susan g. komen®

COMMUNITY PROFILE REPORT 2015

SUSAN G. KOMEN® KANSAS

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® Kansas would like to extend its deepest gratitude to the Board of Directors and the following individuals who participated on the 2015 Community Profile Team:

Kirsten Bruce, LMSW
Executive Director
Susan G. Komen Kansas

Shelly Hipfl RN, BSN
Southeast Kansas Regional Nurse
Early Detection Works

Peggy Johnson
Executive Director, Wichita Medical Research and Education Foundation
Public Policy and Grants Chair, Komen Kansas Mission Advisory Council

Emily Lucille Millspaugh
Office Administrator
Susan G. Komen Kansas

Jeremy Mock
Business Development and Event Manager
Susan. G. Komen Kansas

Kelli Netson, PhD, ABPP
Board Certified in Clinical Neuropsychology, Assistant Professor
Director Department of Psychiatry & Behavioral Sciences
University of Kansas School of Medicine – Wichita

Cari Schmidt, PhD
Associate Research Professor
Office of Research
University of Kansas School of Medicine – Wichita

Gayle Thomas, MPH
Executive Director
Witness Project of Kansas

Kelly York
Southeast Kansas Regional Outreach Coordinator
Early Detection Works

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

Marcela Cousens
Education and Information Officer
Kansas Department of Health and Environment

Rita Davenport RN, BSN
Nurse Clinician/Administrator
Kansas Dept of Health and Environment

Audrey Nyugen
Education and Information Officer
Kansas Department of Health and Environment

Austin Rogers, MPH
Cancer Epidemiologist
Bureau of Health Promotion
Kansas Department of Health and Environment

Julie Sergeant, PhD
Section Director, Health Systems
Kansas Department of Health and Environment

Ericka Welsh, PhD
Senior Chronic Disease Epidemiologist
Bureau of Health Promotion
Kansas Department of Health and Environment

Report Prepared by:

Susan G Komen® Kansas
3243 E. Murdock St., Suite 103
Wichita, KS 67208-3018
316-683-8510
www.komenkansas.org
Contact: Kirsten Bruce, Executive Director

Executive Summary

Introduction to the Community Profile Report

Susan G. Komen Wichita Race for the Cure® was started in 1990 by the Junior League of Wichita. The Komen Wichita Race for the Cure was the first Komen co-ed Race for the Cure and the fourth Race for the Cure in the series. The 1990 race was the largest first-year road race in Kansas' history. More than 1,400 participants took part in the first Wichita Race for the Cure.

As a result of this initial success, the Susan G. Komen® Kansas Free Mammography Program was started with the event's proceeds. The Affiliate's program was the first such program for Komen nationally and served as a model program for many cities. The program predated the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). When the NBCCEDP was organized in Kansas in the mid-1990s, the Free Mammography Program rolled into the NBCCEDP. Historically, the State Health Department, who oversees the NBCCEDP, has been the Affiliate's largest grantee. The State Health Department has received grant funding to provide screening to individuals who do not qualify for the federal program. In Kansas, the federal program is only available to women who are age 50 and over. Funding from Komen grants have been used to pay for services for women under the age of 50 and for men. Additionally, providers from Sedgwick County give screening and diagnostic vouchers as in-kind sponsorships for the Wichita Race. These vouchers are used to supplement the NBCCEDP for people who do not qualify for the program but are still in need of services. The programs have provided over 44,000 free mammograms in the State of Kansas.

In 1993, the Susan G. Komen Kansas Affiliate was officially formed. Through events like the Race, the Affiliate has raised over $6 million to invest in research, education, outreach, and screening services. Up to 75 percent of net funds generated by the Affiliate stay in the 95 county service area to grant out for education, patient navigation, survivorship and screening services. The remaining 25 percent of funds raised by the Affiliate go toward the Susan G. Komen Research Programs supporting research awards and educational and scientific programs around the world.

