



# COMMUNITY PROFILE REPORT

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## **Executive Summary**

### **Introduction**

The Columbus Affiliate of Susan G. Komen for the Cure is a non-profit, volunteer driven organization serving 30 counties in Central and Southeastern Ohio. Since our first Race for the Cure in 1993, we have been raising funds through our yearly Race and other annual campaigns and activities. In addition to fundraising, our staff and volunteers work diligently to spread the message of early detection and breast health awareness through a variety of mediums and initiatives and to advocate for increased access to care for women in Ohio throughout each year.

More than 75% of the funds we raise are given back to local organizations and hospitals to support breast health screening and education. Over the past eighteen years, the Columbus affiliate has funded more than \$18million in community health grants to provide education, screening and treatment assistance programming to underserved women in need. Several of our grant programs assist minority or special populations that face unique circumstances or barriers, including African American, Asian, Somali, Latina and Appalachian women.

The Community Profile report will serve as a foundation for affiliate priorities and action items in the coming years. The Columbus Affiliate conducted quantitative and qualitative research to identify the needs, resources and issues related to the breast cancer continuum of care in our service area. The findings from this research provide a basis for the affiliate to make strategic decisions about grant funding, partnership-building, fundraising efforts and volunteer engagement. While the Community Profile process and report are not exhaustive and therefore limited, we believe our efforts to identify community needs were comprehensive and provide sound justification for our future plans.

### **Statistics and Demographic Review**

Breast cancer incidence and mortality statistics from the American Cancer Society's 2009 and 2010 Facts and Figures Reports, as well as stage at diagnosis data from the Ohio Cancer Incidence and Surveillance System, were analyzed for trends in breast health throughout the 30-county service area. Mammography data from the Ohio Department of Health's Behavior Risk Factor Surveillance System was also reviewed to learn more about screening behaviors of women in the service area. To learn more about population demographics and socioeconomic variables, data provided by Komen Headquarters and Thomson Reuters was referenced, and supplemented by data from the United States 2000 Census Report.

The state of Ohio ranks below average for breast cancer incidence (121.9 /100,000 women in Ohio compared to 123.6 /100,000 in U.S.), but fourth in the country for breast cancer mortality (27.6 /100,000 women in Ohio compared to 25 /100,000 in U.S.). This disparity can also be seen at the county level within the Affiliate service area, with many

counties reporting a higher burden of breast cancer deaths compared to state and national averages. Lawrence County ranks first in the state for breast cancer mortality with 35.1/100,000 women dying from breast cancer (American Cancer Society, 2010). Several other counties report high mortality rates and more late-stage diagnoses than the state and national averages, including Licking, Fayette, Franklin, Clark, Delaware, Fairfield, Muskingum, Union, and Washington.

Understanding the socioeconomic and demographic statistics of the affiliate service area is critical to appreciating the general and breast health needs. The affiliate service area is made up of a generally homogenous and low-income population. In the thirty county service area, twenty-six counties have populations that are least 90% Caucasian, only four have more than an 8% black population and none have more than a 5% Hispanic population. Three-quarters of our entire service area population lives within ten counties: Clark, Delaware, Fairfield, Franklin, Licking, Marion, Muskingum, Ross, Scioto, and Washington.

Despite the apparent homogeneity of the service area, it is important to note that areas of diversity and cultural differences do exist and may influence health behaviors and barriers to care. Franklin County is home to an urban population of multiple ethnic, racial and social subgroups including the third largest population of Somalis in the world, several additional populations that encounter discrimination and language barriers, and an established homosexual community that does not frequently require gynecologic and family planning services and therefore do not receive provider recommendations for early detection and screening services. Seventeen of our counties are classified by the government as Appalachian; a geographic region characterized by isolation, poverty, lower educational attainment and social characteristics that affect health behaviors such as modesty and privacy.

Fourteen of our counties have more people below the poverty level than both the state and national average. Comparing rates of insurance, both private and Medicaid/Medicare, the affiliate service area has a higher proportion of uninsured females than the state average; thirteen of the affiliate counties have more uninsured females than the national average. More than half of the Affiliate's counties have higher rates of adults who did not complete high-school than both the state and national average, making health literacy and knowledge of health issues and behaviors a concern.

For the Community Profile exploratory data collection process, the Affiliate identified four counties to target that report breast health statistics which may indicate problems within the continuum of care. The four target counties also represent four distinct regions of the service area, each characterized by differences in population size, diversity and socioeconomic status: urban (Franklin County), contiguous (Licking County), non-contiguous and non-Appalachian (Fayette County), and Appalachian (Lawrence County).

## **Health Systems Analysis**

Assets such as mammography locations, diagnostic and treatment providers including surgery, chemotherapy, radiation, reconstruction and follow-up care, as well as public health departments, federally qualified health centers and organizations offering cancer support services were identified and mapped to identify local resources as well as gaps throughout the service area. Key informant interviews with medical providers, clinicians and grantees were conducted within the target communities and other counties of concern. Key informant responses were analyzed for common themes and gaps identified for specific populations or communities along the continuum of care.

Beyond Central Ohio, most counties do not offer a comprehensive continuum of care, but are able to provide digital screening mammography services and follow-up care. However, seven counties within the service area do not have a hospital and five do not have screening mammography within county lines. Lawrence County, which ranks highest in mortality, does not have any breast health services beyond medical providers who can provide clinical breast exams to women with insurance and a local health department that can refer women to services when accessed. The state and federally-funded Ohio Breast and Cervical Cancer Program (BCCP) offers early detection services through contracted providers to low-income uninsured women; however with limited funding available, a significant number of eligible women are not screened through Ohio BCCP.

Until the new Ohio biennial budget is finalized by the legislature, the Affiliate is unsure of how the Ohio BCCP will be impacted by potential budget cuts. Regardless of the amount of state general revenue funds appropriated for this vital screening and early detection program, the need to create additional revenue streams and increase sustainability of the program must remain an advocacy priority. Without the Ohio BCCP, the number of women facing barriers to screening and diagnostic services, as well as the BCCP Medicaid Treatment option, will increase drastically.

While screening, diagnostic and treatment facilities are abundant in Franklin County and the Central Ohio region, many populations including immigrants, the working poor, and uninsured women have trouble accessing them due to common barriers. Provider key informants validated several issues as potential barriers hindering timely entrance to all areas of the continuum of care: insurance status, poverty status, transportation, inconvenience, fear, and other health priorities including co-morbidities or chronic health conditions. Key informants also highlighted the importance of provider and patient education, as it relates to screening recommendations, treatment options and knowledge of available resources.

### **Qualitative Data Overview**

To learn more about the barriers and gaps faced by women in the target communities, nine focus groups were conducted:

- Fayette County women, ages 35-65
- Franklin County

- African American women including survivors
- Latina women, documented
- Latina women, undocumented
- Low-income Caucasian women
- Recently diagnosed survivors (<5years)
- Long-term survivors (>5years)
- Lawrence County women, ages 18-65
- Licking County women, ages 35-65 including survivors

Each focus group session lasted between 45 and 90 minutes duration, depending on the number of participants and the level of participation in the discussion. Each discussion was transcribed by a note taker and recorded so that they could be further analyzed for participant quotations and themes.

Most of the focus group discussions corroborated the general themes and barriers identified by key informants and the asset mapping process: insurance status or poverty, transportation barriers, lack of knowledge about screening recommendations and resources, and lack of education about follow-up/survivorship care

The consensus among focus group participants concluded that screening was the highest priority and that Komen should focus its efforts on specifically reaching the under/uninsured populations that have limited assistance available for early detection and preventative health services. Specifically, mobile units were recommended to target populations with isolation or transportation concerns. Low literacy populations were mentioned in several focus groups, highlighting the need for culturally appropriate outreach and educational materials.

Services along the continuum of care, as suggested in the key informant interview findings, are available to most insured women in the target areas. Focus group participants highlighted the disparity in access to services for women who could not afford to pay. Many participants did not know about reconstruction and follow-up care, and they were surprised that cancer patients should expect much beyond treatment. Participants also highlighted the distance a woman might have to travel to reach a mammography service or hospital, especially in northern Lawrence County and parts of Fayette County.

Lack of survivorship care was noted and most participants were not educated about breast cancer survivorship and what long-term follow-up might include and could therefore not speak to the lack of services in their community. Overall, survivorship education and services were deficient throughout the service area.

## **Conclusions**

Depending on the community of interest, barriers and gaps exist throughout the breast health continuum of care that prevent many women from accessing affordable and quality care in a timely manner.

The Affiliate can address several of the education, screening and treatment concerns through the Community Health Grants program as well as Affiliate initiatives with the assistance of our volunteer committees, Medical Advisory Council, Survivorship Advisory Council and Public Policy efforts.

