susan g. komen®

# COMMUNITY PROFILE REPORT 2015


## SUSAN G. KOMEN® CHICAGOLAND AREA

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# Executive Summary

## Introduction to the Community Profile Report

Susan G. Komen® Chicagoland Area was established in 1997 and held the first Susan G. Komen Chicagoland Area Race for the Cure®. With the support of the signature fundraiser, the Komen Chicagoland Area Race for the Cure, Komen Chicagoland Area has awarded over $15 million towards the fight against breast cancer in the five county service area of Cook, DuPage, Kane, Lake and McHenry Counties.

Komen Chicagoland Area was awarded the 2010 Affiliate of the Year by Susan G. Komen. In 2014, Susan G. Komen Chicagoland Area received the Inspire Award from Presence Saints Mary and Elizabeth Medical Center for exceptional leadership and bringing a spirit of hope to the community.

Komen Chicagoland Area remains a leader in the breast health community by serving on the McHenry County Women's Cancer Task Force, the Greater Roseland Breast Health Consortium, and the Chicago Women's Health Awareness Council, as well as providing funding for five lead agencies in the Illinois Breast and Cervical Cancer Program.

Susan G. Komen Chicagoland Area completed the 2015 Community Profile in order to better understand its service area, to establish focused Community-Based Grant priorities, identify community education needs, strengthen sponsorship and fundraising efforts in the five-county service area, drive public policy efforts, establish directions for marketing and outreach, align the Affiliate's strategic and operational plan and drive inclusion efforts in the community.

The 2015 Community Profile Report will be used to educate and inform the Affiliate's stakeholders (including but not limited to: grantees, partners, donors, sponsors, legislators, other breast cancer-focused organizations and the community-at-large) regarding the state of breast cancer in the service area, the Affiliate's current Mission priorities, and the plan to address the identified breast health and breast cancer needs within the target communities of Cook and McHenry Counties in Illinois

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

At the county level, the City of Chicago (Cook County, IL) had the largest amount of women who have never received a mammogram. It was followed by Suburban Cook County, which had the second highest amount of women whom either have never received a mammogram or had not received a mammogram in the last 12 months. This is in stark contrast to some of the other counties in the Komen Chicagoland Area service area. McHenry County has the lowest prevalence or percentage of women who reported never having a mammogram, but due to the smaller population of the county compared to Chicago and Cook County, the actual numbers are much lower.

In order to be the most efficient stewards of resources, Susan G. Komen® Chicagoland Area has chosen two target communities within the service area. The Affiliate will focus strategic efforts on these target communities over the course of the next four (4) years. Target communities are those communities 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 to accessing care.

When selecting target communities, the Affiliate reviewed Healthy People 2020, a major federal government initiative that provides specific objectives for communities and the country as a whole. Specific to Komen Chicago's work, goals around reducing women's death rate from breast cancer and reducing the number of breast cancers found at a late-stage were analyzed. Through this review, areas of priority were identified based on the time needed to meet Healthy People 2020 targets for breast cancer.

The selected target communities are:

- **Cook County, Illinois**
- **McHenry County, Illinois**

Cook County has been identified as a high priority county due to the amount of intervention time needed to achieve the HP2020 targets. For instance, the county's death rate of breast cancer is 25.5 per 100,000, which represents the highest in the Affiliate's service area and is higher that state and national rates (Table 1). The target for HP2020 is 20.6 deaths per 100,000. In addition to the alarmingly high breast cancer death rates and the unlikeliness that Cook County will achieve the target, this county has also been chosen due to low screening percentages, unique population demographics, and identification and medically underserved and having lower income levels.

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

| | Cook County | Affiliate Service Area | US Rates |
|---|---|---|---|
| **Incidence Rate*** | 125.9 | 128.8 | 122.1 |
| **Death Rate*** | 25.5 | 24.5 | 22.6 |
| **Late-Stage Rate*** | 48.7 | 48.8 | 43.7 |

Source: 2006-2010
*Age-Adjusted Rates per 100,000 women

McHenry County has been selected as a target community due to the amount of intervention time needed to achieve the HP2020 targets based on the rates and trends regarding breast cancer deaths, as well as the rates of breast cancer incidence and late-stage diagnosis (Table 2). The raising trend for late-stage breast cancer diagnosis is 16.2 percent, the highest in the Affiliate's service area as well as more than doubles the trend in the State of Illinois and the United States. There is a high likelihood that female breast cancer occurred more frequently among women in McHenry County than among those in the Affiliate as a whole, which is unfavorable for the county. McHenry County residents reflect a diverse population with many

women who may be more vulnerable to breast cancer due to known poorer prognosis rates (i.e., late-state diagnosis or more aggressive cancers).

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

| | McHenry County | Affiliate Service Area | US Rates |
|---|---|---|---|
| **Incidence Rate*** | 126.8 | 128.8 | 122.1 |
| **Death Rate*** | 25.1 | 24.5 | 22.6 |
| **Late-Stage Rate*** | 49.9 | 48.8 | 43.7 |

Source: 2006-2010
*Age-Adjusted Rates per 100,000 women

## Health System and Public Policy Analysis

There are well over 350 health care facilities located within Cook, DuPage, Kane, Lake, and McHenry Counties in Illinois. Using the Health System Analysis Template provided by Komen Headquarters, Komen Chicago's Community Profile Team analyzed the locations of 157 Hospitals, Federally Qualified Health Centers, Grantee organizations, Title X facilities, Free Health care and Mammography Clinics according to the total number of facilities in conjunction with the total number of services offered throughout Cook and McHenry Counties.

There are 157 permanent mammography facilities in Cook and McHenry Counties. There are a substantial number of facilities that provide mammography screening and diagnostic services in the aforementioned counties. The majority of these facilities are located in Cook County (93.0 percent), with the highest concentration of locations being in the City of Chicago (55.0 percent). Only 12 locations are identified within McHenry County (7.0 percent). There are only three health care facilities in McHenry County that encompass the entire continuum of care. In addition to having few treatment and support facilities in McHenry County, it also appears that many people must cross the state line to receive treatment (i.e. Mercy Hospital Health System sends its patients to Lake Geneva, WI.) Across both Cook and McHenry Counties, there is a lack of available support services. A deeper understanding of the barriers to accessing breast cancer care will be examined in the Qualitative Data collection and analysis section of the Community Profile Report.

An analysis of the continuum of care in the targeted communities through a review of existing community assets and legislative issues reveal a shortage of medical providers, facilities and resources in certain areas of the target communities. Focusing on the continuum of care will ensure access into and through the breast health care system at each level by addressing the barriers that women seeking services encounter as well as the barriers that agencies providing those services face.

The Affiliate has several opportunities to deepen existing partnerships and create new venues that lead to policy change and access to quality breast health services in Illinois. The Affiliate is excited to continue its work with the Metropolitan Chicago Breast Cancer Task Force Quality Consortium and the Greater Roseland Breast Health Consortium which both address the

growing disparity in breast cancer deaths between Black/African-American and White women in Chicago. The Affiliate will also continue to strengthen the relationship with its community partners at the McHenry County Breast Cancer Task Force. By joining the Illinois Cancer Partnership, the Affiliate is expanding its network as well as joining forces statewide to reduce the incidence, morbidity and mortality of cancer and enhance survivorship in Illinois.

Public policy directly impacts breast health care. Laws regulate and support access to care and the health care system. There have been and continue to be monumental changes within the US health care system; however, the need to ensure access to quality, evidence-based health care institutions and screening equipment for all women nationwide remains.

Komen Chicagoland Area is committed to continue its vital public policy campaign to help reduce the toll of breast cancer disparities in Illinois women. The Affiliate will work collaboratively with all Illinois Affiliates to ensure the use of a statewide strategy to create public policy change. The key goals for the following years are as follows:

- Maintaining funding for the Illinois Breast and Cervical Cancer Program, the state's CDC-funded screening program for uninsured women, in the face of massive state budget cuts to health and human services programs.
- Supporting other federal public policy initiatives as outlined by Komen Headquarters.
- Continue to work with partners to ensure more patient navigation programs, and that screenings are covered by public and private insurance plans, at a quality academic or medical facility.

**Qualitative Data: Ensuring Community Input**

Information was collected to document important attitudes and beliefs of women utilizing the breast health care system that impact breast cancer outcomes for underserved women. Both women in the community and key informants (health care professionals, community stakeholders and breast cancer survivors) were surveyed. Focus group discussions (FGDs), key informant interviews and surveys were conducted in Komen's target communities, Cook and McHenry Counties, between October and November 2014. Information was gathered from three FGDs consisting of 32 women, 30 key informant interviews, and 126 completed surveys. Socio-demographic and community resource information was also obtained from all participants before or after completion of the FGDs, key informant interviews, and surveys. All data were imported into an Excel spreadsheet, verified and cleaned. Analysis of data themes was done using a content analysis approach to report findings.

A small sample size for focus group discussions, key informant interviews, and surveys makes findings not representative of the whole population. Though the sample size is small, one is able to generalize findings to the accessible population, which were the participants that were able to engage for the purpose of this report (Patten, 2011). Although the Affiliate was looking to examine both Cook and McHenry Counties, due to extremely limited knowledge of the resources and access to community organizations and their personnel, findings of this report reflect more on Cook County, which is a county that has established relationships with the

Komen Chicagoland Area. The Affiliate intends to address the apparent lack of available specific breast health data in McHenry County by initiating partnerships with community organizations, academic institutions, and public entities to help create an environment in which this vital information can be queried and made readily available. The creation of a breast health partnership within this county will help to inform service organizations about the needs within this vastly rural county. The Affiliate's Mission Action Plan will address the next steps towards ensuring the breast health needs of McHenry County women will be addressed.

Qualitative data collected for this Community Profile reflects the diversity and complex health care landscape of Cook County, Illinois. The majority of survey respondents were Black/African-American women residing in neighborhoods and community areas in Cook County, IL designated high-risk for breast cancer by Metropolitan Chicago Breast Cancer Task Force (MCBCTF, 2014). It should be noted that qualitative data collection relied on self-reported information. It is reasonable to assume that actual mammography utilization may differ from the numbers included in this report.

Concurrent with the Health Systems and Policy Analysis, many of the Cook County female respondents suggested that they either did not know where mammography resources were located in their immediate community, or chose not to access those services in their local community. This disconnect from community health resources reflects a broader issue regarding the disproportionate allocation of health care centers equipped to provide quality mammography and follow-up care to women in majority Black/African-American and Hispanic/Latino communities on the South and West sides of Chicago. Access and quality of care in target communities is a source of concern for women and was echoed in the responses of several key informant interviews. The qualitative report revealed the importance of state funded programs like the Illinois Breast and Cervical Program (IBCCP) from community members and health professionals alike. Such programs support the breast cancer continuum of care and support closing the disparities gap in communities of women.

The demography and health care service allocation in McHenry County is substantially different from Cook County. As stated in the health systems analysis, McHenry County is markedly rural. Women residing here often must travel several miles, often times across state lines, to reach a mammography facility. Other concerns from key informants reflected a Hispanic/Latino population (12 percent) experiencing a level of anxiety from language and immigration status barriers that make accessing health care and preventative services more difficult.

With the implementation of the Affordable Care Act over the last two years, more women are becoming insured, some gaining access to consistent health care for the first time. Fear, health literacy deficits, economic constraints, and mistrust of the health care system are just some of the most common obstacles that affect access and utilization of the continuum of care in breast health in Cook and McHenry Counties. Low prevalence of mammography screening among women over 40 years of age in both counties may be a result of numerous interconnected social and health systems level barriers that need to be addressed.

The Qualitative Data Report revealed powerful themes of fear, mistrust of the health care system, low health literacy, and lack of affordability in both Cook and McHenry Counties. Participants in focus group discussions, key informant interviews, and surveys repeatedly attributed a woman's disinclination to screening with feelings of fear of cancer diagnosis or discomfort. Poor understanding of the screening process due to limited knowledge of preventative health recommendations and low utilization of screening among a woman's family and social groups was also found to be a contributing factor. Coupled with the concern of high cost of mammography for uninsured and underinsured women, regular screenings are often foregone due to other obligations, such as bills or medical needs.

Misconception and mistrust unfortunately persist surrounding topics of medicine and health care in the Affiliate's target communities. Beliefs that radiation from mammography cause cancer continue despite attempts by organizations such as Susan G. Komen to inform the public about the benefits of screening. Additionally, mistrust of the health care system as an institution, particularly among African-Americans continues to shape how this community engages with health care. The mistrust of the medical community may likely contribute to low screening and health literacy due to a lack of comfort and familiarity. The literature shows that low screening percentages directly correspond to the delay in cancer diagnosis, which can lead to a poorer prognosis. These barriers appear to overlap and fuel a cycle of negative health behaviors that can lead to poor health outcomes, contributing to even more apprehension and fear.

While the Qualitative Report availed important insights on attitudes, behaviors and perceptions about breast health in the target communities, limitations in data collection for McHenry County must be addressed in future needs assessments for the Community Profile.

Key Questions from Qualitative Data:

- What health systems improvements can be implemented to avail greater access to screenings and other preventative health services for women with social, financial or other barriers that frequently prevent adherence to annual screening recommendations?
- What innovative measures can be taken to address deep-seated feelings of mistrust many racial minority groups harbor towards the health care system?
- How can the Affiliate further support robust r health education in the target communities?
- How can the Affiliate help facilitate greater communication and partnership among McHenry County community stakeholders and breast health professionals to ensure access to women?

**Mission Action Plan**

# Susan G. Komen®- Chicagoland
# Mission Action Plan
# 2016-2019

**Problem Statement**

African American/Black and Hispanic/Latina women in Cook and McHenry Counties have limited access to high quality breast cancer screening and breast health services. Cook and McHenry Counties are also unlikely to meet the Healthy People 2020 target interventions for their breast cancer death rate, low screening proportions and late-stage breast cancer diagnosis. Lastly, in both counties, there is a consensus for mistrust of the healthcare system, low health literacy and lack of affordability.

## *Grant Making*

**Priority 1:**

Increase access to quality breast cancer screening, diagnosis and treatment services by reducing financial barriers for uninsured and under-insured African American/Black and Hispanic/Latina women residing in Cook and McHenry Counties.

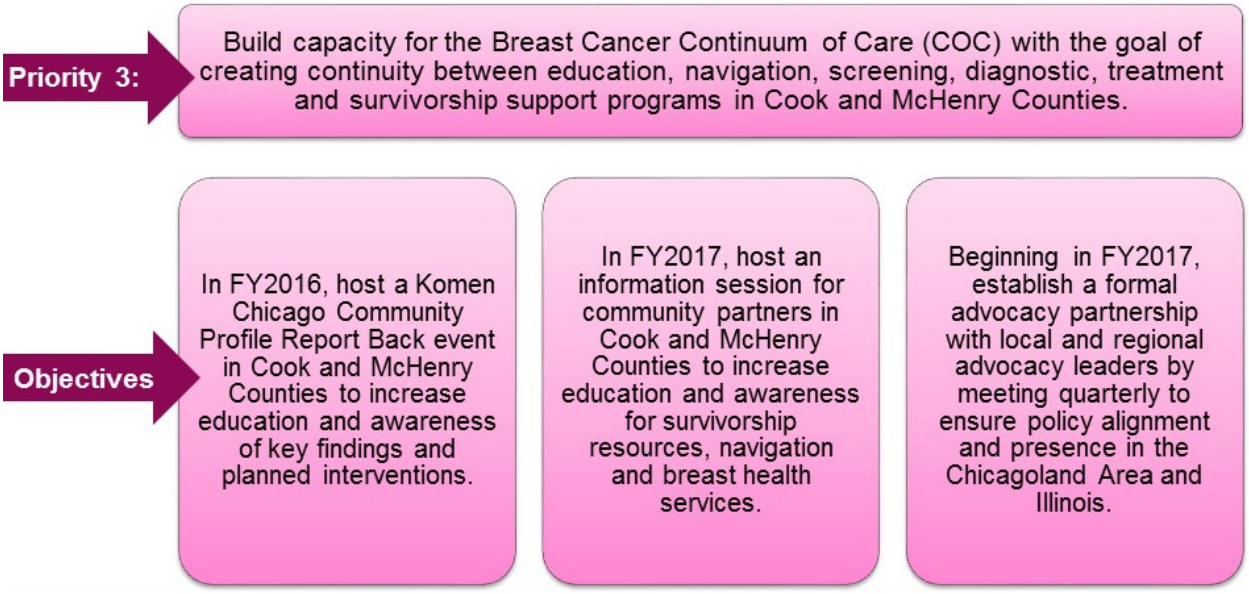
**Objectives**

The FY 2017 Community Grant RFA will give special consideration to applicants who are participating in the Metropolitan Chicago Breast Cancer Task Force's Quality Care Consortium.