Susan G. Komen Kansas is actively involved in the Kansas Cancer Partnership. The partnership provides statewide leadership in the development, coordination and implementation of cancer prevention and control in Kansas. The partnership brings together individuals and organizations from across the state to work toward reducing the burden and suffering of cancer in Kansas. The Susan G Komen Kansas Mission Advisory Council chair currently co-chairs the Kansas Cancer Partnership. The Mission staff chairs the Survivorship cancer action team for the partnership.

Affiliate Service Area

The Affiliate serves 95 of the 105 counties in the State of Kansas; the remaining ten counties are served by the Greater Kansas City Affiliate (Figure 1). As a whole, Kansas does not have exceptionally high or low incidences of breast cancer when compared to the rest of the country, but some troubling disparities in access to care and breast health education do exist upon closer examination of the data.

Kansas is a largely White state of approximately 2.9 million adult residents, half of whom are women. A large percentage of Kansas residents live in rural areas and many counties are considered to be frontier. This means they are the most geographically isolated areas in the country. Frontier counties are sparsely populated and face large distances and long travel time to access health services. Based on the statistics and demographics within the state, four counties, Cherokee County, Montgomery County, Sedgwick County and Shawnee County were chosen as the four focal point sites for the Community Profile. Cherokee and Montgomery Counties are both considered to be medically underserved and experience gaps in breast health services. This, obviously, could impact women's access to quality breast health care. Montgomery County also has a significantly lower mammography rate than the rest of the Affiliate service area. Sedgwick and Shawnee Counties make up one-third of all late-stage diagnoses of breast cancer in Kansas and have the highest percentage of Black/African-American women in the Affiliate service area. These two counties mirror alarming national data that show that Black/African-American women are more likely to die of breast cancer because of a later stage diagnosis.