The findings and conclusions of each module of the Community Profile assessment were analyzed and lists of priorities for each were constructed; recurrent priorities were considered and a final set of affiliate priorities was formed.

### **Affiliate Priorities and Action Plan**

While the Affiliate does not want to establish priorities that may limit our ability to serve women and men throughout the service area, additional consideration and preference will be given to high-risk populations and those target communities identified in this report.

The following measurable objectives will enable the Affiliate to monitor its progress and upon completion of the action plan, the Affiliate will be able to re-evaluate the state of breast health in the service area and adjust the outreach and mission activities accordingly.

- By August, 2011 the Affiliate's Community Health Grants Program will be revised to offer two separate Requests For Proposals (RFP); the majority of Affiliate funding (70%) will support programs focusing on early detection and patient navigation services, while programs focusing on survivorship care, long-term wellness services and medical provider education will be considered for Affiliate funding as well (30%).
- During 2011 and 2012, the Affiliate will consider and investigate the potential to offer multi-year grants that would provide additional opportunities for grantee's to increase sustainability and increase impact.

#### **Priority 1:**

**Increase and improve delivery of early detection services, including (re)screening and diagnostics that will improve mortality rates.**

- Objective 1: Following the release of the 2012 Ohio state budget, the Affiliate will engage with elected officials and Ohio BCCP constituents to advocate for funding of the state screening program.

- Objective 2: By August, 2011, refine the 2012-2013 RFP to focus on programs that incorporate culturally competent outreach, patient navigation, financial and transportation assistance.
- Objective 3: By March 31, 2012 the Komen Columbus Medical Advisory Council will create a medical provider campaign to educate Primary Care Physicians and OB/GYNs in the 30-county service area about recommended screening recommendations and available resources.

**Priority 2:**

**Improve survivorship support that is evidence-based and/or represents an innovative approach.**

- Objective 1: By July, 2011, the Komen Columbus Survivorship Advisory Council, Medical Advisory Council and survivor advocates will establish a definition of expected survivorship care that can be used for ongoing education initiatives, as well as the Community Health Grants RFP.
- Objective 2: By August, 2011 the 2012-2013 Community Health Grants RFP will solicit programs that support and advocate for systemic approaches that transform delivery of care to breast cancer patients.
- Objective 3: By August, 2011 the 2012-2013 Community Health Grants RFP will solicit wellness programs that improve health outcomes through quality of life and/or psychosocial focus, especially in underserved populations.
- Objective 4: By March 31, 2012 the Affiliate will create a survivor advocate training program to engage a total of 30 survivors, one from each county in the service area, to be educated on survivorship concerns, long-term follow-up expectations, and available resources.

## **Introduction**

### **Affiliate History**

The Komen Columbus Affiliate began in 1993 as a volunteer-operated organization to support breast cancer initiatives. The annual Columbus Race for the Cure® has raised over \$18 million since it began and is now the largest road race in the state of Ohio with over 50,000 participants at the 2010 Race.

As an affiliate of Susan G. Komen for the Cure, Komen Columbus gives 25% of our net funds to the Komen National Grants Program which funds scientific research. The majority of our funding, 75% annually, is given to local community grants for education, screening and treatment. Our partners in the community include each major hospital system in Central Ohio, a variety of state- and federally-funded health departments, as well as multiple non-profit organizations that reach underserved communities in need. The programming we have been able to support through the years has increased access to care, improved health outcomes for women and provided thousands of women with early detection messaging and breast health awareness.

In partnership with the other Ohio Komen affiliates, and other prominent cancer organizations, the Columbus Affiliate has been able to advocate for increased funding for breast cancer programming at the Ohio Department of Health, as well as provided significant awareness to the cancer burden in many of the legislative districts we serve. Our state, like many others, faces momentous budget shortfalls in the coming biennium; our affiliate aims to advocate and lobby for funding solutions that will allow vital breast health services to be maintained, in addition to increasing awareness of the high mortality rate of breast cancer for women in our state which requires crucial attention from leaders in our communities.

In 2010, the Columbus Affiliate was able to provide grant funding of a digital mobile mammography unit that will provide screening access to women throughout our service area; this unique partnership will allow the affiliate to promote screening and early detection efforts through a logo-branded unit that aims to empower women and increase education as well. This grant-funded program exemplifies the Affiliate's current strategic plan and goal to impact women in our community.

### **Organizational Structure**

The Columbus Affiliate has grown steadily from an exclusively volunteer organization just ten years ago to six staff members currently working at the affiliate. As Figure 1 highlights below, the governing Board of Directors oversees fundraising, events and community outreach activities in the 30 counties the affiliate services. Board members play strategic roles as leaders of committees and special initiatives in order to maximize the staff's time on current and prospective key priorities.

Within the past two years, the Columbus affiliate established a Medical Advisory Council and a Survivor Advisory Council to increase our presence in the communities we serve, as well as to guide our mission initiatives based on professional expertise and experience. The councils are chaired by board members with professional credibility and passion; the members of each council represent a spectrum of healthcare professions: public health researchers, oncology nurses, obstetricians and gynecologists, family medicine practitioners, breast surgeons, plastic surgeons, mental health professionals and survivor advocates. These councils create opportunity for affiliate growth, increased impact in our service area and improved access to valuable local resources.

