

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



SUSAN G. KOMEN®  
QUAD CITIES

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# Executive Summary

## **Introduction to the Community Profile Report**

The first Komen Quad Cities Race for the Cure® occurred in 1990 and holds the distinction as one of the very first Races held. Komen Quad Cities officially incorporated in 1999. In the last 26 years, thanks to events like the Komen Quad Cities Race for the Cure and the many community events hosted to benefit the work of the Affiliate, Komen Quad Cities has invested more than \$5.7 million in local breast health and breast cancer awareness projects in the eight county service area that includes Henry, Mercer, Rock Island and Whiteside Counties in Illinois and Cedar, Clinton, Muscatine and Scott in Iowa.

In the fall of 2014 Komen Quad Cities hosted Race to Research, a three-part full-day event that included a luncheon for survivors, sponsors, grantees, and Race participants, an educational session for medical professionals in the afternoon and a free community forum in the evening. The Affiliate invited Komen Scholar Dr. Olufunmilayo Olopade, M.D., F.A.C.P. to speak as the featured guest for the entire event, as well as some of the local physicians to speak at the community forum. The goal of Race to Research was to bridge the gap of where the funds raised at Race for the Cure and other fundraisers go exactly. The event was a success and many left with a better understanding of how funds are being used.

Additionally, the Affiliate's main activities revolve around granting funds raised to deserving community organizations. The annual competitive Community Grant Program offers opportunities for organizations within the service area to compete for funds for programs in education, outreach, and support for breast health and breast cancer patients and survivors. In the last two years, the Community Grants Program has offered bonus points for serving women in the targeted communities identified in the last Community Profile Report. During that time, the Affiliate also expanded the grant review process to include a larger number of community members on a community advisory board who make recommendations to the board for funding Community Grants.

Based on feedback from some community organizations that larger grants seem to squeeze out smaller, deserving programs, the Affiliate implemented a Small Grants program in 2014. With funds available of up to \$5,000 for deserving projects within the Affiliate services area, three community organizations have received small grants for a total amount of \$14,251. Komen Quad Cities continues to market these as options to organizations that can meet their needs with the smaller dollar amounts available through this means.

The Community Profile Report provides information to inform the activities of Komen Quad Cities, including focus for the Community Grant Program, over the next four years.

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

Susan G. Komen Quad Cities identified three target counties in the service area to focus efforts over the next four years. Target counties have cumulative key indicators that show an increased

risk of vulnerable populations experiencing gaps in breast health services and/or barriers in access to care.

When selecting target communities, Komen Quad Cities reviewed Healthy People 2020, a major federal government initiative that provides specific health objectives for communities and the country as a whole. Through this review and the Quantitative Data Report for the Komen Quad Cities' service area, priority areas emerged based on the time needed to meet the Healthy People 2020 targets for breast cancer.

Key indicators the Affiliate reviewed when selecting target counties included:

- Incidence Rates
- Death Rates
- Later-Stage diagnosis
- Mammography screening percentages
- Demographic and socioeconomic measures

Based in that analysis, the following three target communities emerged:

- Clinton County, Iowa
- Muscatine County, Iowa
- Mercer County, Illinois

Out of the Affiliate's entire eight-county service area, Clinton and Muscatine Counties had the highest or high priority in one of the key areas. Mercer County had poor key indicators. Scott County became a Medium High priority and forecasted as not likely to meet the late-stage incidence HP2020 target rate. Despite this indication, the Affiliate chose not to add Scott County as a target community' as a more populous area, its residents have better access to care compared to most of the service area, especially these three target areas.

### **Clinton County, Iowa**

Death rates in Clinton County are higher than the Affiliate's service area as a whole at 26.6 (Table 1). At this rate, the county will likely miss the HP2020 death rate target. Age-adjusted late-stage cancer rates are slightly lower in Clinton County at 45.3; however, the late-stage diagnosis rate has an undesirable positive trend. Three out of every 10 (30.7 percent) Clinton County residents have an income below 250 percent of the federal poverty level compared to 30.1 percent for the Affiliate and 27.6 percent for Iowa. The population of Clinton County is 32.2 percent rural. People in rural areas may face more barriers to accessing quality health care, such as transportation issues.

**Table 1. Clinton County breast cancer statistics**

	<b>Clinton County</b>	<b>Affiliate Service Area Rate</b>	<b>US Rate</b>
Incidence Rate*	128.9	130.4	122.1
Death Rate*	26.6	20.9	22.6
Late-stage Rates*	45.3	46.7	43.8

\*Rates are age-adjusted and are figured per 100,000 women

### **Muscatine County, Iowa**

Muscatine County has a rising late-stage diagnosis rate of 45.5. As a result, the county will not likely to meet the HP2020 target for late-stage incidence. A greater percentage of Muscatine County's population has less than a high school education: 14.5 percent compared to 11.5 percent for the Affiliate as a whole. Muscatine County has an elevated unemployment level at eight percent and a substantially higher Hispanic/Latina population than the Affiliate service area at 15.7 percent. Research shows that women from minority and medically underserved populations will more likely receive a breast cancer diagnosis at an advanced or late-stage, likely due to the socioeconomic factors mentioned above that delay screenings and certain biological factors that affect Hispanic/Latina women.

### **Mercer County, IL**

Similar to Muscatine County in demographic makeup, Mercer County's has fewer females; as such too few deaths exist to provide statistically meaningful information. The late-stage diagnosis age-adjusted rate of 60.5 exceeds that of the Affiliate level, although with a positive, downward annual trend (Table 2). Lower education (11.9 percent of Mercer County residents have earned less than a high school diploma), high rurality (77.8 percent reside in rural areas), and low insurance rates (11.1 percent of residents age 40-64 have no health insurance) add to the risk factors for Mercer County women. These socioeconomic factors put Mercer County at risk of not meeting the HP2020 target for late-stage incidence.

**Table 2. Mercer County breast cancer statistics**

	<b>Mercer County</b>	<b>Affiliate Service Area Rate</b>	<b>US Rate</b>
Incidence Rate*	139.8	130.4	122.1
Death Rate*	SN	20.9	22.6
Late-stage Rates*	60.5	46.7	43.8

\*Rates are age-adjusted and are figured per 100,000 women

SN: data suppressed due to small numbers (15 cases or fewer for the 5-year data period)

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

The Affiliate looked at providers across the continuum of care in each of the chosen target communities and identified some common needs of all three target communities. Clinton and Muscatine Counties each have two hospitals and Mercer County has one hospital that are available for screening and diagnosis; however, none have sufficient options (if any) for treatment and support services. Clinton and Mercer Counties both have a high population of

rural residents thus creating a transportation barrier to accessing quality health care, especially when needing to travel long distances to receive care. Each target area also lacks outreach and education. Komen Quad Cities needs to align with partners in these target areas to help individuals receive the information, screenings, treatment, and support they need.

To find potential new partners, Komen Quad Cities needs to become more visible in these communities. In addition to goals to strengthen ties to the state Breast and Cervical Cancer Early Detection Programs and cancer coalitions in both Iowa and Illinois, the Affiliate needs to solidify working relationships with the health departments in each county and provide education and resources to individuals in need and to organizations in these communities that may ultimately develop needed programs, possibly with support from Komen grant dollars.

Komen Quad Cities understands the importance of public policy and sees its value in better serving all women in the service area and beyond. The Affiliate plans to become active in advocacy at the state and federal levels in the next four years by partnering with existing efforts undertaken by Komen Iowa and Komen Memorial. In addition to providing good use of existing resources, these partnerships uphold the collective goal of Susan G. Komen to remain united as “one voice.”

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

Based on the results of the quantitative data and health system and public policy analysis, Komen Quad Cities conducted a series of focus groups and interviews with key informants in these target communities to gather additional information about their perceptions of the importance of breast health care including the need for breast self-awareness and routine mammography. The Affiliate anticipated that those who understood the need but did not access these services did so because of transportation, childcare or financial barriers.

Data collected from the focus groups and key informants identified barriers to improving breast health in these counties that fell within five overall themes: systemic, attitudinal, cultural, logistical, and educational. As discussed in more detail below, only cultural barriers emerged as county-specific. The others emanated more from the rurality or socioeconomic status of residents than their specific place of residence.

Systemic barriers included processes and procedures within the medical community that presented a potential barrier or a hurdle which women must overcome to improve their breast health and breast health care. The systemic barriers mentioned by individuals in this study included:

- Doctors who do not take women’s concerns seriously
- Insurance companies that limit or refuse to pay for mammography services for some women especially those under the age of 40 regardless of their family history or presentation with a potential carcinoma
- Too few women physicians
- Poor quality health care especially in rural communities

- Requirements to have a physician referral for a mammogram which creates unnecessary expense and time commitment
- Perceived delays in the health care system especially after a suspicious finding

Systemic barriers represent the most difficult to change as they occur in the broader environment in which women seek breast health care. Better education about navigating the health care system and self-advocacy for women might begin to provide the knowledge they need to receive better care in this imperfect system. Concurrently, more education of physicians about women's perceptions of their breast health care might help them begin to change their communication styles with women.

Attitudinal barriers include certain attitudes or beliefs that a woman has about breast cancer or mammography that prevent her from adequately seeking screenings or addressing her breast health. This study revealed the following attitudinal barriers:

- A belief that breast cancer happens to "someone else"
- Fear of the known rather than the unknown
- Fear of x-rays or mammography
- Belief that men cannot get breast cancer

Education helps to overcome some of these attitudinal barriers with that education occurring at a younger age and with multiple generations of women. Women should know their own genetic predisposition and other risk factors as they relate to breast cancer and encourage each other to overcome these attitudinal barriers.

Cultural barriers include attitudes and beliefs deeply engrained in a particular culture, in this case, the Hispanic/Latino culture in Muscatine County since that provided one focus for this study. Hispanic/Latina women in this study commented that Hispanic/Latina women:

- Are more timid or shy about their bodies and health than White women
- Do not take sufficient time to care for themselves
- Distrust the medical profession

These cultural barriers become the most challenging to overcome because they are deeply ingrained in the individual's psyche and become part of how they identify themselves and the world around them. Having women of a similar culture tell their stories can begin to address some of these cultural barriers.

Logistical barriers – or physical elements within an individual's environment that make pursuing adequate breast health care more difficult – include lack of transportation, finances, time, family support, or child care as well as barriers that come from language differences, not having a personal physician, and legal status (which some fear their health care provider will report). Komen Quad Cities has funded a Voucher Program for a number of years that helps women pay for diagnosis and screening services; however, few in the focus groups knew this resource existed or thought it only existed during October. Key informants mentioned a plethora of other programs designed to help people with many of these logistical barriers. Assuring that all of the

rural communities in the target counties have these services – and providing resources to get them set up if they do not – and then educating women and other providers of their existence would go a long way toward alleviating many of these logistical barriers.

Educational barriers conclude the list of reasons why women do not receive adequate breast health care. These fell under the overall themes of lack of knowledge about the need for breast self-awareness or an individual's risk factors as well as specific education about things like where to access care, when to start obtaining certain types of breast health care, and existence of programs to help overcome logistical barriers. Some of the participants suggested improving education by starting to talk about the need for breast self-exams with girls as young as middle school including stories from survivors; using mass media and billboards to get the message out; putting brochures in locations where women frequent including grocery stores, laundromats, churches, preschools, agencies that serve low-income women and families (such as WIC); large companies; and materials that residents already receive (e.g., flyers for city services, electric bills, newspapers). *Note: Susan G. Komen uses breast self-awareness messaging because breast self-exams are not an evidence-based practice. To learn more about breast self-awareness, go to <http://www5.komen.org/BreastCancer/BreastSelfAwareness.html>.* To reach younger audiences, others suggested a social media campaign. Having these materials available in Spanish (and other languages prevalent in the service area) will allow Komen Quad Cities to reach and educate more women and begin to address some of the cultural barriers as well.

### **Mission Action Plan**

To alleviate the problems that were highlighted through the qualitative and quantitative data analyses, the Komen Quad Cities board identified the following three priorities for the Affiliate's focus over the next four years. The board selected these priorities as those whose resolution has the potential to impact the largest number of individuals within the service area or the target community and the greatest likelihood to improve outcomes and survival data.

**Problem Statement:** Quantitative data suggest that Muscatine County has a rising level of late-stage diagnoses. A large percentage of residents with less than a high school education (14.5 percent), high unemployment (eight percent), and substantially higher Hispanic/Latino population than the Affiliate as a whole (15.7 percent) contribute to this trend. Research shows that minority and medically-underserved populations tend to receive a diagnosis at a later disease state, likely due to socioeconomic factors and other barriers to routine screenings. Certain biological and cultural factors also affect the diagnosis rate for Hispanic/Latina women. Qualitative data suggest that cultural and language differences serve as barriers for Hispanic/Latina women. (**Target Communities:** Hispanic/Latina women in Muscatine County)

**Priority:** Reach out to Hispanic/Latina women in Muscatine County with culturally-appropriate messages delivered in Spanish when appropriate.

*Objectives:*

1. By December 2016, reach out to groups that serve Hispanic/Latina women in Muscatine County to identify natural partners and culturally-appropriate best practices to educate and encourage this population to seek regular breast health care.
2. By December 2017, implement and evaluate culturally-sensitive outreach and educational programs annually to encourage Hispanic/Latina women in Muscatine County to seek regular breast health care that: (a) reach at least 100 Hispanic/Latina women through personal contacts and (b) include at least three mass media campaigns targeted toward Hispanic/Latina women.
3. By December 2019, implement and evaluate educational, outreach, partnership and financial assistance programs to increase the number of Hispanic/Latina women in Muscatine County diagnosed with breast cancer at an earlier stage.

**Problem Statement:** Women in the focus groups and key informants in all three target counties identified cost as a major barrier to seeking breast health services. They also repeatedly mentioned other physical and logistical barriers such as transportation, child care, and the cost of living expenses or co-payments after a breast cancer diagnosis. Several mentioned the availability of vouchers in October – Breast Cancer Awareness Month – but few knew of their existence during the other 11 months. Furthermore, one key informant noted that her job consists of helping women overcome these types of barriers in her county. Both findings point to a need for better education and marketing in these counties – and across the Affiliate – for these services that make breast cancer screenings, education, and treatment more accessible to all women. (**Target Communities:** Muscatine and Clinton Counties in Iowa and Mercer County in Illinois)

**Priority:** Expand educational outreach regarding the availability of services that minimize barriers to seeking breast health services.

*Objectives:*

1. By early 2016, identify resources and partners available in the target communities of Muscatine, Clinton, and Mercer Counties to provide logistical and financial support for breast cancer screenings and treatment.
2. By the end of 2016, develop a marketing plan targeted to low income women in Muscatine, Clinton, and Mercer Counties that outlines resources available to them to offset the costs and logistical barriers to breast health care.

**Problem Statement:** Much of the focus group discussions revolved around ways to remind women to seek subsequent mammograms on a schedule that fits her needs and individual risk scenario. These discussions evolved into questions of ways to encourage women to get their first mammogram. Some of the identified barriers included lack of a personal physician, lack of knowledge, and lack of insurance. This priority seeks to bring more women into the health care system for breast care. Once they have that first mammogram, existing systems encourage

most to continue screenings as appropriate. (**Target Communities:** Muscatine and Clinton Counties in Iowa and Mercer County in Illinois)

**Priority:** Reach out to at-risk women (especially from low-income and rural households) who have never had a mammogram to encourage them to receive regular breast health care.

*Objectives:*

1. By early 2016, identify resources and partners available in Muscatine, Clinton, and Mercer Counties to provide education that encourages women to have a first mammogram based on her individual risk factors.
2. By the end of 2016, develop a targeted education plan for women in Muscatine, Clinton, and Mercer Counties that outlines the basics of breast health including the need for routine screenings, screening recommendations, and places to access screenings.
3. By December 2018, education, outreach, partnerships, and financial assistance to women in Muscatine, Clinton, and Mercer Counties will increase in the number of women who seek breast health care as measured by the number of mammograms or breast health-related visits.

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

# Introduction

## **Affiliate History**

The inaugural Susan G. Komen Quad Cities Race for the Cure® was held in 1990 at Bettendorf High School. It was a women's only race with 1,714 participants and 23 survivors. In 1999, Susan G. Komen® Quad Cities became an official Affiliate of Susan G. Komen. In June 2014, the Affiliate celebrated its 25<sup>th</sup> Anniversary Race for the Cure. Since its inception in 1990, more than 11,000 breast cancer survivors have crossed the Affiliate's Race finish line.

