



SUSAN G. KOMEN®  
COLUMBUS  
EXECUTIVE SUMMARY

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# Executive Summary

## Introduction to the Community Profile Report

Susan G. Komen® Columbus serves a 30 county service area in central and southeastern Ohio. The service area consists of a large White, rural and Appalachian population, a mixture of several suburban areas and a major Metropolitan area, Columbus, which has a more diverse population. Komen Columbus' signature event, the annual Race for the Cure®, together with special events, third party fundraisers and major donors have collectively raised and invested \$24.8 million in community programs and research since it was founded in 1993. It is the only breast cancer organization in central and southeastern Ohio combating the area's high late stage diagnosis and death rates with a combination of research and live-saving local programs to address barriers in the community. Affiliate operates efficiently and cost-effectively, focusing on making a measurable impact and moving the needle to improve poor breast cancer outcomes.

Komen Columbus funds research while also investigating and implementing evidence-based methods to make sure that research brings quality of life and survival outcomes to the Affiliate's entire service area. As of July 2015, 751 community partnerships had provided 681,289 services. The impact of this work is most clearly demonstrated by the fact that more than 579 breast cancers were diagnosed by this community work in only the last decade.

Komen Columbus is a community leader in building and advocating programming that educates women in breast self-awareness, links them to screening, and provides financial and navigational support through diagnosis, treatment and survivorship as needed. The Affiliate conducts the only assessment of breast health needs of its kind in the service area, offering not only the mechanisms to direct funding to the most impactful areas, but the expertise to identify where funding is needed and for what issues. In addition to work with community partners to deliver evidence based programming, the Affiliate educates volunteers and the community through its Breast Cancer 101 series. To address breast cancer disparities, the Affiliate has a team of Komen Ambassadors, trained education volunteers who share lifesaving breast health messages with the community by attending health fairs and community events. The Affiliate is also active in several statewide coalitions as a breast health and breast cancer leader and expert in advocacy for women and patients. The Affiliate advocates for and works with the Ohio Breast and Cervical Cancer Program and works collaboratively with Greater Cincinnati, Northeast Ohio, Northwest Ohio and other Komen Affiliates across the country as needed to maximize information sharing and impact.

The Community Profile Report assesses quantitative, health systems, policy and qualitative data to identify areas of need in the Komen Columbus service area. The collected data are used to develop a plan to address those needs, using evidence-based or best practice approaches whenever possible. The plan will incorporate all aspects of the Affiliate, including development and mission. Action items in the resulting Mission Action Plan will include grantmaking, programming and advocacy priorities.

The Community Profile demonstrates what is important to the community and what things the community would like their local businesses to focus on when investing in the community. This information on community needs and values can inform Affiliate partnerships, sponsor and donor relationships.

### **Quantitative Data: Measuring Breast Cancer Impact in Local Communities**

Overall, breast cancer incidence in the service area and State of Ohio is similar to the rest of the U.S (32nd highest incidence rate), but death rates and late-stage incidence rates are higher than the rest of the US (5th highest death rate, 22nd highest late-stage incidence rate). Self-reported mammography use among women 50-74 years of age in the area is similar of the rest of the country (25th highest screening proportion). Based on the Healthy People 2020 breast cancer targets, Ohio is predicted to need ten years to reach the death rate target and 13 years or longer to reach the late-stage incidence target, making it a high priority state in the US.

Though breast cancer incidence rates and trends in the Komen Columbus service area were similar to that observed in the US and the rest of Ohio as a whole, the breast cancer death rate in the Komen Columbus service area was higher than that observed in the US as a whole and the death rate trend was not available for comparison with the US as a whole. The death rate of the Affiliate service area was not significantly different than that observed for the State of Ohio. For the Affiliate service area as a whole, the death rate was higher among Black/African-Americans than Whites. The breast cancer death rate reflects the access to care and the quality of care in the health care delivery area, as well as cancer stage at diagnosis.