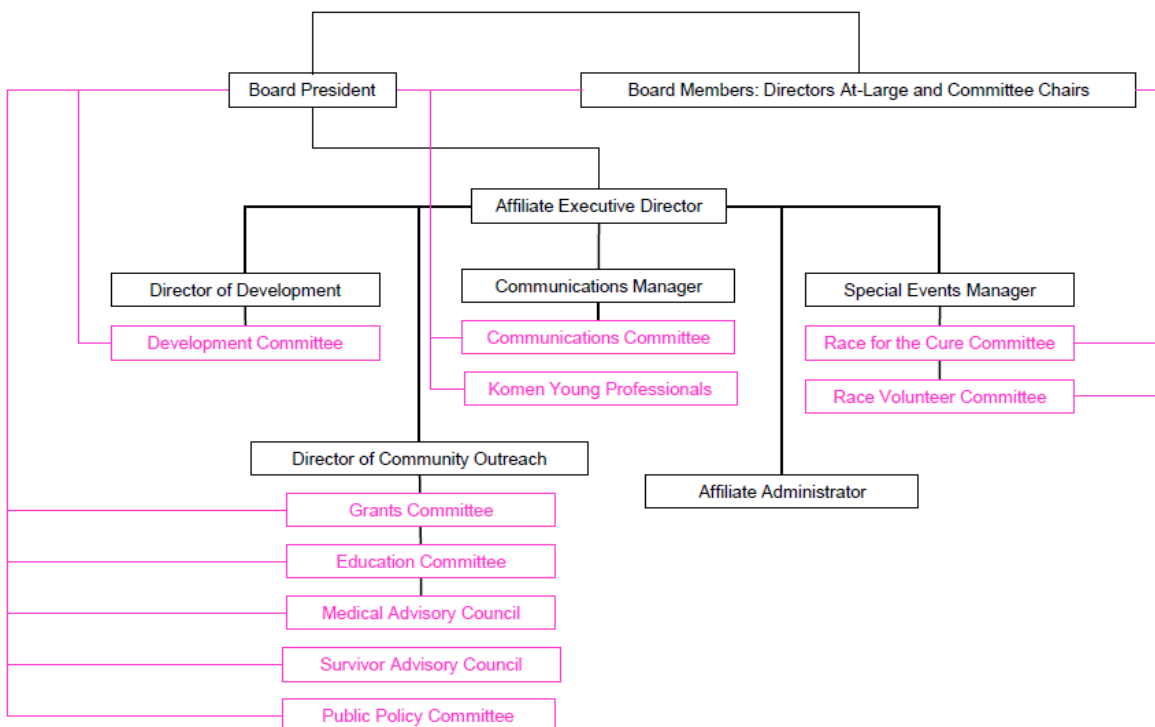


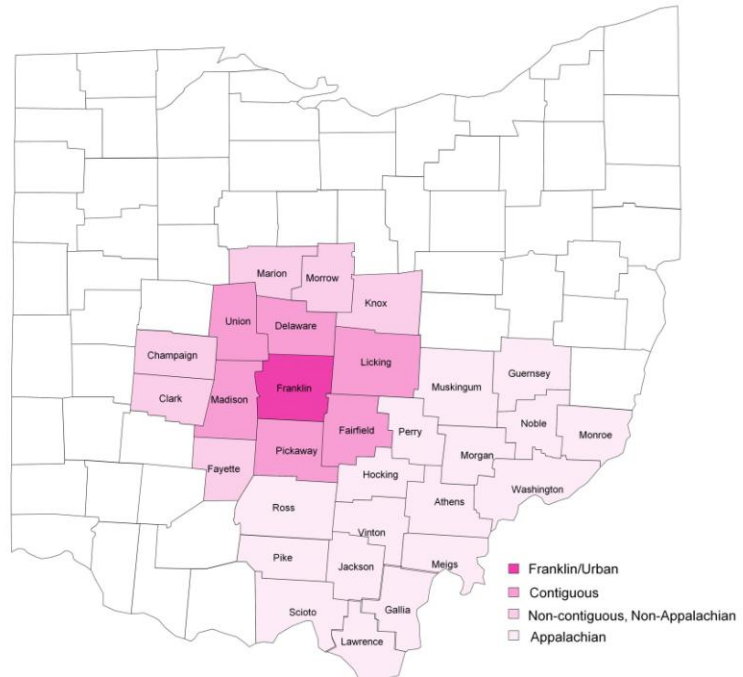
Figure 1. Affiliate Hierarchy Structure

### Description of Service Area

The Affiliate office is located in Columbus, the state capital and largest metropolitan area within our service area. We currently serve 30 counties in Central and South-eastern Ohio (see Figure 2). The total population for the 30-county service area is 2,798,351 and is large and diverse. Columbus, the capital of Ohio and the urban center of Franklin County is home to more than 40% of the affiliate service area’s population. Franklin and the contiguous counties are racially, ethnically and economically diverse; outside of the suburban areas of Central Ohio, our service area is rural and largely socioeconomically disadvantaged. The Southeastern portion of the Komen Columbus service area is part of the geographic area designated by the federal government as the

Appalachian Region. Appalachia is characterized by rural or isolated geography, a focus on oral traditions, cultural importance of family, personal modesty, strong religious beliefs and often a scarcity of money.

Figure 2. Columbus Affiliate Service Area



### Purpose of Report

The goal of the Community Profile is to gather information about each of the counties we serve so that we can identify needs and opportunities in the service area. The affiliate will utilize the Community Profile report to focus our resources in the areas that need them most by using data and statistics, qualitative information gathered from key informants and community members, as well as an analysis of available resources in the service area to discover the state of breast health in the Columbus Affiliate’s service area. We will form goals and mission objectives for the upcoming grant cycle using our Community Profile report, as well as guide development initiatives, outreach and education programming, advocacy campaigns and volunteer recruitment based on our findings. Congruent with our national mission, the affiliate strives always to save lives and end breast cancer forever; the Community Profile will provide a targeted road map for subsequent years that will allow us to most efficiently apply our resources to work towards these goals.

## **Breast Cancer Impact in Affiliate Service Area**

### **Methodology**

Breast Health Statistics from the American Cancer Society's 2009 and 2010 Facts and Figures Report were analyzed for breast cancer incidence and mortality data. The ACS reports rely on data provided by the Ohio Cancer Incidence and Surveillance System (OCISS) at the Ohio Department of Health. The Community Profile team analyzed both 2009 and 2010 breast health statistics to identify potential trends. Screening rates and stage at diagnosis information were also gained from the Ohio Department of Health and were originally collected through the 2006-2007 Ohio Behavioral Risk Factor Surveillance System. (BRFSS).

Demographic and socioeconomic data from the Thomson-Reuters' data pack provided to the affiliate by Komen Headquarters were supplemented by additional United States Census 2000 data, as well as National Cancer Institute's 2000 State Cancer Profile for Ohio.

### **Limitations of Analysis**

While the Community Profile team had hoped to analyze data at the zip code level, most of the counties in our service area do not have adequate population sizes to allow for this type of analysis and all data that could be obtained were estimates that limited our analysis. County-level data were used to give the most complete and thorough picture of the breast cancer burden throughout our service area.

For the mammography and screening behavior data, we had to analyze a composite data set of the entire 30-county service area rather than county level data. Additional limitations of the BRFSS mammography data include the usage of self-reported data and exclusion of households without telephones which potentially under represents certain populations.

Because the 2010 United States Census data were not yet available, demographic data and statistics from the 2000 U.S. Census were used; therefore, the information included is not current and may not adequately reflect population diversity, immigration or emigration or accurate economic conditions that potentially impact health behaviors and access to care throughout the Affiliate service area.

### **Overview of the Affiliate Service Area**

While the state of Ohio ranks below average for breast cancer incidence, we are 4<sup>th</sup> in the nation for breast cancer mortality. The Columbus Affiliate 30-county service area has significant variance in breast health statistics as well as demographics that may also impact a woman's experience throughout the continuum of care.

Many of the counties in our service area report relatively low incidence rates for breast cancer, but several counties are impacted with mortality rates that are highest in the state. As the American Cancer Society's 2010 Facts & Figures report reveals, 29% of breast cancer diagnoses in Ohio are late-stage, meaning regional or distant metastases; this percentage does vary considerably within our service area (American Cancer Society [ACS], 2010).

The screening behaviors of women in our service area are comparable to national and state averages. Though the Ohio BRFSS data we analyzed could not be separated by county, as the data below show, mammography usage within the service area depends greatly on educational attainment; income level and insurance status (see Table 3) (Ohio BRFSS, 2006-2007). Women in the service area impacted by poverty and other socioeconomic factors may face barriers that impact screening behaviors which can lead to late-stage diagnoses and increased mortality rates.

The majority of the Affiliate service area is burdened by a variety of negative socio-economic issues; poverty status, lack of health insurance and low educational attainment that may all impact a woman's ability to progress through the continuum of care without difficulty or delay. As data from the 2000 United States Census and Thomson Reuters show, nineteen of the Affiliate's thirty counties have more people living below the federal poverty level than the state and national average; ten of our counties rank highest in the state for poverty. Eighteen of the counties the Affiliate serves have more people with less than a high school diploma than the state and national averages (see Table 1). Comparing rates of insurance, both private and Medicaid/Medicare, the affiliate service area has a higher proportion of uninsured females than the state average; thirteen of the affiliate counties have more uninsured females than the national average. More than half of the Affiliate's counties have higher rates of adults who did not complete high-school than both the state and national average, making health literacy and knowledge of health issues and behaviors a concern. National trends also show that low literacy and education levels can impact health behaviors and lead to disparities in health outcomes (United States Census, 2000).

While the majority of the Affiliate's service area is homogenous, Franklin County's population is rather diverse racially and ethnically (see Table 1). Franklin County is home to large populations of African American, Hispanic, Asian, and Somali residents. Though race and ethnicity does not always impact breast cancer incidence or outcomes, national trends show that disparities exist and these populations often require specific, culturally sensitive outreach. In addition to the diversity of Central Ohio, the Affiliate service area includes seventeen counties that are classified by the government as Appalachian; this geographic region is characterized by isolation, poverty, lower educational attainment and social characteristics that affect health behaviors such as modesty and privacy.

Table 1.  
Demographic and Socioeconomic Statistics by county, Komen Columbus Service Area

