

susan g. komen.  | **COMMUNITY**
PROFILE REPORT 2015



SUSAN G. KOMEN®
GREATER KANSAS CITY
EXECUTIVE SUMMARY

Acknowledgments

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Executive Summary

Introduction to the Community Profile Report

Susan G. Komen® Greater Kansas City began with a Race for the Cure® event in 1994, organized by three inexperienced, headstrong women who relocated to Kansas City from Washington, DC, with a “can do” attitude. In those days, a small core of committed women kept files in their homes and cars, had all Race phone calls on an answering machine in a spare bedroom and treated Komen as their second job. It was truly a grassroots effort.

The need for management grew increasingly evident over the years. Thus, the first Board of Directors was formed and an office was generously donated in 1999. Today, Komen Kansas City serves ten counties in Kansas and seven counties in Missouri, and has a staff of six while continuing to have nearly 200+ active volunteers serving on various committees. The annual Race for the Cure has grown to be the largest nonprofit run/walk in the Greater Kansas City community with over 15,000 in attendance annually.

With the help of passionate volunteers, a dedicated board and staff members, Komen Kansas City has funded over \$19 million in support of the mission. \$11 million dollars has been invested in grants to local community organizations, nearly \$4 million has been given in support of scientific research, and over \$4 million has been used in support of educational events, outreach programs, referrals to services, public policy and more. Komen Kansas City prides itself on being invested in the community. Staff actively participate in several local and state wide groups including serving as the Chair for the State of Missouri Show Me Healthy Women Advisory Board and also the Missouri Cancer Summit Planning Committee. Throughout the year, the Affiliate takes on a voice for the community through advocacy efforts with state and federal breast health legislation. Also, community members come to Komen for their breast health needs including speakers for events, information on breast screening services, and support during their fight against breast cancer. Many survivors come to Komen to volunteer or access resources and quickly become part of the Affiliate’s family as Komen journeys beside them during difficult times.

In recent years, Susan G. Komen Greater Kansas City has been recognized for excellent work in both the breast health and nonprofit fields. Staff proudly accepted an award for first place in the NonProfit Connect Philly Awards for social media. The Philly Awards are an annual competition honoring excellence in nonprofit communications. Additionally, in 2014 Susan G. Komen Greater Kansas City was honored to receive the National “Promise Award” from Susan G. Komen headquarters. This award, named in honor of the promise Komen’s founder made to her dying sister, Susan G. Komen, recognizes the Affiliate’s commitment to forward thinking in reducing overall breast cancer death, as well as disparities in breast cancer death.

Komen’s promise is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to discover the cures. To meet this promise, Komen Kansas City relies on the information obtained through the Community Profile process to guide the work needed to accomplish the promise in its communities.

The purpose of the 2015 Community Profile report (CP) is to conduct an updated needs assessment of Komen Kansas City’s 17 county service area. This comprehensive study utilizes quantitative (statistical) and qualitative (focus group and provider interview) data collection and analysis. The assessment is used to establish priorities for the Affiliate’s decisions regarding grant funding, education, marketing and outreach and public policy activities. It is a road map for future funding and will guide the Affiliate’s Strategic Plan for the next several years.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

In order to be efficient stewards of resources, Susan G. Komen Greater Kansas City has chosen five target communities within the service area. The Affiliate will focus their strategic efforts on these target communities over the course of the next five years. Target communities are those communities which have cumulative key indicators showing an increased chance of vulnerable populations likely at risk for experiencing gaps in breast health services and/or barriers in access to care.

The selected target communities are:

- Clay County, Missouri
- Jackson County, Missouri
- Johnson County, Missouri
- Northeast Kansas Region (Atchison, Brown, Doniphan, Jackson Counties)
- Wyandotte County, Kansas

Northeast Kansas Region, Kansas (Atchison, Brown, Doniphan, Jackson Counties, Kansas):

Due to small population sizes, data have been suppressed for many of Northeast Kansas counties. These counties have been combined into one region for the purpose of this report and for the Affiliate's targeted efforts. The Northeast Kansas Region is located in eastern Kansas and aligns with the Missouri state border. All counties in the region are considered rural.

