic services for women.

Consistent across all four areas were three recurring themes. First, overall awareness of breast cancer had increased in recent years, but this awareness did not translate into action. Second, there was a lack of knowledge regarding Komen St. Louis and its Community Grants Program. Third, there was a consistent fearful mentality associated with cancer, dealing with pain and the unknown, and ultimately was considered a death sentence by many.

Breast Health and Breast Cancer Findings of the Target Communities

Quantitative Summary

The purpose of the Quantitative Data Report (QDR) is to use reliable data to identify the highest priority areas for breast cancer interventions. Four target communities (Perry County, Missouri; St. Louis City and St. Louis County, Missouri; St. Clair County, Illinois; and St. Charles County, Missouri) were selected based on estimates of how long it would take each county to achieve the Healthy People 2020 objectives for breast cancer late-stage incidence and death rate.

It was estimated that it would take Perry County 13 years or longer to achieve the late-state incidence target; Perry County's current rate is higher than both the US and Komen St. Louis' service area averages and is predicted to increase. Perry County's population also has lower education levels and a higher percentage of the population at or below 250 percent of the Federal Poverty Level (FPL).

St. Louis County is the most populous county in the Affiliate's service area. When combined with St. Louis City, the total population makes up almost half of the service area. It is estimated that it will take both St. Louis County and St. Louis City 13 years or longer to reach both HP2020 targets. This target community also has a more racially diverse population; St. Louis City has the highest percentage of Blacks/African-Americans in the service area. St. Louis City also has concerning data around education, unemployment, lack of insurance, and the high percentage of the population living in poverty.

St. Clair County also has a larger Black/African-American population. It is estimated to take nine years to meet the HP2020 death-rate target and 13 years or longer to reach the late-stage incidence target.

St. Charles County has the lowest percentage of people living in poverty. The county also has the lowest percentage of people with less than a high school education. St. Charles County was selected as a target community due to the estimated 11 years to reach the HP2020 death-rate goal and 13 years or longer to reach the late-stage incidence goal.

The subsequent data focuses on explaining why the target communities were not on track to meet HP2020 goals and assessing how population characteristics such as education and poverty may impact these statistics.

Health Systems and Public Policy Summary

The Health Systems Analysis (HSA) and Public Policy Summary seeks to gain a comprehensive understanding of the programs and services in each of the four target communities and helps identify potential gaps in the Breast Cancer Continuum of Care that could contribute to late-stage diagnosis and death.

Show Me Healthy Women (SMHW) is Missouri's Breast and Cervical Cancer Early Detection Program. In Illinois the program is known as the Illinois Breast and Cervical Cancer Program

(IBCCP), with qualifying criteria differing slightly between the two states. Eligible women can receive free screenings and diagnostic services. There are 188 SMHW provider locations throughout Missouri and 34 IBCCP provider locations in Illinois. Komen St. Louis is an identified partner for the Show Me Healthy Women Program and has an established relationship with the Illinois Breast and Cervical Cancer Program.

Regarding the Affordable Care Act (ACA), Illinois has chosen to expand Medicaid, while Missouri does not have a current plan to implement expansion. Missouri opted to use the Federal Health Insurance Marketplace, Healthcare.gov. One challenge for Missouri is the coverage gap for nonelderly adults who do not have the benefit of Medicaid expansion and are not eligible for marketplace subsidies. SMHW, free clinics, and community health centers will continue to play an important role in providing coverage for those who remain uninsured. Of the three Missouri target counties, all but one has licensed navigators to help identify coverage options and eligibility. As of 2014, Perry County did not have a licensed navigator.

Illinois opted for a state Partnership Marketplace, getcoveredillinois.gov. Gaps still remain for women who will continue to be uninsured or underinsured. The implementation of the ACA provides a greater focus on preventative care services and covers Essential Health Benefits, which includes breast cancer screening. Many implications of the ACA are still unknown and will likely develop over the coming years. Both Missouri and Illinois have Comprehensive Cancer Control Plans with specific goals and objectives to address breast cancer in each state. Komen St. Louis partners with Susan G. Komen headquarters and other Komen Affiliates to address certain public policy issues.

