



SUSAN G. KOMEN®
SOUTH DAKOTA
EXECUTIVE SUMMARY

Susan G. Komen® Great Plains Prelude

In January 2017 Susan G. Komen® Nebraska, based in Omaha, Neb., and Susan G. Komen® South Dakota, based in Sioux Falls, S.D., joined forces to make a bigger impact in the fight against breast cancer and will operate as one entity – Susan G. Komen® Great Plains.

The consolidated organization serves residents in Nebraska and South Dakota, with plans to expand into North Dakota in the future.

The 2015 Community Profile for Susan G. Komen South Dakota was completed under the previous Affiliate name, but the data and findings are still relevant in Komen Great Plains operations and the Mission Action Plan is germane for priorities and objectives in the area.

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

Patty Kussman, LPN, CBPN
Board Member
Susan G. Komen South Dakota

Mary Kolsrud
Executive Director
Susan G. Komen South Dakota

Meagan Huisman
Affiliate Coordinator
Susan G. Komen South Dakota

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:

- Susan G. Komen Headquarters Community Profile Team
- South Dakota Department of Health

For Questions Related to the Community Profile Report Contact:

Susan G Komen® Great Plains

Sioux Falls Office

101 N. Main Ave; Suite 209

Sioux Falls, SD 57104

605-271-1751

<http://komengreatplains.org/>

Contact: Karen Daneu, Executive Director

Executive Summary

Introduction to the Community Profile Report

Susan G. Komen® South Dakota (SD) was created in 2005 to carry the Komen vision throughout the State of South Dakota. Since its inception, the Affiliate has granted over \$1.5M to programs across the state which support breast health and breast cancer education, screening and treatment. As a result of the hard work of volunteers and staff members, the Affiliate has positively touched 61 of its 65 counties and impacted the lives of over 39,372 women. More than 7,928 mammograms and clinical breast exams have been provided and 177 cases of breast cancer have been detected as a result of Komen SD funded grants. In 2015, the Affiliate was awarded a grant to start an educational outreach program focused on the Hispanic and Latina population in Sioux Falls with plans to expand the program to rural areas to educate minority populations in 2015.

The Affiliate also collaborates and partners with entities across the state such as the South Dakota Comprehensive Cancer Coalition Program to further eliminate breast cancer disparities. The Affiliate recognizes the importance of further collaboration with new organizations in order to make a greater impact in the state.

The organization is led by an Executive Director and Affiliate Coordinator who oversee all day-to-day responsibilities of effectively operating the Affiliate. The Affiliate also receives considerable support from volunteers across the state to carry out its mission. The Affiliate is governed by the Board of Directors which currently has 11 members who oversee the strategic direction of the Affiliate. Committees of the Affiliate include a Race for the Cure® Committee, Grants Committee, Development Committee and Finance Committee.

Komen South Dakota serves the entire state of South Dakota, less Union County, which is served by Susan G. Komen Siouxland (Figure 1). Geographic distance is something South Dakotans have addressed for years as population has declined, but continued population shifts and fewer services make it more challenging to provide quality, state-of-the-art care and ongoing survivor support programs to people in rural areas. The challenge for breast health and breast cancer support services in South Dakota exists primarily in the rural areas, with low income families, and on American Indian reservations. South Dakota has state-of-the-art breast health and cancer facilities in the metropolitan areas, but the distances that women travel to receive screening and treatment is substantial.