These counties have been chosen due to low screening rates, unique population demographics, and identification as medically underserved and having lower income levels.

Although, the demographic makeup of this region's female residents is primarily Caucasian, several American Indian reservations are located in the region. In the past, breast cancer in American Indians was rare. Unfortunately, the last two decades have seen large increases in both incidence and death rates for this group of women.

Additionally, socioeconomic characteristics of the region indicate a potential concern about women's access to affordable breast health care. All counties in the region, with the exception of Jackson County, Kansas have substantially higher percentages of residents living below 250 percent poverty income than the service area average. Additionally, Doniphan County is considered to be in a medically underserved area compounding potential barriers to breast health care. Only two providers in the entire region participate in the National Breast and Cervical Cancer Early Detection Program; and one of those providers is limited to only providing services to American Indian women.

Wyandotte County, Kansas:

Wyandotte County, Kansas represents the most diverse population in the service area. 27.8 percent of women are Black/African-American, a rate higher than the national average and double that of the service area average. This is significant due to the high death rates Black/African-American women experience from breast cancer when compared to other races. Additionally, 24.9 percent of the county is Hispanic/Latina, 7.2 percent are linguistically isolated, and 14.2 percent are foreign born. All of these percentages are substantially higher than the service area's averages.

Wyandotte has been identified as a high priority county due to the amount of intervention time needed to achieve the federal government's healthy people 2020 goals. For instance, the county's death rate of breast cancer was 28.5 per 100,000 women. This is higher than the United States rate (22.6), as well as the service area's rate (24.9). The death rate is expected to decrease over the next few years. But currently, the county

continues to have one of the highest rates of breast cancer death in the service area. Data showing late-stage diagnosis rates and trends were not available for this county.

Screening rates in Wyandotte County are lower than the United States; and service area averages and socioeconomic data for the county show several concerning areas. Wyandotte residents are substantially more likely to have less than a high school education, an income below 250 percent poverty, and be unemployed than others in the United States and the service area. Wyandotte County residents are also the least likely in the service area to have health insurance.

Clay County, Missouri:

Clay County has been chosen as a target community due to breast cancer death rates and trends, as well as the breast cancer incidence and late-stage diagnosis of breast cancer rates. It is also a high priority county based on the intervention times needed to meet Healthy People 2020 goals.

The county's breast cancer incidence, death, and late stage diagnosis rates are all higher than the United States, as well as the service area's averages. Additionally, trends in data show these incidence rates and late-stage diagnosis rates are getting higher. Simultaneously, the breast cancer death rates are lowering.

On the plus side, Clay County women (ages 50-74) self-reported obtaining a screening mammogram within the last two years at a rate higher than the service area and the United States averages. The increase in incident rates may be correlated to the above average mammography screening rates in Clay County.

Jackson County, Missouri:

Jackson County, Missouri, is a high priority county in regards to meeting the Healthy People 2020 goals. Jackson County has been chosen as a target community due to rates and trends regarding breast cancer deaths, as well as the rates of breast cancer incidence and late-stage diagnosis. Additionally, Jackson County residents reflect a diverse population with many women who may be more vulnerable to breast cancer due to known poorer prognosis rates (i.e., late-stage diagnosis or more aggressive cancers). Finally, compared to the service area average, more residents in this county are living below 250 percent poverty, have higher unemployment rates, and are less likely to have health insurance making affordable access to breast health care potentially difficult.

Data for Jackson County show the breast cancer death and late-stage diagnoses rates are currently higher than both the United States' and the service area's average rates. However, there are promising trends in the rates of incidence, deaths from breast cancer and late-stage diagnoses. All categories are expected to show lowering rates in upcoming years.

Women in Jackson County, ages 50-74, have reported obtaining a screening mammogram at a rate comparable to the service area average. This is positive since mammography can facilitate early detection.

Johnson County, Missouri:

Johnson County, Missouri, has been chosen as a target community due to higher than average breast cancer death rates, late-stage diagnosis rates and an increasing trend in incidence rates. In the Affiliate's 17-county service area, Johnson has one of the highest death rates and the highest rates of late-stage breast cancer diagnosis. Consequently, Johnson County has also been identified as a high priority county due to the amount of time needed to meet the Healthy People 2020 goals.