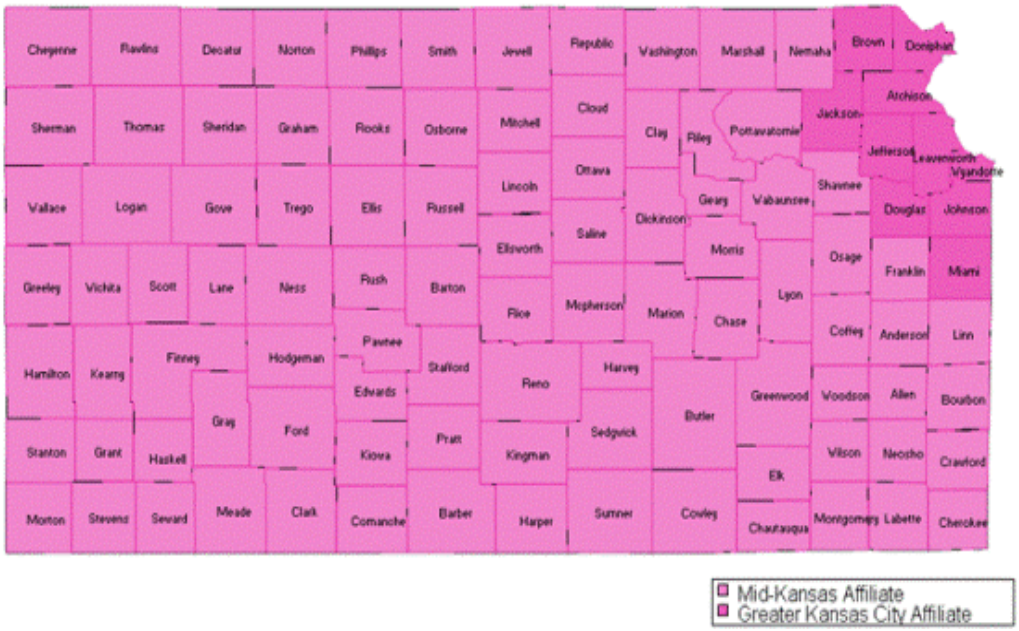

Figure 1. Susan G Komen Kansas service area

Purpose of the Community Profile Report

The Community Profile is the result of an assessment process the Affiliate performs. The Community Profile document is developed to understand and communicate the state of breast cancer, general breast health, and services available in the Affiliate service area. The Community Profile assists Affiliates to establish focused granting priorities, establish focused education and outreach needs and activities, drive public policy efforts and strengthen partnerships. The purpose of the Community Profile is to make data driven decisions about how to use resources in the best way and set priorities to ensure that the Affiliate serves the people who are in the most need.

The Community Profile guarantees mission and non-mission work is targeted and non-duplicative. It is used to create strategic and operational plans and is one way that the Affiliate communicates with community members, grantees, partners, sponsors and policymakers. The Affiliate knows its resources and limitations and the importance of these factors in setting realistic priorities and an action plan based on this report.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Exploratory data provided Komen Kansas the opportunity to determine the most appropriate target communities for the Community Profile. Based on review of the Quantitative Data Report and additional quantitative data provided by the Kansas Department of Health and Environment (KDHE), the Affiliate chose Cherokee County, Montgomery County, Sedgwick County and Shawnee County as the four target areas for this document. The Affiliate will focus outreach efforts on these four areas with the idea of replicating successful outreach practices in other areas of the 95 county service areas. The target communities were identified as regions that were experiencing gaps in breast health services and where the Affiliate could focus efforts in order to be the most efficient stewards of resources. It is important to note that no county in the Affiliate service area demonstrated statistically significantly higher crude or age-adjusted rates for female breast cancer incidence (overall or late-stage) or death. Thus, absolute measures of burden including counts and crude rates of late-stage breast cancer were considered in determining where to focus limited resources. Of the 95 counties in the Affiliate service area, Sedgwick and Shawnee Counties comprised over one-third (36.9 percent) of all late-stage breast cancer diagnoses from 2006 to 2010.

Additionally, the Affiliate selected target communities by reviewing breast cancer county level incidence data as identified in the previous section and data related to Healthy People 2020 (HP2020) objectives, including:

- Reducing women's death rate from breast cancer
- Reducing the number of breast cancers that are found at a late-stage

Additional key indicators the Affiliate reviewed when selecting target communities included but were not limited to:

- Incidence rates (overall and late-stage)
- Death rates
- Mammography percentages
- Education level
- Residents with incomes less than 100 percent poverty level
- Residents living in medically underserved areas
- Unemployment percentages

Additional Quantitative Data Exploration

The Quantitative Data Report for Komen Kansas did not include data on breast cancer incidence, including late-stage breast cancer incidence counts or rates. To fill this gap, county-level incidence rates were computed for all the Affiliate counties for 1) breast cancer incidence and 2) late-stage breast cancer incidence. In addition, the proportions of breast cancer incident cases that were localized vs. regional/distant/unstaged were computed for White and Black/African-American women in Sedgwick and Shawnee Counties. This analysis was not

possible for other counties due to low counts of breast cancer incident cases among non-White women.

The Kansas Department of Health and Environment's Senior Chronic Disease Epidemiologist examined female breast cancer incidence rates (all stages) among Kansas women for the 95 counties in the Komen Kansas service area for 2006-2010. Counts of incident female breast cancer cases during the five-year period were reviewed by county, along with the county-specific female population total, the county-specific crude rate (i.e. total count / total population), the county-specific age-adjusted rate and accompanying 95 percent confidence limits. Incidence data were obtained from the Kansas Cancer Registry (KCR) 2001-2010 dataset.