County	Population <sup>1</sup>			Race/Ethnicity <sup>1</sup>				Socioeconomic Characteristics		
	Total	Female	40+	White	African American	Asian	Hispanic	Less than HS diploma <sup>1</sup>	% Below Poverty Level <sup>2</sup>	Uninsured Females 18-64 <sup>1</sup>
<b>Komen Columbus Total</b>	<b>2,798,351</b>	<b>1,418,517</b>						<b>17%</b>	<b>7.80%</b>	<b>15.50%</b>
Athens	68,758	34,805	35.8%	91.5%	2.7%	2.3%	1.2%	17.1%	14.00%	34.3%
Champaign	37,964	19,292	48.5%	94.2%	2.5%	0.5%	1.0%	17.7%	5.10%	12.5%
Clark	138,246	71,578	49.3%	86.6%	8.8%	0.7%	1.7%	18.8%	7.90%	15.0%
Delaware	171,280	86,675	40.2%	88.1%	3.9%	4.4%	1.9%	7.1%	2.90%	5.2%
Fairfield	132,758	66,861	45.7%	90.7%	5.7%	0.9%	1.3%	12.4%	4.50%	8.8%
Fayette	25,510	13,003	48.1%	93.5%	2.2%	0.8%	1.9%	21.3%	7.70%	13.2%
Franklin	1,150,086	585,514	42.0%	70.2%	19.2%	4.0%	3.9%	14.3%	8.30%	15.5%
Gallia	32,147	16,454	48.8%	94.3%	2.6%	0.6%	0.7%	26.3%	13.50%	23.3%
Guernsey	40,834	20,964	49.0%	95.3%	1.5%	0.3%	0.9%	21.6%	12.90%	20.6%
Hocking	27,527	14,017	47.8%	96.7%	0.5%	0.4%	0.7%	22.0%	10.30%	18.6%
Jackson	31,838	16,509	46.8%	96.4%	0.6%	0.4%	1.4%	26.5%	13.60%	24.4%
Knox	61,481	31,472	46.1%	96.3%	1.0%	0.4%	1.0%	18.2%	7.40%	12.5%
Lawrence	62,540	32,456	48.3%	95.4%	2.3%	0.5%	0.7%	24.4%	18.9%	24.1%
Licking	144,693	74,079	47.2%	94.5%	2.2%	0.7%	1.0%	15.3%	5.50%	10.9%
Madison	49,653	23,184	46.6%	91.3%	5.5%	0.8%	1.0%	21.0%	6.20%	7.6%
Marion	65,329	30,953	48.5%	90.2%	6.2%	0.6%	1.5%	19.7%	7.40%	13.8%
Meigs	21,298	10,948	49.6%	96.8%	0.9%	0.3%	0.7%	26.8%	14.30%	27.6%
Monroe	13,919	7,050	54.5%	98.2%	0.2%	0.2%	0.4%	21.2%	11.00%	22.3%
Morgan	12,307	6,267	51.7%	92.0%	4.1%	0.1%	0.4%	19.4%	15.70%	26.7%
Morrow	25,227	12,639	46.9%	96.4%	1.2%	0.3%	1.0%	21.4%	6.60%	10.9%
Muskingum	90,448	46,961	47.8%	93.4%	3.7%	0.3%	0.6%	19.4%	9.90%	17.2%
Noble	11,180	4,551	44.0%	89.6%	9.0%	0.3%	0.5%	21.4%	8.30%	14.4%
Perry	38,567	19,379	47.3%	97.6%	0.4%	0.2%	0.6%	21.1%	9.40%	13.5%
Pickaway	51,271	24,649	46.6%	92.2%	5.1%	0.4%	0.9%	22.8%	7.60%	13.7%
Pike	25,133	12,959	46.2%	95.5%	1.1%	0.4%	0.7%	29.9%	15.10%	23.4%
Ross	76,024	36,265	48.0%	90.7%	6.3%	0.5%	0.7%	23.9%	9.10%	16.7%
Scioto	77,075	39,581	47.4%	94.3%	2.4%	0.4%	0.8%	25.9%	15.20%	27.6%
Union	39,702	20,724	41.4%	91.8%	3.9%	1.7%	1.2%	14.0%	3.60%	8.3%
Vinton	12,730	6,438	46.1%	96.8%	0.9%	0.1%	0.6%	29.3%	15.10%	25.4%
Washington	62,826	32,290	52.3%	96.4%	1.0%	0.6%	0.6%	15.5%	8.60%	15.7%

<sup>1</sup>Thomson Reuters © 2010, U.S. Census Data. <sup>2</sup>National Cancer Institute; State Cancer Profile, 2000.

Table 2. Breast Health Statistics by County, Komen Columbus Service Area

County	Incidence		Mortality		Stage at Diagnosis <sup>2</sup>	
	Incidence 2009 <sup>1</sup>	Incidence 2010 <sup>2</sup>	Mortality 2009 <sup>1</sup>	Mortality 2010 <sup>2</sup>	% Late Stage	% Stage Unknown
<b>Ohio Total</b>	<b>120.4</b>	<b>119.9</b>	27	26.5	<b>29%</b>	3%
Athens	113.2	102.8	13.5	12.7	29%	5%
Champaign	102.8	110.9	17.4	18.5	31%	3%
Clark	119.3	118.7	25.9	25.3	31%	3%
Delaware	133.3	148.1	29.1	28.6	27%	2%
Fairfield	127.7	128.1	28.1	29.3	29%	3%
Fayette	107.4	98.2	34.7	34.4	20%	7%
Franklin	127.2	128.8	27.5	27.4	30%	3%
Gallia	97.6	95.3	16.8	18.2	29%	2%
Guernsey	138.3	143.4	28.9	26.2	36%	0%
Hocking	114.7	113.7	22.1	19.2	23%	5%
Jackson	107.7	105.8	23.1	23.6	30%	3%
Knox	127.5	125.4	25.6	26.3	29%	5%
Lawrence	136.8	131.5	38.9	35.1	33%	5%
Licking	125.8	135.3	35	32.9	27%	4%
Madison	108.9	111	29.1	26.5	40%	4%
Marion	116.3	116.8	22.3	21	33%	3%
Meigs	89.9	78.5	20.7	16.8	22%	0%
Monroe	101.2	94.2	12.7	16.6	31%	3%
Morgan	108.2	103.2	19.3	24.2	33%	2%
Morrow	111.3	115.4	16.4	24.3	33%	10%
Muskingum	113.9	108.6	28.2	27.5	32%	2%
Noble	79.1	86.5	16.3	16.3	30%	0%
Perry	109.4	111.8	27	26.7	39%	3%
Pickaway	122.9	123.8	26	28.1	29%	5%
Pike	94.4	102.6	27.4	25.6	38%	2%
Ross	116.9	114.8	30.9	28.2	28%	3%
Scioto	103.1	99.8	24	24.3	34%	3%
Union	122.4	120.9	24.1	27.7	32%	6%
Vinton	106.7	114.7	15.3	17	25%	6%
Washington	110.5	112.3	31.4	32.3	26%	2%

<sup>1</sup>American Cancer Society, *Ohio Cancer Facts & Figures 2009*.

<sup>2</sup>American Cancer Society, *Ohio Cancer Facts & Figures 2010*.

Table 3.  
Estimated Prevalence of Mammography Breast Screening, Komen Columbus Service Area, 2008<sup>1</sup>

	Ever had a mammogram		Had a mammogram within the past 2 years	
	Yes	No	Yes	No
<b>Total</b>	93.8%	6.2%	76.3%	23.7%
<b>Race</b>				
White	93.9%	6.2%	77.1%	22.9%
Black	97.6%	2.4%	78.2%	21.8%
<b>Age</b>				
40-49	88.7%	11.3%	73.8%	26.2%
50-64	96.3%	3.7%	78.6%	21.4%
65+	95.1%	5.0%	75.2%	24.8%
<b>Household income</b>				
<\$15,000	92.5%	7.5%	64.6%	35.4%
\$15,000-\$24,999	95.9%	4.1%	65.3%	34.7%
\$25,000-\$34,999	94.3%	5.7%	75.1%	24.9%
\$35,000-\$49,999	93.3%	6.7%	72.9%	27.1%
\$50,000+	93.7%	6.3%	84.5%	15.5%
<b>Educational attainment</b>				
Did not graduate high school	91.4%	8.6%	60.8%	39.2%
Graduated high school/GED	93.9%	6.1%	76.2%	23.8%
Some college/technical school	93.3%	6.7%	72.1%	27.8%
Graduated from college/technical school	94.9%	5.1%	84.1%	15.9%
<b>Has a healthcare plan<sup>2</sup></b>				
Yes	95.6%	4.4%	80.3%	19.7%
No	75.8%	24.2%	36.0%	63.6%

<sup>1</sup>Ohio Behavioral Risk Factor Surveillance System, 2006-2007.

<sup>2</sup>Determined by response to: Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare?

## Communities of Interest

Target areas were determined by analyzing data to find counties which exceeded state and national levels of incidence, mortality, and late stage diagnoses; the counties were ranked across the service area and those that demonstrated health disparities in more than one of the categories were considered as potential target areas. The Community Profile team decided to focus on at least one target area in each of the regions of our service area to reflect demographic differences: Franklin County, Contiguous counties, Non-Contiguous/Non-Appalachian and Appalachian counties.

Due to high mortality rates, late-stage diagnoses, and increasing incidence, the following counties were all identified as additional areas of concern: Clark, Delaware, Fairfield, Muskingum, Union, and Washington. While the Community Profile process does not allow the affiliate to explore all areas with the same level of attention, the affiliate did reach out to key informants to assess the breast cancer continuum through-

out the service area and will continue to prioritize funding in these additional areas so as not to limit our impact.

It is also important to recognize that while several counties within the service area report below average mortality rates, compared to other counties and the state and national averages, a few counties like Morgan, Morrow, and Pickaway report increasing mortality rates (ACS, 2009; ACS, 2010). The Affiliate will need to monitor these statistics over the next few years to identify any trends of concern.



