



SUSAN G. KOMEN®
SOUTHWEST OHIO
EXECUTIVE SUMMARY

Acknowledgments

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Executive Summary

Introduction to the Community Profile Report

Founded in 1997 as Susan G. Komen Greater Cincinnati Race for the Cure® (RFTC), Susan G. Komen® Greater Cincinnati has grown from a RFTC event with 2,700 participants realizing an approximate \$170,000 in revenue to combined RFTC/Affiliate revenue of just under \$1M in fiscal year 2015. In 2016, Komen Greater Cincinnati became Susan G. Komen® Southwest Ohio.

Over the last 17 years, the Affiliate has funded over \$10.3M in local programs to address screening and diagnostic mammograms, education, support resources, financial assistance and treatment of breast cancer. Additionally, the Affiliate has contributed over \$2.6M toward the Susan G. Komen Research Programs. The contributions to these programs made by the Affiliate are in support of the Komen mission.

The Affiliate serves as an indirect service provider, fundraising and granting funds to organizations, agencies and direct service providers of breast health education, screening, treatment and support in the Affiliate service area:

SW Ohio Counties

Adams, Brown, Butler, Clermont, Clinton, Darke, Greene, Hamilton, Highland, Miami, Montgomery, Preble and Warren.

SE Indiana Counties

Dearborn, Ohio and Switzerland.

Northern Kentucky Counties

Boone, Campbell, Gallatin, Grant and Kenton.

As a breast health and breast cancer leader and expert in the community, the Affiliate is a member of the Ohio Partners for Cancer Control and the State Cancer Control Plan. In addition, within the state of Ohio, Kentucky and Indiana, the Affiliate collaborates with the local Breast and Cervical Cancer Early Detection Programs to ensure women have access to and navigated within the continuum of care. The Affiliate is the only organization in the breast health community of Greater Cincinnati who conducts an assessment of the breast health needs to ensure funding is provided to those areas of greatest needs. To be efficient stewards of resources, Komen Southwest Ohio collaborates with Komen Affiliates in Ohio, Kentucky, and Indiana and across the United States to share ideas and resources.

Komen Southwest Ohio service area consists of 21 counties spanning nearly 7600 square miles. The service area within the tristate area includes counties within Ohio, Kentucky and Indiana, resulting in a total population of just over 3.1 million people. Within the service area, there are four urban counties, including Hamilton, Montgomery, Kenton and Butler Counties, which each have less than 10.0 percent of their population living in rural areas. On the contrary, Komen Southwest Ohio service area also has several substantial rural counties that it serves, including Ohio, Switzerland, and Gallatin, which have 100 percent of their population

living in rural areas. The population demographics within Komen Southwest Ohio service area are primarily White and Black/African-American, making up 83.9 percent and 13.6 percent respectively. The remaining portion of the population consists of Hispanic/Latino and Asian, making up 2.3 percent and 0.2 percent respectively.

Komen Southwest Ohio service area has a diverse socioeconomic range, which includes counties that have a median household income of \$35,000 and nearly 23.0 percent of the county living below the poverty level to a county with a median household income of greater than \$70,000 and less than 6.5 percent of that county living below the poverty level. The median household income across the entire service area is just over \$50,000 with 14.5 percent of the population living below the poverty line, which is slightly worse than the national percentage of 14.3 percent.

The purpose of the Community Profile Report is to identify, analyze and prioritize the demonstrated needs, for breast health services and resources in the Komen Southwest Ohio service area. Funding for these prioritized needs will be strategically planned to ensure meeting all demonstrated, prioritized needs. The Community Profile will be the primary document to identify and fund all aspects of the work of the Affiliate in the target counties and entire service area.

The Community Profile documents where there are gaps in providing services provides direction toward the needs of the community in order to close these gaps and provide more effective delivery of resources to the community. The Profile document will be used to guide the work of the Board of Directors, grant funding decisions and to partner and collaborate with sponsors, donors and fundraising events of the Affiliate.

The Community Profile Report will be shared in the local community with all media outlets, corporate and partners, sponsors, grantees, Board, State legislators, volunteers, and collaborative partners of the Affiliate.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

The Community Profile Team first looked at the overall regional data for Komen Southwest Ohio service area to determine a quantitative snapshot of the breast health needs. Regionally, the age-adjusted breast cancer incidence rate is higher than both national and state rates. Regional female breast cancer death rates are higher than the national, Indiana, and Kentucky rates. Regional late-stage trends are also higher than they are for all state and national rates. While incidence rates are higher for the regional, this could indicate that more women are engaging in breast health services. However, the higher regional late-stage and death trends could indicate that these women are not being screened on a regular basis. As the data were reviewed and discussed, five counties emerged target communities of highest priority. These counties include Grant County, KY, Adams County, OH, Butler County, OH, Hamilton County, OH, and Highland County, OH.