In the Fall of 2015, host two grant writing workshops in Cook and McHenry Counties that emphasize the importance of program evaluation and data collection.

## Education and Community Outreach


## Health Systems Variation/Public Policy




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

# Introduction

## Affiliate History

Susan G. Komen® Chicagoland Area was established in 1997 and held the first Susan G. Komen Chicagoland Area Race for the Cure®. With the support of the signature fundraiser, the Komen Chicagoland Area Race for the Cure, Komen Chicagoland Area has awarded over $15 million towards the fight against breast cancer in the five county service area of Cook, DuPage, Kane, Lake and McHenry Counties.

In 2014, Komen Chicagoland Area granted nearly $1.3 million to 17 local organizations funding lifesaving breast health navigation, breast cancer screening, diagnostics, treatment and treatment support services for uninsured and underinsured men and women, as well as national research. In response to the 2011 Community Profile Report, Komen Chicagoland Area successfully launched the small grants program which provides organizations with technical assistance and capability-building to support the operations of their programs. To date, Komen Chicagoland Area has awarded over $35,000 to four community organizations. Seventy-five percent of the net proceeds raised by the Affiliate are dedicated to fighting breast cancer locally in the Chicagoland metropolitan area. The remaining 25 percent of net proceeds raised are contributed to the Komen Headquarters Research Programs.

Komen Chicagoland Area was awarded the 2010 Affiliate of the Year by Susan G. Komen. In 2014, Susan G. Komen Chicagoland Area received the Inspire Award from Presence Saints Mary and Elizabeth Medical Center for exceptional leadership and bringing a spirit of hope to the community.

Komen Chicagoland Area remains a leader in the breast health community by serving on the McHenry County Women's Cancer Task Force, the Greater Roseland Breast Health Consortium, and the Chicago Women's Health Awareness Council, as well as providing funding for five lead agencies in the Illinois Breast and Cervical Cancer Program.

## Affiliate Organizational Structure

Komen Chicagoland Area staff positions, as of March 2015, include:

- Chief Executive Officer
- Director – Income Development & Marketing
- Director – Community Programs
- Community Programs Manager
- Senior Manager, Development & Volunteer Programs
- Senior Manager, Finance & Operations
- Office Coordinator & Executive Assistant

Please see Figure 1.1 for the Komen Chicagoland Area Board of Directors organizational structure.

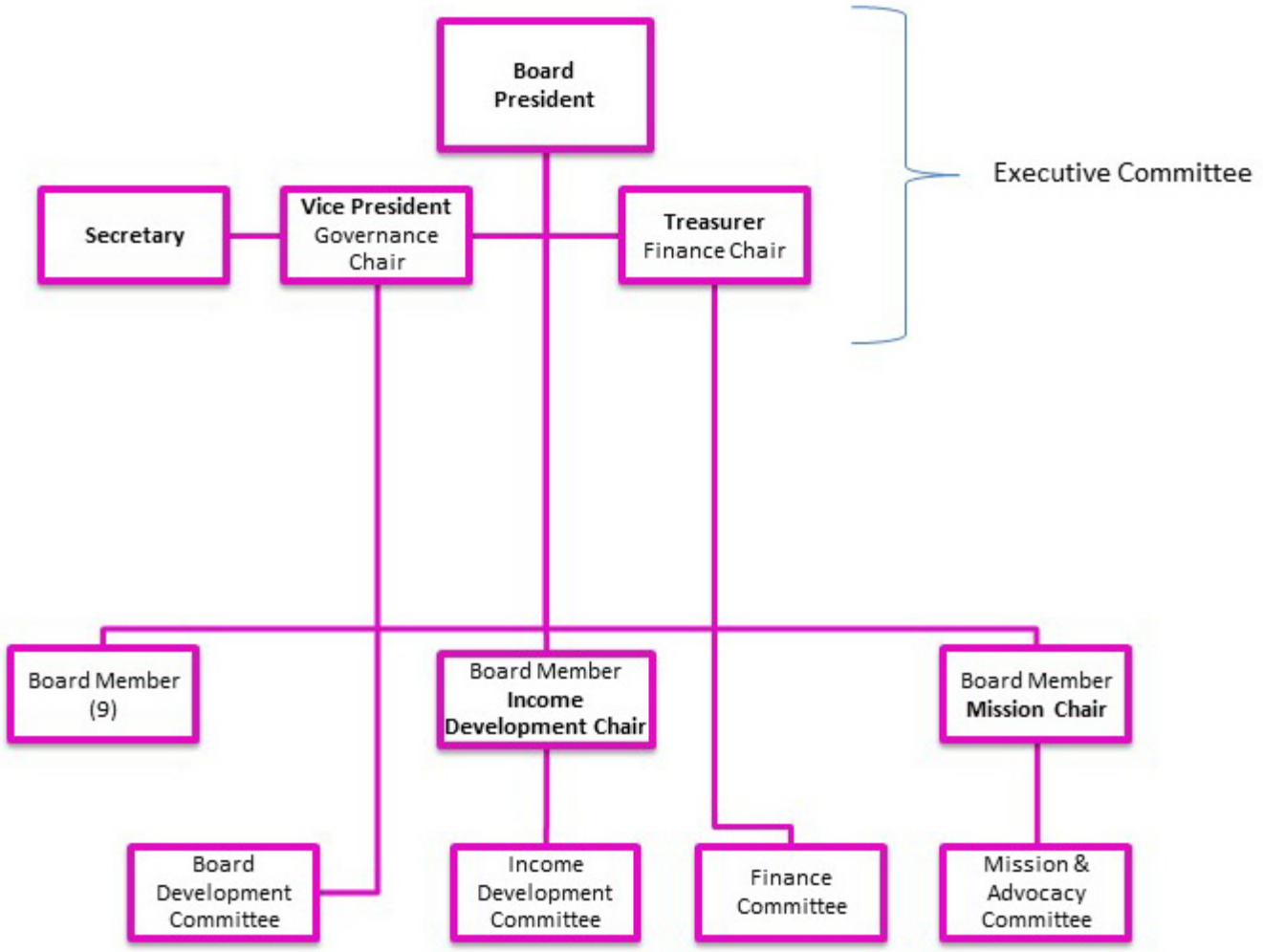



**Figure 1.1.** Komen Chicagoland Area Board of Directors organizational structure

## Affiliate Service Area

The female population of Susan G. Komen Chicagoland Area is 71.8 percent White, 21.5 percent Hispanic/Latino, and 20.3 percent Black/African-American. While Cook County is an urban county, DuPage, Lake, and Kane Counties are suburban, and McHenry County is the most rural in the five county service area (Figure 1.2). With 35.8 percent of the population living below the national 250 percent poverty line, Komen Chicagoland Area has a higher percentage of poverty than the national average of 33.3 percent. Komen Chicagoland Area also has higher rates of unemployment, and individuals who are reportedly uninsured.

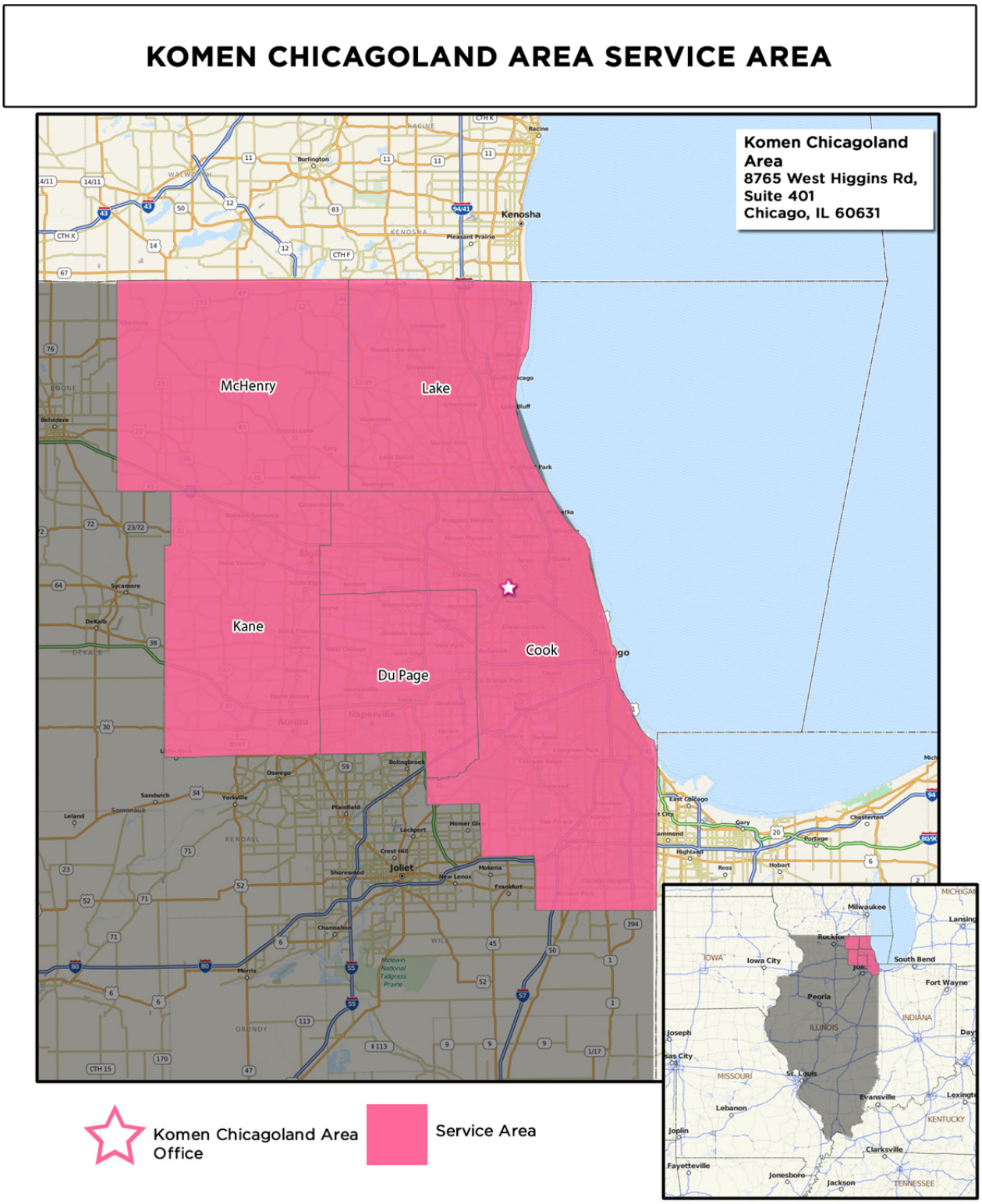



**Figure 1.2.** Susan G. Komen Chicagoland Area service area

## Purpose of the Community Profile Report

Susan G. Komen Chicagoland Area completed the 2015 Community Profile in order to better understand its service area, to establish focused Community-Based Grant priorities, identify community education needs, strengthen sponsorship and fundraising efforts in the five county service area, drive public policy efforts, establish directions for marketing and outreach, align the Affiliate's strategic and operational plan and drive inclusion efforts in the community.

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The 2015 Komen Chicagoland Area Community Profile report will be posted on the Affiliate's website, referenced in all Komen Chicagoland Area Volunteer Orientations and Grantee Trainings, as well as the mandatory Grant Application Workshops. The findings from the 2015 Community Profile Report will also be shared with the community at large at the annual Komen Chicagoland Area Hope Impact Awards, The Greater Roseland Breast Health Consortium meeting, McHenry County Women's Task Force meeting, and various community outreach events in the Chicagoland area.

# Quantitative Data: Measuring Breast Cancer Impact in Local Communities

## Quantitative Data Report

### Introduction

The purpose of the quantitative data report for Susan G. Komen® Chicagoland Area 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 rates (http://www.healthypeople.gov/2020/default.aspx).

The following is a summary of Komen® Chicagoland Area's 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

| | | Incidence Rates and Trends | | | Death Rates and Trends | | | Late-stage Rates and Trends | | |
|---|---|---|---|---|---|---|---|---|---|---|
| Population Group | 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% |
| Komen Chicagoland Area Service Area | 3,885,904 | 5,318 | 128.8 | 0.4% | 1,043 | 24.5 | NA | 2,014 | 48.8 | 0.7% |
| White | 2,794,166 | 4,037 | 131.5 | 0.3% | 749 | 23.1 | NA | 1,444 | 47.3 | 0.7% |
| Black/African-American | 802,978 | 999 | 124.8 | 0.6% | 270 | 34.1 | NA | 456 | 56.6 | -0.2% |
| American Indian/Alaska Native (AIAN) | 28,517 | 4 | 26.1 | -4.6% | SN | SN | SN | SN | SN | SN |
| Asian Pacific Islander (API) | 260,243 | 217 | 86.8 | 2.3% | 23 | 9.8 | NA | 91 | 35.6 | 3.7% |
| Non-Hispanic/ Latina | 3,097,590 | 4,919 | 134.4 | 0.5% | 988 | 25.7 | NA | 1,837 | 50.6 | 0.8% |
| Hispanic/ Latina | 788,315 | 398 | 84.8 | 1.2% | 49 | 10.9 | NA | 177 | 36.0 | 0.5% |
| Cook County - IL | 2,668,038 | 3,596 | 125.9 | 0.5% | 756 | 25.5 | -2.4% | 1,384 | 48.7 | -0.2% |
| DuPage County - IL | 464,140 | 725 | 142.0 | 0.0% | 116 | 21.9 | -3.3% | 262 | 51.4 | 0.5% |
| Kane County - IL | 251,575 | 306 | 126.6 | 0.2% | 54 | 22.3 | -2.9% | 108 | 44.4 | 0.1% |
| Lake County - IL | 348,833 | 489 | 135.2 | -1.5% | 79 | 22.4 | -2.4% | 180 | 49.6 | 1.9% |
| McHenry County - IL | 153,318 | 202 | 126.8 | 4.1% | 38 | 25.1 | -2.4% | 80 | 49.9 | 16.2% |

*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) mortality 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 and trend in the Komen Chicagoland Area service area were higher than that observed in 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.

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, lower among APIs than Whites, and lower among AIANs than Whites. The incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

The following county had an incidence rate **significantly higher** than the Affiliate service area as a whole:

- DuPage County

The rest of the counties had incidence rates and trends that were not significantly different than the Affiliate service area as a whole or did not have enough data available.

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 Chicagoland Area service area was slightly higher than that observed in the US as a whole and the death rate trend was not available for comparison with the US as a whole. The death rate of the Affiliate service area was not significantly different than that observed for the State of Illinois.

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. For the Affiliate service area as a whole, the death rate was higher 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 death rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

The death rate was significantly lower in the following county:

- DuPage County

The rest of the counties had death rates and trends that were not significantly different 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 and trend in the Komen Chicagoland Area service area were higher than that observed in the US as a whole. The late-stage incidence rate of the Affiliate service area was **significantly higher** than that observed for the State of Illinois and the late-stage incidence trend was not significantly different than the State of Illinois.