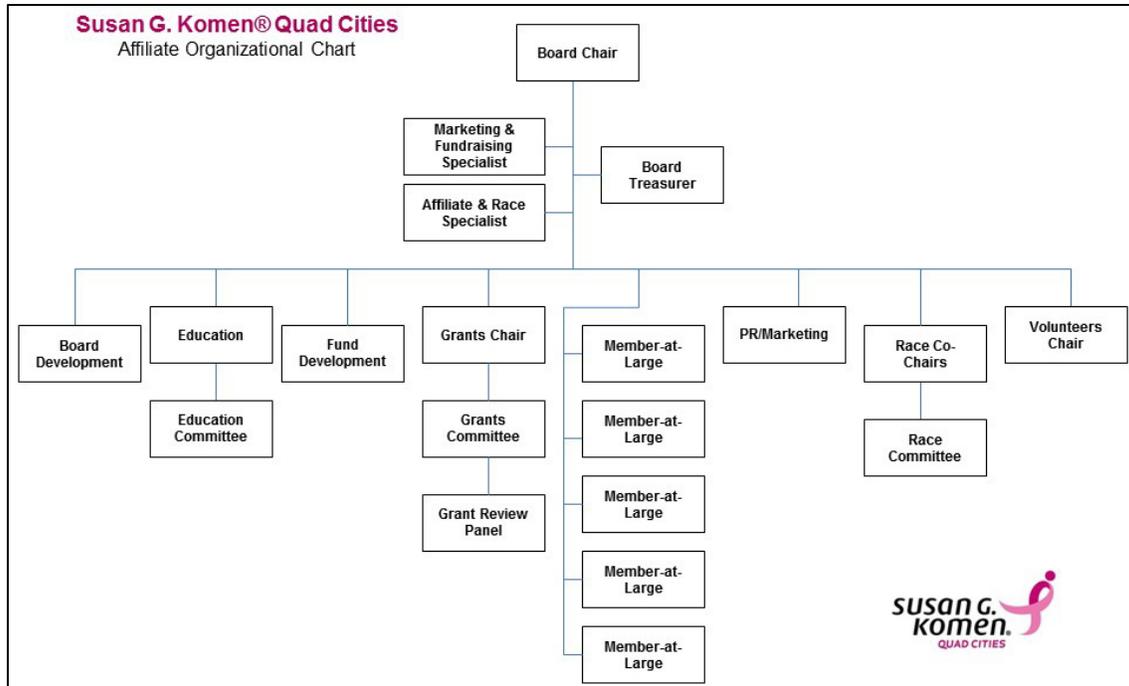
In November 2014, Komen Quad Cities hosted Race to Research with featured guest Komen Scholar Olunfunmilayo Olopade, MD, FACP, OON. The goal of Race to Research was to bring the Affiliate's mission full circle. Funds raised at Race and throughout the year, fuel the local grants programs, education and outreach. And, on a national level these contributions drive breast health breakthroughs by funding scientific research grants.

Komen Quad Cities has raised over \$5.5 million dollars since its inception, with \$4 million funding local breast health programs and \$1.5 million supporting Susan G. Komen Research Programs. The Affiliate works to ensure that all people, regardless of race, income, geographic location, sexual orientation or insurance status, have access to screening, and if diagnosed, to quality, effective treatment and treatment support service. In support of these efforts Komen funding has provided more than 45,000 no cost mammograms in its eight-county service area.

Komen Quad Cities funds local breast health initiatives through both the Community Grants program, which solicits applications each fall, and the Small Grants Program (up to \$5,000) which awards grants monthly.

## **Affiliate Organizational Structure**

The Komen Quad Cities' Board of Directors is a working board and consists of several dedicated individuals who strive to fulfill the Komen mission through their volunteer efforts. The Affiliate staffs one full-time individual, the Affiliate & Race Specialist, as well as a part-time Affiliate Administrative Assistant. Additionally, the Affiliate engages a part-time consultant, to provide marketing and fundraising support. See Figure 1.1 for the Komen Quad Cities organizational chart.

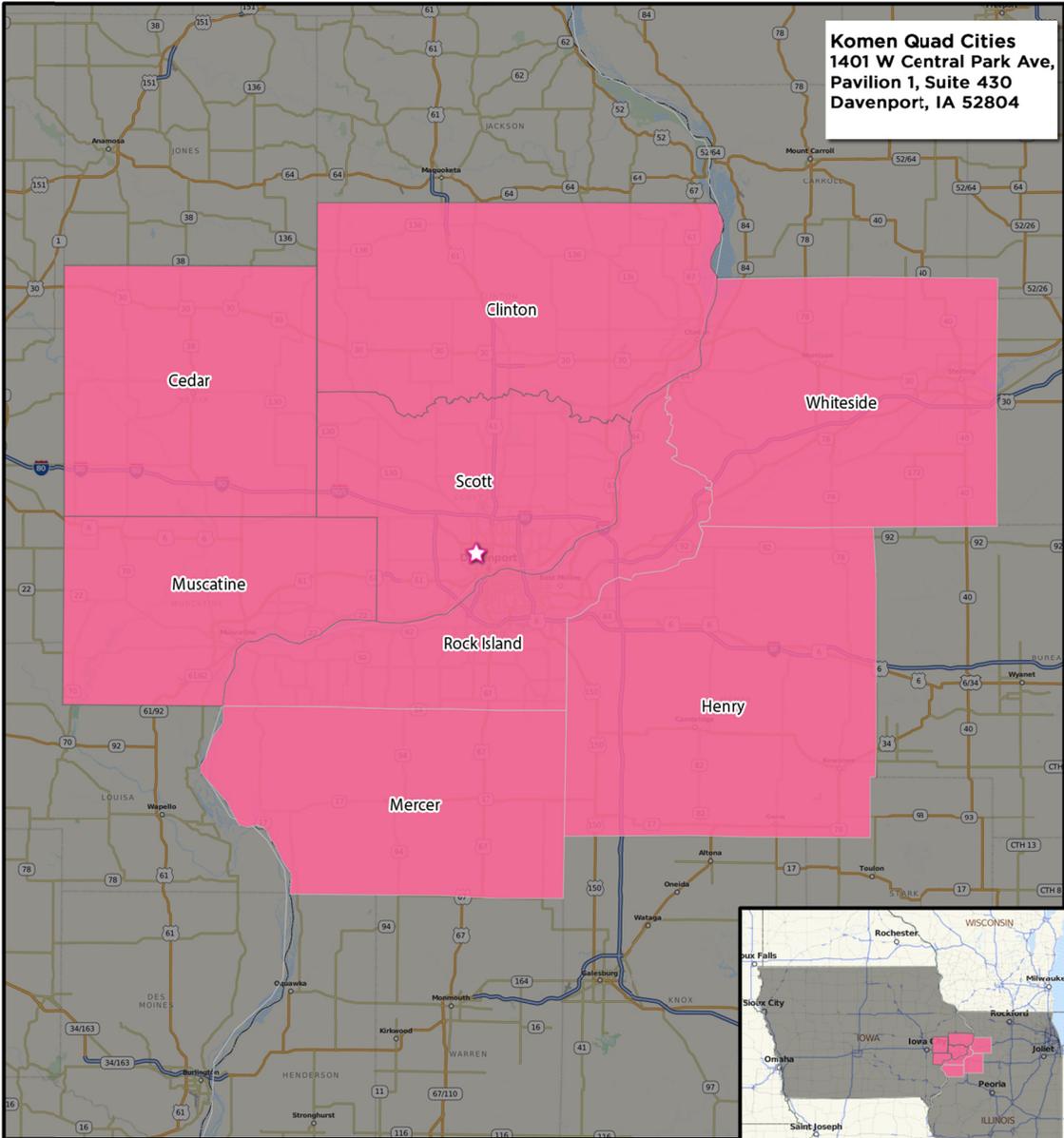


**Figure 1.1.** Susan G. Komen Quad Cities organizational chart

**Affiliate Service Area**

Komen Quad Cities is strategically located at the center of its service area, spanning the Mississippi River in Iowa and Illinois. The service area consists of eight counties including Cedar, Clinton, Muscatine and Scott in Iowa, and Henry, Mercer, Rock Island, and Whiteside in Illinois. See Figure 1.2 for the Komen Quad Cities service area map. As is with all other Affiliates, up to 75 percent of net funds raised stays in the service area while the remaining 25 percent goes to fund scientific research through Susan G. Komen’s Research Programs.

# KOMEN QUAD CITIES SERVICE AREA



★ Komen Quad Cities Office      ■ Service Area

Figure 1.2. Susan G. Komen Quad Cities service area

The Komen Quad Cities' service area consists of approximately 277,570 women, with approximately 25 percent living in rural areas. Of those women, the majority are White and over 50 percent are age 40 or older. Around 30 percent of the Affiliate's population has an income below 100 percent poverty level and 11 percent of the population age 40-64 have no health insurance. This data are all detailed in the Quantitative Data section found later in this report.

### **Purpose of the Community Profile Report**

The purpose of the Community Profile Report is to:

- Align the Affiliate's strategic and operational plans
- Drive inclusion efforts in the community
- Drive public policy efforts
- Establish focused granting priorities
- Establish focused education needs
- Establish objectives for marketing and outreach
- Strengthen sponsorship efforts

The Community Profile is used by the Affiliate in a multitude of ways. Primarily, it serves as the basis of the Community Grants Program and helps identify the areas of greatest need within the eight-county service area. Priority points are given to Community Grant applicants with programing which targets high priority needs as outlined in the Community Profile. Secondly, the Community Profile will be used as a community outreach tool to help educate the constituents, survivors, Race participants, legislators, and health system employees to illustrate the need for breast health funding, outreach and education in the community. The relationships are formed and strengthened with key informant interviews and focus groups participants, during the course of this Community Profile project. Ultimately these partnerships strengthen the Affiliate's mission work, helping more women and men in need.

# Quantitative Data: Measuring Breast Cancer Impact in Local Communities

## **Quantitative Data Report**

### **Introduction**

The purpose of the quantitative data report for Susan G. Komen® Quad Cities is to combine evidence from many credible sources and use the data to identify the highest priority areas for evidence-based breast cancer programs.

The data provided in the report are used to identify priorities within the Affiliate's service area based on estimates of how long it would take an area to achieve Healthy People 2020 objectives for breast cancer late-stage diagnosis and death (<http://www.healthypeople.gov/2020/default.aspx>).

The following is a summary of the Komen Quad Cities' Quantitative Data Report. For a full report please contact the Affiliate.

### **Breast Cancer Statistics**

#### **Incidence rates**

The breast cancer incidence rate shows the frequency of new cases of breast cancer among women living in an area during a certain time period (Table 2.1). Incidence rates may be calculated for all women or for specific groups of women (e.g. for Asian/Pacific Islander women living in the area).

The female breast cancer incidence rate is calculated as the number of females in an area who were diagnosed with breast cancer divided by the total number of females living in that area. Incidence rates are usually expressed in terms of 100,000 people. For example, suppose there are 50,000 females living in an area and 60 of them are diagnosed with breast cancer during a certain time period. Sixty out of 50,000 is the same as 120 out of 100,000. So the female breast cancer incidence rate would be reported as 120 per 100,000 for that time period.

When comparing breast cancer rates for an area where many older people live to rates for an area where younger people live, it's hard to know whether the differences are due to age or whether other factors might also be involved. To account for age, breast cancer rates are usually adjusted to a common standard age distribution. Using age-adjusted rates makes it possible to spot differences in breast cancer rates caused by factors other than differences in age between groups of women.

To show trends (changes over time) in cancer incidence, data for the annual percent change in the incidence rate over a five-year period were included in the report. The annual percent change is the average year-to-year change of the incidence rate. It may be either a positive or negative number.

- A negative value means that the rates are getting lower.

- A positive value means that the rates are getting higher.
- A positive value (rates getting higher) may seem undesirable—and it generally is. However, it's important to remember that an increase in breast cancer incidence could also mean that more breast cancers are being found because more women are getting mammograms. So higher rates don't necessarily mean that there has been an increase in the occurrence of breast cancer.

### **Death rates**

The breast cancer death rate shows the frequency of death from breast cancer among women living in a given area during a certain time period (Table 2.1). Like incidence rates, death rates may be calculated for all women or for specific groups of women (e.g. Black/African-American women).

The death rate is calculated as the number of women from a particular geographic area who died from breast cancer divided by the total number of women living in that area. Death rates are shown in terms of 100,000 women and adjusted for age.

Data are included for the annual percent change in the death rate over a five-year period.

The meanings of these data are the same as for incidence rates, with one exception. Changes in screening don't affect death rates in the way that they affect incidence rates. So a negative value, which means that death rates are getting lower, is always desirable. A positive value, which means that death rates are getting higher, is always undesirable.

### **Late-stage incidence rates**

For this report, late-stage breast cancer is defined as regional or distant stage using the Surveillance, Epidemiology and End Results (SEER) Summary Stage definitions (<http://seer.cancer.gov/tools/ssm/>). State and national reporting usually uses the SEER Summary Stage. It provides a consistent set of definitions of stages for historical comparisons.

The late-stage breast cancer incidence rate is calculated as the number of women with regional or distant breast cancer in a particular geographic area divided by the number of women living in that area (Table 2.1). Late-stage incidence rates are shown in terms of 100,000 women and adjusted for age.

**Table 2.1.** Female breast cancer incidence rates and trends, death rates and trends, and late-stage rates and trends

Population Group	Incidence Rates and Trends				Death Rates and Trends			Late-stage Rates and Trends		
	Female Population (Annual Average)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of Deaths (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)
US	154,540,194	182,234	122.1	-0.2%	40,736	22.6	-1.9%	64,590	43.8	-1.2%
HP2020	.	-	-	-	-	20.6*	-	-	41.0*	-
Illinois	6,492,949	9,039	126.4	-0.1%	1,763	23.6	-2.4%	3,341	47.1	0.1%
Iowa	1,525,409	2,241	123.4	1.1%	431	21.3	-2.4%	755	42.7	1.0%
Komen Quad Cities Service Area	277,570	447	130.4	-1.5%	77	20.9	NA	153	46.7	-1.2%
White	256,897	429	130.6	-1.4%	75	21.2	NA	146	46.7	-1.7%
Black/African-American	15,699	13	122.6	2.1%	SN	SN	SN	5	51.9	11.5%
American Indian/Alaska Native (AIAN)	1,226	SN	SN	SN	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	3,748	3	106.8	-12.7%	SN	SN	SN	SN	SN	SN
Non-Hispanic/ Latina	257,584	435	131.6	-1.8%	76	21.3	NA	148	47.1	-1.2%
Hispanic/ Latina	19,986	12	102.2	11.7%	SN	SN	SN	5	38.0	-1.6%
Henry County - IL	25,394	42	123.2	-5.6%	8	21.2	-2.3%	15	45.1	-12.6%
Mercer County - IL	8,389	16	139.8	3.1%	SN	SN	SN	7	60.5	-5.3%
Rock Island County - IL	75,307	122	128.8	-1.6%	21	20.6	-1.9%	41	45.9	0.6%
Whiteside County - IL	29,902	53	134.6	-7.6%	8	18.7	-2.6%	20	53.0	-7.1%
Cedar County - IA	9,294	12	99.0	11.6%	SN	SN	SN	3	28.9	1.5%
Clinton County - IA	25,114	41	128.9	-3.5%	9	26.6	-1.6%	13	45.3	5.8%
Muscatine County - IA	21,401	28	111.5	21.1%	4	17.2	-2.9%	11	45.5	11.3%
Scott County - IA	82,769	133	141.5	-1.8%	22	22.4	-1.7%	44	47.3	1.3%

\*Target as of the writing of this report.

NA – data not available

SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period).

Data are for years 2006-2010.

Rates are in cases or deaths per 100,000.

Age-adjusted rates are adjusted to the 2000 US standard population.

Source of incidence and late-stage data: North American Association of Central Cancer Registries (NAACCR) – Cancer in North America (CINA) Deluxe Analytic File.

Source of death rate data: Centers for Disease Control and Prevention (CDC) – National Center for Health Statistics (NCHS) death data in SEER\*Stat.

Source of death trend data: National Cancer Institute (NCI)/CDC State Cancer Profiles.

### ***Incidence rates and trends summary***

Overall, the breast cancer incidence rate in the Komen Quad Cities service area was higher than that observed in the US as a whole and the incidence trend was lower than the US as a whole. The incidence rate and trend of the Affiliate service area were not significantly different

than that observed for the State of Illinois. The incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of Iowa.

For the United States, breast cancer incidence in Blacks/African-Americans is lower than in Whites overall. The most recent estimated breast cancer incidence rates for Asians and Pacific Islanders (APIs) and American Indians and Alaska Natives (AIANs) were lower than for Non-Hispanic Whites and Blacks/African-Americans. The most recent estimated incidence rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the incidence rate was lower among Blacks/African-Americans than Whites and lower among APIs than Whites. There were not enough data available within the Affiliate service area to report on AIANs so comparisons cannot be made for this racial group. The incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

**Significantly less favorable trends** in breast cancer incidence rates were observed in the following county:

- Muscatine County, IA

The rest of the counties had incidence rates and trends that were not significantly different than the Affiliate service area as a whole.

It's important to remember that an increase in breast cancer incidence could also mean that more breast cancers are being found because more women are getting mammograms.

### ***Death rates and trends summary***

Overall, the breast cancer death rate in the Komen Quad Cities service area was slightly lower 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 Illinois. The death rate of the Affiliate service area was not significantly different than that observed for the State of Iowa.