Key characteristics were taken into consideration as the review of the Quantitative Data Report progressed. The key characteristics included county-level data, such as female breast cancer incidence rate, female breast cancer death rate, female late-stage incidence rate, demographic

information, and Healthy People 2020 (HP2020) targets. The counties that were identified as possible target communities above were examined on these factors and included negative or discouraging findings for each of the key characteristics. These counties were found to be those that were most at risk for negative outcomes related to breast health incidence, late-stage diagnosis or breast cancer death as a result of the key characteristics presented in the Quantitative Data Report.

Grant County, Kentucky

Grant County, Kentucky, was found to have both high breast cancer incidence and late-stage diagnosis rates. Each of these rates was higher than the regional, state and national rates. This county is identified as a rural county in Komen Southwest Ohio's service area and is likely to have an issue with lack of resources available to meet the breast health needs of women in the community. Nearly 42.6 percent of people within this county have an income below the 250 percent poverty level and 16.7 percent report that they do not have health insurance. Both of these rates are higher than the regional, state, and national rates for the same characteristics. It is also estimated that this county will not meet the HP2020 target for female breast cancer late-stage incidence rates for at least 13 years.

Adams County, Ohio

Adams County, Ohio, is both a medically underserved and rural county in Komen Southwest Ohio's service area. Nearly 54.0 percent of persons in the county are below the 250 percent poverty level. In addition, 14.5 percent of people in the county report that they are unemployed and 18.3 percent report that they do not have health insurance. The demographics rates mentioned above are all much higher than the rates reported for regional, state, and national. The breast cancer death rate for this county was very high at 28.9/100,000. This rate was higher than the each of the following: regional, state, and national breast cancer death rates. In this county, it is estimated that it will take 13 years or longer to achieve the HP2020 targets for both late-stage incidence of breast cancer and female breast cancer death rates.

Butler County, Ohio

Butler County, Ohio, has high breast cancer incidence, late-stage breast cancer diagnosis, and breast cancer death rates (120.2/100,000, 43.6/100,000, and 24.7/100,000, respectively). While this county's breast cancer incidence and late-stage diagnosis rates appear to hover around the same rate for each regional, state, and national rates, the breast cancer death rate for this county is higher than both the regional and national rates. This county reports the 4th highest population of Black/African-American community members in the Affiliate service area and the 2nd highest percentage of Hispanics/Latinos. In Butler County, Ohio, it is estimated that it will take 13 years or longer to achieve the HP2020 targets for both breast cancer incidence and female breast cancer death rates.

Highland County, Ohio

Highland County, Ohio, is identified as a county with a high percentage of unemployed (13.1 percent), a large percentage of residents who have an income level below 250 percent poverty (45.6 percent), a large percent of residents with no health insurance (16.9 percent), and a very rural community. In this county, it is expected that the HP2020 target for female breast cancer death rates will take at least 7 years to meet and the HP2020 target for late-stage diagnosis rate will take 13 years or longer.

Hamilton County, Ohio

Hamilton County, Ohio, has very high breast cancer incidence, late-stage diagnosis, and breast cancer death rates. Each of these rates is much higher than the same rates for the region, state, and nation. It is estimated that the HP2020 targets for both late-stage diagnosis and breast cancer death will take 13 years or longer to meet. The demographics in this county also include the highest regional service area percentage of Black/African-American residents.

In many cases, the Quantitative Data Report has provided a snapshot of the breast health data available for some of the areas and counties with the Komen Southwest Ohio service area, yet more information is necessary. In order for the Affiliate to develop a comprehensive and inclusive regional plan to address the breast health needs within the service area, an evaluation of the currently available resources and an evaluation of the cultural and social barriers in place will be conducted. The next steps in the Community Profile process will be the Affiliate's ability to collect this valuable information.

Health Systems and Public Policy Analysis

The Community Profile Team for Komen Southwest Ohio conducted open discussions about the continuum of care (CoC) practices used in the Affiliate community. In order to better define these CoC practices, discussions were held with breast health professionals, research was conducted using reputable web resources, health resource trends were examined and breast health community organizations in the selected target communities were surveyed. The Affiliate confirmed the locations of agencies providing breast health services on the CoC and resources as provided by Komen Headquarters.