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 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 late-stage incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

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

- McHenry County

The rest of the counties had late-stage incidence rates and trends that were not significantly different than the Affiliate service area as a whole or did not have enough data available.

**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 Cancer Institute | National Comprehensive Cancer Network | US Preventive Services Task Force |
|---|---|---|---|
| Mammography every year starting at age 40 | Mammography every 1-2 years starting at age 40 | Mammography every year starting at age 40 | Informed decision-making with a health care provider ages 40-49<br><br>Mammography every two years ages 50-74 |

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. BRFSS is the best and

most widely used source available for information on mammography usage among women in the United States, although it does not collect data matching Komen screening recommendations (i.e. from women age 40 and older). 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% |
| Komen Chicagoland Area Service Area | 883 | 678 | 79.2% | 75.6%-82.5% |
| White | 676 | 512 | 79.6% | 75.4%-83.2% |
| Black/African-American | 163 | 128 | 78.2% | 68.7%-85.4% |
| AIAN | SN | SN | SN | SN |
| API | 16 | 14 | 79.0% | 52.1%-92.9% |
| Hispanic/ Latina | 64 | 54 | 85.9% | 69.8%-94.1% |
| Non-Hispanic/ Latina | 814 | 621 | 78.4% | 74.6%-81.7% |
| Cook County - IL | 528 | 401 | 79.7% | 74.8%-83.8% |
| DuPage County - IL | 137 | 111 | 81.4% | 71.4%-88.5% |
| Kane County - IL | 72 | 53 | 77.5% | 63.9%-87.0% |
| Lake County - IL | 94 | 77 | 80.8% | 69.5%-88.6% |
| McHenry County - IL | 52 | 36 | 67.8% | 49.8%-81.7% |

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 Chicagoland Area 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.

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. For the Affiliate service area as a whole, the screening proportion was not significantly different among Blacks/African-Americans than Whites and not significantly different 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 screening proportion among Hispanics/Latinas was not significantly different than among Non-Hispanics/Latinas.

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 % |
| Komen Chicagoland Area Service Area | 71.8 % | 20.3 % | 0.8 % | 7.1 % | 78.5 % | 21.5 % | 46.4 % | 32.5 % | 13.4 % |
| Cook County - IL | 65.3 % | 26.9 % | 0.9 % | 6.9 % | 77.0 % | 23.0 % | 45.7 % | 32.5 % | 13.9 % |
| DuPage County - IL | 83.0 % | 5.6 % | 0.5 % | 11.0 % | 87.1 % | 12.9 % | 49.8 % | 34.6 % | 13.4 % |
| Kane County - IL | 88.0 % | 6.8 % | 1.1 % | 4.1 % | 70.1 % | 29.9 % | 44.0 % | 29.2 % | 11.2 % |
| Lake County - IL | 83.8 % | 8.0 % | 1.0 % | 7.2 % | 80.5 % | 19.5 % | 48.0 % | 32.2 % | 12.0 % |
| McHenry County - IL | 95.0 % | 1.4 % | 0.5 % | 3.1 % | 88.9 % | 11.1 % | 49.2 % | 32.0 % | 11.7 % |

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 % |
| Komen Chicagoland Area Service Area | 14.6 % | 13.2 % | 30.3 % | 10.0 % | 19.8 % | 8.0 % | 0.8 % | 15.7 % | 17.2 % |
| Cook County - IL | 16.3 % | 15.8 % | 35.8 % | 10.8 % | 21.0 % | 8.8 % | 0.0 % | 21.5 % | 20.1 % |
| DuPage County - IL | 8.1 % | 6.2 % | 17.2 % | 7.7 % | 18.3 % | 5.4 % | 0.0 % | 0.0 % | 10.4 % |
| Kane County - IL | 16.9 % | 10.1 % | 24.5 % | 8.7 % | 18.1 % | 10.4 % | 3.6 % | 12.6 % | 14.2 % |
| Lake County - IL | 11.4 % | 8.2 % | 19.5 % | 8.6 % | 18.1 % | 5.5 % | 1.3 % | 2.9 % | 11.6 % |
| McHenry County - IL | 8.1 % | 6.9 % | 19.3 % | 8.8 % | 9.8 % | 3.2 % | 9.9 % | 0.0 % | 10.9 % |

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

The following county has substantially larger Black/African-American female population percentages than that of the Affiliate service area as a whole:

- Cook County

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

- DuPage County

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

- Kane County

**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: 41.0 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 Chicagoland 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 | | | | |
|---|---|---|---|---|---|---|
| **Time to Achieve Death Rate Reduction Target** | | 13 years or longer | 7-12 yrs. | 0 – 6 yrs. | Currently meets target | Unknown |
| | 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 Chicagoland 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 |
|---|---|---|---|---|
| Cook County - IL | High | 9 years | 13 years or longer | %Black/African-American, medically underserved |
| McHenry County - IL | High | 9 years | 13 years or longer | Rural |
| DuPage County - IL | Medium High | 2 years | 13 years or longer | %API |
| Kane County - IL | Medium High | 3 years | 13 years or longer | %Hispanic/Latina |
| Lake County - IL | Medium High | 4 years | 13 years or longer | |

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.

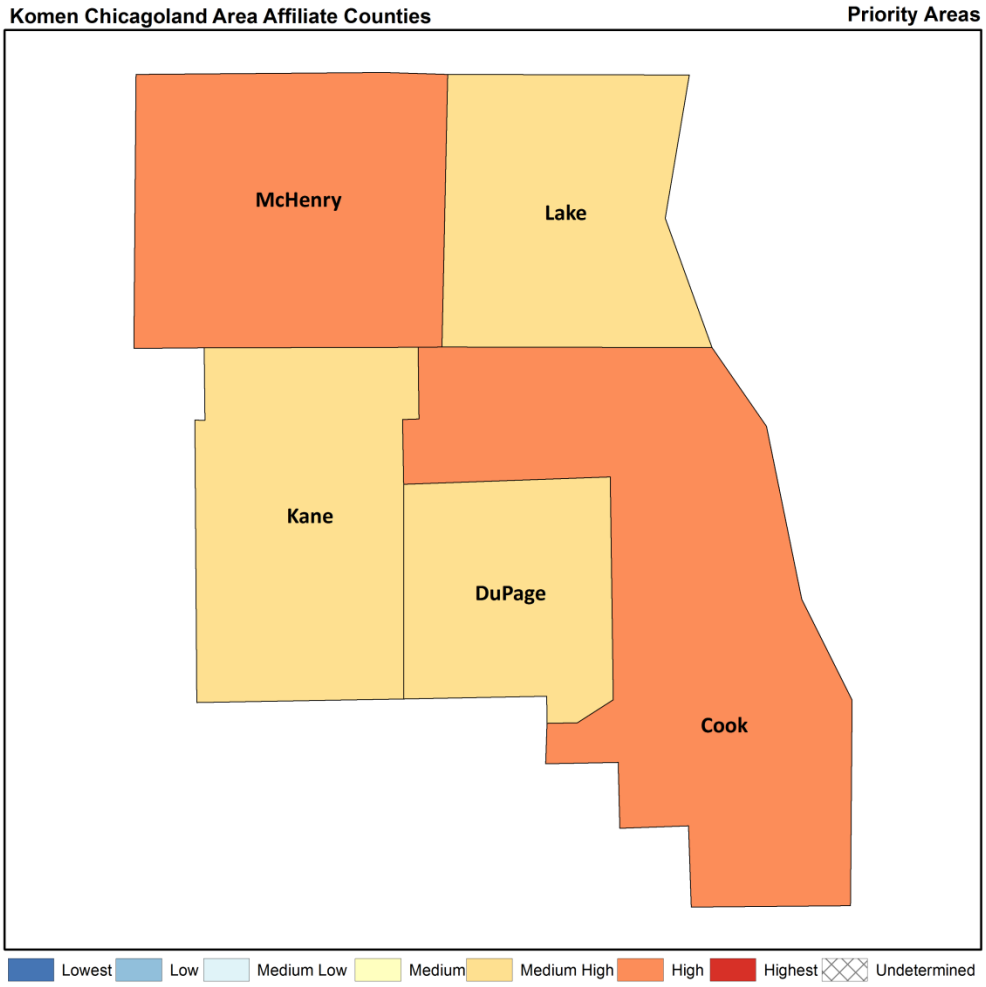



**Figure 2.1.** Intervention priorities

**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**

***High priority areas***

Two counties in the Komen Chicagoland Area service area are in the high priority category. Both of the two, Cook County and McHenry County, are not likely to meet the late-stage incidence rate HP2020 target.

Late-stage incidence trends in McHenry County (16.2 percent per year) are significantly less favorable than the Affiliate service area as a whole (0.7 percent per year).
Cook County has a relatively large Black/African-American population.

***Medium high priority areas***

Three counties in the Komen Chicagoland Area service area are in the medium high priority category. All of the three, DuPage County, Kane County and Lake County, are not likely to meet the late-stage incidence rate HP2020 target.

The incidence rates in DuPage County (142.0 per 100,000) are significantly higher than the Affiliate service area as a whole (128.8 per 100,000).

DuPage County has a relatively large API population. Kane County has a relatively large Hispanic/Latina population.

## Additional Quantitative Data Exploration

The data provided by Susan G. Komen for the screening mammography utilization was taken from an unreliably small sample size. In order to do due diligence, Komen Chicagoland Area collected and analyzed data from the Illinois Behavioral Risk Factor Surveillance System, which provided data from 2007-2009. Table 2.8 shows the percentage of women 40 years of age and older who reported never having had a mammogram, and those who reported having a mammogram more than a year prior. Because this information relies on self-report, it may not paint an accurate picture of mammography utilization in the Komen Chicagoland Area service area.

**Table 2.8**. Mammography Utilization for Females 40 Years of Age and Older by County, Komen Chicagoland Area Service Area, 2007-2009

| Area | Count | Prevalence (%) | Confidence Interval (%) |
|---|---|---|---|
| **Have never had a mammogram (Women 40+)** | | | |
| Chicago | 57,883 | 9.8% | ± 5.7% |
| Suburban Cook | 50,342 | 8.5% | ±6.2% |
| DuPage | 11,441 | 5.5% | ± 3.9% |
| Kane | 4,988 | 5.1% | ± 3.2% |
| Lake | 6,149 | 4.1% | ± 3.2% |
| McHenry | 8,369 | 4.1% | ± 3.7% |
| ***Total for Service Area*** | ***139,172*** | | |
| **No Mammogram in the last 12 months (Women 40+)** | | | |
| Chicago | 167,265 | 68.7% | ± 9.9% |
| Suburban Cook | 196,414 | 36.4% | ± 8.2% |
| DuPage | 58,803 | 29.7% | ± 7.9% |
| Kane | 31,304 | 33.7% | ± 8.0% |
| Lake | 45,346 | 31.7% | ± 7.5% |
| McHenry | 18,908 | 32.6% | ± 7.5% |
| ***Total for Service Area*** | ***518,040*** | | |

Source: 2007-2009 Illinois Behavioral Risk Factor Surveillance System

At the county level, the City of Chicago (Cook County, IL) had the largest amount of women who have never received a mammogram. It was followed by Suburban Cook County, which had the second highest amount of women whom either have never received a mammogram or had not received a mammogram **in the last 12 months.** This is in stark contrast to some of the other counties in the Komen Chicagoland Area service area. McHenry County has the lowest prevalence or percentage of women who reported never having a mammogram, but due to the smaller population of the county compared to Chicago and Cook County, the actual numbers are much lower. Table 8 also reveals that DuPage County also has the lowest percentage of those not having a mammogram in the past year.

Table 2.9 shows the percentage of women 40 years of age and older who have ever received a mammogram. Because this information relies on self-report, it may not paint an accurate picture of mammography utilization in the Komen Chicagoland Area service area. These data show that more than 60.0 percent of White women and those with either a high school diploma or some college reported having ever had a mammogram. Data for all other ethnic groups and education levels were unavailable.

**Table 2.9.** Mammography Utilization (women who have ever received a mammogram) by Race/Ethnicity and Education, Females Ages 40 Years and Over, 2014

| **Service Area** (Cook, DuPage, Kane, Lake, McHenry) | **Prevalence** |
|---|---|
| **Race/Ethnicity** | |
| White | 62.2% |
| African-American | NA% |
| Hispanic | NA% |
| Other | NA% |

| **Service Area** (Cook, DuPage, Kane, Lake, McHenry) | **Prevalence** |
|---|---|
| **Education Level** | |
| Less than High School | NA% |
| High School Graduate | 66.5% |
| Some College | 60.2% |
| College Graduate | NA% |

Source: Illinois Behavioral Risk Factor Surveillance System, 2014

## Selection of Target Communities

In order to be the most efficient stewards of resources, Susan G. Komen® Chicagoland Area has chosen two target communities within the service area. The Affiliate will focus strategic efforts on these target communities over the course of the next four years. Target communities are those communities 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 to accessing care.

When selecting target communities, the Affiliate reviewed Healthy People 2020, a major federal government initiative that provides specific objectives for communities and the country as a whole. Specific to Komen Chicagoland Area's work, goals around reducing women's death rate

from breast cancer and reducing the number of breast cancers found at a late-stage were analyzed. Through this review, areas of priority were identified based on the time needed to meet Healthy People 2020 targets for breast cancer.

Additional key indicators the Affiliate reviewed when selecting target counties included, but were not limited to:

- Incidence rates and trends
- Death rates and trends
- Late-stage rates and trends
- Below average screening percentages
- Residents living below poverty level
- Residents living without health insurance
- Unemployment percentages
- Residents who are culturally and linguistically isolated and/or foreign born

The selected target communities are:

- **Cook County, Illinois**
- **McHenry County, Illinois**

**Cook County, Illinois**

A high priority county in regards to meeting the Healthy People 2020 goals, Cook County, IL is comprised largely of the City of Chicago, IL. It is an urban county located just west of Lake Michigan. The county's 2,668,038 women represent the most diverse population in the Affiliate's service area. Of these women, 26.9 percent are Black/African-American, a rate higher than the national average and the service area average. This is important due to the high death rate Black/African-American women experience from breast cancer when compared to other races. Additionally, 23.0 percent of the county is Hispanic/Latina, 8.8 percent is linguistically isolated, and 21.0 percent are foreign born. All of these percentages are higher than the Affiliate service area's average.

Cook County has been identified as a high priority county due to the amount of intervention time needed to achieve the HP2020 targets. For instance, the county's death rate of breast cancer is 25.5 per 100,000, which represents the highest in the Affiliate's service area and is higher that state and national rates (Table 2.10). The target for HP2020 is 20.6 deaths per 100,000. In addition to the alarmingly high breast cancer death rates, this county has also been chosen due to low screening percentages, unique population demographics, and higher percentages of those that are medically underserved and have lower income levels.

**Table 2.10:** Cook County breast cancer statistics

| | Cook County | Affiliate Service Area | US Rates |
|---|---|---|---|
| **Incidence Rate*** | 125.9 | 128.8 | 122.1 |
| **Death Rate*** | 25.5 | 24.5 | 22.6 |
| **Late-Stage Rate*** | 48.7 | 48.8 | 43.8 |

Source: 2006-2010
*Age-Adjusted Rates per 100,000 women

The City of Chicago is well-known for Illinois Medical Districts, which include four world-class hospitals: Rush University Medical Center, Jesse Brown VA Medical Center, John H. Stroger, Jr., Hospital of Cook County, and the University of Illinois Hospital and Health Sciences System. For many of Cook County residents these institutions are out of reach and make identifying and accessing quality community facilities even more difficult.

Finally, the socioeconomic characteristics of this county indicate a potential concern about women's access to affordable breast health care. Cook County leads the Affiliate service area in residents living below 250 percent of poverty, unemployment, foreign born, residing in medically underserved areas as well as uninsured.