For the United States, breast cancer death rates in Blacks/African-Americans are substantially higher than in Whites overall. The most recent estimated breast cancer death rates for APIs and AIANs were lower than for Non-Hispanic Whites and Blacks/African-Americans. The most recent estimated death rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African-Americans. There were not enough data available within the Affiliate service area to report on Blacks/African-Americans, APIs, and AIANs so comparisons cannot be made for these racial groups. Also, there were not enough data available within the Affiliate service area to report on Hispanics/Latinas so comparisons cannot be made for this group.

None of the counties in the Affiliate service area had substantially different death rates than the Affiliate service area as a whole or did not have enough data available.

**Late-stage incidence rates and trends summary**

Overall, the breast cancer late-stage incidence rate in the Komen Quad Cities service area was slightly higher than that observed in the US as a whole and the late-stage incidence trend was similar to 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 Illinois. The late-stage incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of Iowa.

For the United States, late-stage incidence rates in Blacks/African-Americans are higher than among Whites. Hispanics/Latinas tend to be diagnosed with late-stage breast cancers more often than Whites. For the Affiliate service area as a whole, the late-stage incidence rate was higher among Blacks/African-Americans than Whites. There were not enough data available within the Affiliate service area to report on APIs and AIANs so comparisons cannot be made for these racial groups. The late-stage incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

None of the counties in the Affiliate service area had substantially different late-stage incidence rates than the Affiliate service area as a whole.

**Mammography Screening**

Getting regular screening mammograms (and treatment if diagnosed) lowers the risk of dying from breast cancer. Screening mammography can find breast cancer early, when the chances of survival are highest. Table 2.2 shows some screening recommendations among major organizations for women at average risk.

**Table 2.2.** Breast cancer screening recommendations for women at average risk\*

American Cancer Society	National Comprehensive Cancer Network	US Preventive Services Task Force
<p>Informed decision-making with a health care provider at age 40</p> <p>Mammography every year starting at age 45</p> <p>Mammography every other year beginning at age 55</p>	<p>Mammography every year starting at age 40</p>	<p>Informed decision-making with a health care provider ages 40-49</p> <p>Mammography every 2 years ages 50-74</p>

\*As of October 2015

Because having regular mammograms lowers the chances of dying from breast cancer, it's important to know whether women are having mammograms when they should. This

information can be used to identify groups of women who should be screened who need help in meeting the current recommendations for screening mammography. The Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factors Surveillance System (BRFSS) collected the data on mammograms that are used in this report. The data come from interviews with women age 50 to 74 from across the United States. During the interviews, each woman was asked how long it has been since she has had a mammogram. The proportions in Table 2.3 are based on the number of women age 50 to 74 who reported in 2012 having had a mammogram in the last two years.

The data have been weighted to account for differences between the women who were interviewed and all the women in the area. For example, if 20.0 percent of the women interviewed are Hispanic/Latina, but only 10.0 percent of the total women in the area are Hispanic/Latina, weighting is used to account for this difference.

The report uses the mammography screening proportion to show whether the women in an area are getting screening mammograms when they should. Mammography screening proportion is calculated from two pieces of information:

- The number of women living in an area whom the BRFSS determines should have mammograms (i.e. women age 50 to 74).
- The number of these women who actually had a mammogram during the past two years.

The number of women who had a mammogram is divided by the number who should have had one. For example, if there are 500 women in an area who should have had mammograms and 250 of those women actually had a mammogram in the past two years, the mammography screening proportion is 50.0 percent.

Because the screening proportions come from samples of women in an area and are not exact, Table 2.3 includes confidence intervals. A confidence interval is a range of values that gives an idea of how uncertain a value may be. It's shown as two numbers—a lower value and a higher one. It is very unlikely that the true rate is less than the lower value or more than the higher value.

For example, if screening proportion was reported as 50.0 percent, with a confidence interval of 35.0 to 65.0 percent, the real rate might not be exactly 50.0 percent, but it's very unlikely that it's less than 35.0 or more than 65.0 percent.

In general, screening proportions at the county level have fairly wide confidence intervals. The confidence interval should always be considered before concluding that the screening proportion in one county is higher or lower than that in another county.

**Table 2.3.** Proportion of women ages 50-74 with screening mammography in the last two years, self-report

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
US	174,796	133,399	77.5%	77.2%-77.7%
Illinois	2,253	1,703	76.4%	74.0%-78.6%
Iowa	2,713	2,106	78.2%	76.2%-80.1%
Komen Quad Cities Service Area	337	266	78.6%	72.4%-83.7%
White	328	259	77.9%	71.8%-83.0%
Black/African-American	SN	SN	SN	SN
AIAN	SN	SN	SN	SN
API	SN	SN	SN	SN
Hispanic/ Latina	SN	SN	SN	SN
Non-Hispanic/ Latina	329	259	77.9%	71.7%-83.0%
Henry County - IL	20	13	57.0%	31.8%-79.0%
Mercer County - IL	SN	SN	SN	SN
Rock Island County - IL	31	23	76.8%	53.4%-90.5%
Whiteside County - IL	13	11	94.3%	59.8%-99.5%
Cedar County - IA	31	24	85.9%	66.2%-94.9%
Clinton County - IA	53	40	73.2%	55.4%-85.7%
Muscatine County - IA	56	45	86.9%	70.2%-94.9%
Scott County - IA	131	108	87.3%	78.5%-92.8%

SN – data suppressed due to small numbers (fewer than 10 samples).

Data are for 2012.

Source: CDC – Behavioral Risk Factor Surveillance System (BRFSS).

### ***Breast cancer screening proportions summary***

The breast cancer screening proportion in the Komen Quad Cities 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 Illinois and was not significantly different than the State of Iowa.

For the United States, breast cancer screening proportions among Blacks/African-Americans are similar to those among Whites overall. APIs have somewhat lower screening proportions than Whites and Blacks/African-Americans. Although data are limited, screening proportions among AIANs are similar to those among Whites. Screening proportions among Hispanics/Latinas are similar to those among Non-Hispanic Whites and Blacks/African-Americans. There were not enough data available within the Affiliate service area to report on Blacks/African-Americans, APIs, and AIANs so comparisons cannot be made for these racial groups. Also, there were not enough data available within the Affiliate service area to report on Hispanics/Latinas so comparisons cannot be made for this group.

None of the counties in the Affiliate service area had substantially different screening proportions than the Affiliate service area as a whole.

### **Population Characteristics**

The report includes basic information about the women in each area (demographic measures) and about factors like education, income, and unemployment (socioeconomic measures) in the areas where they live (Tables 2.4 and 2.5). Demographic and socioeconomic data can be used to identify which groups of women are most in need of help and to figure out the best ways to help them.

It is important to note that the report uses the race and ethnicity categories used by the US Census Bureau, and that race and ethnicity are separate and independent categories. This means that everyone is classified as both a member of one of the four race groups as well as either Hispanic/Latina or Non-Hispanic/Latina.

The demographic and socioeconomic data in this report are the most recent data available for US counties. All the data are shown as percentages. However, the percentages weren't all calculated in the same way.

- The race, ethnicity, and age data are based on the total female population in the area (e.g. the percent of females over the age of 40).
- The socioeconomic data are based on all the people in the area, not just women.
- Income, education and unemployment data don't include children. They're based on people age 15 and older for income and unemployment and age 25 and older for education.
- The data on the use of English, called "linguistic isolation", are based on the total number of households in the area. The Census Bureau defines a linguistically isolated household as one in which all the adults have difficulty with English.

**Table 2.4.** Population characteristics – demographics

Population Group	White	Black /African-American	AIAN	API	Non-Hispanic /Latina	Hispanic /Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
US	78.8 %	14.1 %	1.4 %	5.8 %	83.8 %	16.2 %	48.3 %	34.5 %	14.8 %
Illinois	78.2 %	16.0 %	0.7 %	5.2 %	84.7 %	15.3 %	47.6 %	33.9 %	14.4 %
Iowa	94.1 %	3.4 %	0.5 %	2.0 %	95.2 %	4.8 %	49.6 %	36.8 %	16.9 %
Komen Quad Cities Service Area	92.0 %	5.9 %	0.5 %	1.5 %	92.2 %	7.8 %	51.6 %	38.6 %	17.4 %
Cedar County - IA	98.7 %	0.6 %	0.2 %	0.6 %	98.6 %	1.4 %	54.6 %	39.9 %	18.9 %
Clinton County - IA	95.8 %	3.1 %	0.4 %	0.7 %	97.7 %	2.3 %	53.6 %	40.3 %	18.8 %
Muscatine County - IA	96.6 %	1.8 %	0.6 %	1.0 %	84.3 %	15.7 %	49.3 %	35.8 %	15.6 %
Scott County - IA	89.1 %	8.0 %	0.5 %	2.4 %	94.7 %	5.3 %	48.6 %	35.4 %	14.8 %
Henry County - IL	97.1 %	2.0 %	0.3 %	0.6 %	95.3 %	4.7 %	54.7 %	41.4 %	19.4 %
Mercer County - IL	99.0 %	0.4 %	0.1 %	0.5 %	98.0 %	2.0 %	56.5 %	42.0 %	20.1 %
Rock Island County - IL	87.6 %	9.9 %	0.7 %	1.9 %	88.6 %	11.4 %	52.0 %	39.8 %	18.4 %
Whiteside County - IL	96.8 %	2.0 %	0.5 %	0.7 %	89.3 %	10.7 %	54.5 %	41.6 %	19.9 %

Data are for 2011.

Data are in the percentage of women in the population.

Source: US Census Bureau – Population Estimates

**Table 2.5. Population characteristics – socioeconomics**

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistic-ally Isolated	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age: 40-64)
US	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
Illinois	13.4 %	13.1 %	30.1 %	9.3 %	13.7 %	5.3 %	11.5 %	16.2 %	15.2 %
Iowa	9.7 %	11.9 %	27.6 %	5.5 %	4.2 %	1.6 %	36.0 %	10.9 %	9.4 %
Komen Quad Cities Service Area	11.5 %	12.1 %	30.1 %	6.7 %	4.1 %	1.6 %	25.6 %	9.5 %	11.0 %
Cedar County - IA	7.7 %	7.8 %	22.4 %	3.5 %	0.9 %	0.2 %	83.4 %	0.0 %	8.2 %
Clinton County - IA	10.3 %	11.8 %	30.7 %	7.0 %	1.4 %	0.7 %	32.2 %	3.3 %	8.4 %
Muscatine County - IA	14.5 %	13.9 %	29.3 %	8.0 %	6.4 %	1.8 %	25.6 %	0.0 %	9.9 %
Scott County - IA	8.8 %	12.8 %	27.0 %	5.6 %	3.4 %	1.2 %	13.5 %	16.0 %	9.3 %
Henry County - IL	12.3 %	10.2 %	28.4 %	5.9 %	2.2 %	0.9 %	50.3 %	20.0 %	12.2 %
Mercer County - IL	11.9 %	9.5 %	27.7 %	5.7 %	0.7 %	0.1 %	77.8 %	0.0 %	11.1 %
Rock Island County - IL	13.2 %	12.4 %	34.3 %	7.7 %	6.9 %	3.0 %	10.9 %	0.0 %	13.4 %
Whiteside County - IL	13.5 %	11.7 %	33.3 %	8.0 %	3.0 %	1.1 %	37.3 %	23.8 %	13.0 %

Data are in the percentage of people (men and women) in the population.

Source of health insurance data: US Census Bureau – Small Area Health Insurance Estimates (SAHIE) for 2011.

Source of rural population data: US Census Bureau – Census 2010.

Source of medically underserved data: Health Resources and Services Administration (HRSA) for 2013.

Source of other data: US Census Bureau – American Community Survey (ACS) for 2007-2011.

### **Population characteristics summary**

Proportionately, the Komen Quad Cities service area has a substantially larger White female population than the US as a whole, a substantially smaller Black/African-American female population, a substantially smaller Asian and Pacific Islander (API) female population, a slightly smaller American Indian and Alaska Native (AIAN) female population, and a substantially smaller Hispanic/Latina female population. The Affiliate’s female population is slightly older than that of the US as a whole. The Affiliate’s education level is slightly higher than and income level is slightly higher than those of the US as a whole. There are a slightly smaller percentage of people who are unemployed in the Affiliate service area. The Affiliate service area has a substantially smaller percentage of people who are foreign born and a substantially smaller percentage of people who are linguistically isolated. There are a substantially larger percentage of people living in rural areas, a substantially smaller percentage of people without health insurance, and a substantially smaller percentage of people living in medically underserved areas.

The following county has substantially larger Hispanic/Latina female population percentages than that of the Affiliate service area as a whole:

- Muscatine County, IA

## **Priority Areas**

### ***Healthy People 2020 forecasts***

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 as of the writing of this report: 20.6 cases per 100,000 women).
- Reducing the number of breast cancers that are found at a late-stage (Target as of the writing of this report: 41.0 cases per 100,000 women).

To see how well counties in the Komen Quad Cities service area are progressing toward these targets, the report uses the following information:

- County breast cancer death rate and late-stage diagnosis data for years 2006 to 2010.
- Estimates for the trend (annual percent change) in county breast cancer death rates and late-stage diagnoses for years 2006 to 2010.
- Both the data and the HP2020 target are age-adjusted.

These data are used to estimate how many years it will take for each county to meet the HP2020 objectives. Because the target date for meeting the objective is 2020, and 2008 (the middle of the 2006-2010 period) was used as a starting point, a county has 12 years to meet the target.

Death rate and late-stage diagnosis data and trends are used to calculate whether an area will meet the HP2020 target, assuming that the trend seen in years 2006 to 2010 continues for 2011 and beyond.

### ***Identification of priority areas***

The purpose of this report is to combine evidence from many credible sources and use the data to identify the highest priority areas for breast cancer programs (i.e. the areas of greatest need). Classification of priority areas are based on the time needed to achieve HP2020 targets in each area. These time projections depend on both the starting point and the trends in death rates and late-stage incidence.

Late-stage incidence reflects both the overall breast cancer incidence rate in the population and the mammography screening coverage. 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.

There has not been any indication that either one of the two HP2020 targets is more important than the other. Therefore, the report considers them equally important.

Counties are classified as follows (Table 2.6):

- Counties that are not likely to achieve either of the HP2020 targets are considered to have the highest needs.
- Counties that have already achieved both targets are considered to have the lowest needs.
- Other counties are classified based on the number of years needed to achieve the two targets.

**Table 2.6.** Needs/priority classification based on the projected time to achieve HP2020 breast cancer targets

		Time to Achieve Late-stage Incidence Reduction Target				
		13 years or longer	7-12 yrs.	0 – 6 yrs.	Currently meets target	Unknown
Time to Achieve Death Rate Reduction Target	13 years or longer	Highest	High	Medium High	Medium	Highest
	7-12 yrs.	High	Medium High	Medium	Medium Low	Medium High
	0 – 6 yrs.	Medium High	Medium	Medium Low	Low	Medium Low
	Currently meets target	Medium	Medium Low	Low	Lowest	Lowest
	Unknown	Highest	Medium High	Medium Low	Lowest	Unknown

If the time to achieve a target cannot be calculated for one of the HP2020 indicators, then the county is classified based on the other indicator. If both indicators are missing, then the county is not classified. This doesn't mean that the county may not have high needs; it only means that sufficient data are not available to classify the county.

**Affiliate Service Area Healthy People 2020 Forecasts and Priority Areas**

The results presented in Table 2.7 help identify which counties have the greatest needs when it comes to meeting the HP2020 breast cancer targets.

- For counties in the “13 years or longer” category, current trends would need to change to achieve the target.
- Some counties may currently meet the target but their rates are increasing and they could fail to meet the target if the trend is not reversed.

Trends can change for a number of reasons, including:

- Improved screening programs could lead to breast cancers being diagnosed earlier, resulting in a decrease in both late-stage incidence rates and death rates.
- Improved socioeconomic conditions, such as reductions in poverty and linguistic isolation could lead to more timely treatment of breast cancer, causing a decrease in death rates.

The data in this table should be considered together with other information on factors that affect breast cancer death rates such as screening percentages and key breast cancer death determinants such as poverty and linguistic isolation.