Combining the Quantitative Data Report results with the Health System Analysis, the Affiliate labeled five counties as high priority counties within Komen Southwest Ohio service area. The target communities that were selected as part of this report include Grant County, Kentucky, Adams County, Ohio, Butler County, Ohio, Hamilton County, Ohio, and Highland County, Ohio. The breast health continuum of care services available within each of these counties were identified, examined, and used to illustrate the effectiveness of the current CoC coverage serving women in the target communities.

In order to determine the nature of the breast health services in the selected target communities, the Affiliate examined the list of providers compiled by the Affiliate representing providers on the breast health continuum of care.

The Continuum of Care (CoC) flow chart (Figure 1) illustrates the Affiliate's intended process for offering breast health service entry of every woman in Komen Southwest Ohio service area, which will expose all women to education and outreach services offered by agencies and organizations

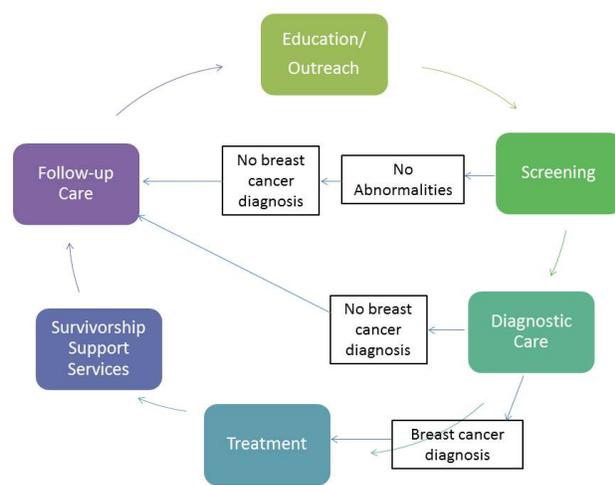


Figure 1. Breast Cancer Continuum of Care (CoC)

within Komen Southwest Ohio service area. If the education and outreach process proves to be successful and women become connected to local resources which will help to reduce current barriers, then women in the high risk counties will begin to seek screening services from the local breast health service providers. These primary screening services include both clinical breast exams (CBEs) and screening mammography. CBEs, which are the primary risk reduction method of care, are recommended for women in Komen Southwest Ohio service area beginning every three years starting at age 20 and every year beginning at age 40. Screening mammography is recommended for women in the Affiliate's service area annually beginning at age 40 (for women of average risk) and earlier, if recommended by a doctor.

If the outcome of a screening mammography reveals no breast abnormalities, then providers will suggest follow-up care recommendations to these women and they will also return to the process of education and outreach and continue to engage in primary screening recommendations. If there happens to be an abnormal finding after the screening process, then these women in the Affiliate service area will be recommended for diagnostic care.

Diagnostic care includes breast health services such as diagnostic mammograms, stereotactic mammograms, breast ultrasounds, breast biopsies, MRIs, and surgical biopsies. If there is no breast cancer diagnosis as a result of diagnostic care, then these women in the Affiliate service area will be recommended for support services and follow-up care, also returning to the cycle of education/outreach and screening (although screening may now be recommended more frequently). If there is a breast cancer diagnosis, women in Komen Southwest Ohio service area will be recommended for treatment. Treatment services may consist of surgical intervention (lumpectomy, mastectomy, lymph node removal), hormonal therapy, targeted therapy, neoadjuvant therapy, chemotherapy, or radiation. The extent, frequency and duration of treatment services will be based on several factors, including stage of diagnosis, breast cancer type, oncologist recommendations, and patient decision-making.

For those women in Komen Southwest Ohio service area that progress through and complete the treatment service Continuum of Care program, they will be referred to survivorship support programs and follow-up care. Survivorship support programs in the Affiliate service area vary greatly in regard to the services that they provide. Many of the support programs offer financial aid and several offer survivors the choice of receiving individual/group/family counseling, side effect management, physical activity/nutrition programs, alternative support programs, and psychoeducational group sessions. Follow-up care for these women and their families that have been touched by a breast cancer diagnosis may include recommendations for follow-up medical and non-medical care or hospice care recommendations. Those women released from an oncologist's care will re-enter the education/outreach stage in the community and continue to receive educational information for managing their health as a breast cancer survivor (which may include multiple areas of targeted healthy interventions to maintain their overall health and well-being).