The health system analysis component of this report will take a deeper look at the availability of breast health services in the county. Due to the county's urban nature and many areas being designated as medically underserved, it is vitally important to gain a clear understanding of how accessible breast health services are in the county.

**McHenry County, IL**

Located 55 miles northwest of the City of Chicago, McHenry County, IL, with 9.9 percent of residents residing in rural areas, is considered to be the most rural county within the Affiliate's services area. The annual average female population is 153,318. White women make up approximately 95.0 percent; 1.4 percent of women are Black. Approximately, 11.1 percent of the population identify themselves as Hispanic/Latina.

McHenry County has been selected as a target community due to the amount of intervention time needed to achieve the HP2020 targets based on the rates and trends regarding breast cancer deaths, low mammography utilization percentage, as well as the rates of breast cancer incidence and late-stage diagnosis. For instance, the county's late-stage breast cancer diagnosis rate is 49.9 per 100,000, which represents the second highest in the Affiliate's service area and is higher than state and national rates (Table 2.11). The target for HP2020 is 41.0 cases per 100,000. The rising trend for late-stage breast cancer diagnosis is 16.2 percent, the highest in the Affiliate's service area and significantly higher than the trend in the state of Illinois and the United States. There is a significant likelihood that female breast cancer occurred more frequently among women in McHenry County than among those in the Affiliate as a whole, which is unfavorable for the county.

**Table 2.11.** McHenry County Breast Cancer Statistics

| | McHenry County | Affiliate Service Area | US Rates |
|---|---|---|---|
| **Incidence Rate*** | 126.8 | 128.8 | 122.1 |
| **Death Rate*** | 25.1 | 24.5 | 22.6 |
| **Late-Stage Rate*** | 49.9 | 48.8 | 43.8 |

Source: 2006-2010

*Age-Adjusted Rates per 100,000 women

Finally, much of the county is rural, where services may not be readily accessible. A health system analysis will provide a deeper look at any underserved areas in McHenry County. It appears that many residents would benefit from services within their neighborhoods that are no-cost or reduced cost, culturally sensitive and easily accessible. The actual availability of these services will be reviewed in a health system analysis.

## Health Systems Analysis Data Sources

The Health System Analysis is an effort to understand the gaps, needs and limitations in the health system that affect a woman's transition throughout the breast cancer continuum of care (education, screening, diagnosis, treatment, follow-up care, and survivorship). Susan G. Komen® Chicagoland Area utilized various resources to create a comprehensive listing of all breast health care facilities in the service area including: The National Association of County and City Health Officials website, The National Association of Free and Charitable Clinics, Medicare.gov, current and past Komen Chicagoland Area grantees, the Cancer Matters 2014-2015 Resource Guide as well as a comprehensive state list provided by Susan G. Komen Headquarters. The Affiliate did not include children's hospitals, long-term care hospitals, rehabilitation institutions, or behavioral health facilities.

Based on the quantitative findings and the Health System Analysis Template, asset maps are being created by Komen Headquarters for Cook and McHenry Counties to better understand the issues concerning the continuum of care. The data collection included findings from the above aforementioned websites, publications and follow up phone calls.

There are well over 350 health care facilities located within Cook, DuPage, Kane, Lake, and McHenry Counties in Illinois. Using the Health System Analysis Template provided by Komen Headquarters, Komen Chicagoland Area's Community Profile team analyzed the locations of 157 Hospitals, Federally Qualified Health Centers, Grantee organizations, Title X facilities, Free Health care and Mammography Clinics according to the total number of facilities in conjunction with the total number of services offered throughout Cook and McHenry Counties.

## 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. 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.

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-

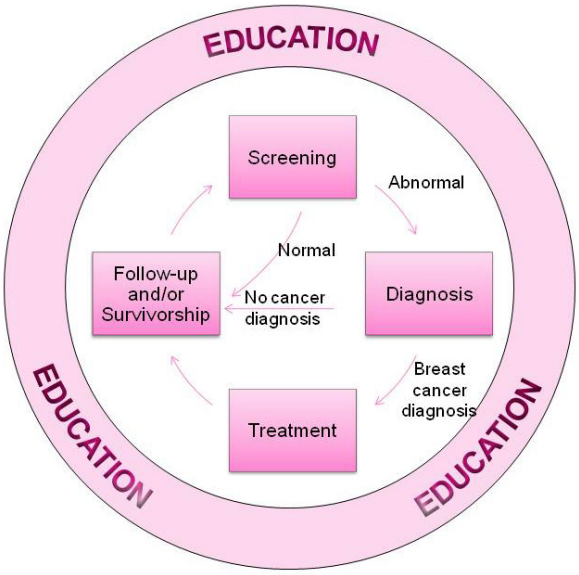



**Figure 3.1.** Breast Cancer Continuum of Care (CoC)

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.

There are 157 permanent mammography facilities in Cook and McHenry Counties. There are a substantial number of facilities that provide mammography screening and diagnostic services in the aforementioned counties. The majority of these facilities are located in Cook County (93.0 percent), with the highest concentration of locations being in the City of Chicago (55.0 percent) (Figure 3.2). Only 12 locations are identified within McHenry County (7.0 percent) (Figure 3.3). There are only three health care facilities in McHenry County that encompass the entire

continuum of care. In addition to having few treatment and support facilities in McHenry County, it also appears that many people must cross the state line to receive treatment (i.e. Mercy Hospital Health System sends its patients to Lake Geneva, WI.) Across both counties, there is a lack of available support services. A deeper understanding of the barriers to accessing breast cancer care will be examined in the Qualitative Data collection and analysis section of the Community Profile Report.

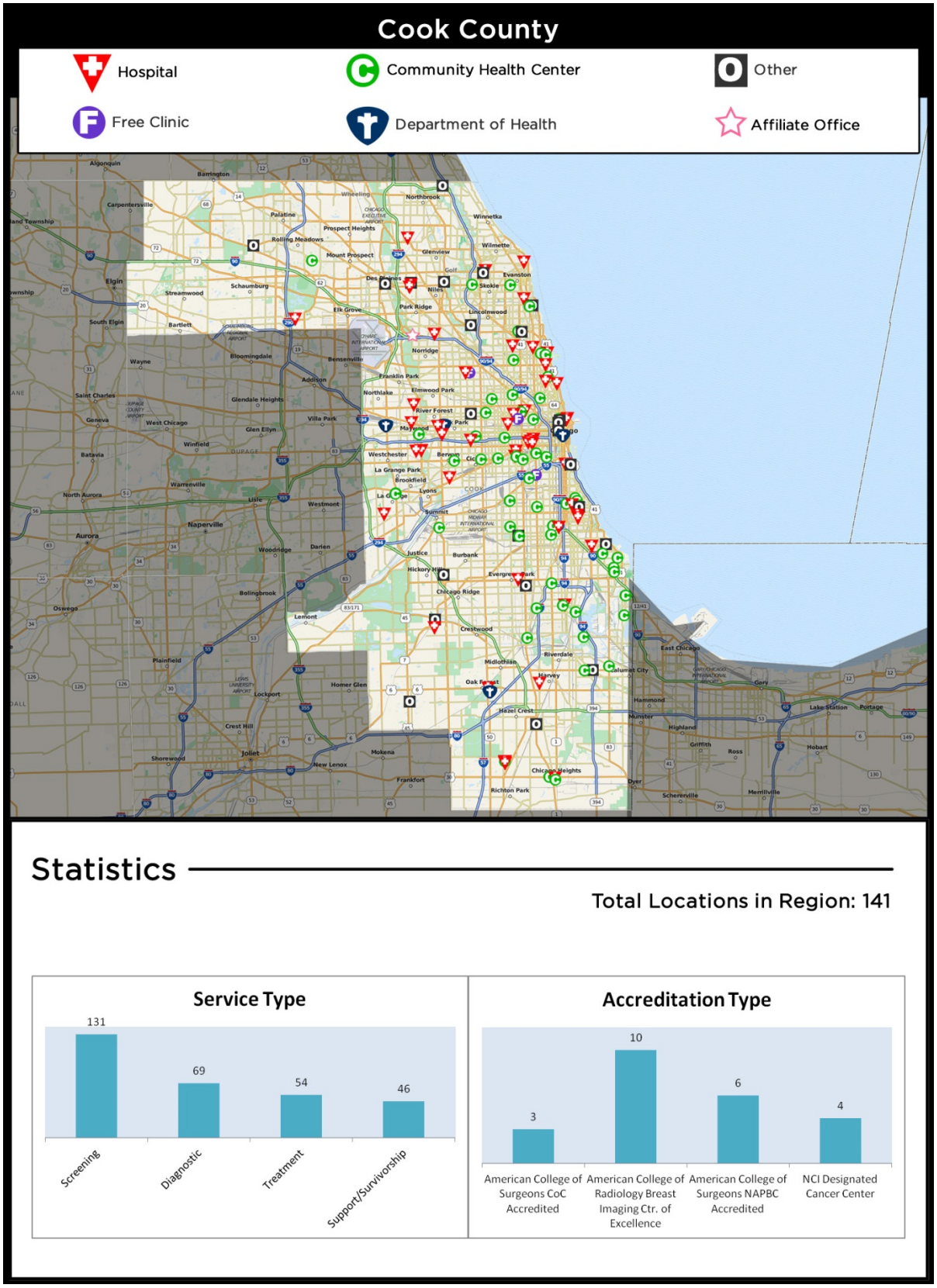



**Figure 3.2.** Breast cancer services in Cook County

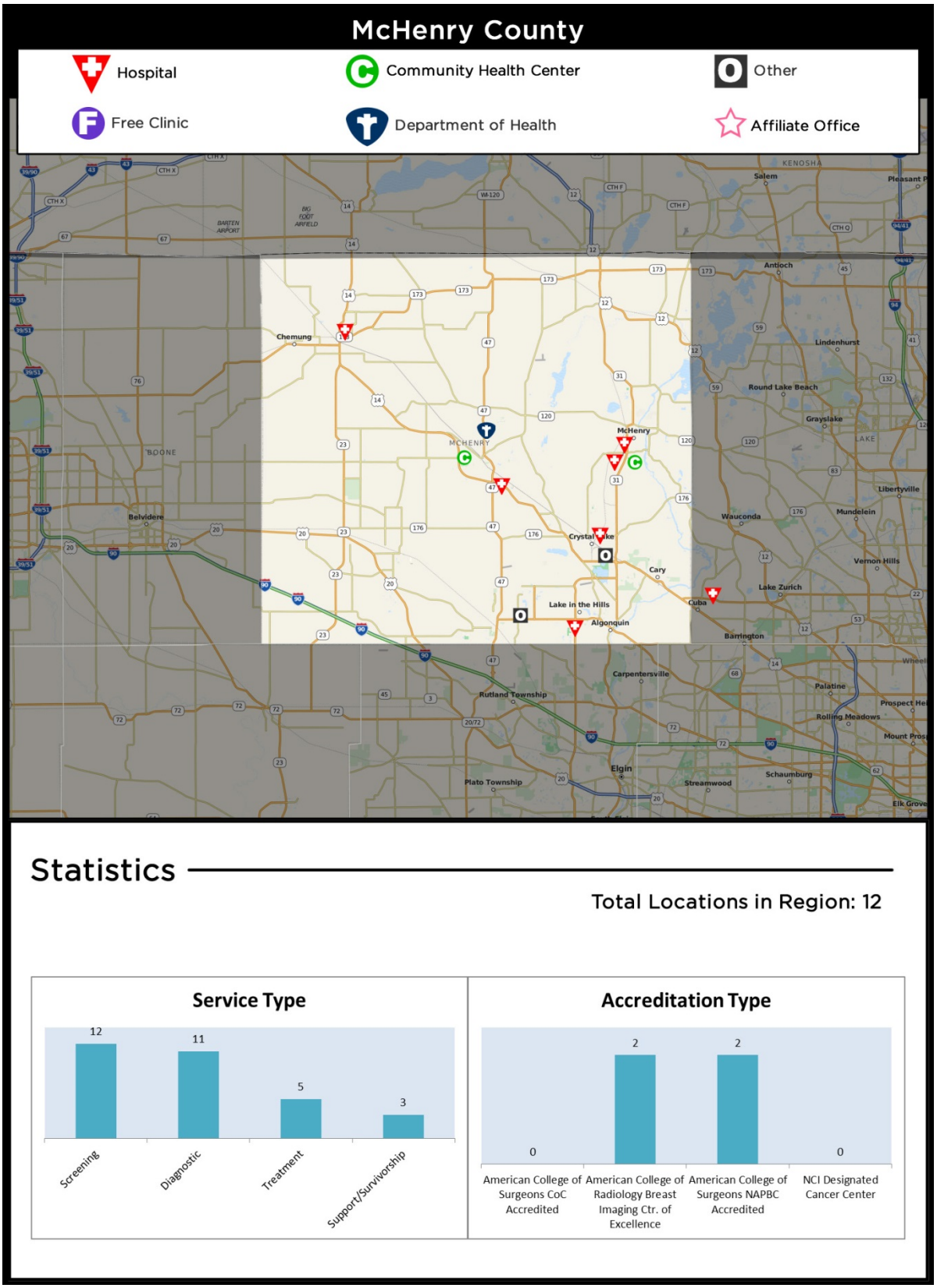



**Figure 3.3.** Breast cancer services in McHenry County

The metropolitan Chicago area has numerous community organizations and faith groups that improve breast health outcomes. In the target communities of Cook and McHenry County these partnerships and coalitions include:

- The Metropolitan Chicago Breast Cancer Task Force

  A group of dedicated community leaders, advocates, and professionals concerned with the growing breast cancer death disparity in Chicago. The Task Force is focused on three key elements that impact breast health outcomes: 1) access to mammography 2) quality of services; and 3) access to treatment. The Susan G. Komen Chicagoland Area has been involved with Task Force governance, as well as coordinating outreach events and state policy initiatives.

- Family Health Partnership Clinic

  For the fifth year, Komen Chicagoland Area has granted funding to Project Access, a collaborative project between the Family Health Partnership Clinic and Centegra Gavers Breast Center. It focuses on providing the continuum of care for Breast Health, targeting low income Hispanic/Latina women in McHenry County.

- McHenry County Breast Cancer Task Force

  This group represents over 15 vital constituent organizations, key representatives, and community members in the McHenry County area with a goal of impacting the health and wellbeing of women by encouraging prevention, early detection, and supportive systems related to women and cancer. It serves as an active resource to the community in engaging three objectives:

  1) Expand awareness and accessibility of community resources and support services to women, cancer clients, their families, and caregivers;
  2) Educate coalition constituents on latest developments, trends in cancer detection, treatment, and cancer-related needs and services; and,
  3) Identify and create opportunities within the community to educate, detect early, and provide supportive resources to persons with breast, cervical, and other gynecologic cancers.

As a leading breast cancer foundation, Susan G. Komen Chicagoland Area is committed to strengthening its scope of community partners by collaborating with similar organizations that align with the Affiliate's mission. These organizations include:

- The Greater Roseland Breast Health Consortium

  On March 5, 2014 the Auxiliary of the Roseland Community Hospital Foundation, in partnership with Komen Chicagoland Area and the Chicago Department of Public Health hosted a Breast Health Summit to highlight the need to reduce breast cancer and breast cancer deaths in the Greater Roseland Communities on Chicago's south side (Chatham, Roseland, Pullman, West Pullman, Riverdale, Auburn Gresham, Beverly, Washington Heights, Morgan Park). The

group exchanged ideas and concerns regarding efforts to increase minority and medically underserved women's access to mammography screenings, treatment, and follow up care. From this meeting, the group has now formed "the Greater Roseland Breast Health Consortium", an integrated partnership among stakeholders who will continue to work collaboratively to address the breast cancer disparities in Greater Roseland.

- Comprehensive Cancer Control Program

  The Illinois Comprehensive Cancer Control Program located in the Illinois Department of Public Health, integrates and coordinates a wide range of cancer related activities through a broad partnership of public, private and nonprofit sector stakeholders with a common mission to save lives and reduce the overall burden of cancer.