Figure 3. Community Profile Communities of Interest

### Conclusions: Rationale for Identified Target Counties

- **Franklin County**
  - Above average breast cancer incidence rate, high breast cancer mortality rate; significant population density, segmentation and diversity. Represents the urban center of the Affiliate service area.
- **Lawrence County:**
  - This county reports the highest breast cancer mortality rate in Ohio, as well as high incidence and high late-stage diagnoses.
  - Does not have a hospital and lacks additional healthcare resources; the population is rural and isolated especially in the Northern part of the county. This county is also below average socioeconomically and is representative of the Appalachian counties in the Affiliate service area.
- **Fayette County:**
  - High breast cancer mortality rate; this county also lacks access to comprehensive care and is representative of the Affiliate service area's non-contiguous and non-Appalachian counties.
- **Licking County:**
  - High breast cancer mortality rate, increasing incidence rate and population size. Licking County is also representative of the contiguous/non-Appalachian counties in the Affiliate service area.

## Health Systems Analysis of Target Communities

### Overview of Continuum of Care

The breast health Continuum of Care is a framework that allows for analysis and discovery of issues related to health behaviors, health barriers, and potential delays as they are related to each step: screening, diagnosis, treatment, and follow-up care. The goal is for all women of the recommended screening age to enter the continuum annually and be provided follow-up care with a reminder to be screened again the following year. When a woman is screened but receives an abnormal finding, the goal shifts to move her through to diagnostic services and then on to treatment and follow-up care as needed, without delay or interruption. It is also important to consider the special needs along the continuum for high-risk populations including survivors who are being screened for potential recurrence.

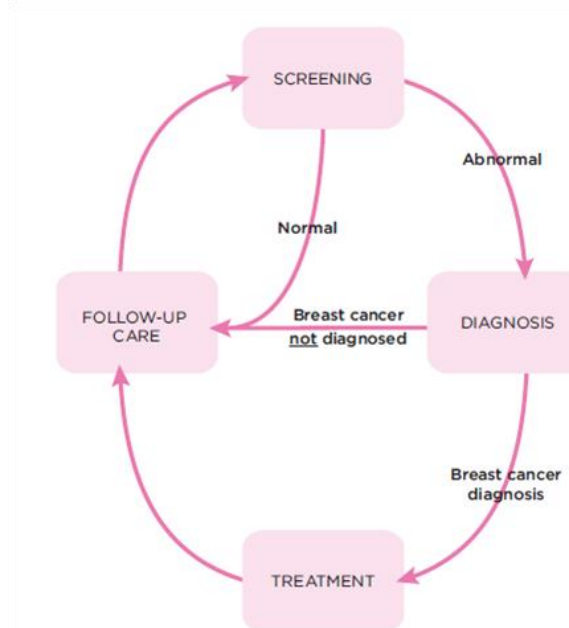


Figure 4. Breast Health Continuum of Care

For the Community Profile assessment, the Affiliate analyzed the gaps, barriers and issues that may be present in our service area at each phase. Our findings will allow us to identify factors that contribute to these barriers and recognize the potential for improvement within the Continuum of Care.

### Methodology

#### Asset Mapping

Community assets that are directly linked to the breast health continuum of care were identified through systematic review and analysis of local cancer resource directories and online databases. Each resource was added to the inventory of service area assets and mapped with Google Batchgeo.com mapping program. Key assets included

mammography locations, hospitals offering diagnostic and treatment services, health departments, cancer support organizations and federally qualified health centers.

Though many community organizations, for example churches or libraries, could potentially partner with the affiliate for breast cancer outreach and education initiatives, they were not all included because of their indirect link to the continuum and the sheer volume of such entities within the service area.

### **Key Informant Interviews**

Breast health professionals who had previously participated in surveys administered by the Columbus Affiliate were invited via e-mail to share information about their organization's services and experiences with the community. Nineteen providers in the Columbus Affiliate service area participated. Interviewees were asked about breast health resources and services, patient populations, barriers, and needs. Provider roles ranged from community health educators to registered nurses to physicians. Interviews were conducted by phone with an average duration between twenty and forty-five minutes. No compensation was provided to the breast health professionals who were surveyed. Notes from the interviews were compiled and combined into a master transcript for analysis of services by area and determining overall themes for the region's continuum of care.

### **Limitations**

Though our attempt was to gather information and insight from key informants throughout the identified target counties, there were some issues related to finding an appropriate contact in each target area. We did utilize key informants from outside the target communities in order to provide a thorough analysis of the assets and gaps in our service area.

### **Findings**

#### **Community Assets and Gaps**

The assets in the Affiliate service area are vast and diverse. Many communities have local healthcare organizations available, yet many are not easily accessible or do not provide comprehensive breast health services or specialty services.

There are gaps throughout the continuum of care; screening and diagnostic locations and access to financial resources for the under- and uninsured and treatment services are present in all counties with hospital systems but may not provide the most comprehensive or specialized options available. Evidence-based survivorship care planning and comprehensive support is lacking in most communities.

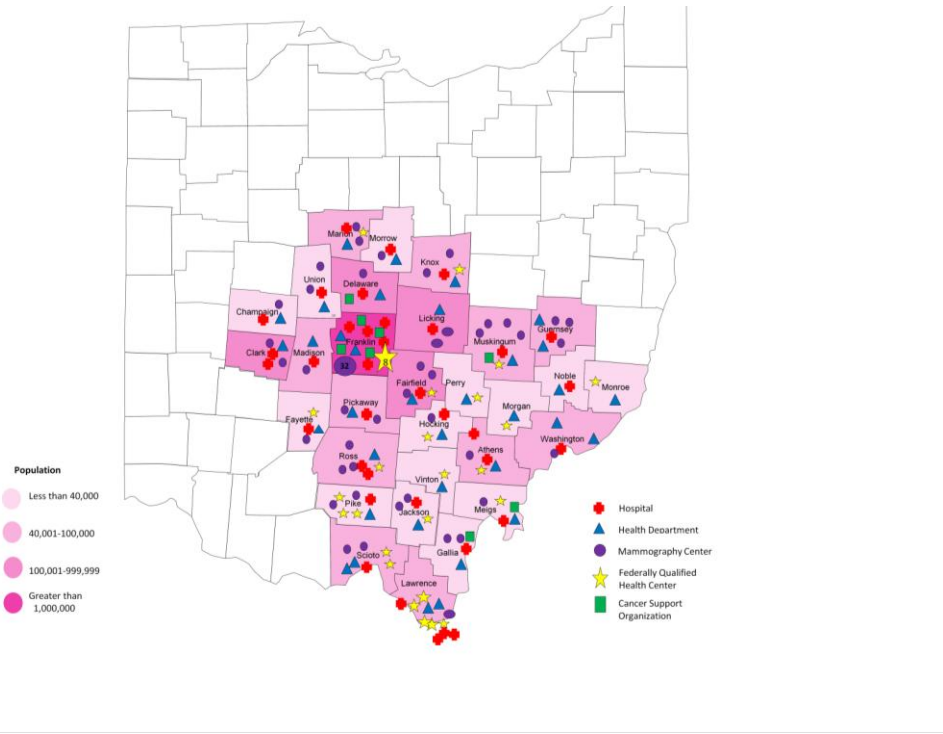


Figure 5. Health Systems Analysis: Service Area Asset Map

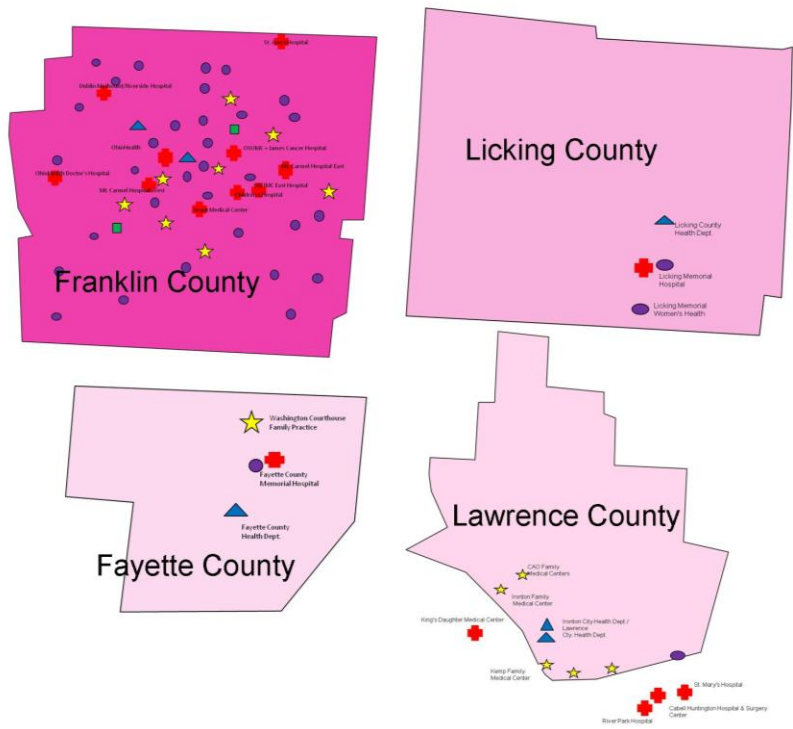


Figure 6. Target Communities: Asset Maps

Seven of the Affiliate's Appalachian counties do not have a hospital: Lawrence, Meigs, Monroe, Morgan, Noble, Perry and Vinton. In addition to the lack of hospital services in several counties, services like reconstruction and follow-up care are not available in the majority of the service area counties.