KOMEN SOUTH DAKOTA SERVICE AREA

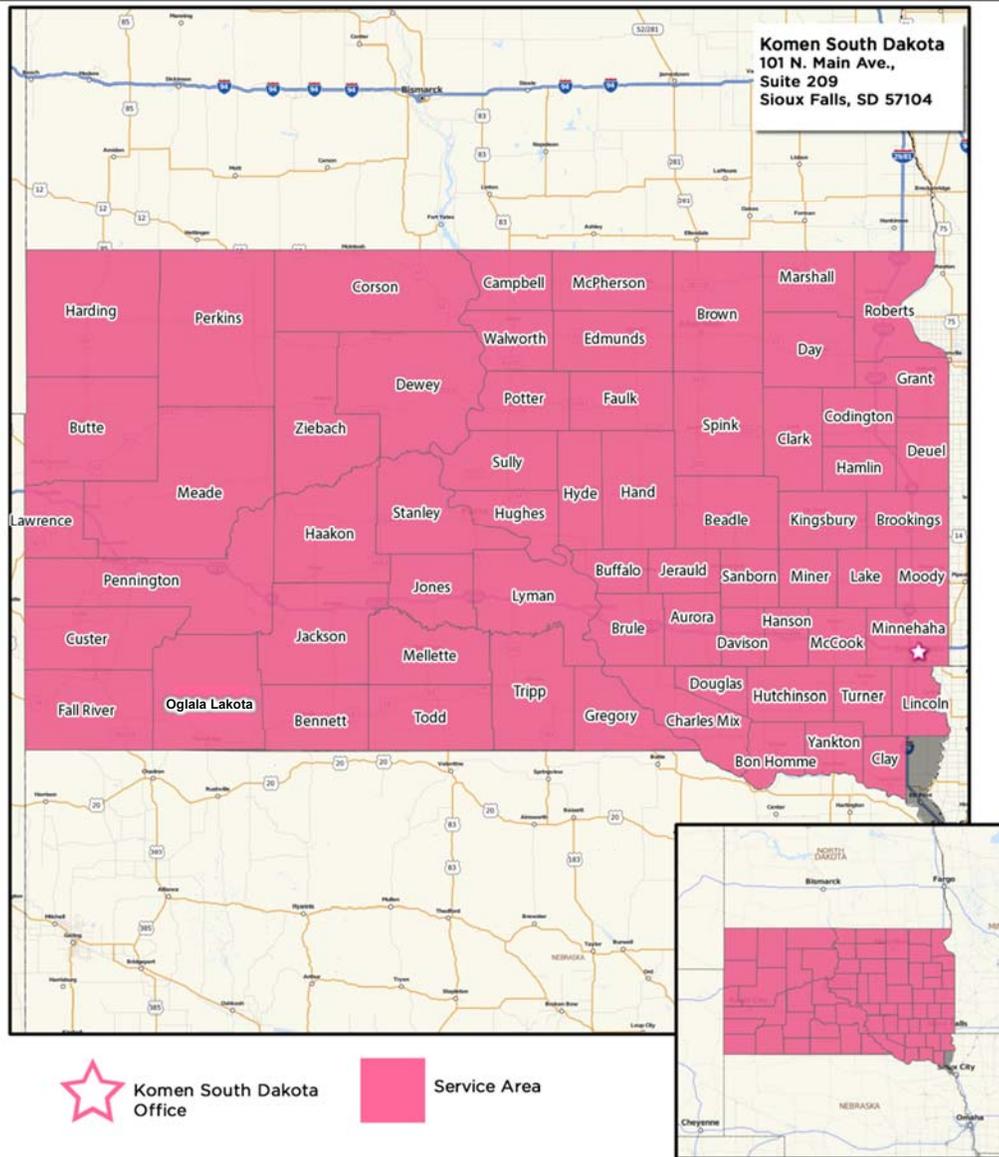


Figure 1. Susan G. Komen South Dakota service area

To meet Komen South Dakota’s promise, the Affiliate relies on the Community Profile process to guide its work. The Community Profile includes an overview of demographic and breast cancer statistics which highlight target areas, groups or issues. The statistics pinpoint where efforts will have the most impact. To ensure effective and targeted efforts, it is important to also understand what programs and services gaps, needs and barriers exist.

The purpose of this Community Profile Report will not only drive grantmaking priorities but will also:

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

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Overall, the quantitative data showed the breast cancer incidence rate, incidence trend, and death rates were slightly lower than the US as a whole. Furthermore, late-stage incidence rate was similar to that observed in the US as a whole and late-stage incidence trend was higher than the US as a whole. However, it must be noted, much of the service area was not available for comparison as much data were suppressed due to the small sample size of the population base across the state.

An analysis of the quantitative data from communities across the state identified the three highest need areas in which the Affiliate will focus its resources over the next four years. Multiple counties within the service area had data suppressed due to small numbers for breast cancer incidence, death rates and trends; therefore, socioeconomic factors were also relied upon with the addition of supplemental data collected on minority populations within the state. The additional data collected was used to outline both tribal communities and vulnerable populations in the state. The data were also used to further investigate the link between tribal populations, rural regions and subsequent socioeconomic issues in these areas.

Attention was given to where time and resources would make the largest impact with a focus given to both the Healthy People 2020 (HP2020) data and the most vulnerable populations in the service area. The three target communities selected include: Oglala Lakota, Jackson and Bennett Counties with a focus on women living within the Pine Ridge Reservation, Lawrence and Pennington Counties and Beadle County.