- Illinois Cancer Partnership

  The Illinois Cancer Partnership is a broad-based, multi-organizational partnership that integrates public, private and nonprofit sectors in a collaborative effort with common goals and objectives that promotes cancer prevention, reduces cancer deaths and minimizes the burden of cancer for all individuals throughout the state. Their mission is to reduce the incidence, morbidity and mortality of cancer and enhance survivorship in Illinois.

- Breast Cancer Quality Screening and Treatment Initiative Advisory Board

  The Breast Cancer Quality Screening and Treatment Initiative (BCQSTI) is a joint project of the Illinois Department of Health Care and Family Services and the Department of Public Health. To help ensure that women in all communities have access to high quality mammograms and breast cancer information, the State has appointed the Breast Cancer Quality Screening and Treatment Board.

## Public Policy Overview

### National Breast and Cervical Cancer Early Detection Program

The Center for Disease Control and Prevention (CDC) operates the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), which removes barriers to breast and cervical cancer screening among low-income, uninsured women. The program is administered through state-level grants, and Illinois' portion is known as the Illinois Breast and Cervical Cancer Program (IBCCP). IBCCP contracts with both private and public health care providers, reimbursing them for a set of breast and cervical cancer screening and diagnostic services provided to uninsured women ages 35-64 (ages 40-64 for breast screenings) below 200 percent of the federal poverty level.

Covered services include all of the most commonly used detection procedures: clinical breast examinations, screening and diagnostic mammograms, Pap tests, pelvic exams, ultrasounds, colposcopies, conizations, biopsies, and more. Patients must demonstrate their eligibility and

sign a consent form. IBCCP thus provides a framework for total coverage of the breast and cervical cancer detection and treatment process. Patients with cancer or pre-cancer, and documented Illinois residency, are eligible for Medicaid coverage through Illinois' Cancer Treatment Act, which provides treatment services at no charge to the patient. Nurse Case Managers assist the women with their application for treatment coverage. IBCCP Referrals can be made by calling the Illinois Department of Public Health's Women's Health-Line at 888-522-1282, or by contacting one of the 34 state lead agencies. To apply for Medicaid, women need to fill out and submit a Medicaid application to the nearest Illinois Department of Human Services (DHS) office. The Illinois Breast and Cervical Cancer Program (IBCCP) provides all qualified women with full health care benefits through Medicaid at no cost or for a nominal copayment. Women screened through this program and diagnosed with breast or cervical cancer may be eligible for free health coverage through Medicaid which extends throughout the duration of treatment. In addition, Medicaid will cover all of their medical needs including treatment for non-cancer related medical services. IBCCP reimburses at a set fee schedule based on Medicare rates.

In 2007, Komen Chicagoland Area was instrumental in drafting a legislative plan to reduce breast cancer disparities statewide. The Reducing Breast Cancer Disparities Act addressed several necessary points, some of which were:

- Requires insurers to cover needed pain medication and therapy for breast cancer patients.
- Eliminates co-pays and deductibles as a barrier for mammography screening.
- Attempts to increase the number of mammography providers for underserved women by increasing Medicaid reimbursements for mammography including digital mammography.
- Reimburses community health centers if they provide mammography services to Medicaid beneficiaries and lets them partner with hospitals to provide mammograms.
- Establishes a "bonus quality performance payment" for primary care providers in the state's Medicaid and FamilyCare programs with respect to receipt of annual mammograms.

Currently Komen Chicagoland Area funds five of the 34 lead state agencies through the community grants program, ensuring access to quality breast health care and targeting low income, uninsured and underinsured women. The Illinois Breast and Cervical Cancer Pink Potluck is an opportunity for women to talk with other women about the importance of screenings and early detection of breast and cervical cancer while hosting a fun potluck. Komen Chicagoland Area hopes to partner with IBCCP to rebrand and promote this breast cancer awareness program to interested individuals statewide.

**State Comprehensive Cancer Control Plan**

The Illinois Comprehensive Cancer Control Plan provides a framework for action to reduce the burden of cancer in Illinois. Its purpose is to provide an organized approach to cancer prevention and control efforts for use by individuals and organizations, in all areas of cancer prevention and control throughout the state. This comprehensive cancer control plan addresses six priority focus areas: Primary Prevention, Early Detection, Access to Care, Survivorship, Data

and Surveillance, and Research and Clinical Trials. The following is the detailed list of focus areas and their corresponding goals.

Primary Prevention Goals:

- Goal 1: Decrease the proportion of Illinois residents who use tobacco products.
- Goal 2: Decrease the proportion of Illinois residents who are overweight.
- Goal 3: Decrease the proportion of Illinois residents who are exposed to unsafe levels of environmental carcinogens.

Early Detection Goal:

- Goal 1: Increase the knowledge of the general public to include all diverse groups and health care providers regarding early detection guidelines and the importance of screenings for breast, cervical, colorectal, oral, prostate, skin and testicular cancers.

Access to Care Goal:

- Goal 1: Increase access to cancer resources and services, especially among diverse, underserved, and underinsured populations.

Survivorship Goal:

- Goal 1: Increase access to survivorship and palliative care programs, especially among diverse, underserved and underinsured populations.

Data and Surveillance Goal:

- Goal 1: Ensure adequate funding for the Illinois State Cancer Registry.
- Goal 2: Increase the visibility of cancer data utilization reported by ISCR by increasing collaboration and accessibility of ISCR data to support research aimed at improving public health.
- Goal 3: Support rapid case ascertainment (RCA) to better connect newly diagnosed cancer patients with research studies.

Research and Clinical Trials Goals:

- Goal 1: Raise awareness of cancer research among policymakers and the general public.
- Goal 2: Monitor the geographic distribution throughout Illinois of persons participating in therapeutic cancer clinical trials.

Currently Komen Chicagoland Area has two members of the Illinois Comprehensive Cancer Control Program who serve on the Affiliate's Mission and Advocacy Committee**.** Komen Chicagoland Area is in the early stages of applying to be a member of the Illinois Cancer Partnership which works in tandem with the Illinois Cancer Control Program.

**Affordable Care Act**

The Affordable Care Act (ACA) was passed by Congress and then signed into law by President Barack Obama on March 23, 2010. The objectives of the ACA are to increase the quality and affordability of health insurance, lower the uninsured rate by expanding public and private insurance coverage, and to reduce the costs of health care for individuals and the government.

The Affordable Care Act extends Medicaid while treating all States equally. The Act gives flexibility to States to adopt innovative strategies to improve care and the coordination of

services for Medicare and Medicaid beneficiaries. Twenty-six states, including Illinois, and the District of Columbia decided to expand Medicaid.

According to the Council of Economic Advisors, the following are estimated for Illinois based on changes due to the Affordable Care Act:

- 398,000 people in Illinois will have health insurance by 2016. The last reported data from the state was approximately 287,000 people as of April 2014 gained health insurance. About 1.6 million uninsured lived in Illinois before Oct. 2013, according to the US Census Bureau.
- 14,700 will have a mammogram to look for breast cancer.
- 56,600 fewer people will need to borrow money to pay medical bills or skip paying them entirely.
- 56,000 jobs will be created between 2014 and 2016.
- The state will receive more than $4 million in federal aid for Medicaid between 2014 and 2016.

A recent study by the Kaiser Family Foundation (KFF) provides the best estimate to date of the proportion of private health plan enrollees under the ACA who previously lacked health insurance and therefore would be gaining coverage under the new law. Based on their nationally representative survey of adults who purchase their own insurance, KFF finds that 57 percent of private plan enrollees were previously uninsured.

Combining this new data point with information on the number of new Medicaid recipients and private plan enrollees under the ACA, WalletHub analysts have offered an initial projection of uninsured rates post-ACA for 43 states and the District of Columbia. Illinois ranks 27$^{th}$ with approximately 14.2 percent of people still uninsured (Table 3.1).

**Table 3.1.** Uninsured pre- and post-ACA in Illinois

| Uninsured Rank | State Name | Uninsured Rate Pre-ACA | Projected Uninsured Rate Post-ACA | Difference Before and After |
|---|---|---|---|---|
| 27 | Illinois | 16.2% | 14.2% | -2.0% |

Illinois Breast and Cervical Cancer Program will continue operations as normal. However there are still concerns of funding being cut or funds being depleted. While Illinois has been at the forefront of expanding health coverage for breast screening and treatment services, IBCCP faces some issues with serving all qualified women. The first issue is limited funding; Illinois' grant features a maximum amount, and in the event of a major increase in demand for IBCCP services, the state of Illinois would need to apply to the CDC for additional funds. The second issue is limited participating providers; IBCCP reimburses at a set fee schedule based on Medicare rates, which are not high enough to attract all providers. As a result, women can only receive services at certain locations, sometimes resulting in transportation barriers, especially in the southern part of the state.

Health care providers commonly lack current knowledge about, and easy access to, needed services for patients. These services include social, financial, and psychological support for patients and families; the best medical care; and access to the latest treatment through the availability of clinical trials. This information is needed to better serve all people affected by breast cancer regardless of age, gender, race/ethnicity, health coverage, or income. This will be more even more crucial with the anticipated influx of individuals who will now have access to health care under the Affordable Care Act.

As The Affordable Care Act goes into effect, Komen Chicagoland Area will remain focused on the goal of ensuring all women in need receive care. There are still many undocumented and uninsured women who will continue to need access to quality screenings and treatment in the Affiliate service area.

**Affiliate Public Policy Activities**

Komen Illinois Affiliates, the Metropolitan Chicago Breast Cancer Task Force, and breast cancer advocates across the state are deeply concerned about potential underfunding of the Illinois Breast and Cervical Cancer Program (IBCCP). Cuts to IBCCP will deny cancer screenings, including mammograms, to thousands of Illinois women. Trying to balance Illinois' budget by reducing funds for breast cancer screenings will be harmful, both to women's health and Illinois' fiscal health. Any short-term budget savings will be quickly offset by increases in women suffering, death from more advanced cancers, and far higher treatment costs paid for by Illinois Medicaid, which will ultimately cost taxpayers more. The Governor's Illinois Fiscal Year 2015 budget for the IBCCP, proposed to fund IBCCP at the same level as last year with the hope that with additional enrollment in Affordable Care Act (ACA) options, the waitlists that have resulted this year will not happen in FY15.

On May 15, 2014 Komen Chicagoland Area joined the Metropolitan Chicago Breast Cancer Task Force for their annual Advocacy Day at the Illinois State Capital. This event was an important opportunity to continue to stress the importance of breast health in Illinois. The Affiliate, along with the Task Force, met with lawmakers to advocate for maintaining current funding for the Illinois Breast and Cervical Cancer Program (IBCCP). On the way back to Chicago, the House passed a package of appropriation bills which has adequate funding for many health programs including the Illinois Breast and Cervical Cancer Program.

Komen Illinois Affiliates and the Metropolitan Chicago Breast Cancer Task Force will continue to work with partners and stakeholders to increase funding and access for breast cancer patient navigation programs in rural and underserved parts of the state of Illinois, ensure that screenings recommended by physicians are covered by public and private insurance plans, and ensure that every insurance plan in the state includes a quality academic center or medical center with breast cancer services.

## Health Systems and Public Policy Analysis Findings

Convenient access to quality health care services is necessary for effective cancer risk reduction, early detection, timely and accurate diagnosis of cancer, appropriate treatment, supportive care, and follow-up for patients and family members. Disparities in access to cancer control and treatment can have many causes, starting with patients and providers lacking the necessary information to access good care, and extending to insurance status, limited transportation options, limited availability of local health care providers, cultural and language barriers, and uncertain quality of existing available services. Illinois faces all of these disparities according to the state's Comprehensive Cancer Control website.

An analysis of the continuum of care in the targeted communities through a review of existing community assets and legislative issues reveal a shortage of medical providers, facilities and resources in certain areas of the target communities. Focusing on the continuum of care will ensure access into and through the breast health care system at each level by addressing the barriers that women seeking services encounter as well as the barriers that agencies providing those services face.

The Affiliate has several opportunities to deepen existing partnerships and create new venues that lead to policy change and access to quality breast health services in Illinois. The Affiliate is excited to continue its work with the Metropolitan Chicago Breast Cancer Task Force Quality Consortium and the Greater Roseland Breast Health Consortium which both address the growing disparity in breast cancer deaths between Black/African-American and White women in Chicago. The Affiliate will also continue to strengthen the relationship with its community partners at the McHenry County Breast Cancer Task Force. By joining the Illinois Cancer Partnership, the Affiliate is expanding its network as well as joining forces statewide to reduce the incidence, morbidity and mortality of cancer and enhance survivorship in Illinois.

Public policy directly impacts breast health care. Laws regulate and support access to care and the health care system. There have been and continue to be monumental changes within the US health care system, however the need to ensure access to quality, evidence-based health care institutions and screening equipment for all women nationwide remains.

Komen Chicagoland Area is committed to continue its vital public policy campaign to help reduce the toll of breast cancer disparities in Illinois women. The Affiliate will work collaboratively with all Illinois Affiliates to ensure the use of a statewide strategy to create public policy change. The key goals for the following years are as follows:

- Maintaining funding for the Illinois Breast and Cervical Cancer Program, the state's CDC-funded screening program for uninsured women, in the face of massive state budget cuts to health and human services programs.
- Supporting other federal public policy initiatives as outlined by Komen Headquarters.
- Continue to work with partners to ensure more patient navigation programs, and that screenings are covered by public and private insurance plans, at a quality academic or medical facility.

## Qualitative Data Sources and Methodology Overview

This report also seeks to describe the breast health care system as women experience it today. Information was collected to document important attitudes and beliefs of women utilizing the breast health care system that impact breast cancer outcomes for underserved women. Both women in the community and key informants (health care professionals, community stakeholders and breast cancer survivors) were surveyed. Focus group discussions (FGDs), key informant interviews and surveys were conducted in Komen's target communities, Cook and McHenry Counties, between October and November 2014. Information was gathered from three FGDs consisting of 32 women, 30 key informant interviews, and 126 completed surveys. Focus group and key informant participants received either a $10 gift card, t-shirt, pen, and/or goodie bag as a token of appreciation for their participation. Socio-demographic and community resource information was also obtained from all participants before or after completion of the FGDs, key informant interviews, and surveys. All data were imported into an Excel spreadsheet, verified and cleaned. Analysis of data themes was done using a content analysis approach to report findings. The following section details the methodology utilized in data collection and analysis as well as the findings revealed from these efforts.

### Focus Group Discussions (FGDs)

Participants were recruited by a Komen employee. Three FGDs were conducted with 10 to 11 women each, for a total of 32 participants. The discussions were held in the following community settings: a health center, Baptist church, and a community center. Two FGD's were conducted in English and one was conducted in Spanish. Komen staff facilitated the focus groups conducted in English, with the assistance of staff from the Metropolitan Chicago Breast Cancer Task Force (MCBCTF) to record and document the discussion. A bi-lingual Komen representative conducted the focus group for Spanish –speaking participants. A discussion guide with specific questions was developed before the sessions to facilitate the discussion, however, the note-taker recorded other themes that emerged during the conversation (Appendix A. Focus Group Discussion Guide). The aim of the FGD question guide was to assess the women's knowledge, experiences and perceptions of breast cancer; and available community resources, if any. Focus group discussions lasted for approximately fifty minutes to two and a half hours. Discussions were audio recorded using a digital voice recorder, translated and transcribed into English by MCBCTF and a Komen Intern who is fluent in both English and Spanish.