Most widespread is a lack of survivorship support services and educational programming. With the exception of the major healthcare systems in Columbus, survivorship care planning, medically supervised wellness and quality of life programming, and psychosocial support beyond treatment are lacking in each county.

The asset mapping process also identified gaps in partnerships within several counties in the service area. Several counties, including Lawrence, Fayette, Clark and Marion, have been approached and encouraged to submit grant proposals but have never applied for funding. Given the racial disparities reflected in national trends, the Affiliate would benefit from partnering with additional community partners to increase African American and minority outreach. There is a need for a tiered approach to provide outreach, patient services and follow-up throughout the continuum of care. Many organizations are not best suited to manage the patient navigation needed while others do not have the capacity to reach targeted populations with culturally competent outreach. This need highlights the role the Affiliate could play and demonstrates the need to increase provider and patient education about the continuum of care.

### **Ohio Breast and Cervical Cancer Program**

As a vital program for uninsured, low-income women, the Ohio BCCP is a great partner to the Affiliate. However, the program is only able to serve a small number of the eligible population and without guaranteed funding from year to year, is not able to operate at its full potential. Based on eligibility criteria, Ohio BCCP will only provide screening mammography to women ages 50-64, so the women in the 40-49 range who are uninsured are not eligible to receive BCCP services unless they are symptomatic. The Ohio legislature also chose to implement the most restrictive treatment option (3), meaning that women eligible for BCCP Medicaid must be diagnosed through Ohio BCCP, yet often Komen-funded programs must fill the gap because funding for the screening program is exhausted. Undocumented Latina women face additional barriers to care due to immigration status and new provisions to BCCP eligibility criteria which excludes them from receiving services.

During 2009-2010, Ohio BCCP provided more than 13,500 screening mammograms and diagnosed 213 women with breast cancer. As of 2008, more than 150,000 women in Ohio were eligible for BCCP services, meaning that current funding levels and program capacity can only serve 9% of the eligible women (Ohio Family Health Survey, 2004).

## **Legislative and Advocacy Issues**

Women in the state of Ohio who are eligible to receive screening and diagnostic services through BCCP cannot all be served due to limited funding. Ohio must have a balanced budget and faces a current \$8billion deficit. The Affiliate is working to advocate for state general revenue funds to be appropriated for the Ohio BCCP, but we recognize that this program is in jeopardy due to imminent budget cuts to many state programs. Ohio BCCP was recently awarded Tobacco Master Settlement Account monies to supplement state and federal appropriations; these funds must be utilized before the end of the current fiscal year (6/30/11) which presents a challenge due to limited capacity to enroll and provide case management services to women in each region before this deadline.

## **Gaps and Needs Identified by Key Informants**

Based on our key informant interviews, the Affiliate found that the widest and most complete spectrum of services is offered in the Columbus area, particularly at major hospital systems. Most counties have organizations that provide screening through mammography services, either through a community clinic or mobile unit. In counties where there is a hospital, the range of breast health services is larger and also includes diagnostic, surgery, chemotherapy and/or radiation options, and reconstructive surgery is available in some outlying counties. Patient Navigators were available in a majority of the organizations providing cancer diagnostic and treatment options. Survivorship care is the area of the continuum that is not as well developed as screening, diagnosis, and treatment. For many counties, the primary service offered for survivors is a support group. In the Columbus area, survivor education on topics like exercise and lymphedema prevention and management is available for women of all incomes. One Franklin county provider explained that survivorship care can sometimes be in “limbo” because the patient can see several providers during their treatment who have not communicated or agreed on the responsibility of patient education and follow-up. Two providers interviewed suggested that nurse practitioners have the greatest potential for handling survivorship health needs.

Organizations in urban Franklin County serve the most diverse patient population, including African-Americans, Caucasians, Hispanics and Asians, low-income populations, and immigrants from around the world. Rural and Appalachian areas also serve ethnic and cultural minorities such as the Amish and undocumented migrant workers who are mostly Hispanic.

With the exception of one provider in a more affluent Franklin county suburb, all organizations served women who are uninsured or underinsured, and also the working poor. Accordingly, providers reported that financial concern was the most ubiquitous barrier for patients entering any part of the continuum of care for breast health. Fear of the cost of services is present for many uninsured or underinsured women. Nearly all counties offer various types of financial assistance, including free or reduced cost services, financial counselors, HCAP or charity care, vouchers for gas/travel, and

access to social workers. Despite the multiple sources of aid, providers reported that many women are either unaware of these services altogether, doubtful of their eligibility to receive them, or reluctant to take advantage of financial aid because they assume that others need it more than they do.

One provider stated that better materials with 3<sup>rd</sup> grade reading levels should be developed to communicate information about breast cancer prevention, screening, and treatment to patients with low education and literacy levels.

Some providers admitted they do not discuss recommended screening practices with all female patients over the age of 40. One provider explained that physicians can be very pressed for time, at that screening is not discussed because of this reason. Another elaborated that some women may have other health issues that come as a priority during visits, for example diabetes or cardiovascular disease.

Provider key informants from Affiliate contiguous and surrounding counties frequently mentioned that some patients thought the level of care was higher in the Columbus area. These providers explained that while their organizations offered many of the same services locally, there were certain types of radiation that was only available in Franklin County.

Table 4.  
Assessment of the Continuum of Care: Gaps and Needs Identified by Key Informants

	<b>Screening</b>	<b>Diagnostic</b>	<b>Treatment</b>	<b>Follow-Up Care &amp; Survivorship Support</b>
<b>Franklin County/ Urban</b>	Lack of awareness of resources; Lack of appropriate literacy materials; Genetic testing for uninsured unavailable; Lack of reminder from provider	Few free or low-cost services for women under 40; BCCP funds not always available	Under/Uninsured may have interrupted care or alter medication due to costs; BCCP Treatment Option 3	Insurance may not cover needed follow-up care; Not all facilities offer (free) support or wellness services; Providers do not always provide long-term follow-up
<b>Contiguous Counties</b>	Awareness of local resources; Limited resources for Uninsured/Low-income	Few free or low-cost services for women under 40; Some resources available to residents of specific counties only	Radiation & reconstruction not available in all counties; Some resources available to residents of specific counties; BCCP Treatment Option 3	Survivorship care planning & wellness services are limited and inconsistent; Under/Uninsured populations offered limited follow-up

<p><b>Non-Contiguous/ Non-Appalachian Counties</b></p>	<p>Awareness of local resources; Limited resources for Uninsured/ Low-income</p>	<p>Few free or low-cost services for women under 40; Some resources available to residents of specific counties only</p>	<p>Radiation &amp; Reconstruction not available in all counties; Some resources available to residents of specific counties; BCCP Treatment Option 3</p>	<p>Survivorship care planning &amp; wellness services are limited and inconsistent; Under/Uninsured populations offered limited follow-up</p>
<p><b>Appalachian Counties</b></p>	<p>No mammography providers in some counties; Awareness of resources</p>	<p>Few free or low-cost services for women under 40; Some resources available to residents of specific counties only</p>	<p>Comprehensive treatment not available in some counties; 7 counties without hospitals; Reconstruction surgery not available in most counties; BCCP Treatment Option 3</p>	<p>No survivorship care planning or wellness services beyond support groups in most counties</p>

## Conclusions

While the Columbus Affiliate service area is home to several comprehensive breast health programs and local hospitals offering services throughout the communities we serve, many populations face barriers throughout the continuum of care.

Until the new Ohio biennial budget is finalized by the legislature, the Affiliate is unsure of how the Ohio Breast and Cervical Cancer Program will be impacted by potential budget cuts. Regardless of the amount of state general revenue funds appropriated for this vital screening and early detection program, the need to create additional revenue streams and increase sustainability of the program must remain an advocacy priority. Without the Ohio BCCP, the number of women facing barriers to screening and diagnostic services, as well as the BCCP Medicaid Treatment option, will increase drastically.

Provider key informants validated several issues as potential barriers hindering timely entrance to all areas of the continuum of care: insurance status, poverty status, transportation, inconvenience, fear, and other health priorities including co-morbidities or chronic health conditions. Key informants also highlighted the importance of provider and patient education, as it relates to screening recommendations, treatment options and knowledge of available resources.