**Table 2.7.** Intervention priorities for Komen Quad Cities service area with predicted time to achieve the HP2020 breast cancer targets and key population characteristics

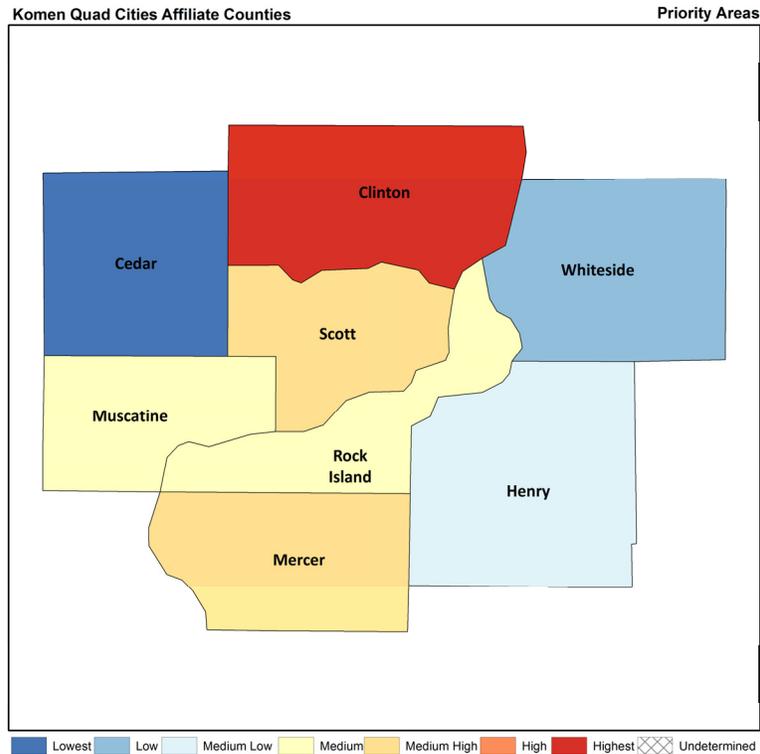
County	Priority	Predicted Time to Achieve Death Rate Target	Predicted Time to Achieve Late-stage Incidence Target	Key Population Characteristics
Clinton County - IA	Highest	13 years or longer	13 years or longer	Rural
Mercer County - IL	Medium High	SN	8 years	Rural
Scott County - IA	Medium High	5 years	13 years or longer	Medically underserved
Rock Island County - IL	Medium	Currently meets target	13 years or longer	
Muscatine County - IA	Medium	Currently meets target	13 years or longer	%Hispanic/Latino
Henry County - IL	Medium Low	2 years	1 year	Rural, medically underserved
Whiteside County - IL	Low	Currently meets target	4 years	Rural, medically underserved
Cedar County - IA	Lowest	SN	Currently meets target	Rural

NA – data not available.

SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period).

### **Map of Intervention Priority Areas**

Figure 2.1 shows a map of the intervention priorities for the counties in the Affiliate service area. When both of the indicators used to establish a priority for a county are not available, the priority is shown as “undetermined” on the map.



**Figure 2.1.** Intervention priorities

### Data Limitations

The following data limitations need to be considered when utilizing the data of the Quantitative Data Report:

- The most recent data available were used but, for cancer incidence and deaths, these data are still several years behind.
- For some areas, data might not be available or might be of varying quality.
- Areas with small populations might not have enough breast cancer cases or breast cancer deaths each year to support the generation of reliable statistics.
- There are often several sources of cancer statistics for a given population and geographic area; therefore, other sources of cancer data may result in minor differences in the values even in the same time period.
- Data on cancer rates for specific racial and ethnic subgroups such as Somali, Hmong, or Ethiopian are not generally available.
- The various types of breast cancer data in this report are inter-dependent.
- There are many factors that impact breast cancer risk and survival for which quantitative data are not available. Some examples include family history, genetic markers like HER2 and BRCA, other medical conditions that can complicate treatment, and the level of family and community support available to the patient.
- The calculation of the years needed to meet the HP2020 objectives assume that the current trends will continue until 2020. However, the trends can change for a number of reasons.
- Not all breast cancer cases have a stage indication.

## **Quantitative Data Report Conclusions**

### ***Highest priority areas***

One county in the Komen Quad Cities service area is in the highest priority category. Clinton County, IA is not likely to meet either the death rate or late-stage incidence rate HP2020 targets. The death rates in Clinton County, IA (26.6 per 100,000) appear to be higher than the Affiliate service area as a whole (20.9 per 100,000) although not significantly. The late-stage incidence trends in Clinton County, IA (5.8 percent per year) indicate that late-stage incidence rates may be increasing.

In Clinton County, IA a relatively large proportion of the population is living in rural areas.

### ***Medium high priority areas***

Two counties in the Komen Quad Cities service area are in the medium high priority category. One of the two, Scott County, IA, is not likely to meet the late-stage incidence rate HP2020 target. One of the two, Mercer County, IL is expected to take eight years to reach the late-stage incidence rate HP2020 target.

The incidence rates in both Mercer County, IL (139.8 per 100,000) and Scott County, IA (141.5 per 100,000) appear to be higher than the Affiliate service area as a whole (130.4 per 100,000) although not significantly. The late-stage-incidence rates in Mercer County, IL (60.5 per 100,000) appear to be higher than the Affiliate service area as a whole (46.7 per 100,000) although not significantly.

In Mercer County, IL, a relatively large proportion of the population is living in rural areas. In Scott County, IA, a relatively large proportion of the population is living in medically underserved areas.

## **Selection of Target Communities**

In order to be the most efficient stewards of resources, Susan G. Komen Quad Cities has chosen three target counties within the service area to focus efforts over the next four years. Target counties are those which have cumulative key indicators showing an increased chance of vulnerable populations likely at risk for experiencing gaps in breast health services and/or barriers in access to care.

When selecting target communities, Komen Quad Cities reviewed Healthy People 2020, a major federal government initiative that provides specific health objectives for communities and the country as a whole. Through this review, as well as utilizing the Quantitative Data Report for the Komen Quad Cities' service area, areas of priority were identified based on the time needed to meet the Healthy People 2020 targets for breast cancer.

Key indicators the Affiliate reviewed when selecting target counties included:

- Incidence Rates
- Death Rates

- Later-Stage diagnosis
- Mammography screening percentages
- Demographic and socioeconomic measures

The selected target communities are:

- Clinton County, Iowa
- Muscatine County, Iowa
- Mercer County, Illinois

Out of the Affiliate’s entire eight-county service area, Clinton and Muscatine Counties were shown to be of the highest or high priority in one of the key areas. Mercer County was included in the analysis because of poor key indicators. Scott County was listed as a Medium High priority and forecasted as not likely to meet the late-stage incidence rate HP2020 target. Despite this indication, the Affiliate chose to not add Scott County as a target community due to the fact that it is a more populous area that has more access to care compared to most of the service area.

**Clinton County, Iowa**

The death rates in Clinton County are higher than the Affiliate’s service area as a whole at 26.6 (Table 2.8). At this current rate, the county is likely to miss the HP2020 death rate target. Age-adjusted late-stage cancer rates are slightly lower in Clinton County at 45.3; however, the late-stage diagnosis rate has a positive trend which is undesirable. The percentage of the population in Clinton County that has an income below 250 percent of the federal poverty level is 30.7 percent compared to 30.1 percent for the Affiliate and 27.6 percent for Iowa. The population of Clinton County is 32.2 percent rural. People in rural areas may face more barriers to accessing quality health care, such as transportation issues.

**Table 2.8.** Clinton County breast cancer statistics

	<b>Clinton County</b>	<b>Affiliate Service Area Rate</b>	<b>US Rate</b>
Incidence Rate*	128.9	130.4	122.1
Death Rate*	26.6	20.9	22.6
Late-stage Rates*	45.3	46.7	43.8

\*Rates are age-adjusted and are figured per 100,000 women

**Muscatine County, Iowa**

Muscatine County has a rising late-stage diagnosis rate of 45.5. As a result of this growing trend, the county is unlikely to meet the HP2020 target for late-stage incidence. The population in Muscatine County that has less than a high school education is at 14.5 percent compared to the Affiliate level of 11.5 percent. Muscatine County has an elevated unemployment level at eight percent, and a substantially higher Hispanic/Latina population than the Affiliate service area at 15.7 percent. Research shows that women from minority and medically underserved populations are more likely to be diagnosed with advanced or late-stage breast cancer, likely due to the socioeconomic factors mentioned above and certain biological factors that affect Hispanic/Latina women.

## **Mercer County, IL**

Mercer County is somewhat similar to Muscatine County in demographic makeup; however, the female population is smaller and as such there are too few deaths to provide statistical information. The late-stage diagnosis age-adjusted rate of 60.5 is higher than the Affiliate level, yet is trending downward annually (Table 2.9). The population in Mercer County that has less than a high school education is 11.9 percent. The population of Mercer County is 77.8 percent rural and 11.1 percent of residents age 40-64 have no health insurance. These socioeconomic factors in addition to the larger proportion of residents living in rural areas put Mercer County at risk of not meeting the HP2020 target for late-stage incidence.

**Table 2.9.** Mercer County breast cancer statistics

	<b>Mercer County</b>	<b>Affiliate Service Area Rate</b>	<b>US Rate</b>
Incidence Rate*	139.8	130.4	122.1
Death Rate*	SN	20.9	22.6
Late-stage Rates*	60.5	46.7	43.8

\*Rates are age-adjusted and are figured per 100,000 women

SN: data suppressed due to small numbers (15 cases or fewer for the 5-year data period)

In the Health Systems and Public Policy Analysis section, the Affiliate will further explore barriers to quality breast health care in these target communities.

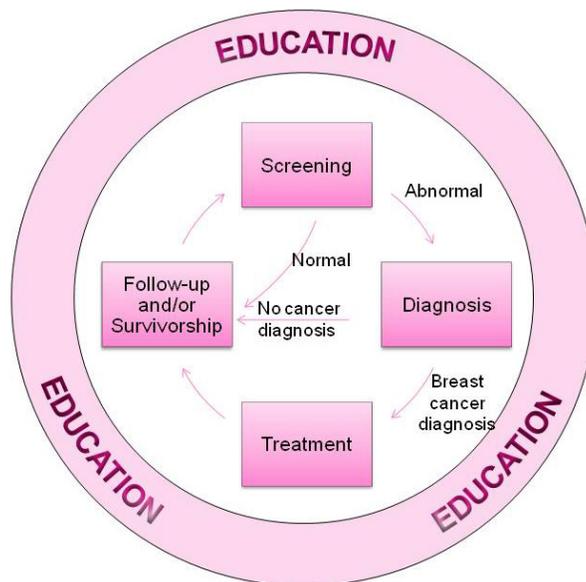
# Health Systems and Public Policy Analysis

## Health Systems Analysis Data Sources

Komen Quad Cities used several sources to create a comprehensive inventory of the breast cancer programs and services in the three target counties for the Health Systems Analysis. Initially, the Affiliate looked to past and current grantees by utilizing the Grants eManagement System (GeMS), the program that all Komen Affiliates use to grant funds for both Community Grants and Small Grants. Next the Affiliate used the FDA Certified Mammography Facilities website to list mammography centers within the target areas (<http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMQSA/mqsa.cfm>). Then the Health Resources and Services Administrations (HRSA) website was searched for community health centers ([http://findahealthcenter.hrsa.gov/Search\\_HCC.aspx](http://findahealthcenter.hrsa.gov/Search_HCC.aspx)); however, none were found within the target areas. Similarly, there were no results for free clinics in the target areas when searching the National Association of Free and Charitable Clinics website (<http://www.nafclinics.org/clinics/search>). Finally, the Affiliate performed Google searches to find any providers or support groups that fell in the follow-up and survivorship category of the Continuum of Care.

## Health Systems Overview

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 (Figure 3.1). 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.



**Figure 3.1.** Breast Cancer Continuum of Care (CoC)

While a woman may enter the continuum at any point, ideally, a woman would enter the CoC by getting screened for breast cancer with a clinical breast exam or a screening mammogram. If

the screening test results are normal, she would loop back into follow-up care, where she would get another screening exam at the recommended interval. Education plays a role in both providing education to encourage women to get screened and reinforcing the need to continue to get screened routinely thereafter.

If a screening exam resulted in abnormal results, diagnostic tests would be needed, possibly several, to determine if the abnormal finding is in fact breast cancer. These tests might include a diagnostic mammogram, breast ultrasound or biopsy. If the tests were negative (or benign) and breast cancer was not found, she would go into the follow-up loop, and return for screening at the recommended interval. The recommended intervals may range from three to six months for some women to 12 months for most women. Education plays a role in communicating the importance of proactively getting test results, keeping follow-up appointments and understanding what it all means. Education can empower a woman and help manage anxiety and fear.

If breast cancer is diagnosed, she would proceed to treatment. Education can cover such topics as treatment options, how a pathology reports determines the best options for treatment, understanding side effects and how to manage them, and helping to formulate questions a woman may have for her providers.

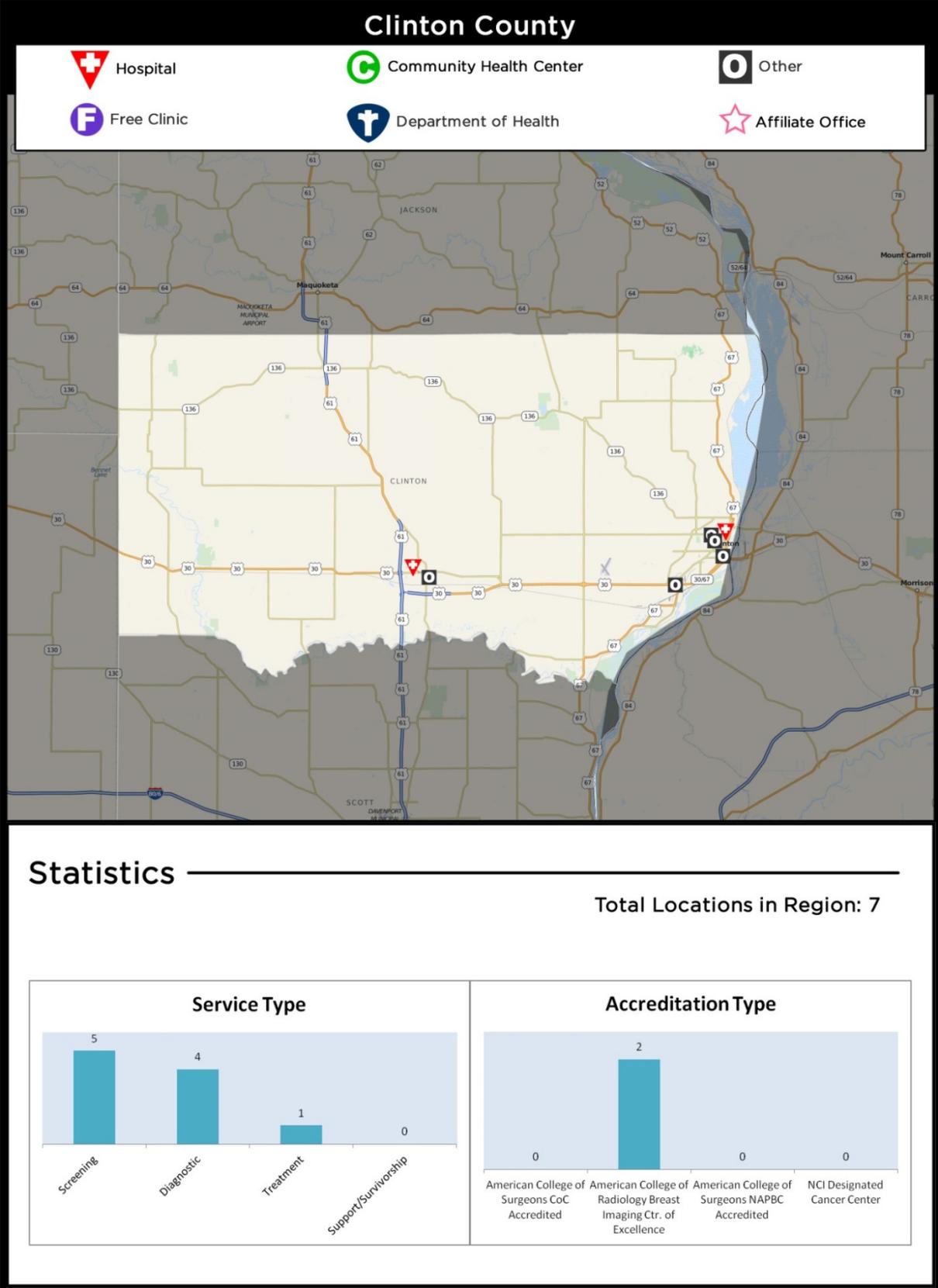
For some breast cancer patients, treatment may last a few months and for others, it may last years. While the CoC model shows that follow up and survivorship come after treatment ends, they actually may occur at the same time. Follow up and survivorship may include things like navigating insurance issues, locating financial assistance, symptom management, such as pain, fatigue, sexual issues, bone health, etc. Education may address topics such as making healthy lifestyle choices, long term effects of treatment, managing side effects, the importance of follow-up appointments and communication with their providers. Most women will return to screening at a recommended interval after treatment ends, or for some, during treatment (such as those taking long term hormone therapy).

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.

The Affiliate looked at providers across the CoC in each of the chosen target communities. There are three target communities identified in the Komen Quad Cities' Health Systems Analysis: Clinton and Muscatine Counties in Iowa and Mercer County in Illinois.