### Key Informant Interviews

Key informant interviews were conducted to gather information and insight on breast health from a diverse spectrum of stakeholders ranging from health care professionals, breast cancer survivors, researchers, and community leaders. These informants would have knowledge of the experience of a larger number of women as they access breast health care services. This method of data collection was favorable to the goals of the report due to its ability to obtain detailed information and gain health systems level understanding of barriers affecting women. Thirty key informant interviews were completed in-person or via phone ranging from 20-45

minutes. Key informants were selected due to their level of expertise and experience in the breast health continuum of care of target communities. The interview questions included a revised version of the Susan G. Komen Key Informant Questionnaire, which was tailored for the purpose of those participating. The questionnaire also examined screening percentages, barriers to screening, diagnostics and treatment, knowledge and perception of breast cancer, and future recommendations (Appendix B. Key Informant Interview Guide).

**Surveys**

Surveys were distributed at community events, churches, and doctors' offices. The objective of the surveys was to gather information from a larger number of individuals on socio-demographics of the population being served, services they receive, their perceptions and experiences, barriers to seeking services, and existing community services (Appendix C. Breast Health Participant Survey). Several of the questions, including socio-demographic information, were multiple-choice and other questions were open-ended. A total of 126 surveys were completed.

**Sampling**

Participants for the focus group discussions, key informant interviews, and surveys were targeted using purposeful sampling to select a group of participants from a range of backgrounds and experiences. Purposeful sampling seeks to maximize the value of data by selecting participants that are homogenous with respect to similarities regarding breast health, yet diverse in cultural background, in order for researchers to learn from a varied set of experiences (DiCicco-Bloom & Crabtree, 2006; Kuzel, Crabtree, & Miller, 1992). Convenience sampling was utilized for surveys to capture maximum participation during the data collection period. Participants included survivors, health professionals, breast health advocates, and community leaders that are of different sex, races/ethnicities, occupations, and ages.

**Ethics**

Before the start of FGDs, key informant interviews, and surveys, verbal or written consent was sought from all participants. For anonymity, some participants identified themselves using their initials and/or chose to not be quoted directly. All data shared for the Qualitative report will only be used for the purpose of the Community Profile Report.

**Analysis**

In order to understand analysis of the data, findings were grouped using an interpersonal and health systems barriers framework, which enabled the research team to relate results and help understand the barriers to access to screening mammography. The preexisting Komen "Screening Mammography Themes/Categories and Codes," which includes sub-categorical themes was used in addition to other sub-categorical themes that emerged while coding. These themes/categories explored women's fear, knowledge deficit, physician/health system issues, mammograms not being a priority, access to services, medical complications, cultural barriers, and their perception on breasts. Focus group discussion and key informant interview data were transcribed into a Word document. A database was created solely for the purposes of capturing

data for this qualitative report. For analysis, all data were imported into an Excel spreadsheet to be verified and prepared.

## Qualitative Data Overview

### Demographic Characteristics of participants

Table 4.1 illustrates the characteristics of the key informant interviews, focus groups and survey participants. Survey participants were predominately Black/African-American women who were mostly 39 years of age or younger or 60 years of age or older. Several (n=66, 54.6 percent) of the respondents had less than an associate's degree with most common occupations being clinical and non-clinical health care professionals, other occupations not specified, retirees, and homemakers.

**Table 4.1.** Demographic characteristics of participants

| | | Key Informant Interviews N=30 | | Focus Group Discussions N=32 | | Surveys N=126 | |
|---|---|---|---|---|---|---|---|
| **Background Characteristics** | | n | % | n | % | n | % |
| **Gender** | Female | 26 | 86.7 | 32 | 100 | 125 | 99.2 |
| | Male | 4 | 13.3 | 0 | 0.0 | 1 | 0.8 |
| **Race** | Black or African-American | . | . | 5 | 45.5 | 105 | 92.1 |
| | White | . | . | 6 | 54.5 | 7 | 6.1 |
| | Mixed | . | . | . | | 2 | 1.8 |
| **Ethnicity** | Hispanic | . | . | 2 | 20.0 | 71 | 92.2 |
| | Non-Hispanic | . | . | 8 | 80.0 | 6 | 7.8 |
| **Age** | 39 or ≤ | . | . | 3 | 20.0 | 32 | 25.8 |
| | 40.49 | . | . | 5 | 33.3 | 30 | 24.2 |
| | 50.59 | . | . | 4 | 26.7 | 28 | 22.6 |
| | 60 or ≥ | . | . | 3 | 20.0 | 34 | 27.4 |
| **Occupation** | Homemaking | 0 | 0.0 | 9 | 50.0 | 9 | 8.3 |
| | Social Work | 0 | 0.0 | 1 | 5.6 | 8 | 7.3 |
| | Education | 1 | 3.3 | 1 | 5.6 | 4 | 3.7 |
| | Computer/Office | 0 | 0.0 | . | . | 9 | 8.3 |
| | Beautician/Salon | 0 | 0.0 | . | . | 4 | 3.7 |
| | Housekeeping | 0 | 0.0 | . | . | 2 | 1.8 |
| | Sales | 0 | 0.0 | 4 | 22.2 | 4 | 3.7 |
| | Health Care-clinical | 6 | 20.0 | . | . | 11 | 10.1 |
| | Health Care-non-clinical | 17 | 56.7 | . | . | 15 | 13.8 |
| | Retired | 0 | 0.0 | 3 | 16.7 | 16 | 14.7 |
| | Other | 6 | 20.0 | . | . | 27 | 24.8 |
| **Highest Level of Education** | ≤ Associate's Degree | . | . | 11 | 78.6 | 55 | 46.2 |
| | Associate's Degree | . | . | . | . | 10 | 8.4 |
| | Bachelor's Degree | . | . | 2 | 14.3 | 21 | 17.6 |
| | Master's Degree | . | . | 1 | 7.1 | 27 | 22.7 |
| | Professional/Doctorate Degree | . | . | . | . | 6 | 5.0 |
| **Income** | ≤ Less than $10,000 | . | . | 1 | 7.1 | 8 | 7.0 |
| | $10,001.$20,000 | . | . | 3 | 21.4 | 15 | 13.0 |
| | $20,001.$30,000 | . | . | 3 | 21.4 | 13 | 11.3 |
| | $30,001.$40,000 | . | . | 1 | 7.1 | 17 | 14.8 |
| | $40,001.$50,000 | . | . | 1 | 7.1 | 12 | 10.4 |
| | More than $50,000 | . | . | . | . | 34 | 29.6 |
| | Don't know/Not Sure | . | . | 3 | 21.4 | 3 | 2.6 |
| | Would prefer not to disclose | . | . | 2 | 14.3 | 13 | 11.3 |

Note: "."Indicates missing data, N= overall sample size, n= each variable sample size. Calculations are based on participant responses for each variable. Because there is missing data for some of the variables, for example, Race (n=114), therefore, 105/114=92.1% would be appropriate.

**Cook County**

***Focus Group Discussion #1***

The first FGD conducted for this qualitative assessment on breast health was held at a church in the Englewood community, a predominately Black/African-American neighborhood located on the Southside of Chicago.

*Interpersonal Barriers*

According to the women, fear of discomfort and lack of understanding about the health benefits of routine screenings all play a role in explaining the low screening percentages among Black/African-American women. All the women in this group self-reported they receive mammograms annually. However, University of Illinois research suggests considerable over reporting of screening from self-reports (Allgood, Rauscher, Whitman, Vasquez-Jones, & Shah, 2014). Additionally, data from the MCBCTF suggests that only 25.0 percent of women in Englewood are annually screened (MCBCTF, 2014). This would suggest that either this sample of women was not generally representative or that there was considerable over reporting of screening. When asked why they chose to get mammograms, many said that they wanted to be knowledgeable about their bodies. One participant said that she chooses to get a mammogram due to lack of confidence in her ability to render an effective self-breast exam. Another participant posed a deeply thoughtful question, revealing poignant realities of disparity in breast health:

*"The incidence is higher among white women, but the death rate is higher among Black women and Hispanics. So we don't get checked; we don't. Does it actually have to do with the expense or the way we are treated differently than the white women… Is that a part of it?"*

Barriers within the health system presented themselves in various forms. Uncertainty regarding the location of health care resources and facilities were found to be major concerns for participants. One participant replied that though she knew the information was available, for a woman who was unconnected to the health care system, the information is not easily accessible. She also shared her belief that this lack of knowledge regarding local services has contributed to the breast cancer story for Black/African-American women. Associated feelings of disconnection from the health care system were expressed when talking about how improvements can be made to the way in which breast cancer information is presented. A woman shared a story of receiving conflicting recommendations regarding the proper age to begin receiving annual mammograms by her health care providers, *"I was told to go when I was 35, but after getting a mammogram at 35,36,37,38, and 39, my doctor said then that's too much radiation. He said instead after 40, that's when you should get one regularly."* Another participant expressed the need for person-to-person dialogue regarding breast cancer information. This highlights the importance of personal communication/interaction with health care providers as opposed to voice machines, which some women stated to be barrier.

***Focus Group Discussion #2***

A breast cancer support group hosted the second focus group, which was held at a Chicago safety net hospital. Those participating in this FGD were very knowledgeable about breast health services in their community.

*Interpersonal Barriers*

Similar to the first FGD, lack of information about available assistance was a major concern.

*"Why are the resources not available to everyone regardless of who you are?"*

*"People need to know because a lot of people don't say for their reasons why they won't get screened, but sometimes it's financial; they don't have insurance. There's a copay, there's an out of pocket deductible or something…that's why they need to know about programs",* one participant explained. Choosing between financing a round of chemotherapy or groceries was a decision one woman shared. She explained that women continuously have to make difficult decisions when faced with fear of losing their job because of missing too many days of work while receiving treatment for cancer. Another participant shared that some women do not feel empowered to advocate for their health. She shared her experience as a survivor with three other friends diagnosed with breast cancer, one who would eventually pass away due in part to denial of her diagnosis.

*Health Systems Barriers*

Mistrust of the health care system in communities of color is a serious obstacle for screening compliance. One participant, who works as a nurse in breast health confided,
*"A lot of our community; they don't trust the system because they are treated so bad."*
Other issues include lack of minority representation in health care and language and immigration status barriers. Some women mentioned wanting to see fellow Black/African-American breast cancer representatives from different organizations by their bedside because they felt that their counterparts (White) are not able to relate to them. In addition, securing interpretive services at Chicago hospitals for Hispanic/Latina women was said to be a challenge for one participant who works in breast cancer advocacy.

***Focus Group Discussion #3***

The final focus group conducted for this Community Profile was held at a Hispanic/Latino community center on Chicago's West Side.

*Interpersonal Barriers*

Analogous to the previous focus group discussions, low health literacy and understanding about breast cancer and cancer in general still exists. Participants shared that though they were not clear on how a person can get cancer, its causes, or what to do if diagnosed, all present were aware that women of any age could be diagnosed. Several women knew peers in the same community who didn't know how to request a mammogram. In some cases, the reason given was the inconvenience of making an additional trip to the doctor's office to get a physician's order for the mammogram. A few women in attendance also shared that in the past they had forgotten to attend their scheduled mammography appointment because of time constraints and family responsibilities.

*Health Systems Barriers*

Common themes were mentioned during this discussion regarding challenges from the health care system. Some mentioned that long wait times for mammography appointments deter women from following through with getting screened. Interestingly, one participant indicated concern of encountering negligent medical providers and staff was a primary reason for her hesitation to receive breast health services.

**Key Informant Interviews**

Cook County key informant interviewees spanned a diverse range of experience from health care providers and administrators, community leaders, breast cancer survivors and current breast cancer patients, and public health professionals. Among the 27 key informant interviewees participating in Cook County, 44.0 percent were either breast cancer survivors or currently undergoing treatment. Access to services proved to be the most prevalent theme, followed by knowledge deficit, and health system issues.

*Interpersonal Barriers*

Low health literacy, fear, and family obligations were noted as the most common interpersonal barriers affecting adherence to annual mammography in Cook County. Limited health literacy among women seeking screening services was cited by 17 out of 27 (63.0 percent) of participants as a critical barrier. When asked which factors most affect screening adherence among women in Chicago and Cook County, one community health researcher and physician said, *"...health literacy is a huge factor... I think that often prevents women from seeking care or accessing care."*

According to 48 percent of key informants, fear of being diagnosed with breast cancer negatively affects breast health screening in their communities. A breast health nurse navigator in Cook County shared, *"Many women are afraid to know their results. Lack of education can also make a huge impact"*. Mammograms have also been found not to be a top priority for women often burdened by inflexible work, family and childcare obligations. One breast cancer survivor informed that challenges such as *"lack of childcare, working multiple jobs, shift work"* prove formidable barriers for women in scheduling mammograms and maintaining healthy screening habits.

"...health literacy is a huge factor... I think that often prevents women from seeking care or accessing care".

*Health Systems Barriers*

High cost, lack of insurance coverage, and an unsatisfactory doctor-patient relationship represent the most common health systems barriers in Cook County according to key informants. Eighty-one percent of interviewees indicated that cost of getting a mammogram, lack of health insurance, or limited understanding of newly acquired health insurance were obstacles facing women seeking breast health services. On accessing low cost mammograms through state supported programs, a public health professional said, *"Advertising reduced cost mammograms to communities that cannot afford even reduced cost services is a barrier. I would like to see these hospitals seek out subcontracts with IBCCP, SAC, and A Silver Lining to offer more accessible care"*. She continued, *"...lack of insurance and lack of understanding how the insurance process works are what makes seeking breast screening services difficult. Even the newly insured are skeptical that Well Woman services (preventative health screening services) are 100 percent covered"*. The financial barriers are an impediment tightly related to long standing race and class issues in Cook County.

Key informants expressed concern of racial and class discrimination rendering serious system level barriers that turn women away from seeking the health care they need. When asked about the cause of the Black/White breast cancer deaths disparity, a health care administrator replied *"Racism and concentrated disadvantage".* Similar to several other key informants, the

investment and allocation of high quality resources to disadvantaged communities was found to be an important component of closing the disparity gap in the Chicago area. Insurance-based discrimination has also been cited as a problem women face when accessing care. One interviewee recalled an experience witnessing discrimination towards Medicaid patients by staff at a neighborhood clinic.

This disconnect unfortunately exists between providers and their patients during office visits, contributing to barriers throughout the continuum of care in breast health for low-income women of color. Mistrust of the health care system by communities of color, especially within the Black/African-American community, poses a barrier that requires particular attention. One community health researcher explained this mistrust as undoubtedly intercepting women of these communities from screening*, "...there is an issue of historical mistrust, particularly among ethnic communities of color, when it comes to accessing and navigating health systems. It's documented. There is documented literature that shows many African-American communities still have historical mistrust with the medical system. So when you couple that with screening, screening is a proactive activity that you have to do when in many instances there is no incentive. And so to be proactive with a system you don't trust is again I think unrealistic"*.

The last common health systems barrier noted in key informant interviews was the failure to sufficiently advertise mammography programs and health resources designed to serve target population - women at highest risk for non-compliance. Several informants recommended creating a more centralized referral system or information portal (i.e. a breast health hotline) directing women to free or low-cost screening programs. The lack of messaging promoting preventative health to target populations was the most critical component missing in breast health campaigns according to one key informant, a physician-surgeon serving a patient population predominately of Black/African-American women.

**Surveys**

*Interpersonal Barriers*

Several participants mentioned fear being a determinant as to whether they would seek screening mammograms. Being fearful of being diagnosed with breast cancer, of radiation, of hospitals and doctors, and not knowing what to expect were common reported descriptions by participants. A respondent describes their fear: *"…..radiation from mammograms will cause cancer, or that radiation after a lumpectomy will cause more cancer to grow."*

Nevertheless, 71.0 percent of women surveyed stated that they have had a mammogram. Forty-three percent had a mammogram within the past year, while 26.0 percent of participants had a mammogram within two - five years, and two percent were not sure or didn't know when they last had a mammogram. Several (74.0 percent) participants also mentioned spirituality playing a part in whether they get regular mammograms. Regarding health education, the majority indicated that they typically receive their health information from their church, doctor/health provider, social media, and word of mouth from family members and friends. Several participants, however, mentioned not being aware of where to go or how to find information about mammograms. When asked their level of satisfaction with the resources in their communities, fair to good satisfaction levels were indicated by

several survey participants. Women suggested that an increase of breast health services, education, and preventative health care were much needed in their neighborhoods.