Johnson County currently has breast cancer incidence rates lower than both the United States and service area averages. However, trends show incidence rates increasing. Also problematic, both breast cancer death

and late-stage diagnosis rates are above the United States and service area averages, with an increasing trend for late-stage diagnosis. No data is available for trends related to the death rates from breast cancer.

With screening rates in Johnson County below the United States and service area averages, it is possible women are experience barriers to receiving mammography screening. This may be associated with higher rates of late-stage diagnoses and more women dying from breast cancer. It may also explain the lower rates of incidence.

Health System and Public Policy Analysis

In addition to quantitative data review, Komen Kansas City utilized multiple sources to collect data for an analysis on the breast health systems of the service area. The information and data collected from these resources was obtained and analyzed in order to create an accurate depiction of the systems and services impacting breast health in the target communities of the Greater Kansas City area. Identifying services available in target communities allows Komen Kansas City to understand the strengths and opportunities for growth in each county. This includes all aspects of breast health and care, revealing where the counties are excelling and any gaps that may be present.

Analysis by Target Community

Clay

Clay County has a substantial amount of breast health services available to residents. Multiple hospitals provide a full “continuum of care” for breast cancer. However, Clay County also has a relatively high number of breast cancer deaths and late stage diagnosis rate. Considering that screening rates in this county are not significantly different than the service area’s average, a strong emphasis must be placed on navigation, diagnosis, and treatment of breast cancer. In addition, the analysis reveals that the majority of breast health services, particularly treatment, are in the Southwest region of the county, centered in North Kansas City and Liberty. Those in other regions of the county have very few readily accessible breast health services.

Jackson

As seen through mapping of services, Jackson County has breast health resources all along the “continuum of care.” Kansas City, Missouri, and the immediate area have numerous health centers providing screening, diagnostics, treatment, and support. However, urban Jackson County remains a target area due to late-stage diagnosis rates, education levels, poverty levels, and hard to reach populations. Therefore, Komen Kansas City works with multiple partners to provide better access to breast health to the least reached populations of Jackson County.

Johnson

Johnson County, Missouri, lacks the breast health services of the metropolitan regions of Komen Kansas City’s service area. With the only health department and hospital located in Warrensburg, Missouri, any residents not living in this city lack convenient access to services. Western Medical Center in Warrensburg partners with Saint Luke’s Hospital to provide diagnostic and screening services, as well as a biweekly oncology clinic providing physicians, infusion therapy, and labs. However, patients needing radiation therapy are sent to Saint Luke’s East in Lee’s Summit, Missouri. Residents in Johnson County Missouri, have limited access to treatment and survivorship services, forcing them to travel to the nearby cities in order to receive care. Johnson County Cancer Foundation provides financial assistance to cancer patients. However, barriers faced are not solely financial in nature.

Northeast Kansas

Atchison, Brown, Doniphan, and Jackson Counties make up the target community of the Northeast Region of Kansas. This rural area of Kansas, while having a hospital and health department in each county, lacks readily accessible services along the complete “continuum of care.” Residents of this area without independent

transportation would most likely be unable to receive any breast care. In addition, Atchison, Kansas has the lowest screening rate in Komen Kansas City's entire service area.

Wyandotte

As seen through mapping of services, Wyandotte County has breast health resources all along the Continuum of Care. Despite the resources available, breast health screening rates and late-stage diagnosis in Wyandotte County remain a concern. Low income, racial and ethnic disparities, and lack of insurance continue to create barriers in this area.

Komen Kansas City's target communities each face different but equally challenging barriers to breast health. While Clay, Jackson, and Wyandotte counties have various services available in all areas of the Continuum of Care (CoC), women are not accessing these services fully. Neither Johnson County, Missouri, nor the Eastern Kansas region has readily available services in all areas of the CoC. Residents of these counties face the barrier of traveling to other counties for many of their necessary screening, diagnostic, treatment, and survivorship services.