In the four target counties, as well as throughout the service area, there are several widespread gaps within the health systems continuum of care, as well as issues that are specific to a smaller population within the community such as language and cultural barriers related to ethnicity and immigration status.

## **Breast Cancer Perspectives in the Target Communities**

### **Data Sources and Methodology**

In order to supplement the information gained from our analyses of the statistics and existing community assets, as well as the information provided by key informants, the Community Profile team conducted several focus groups in the target counties.

Nine focus groups were conducted:

- Fayette County women, ages 35-65
- Franklin County
  - African American women including survivors
  - Latina women, documented
  - Latina women, undocumented
  - Low-income Caucasian women
  - Recently diagnosed survivors (<5years)
  - Long-term survivors (>5years)
- Lawrence County women, ages 18-65
- Licking County women, ages 35-65 including survivors

With the help of a Komen Columbus board member who serves as an assistant health commissioner in Franklin County, a script and question guide were created based on information gaps following analysis by the Community Profile team. Each facilitator was trained so that the focus groups would be conducted under similar conditions with similar expectations for outcomes. Consent forms were signed by each participant and each group participant was offered a \$10 Wal-Mart gift card as an incentive to participate. Each focus group session lasted between 45 and 90 minutes duration, depending on the number of participants and the level of participation in the discussion.

Facilitators were assisted by a note-taker and most focus group discussions were recorded. Major themes and notes were documented during the discussions and the recordings were later analyzed for transcription of specific comments and common themes. The Latina focus groups were conducted in Spanish and translated to English for the Community Profile team to analyze the transcript.

### **Exploratory Data Findings**

Most of the focus group discussions corroborated the general themes and barriers identified by key informants and the asset mapping process: insurance status or poverty, transportation barriers, lack of knowledge about screening recommendations and resources, and lack of education about follow-up/survivorship care

The consensus among focus group participants concluded that screening was the highest priority and that Komen should focus its efforts on specifically reaching the under/uninsured populations that have limited assistance available for early detection

and preventative health services. Specifically, mobile units were recommended to target populations with isolation or transportation concerns.

Services along the continuum of care, as suggested in the key informant interview findings, are available to most insured women in the target areas. Focus group participants highlighted the disparity in access to services for women who could not afford to pay. Many participants did not know about reconstruction and follow-up care, and they were surprised that cancer patients should expect much beyond treatment. Participants also highlighted the distance a woman might have to travel to reach a mammography service or hospital, especially in northern Lawrence County and parts of Fayette County.

Lack of survivorship care was noted specifically in the Lawrence County focus group. When asked what survivorship services were offered in the county, the group highlighted the major survivorship support offered was an Anniversary card each year sent to a patient to mark another year beyond treatment. With the exception of the Franklin County survivor group sessions, most participants were not educated about breast cancer survivorship and what long-term follow-up might include and could therefore not speak to the lack of services in their community.

Supporting the provider suggestion that low-literacy materials are needed, many focus group participants highlighted the need for increased awareness and education among certain populations, especially in rural areas where general education attainment has limited the knowledge of recommended health behaviors and in minority populations that may be uninformed of their breast cancer risk.

One Caucasian woman said,

“Insurance is an issue for people, and is a major barrier. Doctors need to tell people ways to find affordable (breast health) care. It’s up to us (women) to pay, and some of us really don’t have the money to.”

Echoing this observation, several providers had observed that practitioners in their organizations may be unaware of resources available for low-income patients, and unable to refer patients to needed services that may be more affordable.

A Survivor mentioned that,

“Patient navigators are the key to get through the system. Not having health insurance would be the worst thing, though.”

Overall, survivorship initiatives were ranked lowest as a funding priority, even by the survivors themselves. Lymphedema and wigs were the most valued survivorship initiatives and support groups were available to most. Not surprisingly with limited knowledge about survivorship care as part of the continuum, survivorship initiatives were ranked lowest as a funding priority. Focus group participants mentioned several

times that they did not even know what to ask for, because they have no idea what they should expect, or what might be available to them.

The Licking County focus group did specifically mention the importance of mobile mammography initiatives:

“It (mobile mammography) could be an entry point for those without a medical home. I don’t have a family doctor because I don’t know who to go to. It would be nice to have it (mobile mammography units) at work, Wal-mart and the health department.”

The target age group identified by the community members for affiliate outreach and grant funding was women below 40 and those 40-49. The barriers to adequate breast health care were abundant and myriad. Financial barriers, including but not limited to lack of insurance, accounted for the bulk of problems mentioned in the focus groups. Transportation, not being able to take time away from work, childcare and a limited number of local providers were also mentioned as potential barriers. The Affiliate found it interesting that many focus group participants suggested that while the financial and time related barriers may be real, they are often used as excuses for women who are simply afraid of being screened.

A Lawrence County participant highlighted the significant transportation barrier in her community:

“I don’t even know how to get on the bus. I can’t afford to get on the bus. If you’re way out in Lawrence County, forget it, you can’t get to a bus.”

Fear was also a significant barrier identified by most participants and virtually all survivors. Clarification of what type of fear would prevent a woman from accessing breast health services highlighted the fear of cancer, fear of death, fear of having a mammogram, fear of the medical community and fear of not being able to pay for needed treatment.

From the documented Latina group:

“It’s confusing to know what to do. I do mammogram every year. I don’t do self-exam, I feel weird.”

An undocumented Latina woman said:

“We (Latinas) are used to home remedies. It’s not part of our culture to go to the doctor. I don’t know where to go, and I am scared of the doctors.”

One African American participant said:

“Black women are afraid of clinical trials, and we need someone to reach out to us so we are not afraid of treatment. We need women to speak out, and we need to talk about it. There is reluctance to talk about it (breast health) and outreach is important.”

While the city of Columbus has world renowned health facilities, many focus group participants in the Contiguous and Appalachian communities felt they could receive quality care close to home and did not need to travel to Columbus.

A Fayette County woman said,

“Our facilities down here (in Fayette County) are just as capable as in Columbus. A lot of doctors are moving away though, and then people do not know how to choose another care provider. We need knowledge of where new doctors are and how to get an appointment.”

Table 5.  
Target Community Perspectives: Themes Identified in Focus Groups

	Barriers	Funding Priority	Special Populations	Potential Partners	Other	Komen Awareness
<b>Fayette County n=8</b>	Money/Insurance status; Fear; Lack of knowledge; Denial; Transportation	Screening; Education	Rural populations without transportation	Health Department; Hospital; American Cancer Society; Wal-Mart	Free services should be offered 1st of month to increase utilization of those on Govt. Assistance	Race; Research; Pink Wigs; Heather Pick; Pink Ribbons
<b>Franklin County African Americans n=14</b>	Under/Uninsured status; Age; Lack of communication; Education; Access	Screening & Education	Low-income	Churches; Employers; Radio; TV; Schools; Libraries; Columbus Cancer Clinic; Hospitals	Young women need to be educated earlier about what is normal for their bodies	Race; Healthy Spirit, Healthy Bodies Program; Research; Survivor Support
<b>Franklin County Latinas (Documented) n=6</b>	Under/Uninsured status; Fear; Language barrier; Cultural differences in health behaviors; Transportation	Education & Screening	Low-income; Undocumented	Churches; Centro Esperanza; Radio; Small grocery stores; Schools	Phone line with someone who speaks Spanish is vital, not just hospital interpreters	Race; Scientific Research; knew of local grantee program

<b>Franklin County Latinas (Undocumented) n=9</b>	Undocumented status/Fear of deportation; Language barrier; Transportation; Lack of knowledge; Work schedule	Education & Screening	Undocumented; Low-income	Churches; Centro Esperanza; Radio; Small grocery stores; Schools; Employers	Undocumented women are not going to risk deportation for a health screening	Very Little; Knew it was Named After a Person
<b>Franklin County Low-Income Caucasian n=14</b>	Under/Uninsured status; Fear; Embarrassment; Lack of reminders; Work schedule; Language barriers; Navigating healthcare system	Screening; Education	Low Income; Latina; Somali	Insurance Companies; High Schools; Employers; Jobs and Family Services	Girls should be educated in school when they are younger because not all moms talk about breast health	Support Groups; 10TV (Heather Pick); Race
<b>Franklin County Survivors &lt;5yrs n=11</b>	Embarrassment; Money; Fear; Cultural Differences; Lack of provider communication	Screening; Survivor Support	Survivors with (risk of) lymphedema; Low-income	Churches; Jobs and Family Services; Food Banks; Schools; TV Stations	Need individual education rather than books; personal experiences vary; wellness classes serve as a non-traditional support group	Support Groups; Website; Race; Advocacy; Education; Awareness; Research
<b>Franklin County Survivors &gt;5yrs n=9</b>	Embarrassment; Money; Fear; Cultural Differences; Lack of follow-up	Screening; Survivor Support	Survivors with (risk of) lymphedema; Depressed survivors; Low-income; Survivors with metastatic disease	Churches; Jobs and Family Services; Food Banks; Schools; TV Stations	Need individual education rather than books; personal experiences vary	Support Groups; Website; Race; Advocacy; Education; Awareness; Research
<b>Lawrence County n=11</b>	Under/Uninsured; Transportation; Inability to get off Work; Money; Lack of Education; Fear; Denial	Screening; Education	Low-income; Rural without transportation	Churches; McDonalds; Cable Company; Post Office; Colleges	Reading/Literacy is important, just because you read something doesn't mean you understand	None
<b>Licking County n=8</b>	Under/Uninsured; Fear; Denial; Inability to get off work; Embarrassment; Transportation	Screening; Education; Survivor Support	Low-income	Hospitals; Health Department; Churches; Grocery Stores; Physician Offices	Family and Community support is vital; need to know about local resources (guide)	Race; Heather Pick; Awareness; Fundraiser, not Information Source