While some participants are aware of the benefits of annual screening mammograms, for some participants, mammograms are not a priority for several reasons despite 71.0 percent of respondents stating that they are related to someone who has had breast cancer. In addition, 73.0 percent of participants stated that if they were under 40 years old, they would not receive a clinical breast exam. This could possibly highlight the women's lack of knowledge on breast health considering so many respondents might be at higher risk of breast cancer due to family history. Nevertheless, 81.0 percent of women stated they get yearly checkups, which in turn may mean that women place a higher importance on other medical conditions than breast health when visiting a health facility or they are not educated about breast health during their yearly checkups. Or the fact that a mammogram is performed at a location separate from their primary care provider and often requires a physician's order and a separate visit is a barrier.

*Health System Barriers*

Several participants mentioned out-of-pocket expenses as a recurring challenge when seeking health care. Out-of-pocket expense or perceived out of pocket expense, is another reason utilization of services among participants is low. While the Affordable Care Act requires most health plans to provide screening mammograms without cost and Medicaid and Medicare also provide screening mammograms without co-pays, this may not be as widely known as necessary to promote utilization. Participant's satisfaction and acceptability with community services is dependent upon the cost. In order to encourage repeat visits particularly for those who need additional imaging, information of available financial assistance for out-of-pocket expenses should be offered to women. They also mentioned that long wait times and untimely responses for services were drawbacks. In addition, the lack of transportation as well as the inability to locate health facilities also poses a problem.

**McHenry County**

*Interpersonal Barriers*

Half of McHenry County key informants indicated fear of deportation to be of major concern for women of screening age. Correspondingly, 66.0 percent believed that language barriers prevent women within the increasing Hispanic/Latino population from receiving screening mammograms. One key informant further emphasized that fear of diagnosis and misinformation contributes to the lack of mammography screening regardless of health insurance status. Additionally, similar to respondents in Cook County, key informants in McHenry indicated that mammograms may not be the primary concerns on the minds of women who juggle several family and work responsibilities.

*Health Systems Barriers*

Sample size for McHenry County data collection was extremely limited. Health systems barriers that were mentioned during data collection include: the need for further physician training on clinical breast exam protocol, and the difficulty in accessing the small number of facilities in the county results in access barriers to breast health care. Further investigation of health systems barriers is needed to provide an informative perspective on the challenges in breast health in this county. Despite attempts to access breast health data from multiple facilities, including hospitals and an academic institution tasked with conducting the county community analysis,

specific breast health data in the form of reports or articles were not available. While community assessments were located from several hospitals, none included specific breast health information needed to inform the Affiliate's Community Profile. Plans to address these limitations are mentioned below.

## Qualitative Data Findings

### Limitations of the Qualitative Data

A small sample size for focus group discussions, key informant interviews, and surveys makes findings not representative of the whole population. Though the sample size is small, one is able to generalize findings to the accessible population, which were the participants that were able to engage in process for the purpose of this report (Patten, 2011). Although the Affiliate was looking to examine both Cook and McHenry Counties, due to extremely limited knowledge of the resources and access to community organizations and their personnel, findings of this report reflect more on Cook County, which is a county that has established relationships with the Komen Chicagoland Area. The Affiliate intends to address the apparent lack of available specific breast health data in McHenry County by initiating partnerships with community organizations, academic institutions, and public entities to help create an environment in which this vital information can be queried and made readily available. The creation of a breast health partnership within this county will help to inform service organizations about the needs within this vastly rural county. The Affiliate's Mission Action Plan will address the next steps towards ensuring the breast health needs of McHenry County women will be addressed. In addition, there was no statistical analysis that examined the response rate of those who declined participation in the FGDs, key informant interviews, and surveys.

### Cook County

Qualitative data collected for this Community Profile reflects the diversity and complex health care landscape of Cook County, Illinois. The majority of survey respondents were Black/African-American women residing in neighborhoods and community areas in Cook County, IL designated high-risk for breast cancer by Metropolitan Chicago Breast Cancer Task Force (MCBCTF, 2014). It should be noted that qualitative data collection relied on self-reported information. It is reasonable to assume that actual mammography utilization may differ substantially from the numbers included in this report.

Concurrent with the Health Systems and Policy Analysis, many of the Cook County female respondents suggested that they either did not know where mammography resources were located in their immediate community, or chose not to access those services in their local community. This disconnect from community health resources reflects a broader issue regarding the disproportionate allocation of health care centers equipped to provide quality mammography and follow-up care to women in majority Black/African-American and Hispanic/Latino communities on the South and West sides of Chicago. Access and quality of care in target communities is a source of concern for women and was echoed in the responses of several key informant interviews. The qualitative report revealed the importance of state funded programs like the Illinois Breast and Cervical Program (IBCCP) from community members and health professionals alike. Such programs support the breast cancer continuum of care and support closing the disparities gap in communities of women.

**McHenry County**

The demography and health care service allocation in McHenry County is substantially different from Cook County. As stated in the health systems analysis, McHenry County is markedly rural. Women residing here often must travel several miles, often times across state lines, to reach a mammography facility. Other concerns from key informants reflected a Hispanic/Latino population (12.0 percent) experiencing a level of anxiety from language and immigration status barriers that make accessing health care and preventative services more difficult.

**Conclusions**

With the implementation of the Affordable Care Act over the last two years, more women are becoming insured, some gaining access to consistent health care for the first time. Fear, health literacy deficits, economic constraints, and mistrust of the health care system are just some of the most common obstacles that affect access and utilization of the continuum of care in breast health in Cook and McHenry Counties. Low prevalence of mammography screening among women over 40 years of age in both counties may be a result of numerous interconnected social and health systems level barriers that need to be addressed.

**Recommendations for Consideration**

Throughout the process of collecting data for this qualitative report, participants generously offered their suggestions to help improve the impact Susan G. Komen Chicagoland Area has in its target communities. Below is a list of recommendations for consideration when contemplating future directions for breast health awareness and service efforts in Cook and McHenry Counties:

- Establish a general number or hotline available for women who need assistance accessing breast health services
- Reduce fear and anxiety in women by promoting health education
- Greater allocation of financial resources to breast cancer patients to support expenses while undergoing treatment
- Train physicians on how to give thorough clinical breast exams
- Eliminate the requirement of a physician's order for a screening mammogram
- Require mammography grantees to comply with breast screening quality standards and participate in the Chicago Breast Quality Consortium
- Disseminate and increase breast health information on social media and television ads
- Shift the focus to prevention, healthy eating habits and exercise beginning in elementary school; focus more on preventative health messaging and less solely on screening
- Promote cultural sensitivity toward different ethnic groups and provide interpreters
- Provide health information for those who are undocumented
- Educate providers to ensure proper follow-up for recently diagnosed breast cancer patients to ensure understanding of next steps and options for treatment

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

Due to the alarmingly high breast cancer death rates, Cook County has been identified as a target community. In the five county service area of the Komen Chicagoland Area, Cook County had the largest number of women who have never received a mammogram (data from the 2007-2009 IL Behavioral Risk Factor Surveillance System). This county has also been selected due to low screening percentages, unique population demographics, and higher percentages of those that are medically underserved and have lower income levels. The socioeconomic characteristics of this county indicate a potential concern about women's access to affordable breast health care. Cook County leads the Affiliate service area in residents living below 250 percent of poverty, unemployment, foreign born, residing in medically underserved areas as well as uninsured.

McHenry County has been selected as a target community due to the rates and trends regarding breast cancer deaths, low mammography utilization proportions, and more specifically their high late-stage diagnosis rate (the highest of the five counties). It is also important to note that McHenry County is the most rural county in the Komen Chicagoland Area's service area, with 95 percent of the women being identified as White, 1.4 percent African-American, and 11.1 percent Hispanic/Latina.

There are 157 permanent mammography facilities in Cook and McHenry Counties. There are a number of facilities that provide mammography screening and diagnostic services in the aforementioned counties. Analysis of programs and services reveal that the majority of these facilities are located in Cook County, with the highest concentration of locations being in the city of Chicago. Only 12 locations are identified within McHenry County. There are merely three health care facilities in McHenry County that encompass the entire breast cancer continuum of care. In addition to having few treatment and support facilities in McHenry County, in many cases residents must travel across the state line in order to receive treatment. Across both counties, there is a lack of available support services in general.

As reported in the Quantitative Data Report, target communities have low mammography utilization rates while incurring increased late-stage breast cancer. Upon examination of the health care landscape, issues of accessibility to care and health coverage shortfalls were found to be key barriers to breast health services and mammography utilization for women in the target communities.

The quantitative and health systems analysis data helped to inform a targeted qualitative data collection effort which focused on obtaining the perspectives of community members, breast health and primary care professionals, and survivors. The qualitative data revealed powerful themes of fear, mistrust of the health care system, low health literacy, and lack of affordability in both Cook and McHenry Counties. Participants in focus group discussions, key informant interviews, and surveys repeatedly attributed a woman's disinclination to screening with feelings of fear of cancer diagnosis or discomfort. Poor understanding of the screening process due to limited knowledge of preventative health recommendations and low utilization of screening

among a woman's family and social groups was also found to be a contributing factor. Coupled with the concern of high cost of mammography for uninsured and underinsured women, regular screenings are often foregone due to other obligations, such as bills or medical needs.

Misconception and mistrust unfortunately persists surrounding topics of medicine and health care in the Affiliate's target communities. Beliefs that radiation from mammography cause cancer continue despite attempts by organizations such as Susan G. Komen to inform the public about the benefits of screening. Additionally, mistrust of the health care system as an institution, particularly among African-Americans continues to shape how this community engages with health care. The mistrust of the medical community may likely contribute to low screening and health literacy due to a lack of comfort and familiarity. The literature shows that low screening percentages directly correspond to the delay in cancer diagnosis, which can lead to a poorer prognosis. These barriers appear to overlap and fuel a cycle of negative health behaviors that can lead to poor health outcomes, contributing to even more apprehension and fear.

While the qualitative data availed important insights on attitudes, behaviors and perceptions about breast health in the target communities, limitations in data collection for McHenry County must be addressed in future needs assessments for the Community Profile.

Key Questions from Qualitative Data:

- What health systems improvements can be implemented to avail greater access to screenings and other preventative health services for women with social, financial or other barriers that frequently prevent adherence to annual screening recommendations?
- What innovative measures can be taken to address deep-seated feelings of mistrust many racial minority groups harbor towards the health care system?
- How can the Affiliate further support robust preventative health education in the target communities?
- How can the Affiliate help facilitate greater communication and partnership among McHenry County community stakeholders and breast health professionals to ensure access to women?

# Susan G. Komen®- Chicagoland
# Mission Action Plan
# FY2016- FY2019

**Problem Statement**

African American/Black and Hispanic/Latina women in Cook and McHenry Counties have limited access to high quality breast cancer screening and breast health services. Cook and McHenry Counties are also unlikely to meet the Healthy People 2020 target interventions for their breast cancer death rate, low screening proportions and late-stage breast cancer diagnosis. Lastly, in both counties, there is a consensus for mistrust of the healthcare system, low health literacy and lack of affordability.

## *Grant Making*

**Priority 1:**

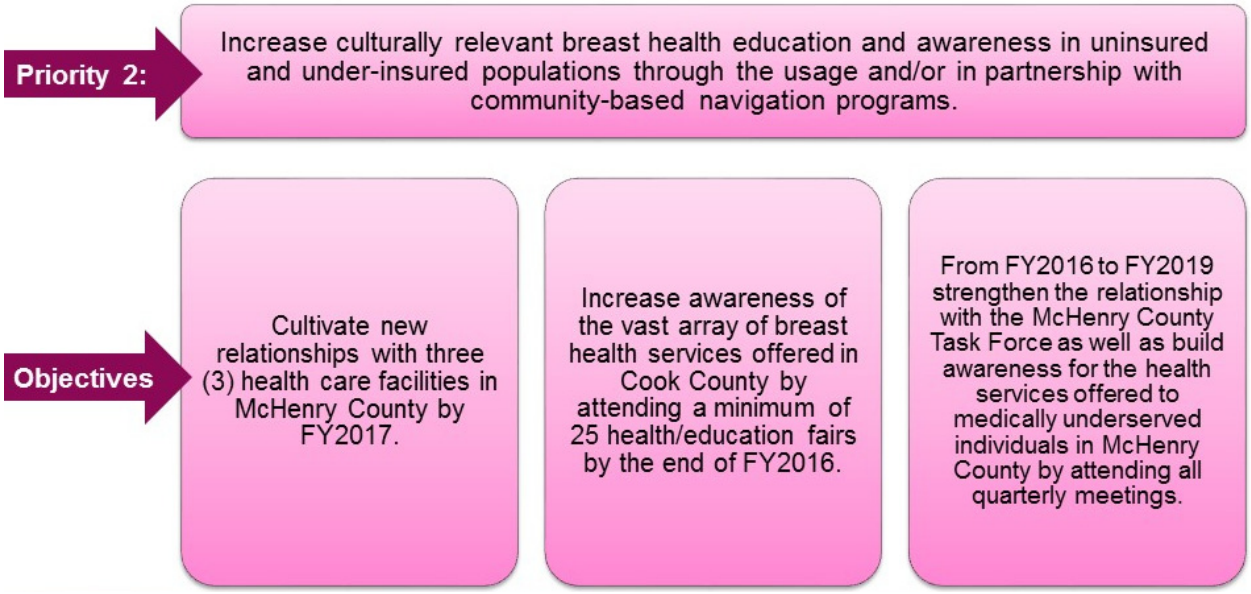
Increase access to quality breast cancer screening, diagnosis and treatment services by reducing financial barriers for uninsured and under-insured African American/Black and Hispanic/Latina women residing in Cook and McHenry Counties.

**Objectives**

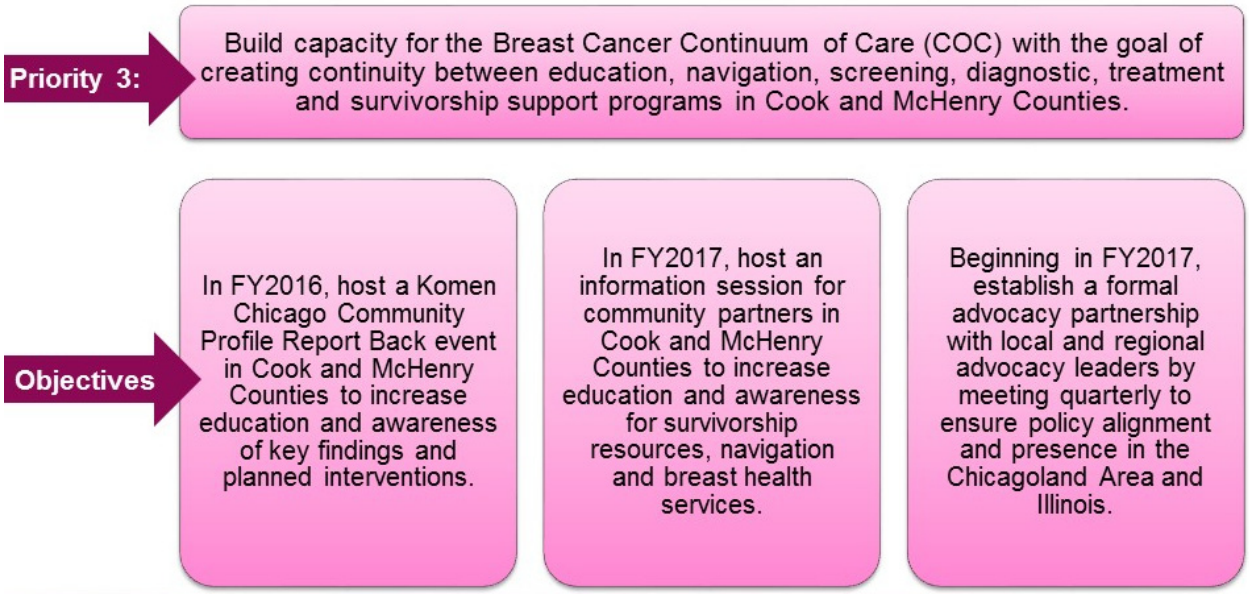
The FY 2017 Community Grant RFA will give special consideration to applicants who are participating in the Metropolitan Chicago Breast Cancer Task Force's Quality Care Consortium.