The Health Systems Analysis confirmed that St. Louis City/St. Louis County has multiple hospitals that provide breast health services across the Breast Cancer Continuum of Care. Additionally, there are 24 SMHW providers in this target community. However, there are only two free clinics in this target community; given the high percentage of people living below 250 percent of the Federal Poverty Level, access to services may be a barrier. St. Charles County also has numerous quality providers offering breast health services, including three SMHW providers and one free clinic. Perry County only has one hospital, the only facility in the county to have screening and diagnostic mammography and to provide treatment services. Perry County only has one SMHW provider, a potential challenge for the uninsured and underinsured in terms of getting regular screening. Two hospitals in St. Clair County provide services across the Breast Cancer Continuum of Care, and the St. Clair County Health Department is a lead agency for the Illinois Breast and Cervical Cancer Prevention Program. The HSA revealed a lack of support for survivorship services beyond financial assistance and end of life care in St. Clair County. The HSA prompted Komen St. Louis to question how differing state policies (specifically, Medicaid expansion and NBCCEDP) affected St. Clair County compared to the service area's Missouri counties.

Qualitative Summary
Different qualitative data methods were utilized to help answer questions that arose for each county—specifically, why late-stage incidence and death rates were elevated and what were the major contributing factors.

For Perry County, Komen St. Louis wanted to further investigate how characteristics such as higher poverty and lower education levels may contribute to the high late-stage breast cancer incidence rate. The HSA revealed a limited access to screening services, plus the Affiliate did not have any current partners in the area. Key informant interviews and provider surveys helped answer some of the questions around gaps in knowledge and access to care. Data revealed a lack of available services and education as well as a lack of understanding about Komen St. Louis. It was also concluded that Perry County has a close-knit community dynamic that could make it challenging for outside organizations to get involved.

The main questions at hand for St. Louis City/St. Louis County related to the higher proportion of Black/African-American women, specifically looking at how well these women were being served, considering the disparity in breast cancer survival, and at barriers to service given the large number of providers in the area. Focus groups and surveys revealed that women have conflicting demands, which can make it hard to give breast health top priority. It was also concluded that there was a lack of knowledge of services available, and barriers related to fear and financial constraints were common.

Focus groups in St. Clair County targeted Black/African-American females, addressing specific barriers they face that could account for the disparity in breast cancer survival. Provider surveys considered additional barriers patients encounter as well as the implications of St. Clair not being a Missouri County and how that could affect services offered in the greater St. Louis area. Findings showed a large amount of racial disparities present within St. Clair County that spills over into health care. It was also concluded that there is a high rate of mental illness and substance abuse in St. Clair County, along with barriers related to fear and financial constraints.

Qualitative data in St. Charles County focused on answering questions as to how factors such as high socioeconomic status, high education levels, and being White contribute to breast cancer risk. The Quantitative Data Report revealed an above-average percentage of women who self-reported a mammogram in the last two years, and the HSA identified several quality providers and facilities within the county. Results were limited in St. Charles, and there was a great deal of outdated information on various websites. With the information collected, it was concluded that there was a lack of focus on preventative health, and the county had a lack of understanding of Susan G. Komen St. Louis.

Mission Action Plan

After reviewing both quantitative and qualitative data in the target communities, the following needs and priorities were selected for Komen St. Louis, along with the proposed objectives:

Problem/Need Statement #1
According to the Quantitative Data Report (QDR), all four target communities (Perry County, St. Louis City/County, St. Charles County, and St. Clair County) have higher than desired late-stage breast cancer incidence rates and are not predicted to meet the Healthy People 2020 target of 41.0 for late-stage breast cancer incidence.

Priority
Promote activities and initiatives that improve early detection and reduce late-stage diagnosis within the four target communities of Perry County, St. Louis City/County, St. Charles County, and St. Clair County.