## **Clinton County**

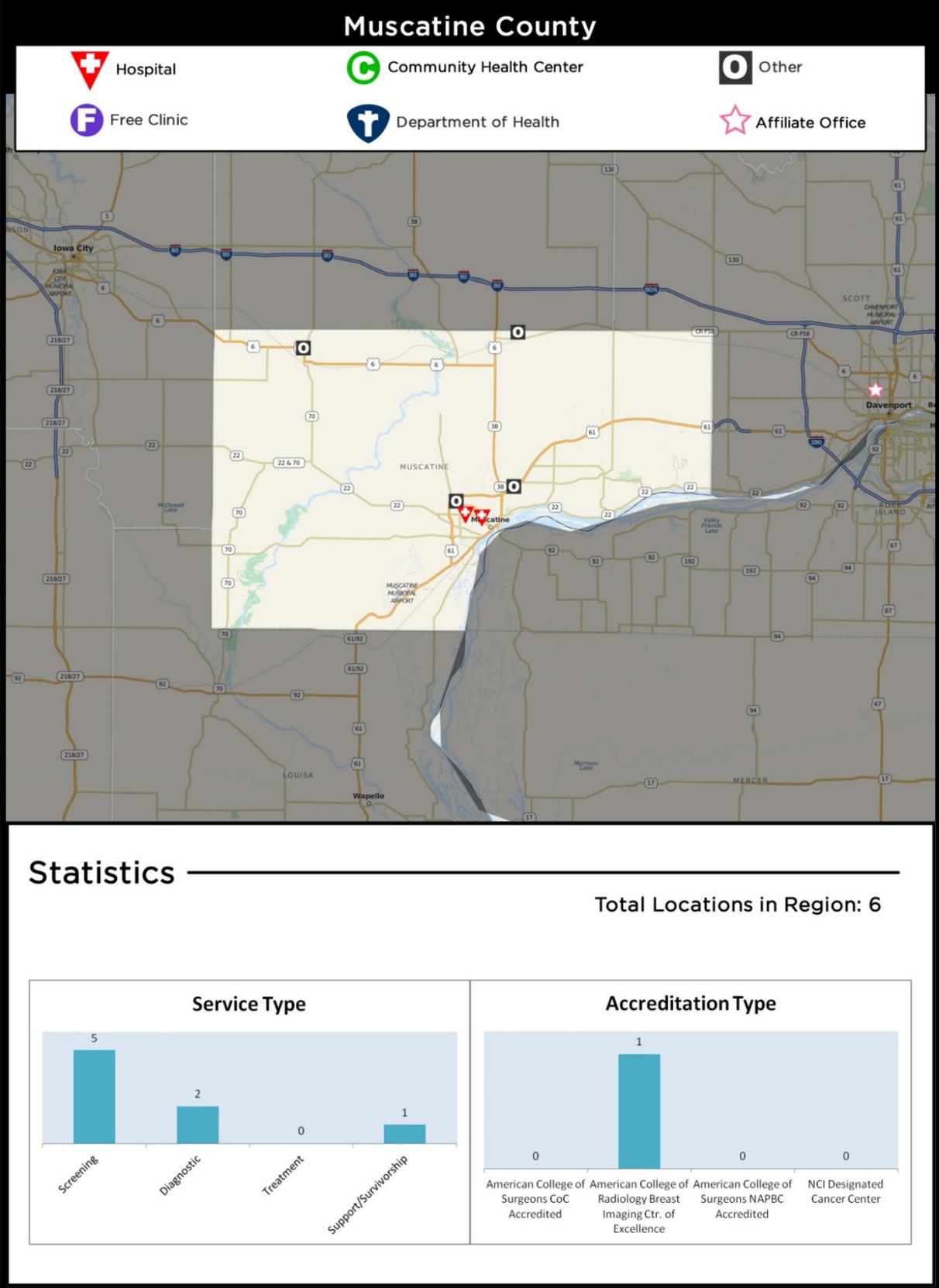
There are several providers that participate in the Iowa Breast and Cervical Cancer Early Detection Program, known as Care for Yourself (CFY), in Clinton County. The CFY Coordinator (Dona Bark, RN) for Clinton, Jackson and Scott Counties is located in Clinton, Iowa and is a resource to individuals in need as they proceed through the CoC. Many of the assets listed within Clinton County are participants in the CFY program in conjunction with the Voucher Program, a past and current grantee of Komen Quad Cities, which provide both screening and diagnostic services for women in need. However, there are little to no treatment or support/survivorship services provided for breast cancer patients in Clinton County, leaving the closest option to be for individuals to go to the Quad Cities (Scott County) (Figure 3.2). The physical distance, as well as transportation issues, may serve as the barrier for the county's rural population, who might choose to forgo treatment or support services if they are unable to more readily access quality health care.



**Figure 3.2.** Breast cancer services available in Clinton County

### **Muscatine County**

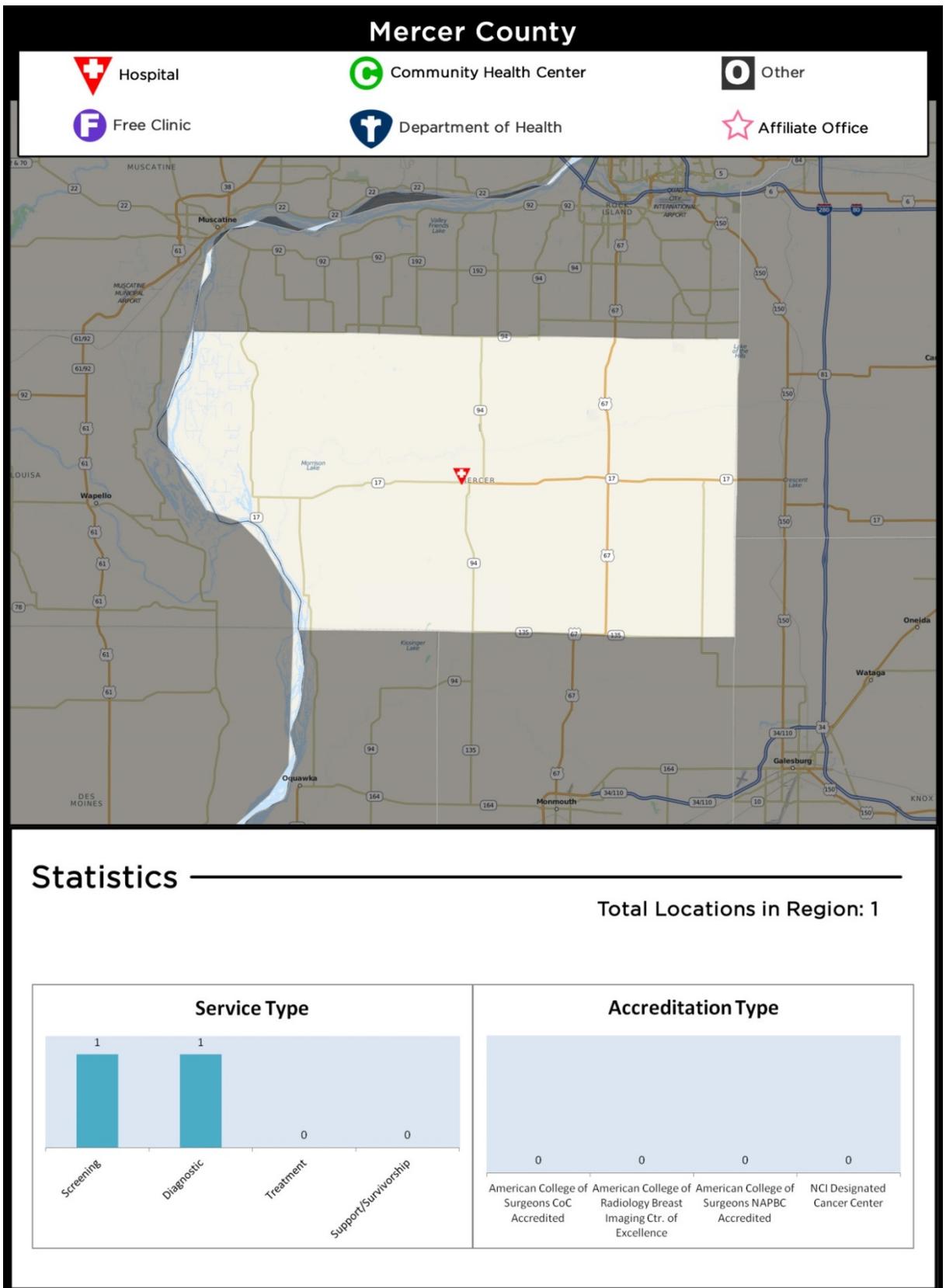
The CFY Coordinator for Muscatine County, Lisa Heisdorffer, is located in Washington County. Similarly to Clinton County, many of the providers in Muscatine County are participants of the CFY and Voucher Programs to provide financial assistance for uninsured and underinsured women. Also similarly to Clinton County, there is little available for treatment. Individuals in need must travel to either the Quad Cities or Iowa City for treatment of their breast cancer (Figure 3.3). In terms of support services, Komen Quad Cities has granted funds to Gilda's Club Quad Cities to provide education information on breast health, screening, care, and available resources for breast cancer patients and survivors, geared specifically for the Hispanic/Latino population which is substantially higher in Muscatine County. Providing the resources and support for this target population will help to ultimately bring down the rising late-stage diagnosis rate in the county (Table 2.1).



**Figure 3.3.** Breast cancer services available in Muscatine County

**Mercer County**

The Rock Island County Health Department is the lead agency that serves Mercer County for the Illinois Breast and Cervical Cancer Program. Karri Williams, RN is the coordinator. Mercer County has very little resources available that fall into the CoC (Figure 3.4). Genesis Medical Center in Aledo is the only facility in the county that individuals can go to for screening and diagnostic services; however, patients are required to travel considerable distances for any treatment and support services. This becomes extremely problematic for individuals without money or access to transportation for the nearly 80 percent of rural residents that reside in the county. Without resources to aid in the transportation or facilitation of much needed treatment and support services, Mercer County is unlikely to meet the HP2020 target for late-stage breast cancer incidence.



**Figure 3.4.** Breast cancer services available in Mercer County

## **Public Policy Overview**

### **Iowa Breast and Cervical Cancer Early Detection Program**

The Iowa Breast and Cervical Cancer Early Detection Program, known as the *Care for Yourself Program*, is administered by the Iowa Department of Public Health (IDPH) within the Bureau of Chronic Disease Prevention and Management. The program is funded primarily through a cooperative agreement with Centers for Disease Control and Prevention. The Iowa program just entered its 3<sup>rd</sup> year of a 5-year project period within the cooperative agreement with the CDC. The program also administers funding from Komen Iowa for breast cancer screening within the NBCCEDP framework. The program is organized under the following components of the NBCCEDP:

- Partnerships, coordination, collaboration
- Public education and targeted outreach
- Screening, diagnostics, and patient navigation services
- Quality assurance & quality improvement
- Professional development
- Data management and utilization
- Program monitoring and evaluation

Enrollment for breast and cervical cancer screening services within BCCEDP can occur by several means. The IDPH contracts with 27 local boards of health across the state to provide local opportunities for enrollment of eligible women. This enables women to have a trusted local contact for enrollment, service access and case management. IDPH offers information on its website for women who are seeking to enroll in the program (<http://www.idph.state.ia.us/CFY/Public.aspx>). The website holds an interactive map that will guide women to the local enrollment contact nearest their home. Another means for enrollment is phone contact through the Healthy Families Line, 1-866-227-9878, a program of Iowa State University Extension Services. The Healthy Families Line is contracted to provide 24-hour, 7-days a week telephone answering and referral to interested women.

The program prides itself on efforts to ensure that once enrolled in the program, women are contacted annually through a mailed rescreening reminder letter. Other efforts include local outreach to health care provider facilities and social marketing initiatives that lead to the initial referral to the program. Enrollment guidelines for BCCEDP include that a woman must: be between the ages of 40-64 years of age; be 65 years old or older and without Medicare Part B coverage; be under 40 years old and have a breast lump or other signs of breast cancer; and meet the state income requirements which is set at 250 percent of the Federal Poverty Guideline. Women may be uninsured or underinsured. The most recent rules of the Iowa Care For Yourself Program can be found starting on page 1026 of the Iowa Administrative Bulletin (Feb. 8, 2012): <https://www.legis.iowa.gov/docs/aco/bulletin/02-08-2012.pdf>.

If a woman has been diagnosed with a breast cancer, a precancerous cervical condition or cervical cancer, and has no creditable insurance coverage, she may apply for services under the Iowa Breast and Cervical Cancer Prevention and Treatment Act Medicaid Option. Iowa has

three mechanisms for women to gain access to the BCCT Medicaid Option: 1) an individual may be screened through the Care for Yourself Program; 2) an individual may be screened with funds provided by Susan G. Komen®; and 3) an individual may be screened with funds paid by a nonprofit entity.

To facilitate ease in gaining presumptive eligibility for treatment services, IDPH has its local program contractors assist women served by the BCCEDP with signing up for BCCT coverage. All women seeking treatment services through these mechanisms must meet the eligibility requirements as established by the Care for Yourself Program. Through legislative action, and beginning January 1, 2014, eligible persons diagnosed in a free-clinic/nonprofit clinic (regardless of screening through BCCEDP or with Komen funding) could be deemed eligible for treatment through the BCCT. Although there are no age requirements for treatment through the BCCT in Iowa, the income guideline for the program is 250 percent of the Federal Poverty Guideline.

The main aspect of the working relationship between the state BCCEDP and Medicaid in Iowa is focused on the determination of the eligibility for the BCCT. Iowa Medicaid Enterprise is the Medicaid agency in the state. IDPH BCCEDP staff person, Jolene Carver, Care for Yourself Health Service Coordinator, is the administrator for the department's role with BCCT eligibility determination. She collaborates with the Iowa Medicaid Enterprise staff regarding the administration of the BCCT across the state.

Komen Quad Cities has recently engaged in the Iowa Cancer Consortium, a collective of entities, organizations and individuals working to reduce the burden of cancer across the state through the continuum of care approach. The Affiliate plans to strengthen the relationship with ICC to work together on projects that mutually benefit the work of the Affiliate and the program with its contractors in the Komen Quad Cities service area. Thanks to Komen Iowa and their collaboration with the State of Iowa, Komen Quad Cities receives funds (special fees) raised through the sale of breast cancer license plates, and puts them to use in supporting screening activity for men and women. Over the next four years Komen Quad Cities plans to become more actively engaged in the state BCCEDP program by attending a regional BCCEDP meeting with its contractors that is held annually.

### **Illinois Breast and Cervical Cancer Early Detection Program**

The Illinois Breast and Cervical Cancer Early Detection Program (IBCCP) is supported through both State General Revenue (approximately \$12m) and Federal funds (approximately \$6m). While both funds have declined over recent years, the IBCCP has long benefited from a substantial amount of State General Revenue funds. The program is administered by the Office of Women's Health (OWH) at the Illinois Department of Public Health (IDPH). Services are provided through a network of about 34 Lead agencies that offer services to eligible women in all 102 Illinois counties. To receive IBCCP services, you must live in Illinois, be without insurance, have an income under 250 percent FPL and be 35-64 years of age (although younger women may in some cases be eligible). The program caseload for 2014 is projected to be approximately 27,500 women, with three percent of women screened having cancer. The

cumulative percentage of women screened through the IBCCP identifying as Hispanic/Latina (all races) was 22.1 percent, Black/African-American was 23.3 percent and Asian was 7.0 percent (information from the IBCCP FOIA request dated March 24, 2014).

The IBCCP is in the middle of a five-year funding project period with the Centers for Disease Control and Prevention (CDC). Due to declining State and Federal funding over the last five years, the IBCCP caseload has steadily declined. The program achieved its highest caseload numbers (just under 40,000 women) in 2011. The 2012 Census estimates that currently there are 310,362 uninsured women 40-64 years of age in Illinois. The IBCCP has never been able to serve more than 14.4 percent of the eligible population, even with State and Federal funding. The program uses Cook County Medicare reimbursement rates for services statewide. The average cost per woman served in FY 14 was \$511 (FOIA March 24, 2014). The rate of abnormal screening results has been on the rise (largely due to the need for Priority Lists which are discussed later) to 27.2 percent in FY2013.

To accommodate the steady reduction in grant funds over the years, the IBCCP implemented a “priority list” process that most lead agencies have needed to initiate at some point each fiscal year in order to stay within the grant award limit. Complete guidelines are available through the IBCCP Policy and Procedure Manual Revised 2014; however, immediate service has been directed to current IBCCP women with a history of abnormal results or women referred-in with documented symptoms on a Clinical Breast Exam, screening mammogram or pap. The IBCCP has maintained a priority list for many years, with 7,000 women on the priority list at the start of this fiscal year. Efforts are underway to introduce eligible women to services through ACA. Women can enroll in IBCCP through the following means:

- Call the Women’s Health Line at 888-522-1282 where an operator will walk through the eligibility requirements and screening process and link them with an area provider
- Contact the local IBCCP program provider and schedule an appointment. Information is available through their website at <http://cancerscreening.illinois.gov/howToApply.htm>

Women screened through IBCCP who test positive for breast cancer or uninsured women diagnosed through other external means and contact the IBCCP for assistance are referred to Illinois Medicaid for treatment. Medicaid is administered through a separate state agency, Illinois Health Care and Family Services (HFS). They are responsible for administering the Illinois Treatment Act.