As a result of the initial quantitative data review, it was concluded Oglala Lakota, Jackson and Bennett Counties are at high risk of breast cancer disparities due to socioeconomic factors including high unemployment percentages, low education levels, high uninsured percentages and high poverty levels. Further, each of these counties are medically underserved.

Lawrence and Pennington Counties were defined as areas of high and highest priority with respect to the HP2020 initiative. Pennington County is only one year shorter (12 years compared to the baseline 13 years) in its predicted time to achieve death rate target. Also, Pennington County accounts for nearly 12.3 percent of all new late-stage cases in the state.

Finally, a rural county in the Affiliate's service area, Beadle County, was chosen as a target community based on low socioeconomic factors and the high percentage of minority populations. Additionally, it is not predicted to meet the HP2020 initiative for late-stage incidence.

Health System and Public Policy Analysis

After conducting the Health Systems and Public Policy Analysis, it was found that the needs are great across all target communities within Komen South Dakota's service area.

Specifically, the Pine Ridge Indian Reservation has great need throughout the entire CoC because programs and services on the reservation are severely lacking. Continuing to build the outreach programs already in place will decrease the barriers found throughout the CoC in this community.

While great services and programs exist within Lawrence and Pennington Counties through access to its Cancer Care Institute, travel still remains a hurdle for rural women and the late-stage diagnosis rate continues to trend higher than the Affiliate service area as a whole. The partnership with Healing Pathways is important to Komen South Dakota and the Walking Forward program is an area in which the Affiliate could provide assistance. Education could also help eliminate delayed entry into the CoC for this community.

Beadle County offers a medical center with treatment programs, but again, travel in this rural county is an issue and considerable weakness. Through collaboration with Huron Regional Medical Center to address the unique needs of the community and the increasing minority population, gaps in language barriers and entry into the CoC could be addressed.

The Affiliate also dedicates time and resources to advocating for patient rights and continues to look for opportunities to strengthen its policy work. Collaboration between other state organizations including the American Cancer Society Cancer Action Network and the SD Department of Health, among others, will enhance the Affiliate's policy work to educate lawmakers on the importance of breast health issues.

The state has yet to expand Medicaid upon publication of this paper, thereby leaving gaps in coverage for thousands of individuals. Further, with the initial enrollment of ACA, it may be too early to tell the implications of additional insured and what it might mean for patient navigation services as new women enter the CoC.

Qualitative Data: Ensuring Community Input

The qualitative data findings for Oglala Lakota, Jackson, and Bennett Counties are linked to the key assessment question: Why are women living on the Pine Ridge Reservation not utilizing CoC services? It became apparent most women over 40 do not enter the CoC because they do not get screened annually. The largest barriers are lack of Native-specific education, little accessibility to screening services, and lack of trust with providers. If a woman does receive screening, and has an abnormal mammogram, no issues were apparent regarding a woman remaining in the CoC. Therefore, the conclusions drawn in the target community of Oglala Lakota, Jackson and Bennett Counties lead to the fact women are diagnosed at a late-stage because they never enter the continuum due to lack of accessible screening sites and lack of Native-specific education. Women are often unaware of their risk due to low education levels. If they do wish to be screened, it is difficult to pay for transportation to a screening facility in this very rural area. Data collection methods used in this community included document review.

Qualitative data findings for Lawrence and Pennington were directly tied to the key assessment question: Why are women over 40 not getting screened? Fear, discomfort and cost were all determined to be barriers to screening; however, more emphasis was placed on where the responsibility for scheduling screening should be placed. Some women agreed the Primary Care Physician should schedule each patient's screening with the use of a reminder card, yet others noted women over 40 do not attend an annual physical at all, making it difficult for the provider to recommend yearly screening. A larger push for breast cancer education on various media channels was suggested by many focus group participants as a solution to this issue. Therefore, the conclusions drawn from Lawrence and Pennington Counties point to an increased need in education which encourages women to seek screening. Both at the provider level and in the community, awareness and education on the importance of early detection must be a focus. Data collection methods used in this community included focus groups and key informant interviews.