As part of the Continuum of Care, breast health navigators are often an ongoing part of the breast health process in Komen Southwest Ohio service area community. Unfortunately, not all of the providers in the Affiliate service area have a breast health navigator on staff, thus, they are not noted on the diagram above. Yet, most of the providers that offer treatment services for a woman that received a positive breast cancer diagnosis also have the breast health navigator

program built into the process just prior to or post diagnosis. Breast health navigators can be an integral part of the breast cancer diagnosis process as they guide women and their families through the process of medical care, appointments, and healing.

Susan G. Komen Southwest Ohio supports and engages in the same public policy activities that are the objectives of Susan G. Komen Headquarters. These public policy objectives include, but not limited to:

- **National Breast and Cervical Cancer Early Detection Program:** Protecting efforts of and funding for the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) to ensure that women continue to have access to breast health screening.
- **Cancer Research:** Ensuring continued federal investment in cancer research through the National Institutes of Health (NIH), National Cancer Institute (NCI) and Department of Defense (DOD), to discover and deliver the cures.
- **Coverage for Oral Anti-Cancer Drugs:** Requiring insurance companies to provide coverage for oral anti-cancer drugs at the same rate as intravenously-administered chemotherapy.
- **Medicaid Coverage:** Expanding Medicaid coverage to increase availability and coverage of breast health services to low-income women.

In order to support these national and state-level objectives, Komen Southwest Ohio participates in state Lobby Day, engages in statewide advocacy efforts in both Ohio and Indiana, and plans to reach out to statewide organizations in both Kentucky and Indiana to grow efforts in those areas. Komen Southwest Ohio will plan to participate in National Lobby Day. In Ohio, Komen Southwest Ohio will maintain active participation in all-Ohio Affiliate advocacy efforts and campaigns.

It is anticipated that both the ACA and Medicaid will continue to have an impact on breast health care delivery and grantmaking by Komen Southwest Ohio in the coming years. While Komen Southwest Ohio will continue to support the provision of services for women in need, the Affiliate will also advocate for additional resources to be made available for women of the greatest need in the Affiliate service area

Qualitative Data: Ensuring Community Input

The geographic range of the communities identified in previous sections of the assessment, key informant interviews and strategically placed focus groups were the most feasible options for further qualitative data collection about the strengths, challenges and opportunities to improve breast cancer outcomes in the target communities. Key informant interviews were used to gather breast health information within the regions identified for further focus by quantitative data and health systems and public policy analysis. This method facilitated data collection from a limited number of well-connected and informed community leaders and professionals, and to shape an understanding of the attitudes and beliefs of survivors. Focus groups were set-up through key community members in each community identified and invitees were offered incentives in an effort to encourage attendance.

Common findings from the qualitative data collected were represented by the following themes:

- Barriers to accessing breast health,
- Disparities in access to breast health services,
- Education/awareness,
- Support Services for Breast Cancer survivors and their families.

Qualitative data findings were supportive of the previous findings in the health systems analysis. Those included primarily, navigation for patients of available, existing, community resources. Barriers to access include screening and diagnostic mammograms, breast ultrasound, lack of transportation options, patient and survivor resources and follow-up care. As indicated by the data collected, Hamilton has the widest variety of services available and ready access to multiple forms of transportation make these services more accessible. The rural communities face a far more limited range of services and resources; transportation is an issue in that patients must travel further and incur greater expense to access the services available in these communities. In all target communities access to services under the Affordable Care Act (ACA) and private health care insurance is unclear and confusing both patients and providers alike.

Mission Action Plan

Problem statements, priorities and objectives, in the form of action steps were determined by review of the previous data sections of the Community Profile. Discussions with key stakeholders and suggestions from the Community Profile Team and Affiliate staff gave input to develop objectives that were relevant and specific within the Affiliate Request for Proposals to potential grantees, moving forward.

Problem Statement

Within the Komen Southwest Ohio service area, the counties Hamilton (OH), Butler (OH), Adams (OH), Highland (OH) and Grant (KY) the health system analysis and qualitative data identified overarching barriers that may prevent individuals from entering the continuum of care. The identified barriers experienced by individuals were informational, financial, logistical and physical. These barriers may contribute to higher than average late-stage diagnosis and death rates in each target community.

Priority 1: To reduce informational barriers, the Affiliate will increase opportunities for education based projects that will focus on breast self-awareness, risk reduction and the psychosocial aspects of a breast cancer diagnosis.