Public Policy Implications

The Affordable Care Act (ACA) works to expand access to care through insurance, enhance the quality of health care, improve coverage for those with insurance, and make health care more affordable. ACA mandates health insurance for Americans (with a few exemptions). ACA prohibits denying coverage based on pre-existing conditions, annual or lifetime caps, and rescinding coverage. It also establishes minimum benefit standards and coverage for preventative services. In both Kansas and Missouri, a federally administered plan was chosen as the method for the insurance exchange program.

For breast cancer, ACA impacts all parts of the continuum of care. ACA includes breast cancer education for young women, mammography as a required benefit, and increased access to clinical trials and patient navigation. Eliminating pre-condition exclusions and lifetime and annual caps are also vital for breast cancer treatment and follow-up care.

Despite these positive changes, gaps will still exist. Undocumented immigrants, un-enrolled Medicaid eligible individuals, those exempt from the mandate, and those that choose not to enroll will remain without insurance. It is estimated that this will make up 30 million Americans that will remain uninsured in 2016.

Because Missouri and Kansas chose not to expand Medicaid, a coverage gap is left of people making too little to qualify for federal help. The authors of ACA intended these individuals to be covered by Medicaid expansion, but both states in the service area opted to not expand. Therefore, most of Kansas and Missouri's poorest, working-age residents — those under age 65 and below the poverty line of \$11,490 for an individual and \$15,510 for a couple — aren't eligible for government help. In Kansas, there are currently 369,000 uninsured individuals- 78,000 in Kansas (21 percent of uninsured) who would have been eligible for Medicaid if the state expanded will fall into the coverage gap. In Missouri, 93,000 of the 834,000 uninsured adults (23 percent of the uninsured) will fall into this gap.

Through advocacy efforts and partnerships, Komen Kansas City continues to be a voice for breast health in both Missouri and Kansas. Komen Kansas City advocates for funding of breast health screening, research, and treatment programs.

Qualitative Data: Ensuring Community Input

In order to gain a deeper understanding of the communities above, qualitative data was collected through focus groups and contacts with community providers. The use of two different data collection methods as well as the efforts to have multiple groups from each target area assisted with triangulation of the data. This allowed for the community to be directly involved in assessing the needs and issues, as well as potential solutions, to the initial findings from the quantitative data. By directly working with those living in the

communities targeted, the Affiliate explored beliefs and behaviors around disparities, knowledge of breast health, access to services, utilization of services and more regarding breast health and breast cancer care. This process allowed for comments by the community on what is working and what can be improved.

Conclusions:

Similar themes often correlated between focus group findings and provider interview findings. Barriers were often confirmed by both parties, such as cost of health care and access to transportation. In some instances one data source (focus groups or providers) were unaware or did not commonly express that certain barriers existed for the other party. For example, the women in the community repeatedly expressed frustration with the communication from providers but the providers did not note that time with the patient or communication of health information with the patient was an issue. Providers listed a lack of desire to access health care as a barrier. Some women in the focus groups shared they didn't want to go to the doctors, but not because a lack of desire to receive health care. Rather, they expressed a lack of confidence in the providers stemming from a negative experience as the rationale behind not seeking care. The combination of information from each party led to a deeper understanding of key issues.

Some questions asked of focus group participants touched on key issues around access to health care, such as where individuals go when they need to see a doctor and what are perceived barriers to accessing health care. Sixteen percent listed they had no one they considered their primary care giver. Additionally, 55.0 percent of women disclosed they had not seen a doctor in the past year due to cost. Cost was always listed as the number one factor in preventing women from accessing health care.

Fortunately, the Affiliate has strong National Breast and Cervical Cancer Early Detection Programs on either side of the service area state line. However, it is clear that women and providers are unaware of the resources that this program provides. Furthermore, for women who do have insurance, there is little known about the recent provisions in the Affordable Care Act which often times remove the copay for preventative services such as mammograms. With cost being the biggest barrier for many women, it is imperative that time and education is spent around what is already available to those who cannot or think they cannot afford a mammogram.

It is also clear, by the numerous discussions around breast health education, that women, in general, realize they are at risk for breast cancer but are still unaware of their personal risk factors and the things they can do to lower their risk for breast cancer. On a positive note, women do tend to share health information with their friends and family. However, it is important that educators are getting accurate material to women so they do not share inaccurate information. Continued year-long education around breast self-awareness and other evidence based information is needed to be delivered to the community in an innovative way that people will retain. Additionally, bringing the education to the appointment itself, whether by the nurse or physician, seems to have strong potential for making a larger impact on patients instead of relying on them to digest materials available in the lobby.