Health System and Public Policy Analysis

The continuum of care is available in all four of the Affiliate's target communities. The two more urban areas, Sedgwick and Shawnee Counties, have more services available in a smaller geographical area, but all four communities have access to the entire continuum within 25 miles. Access to transportation is an issue in all four communities, but by rural standards 25 miles is not a long distance. Survivorship services are consistently the weakest portion of the continuum in all four communities. Survivorship services are a relatively new concept in the Komen Kansas service area, but both survivors and the medical community are recognizing that survivorship services greatly impact quality of life. All four communities have access to a cancer center with American College of Surgeons Cancer Program accreditation. Improving survivorship services in the target communities is a tangible area in which Komen Kansas can have a great impact. Partnering with state programs as well as with other nonprofits will give Komen partnership opportunities with front line professionals who have access to survivors and providers and can ensure breast cancer survivors have access to the highest quality of support throughout their lives.

In the policy arena Komen Kansas will continue to encourage the state to expand Medicaid and will encourage the legislature to supplement the Early Detection Works (EDW) program with state funding. If the State of Kansas continues to refuse to expand Medicaid services to those most in need, additional supplemental funding would ensure that citizens of Kansas get the breast health services they need.

The findings of the Community Profile are impacted by several unique situations in the State of Kansas. Services are readily available in the four target communities of focus for the Profile, although travel can be a concern. Some residents may have to travel 25 miles to receive services. To most people who live in rural areas that's not an issue, but to some 25 miles will be a barrier. Additionally, the current political environment, with a legislature and governor who have refused to address the possibility of Medicaid expansion, impacts the access to quality care. Their refusal to expand Medicaid has left many women and men in Kansas without the ability to access available medical services because they lack health insurance. Komen Kansas was a member of two statewide coalitions during the 2015 legislative session to address the issue of Medicaid expansion and coverage for out of pocket services. Neither issue was able to move forward because of outstanding monetary issues with the state deficit. The budget crisis and gridlocked government in Kansas are issues that Komen Kansas will continue to face. As

an organization, the Affiliate will need to find new ways to ensure that the mission has a voice in the public policy arena

Qualitative Data: Ensuring Community Input

Data compiled by The Affiliate revealed little variability across the 95 counties served by the Affiliate with regard to diagnostic and service-related discrepancies. The Affiliate chose to focus on two urban counties (Shawnee and Sedgwick) where Black/African-American women tended toward later stage diagnosis, and two rural counties (Montgomery and Cherokee) where access to care is a concern for all women.

Key assessment questions and variables such as access to health care, attitude toward health care, knowledge about breast cancer, and barriers to obtaining treatment were identified based on multiple data sources. Specific focus group questions were selected after review of data and conversations with community partners and key informants. Data gathered from the community ad hoc committee, Sister to Sister, made up of multiple organizations that serve the Black/African-American community in Sedgwick County, focused on dissemination of information to target communities. KDHE epidemiologists suggested a need to focus on late-stage diagnosis among Black/African-American women in Shawnee and Sedgwick Counties. Board members at The Witness Project, staff from the Midwest Cancer Alliance and staff from Early Detection Works all voiced concerns about education and access to care for all communities. Focus group questions and provider survey questions were reviewed by a team of survey experts and specifically tailored questions were derived to maximize the impact of information obtained.

Original data include interview notes, focus group notes, use of verbatim quotes where available, and provider survey data. The rationale for using focus group notes was to identify qualitative themes that emerged in the communities of interest. Focus group notes were reviewed by the primary lead and specific themes were identified using an *a priori* determination of inclusion with at least three participants in the same community or at least two participants across different communities raising the issue. Themes from the provider survey and from particular focus groups were compared to examine discrepancies between the general public and breast health providers.

Qualitative Data Findings

Across multiple data methods, financial concerns are a clear issue that will require ongoing intervention. Monetary concerns were identified as a primary barrier to receiving screenings, but even more concerning, to receiving follow-up care after a positive mammogram. A related and growing concern is navigation of health insurance, the health care industry, and community programs available to support women in their pursuit of breast care. An important finding is the discrepancy between the provider survey and focus groups, where many providers feel that they are adequately educating patients about programs such as Early Detection Works, while community members do not feel that they have sufficient information about these programs to use them as they are intended. Bridging this gap will be an ongoing target for intervention.

