

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



SUSAN G. KOMEN®
NEBRASKA
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 Nebraska was completed under the previous Affiliate names, 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, including Kate Sommer. Susan G. Komen Nebraska dedicates this report and its ongoing, collaborative efforts in memory of Kate Sommer who lost her life to metastatic breast cancer in July 2015. Kate brought the Race for the Cure to Nebraska in 1994 and was instrumental in founding Susan G. Komen Nebraska. She took an active role at the local and national levels of Susan G. Komen that allowed her to share her wisdom and inspiration with many people. Kate was an unrelenting advocate for education and research whose spirit will continue to inspire us for years to come.

Susan G. Komen® Nebraska would like to extend its deepest gratitude to the Board of Directors and the following individuals who participated on the 2015 Community Profile Team:

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

- Sarah Daehling, Rosenda Ebert, Shelby Gowen, Madison Miller; University of Nebraska Medical Center Accelerated Nursing Program students
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Executive Summary

Introduction to the Community Profile Report

Susan G. Komen Nebraska began like most other Komen Affiliates. Many brave breast cancer survivors worked diligently to bring a Race for the Cure® to their home town. In 1994, this occurred in Omaha, Nebraska. As breast health needs persisted in Nebraska, organizational incorporation soon followed in 2002. Currently, the Affiliate's service area is comprised of 91 out of 93 counties in Nebraska, with Komen Siouxland serving Dakota and Thurston Counties near Sioux City, Iowa. With a very large number of counties with dispersed populations in Nebraska, it has been a challenge to address the breast health needs of the state with only volunteers. To answer the call brought forth by this challenge, Komen Nebraska hired its first staff in 2007 and four full-time staff currently operate its Omaha office. To further increase Komen's reach across the state of Nebraska and provide a visible presence outside the eastern part of the state, a second Race for the Cure was added in 2011 in Kearney, Nebraska.

Over two decades, the Affiliate has invested over eight million dollars to improve the breast health services and address the needs of the underserved and uninsured breast cancer survivors across the state. Over six million dollars in grants have helped address breast health education, breast cancer screening and treatment support / survivorship programs for Nebraska women, men and families who have been touched by breast cancer. There have been some notable highlights in awarded grants, including: *A Time To Heal* breast cancer survivorship program first funded by Komen Nebraska; the *Breast Cancer Hotline* conducted by Legal Aid of Nebraska, the second such program in the nation; and the University of Nebraska Medical Center Community *Breast Health Navigator and Cancer Support Program* (again, the second such program in the nation), provides resources for breast cancer patients to empower their own advocacy.

Komen Nebraska is involved in several breast cancer and breast health coalitions across the state, and prides itself on connecting those in need with resources to help with education, screening, treatment support and survivorship programs. Komen Nebraska has brought breast cancer researchers to Nebraska to provide health care practitioners first hand exposure to the latest advances in care. Komen Nebraska is a partner in the Nebraska Breast Cancer Control Partnership, is active with the Metro African-American Breast Cancer Task Force, and participates in the North Omaha and South Omaha Community Care Councils. The Affiliate routinely participates in health fairs and community engagement forums to promote breast health self-awareness.

As resources for overall health continue to evolve and access to care improves, it is important to understand the state of breast health in Nebraska. This Community Profile is the product of assessing the community needs for breast health resources using quantitative, qualitative, health system and public policy analysis. This report identifies the gaps in the breast health system within the target communities to help determine the focused priorities of Komen Nebraska. It will help align strategic and operational plans to drive collective efforts in the Affiliate communities, identify public policy efforts, establish focused grantmaking priorities and educational needs, provide for targeted marketing and outreach, and strengthen sponsorship efforts. This Community Profile is created to be a resource and a guide for Komen Nebraska,

breast health stakeholders, and lay community members to direct and commonly align efforts that fight breast cancer morbidity and death in Nebraska. Achieving these goals will help save lives and eventually end breast cancer forever by empowering people, ensuring quality care for all and energizing science to continue its search for cures.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

The first step in analysis included reviewing the quantitative data for the Affiliate service area. The Healthy People 2020 report (HP2020) was used to prioritize those communities in Nebraska with high breast cancer death and late-stage breast cancer diagnosis. It is important to note that Nebraska as a whole may achieve the HP2020 targets for breast health, but certain counties will not meet these goals. And while these particular counties are singled out, it is also important to note that Nebraska's population is small as compared to other states. There are many counties with small population densities that do not have large enough numbers of breast cancer cases or breast cancer deaths to support the generation of reliable statistics. A similar statistical issue is also seen in screening mammography, as data is derived from a survey of a percentage of the total population; and screening rates may not be available for counties with small populations. The Community Profile team chose the geographical construct of Nebraska's U.S. Congressional Districts as a framework to identify the target communities that would ensure urban, rural and mixed urban/rural areas of the state would be represented regardless of the statistically relevant data available.