## Conclusions

The exploratory data provided the affiliate with additional depth and specific commentary about what programs and initiatives will be most effective in the respondents' communities and which existing community organizations may be helpful partners. In general, the Community Profile team was able to solidify its priorities and gain a better understanding of barriers and deficits in specific communities that may inhibit the affiliate's efforts. The participants were overwhelmingly supportive of the

affiliate's assessment and were delighted to contribute. The survivors were especially willing to provide open and honest feedback and were interested in any information they were able to provide the Community Profile team.

Throughout the exploratory research process, the Community Profile team learned that the visibility of the affiliate is lacking in several communities, especially outside of the Columbus metropolitan area. Many respondents and participants were aware of the Race for the Cure, or agreed with others when the Race was mentioned, but knew little else about Susan G. Komen for the Cure. There is a significant opportunity in the affiliate's Appalachian region to increase knowledge of Susan G. Komen for the Cure, so that women and men understand the resources available to them and to increase the Affiliate's role as a prominent partner in screening and early detection efforts.

Common barriers at entry-points in the Continuity of Care include lack of knowledge about resources, logistical issues of keeping appointments, fears of financial burden, and communication barriers between providers and patients and also between providers at various levels of the Continuum of Care. It is also important to note that survivorship care may be the least developed and coordinated area of the Continuum. Addressing the issues presented in the focus groups and interviews will be important to improving the accessibility and quality of breast health care in the Affiliate. While there may be resources present in the service area, there is great variability among the counties for full continuum of care services. Barriers to access continue to be problematic and document the need to address outreach and education related to increasing knowledge about resources, patient-provider communication, and survivorship care planning and quality of life programming.

Based upon all of the sources of data that were reviewed along with the pertinent issues that were identified in the focus groups and interviews, improving accessibility and quality of breast healthcare in the Affiliate is clearly the priority. Clarification of what cancer survivorship entails, which services might help decrease the risk of recurrence, and programs that reduce side-effects of treatment and improve quality of life for survivors are also needed throughout the service area.

## **Conclusions: What We Learned, What We Will Do**

### **Review of Findings**

The Columbus Affiliate of Susan G. Komen for the Cure has a diverse and large service area impacted by above average rates of breast cancer mortality and poor socio-economic conditions. Ohio ranks 4<sup>th</sup> in the country for breast cancer mortality and several of the Affiliate counties report poor breast health statistics; however, women in counties that report good breast health outcomes may still face individual barriers that hinder their care and ability to navigate the breast health continuum of care.

Fayette, Franklin, Lawrence and Licking Counties were each explored to identify key community assets and resources, as well as gaps and barriers. Community representatives were asked to share their individual opinions, perspectives and experiences in order to clarify and highlight reasons for existing problems as well as potential solutions.

From the asset mapping process, key informant interviews and focus groups, the Affiliate was able to identify several widespread concerns and a number of specific problems that require attention in order to improve the continuum of care. The primary concerns that affect women throughout the service area include poverty and lack of insurance, isolation and transportation barriers, lack of education and awareness of local resources, and lack of education about follow-up/survivorship care.

Key informants identified an array of existing services within their communities, but also highlighted the need to navigate high-risk populations through the continuum and provide financial assistance to those in need. Provider education was identified as a need in many communities, especially related to screening recommendations for high-risk populations and follow-up care for breast cancer survivors.

Focus group participants identified barriers such as fear and denial that impact a woman's motivation and ability to access the services she may need. In addition to emotional barriers, more tangible barriers such as financial concerns, transportation and language barriers were common themes that prevent women in most communities from adhering to health recommendations and access to timely care.

### **Conclusions**

Depending on the community of interest, barriers and gaps exist throughout the breast health continuum of care that prevent many women from accessing affordable and quality care in a timely manner.

The Affiliate can address several of the education, screening and treatment concerns through the Community Health Grants program as well as Affiliate initiatives with the assistance of our volunteer committees, Medical Advisory Council, Survivorship Advisory Council and Public Policy efforts.

Prioritization of the Affiliate's resources will be important to target the needs throughout the continuum of care. While the Affiliate recognizes that the needs in our service area may outweigh our current assets, structuring the Community Health Grants program to focus on early detection services and survivorship support will provide an opportunity to reach high-risk populations and medical providers throughout the service area. Additional internal initiatives and efforts will focus on medical provider education, survivorship advocacy training efforts and educational outreach to target communities.

As health care delivery changes due to budget cuts and implementation of the Affordable Care Act, the affiliate recognizes the need to maintain our focus on early detection efforts that will improve mortality, as well as partnering with organizations and supporting projects that will streamline the delivery of care to patients throughout the continuum of care.

### **Affiliate Priorities**

While the Affiliate does not want to establish priorities that limit our ability to serve women and men throughout the service area, additional consideration and preference will be given to high-risk populations and those target communities identified in this report.

The findings and conclusions of each module of the Community Profile assessment were analyzed and lists of priorities for each were constructed; recurrent priorities were considered and a final set of affiliate priorities was formed.

#### **Priority 1**

Increase and improve delivery of early detection services, including (re)screening and diagnostics that will improve mortality rates.

- *Target populations: high-risk women (BRCA, survivors), minority populations, uninsured*

#### **Priority 2**

Improve survivorship support that is evidence-based and/or represents an innovative approach.

- *Target populations: rural/Appalachian, uninsured, minority populations*

## **Action Plan**

In order to most efficiently use Affiliate resources and to increase our impact in the service area, the Affiliate has identified the following objectives:

- Objective 1: By August, 2011 the Affiliate's Community Health Grants Program will be revised to offer two separate RFPs; the majority of Affiliate funding (70%) will support programs focusing on early detection and patient navigation services, while programs focusing on survivorship care, long-term wellness services and medical provider education will be considered for Affiliate funding as well (30%).
- Objective 2: During 2011 and 2012, the Affiliate will consider and investigate the potential to offer multi-year grants that would provide additional opportunities for grantee's to increase sustainability and increase impact.

### **Priority 1: Increase and improve delivery of early detection services, including (re)screening and diagnostics that will improve mortality rates**

- Objective 1: Following the release of the 2012 Ohio state budget, the Affiliate will engage with elected officials and Ohio BCCP constituents to advocate for funding of the state screening program.
- Objective 2: By August, 2011, the Affiliate will refine the 2012-2013 RFP to focus on programs that incorporate culturally competent outreach, patient navigation, financial and transportation assistance.
- Objective 3: By March 31, 2012 the Komen Columbus Medical Advisory Council will create a medical provider campaign to educate Primary Care Physicians and OB/GYNs in the 30-county service area about recommended screening recommendations and available resources.

### **Priority 2: Improve survivorship support that is evidence-based and/or represents an innovative approach**

- Objective 1: By July, 2011, the Komen Columbus Survivorship Advisory Council, Medical Advisory Council and survivor advocates will establish a definition of expected survivorship care that can be used for ongoing education initiatives, as well as the Community Health Grants RFP.

- Objective 2: By August, 2011 the 2012-2013 Community Health Grants RFP will solicit programs that support and advocate for systemic approaches that transform delivery of care to breast cancer patients.
- Objective 3: By August, 2011 the 2012-2013 Community Health Grants RFP will solicit wellness programs that improve health outcomes through quality of life and/or psychosocial focus, especially in underserved populations.
- Objective 4: By March 31, 2012 the Affiliate will create a survivor advocate training program to engage a total of 30 survivors, one from each county in the service area, to be educated on survivorship concerns, long-term follow-up expectations, and available resources.

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