Objective #1
In FY17, partner with Show Me Healthy Women/Illinois Breast and Cervical Cancer Program providers as applicable in all four target communities (Perry County, St. Louis City/County, St. Charles County, and St. Clair County) to determine ways to facilitate communication about program availability and encourage women to seek recommended regular screening.

Objective #2
By FY17, host a working group with key volunteers, staff, and grantees from all four target communities (Perry County, St. Louis City/County, St. Charles County, and St. Clair County) to evaluate the effectiveness of breast health/breast cancer educational messaging and outreach efforts focusing on early detection.

Objective #3
In FY17, the Komen St. Louis Request for Applications (RFA) for community-based grants will provide details that give funding priority to organizations that offer mobile mammograms, after-hours appointments or other services that increase access to screening and strive to reduce late- stage diagnosis, specifically in Perry County, where facilities are limited.

Problem/Need Statement #2
According to the Quantitative Data Report (QDR), it is predicted to take 13 years or longer for St. Louis City/County to meet the Healthy People 2020 breast cancer death-rate target. The Health Systems Analysis (HSA) and Qualitative Report revealed that despite numerous quality facilities, multiple barriers still limit utilization.

Priority
Increase partnerships with community and health organizations in St. Louis City/County to decrease or remove barriers across the Breast Cancer Continuum of Care.

Objective #1
By March 2017, collaborate with at least two organizations (churches, community organizations, health care facilities, etc.) that can help promote the message of breast cancer early detection in St. Louis City/County.

Objective #2
By March 2017, hold at least three meetings with hospitals, providers, or clinics in St. Louis City/County to discuss promoting breast health as part of an overall preventative health approach.

Objective #3
In FY17, host a meeting with other breast cancer organizations in the community to review coordination of services, reduce overlap, and effectively communicate resources available in St. Louis City/County.

Problem/Need Statement #3

According to the Quantitative Data Report (QDR), Black/African-Americans in the Komen St. Louis service area, specifically St. Louis City/County and St. Clair County, have a high breast cancer death rate and high late-stage incidence rate. Findings from the Health Systems Analysis and Quantitative Data Report revealed that few programs target this population specifically.

Priority
Improve Breast Cancer Continuum of Care coordination in order to reduce the late-stage breast cancer diagnosis rate among Black/African-American women in St. Louis City/County and St. Clair County.

Objective #1
By March 2016, meet with at least three community organizations in St. Louis City/County and/or St. Clair County that work with the Black/African-American population to discuss breast health outreach.

Objective #2
By March 2017, identify and connect with at least three Black/African-American Ambassadors per community in St. Louis County and St. Clair County who can help link women with breast health services.

Objective #3
By March 2017, revise the Request for Applications (RFA) to include a funding priority directed at improving the Breast Cancer Continuum of Care for Black/African-American women in St. Louis City/County and St. Clair County.

Problem/Need Statement #4

Among the target communities of Perry County, St. Louis City/County, St. Charles County, and St. Clair County, the Qualitative Data Report showed a lack of understanding about Susan G. Komen St. Louis in terms of what the organization does and the organization's role in the community.

Priority

Work with the four target communities (Perry County, St. Louis City/County, St. Charles County, and St. Clair County) to promote understanding of Susan G. Komen St. Louis, helping to clarify how events such as the Susan G. Komen St. Louis Race for the Cure raise funds to benefit local breast health programs and breast cancer services through community grants.

Objective #1

By March 2017, conduct an in-house communications audit to analyze current communications efforts and identify opportunities for more effective communication about Komen St. Louis' community grants program.

Objective #2

By March 2017, create a new communication vehicle (such as an annual report) that helps illustrate how Komen St. Louis funding is utilized in the community as well as services available. This report will be made public on the website and distributed to constituents, community partners, donors and potential supporters.

Objective #3

By March 2018, update grantee contracts for FY18 and following to include guidelines on proper acknowledgement of Susan G. Komen St. Louis in outreach efforts and on distributed materials.

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