The breast cancer late-stage incidence rate in the Komen Columbus service area was slightly higher than that observed in the US as a whole and the late-stage incidence trend was higher than the US as a whole. The late-stage incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of Ohio. For the Affiliate service area as a whole, the late-stage incidence rate was higher among Blacks/African-Americans than Whites and lower among APIs than Whites. Late-stage incidence reflects both the overall breast cancer incidence rate in the population and the mammography screening coverage.

The breast cancer screening proportion in the Komen Columbus service area was not significantly different than that observed in the US as a whole. The screening proportion of the Affiliate service area was not significantly different than the State of Ohio. For the Affiliate service area as a whole, the screening proportion was not significantly different among Blacks/African-Americans than Whites. The screening proportion among Hispanics/Latinas was not significantly different than among Non-Hispanics/Latinas. This data seems to indicate that barriers other than or in addition to screening uptake are contributing to the death rate and late-stage incidence disparities in the service area. Insurance status has long been associated with screening adherence under the assumption that the uninsured would be less likely to get recommended screenings. However, the service area data does not support this assumption, and instead shows that the late-stage diagnoses rates among more highly insured populations in Metropolitan and Suburban areas remain comparable to those of the counties in Appalachia or Rural with higher proportions of uninsured residents. On the aggregate level, this may indicate that insured women are not utilizing their preventive benefits, and progress could be

made at relative low expense by motivating insured women to screen, as well as focusing on uninsured women.

The Affiliate determined that using regional frames for analysis will guide the development of culturally competent programming. The service area was broken into three regions, Metropolitan, Suburban and Rural-Appalachian. Priority communities were identified within each region of the service area. The priority communities are made up of the highest priority or high priority counties in each of the three regions of the service area. These counties were identified as highest or high priority due to projected failure to meet Healthy People 2020 targets for death rates and late-stage diagnosis rates.

Healthy People 2020 (HP2020) is a major federal government initiative that provides specific health objectives for communities and for the country as a whole. Many national health organizations use HP2020 targets to monitor progress in reducing the burden of disease and improve the health of the nation. Likewise, Komen believes it is important to refer to HP2020 to see how areas across the country are progressing towards reducing the burden of breast cancer. HP2020 has several cancer-related objectives, including:

- Reducing women's death rate from breast cancer (Target 20.6 per 100,000 women).
- Reducing the number of breast cancers that are found at a late-stage (Target: 41.0 cases per 100,000 women). Death rate and late-stage diagnosis data and trends are used to calculate whether an area will meet the HP2020 target.

For more detail on the three regions of the service area and the rationale behind the selection of the target communities within each, refer to the Quantitative Section of the Community Profile.

The target communities are:

- Metropolitan Target Community: Franklin County
- Suburban Target Community: Clark, Licking and Madison Counties
- Rural or Appalachian Target Community: Guernsey, Hocking, Noble, Marion, Meigs, Monroe, Morgan, Muskingum, Perry, Vinton and Washington Counties

Franklin County was selected as a target community due to its large female population and because it is the county with the highest number of breast cancer cases, highest number of breast cancer deaths, and the highest number of late-stage diagnoses. Given the breast cancer death disparity in the Black/African-American population, Black/African-American women are a special population within this county (the county's population is the largest at 23.0 percent). The Suburban target community (Clark, Licking and Madison Counties) accounts for the second highest number of cases, deaths and late-stage diagnoses. These counties were selected based on their predicted time to achieve death and late-stage diagnosis Healthy People 2020 goals. The Rural-Appalachian target community counties (Guernsey, Hocking, Noble, Marion, Meigs, Monroe, Morgan, Muskingum, Perry, Vinton and Washington Counties) were selected due to their predicted failure to achieve Healthy People 2020 death and late-stage diagnosis goals. The Rural-Appalachian target community is characterized by low-income, lower educational attainment, mistrust of health care providers and fatalistic attitudes towards cancer. Proximity to health care facilities varies in this region- six of the counties have hospitals and six counties are medically underserved.

Though these counties were selected for further exploration in the qualitative and health systems portions of the community profile and results of that work may not be applied to the rest

of the counties in a region, the mission action plan did not limit action or focus to the counties listed above, but will instead focus on the regions each target community is a part of.

### **Health System and Public Policy Analysis**

The Breast Cancer Continuum of Care (CoC) is a model that shows how a woman typically moves through the health care system for breast care. A woman would ideally move through the CoC quickly and seamlessly, receiving timely, quality care in order to have the best outcomes. Education can play an important role throughout the entire CoC. There are often delays in moving from one point of the continuum to another – at the point of follow-up of abnormal screening exam results, starting treatment, and completing treatment – that can all contribute to poorer outcomes. There are also many reasons why a woman does not enter or continue in the breast cancer CoC. These barriers can include things such as lack of transportation, system issues including long waits for appointments and inconvenient clinic hours, language barriers, fear, and lack of information - or the wrong information (myths and misconceptions). Education can address some of these barriers and help a woman progress through the CoC more quickly.

An analysis of the health system assets available in each Komen Columbus target community was conducted. This work gives insight into the strengths and weaknesses of the CoC within each target community. A few themes carry throughout all target communities. Mobile mammography units are only housed in Franklin County, though they are utilized throughout the service area. With the exception of Franklin County, despite the number of resources available, resources are almost always concentrated in one or two cities per county. The availability of patient navigation varies greatly between target communities. Beyond the question of where patient navigation is located, there is also a question of the quality and comprehensiveness of those services. Areas that lacked hospitals were experiencing increasing late-stage diagnosis rates, and experiencing slower improvements in death rates, when compared to areas with hospitals, suggesting areas without hospitals as a potential focus.

Rural-Appalachian counties have fewer specialists and access screening and diagnostics mostly through clinics and health departments. Often, these services are of lower quality. Treatment, reconstruction, survivorship and palliative services are available at hubs where hospitals are located, which means transportation and patient navigation to quality resources is necessary. Suburban counties have slightly better access to quality CoC services, though for survivorship, palliative and reconstruction needs, may also need to travel. The Metropolitan area serves as a large hub to all other areas of the service area, where many comprehensive and high quality services are available. However, education about these resources may be lacking and this area may face different, urban transportation barriers.

Whether or not patient navigation is available in each target community, its quality is unknown, and should be investigated further. As most resources throughout the service areas' counties tend to be concentrated, transportation also remains a critical piece of the CoC.

Several potential partners may be important to addressing these gaps. Hospitals' Community Health Needs Assessments demonstrate that the target communities share concern about breast cancer in their communities. These hospitals will be important partners as the central

providers in those areas. Redefining the role of local health departments (LHDs) in the Affiliate's grant programming is important, and new relationships must be created with several LHDs in the target communities.

The actual quality of cancer care presents an aspect of Komen's mission that has been largely unaddressed through current health care reform, and may vary greatly even in areas with plenty of resources. More information was gathered through qualitative data regarding the dissemination of research and quality of the care which so many have gained access to recently. For example, survivorship care plans, patient navigation and the personalization of treatments are all excellent tools that increase quality of care, but may not be of equal quality or available to much of the service area, even when a hospital or other resource is present.

The effects of the Affordable Care Act's insurance mandate and preventive care coverage first began to be seen in the 2014-2015 grant year. During this year, most grantees saw previous eligible clients enroll in Medicaid or exchange plans, and gain preventive care coverage. Though the need for screening coverage still exists, the specific gaps for who is in need of that coverage are more clear, specific and limited. Meanwhile, more need has been observed for follow-up costs, which are often subject to deductibles or out of pocket limits, and present the next financial barrier in the continuum of care. This need is not limited to uninsured women, but instead includes women with insurance, and even low to middle incomes. Similarly, patient navigation models, at the community and clinical level, are an opportunity to increase adherence to recommended screening and follow-up by addressing non-traditional barriers to the continuum of care.

Komen Columbus participated in advocacy for Medicaid expansion, which was successfully achieved in the fall of 2013, through work with several coalitions and leveraging the Komen Advocacy Alliance (KAA) e-alerts in the area to write legislators. Over 100,000 of the estimated 175,000 uninsured in the service area gained insurance coverage through Medicaid expansion. Many more individuals obtained insurance through the insurance marketplace. Expanded coverage under Medicaid and access to the state insurance marketplace may have implications for BCCP in the future. The proposed FY16 budget eliminated access to the BCCP Medicaid Treatment program for women between 138-200 percent FPL. Statewide advocacy collaboration between the Ohio Affiliates convinced state leaders of the need to modernize the way BCCP funds are used in Ohio. The program was successfully defended and reintroduced into the budget due to these efforts. Future advocacy efforts will focus on modernizing BCCP to expand its use to underinsured women, to cover out of pocket and diagnostic costs, as well as more case management and patient navigation. BCCP remains a crucial safety net program, especially as a transitional resource in between employer based insurance coverage, and as a gateway into medical homes and Medicaid enrollment for eligible women. Several legislators have been interested in proposing legislation to modernize the program. The Affiliate can maximize impact and efficiency by updating grantmaking eligibility and referral criteria to carefully match BCCP's eligibility gaps.

In summary, implications of the Affordable Care Act, while still being surfacing, have shifted much of the need for focus on financial barriers from screening to diagnostic and follow-up costs. Partnerships with health departments, federally qualified health centers and hospitals can be enhanced with coalition building and more seamless navigation. As the number of

insured grows, adjustments in grantmaking eligibility criteria and programming priorities will shift to focus on new gaps and barriers. The financial barriers previously addressed (i.e. free or low cost mammography) may not be as prevalent as insurance coverage includes no cost sharing for preventive care. Instead, new financial barriers are emerging, like out of pocket or deductible costs for follow-up diagnostics after abnormal screening results. Educational barriers about how to use newly obtained insurance coverage may exist, as well as how to navigate through the system and improve the quality of care experienced equally by all patients to reduce breast cancer death disparities. This points to maintaining a focus on screening, but building emphasis on later parts of the continuum of care, including out of pocket costs and patient navigation.

### **Qualitative Data: Ensuring Community Input**

After assessing the quantitative, health systems and policy data, several breast health factors were identified for further qualitative investigation through focus groups and key informant interviews including: attitudes and beliefs, knowledge, utilization, access, transportation to each step of continuum, cost and other barriers, and knowledge of resources including patient navigation. Certain implications of data collection methods limit capability of the findings to represent each target community accurately.

In Metropolitan and Suburban communities, fear of diagnosis, misconceptions about pain or discomfort of screening, and a lack of education about resources, risk or recommendations emerged as the top barriers to care. These concerns were followed by costs and insurance issues, and general access issues like child care, convenience, and the struggle of many women to prioritize their health over competing family needs. Transportation was not nearly as concerning in these areas as it was in Rural-Appalachian areas, where it was the top barrier. After transportation, time and convenience, fear and education emerged as important.

Media, newspaper, TV and internet were used throughout all areas, but more available in Suburban and Metropolitan communities. The Rural-Appalachian community relies more heavily on health departments for health care information.

There are extensive misconceptions about risk and breast cancer in the Rural-Appalachian area. Similar beliefs were reported in the Suburban community, though are not held as deeply or as widely. Understanding of family history and genetic factors varies widely. Participants in all communities were aware of the relationship between family history and genetic factors and breast cancer risk. There was a general understanding that a family history may mean increased risk of breast cancer. However, there was confusion over what constitutes a family history and how the BRCA gene affects risk.

Respondents from all areas have a mixture of experiences with providers. Though most report positive experiences with providers and recommendations, some women did not feel like their provider communicated with them effectively about their care. More information was requested about lifestyle changes after diagnosis such as exercise patterns and dieting recommendations. Almost no women in any area received survivorship care plans, and a few did not feel informed about their reconstruction options.

Among Metropolitan respondents, concerns about trust centered on the time spent with a patient by a provider, costs and fear, more than distrust of the actual provider. In the Suburban areas, many women have the impression that they can access better facilities and care in Columbus, but generally, respondents reported trusting their providers and the health care system. In the Rural-Appalachian area, word of mouth plays a critical role, and one negative experience with a provider leads to distrust within the whole system.

Experiences with patient navigators (PNs) varied from extremely positive to non-existent. Most women in all three communities had never heard of a PN, including survivors. Further investigation of patient navigation in the service area showed wide-ranging definitions, uses, descriptions and training for navigators.

Qualitative data affirmed the findings of the health systems analysis, which identified gaps in follow-up care, patient navigation, survivorship services and transportation in Suburban and Rural-Appalachian communities. Those in the Metropolitan area enjoy a wider variety of services, which are more easily accessible. Those in Suburban and Rural-Appalachian communities must travel farther to screening, though that distance and difficulty varies widely, and lack the variety of options offered in Columbus. Mobile mammography was generally seen as a critical tool in each community, though reasons varied. Health departments play an additional critical role in the Rural-Appalachian counties as a source of information and clearinghouse for resources than in other areas. Providers are relied on less directly than in other areas, and awareness of Komen grant funding opportunities and services offered is poor.

### **Mission Action Plan**

Problem statements were drawn directly from the findings and major themes of the preceding data sections. Priorities and possible action steps were identified through discussions and suggestions from a mission action planning team, made up of key stakeholders, providers and other content experts, who provided input and feedback. Staff used those suggestions to develop objectives that were measurable, time-bound and specific.

**Problem Statement: The Metropolitan, Suburban, and Rural-Appalachian target communities experience informational, financial, logistical and physical barriers to entering the continuum of care through recommended screening which contributes to higher than average breast cancer late-stage diagnosis and death rates. Qualitative and health systems analysis revealed these communities experience communication and access barriers to accessing, adhering to and receiving high quality care in a timely manner.**

**Priority:** Increase the number of women entering the continuum of care through recommended screening by increasing breast self-awareness, understanding of personal risk, inherited risk, and reduce fears and myths surrounding screening and breast cancer, motivating and utilizing available resources, including utilizing existing insurance.

**Objective 1:** By September 2016, an educational webinar will be conducted with at least three community partners in the Suburban community and three community partners in the Metropolitan community.

**Objective 2:** On an annual basis (FY16 –FY19), Affiliate website will be updated with local resources for the Suburban, Metropolitan and Rural-Appalachian Regions, including local community health programs and screening resources.

**Objective 3:** By September 2015, promote local resources by disseminating link to website directory to at least 30 community partners and stakeholders in Suburban, Metropolitan and Rural-Appalachian Regions, repeating on an annual basis (FY16 – FY19).

**Objective 4:** By September 2019, provide support to local health plans in improving the screening rate among the Managed Care Plan members in Ohio by supporting partnerships with funded Komen Columbus programs, providing disparity awareness information, and training in support navigating non-compliant plan members to screening and follow-up.

**Objective 5:** By October 2016, add at least one evidence-based model component to include in the Worship in Pink program in Rural-Appalachian and Metropolitan communities.

1. Increase participation of Metropolitan faith-based organizations in the Worship in Pink program by five percent in FY2016, specifically addressing the Black/African-American population (baseline is 27 organizations in FY2015). Grow participation an additional two organizations in FY2017. Increase participation an additional two organizations in FY2018. Increase participation an additional two organizations in FY2019.
2. Expand participation in the Worship in Pink program from a baseline of five in FY2015 to ten participating organizations in Suburban community in FY2016. Grow by additional two organizations in FY2017. Grow participation an additional two organizations in FY2018. Grow participation an additional two organizations in FY2019.

**Priority:** Increase availability of mobile mammography in Suburban and Rural-Appalachian communities.

**Objective 1:** By 2017, hold a stakeholder meeting with six mobile mammography providers and partner organizations in Rural-Appalachian counties to discuss issues related to mobile mammography, including referrals, sites, target populations and partners, follow-up and availability of mobile units.

**Objective 2:** By FY2017, Community Grant RFA will include mobile mammography as a funding priority for the Rural-Appalachian community.

**Priority:** Improve the quality and capacity of clinical and lay patient navigation in all target communities to assess and address informational, educational, financial, logistical and other barriers to screening or follow-up care

**Objective 1:** In FY16 and FY17, deliver at least one online patient navigator training each year through Walgreens grant to reach at least 25 of patient navigators.

**Objective 2:** From FY2016 to FY2019, Community Grant RFA will include evidence-based education approaches that will dispel fears and measurably increase education and breast self-awareness with appropriate partners as a

funding priority for programs occurring in the Metropolitan, Suburban and Rural-Appalachian regions.

**Objective 3:** From FY2016 to FY2019, Community Grant RFA will include evidence-based approaches to increase utilization of insurance benefits among non-compliant, insured population in Suburban, Metropolitan and Rural-Appalachian counties as a funding priority.

**Objective 4:** In FY2016, create RFA that reduces the financial barriers to screening, diagnostics and follow-up care in Suburban, Metropolitan and Rural-Appalachian counties (may include co-pays, out of pocket costs, genetic testing costs, transportation and more). Evaluate and revise RFA based on new evidence-based models, and previous years' grant outcomes through FY2019.

**Objective 5:** In FY2016, create RFA that reduces the physical and logistical barriers to screening, diagnostics and follow-up care in Suburban, Metropolitan and Rural-Appalachian counties (may include transportation vouchers, extended hours of availability, mobile mammography at workplaces and in communities lacking screening access). Evaluate and revise RFA based on new evidence-based models, and previous years' grant outcomes through FY2019.

**Objective 6:** FY2016 to FY2019, Community Grant RFA includes evidence-based patient navigation targeting vulnerable populations at the point of an abnormal screening result as a funding priority for programs in Rural-Appalachian and Suburban Regions.

**Objective 7:** Create a network for communication between patient navigators (meetings, listserv) to enable promotion of resources to patient navigators by FY2017.

**Objective 8:** Promote the use of available self-advocacy materials (i.e. Questions to Ask the Doctor series) to providers, patients and navigators through at least 10 social media posts, one letter to oncology offices partners by FY2017, and again in FY2019, and communication with navigators funded through Community Grant programs.

**Objective 9:** Improve capacity and quality of patient navigation through new strategic, philanthropic partnerships to support at least one pilot project by September 2018

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

**Objective 1:** Disseminate the Metastatic Breast Cancer Toolkit to at least 30 community partners, hospitals and patient navigators in all target communities by FY2016.

**Objective 2:** Meet with or communicate with at least 30 provider community partners to promote available educational resources for metastatic breast cancer patients (fact sheets) by FY2017.

**Priority:** Increase awareness of and reduce the disparity in breast cancer mortality among local African American women.

**Objective 1:** Conduct quality assessment of resources in Metropolitan target community by June 2018.

**Objective 2:** Incorporate polices that improve overall social determinants of health into FY2018 RFA and other strategic mission partnerships and advocacy work.

**Objective 3:** Provide at least ten trainings (providers, health plans, policymakers, community) about breast cancer disparities and local solutions by June 2018.

**Objective 4:** Identify and implement at least two innovative partnerships to address disparities by July 2018.

**Problem Statement: Health Systems Analysis revealed threats to the funding of the Breast and Cervical Cancer program. Advocacy work to adapt to ongoing health care reform and to protect BCCP are necessary.**

**Priority:** Through advocacy, support the budget for and partner with the Ohio Breast and Cervical Cancer Program to ensure the continuum of care for its clients.

**Objective 1:** Coordinate with the other state affiliates through monthly meetings to support funding in the FY2016-2017 and FY2017-2018 state budgets.

**Objective 2:** Promote the state income tax check-off donation option in February and March of FY2017 so that enough donations are received to keep the check-off on the ballot for the following year.

**Objective 3:** Meet with BCCP quarterly to address any coverage gaps for BCCP clients due to changing eligibility.

**Objective 4:** Incorporate partnerships with BCCP and knowledge of unmet need into RFA by FY2017, to be used through 2019.

**Objective 5:** Promote the state income tax check-off donation option in December- March each year to increase BCCP funding.

**Objective 6:** Coordinate with the other state affiliates through monthly meetings to support increased funding in the FY2019-2020 state budget from FY2017-2018 levels.

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