In the Fall of 2015, host two grant writing workshops in Cook and McHenry Counties that emphasize the importance of program evaluation and data collection.

# Education and Community Outreach




# Health Systems Variation/Public Policy



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# Appendices

## Appendix A. Focus Group Discussion Topic Guide

Komen Chicagoland Area 2015 Community Profile Focus Group Questions

1. Do you have a personal experience with breast cancer?

2. If so, how has that experience affected your perspective on getting screening for breast cancer?
   *If negative experience given by participant, ask questions why = barrier to screening*

3. Do most of your friends and family get mammograms regularly?
   If not, why?

4. Ask for participants to raise their hands if they have ever received a screening mammogram.

5. For those who do not get screening mammograms regularly, please share why not.

6. For regular screeners, ask participant them why they get mammograms on a regular basis.

7. Have you ever been recalled after having a screening mammogram to get additional images?
   If so, how was your experience?

How did you feel, after being asked to return to the facility for additional imaging?

8. What do breast mean to you?

9. Do you feel comfortable with your body?

10. Do you know your breasts (practice self-awareness of your breasts)?
    *If not, this could affect willingness to get a screening mammogram*

11. Does your spirituality affect your perspective on getting regular screening mammograms? If so, how? If not, why not?

12. Are screening mammogram resources available in your community?

13. Do you know how to go about requesting a mammogram?

14. If you do not have insurance, do you know there are services available to help provide free mammograms to women in Chicago?

15. If you have insurance, does the potential of out-of-pocket expense deter you from receiving a mammogram?

16. Please share about your experience at your local mammography facility.
    *If negative, ask more probing questions on why*
    *If they name specific facilities, take note.*

17. Have you ever thought/felt discriminated against during any point of getting a mammogram?
    Ex: type of insurance, Medicaid patient, race?

18. What is your level of satisfaction with the resources in your community?
    Poor Fair Good Excellent

*Both positive and negative responses, ask participants to explain why*

19. What do you think organizations such as Komen, etc could do to help encourage women in your community to receive a screening mammogram?

## Appendix B. Key Informant Interview Guide

1. What comes to mind when you think of breast cancer?

2. Why do you think Cook County has low breast cancer screening percentages?

3. If a women told you she was at risk for breast cancer, what does that mean to you?

4. What are some of the factors that affect whether women seek screening services?

5. What is being done in Chicago to get messages out to the community about breast cancer?

6. Where do you think most people get their breast health information from?

7. What makes it still difficult for women to seek getting clinical breast exams, despite the ACA mandate?

8. What do you think will be the easiest way for women to access breast health services?

9. What suggestions would you have for Komen, other breast health service organizations to help reduce the health disparity?

10. Any other thoughts or comments you would like to share?
Additional Question: One message that would help women seek screening?

# Key Informant Interview Script

**Introduction:**

Hello, my name is _____. I am assisting the Chicagoland Area of Susan G. Komen in assessing where there may be barriers to or gaps in breast health services in the Affiliate's target areas- **(Cook and McHenry Counties).** The themes that emerge from the interviews will be used to set priorities and inform the efforts of **Susan G. Komen Chicago**. The priorities that we establish will help us determine where to target our grantmaking, as well as help us build community relationships, learn about programs taking place in your community, and address outreach and policy needs.

Your knowledge is valuable and the Affiliate appreciates you making yourself available for an interview. The interview will take about 20-30 minutes. Your participation in the interview is voluntary. You may choose not to participate in the interview at any time. Whether you chose to participate or not participate in the interview will in no way impact your relationship with the Affiliate and the services they provide. If you decide to stop prior to the interview being completed, I will ask you how you would like us to handle the data collected up to that point. If you do not want to answer some of the questions, you do not have to. I will be taking notes during the interview and trying to take down as much information as possible. While we use the themes from the interviews, the interviews themselves are confidential. Do you have any questions about the interview process?

- **Ask for verbal consent:** Do you agree to participate in this study knowing that you can withdraw at any point with no consequences to you? (Document date and time)
- **Ask for written consent:** At this time I kindly ask that you read and sign the provided consent form.
-

If you have any questions during the interview, please feel free to ask them at any time.

**Questions:**

- What comes to mind when you think about (breast) cancer, the disease itself?
- Why do you think this community has lower screening percentages than other areas?
- If a woman told you she was at risk for breast cancer, what would that mean to you?
- What are the factors affecting whether or not women seek breast health services?
- What is being done in your community to get breast cancer messages to women? Do you think it is working?
- Where do most people in your community get breast health information?
- What makes it difficult for women to seek breast screening services such as a clinical exam or mammogram?
    - Probe: Consider that some women have the opportunity to get screened under their insurance but decide against it. Why do you think that happens?

- What do you think would be the easiest way for women to get help when they need it?
- What suggestions do you have for Komen in serving the community and improving breast health or reducing breast cancer?
- Is there anything that you would like to add that we did not discuss?

**Closing:**
Thank you very much for your time. Your knowledge and insights will be very helpful in assisting Susan G. Komen Chicagoland Area in identify gaps and unmet needs in the breast health services community.

The 2015 Susan G. Komen Chicagoland Area Community Profile will be completed by June, 2015 and will be posted online at www.komenchicago.org. The 2011 Community Profile can currently be found on the Affiliate website at http://komenchicago.org/grants/applying-for-community-grants/funding-priorities-2/ . Thank you again for your assistance.

# Key Informant Interview Online Questions

## BREAST CANCER SURVIVORS

- Do you feel that your doctor explained your pathology report results in a way that was easy to understand? Do you think there is anything that could have been done differently?
- The recommended time from diagnosis to treatment (or follow up care) is 60 days. Did you experience a delay longer than this? If yes, why do you think this delay occurred?
  - Yes
  - No
- Do you believe patient navigation services are useful? Patient navigators are trained health care workers who provide support and guidance throughout the cancer care continuum.
  - Yes
  - No
- Would you use any of the following patient navigation services?
  - Help with coordinating appointments with providers
  - Language translation or interpretation
  - Arrangement of transportation and/or child/elder care
  - Help locating local support groups
  - Help filling out paperwork
  - Assistance in understanding diagnosis and treatment options

- Please describe any experience you have had with a patient navigator.
- Please describe the survivorship or reconstruction services available to you in your county.

## BREAST HEALTH STAFF/VOLUNTEER

- How does your office/clinic/organization reach out to women who do not access mammography services?
- What type of breast cancer screening and diagnostic services does your office/clinic/organization provide?

- What types of programs (financial, transportation, medical care, etc.) are available to breast cancer survivors at your office/clinic/organization? If there are none, then where do you refer patients?

**CO SURVIVOR**

- How did you communicate about the diagnosis of breast cancer with your friend, colleague or loved one?
- What resources did you use to learn about breast cancer?
- What kind of support did you feel that you needed, in order to be able to support your friend, colleague or loved one, in turn? Did you find this help anywhere? If not, what would have helped?
- From your perspective, what seemed to be the most difficult barriers or issues that the person dealing with breast cancer encountered? Consider the emotional, financial and health care system factors.

**Closing:**
Thank you very much for your time. Your knowledge and insights will be very helpful in assisting Susan G. Komen Chicagoland Area in identify gaps and unmet needs in the breast health services community.

The 2015 Susan G. Komen Chicagoland Area Community Profile will be completed by June, 2015 and will be posted online at www.komenchicago.org. The 2011 Community Profile can currently be found on the Affiliate website at http://komenchicago.org/grants/applying-for-community-grants/funding-priorities-2/ . Thank you again for your assistance.

## Appendix C. Breast Health Participant Survey

**Breast Health Survey Participant Consent Form**

**Susan G. Komen®- Chicagoland**

I understand that I was invited to participate in a survey being conducted by the Chicagoland Area of Susan G. Komen®. By conducting this survey, the Affiliate **will learn what the barriers are to accessing breast cancer screening services in Cook County and the reasons why.** I understand that I am being asked to take part because I fit the eligibility criteria.

I understand that I do not have to participate in this survey and can choose to leave at any time. My participation is voluntary, and I may change my mind at any time. There will be no penalty if I decide not to participate. I understand that my participation in the survey will in no way affect any current or future assistance from Komen Chicagoland Area.

I understand that all information obtained from the survey will be kept strictly anonymous. All participants will be asked not to disclose any personal contact information on the survey. All identifying information will be removed from the collected materials. In addition, all materials will be locked in a file cabinet at shredded after the completion of the Komen Chicagoland Area 2015 Community Profile.

I understand that there are no physical risks to participating in this survey, but I might not be completely comfortable answering some of the questions being asked. I understand that I am free not to answer any of the questions asked.

By signing this consent form, I indicate that I fully understand the above information and I agree to participate in the survey.

| _____ | _____ | _____ |
|---|---|---|
| Participant Printed Name | Participant Signature | Date |

Survey ID: _____

# Cook County
# Breast Health Participant Survey

- Please select **one of the choices** below that best represents your current age:
  _____ 39 years of age and younger
  _____ 40-49 years of age
  _____ 50-59 years of age
  _____ 60 years of age and older

- County/Zip Code of Residence:_____

- Community/Neighborhood: _____

- Have you ever had a mammogram? ☐ Yes ☐ No

  a. If yes, at what age did you have your first mammogram?_____years

  b. How long has it been since you had your last mammogram? **Please check one.**

  ☐ Within the past year (anytime less than 12 months ago)
  ☐ Within the past two years (one year but less than two years ago)
  ☐ Within the past three years (two years but less than three years ago)
  ☐ Within the past five years (three years but less than five years ago)
  ☐ Five or more years ago
  ☐ Don't know or not sure

- If under 40 yrs, do you intend to get a mammogram once you turn 40? ☐ Yes ☐ No

  For the purpose of this survey, a clinical breast exam is defined as a physical exam performed as part of a regular check-up where the provider, or clinical staff member, carefully feels the breasts and underarm and visually checks the breasts for any changes or abnormalities

  a. If under 40yrs, have your ever received a clinical breast exam? ☐ Yes ☐ No

- Do you give yourself breast exams? ☐ Yes ☐ No

- Have you ever been diagnosed with breast cancer? ☐ Yes ☐ No

  a. If yes, at what age were you diagnosed?_____years

  b. What stage of breast cancer were you diagnosed with? **Please check one.**

  ☐ Stage 1 ☐ Stage 2 ☐ Stage 3 ☐ Stage 4

- Has anyone else related to you been diagnosed with breast cancer? **Please check all that apply.**

  ☐ Grandmother ☐ Mother ☐ Sister ☐ Daughter

- Currently, at what age is it recommended for women to have a mammogram once a year?
  **Please check one.**

  ☐30 ☐ 40 ☐ 50 ☐ 60

- What is your primary occupation? **Please check one.**

  ____ Homemaking ____ Computer/Office ____ Sales

  ____ Daycare ____ Beautician/Salon ____ Health care- clinical

  ____ Social Work ____ Housekeeping Services ___ Health care- non-clinical

  ____ Education ____ Other (please list): _____

- What is the highest degree or level of school that you have completed? **Please check one.**

  ____ Did not graduate high school

  ____ High school graduate/GED

  ____ Vocational certification

  ____ Some college credit, but less than one year

  ____ one or more years of college credit, no degree

  ____ Associate's degree

  ____ Bachelor's degree

  ____ Master's degree

  ____ Professional/Doctorate degree

- What language do you most frequently use in writing? _____
- What language do you most frequently use in speaking? _____

- What is your Race? **Please check all that apply.**

  ____ White
  ____ Black or African-American
  ____ American Indian or Alaska Native
  ____ Asian (e.g. Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese)
  ____ Native Hawaiian or Other Pacific Islander (e.g. Native Hawaiian, Guamanian/Chamorro, Samoan)
  ____ Other (please write your race): _____

- Are you of Hispanic, Latino/a or Spanish origin? **Please check all that apply.**

  ____ No, not of Hispanic, Latino/a, or Spanish origin
  ____ Yes, Mexican, Mexican-American, Chicano/a
  ____ Yes, Puerto Rican

____ Yes, Cuban
____ Yes, another Hispanic, Latino/a, or Spanish origin
____ Yes, other (please write your origin): _____

- Where do you receive your health information? **Please check all that apply.**

____ Church ____ Mail delivered to your home

____ Shopping ____ Television

____ Radio ____ Newspapers

____ Internet ____ Social Media (e.g. Facebook, twitter)

____ Word of mouth (From whom or where: _____)

____ Doctor/Health Care provider

- Where or how do you receive community/social information on events?
- What is your household income in **2013 Please check one.**

____ Less than $10,000
____ $10,001- $20,000
____ $20,001-$30,000
____ $30,001-$40,000
____ $40,001-$50,000
____ More than $50,000
____ Don't know/Not sure
____ Would prefer not to disclose

- If you received treatment for breast cancer, how was your treatment paid for? **Please check all that apply.**

____ Private insurance
____ Nonprofit assistance grant
____ Medicaid/Medicare/Government Assistance
____ Self-pay
____ Don't know/Not sure
____ Would prefer not disclose

- Do you have one person you think of as your personal doctor or health care provider?

____ Yes, only one
____ Yes, More than one
____ No

- Do you get a checkup every year? ☐ Yes ☐ No

- Was there a time in the past 12 months when you needed to see a doctor, but could not because of cost?

____ Yes, only one
____ Yes, more than once
____ No

**Please answer the following questions openly and honestly.**

1. Do you have a personal experience with breast cancer? ☐ Yes ☐ No
   a) If yes, then please share 1-2 sentences about the experience:

2. Do most of your friends and family get mammograms regularly?
   ☐ Yes ☐ No ☐ Not sure
   a) If no, why?

3. What do breasts mean to you?

4. Do you feel comfortable with your body? ☐ Yes ☐ No

5. Do you know your breasts (practice self-awareness of your breasts)? ☐ Yes ☐ No

6. Does your spirituality affect your perspective on getting regular screening mammograms?
   ☐ Yes ☐ No
   a) If yes, then please explain how? If no, then why not?

7. Have you ever been recalled after having a screening mammogram to get additional images?
   ☐ Yes ☐ No
   a) If so, how was your experience?
   b) If so, how did you feel, after being asked to return to the facility for additional imaging?

8. Do you know how to go about requesting a mammogram? ☐ Yes ☐ No

9. Do you have health insurance? ☐ Yes ☐ No

   a) If you have insurance, does the potential of out-of-pocket expense deter you from receiving a mammogram? ☐ Yes ☐ No

   b) If no, do you know there are services available to help provide free mammograms to uninsured women in Chicago? ☐ Yes ☐ No

10. Are screening mammogram resources available in your community?
    ☐ Yes ☐ No ☐ Not sure
    a) If yes, then please share about your experience at your local mammography facility.

11. Have you ever thought or felt discriminated against during any point while receiving a mammogram?
    (Ex: type of insurance, Medicaid patient, race) ☐ Yes ☐ No

12. What is your level of satisfaction with the resources in your community?

☐ Poor ☐ Fair ☐ Good ☐ Excellent

a) Why did you select the choice above?

13. What do you think organizations such as Komen, American Cancer Society, etc. could do to help encourage women in your community to receive a screening mammogram?

14. Any other comments/questions/concerns: