

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



SUSAN G. KOMEN®
CHICAGOLAND AREA
EXECUTIVE SUMMARY

Acknowledgments

The Community Profile Report could not have been accomplished without the exceptional work, effort, time and commitment from many people involved in the process.

Susan G. Komen® Chicagoland Area would like to extend its deepest gratitude to Susan Tybon, Chief Executive Officer, the Board of Directors and the following individuals who participated on the 2015 Community Profile Team:

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A special thank you to the following individuals and entities for their assistance with data collection and analyses, as well as providing information included in this report:

- Anne Marie Murphy, Metropolitan Chicago Breast Cancer Task Force
- Maritza Martinez-Pereira, Esperanza Health Centers
- Ofelia Figueroa, Esperanza Health Centers
- Gregory Hampton, Esperanza Health Centers
- Paulina Guzman, Access Community Health Network
- Rochelle Gant, Greater Metropolitan Missionary Baptist Church
- Karriem Watson, University of Illinois Cancer Center
- Angela K. Walker, Loretto Hospital
- Iris Rogers, DDB Chicago
- Jacqueline Kanoon, Mount Sinai Hospital

- Suzanne Hoban, Family Health Partnership Clinic
- YaSiang Wai, Michael Reese Research & Education Foundation
- Gail Briggs, Health care Consortium of Illinois
- Shannon Sikkila, Swedish Covenant Hospital
- Dr. Joseph Thomas, M.D., Advocate Trinity Hospital
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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 than 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 unlikelihood 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-stage 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 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

Priority 2:

Increase culturally relevant breast health education and awareness in uninsured and under-insured populations through the usage and/or in partnership with community-based navigation programs.

Objectives

Cultivate new relationships with three (3) health care facilities in McHenry County by FY2017.

Increase awareness of the vast array of breast health services offered in Cook County by attending a minimum of 25 health/education fairs by the end of FY2016.

From FY2016 to FY2019 strengthen the relationship with the McHenry County Task Force as well as build awareness for the health services offered to medically underserved individuals in McHenry County by attending all quarterly meetings.

Health Systems Variation/Public Policy

Priority 3:

Build capacity for the Breast Cancer Continuum of Care (COC) with the goal of creating continuity between education, navigation, screening, diagnostic, treatment and survivorship support programs in Cook and McHenry Counties.

Objectives

In FY2016, host a Komen Chicago Community Profile Report Back event in Cook and McHenry Counties to increase education and awareness of key findings and planned interventions.

In FY2017, host an information session for community partners in Cook and McHenry Counties to increase education and awareness for survivorship resources, navigation and breast health services.

Beginning in FY2017, establish a formal advocacy partnership with local and regional advocacy leaders by meeting quarterly to ensure policy alignment and presence in the Chicagoland Area and Illinois.

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