In the next four years Komen Quad Cities will strengthen ties with Komen Memorial in their efforts to meet bi-annually with the IBCCP program staff to obtain program updates and demonstrate its interest and support in the program and additionally build relationships with new OWH/IBCCP staff. Additionally, the Affiliate hopes to participate in the annual Illinois Office of Women’s Health Statewide Conference to educate and illustrate its support of IBCCP providers. Finally, in an effort to remain “one voice”, Komen Quad Cities will plan to meet with the other

Affiliates serving Illinois counties to determine a uniform policy message for all to follow in the years ahead.

### **Iowa Comprehensive Cancer Control Coalition**

The Iowa Cancer Plan is the state's comprehensive cancer control plan to provide direction for those involved in the planning, implementation, and evaluation of cancer control programs, research and policy initiatives. It is also a resource for all Iowans looking for support and advocacy. The objectives fall in line with the Continuum of Care model and are strengthened by the partnerships and collaborations around the state.

The Iowa Cancer Plan sets forth four goals with respect to breast cancer:

1. Whenever possible, prevent cancer from occurring.
2. If cancer does occur, find it in its earliest stages.
3. Improve the accessibility, availability, and quality of breast cancer treatment services and programs.
4. Ensure optimal quality of life for people impacted by cancer.

Komen Quad Cities is committed to the mission of the state cancer coalition: to reduce cancer incidence and death in Iowa through collaborative efforts that provide services and programs directed toward comprehensive cancer prevention and control. The issues faced by many of the partners of the Iowa Cancer Plan are in line with the work done at Komen Quad Cities and the four Iowa counties it serves. Over-arching issues critical to success include: Collaboration, Health Disparities, Health Equity, Policy and Systems, and Research and Evaluation. The Affiliate sees tremendous opportunity to be involved in all. Komen Quad Cities plans to continue to grow relationships with partners such as Iowa Department of Public Health, American Cancer Society, Iowa Cancer Consortium, and countless other stakeholders in the fight against breast cancer. It is the goal at Komen Quad Cities to become a convener for those involved in state comprehensive cancer control and the mission to save lives and end breast cancer.

### **Illinois Comprehensive Cancer Control Coalition**

The Illinois Comprehensive Cancer Control Program is administered through the Illinois Department of Public Health (IDPH). The Illinois Cancer Partnership (ICP) has addressed six major cancer-related priority focus areas in this plan:

1. Primary Prevention
2. Early Detection
3. Access to Care
4. Survivorship
5. Data and Surveillance
6. Research and Clinical Trials

All of these focus areas impact breast health and align with the Komen Continuum of Care and efforts of Komen Quad Cities. In addition, it is a wonderful opportunity to partner with other cancer advocates and strengthen collaborations.

In the next four years, Komen Quad Cities will strive to become an active member of the Illinois Cancer Partnership, the working body that endorses and supports the mission of the current Illinois Comprehensive Cancer Plan. The Affiliate will work with Komen Memorial to strengthen the Komen partnership with the ICP and the value it can have in monitoring the rollout of the ACA and Medicaid expansion as it relates to cancer detection and the needs of cancer patients.

### **Affordable Care Act in Iowa**

Iowa is fully participating in Medicaid expansion under the Affordable Care Act. The Iowa Health and Wellness Plan (IHAWP) is a new Medicaid program which is Iowa's version of Medicaid expansion. The program was enacted through bi-partisan legislation to provide comprehensive health care coverage to low income, uninsured adults ages 19-64. The IHAWP is one program that is administrated by Iowa Medicaid Enterprise (IME) and includes two separate coverage options (eligibility is based on household income):

- ***Iowa Wellness Plan:*** covers adults ages 19 to 64 whose income is at or below 100 percent of the Federal Poverty Level (\$11,670 for individuals or \$15,730 for a family of two). Members have access to the statewide Medicaid provider network and have access to care from providers and hospitals in their local communities.
- ***Iowa Marketplace Choice Plan:*** covers adults age 19 to 64 with income from 101 percent through 133 percent of the Federal Poverty Level (between \$11,671 and \$15,521 for individuals or \$15,731-\$20,920 for a family of two). The Marketplace Choice Plan allows members to select from participating commercial health care coverage plans available through the Health Insurance Marketplace. Medicaid pays the premiums to the commercial health plan on behalf of the member. Members have access to the network of local health care providers and hospitals participating in the commercial insurance plan they choose.

Information and fact sheets regarding the Iowa Health and Wellness Plan are found on their website: <http://dhs.iowa.gov/ime/about/iowa-health-and-wellness-plan>.

According to the Iowa Department of Public Health the number of uninsured Iowans in 2013 was 301,601. The best-estimate scenario for uninsured is 242,691 by the end of 2014.

The eligibility guidelines for the Iowa BCCEDP have not changed through the ACA implementation period. The Iowa BCCEDP is seeing a downturn in number of women being screened. Anecdotally, contracted local programs are indicating that many previously served women have gained insurance coverage or have enrolled with the Iowa Health and Wellness Program. The program recently began collecting more detailed information on reasons why women are not re-enrolling for service. The program began special outreach projects in spring 2014 with the intent of contacting the harder to reach population of eligible uninsured women across the state. The program continues its focused outreach efforts in July 2014 in 12 counties that have the highest percentages of Hispanic/Latino population.

While some health care providers are still unsure of the implications of ACA, others have concerns. Many are concerned about a gap in services for those who are covered for screening as a health benefit through insurance coverage, but may not have the resources to access care

due to financial constraints (limited diagnostic coverage or high deductibles) or other barriers (transportation, etc.). Resources and access to care are other concerns, especially for safety net providers in Iowa. Do health care providers (especially those in rural Iowa) have the resources to meet the demands of ACA?

There are several implications for Komen Quad Cities to consider with the continued implementation of the ACA:

- Estimates done in November 2013 by IDPH BCCEDP staff indicate that only 43 percent of the BCCEDP-eligible Iowa population may remain uninsured following implementation of the ACA – that would be a population of approximately 13,000 women. While this estimate is a projection, there remains a lot of uncertainty regarding the actual number of women that have newly-gained insurance coverage.
- With more women having insurance coverage that provides screening at no cost, fewer women will be needing assistance to pay for screening services; however, women that continue to receive services through federally funded programming like the BCCEDP may still need funding to support specific screening or diagnostic-related services. For instance, the national BCCEDP does not allow states to pay for computer-aided detection services. That is a gap that could be filled with Affiliate-raised funds.
- Using Affiliate funds with a greater emphasis on outreach and education may be needed to ensure that women who have newly-acquired insurance coverage actually move forward to get their breast cancer screening.
- Navigation services can be crucial for women that are newly insured or who may not understand how insurance works. They may still need prompts to seek the screening that they are now eligible for and guidance on how to navigate the health care system if abnormal screening results are found.
- It will also continue to be important for the Affiliate to partner with the state BCCEDP through its grant program to assist in paying for mammograms for women under age 50. The National BCCEDP maintains its requirements that no more than 25 percent of the mammograms funded with federal dollars be used for mammography for women under age 50.
- Funding that is used in conjunction with the BCCEDP can be considered as part of the matching funds requirement for the federal funding that supports screening activity in Iowa. CDC requires the state program to provide \$1 in matching funds for every \$3 of awarded federal funds.

### **Affordable Care Act in Illinois**

Illinois is one of many states that have expanded Medicaid under the Affordable Care Act (ACA). Efforts to establish a state-based exchange failed and Illinois entered into a partnership exchange with the Federal government for 2014 with hopes of becoming a state-based exchange in 2015 (pending legislative efforts). As a Partnership Exchange, the Illinois Health and Family Services Department (HFS and formerly known as Medicaid) took responsibility for many consumer assistance functions, including marketing, communications, outreach and consumer education. The Partnership website, named the “Health Insurance Marketplace”, is handled by the Federal HHS (with the assistance of the Governor’s Office and the Illinois

Department of Insurance) and is responsible for enrollment, establishing and maintaining the website and a call center. Illinois now has a multi-benefit, web-based application system known as the Application for Benefits Eligibility (ABE). Through ABE, applicants can apply online for Medicaid, SNAP (formerly food stamps) and Cash Assistance. ABE replaced all previous applications used. Beginning January 1, 2014, all Illinois residents between 19 and 64 years of age, who are US citizens or who have legal status, and who have monthly income less than \$1,342 for an individual or \$1,809 for a couple, are eligible for Medicaid through the new “ACA Adult” category. This means Illinois Medicaid now provides health coverage for low income individuals who are seniors, persons with disabilities, parents or caretakers of dependent children, “ACA adults,” pregnant women and children.

It is anticipated that more than a million Illinois residents who were previously uninsured will receive health care coverage. About 200,000 to 300,000 of these will select coverage by commercial insurers that will be offered through the Health Insurance Marketplace, specifically established for this purpose (<http://www2.illinois.gov/gov/healthcarereform/Pages/HealthInsuranceMarketplace.aspx>). The cost will be on a sliding fee basis according to income, and some individuals or households may be eligible to receive assistance with paying their premiums through federally-subsidized tax credits. About 500,000 to 800,000 will be covered under the restructured Medicaid program at little or no cost to individuals (<http://www2.illinois.gov/hfs/PublicInvolvement/AffordableCareAct/Pages/default.aspx>).

The Illinois enrollment process suffered many of the same challenges as seen nationwide and as a result the enrollment has not been as swift as earlier predicted; however, an awareness campaign – Be Covered Illinois – has been underway for the past year (<http://getcoveredillinois.gov/#>).

Recognizing that ACA enrollment just became effective January of this year, there is not a great deal of data available at this time. The Illinois Department of Public Health recently reported that despite outreach efforts, only about 25 percent of the current IBCCP caseload had elected to transition out of IBCCP and into ACA, either the Exchange or Medicaid. HFS was experiencing a five-month delay in processing new Medicaid enrollees.

Throughout this time of ACA implementation, eligibility guidelines have not changed within the IBCCP. The number of women seeking screening services appears to be declining but many clients are opting to remain with IBCCP for various reasons. Some commonly cited reasons are:

- Apprehension/confusion about enrollment
- Preference to remain with trusted IBCCP services and staff with whom they have a history
- Preference to remain so that they can be screened by their known health care provider
- Fear of the cost of insurance and additional costs associated with co-pays and deductibles
- Electing to pay the fine until they become age-appropriate for Medicare in one or two years

While it is safe to assume that budget needs of the IBCCP should change as a result of the increased access to health care coverage either through the Exchange or Medicaid, the need for IBCCP and the proven network that provides this safety-net of services will remain for some time. The 2012 George Washington Study reported that despite the benefits of the ACA, the screening and services provided through the NBCCEDP (funding source for IBCCP) will be essential to those who remain uninsured.

While the Affiliate values the promise of increased access to health services through ACA, it is too early to know what possible new barriers or gaps may remain. There are several issues that the Affiliate must consider as ACA implementation continues:

- The OWH/IBCCP reports that regardless of the outreach and promotions over the past year, only about 25 percent of the IBCCP caseload has successfully transitioned into ACA – either the Marketplace Exchange or Medicaid Expansion. Funds need to continue to be provided to support this proven program until more data are provided to illustrate future needs.
- Some Illinois policymakers have assumed that with the advent of ACA and Medicaid expansion, IBCCP women now have access to services and that the IBCCP budget can be reduced. However, the 2012 George Washington Study reports that even with the success of ACA, there will remain a substantial number of uninsured women needing these essential services.
- The Illinois General Revenue contribution has exceeded the required match by CDC of \$1 for every \$3 of federal funding received.
- While the ACA provides screening at no cost, there is still concern as to what gaps may present for special screening and/or diagnostic services uncovered by insurance. In addition, as plans can vary from year-to-year, so could the gaps. Funding may be needed to support these services to ensure a continuum of care.

### **Komen Quad Cities' Public Policy Activities**

While Komen Quad Cities currently does not have a robust Advocacy Committee, it is the goal in the next four years to be active at the state and federal level of advocacy issues. The Affiliate intends to partner with the work that Komen Iowa and Komen Memorial are already doing to address issues related to the advocacy priorities of Komen and to follow their lead in an effort to uphold the collective goal of Susan G. Komen to remain united as “one voice”. Komen Quad Cities understands the importance of public policy and sees its value in better serving all women in the service area and beyond.

### **Health Systems and Public Policy Analysis Findings**

In review, there are some common needs of all three target communities that have been identified in the Health Systems Analysis. While all three counties have facilities available for screening and diagnosis, none have many options (if any) for treatment and support services. Clinton and Mercer Counties both have a high population of rural residents, thus creating a transportation barrier to accessing quality health care. Lack of outreach and education are also common issues for each target area. It is imperative for Komen Quad Cities to align with

partners in these target areas in an effort to help individuals in these much needed communities.

To effectively find potential new partners in these target areas, Komen Quad Cities needs to become more prevalent in the communities it serves. In addition to the aforementioned goals to strengthen ties to the state BCCEDP programs as well as the state cancer coalitions in both Iowa and Illinois, the Affiliate needs to solidify working relationships with the health departments in each county and provide education and resources not only to the individuals in need, but also to the organizations in the communities who may ultimately develop the programs needed that the Affiliate will later grant Komen dollars to. With the current restructure of the Community Grants Program and the newly implemented Small Grants Program, the Affiliate hopes to widen its reach to these target areas.

It is the Affiliate's goal in the next four years to be active at the state and federal level of advocacy issues. Komen Quad Cities intends to partner with the work that Komen Iowa and Komen Memorial are already doing to address issues related to the advocacy priorities of Komen and to follow their lead in an effort to uphold the collective goal of Susan G. Komen to remain united as "one voice". Komen Quad Cities understands the importance of public policy and sees its value in better serving all women in the service area and beyond.

# Qualitative Data: Ensuring Community Input

## Qualitative Data Sources and Methodology Overview

### **Methodology**

**Key assessment questions:** Based on the results of the quantitative data, Komen Quad Cities assessed women in the Affiliate's target communities (Mercer County in Illinois and Clinton and Muscatine counties in Iowa) to gather additional information about their perceptions of the importance of breast health care including the need for breast self-awareness and routine mammography. Additionally, the Affiliate anticipated that those who understood the need but did not access these services did so because of transportation, childcare or financial barriers.

**Data collection methods used:** Two different data collection methods tested these hypotheses: a series of focus groups in each of the three target communities and interviewed key informants who professionally serve women in these counties.

**Rationale for selecting these data collection methods:** Komen Quad Cities chose to use these two data collection methods to hear from both the women themselves and the professionals who work with this population to identify their barriers first-hand. Often someone cannot fully understand the barriers that a woman in poverty or a highly rural community faces until she walks a mile in her shoes. The focus groups provided a glimpse into these women's lives.

Because of demographic similarities among these three counties, two focus groups occurred in each county with the exception of Muscatine. Because of their high prevalence of Hispanic/Latina women (15.7 percent of the population), a third focus group in Muscatine, conducted in Spanish and targeted to Hispanic/Latina women occurred.

Similarly, "you do not know what you do not know" so the information collected from professionals who work with and for the women in these target communities augmented focus groups data. These key informant interviews expanded the information received from focus groups with more objective data about the availability of services that the women in the focus group may not know exist. While these key informants may or may not have the direct experience of "walking a mile" in these women's shoes, they see a variety of women from all socioeconomic statuses, educational levels, and backgrounds and can draw informed conclusions based on these experiences about the potential barriers women in these targeted counties face in their breast health.

Eighteen key informants, some with experience in only one county and others with experience in multiple counties, informed this project. Again, because of the similarities between these counties much of the information applied in all three counties which the data confirms. Six key informants addressed the specific challenges and needs of the Hispanic/Latina women in Muscatine County to assure adequate coverage of the unique needs and circumstances of that sub-population.

**Components associated with each data collection method:** Three highly skilled professionals facilitated the focus groups or interviewed the key informants. Because of timing and logistics, one facilitator conduct the focus groups in Mercer and Clinton Counties. A second facilitator conducted all of the key informant interviews (by phone) and as well as the Muscatine County focus groups that occurred in English. The third facilitator – an ESL teacher in Muscatine – conducted the focus group in Muscatine that occurred in Spanish.

Each facilitator audio recorded the focus groups and interviews for later transcription. Tree transcriptionists create a written transcript from the audio recordings. A fourth person – certified in medical translation – transcribed and translated the Spanish focus group into English for data analysis.

The doctoral-prepared researcher with extensive experience in qualitative research reviewed and coded the transcripts for emergent themes. This report comes from her review and analysis of the data.

**Triangulation of the findings:** The use of focus groups and key informant interviews allowed for comparisons of different perspectives about the barriers to diagnostic services and educational resources for all three target communities. Taken together, these two methods gave a comprehensive view of how women in these communities perceive and access breast health services.