The first target community is Saunders County, adjacent to Douglas County in the eastern portion of Nebraska, located within Nebraska's First Congressional District. The data revealed that this county is rural, has a much older population (> 50 years of age), and has a lower overall poverty rate than the rest of the state. The mammography rate is much lower at 65.7 percent than either the Nebraska or U.S. proportion of screened mammography (weighted average). The female breast cancer death rate and late-stage breast cancer diagnostic rate is designated as "high risk" for achieving the Healthy People 2020 goals, i.e., most likely to take more than 13 years to reach the target rates.

The second target community is Douglas County, located within Nebraska's Second Congressional District and including the greater metropolitan area of Omaha and surrounding suburbs. Douglas County is considered urban and has the highest percentage of Black/African-American residents in the state. The county's poverty rate is 8.6 percent overall, but there are smaller areas within the county that have much higher poverty rates. More specifically, Douglas County's northeast quadrant (better known as North Omaha) has the highest concentration of Black/African-Americans and has a poverty rate of 29.6 percent. Furthermore, the breast cancer death rate for Black/African-American women (27.6/100,000) is much higher than the county as a whole (22.1/100,000) and the state (20.2/100,000). The female breast cancer late-stage diagnostic rate is high risk for not achieving the Healthy People 2020 goals, with greater than 13 years to reach the target rate. Given this marked disparity, Black/African-American women who reside in North Omaha are the focus of the study rather than the county as a whole.

The third target community residing in central/western Nebraska is over 200 miles from the other target communities, and is located within Nebraska's Third Congressional District. Custer,

Dawson and Lincoln Counties comprise the third target community for the Community Profile, and while they are contiguous, each has similar, yet independent challenges and issues. Custer County is considered rural, has an older population, a much higher poverty rate, and a much higher proportion of the population without health insurance than the rest of the state. The mammography rate (66.0 percent) is much lower than either the Nebraska or U.S. proportion of screened mammography (weighted average). The female breast cancer late-stage diagnostic rate is designated as high risk for not achieving the Healthy People 2020 goal, with more than 13 years to reach the target rate.

Dawson County has a high percentage of Hispanic/Latino(a) residents, which at 30.9 percent is almost three times the state average. Compared to Nebraska averages, the Dawson County population has a lower number of high school graduates, a higher poverty rate, a very high population without health insurance, and a population that is isolated linguistically. The mammography rate is much lower, and the breast cancer late-stage diagnostic rate is rated high risk for not achieving the Healthy People 2020 goals, with more than 13 years to reach the target rate.

Lincoln County is a mix of both urban and rural communities older than the Nebraska average population. The proportion of persons who are poor, without health insurance, or ethnic/racial minorities are not as great as the other counties in the target community. However, the breast cancer death rate and late-stage diagnostic rate are both rated high risk for not achieving Healthy People 2020 goals, taking more than 13 years to reach the target rates.

Health Systems and Public Policy Analysis

Once the target communities were identified, the second step in the analysis involved reviewing the health systems for the Affiliate service area and breast health public policy for the entire state.

The Breast Cancer Continuum of Care (CoC) model reflects how a person would typically move through the health care system for breast care. With education surrounding the model as the foundation for each segment, a person would ideally move through the CoC (screening, diagnosis, treatment and survivorship) quickly and seamlessly, receiving timely, quality care in order to have the best breast health outcomes. Education is a key element to all aspects of the CoC. Barriers to progressing through the CoC model can contribute to poorer health outcomes.

These barriers can include, but are not limited to, a lack of transportation, system issues including long waits for appointments and inconvenient hours, language, cultural differences, financial issues, lack of information, distrust or wrong information (myths and misconceptions), and general fear. These and many other reasons were explored during the Community Profile assessment. Across the state of Nebraska, access to health care facilities that specialize in breast health is limited and travel distance is great. For example, in Saunders County, there is one facility for mammography, but other breast health services (e.g. surgery, radiation) have to be completed at locations outside the county. Similar environments in Custer and Dawson Counties reflect the limited scope of breast health resources, with many residents in the

counties driving more than 100 miles one way for treatment. On the other hand, Lincoln and Douglas Counties have accredited cancer hospitals that provide all CoC services.

Regarding public policy initiatives, the state of Nebraska does participate in the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) known as the Every Woman Matters (EWM) program. As of the publication of this Community Profile report, Nebraska has elected not to adopt Medicaid expansion and excludes non-citizens from enrolling in the EWM program. According to the EWM office in 2014, approximately one-third of potential EWM enrollees are no longer entitled to services because of changes in eligibility and lack of Medicaid expansion (approximately 54,000 to 80,000 Nebraskans). For breast health / breast cancer needs, these limitations add additional stressors to those trying to access care.