Access to health care is embedded from systematic issues that are difficult to change swiftly. However, small changes can be made in order to accommodate those facing challenges. Examples could include extended hours for screenings and streamlining of services such as clinical breast exams and mammograms at the same appointment. Additionally, there was a strong desire for mobile mammography to be brought back to the area, particularly in geographic locations without nearby access to mammography services. However, in order to be of most use to the community, a mobile program would need to work in partnership with the National Breast and Cervical Cancer Early Detection Programs. When available, additional subcontracts for the state programs may also provide benefit to the service area.

One of the biggest barriers women face is their personal mindset. It is vital for women to understand that their personal health is a key component to their entire family and that it is ok to take care of themselves as they

take care of others. Addressing the resounding fear of a mammogram and fear of a breast cancer diagnosis is also imperative but difficult. These fears are ingrained in the community and although the five-year survival rate for early stage breast cancer is now 99.0 percent, many women still feel that breast cancer, regardless of when found, is deadly.

Lastly, providers reacted positively to the notion of additional training around breast health. It may be useful to find a way to communicate directly with providers to supply the most up to date breast health information whether it is in the form of education to patients, knowledge around new techniques and treatments, or other forms of learning. While providers do have a strong desire for this information, the strong demand and time constraints placed on providers make it difficult to find the most effective way to reach them.

In the words of one focus group participant when discussing why someone would access breast care, "It's either going to be inspiration or desperation." The Affiliate needs to continue to find relevant ways to inspire women so they don't wait until desperation occurs.

Mission Action Plan

Once all data was combined and each county was reviewed for a total picture of the state of breast health, the Affiliate began strategic planning to address the needs found in each county. The Mission Action Plan provides the opportunity to make plausible connections regarding the issues in each county and the establishment of Affiliate priorities in the counties. For each county, a problem statement is presented based on the review of the available data for each community. Then, priorities of intervention have been selected. Finally, each priority has measurable objectives that will be implemented over the next several years.

Problem Statement: Clay County, Missouri

Women in Clay County have incidence rates, death rates and late-stage diagnosis rates that are higher than the US and service area averages. Incidence and late-stage diagnosis rates are expected to increase. The health system analysis found that there are multiple hospitals providing the full breast cancer continuum of care but the majority of those services are available in the Southwest region of the county (North Kansas City and Liberty).

In order to address the issues identified in Clay County, the Affiliate plans to focus efforts around patient navigation support, provision of Affiliate-based education to individuals, and raising awareness amongst the health system of the needs in the county. Komen Kansas City has set the following objectives for work in the community:

- Beginning with FY17, a key funding priority will be developing or improving patient navigation programs targeting Clay County women
- By the end of FY19, a minimum of 15 outings will be conducted in Clay County using the Affiliate's Connecting for a Cure curriculum
- In FY16, hold at least two collaborative meetings with health care providers in Clay County to develop a plan on how to improve breast health needs

Problem Statement: Johnson County, Missouri

Women in Johnson County, Missouri, have high breast cancer death rates & late-stage diagnosis rates. Mammography screening rates are below average. Johnson County can be considered "rural" and outside of Warrensburg, the county has no additional hospitals or health departments. Residents have to travel to the metropolitan area in order to receive the full continuum of care.

To address the high needs in Johnson County, Missouri, the Affiliate will work diligently to increase the number of women getting preventative breast health screening. The Affiliate will also work to pull together the health systems to discuss transitions for treatment of women diagnosed with breast cancer. Additionally, the Affiliate

will work to increase presence in the county as well as increase capacity to provide individual education to women in the area.

- By the end of FY16 identify the best plan for women to receive services from Show Me Healthy Women
- By the end of FY17, develop and implement a campaign encouraging women to make their health care a priority
- By the end of FY17, develop and implement a campaign to educate the population and those who work directly with them on Show Me Healthy Women as well as the breast health provisions outlined with the Affordable Care Act
- In FY16, hold at least two collaborative meetings with health care providers and community organizations to develop a plan on how to improve the breast cancer treatment process
- Beginning with FY17, a key funding priority will be developing or improving patient navigation programs targeting Johnson County women
- By the end of FY19, a minimum of eight outings will be conducted in Johnson County using the Affiliate's Connecting for a Cure curriculum
- By the end of FY19, a minimum of six members will be recruited and remain active in the Komen Kansas City "Pink Army"
- Recruit and retain a minimum of one Board Member who resides in Johnson County, Missouri during FY18

Problem Statement: Jackson County, Missouri

Women in Jackson County have breast cancer death and late-stage diagnosis rates which are higher than the US and service area averages and a higher level of residents who are vulnerable to a poorer prognosis of breast cancer survival. Additionally, more residents are living below poverty, have higher unemployment rates and are less likely to have health insurance.

The Affiliate's work in Jackson County will continue to expand with a strong focus on providing meaningful education to individuals in the community. The Affiliate will also work with the health systems to discuss the found breast needs and collaboratively create a plan to further address those needs. The Affiliate will also work tirelessly to increase the number of women obtaining preventative breast health screenings in the county.

- In FY16, hold at least two collaborative meetings with health care providers in Jackson County to develop a plan on how to improve breast health needs
- By the end of FY18, a minimum of 20 outings will be conducted in Jackson County using the Affiliate's Connecting for a Cure curriculum
- By the end of FY19 hold at least one local "Mammacare" training event for providers
- By the end of FY19, in partnership with other entities, hold at least five breast health screening events for the public
- By the end of FY 17, develop and implement a campaign encouraging women to make their health care a priority
- By the end of FY17, develop and implement a campaign to educate the population and those who work directly with them on Show Me Healthy Women as well as the breast health provisions outlined with the Affordable Care Act

Problem Statement: Northeast Kansas Region

Women living in Northeast Kansas have the lowest screening rates in the entire service area. The area is considered to be "rural" and full breast health services are not available along the continuum of care in the region. Additionally, there are only two Early Detection Works providers in the entire region.

The Affiliate will continue to work in the area with efforts to increase the number of women receiving preventative breast health screenings as well as increase the region's capacity to provide breast health care in Northeast Kansas. Lastly, the Affiliate will work to increase educational outreach to women in the community.

- By the end of FY 2019, a minimum of eight outings will be conducted in Northeast Kansas using the Affiliate's Connecting for a Cure curriculum
- Work with local resources and key influencers in NE Kansas to hold a minimum of four screening events by March, 2019
- By the end of FY17, develop and implement a campaign to educate the population and those who work directly with them on Early Detection Works as well as the breast health provisions outlined with the Affordable Care Act
- Identify and assist with recruiting of one additional Early Detection Works Provider in NE Kansas by October, 2017
- By the end of FY17, a key funding priority will be developing or improving patient navigation programs targeting Northeast Kansas Women

Problem Statement: Wyandotte County, Kansas

Women in Wyandotte County have a higher death rate than the US and service area averages. Women are receiving mammography screenings at a rate that is lower than the comparable averages. The socioeconomic data of the county is concerning with residents being less likely to have a high school education, income below 250.0 percent of the poverty level, and the least likely to have health insurance in the area. Residents also are more likely to be unemployed.

In Wyandotte County, the Affiliate will implement strategies to increase the number of women obtaining a preventative breast health screening. The Affiliate will also enhance the work to provided education to women residing in the county. Lastly, the Affiliate will meet with key players in the health system to discuss the needs of the county and potential ways to address those needs.

- In FY16, hold at least two collaborative meetings with health care providers in Wyandotte to develop a plan on how to improve breast health needs
- By the end of FY19, a minimum of 15 outings will be conducted in Wyandotte using the Affiliate's Connecting for a Cure curriculum
- By the end of FY18 partner with at least two non-health organizations to coordinate comprehensive education and screening events
- By the end of FY17, develop and implement a campaign to educate the population and those who work directly with them on Early Detection Works as well as the breast health provisions outlined with the Affordable Care Act

Disclaimer: Comprehensive data for the Executive Summary can be found in the 2015 Komen Greater Kansas City Community Profile Report.