- ***Objective 1:*** By January 2017, distribute Komen educational materials/tools that address screening, diagnostics and “what to expect” to at least five community partners in Hamilton and Butler Counties. Create an educational marketing campaign for primary targets of Hamilton, and Butler Counties in conjunction addressing mammography, diagnostics and what to expect. Distribute additionally to all community partners no later than January 2017. .
- ***Objective 2:*** By December 2017, Komen Southwest Ohio will provide to at least three partners in Adams, Grant and Highland Counties, education materials and tools that comprehensively address identified educational gaps in service as identified in each county.

Priority 2: To reduce financial and logistical barriers, the Affiliate will focus on increasing awareness of available breast cancer continuum of care services available to uninsured and insured individuals in each of the five target communities.

- *Objective 1:* Beginning with the FY2017 Community Grant Request for Application, programs that use evidence-based strategies to increase the utilization of insurance benefits among currently insured, non-compliant populations in Adams, Butler, Grant, Hamilton and Highland Counties will be a funding priority.
- *Objective 2:* From FY2016 through FY2019, annually update the Affiliate's website, newsletters and all marketing collateral to reflect local resources available to the target communities and entire service area.
- *Objective 3:* From FY2017 through FY2019, annually meet with at least two community partners and stakeholders to ensure dissemination of accurate local resources and collateral materials in each target county (Adams, Butler, Grant, Hamilton and Highland).
- *Objective 4:* From FY2016 through FY2019, the Affiliate will collaborate with the First Ladies Health Initiative of Cincinnati to deliver breast cancer screening resources and educational information to metropolitan, Black women through at least three outreach events in Hamilton County annually.

Priority 3: To reduce identified financial barriers to entering the continuum of care adhering to appropriate follow-up care within the continuum of care, Komen Southwest Ohio will focus efforts on supporting additional assistance programs based on the impact of the Affordable Care Act in the States of Ohio, Kentucky and Indiana as indicated by variance in State law and implementation.

- *Objective 1:* From FY16 to FY19, the Affiliate will conduct an annual survey of community partners and grantees in all target communities to evaluate the impacts of the Affordable Care Act (ACA) and evolving insurance coverage challenges to follow-up care and other continuum of care financial barriers.
- *Objective 2:* By FY19, Komen Southwest Ohio's existing Patient Financial Assistance Program at Cancer Family Care will be expanded to include additional reimbursements for treatment co-pay.

Problem Statement

Within the Komen Southwest Ohio service area, the counties Hamilton (OH), Butler (OH), Adams (OH), Highland (OH) and Grant (KY) there remains barriers to effective communication as well as access to quality of care resources that contributes to the potential of higher than average late stage diagnosis and lower patient survival rates.

Priority 1: Komen Southwest Ohio will expand and strengthen communication opportunities with all target community medical providers.

- *Objective 1:* From FY2016 through FY2019, at least twice annually the Affiliate will promote the use of available self-advocacy and education materials to community providers and patients through social media, availability of collateral materials in direct service providers offices and agencies in each target community.

Priority 2: Komen Southwest Ohio will expand and strengthen all patient navigation programs and resources in the target communities.

- *Objective 1:* From FY2016 through FY2019, the Affiliate will identify and fund those medical providers with limited or non-existent patient navigation resources in each target community.

Problem Statement

Three of the target communities, Adams (OH), Grant (KY) and Highland (OH) are identified as lacking in breast cancer survivor resources, education on breast cancer risk and financial resources to increase quality of life issues; as indicated by the qualitative data collected.

Priority 1: Identify and deliver those survivor resources and education materials to these three target communities to positively impact quality of life issues from screening, through diagnosis, treatment and post-treatment barriers and concerns.

- *Objective 1:* In FY2018 and FY2019, the Affiliate will at least twice annually promote available survivorship resources and education opportunities through Affiliate newsletter and existing community partners and agencies.
- *Objective 2:* By FY2019, the Affiliate will develop, promote and deliver at least one new survivorship program opportunity each of the following target communities: Adams, Butler, Grant, Hamilton and Highland.

Priority 2: Increase awareness of metastatic breast cancer resources and improve sensitivity to, and support of, metastatic breast cancer patients.

- *Objective 1:* Beginning in FY2017 the Affiliate will begin a Join the Conversation at Komen Kafe for metastatic breast cancer patients to share with other survivors the unique challenges they face. The National Metastatic Breast Cancer Network will join us in leading this group.
- *Objective 2:* By March 2017, the Affiliate will partner with a metastatic breast cancer survivor from one of the target counties (Adams, Butler, Grant, Hamilton and Highland) to write a guest blog for the Affiliate website.

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