Geographically, Nebraska is a big state with limited overall breast cancer resources, and cost, distance and fear are some factors complicating care. The individuals within the target communities communicated their thoughts in the qualitative portion of the study.

Qualitative Data: Ensuring Community Input

To obtain community perspectives on the state of breast health in the target communities, the Community Profile team used two qualitative data collection methods. Focus groups and key informant interviews were identified by snowball samplings of organizations that cater to local stakeholders for women's health, Komen Nebraska contacts, past grantees and public health organizations. The assessments were conducted over a three-month period in the target communities through one-on-one interviews with key informants (health care providers or those who provide services to women) and targeted focus groups in the lay community. The intended audiences of the focus groups were women over 40 years of age, and the intended audiences for the key informants interviews were individuals who serve women over the age of 40.

The questions for the focus groups and key informant interviews centered on the knowledge of screening, diagnosis, treatment and survivorship in the communities as components of the CoC. The CoC model was used as a guide to determine why some individuals never enter, delay entry, or fall out of breast health care. This model provides a framework that helps assess the gaps in service availability, identifies the gaps and misunderstanding — or lack of education— about services in the community. This model was used for all qualitative engagements.

Even though the target communities are diverse in age, location (urban vs. rural), race, and number of health facilities readily available, three consistent themes emerged from the focus groups and key informant interviews. First, the qualitative data collection showed that for all the target communities, concern about the affordability of screening and treatment was paramount. Even if the EWM program was known and used, there was concern about the cost of screening and treatment delaying care. For those ineligible for EWM because of citizenship or income status, the concern was even greater.

Secondly, in all the communities there were fears about screening and treatment – how much it hurt and how futile the treatment might be. A number of myths or wrong assertions about current screening and treatment appeared to be the result of misinformation.

Finally, in all groups there was a call to increase access to care, meaning distance to care and availability of care. For women pulled in many directions because of family, work demands, costs, and fear, breast health was not the most important concern.

Mission Action Plan

Using the data collected in the quantitative, health system and public policy analysis, and qualitative sections, a plan of action was developed.

The Community Profile team derived the problem statements from the data obtained in the target communities. There are similar concerns for each of the three target communities, but specific differences do arise. For Saunders County, target community one, the major problems were lack of services and lack of knowledge of local services. Compounding this lack of knowledge were concerns over affordability and the lack of trust in the local services. These same problems were also observed in target community three, Custer, Dawson and Lincoln Counties. Douglas County, target community two, focused on the experiences of Black/African-American women in that county. The data showed that affordability and availability of services for Black/African-American women in North Omaha made it difficult to seek care.

Improving access to care for each specific population in the target communities is the top priority. This priority is for women over 40 who live in all the targeted counties, and for some specific demographic groups, such as Latina women in Dawson County or Black/African-American women in Douglas County.

The objectives for Saunders County over the next four years include partnering with organizations in the community to raise awareness, and providing education classes to address the needs for services and financial support throughout the CoC. Following the education encounters, there should be engagement with health agencies to publicize options to help finance breast health services. And finally, there should be a summit with providers to discuss possible partnerships to increase access to, and seamless progression through, the CoC.

The objectives for Douglas County as target community two include partnering with organizations to discuss breast health outreach and financial options for screening and treatment within the next two years to improve the breast health for Black/African-American women in North Omaha. The long term objective is to improve access to, and seamless progression through, the CoC through referrals, screenings, treatment programs, and support services, within the county.

As noted previously, the problems for Custer and Lincoln Counties (target community three) are not that different from target community one. Over the next four years, the goals include partnering with organizations in the community to raise awareness and have education classes to address the needs for services and financial support throughout the CoC. Following the education encounters, there should be engagement with health agencies to publicize the option to help finance breast health services. And finally, there should be a summit with providers to discuss possible partnerships to increase access to, and seamless progression through, the CoC. For Dawson County, which has a high percentage of Hispanic/Latina women, there are

specific objectives focused on that population. The goal is to provide access to services in a culturally sensitive manner to address the needs for services and financial support. Following the education encounters, there should be engagement with health agencies to publicize the options to help finance breast health services, especially for the target population.

Last, but not least, the Community Profile team highlighted one global problem that spans the entire service area. The problem identified is limited access to breast health services and little to no access to financial support for those with limited ability to pay without Medicaid expansion. One approach to rectify this situation is to increase state legislators' understanding of breast health issues through education. This will be accomplished in the next four years by conducting mailings to legislators to increase Komen's visibility as a resource on breast health. In addition, Komen Nebraska will work with others, including Komen Siouxland, to target public policy efforts, including advocating for increased state funding for breast health.

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