The qualitative data collected in Beadle County was based on the assessment question: Why are women over 40 not getting screened for breast cancer? The Community Profile Team confirmed the qualitative data findings were linked to this question by realizing women are afraid to get screened, have financial constraints or have language barriers which prevent health care. Therefore, the conclusions drawn surround a recent influx of linguistically isolated women including the low-income refugee population, specifically the Karen minority group, and a large Hispanic/Latino population in the community. While translation services are accessible through Lutheran Social Services and clinics such as the James Valley Community Health Center, translators are not always available to be at each appointment with the patient. Additionally, breast health is often not a focus and is outweighed by other, more basic health needs upon initial arrival in the community by refugees. Therefore, translated education must be a focus in this target community. Further, financial constraints are a barrier to care. If a mammogram is referred after a clinical breast exam, oftentimes, a woman will simply not schedule the follow-up appointment out of fear surrounding the ability to pay for it. For this reason, a focus on programs which provide free or low cost screening services must also be a priority. Data collection methods used in this community included key informant interviews and document review.

Mission Action Plan

Triangulation of the data from target communities allowed the Affiliate to develop problem statements and subsequently construct priorities and objectives for each of the target communities.

Oglala Lakota, Jackson and Bennett Counties with a focus on women living within the Pine Ridge Reservation

Problem: The combination of poor health insurance coverage and poverty puts individuals living on American Indian reservations at a tremendous disadvantage to accessing education and screening, as indicated by the quantitative and qualitative data. These barriers are common among all American Indian populations throughout the state.

Priority: *Support outreach and health programs which provide breast health education and services which break down cultural and language barriers for American Indian women, especially in Oglala Lakota, Jackson and Bennett Counties.*

Objective 1: By October 2017, collaborate with the Northern Plains Comprehensive Cancer Program to notify tribal health entities about the Affiliate's RFA and grant funding availability for American Indian reservations. A least one tribal entity who serves Oglala Lakota, Jackson and Bennett Counties will be provided with information about funding opportunities through Komen South Dakota.

Objective 2: By FY 2018, partner with appropriate physician education programs and organizations to create and implement a culturally sensitive training program for new and current medical providers that provide services to American Indians. A least one medical provider that serves Oglala Lakota, Jackson and Bennett Counties will complete the training program.

Objective 3: By October 2015, revise the Community Grant RFA to give funding priority to programs that use innovative or evidence-based approaches that result in documented linkages to breast cancer screening, diagnostic, treatment and/or supportive services among American Indian women living within Oglala Lakota, Jackson and Bennett Counties and throughout the state.

Lawrence and Pennington Counties

Problem: A lack of education on the importance of breast health may be an impediment of early detection for women living in Lawrence and Pennington Counties as indicated by the qualitative data.

Priority: *Promote early detection and the availability of financial assistance programs for uninsured women.*

Objective 1: From 2016-2019 participate in at least two health expos per year in Lawrence and Pennington Counties. Provide 500 pieces of educational material to expo attendees and speak one-on-one with 50 women about the importance of early detection.

Objective 2: In FY 2017 offer two 'Lunch and Learn' opportunities with local employers to provide breast health education and the opportunity for women 40+ to sign up for a mammography appointment.

Priority: Increase provider understanding of breast self-awareness messages supported by Susan G. Komen and knowledge of various referral processes to better navigate their patients through the continuum of care.

Objective 1: Work with the All Women Count! Program in FY 2017 to notify at least 10 providers in Pennington County and at least three providers in Lawrence County about the availability of screening assistance programs in their area.

Beadle County

Problem: Women living in Beadle County struggle with language barriers and financial constraints which may prohibit early detection as indicated by the qualitative data.

Priority: Increase breast health outreach to the Hispanic/Latina and Karen community in Beadle County.

Objective 1: By October 2016 distribute bilingual educational materials to Huron Regional Medical Center, Lutheran Social Services, and at least one other local community partner located in Beadle County.

Objective 2: During FY 2016-2017 provide outreach via Affiliate Education Outreach Coordinator to provide 120 women with one-on-one culturally appropriate breast health education. Translate for 10 Spanish speaking women to enable sign up of mammography appointments for Hispanics/Latinas in Beadle County

Priority: Increase education on screening financial assistance programs available to women in Beadle County.

Objective 1: By October 2016, provide information about availability of financial assistance programs for uninsured women (e.g., All Women Count) to at least three support programs and/or organizations in Beadle County.

Objective 2: By October 2017, collaborate with the Comprehensive Cancer Control Program to establish a formal partnership with at least one large employer in Beadle County to conduct an ongoing annual breast cancer screening campaign.

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