### **Sampling**

**Population of interest:** With the exception of women in Muscatine County, the target community of interest included all women in that target county or those who could report on the general condition of women in that community with no limit on the population by age or other demographic variable. Muscatine County served as an exception to that general rule. In Muscatine County, the study had an interest in hearing from and learning about women across demographic descriptors, a particular interest in Hispanic/Latina women emerged because they comprise nearly one in five women in Muscatine County. A focus group that specifically and exclusively invited Hispanic/Latina women, conducted in Spanish, met this goal.

**Sources of data collection:** Focus groups in the three targeted communities occurred at the end of February and beginning of March. All occurred in a central location within the county. All totaled, 49 women participated in the focus groups, broken down as follows:

- Muscatine County (English): February 26 – two participants
- Muscatine County (English): March 2 – eight participants
- Muscatine County (Spanish): March 6 – 21 participants
- Clinton County: February 24 – two focus groups: 16 participants
- Mercer County: February 26 – two participants

The Clinton County focus groups, scheduled to begin at 4 and 6 PM, had people coming and going approximately every hour. Five people came at 4 PM, two more joined them at 5 PM. Five new people came at 6 PM and four came at 7 PM. The library the focus group occurred closed

at 7 PM so those last four individuals received the focus group questions in writing and returned them via email. This analysis includes their responses.

Two focus groups were scheduled in Mercer County. The second – scheduled for February 25 – became victim of the Midwestern winter. Because of a storm that brought 8” of snow to the area that evening – and the highly rural nature of the county, the second focus group for Mercer County did not occur. Because of the similarities between Mercer and Clinton county and similar experiences with Anglo women in Muscatine County (as evidenced by the findings of this study), these focus groups provided sufficient input to answer the research questions.

Twenty-seven of the women who participated in these focus groups completed a survey as part of their participation. Of these:

- Women range in age from 30-67; average age of 47.7
- Five identified themselves as Caucasian; 21 as Hispanic/Latina
- Twenty-one participants have health insurance; three participants do not
- Eleven participants travel from 0-15 minutes for breast health care; seven participants travel 15-30 minutes; four participants travel 30-60 minutes
- Ten participants have discussed their risk of breast cancer with their health care; 15 have not; one participant answered N/A
- Nineteen participants have discussed breast self-awareness including age-appropriate breast cancer screening options with their health care provider; nine participants have not; three participants answered N/A
- Sixteen participants indicated that their health care provider has demonstrated how to perform a breast self-exam; three participants had not; four participants answered N/A (*Note: Susan G. Komen uses breast self-awareness messaging because breast self-exams are not an evidence-based practice. To learn more about breast self-awareness, go to <http://ww5.komen.org/BreastCancer/BreastSelfAwareness.html>.*)
- Ten participants conduct breast self-exams monthly; four participants answered yearly; one participant answered every two years; three participants answered never; five participants answered “other” (*Note: Susan G. Komen uses breast self-awareness messaging because breast self-exams are not an evidence-based practice. To learn more about breast self-awareness, go to <http://ww5.komen.org/BreastCancer/BreastSelfAwareness.html>.*)
- Thirteen receive a clinical breast exam from a health professional annually; five every two years; one never; four answered “other”
- Eight get a mammogram annually; three every two years; five never; two answered “other”
- One had been diagnosed with breast cancer

Interviews with 18 individuals provided data for the key informants’ portion of this project. All interviews occurred via phone between February 12 and March 16.

Eight key informants came from Clinton County, four from Mercer County, and five from Muscatine County. Five of these individuals serve women from multiple counties. While

associated for the purposes of this study with the county they primarily serve, all commented on more than one of the targeted areas.

**Sample selection:** For the key informant interviews, board members, grantees, and others in the medical community with knowledge of these counties suggested the names of professionals with the knowledge and information sought. Komen Quad Cities has the support of two large hospital systems; at least one of them has a facility in each of these counties. Both provided names of individuals from their own health system as well as public health and social service agencies who could answer the questions asked. Where needed, Internet research found individuals in the targeted communities with the appropriate professional qualifications. For the focus groups, the Affiliate's extensive database of Race participants, email subscribers, and other friends of Komen Quad Cities served as the population from which to draw. All of the women in this sample received an invitation to participate which allowed them to self-select. The first invitation came via email with numerous follow-up phone calls to encourage their participation. Each participant received a \$25 Walmart gift card to thank them.

**Rationale:** To reach broad sample of women in these targeted communities, this study did not target beyond the previously mentioned criteria, e.g., women in these targeted counties. Other than Hispanic/Latina women in Muscatine County, the study not target any other sub-populations.

## **Ethics**

**Consent procedures:** Oral consent from all individuals occurred prior to beginning each focus group and interview to participate and audio record the session for later transcription. All participants received assurances of anonymity with no names associated with any comments made. Participants also received assurances that they could decline to answer any question that they did not feel comfortable answering and could end their participation at any time without any negative consequences.

**Protecting anonymity of sources:** Audio files and transcripts do not identify any participant by name, only by focus group or county represented.

**Confidentiality of data:** To protect the anonymity of sources, audio recordings and transcripts reside in a password protected file on the researcher's computer and shared with the transcriptionists only through password protected Box files. All will be destroyed upon the completion of this project.

## **Qualitative Data Overview**

**Original data format:** The data used in this study came from the transcripts of the interviews and focus groups. Demographic information about focus group participants came from a survey that each completed anonymously prior to the focus groups.

**Rationale for data management method:** This study used a collective case study approach to data collection. Case study offers a means of investigating complex social units consisting of multiple variables of potential importance to understanding the phenomenon. Anchored in real-life situations, the case study results in a rich and holistic account of a phenomenon.

The complexity of human behavior itself points toward a case study approach. In collective case studies, multiple cases are chosen because understanding them leads to better theorizing about a still larger collection of cases. That is, understanding the life circumstances and perceptions of these 49 women and 18 professionals allowed the study to generalize to women as a whole in these three target counties. While generalization from these cases is not a goal of qualitative research, a collective case study approach allowed common elements across examples to emerge. Controlling for as many extraneous variables as possible provided for relatively confident conclusions regarding participant motivation.

This study used interviews and focus groups as the data gathering method. Interviewing and focus groups become necessary when one cannot make direct observation of behaviors, feelings, or how people interpret the world around them. Probing for what motivates a person to manage his or her breast health required focus groups with informants who were willing and able to delve into their own decision-making thought processes. Because of the busy schedules and geographic diversity of the key informants engaged, personal interviews occurred rather than attempting to coordinate schedules. This allowed for more focused questions and in-depth answers.

Interviews followed a protocol that included 12 prepared questions; focus groups likewise followed a protocol with seven prepared questions. Both quickly deviated from the planned script to adequately follow-up on subject-initiated topics. Because of each subject's unique experiences managing their health in general and breast health in particular, this approach provided for a depth and breadth of information that a more structured interview could not have provided.

**Generating themes:** Transcripts were analyzed using the open-coding process described by Strauss and Corbin (1990) to categorize emergent topics. Conceptualizing the data became the first step in the data coding process. Open coding requires breaking down and conceptualizing each utterance as a discrete phenomenon. Questions asked about each one identified the overall themes it represents. Comparing each utterance and theme while coding each discrete observation allowed similar phenomena to receive the same name and categorized as similar themes.

Applying this approach to the current project, this step first identified discrete statements from the transcripts and coded each based upon its theme such as "access to care," "financial issues" or "knowledge of breast health." From there, sorting proceeded within each category with codes that identified each theme. Each utterance could be viewed independently or within the context of the entire transcript which helped assure that assignment of meaning occurred within the context of the entire interview rather than in isolation.

Themes emerged from the transcripts themselves and were not imposed externally. Continually cross-checking themes assured mutual exclusivity across themes and consistency within themes. At this stage, the process moves from coded data to meaningful data by assigning labels and understanding relationships between and among emergent themes. Continually refining the categories and analyzing the relationships between items linked under each category and between different categories began to provide the data to answer the study questions.

Coffey and Atkinson (1996) confirmed that this open coding process “is valuable in encouraging the researcher to move beyond local coding to generate ideas and broader conceptual frameworks” (p. 48). This process provided broader insights into the participants’ knowledge of and attitudes toward their breast health. Tangential items remained un-coded, but were retained as background information to provide more insights into the participant’s motivation or personal history.

For this study, categories stemmed from the interviewees and focus groups themselves rather than imposed from external criteria or expectations. A review of identified categories assured mutual exclusivity followed by analysis of the interrelatedness between categories and the emergence of overall themes. The data analysis and representation took the experiences of these individuals to create a more generalized view of the barriers to superior breast health in these targeted counties.

### **Qualitative Data Findings**

Data collected from the focus groups and key informants identified barriers to improving breast health in these counties that fell within five overall themes: systemic, attitudinal, cultural, logistical, and educational.

**Systemic barriers** included processes and procedures within the medical community that presented a potential barrier or a hurdle over which women must overcome to improve their breast health and breast health care. The systemic barriers mentioned by individuals in this study include:

- Doctors do not take a woman’s concerns seriously, often telling her she is “too young” to have problems. Women frequently mentioned needing to self-advocate for herself to get the care she needed; others mentioned that women need to self-advocate for themselves better and more often.
- Insurance companies limit or refuse to pay for mammography services for some women, especially those under the age of 40 regardless of their family history or presentation with a potential carcinoma. The costs associated with insurance co-pays and deductibles are described elsewhere as a financial barrier. Here, more than one woman mentioned that her doctor told her that “her insurance company would fight” her desire for a mammogram which they did. She ultimately won (as the doctor predicted), but she had many hurdles to overcome to get the procedure covered.

- Too few women physicians especially in gynecology and gynecologic oncology. Hispanic/Latina women in particular mentioned feeling too embarrassed to see a male doctor, especially about a “female problem” (see Cultural Barriers for more information).
- Quality of health care especially in the more rural communities. Many of the women in the focus groups came to the Quad Cities or Iowa City for routine screenings or breast cancer care. One woman commented that their local hospital and doctors have very bad reputations in town, with people saying “I would never go to [Local] Hospital.”
- Requirement to have a physician referral for a mammogram creates an unnecessary and expensive extra step that gets even worse for women with limited transportation or financial options. If women could simply schedule their mammograms themselves, it would save time and money.
- Perceived delays in the health care system. Some women reported what they perceived as an inordinate amount of time between when a health care provider identified “something suspicious” on their mammogram and follow-up appointments to confirm or rule out a problem. Others mentioned the long-time between diagnosis and surgery, surgery and chemotherapy, chemotherapy and radiation. They described this time as highly anxiety producing, often unnecessarily. Upon facing a multi-week delay for a follow up test to confirm a suspicious shadow on a mammogram, one woman came to the Quad Cities, had her test the next day, and results before she left.
- One informant mentioned that “I think some male GP's [general practitioners] don't want to touch women's breasts, so they refer them to a nurse, but some nurses aren't properly trained to do breast exams.”

Systemic barriers represent the most difficult to change as they occur in the broader environment in which Komen exists and women seek breast health care. Better education about navigating the health care system and self-advocacy for women might begin to provide the knowledge she needs to receive better care in this imperfect system. Concurrently, more education of physicians about women’s perceptions of their breast health care might help them begin to change their communication styles with women.

**Attitudinal barriers** include certain attitudes or beliefs that a woman has about breast cancer or mammography that prevent her from adequately seeking screenings or addressing her breast health. This study revealed the following attitudinal barriers:

- A belief among some women that breast cancer happens to “someone else,” even those with a family history or other risk factors
- A fear of the known rather than the unknown (e.g., “as long as I don’t know I have cancer, then I don’t have cancer”)
- Fear of x-rays or mammography, often after hearing other women complain that a mammogram hurts
- A belief that breast cancer only affects women; men get breast cancer too. Breast cancer certainly affects men when the women in their lives get it.

Education helps to overcome some of these attitudinal barriers with that education occurring at a younger age and with multiple generations of women. Women should know their own genetic

predisposition and other risk factors as they relate to breast cancer and encourage each other to overcome these attitudinal barriers. The current focus on BRCA testing brought about by Angelina Jolie's revelations help start that conversation. Women need to know that breast cancer affects women (and men) at any age so they need to know their bodies and their risks and seek medical attention when they note any changes.

**Cultural barriers** include attitudes and beliefs deeply engrained in a particular culture, in this case, the Hispanic/Latino culture since that provided one focus for this study. Hispanic/Latina women in this study commented that Hispanic/Latina women:

- Are more timid or shy than White women, especially about their bodies and health.
  - “We ladies are more timid. We Hispanic women are more timid and more easily embarrassed...”
  - “I never examine myself but then do you also think that We Hispanics also have other customs? I don't know but sometimes husbands are like oh no, you can't go to the doctor for him to feel you up.”
  - “But also when we go to the doctor, be it that we are embarrassed or in pain, we don't tell them and we don't get examined.”
- Do not take the time to take care of themselves sufficiently. Probably true of all women, Hispanic/Latina women indicated that they dedicate even less time to their own health and wellness.
- A distrust of the medical profession. Stated outright, it also emerged as more of an underlying message. For example, one woman told the story of her sister who had a mastectomy after a diagnosis of breast cancer. This woman believes that because her sister had insurance, the doctor “took advantage of the fact that [she had] insurance, and they think ‘here I can get more money out of her.’” Others believed that health care invades their privacy.

These cultural barriers become the most challenging to overcome because they are deeply ingrained in the individual's psyche and become part of how they identify themselves and the world around them. Having women of a similar culture tell their stories can begin to address some of these cultural barriers. Because of a general distrust of the medical profession among Hispanic/Latina women and the shyness they mentioned, having a trusted woman peer lead a discussion might provide the best means to reach women in this culture. The focus group itself – led by a layperson from the Muscatine community who goes to church with a number of the women and teaches ESL – provided strong evidence of the viability of this approach. Women talked openly and freely about their experiences and attitudes and welcomed the opportunity for additional conversations of this type.

**Logistical barriers** – or physical elements within an individual's environment that make pursuing adequate breast health care more difficult – include:

- Lack of transportation, especially for these highly rural communities. Many low income families may have only one vehicle that takes one spouse to work, leaving the other with no way to get to an appointment. For others, even if they have a vehicle or access to a vehicle, living in a highly rural community means it takes a long time to get to a facility,

even the local facility. The gas money for this trip can also become a financial barrier to some women.

- Finances
  - Those without insurance did not know where to get free or reduced cost screenings or care because they could not afford the full cost of a mammogram. Many do not know where to get a voucher for a free mammogram.
  - Those with insurance could not always afford out-of-pocket costs associated with co-pays or deductibles. Often lower income individuals have a higher deductible and co-pays because it lowers the cost of their insurance. Some have insurance coverage for screening mammograms but high deductibles and co-pays for diagnostic tests like an ultrasound or biopsy. Others who fall in a higher risk group may need mammograms more often than annually which can also require a higher deductible or co-pays or not be covered.
  - Many people – regardless of insurance – could not afford to take time away from work for diagnosis and treatment, especially lower income women who tend to work hourly jobs and do not get paid time off.
  - Others cannot afford living expenses because of the high cost of medical care after a cancer diagnosis, even with insurance. When faced with a catastrophic event like cancer, they cannot afford those the resultant high deductibles, medications, and co-pays. One key informant mentioned that they receive requests for assistance with medical and living expenses by individuals with cancer (breast cancer and other types) because of this.
- Time which translates into both remembering to schedule a regular exam or mammogram as well as finding the time to schedule it when offered. Especially for women who work 9-5, they often cannot get off work for a mammogram because they work the hours when the mammography centers are open. Even for those with schedules that allow it, life gets busy. One woman summed it up well: “I think when you’re a young mother; you’re just so busy raising your kids and trying to make ends meet and just trying to go through the daily struggles of life. I think they put their own health, just like we all do, you kind of put your own health and your own families’ kind of aside and you want to deal with it later and sometimes that later is too late.”
- Language: While mentioned most frequently by the Hispanic/Latina women who would like to have more materials and individuals available in Spanish, others mentioned that health care professionals often do not talk in terms they understand. While they speak English, if health care professionals do not take the time to explain things in ways that women can understand, it does no good. For Hispanic/Latina women, language becomes a much more substantial barrier. Often they will bring a family member to interpret but feel embarrassed discussing their medical issues in front of a family member. One mentioned that she feels that Anglo women have much better health and breast health because they have materials available to them in English.
- No doctor: Individuals who do not have a family physician or regular health care provider receive less routine care of any kind and rarely schedule a mammogram.
- Legal status: Some Hispanic/Latina women feared that their health care provider will reveal their illegal status to officials. Multiple people mentioned that the current focus on

immigration reform has a number of illegal immigrants fearing the health system because of their immigration status.

- Lack of family support either to encourage them to get screened, follow up on a suspicious finding, or support them through a diagnosis and treatment. One key informant noted that most noncompliant patients either lack transportation (and programs exist to help that) or family support
- Childcare

Nearly everyone agreed that letters or other communication from their doctors reminding them of the need to schedule an annual exam or mammogram helped to remind them during their busy lives. Not every individual has a doctor who routinely sends these letters. The challenge becomes encouraging women to get that first mammogram.

