



SUSAN G. KOMEN® ST. LOUIS EXECUTIVE SUMMARY

# **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.

# Susan G. Komen® St. Louis extends its deepest gratitude to the Board of Directors and the following individuals who assisted with the 2015 Community Profile:

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# A special thank you to these individuals for their assistance with coordinating focus groups for this report:

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# **Executive Summary**

#### Introduction to the Community Profile Report

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

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 latestage 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 communitybased 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.