Another important theme that emerged across all sources of information was community and patient education. Some excellent ideas were generated by focus groups with regard to venues

that would more adequately target Black/African-American communities and the suggestion for multi-generational education and information targeting younger audiences has merit. It also appears that there are regional differences with regard to health literacy and providers will need ongoing assistance in assessing the needs and understanding of their patients, with adapted educational materials to target those needs.

Finally, the focus groups invariably voiced a concern about access to mobile mammography. This was a much more prevalent service in the past and based on community responses, it would appear that resuming and expanding this service in the Affiliate services area would encourage enhanced screening behaviors. Important suggestions with regard to the hours this service is made available (e.g., after 2:30 when shift workers are able to claim an entire day's work) and the location (e.g., community grocery stores, large industry employer parking lots) offer valuable insight into options that would make screening behaviors more palatable. It should be noted that these suggestions were made regardless of the targeted group – that is, both the urban Black/African-American community and rural participants felt they would benefit from these strategies to make screening more accessible.

In summary, there is agreement about a number of needs in the Affiliate area, and these can be broken down into a few recurrent themes. These themes did not differ based on rural/urban setting or Black/White demographic distinctions, but were raised with almost equal frequency across all focus groups conducted. Excellent suggestions were provided across data sources for strategies the Affiliate could use to improve access to and utilization of breast care resources, particularly in rural communities and urban Black/African-American communities.

Mission Action Plan

Problem Statement

The Community Profile Team reviewed the findings from the data to determine the overarching priority of increasing early detection and access to services across the continuum of care for women in the State of Kansas, with a focus on Black/African-American women in Sedgwick and Shawnee Counties and women in Cherokee and Montgomery Counties in rural Southeast, Kansas.

Priority 1- Actionable Education

Effectively educate women on breast health and services available to them in language and culturally appropriate methods leading to increased screening and knowledge of survivorship services.

> ***Objective 1:*** By the end of April 2016, partner with the Early Detection Works program to host a minimum of a one day workshop in Sedgwick or Shawnee County focusing on evidence-based educational programs with emphasis on health literacy and cultural awareness. Ensure part of this includes "Train the Trainer" methodology so attendees can train providers and other constituents in target communities.
>
> ***Objective 2:*** By December 2016, partner with at least two community-based outreach/health organizations in each region to identify at least three leaders in target communities who are willing to be champions for breast health and educate them on

Komen messaging and resources available. Champions will be expected to share knowledge and resources during at least two community events.

Objective 3: By December 2015 coordinate and sponsor, with the Advocates in Science (AIS) Steering Committee, a Komen event in Sedgwick County focusing on survivorship. A Komen Scholar will be the main speaker. Telemedicine technology will be utilized to make the presentation available to Midwest Cancer Alliance partner cancer centers across the state.

Objective 4: By October 2015 implement the Pink Sunday Program in at least two churches in all four target counties.

Priority 2- Addressing Barriers to Accessing Care

Decrease the difficulty of getting screened by addressing barriers identified in the Community Profile, such as finances, transportation, clinic hours, and cultural norms, to therefore increase screening.

Objective 1: By the end of March 2017, revise Community Grant RFA to indicate after-work screening events are a priority for Cherokee, Montgomery, Sedgwick and Shawnee Counties.

Objective 2: From November 2015 to March 2017, Community Grant RFA funding priorities will include breast cancer screenings for the uninsured, transportation assistance, patient navigation and mobile mammography programs for Cherokee, Montgomery, Sedgwick and Shawnee Counties.

Objective 3**:** By May 2016 become a member of the Kansas Rural Health Association to enhance the health and well-being of rural Kansans through united advocacy, leadership, education, collaboration and resource development.

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