Komen offers vouchers to women in all three of these counties through its grant program. However, most participants did not know where to get a free mammogram through the Komen-funded vouchers. While the study did not ask for income information to know if these women would need a voucher (and most had insurance), the lack of information among these highly engaged women suggests that less engaged and uninformed women likely need more information to access this financial resource. One woman suggested putting information about vouchers at pharmacies as a place all women go; others suggested blanketing public places in the community so all women know the resources available to them, especially the vouchers that Komen funds. More than one woman mentioned the availability of vouchers “during October,” not realizing they can access them at any time during the year. Clearly, education needs to extend beyond Breast Cancer Awareness Month. Another mentioned educating primary care physicians so they know the resources available to their patients who lack financial means for a mammogram or other services.

One person recommended that “...the hospitals dedicate one day/month, for a block of time where people can get a screening for a low-cost price. Then people know that if they can get there on that specific day, they can get a mammogram. Especially if it is a weekend day, so they don't have to miss work. The machines are there. We have the ability to do it. We just need to get the staff on board. We would have people volunteer to drive people on that day, create a shuttle.” Another mentioned that if mammography facilities opened one weekend or evening every few months, it would give women who cannot get there during regular business hours a viable option.

Key informants mentioned a plethora of other community programs designed to help people with many of these other logistical barriers. One – a social worker – mentioned the following:

*“We have found fewer patients with no insurance because of the Affordable Care Act, but if there are some with no coverage we link them up with the IL Breast and Cervical Cancer programs to get the care they need. We can guide women to financial advocates at the hospital to get the coverage they need. I can help them with transportation to appointments. We can help with gas expenses if they have their own transportation but have to drive far to reach an appointment. We can put them in touch with community*

*agencies that can help with other living expenses if they have to miss work because of treatment, or if they can't work at all.”*

Assuring that all of the rural communities in target communities have these services – and helping to set them up if they do not – and then educating women and other providers of their existence would go a long way toward alleviating many of these logistical barriers.

**Educational barriers** conclude the list of reasons why women do not receive adequate breast health care. These fell under the following overall themes:

- Overall education: knowledge about the need for breast self-awareness and an individual's risk factors
- Specific education about things like where to access care; when to start getting certain types of breast health care, especially mammograms; programs to help overcome logistical barriers especially financial ones; and even the need to get mammograms. The changing recommendations on mammography had many women confused. One provider mentioned that a woman told her that she did not think women still needed mammograms after menopause, a myth that she dispelled.

Some of the suggestions participants made to improve education included starting to talk about the need for breast self-exams with girls as young as middle school including stories from survivors; using mass media and billboards to get the message out; putting brochures in locations where women frequent including grocery stores, laundromats, churches, preschools, agencies that serve low-income women and families (such as WIC); large companies; and materials that residents already receive (e.g., flyers for city services, electric bills, newspapers). To reach younger audiences, others suggested a social media campaign. *Note: Susan G. Komen uses breast self-awareness messaging because breast self-exams are not an evidence-based practice. To learn more about breast self-awareness, go to <http://ww5.komen.org/BreastCancer/BreastSelfAwareness.html>.*

Having these materials available in Spanish (and other languages prevalent in the service area) will allow Komen to reach and education more women. The Hispanic/Latina women in the focus groups mentioned numerous times the need for materials in Spanish (written and oral). Making them culturally sensitive with women who “look like us” – raised by an Anglo woman – not just size 5, 20 year old models, makes the material more relevant. Awareness events – especially associated with sporting events – also came up as ways to make people aware of Komen and breast health in general. The basic theme is that the materials need to reach women where they are physically, psychologically, and emotionally. It needs to lay out a need that resonates with their lives and make it as easy as possible to follow-up.

A few women suggested that mammograms become mandatory or that cities send out postcards regularly (twice a year) to all women between a certain age to encourage them to get a mammogram with information on resources available to help pay for them. Others noted that not everyone will get a mammogram no matter how much you educate or cajole them. You just need to put the information out there and hope women will listen before it is too late for them.

For women who had a breast cancer diagnosis, they felt that support was absolutely essential. One woman praised her nurse for getting her through treatment: “If it hadn’t been for Beth, I would have quit treatment. At 30 treatments, if it had not been for Beth giving me a really big pep talk, I would have said, ‘I can’t do this anymore. I just can’t. I can’t take it anymore. I’m tired all the time.’” Another described the support she got from what I assume is a nurse navigator who answered her questions. That woman retired and no replacement ever contacted this woman again. The Hispanic/Latina women in Muscatine specifically mentioned the desire for support groups conducted in Spanish.

**Strengths and weaknesses of data sources and methods:** This assessment method provided a good cross section of women in these three target communities. The similarities in answers across all counties showed that the women in these rural communities in eastern Iowa and western Illinois face similar barriers. The ability to focus on the needs of Hispanic/Latina women with a Spanish-language focus group allowed the Affiliate to delve deeper into this population’s unique needs. While they echoed many of the same themes heard from the Anglo women from all three counties some culturally-specific barriers emerged that the Affiliate can address. Sample size provides the greatest limitation of the data. This study reached out to 1,660 women within these three targeted communities to invite their participation yet only a fraction accepted. Time – a barrier to receiving adequate breast health care – likely became the greatest enemy as many of these women have multiple obligations and could not add a focus group meeting to their busy schedules in spite of best efforts to offer at least two times in each location. Mother Nature also foiled best efforts at a second focus group in Mercer County with a major winter storm on that day. Extreme cold on the days of the other focus groups may have also kept some women at home, especially those who would have to travel a good distance to attend because of the highly rural nature of these communities.

Because of time constraints, this study reached out to women with a prior relationship to Komen and invited them to participate in the focus groups. A slight selection bias likely exists toward women better educated, informed, and motivated about breast health care. The large number of barriers to care identified and suggestions to overcome these barriers suggests that if any bias exists, it did not negatively impact the results in a substantial manner.

**Conclusions:** Substantial differences did not emerge between the communities in this study. All mentioned mostly the same issues. The one exception came with the quality of health care in their local community. Women in Clinton mentioned the very poor reputation of the local medical facilities, a perception not shared by everyone in the room but heard by all of them pointing to its prevalence. This led some women in Clinton to travel further to neighboring communities for screenings and care. Women in Muscatine and Mercer did not mention similar issues with their local health care providers.

Most issues also crossed ethnic boundaries as well. The only that emerged specifically for the Hispanic/Latina community revolved around cultural issues and a desire for more information in Spanish.

Likewise, most barriers did not differentiate the women in these rural communities and women in general. The exceptions came in transportation and economic issues. Economic issues related more to lower income in these communities; financial issues likely exist with low-income women in urban areas as well. Others mentioned the time involved for screenings. While all women have to make time in their busy schedule to schedule an annual exam and mammogram, this time becomes exaggerated with the travel required from more rural areas of a community to their local medical facilities or to the larger medical centers in the local metropolitan area.

This study asked about sub-populations of women who the participants believed receive regular breast cancer screenings less often than other groups. Single mothers emerged numerous times as a population that deserves attention. Some of the reasons posited revolved around financial issues as single mothers tend to have lower incomes than their married peers. Others involved time. Single mothers tend to have little time to complete all of the necessary tasks in a day, let alone include a preventative medical appointment for herself. Most of these women give what they have in terms of time and money to their children, reserving anything leftover for themselves. While not necessarily unique to single mothers, her lack of a partner to share physical, financial and emotional burdens likely exacerbates her time challenges.

African-American women also received mention. One informant noted that she sees mostly white women in her practice although that might reflect the overall population demographics rather than a racial difference in screening prevalence. Past Community Profiles have identified Black/African-American women, especially in Rock Island and Scott Counties, as having a higher prevalence of late-stage diagnosis and a higher death rate than their White peers which mirrors national trends. That finding did not emerge in this study but warrants attention to make sure that any gains seen over the last 5-10 years to not lapse.

Women who do not receive breast care currently also emerged as a sub-population of interest. Most of the focus group participants had some knowledge of the need for breast health care and most of them followed the guidelines (to the best of their ability) to receive such care. Many of their suggestions reflect a need to get women to follow-up and receive future mammograms. How do professionals reach women who have never had a mammogram and do not know they need to? One key informant suggested reaching women in homeless shelters or domestic abuse shelters, although she posited that “those women are probably thinking breast health is not a priority with everything else they have to worry about.”

The “working poor” often fall through the cracks; these women do not qualify for some support services because they work or exceed income guidelines, but cannot afford the high deductibles and other costs associated with regular screenings and, more importantly, treatment. Finding ways to help these women would fill another need within the service area. Given the high number of lower income women in these target communities, many of them likely fall under this category of “working poor.”

On the service provider end, more than one key informant mentioned that while they see a strong willingness to collaborate among them, room for improvement exists to cover any gaps in services and avoid duplication. They would welcome closer collaborations and meetings with Komen Quad Cities to learn ways to better work together to meet these needs.

These findings have shed good light on the direction that the Affiliate needs to move to remove the systemic, attitudinal, cultural, logistical and educational barriers women in the service area face. The next section outlines the next steps Komen Quad Cities will be taking as the Affiliate move forward.

# Mission Action Plan

## **Breast Health and Breast Cancer Findings of the Target Communities**

**Summary of the findings from the Quantitative Data Report:** To most efficiently steward its resources, Susan G. Komen Quad Cities chose three target counties within the service area to focus efforts over the next four years. These target counties have cumulative key indicators -- incidence rate, death rate, later-stage diagnosis, mammography screening percentages, or demographic and socioeconomic measures – that show an increased risk of vulnerable populations experiencing gaps in breast health services and/or barriers in access to care. Out of the Affiliate’s entire eight-county service area, Clinton and Muscatine Counties emerged as the highest or high priority in one of the key areas. Mercer County had poor key indicators. All three counties have large rural populations. Clinton has a higher death rate than the Affiliate as a whole, a trend of increasing late-stage diagnosis, and large number of individuals living below the poverty level. Muscatine County has a high incidence of late-stage diagnosis, low educational attainment, high unemployment and high Hispanic/Latina population. Mercer County has a higher level of late-stage diagnoses with trend of improving. However, their low educational attainment, high rurality, and high number of women between the ages of 40 and 64 without health insurance make them a high risk for not attaining HP2020 goals for late-stage diagnoses.

**Summary of the findings from the Health Systems and Public Policy Analysis:** All three counties have facilities available for screening and diagnosis, but none have many options (if any) for treatment and support services. Clinton and Mercer Counties both have large rural populations which creates a potential transportation barrier to accessing quality health care. Lack of outreach and education also emerged as common issues for each target area.

**Summary of the findings from the Qualitative Data:** Substantial differences did not emerge between the communities in this study. All mentioned mostly the same issues. The one exception came with the quality of health care in their local community. Women in Clinton mentioned the very poor reputation of their local medical facilities, a perception not shared by everyone in the room but heard by all of them which points to the prevalence of this perception. This led some women in Clinton to travel further to neighboring communities for screenings and care. Women in Muscatine and Mercer did not mention similar issues with their local health care providers.

Most issues also crossed ethnic boundaries as well. The only issue that emerged specifically for the Hispanic/Latino community revolved around cultural issues and a desire for more information in Spanish.

Likewise, most barriers did not differentiate the women in these rural communities and women in general. The exceptions came in transportation and economic issues. Economic issues related more to lower income in these communities; financial issues likely exist with low-income women in urban areas as well. Others mentioned the time involved for screenings. While all women have to make time in their busy schedule to schedule an annual exam and

mammogram, this time becomes exaggerated with the travel required from more rural areas of a community to their local medical facilities or to the metropolitan larger medical. Women who do not receive breast care currently emerged as a sub-population of interest. Most of the focus group participants had some knowledge of the need for breast health care and most of them followed the guidelines (to the best of their ability) to receive such care. Many of their suggestions reflect a need to get women to follow-up and receive future mammograms. How do professionals reach women who have never had a mammogram and do not know they need to? One key informant suggested reaching women in homeless shelters or domestic abuse shelters, although she posited that “those women are probably thinking breast health is not a priority with everything else they have to worry about.”

### **Mission Action Plan**

To alleviate the problems that were highlighted through the qualitative and quantitative data analyses, the Komen Quad Cities board identified the following three priorities for the Affiliate’s focus over the next four years. The board selected these priorities as those whose resolution has the potential to impact the largest number of individuals within the service area or the target community and the greatest likelihood to improve outcomes and survival data.

**Problem Statement:** Quantitative data suggest that Muscatine County has a rising level of late-stage diagnoses. A large percentage of residents with less than a high school education (14.5 percent), high unemployment (eight percent), and substantially higher Hispanic/Latino population than the Affiliate as a whole (15.7 percent) contribute to this trend. Research shows that minority and medically-underserved populations tend to receive a diagnosis at a later disease state, likely due to socioeconomic factors and other barriers to routine screenings. Certain biological and cultural factors also affect the diagnosis rate for Hispanic/Latina women. Qualitative data suggest that cultural and language differences serve as barriers for Hispanic/Latina women. (**Target Communities:** Hispanic/Latina women in Muscatine County)

**Priority:** Reach out to Hispanic/Latina women in Muscatine County with culturally-appropriate messages delivered in Spanish when appropriate.

#### *Objectives:*

1. By December 2016, reach out to groups that serve Hispanic/Latina women in Muscatine County to identify natural partners and culturally-appropriate best practices to educate and encourage this population to seek regular breast health care.
2. By December 2017, implement and evaluate culturally-sensitive outreach and educational programs annually to encourage Hispanic/Latina women in Muscatine County to seek regular breast health care that: (a) reach at least 100 Hispanic/Latina women through personal contacts and (b) include at least three mass media campaigns targeted toward Hispanic/Latina women.

3. By December 2019, implement and evaluate educational, outreach, partnership and financial assistance programs to increase the number of Hispanic/Latina women in Muscatine County diagnosed with breast cancer at an earlier stage.

**Problem Statement:** Women in the focus groups and key informants in all three target counties identified cost as a major barrier to seeking breast health services. They also repeatedly mentioned other physical and logistical barriers such as transportation, child care, and the cost of living expenses or co-payments after a breast cancer diagnosis. Several mentioned the availability of vouchers in October – Breast Cancer Awareness Month – but few knew of their existence during the other 11 months. Furthermore, one key informant noted that her job consists of helping women overcome these types of barriers in her county. Both findings point to a need for better education and marketing in these counties – and across the Affiliate – for these services that make breast cancer screenings, education, and treatment more accessible to all women. (**Target Communities:** Muscatine and Clinton Counties in Iowa and Mercer County in Illinois)

**Priority:** Expand educational outreach regarding the availability of services that minimize barriers to seeking breast health services.

*Objectives:*

1. By early 2016, identify resources and partners available in the target communities of Muscatine, Clinton, and Mercer Counties to provide logistical and financial support for breast cancer screenings and treatment.
2. By the end of 2016, develop a marketing plan targeted to low income women in Muscatine, Clinton, and Mercer Counties that outlines resources available to them to offset the costs and logistical barriers to breast health care.

**Problem Statement:** Much of the focus group discussions revolved around ways to remind women to seek subsequent mammograms on a schedule that fits her needs and individual risk scenario. These discussions evolved into questions of ways to encourage women to get their first mammogram. Some of the identified barriers included lack of a personal physician, lack of knowledge, and lack of insurance. This priority seeks to bring more women into the health care system for breast care. Once they have that first mammogram, existing systems encourage most to continue screenings as appropriate. (**Target Communities:** Muscatine and Clinton Counties in Iowa and Mercer County in Illinois)

**Priority:** Reach out to at-risk women (especially from low-income and rural households) who have never had a mammogram to encourage them to receive regular breast health care.

*Objectives:*

1. By early 2016, identify resources and partners available in Muscatine, Clinton, and Mercer Counties to provide education that encourages women to have a first mammogram based on her individual risk factors.

2. By the end of 2016, develop a targeted education plan for women in Muscatine, Clinton, and Mercer Counties that outlines the basics of breast health including the need for routine screenings, screening recommendations, and places to access screenings.
3. By December 2018, education, outreach, partnerships, and financial assistance to women in Muscatine, Clinton, and Mercer Counties will increase in the number of women who seek breast health care as measured by the number of mammograms or breast health-related visits.

# References

HP 2020. Healthy People 2020. US Department of Health and Human Services. December 2, 2010. Available online at <http://www.healthypeople.gov/2020/about/> (accessed 8/2/2013).

SEER Summary Stage. Young JL Jr, Roffers SD, Ries LAG, Fritz AG, Hurlbut AA (eds). *SEER Summary Staging Manual - 2000: Codes and Coding Instructions*, National Cancer Institute, NIH Pub. No. 01-4969, Bethesda, MD, 2001. Available online at <http://seer.cancer.gov/tools/ssm/> (accessed 8/2/2013).