# COMMUNITY PROFILE REPORT



Area Affiliate of Susan G. Komen for the Cure®

Susan G. Komen for the Cure® Chicagoland Area

2011

**Disclaimer:**

The information in this Community Profile Report is based on the work of the Chicagoland Area Affiliate of Susan G. Komen for the Cure® in conjunction with key community partners. The findings of the report are based on a needs assessment public health model but are not necessarily scientific and are provided "as is" for general information only and without warranties of any kind. Susan G. Komen for the Cure® and its Affiliates do not recommend, endorse or make any warranties or representations of any kind with regard to the accuracy, completeness, timeliness, quality, efficacy or non-infringement of any of the programs, projects, materials, products or other information included or the companies or organizations referred to in the report.

## Acknowledgements

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And to all of the key informants who shared their time and knowledge about women and breast cancer in their communities

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# Executive Summary

The Chicagoland Area Affiliate of Susan G. Komen for the Cure® was established in 1997 and held the first Susan G. Komen Chicago Race for the Cure®. With the support of our signature fundraiser, the Komen Chicago Race for the Cure®, the Komen Chicagoland Area Affiliate has awarded over $10 million towards the fight against breast cancer by funding grassroots breast health education and breast cancer screening and treatment projects, as well as global research. 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 National Breast Cancer Research Grants Program.

The Affiliate completed this 2011 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 by allowing the Affiliate to tell the story about breast cancer and breast health care needs in our 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.

**Statistics and Demographic Review**

Demographics data used in this report were obtained from the US Census Bureau, Population Estimates Program. The Affiliate service area includes Cook, DuPage, Kane, Lake, and McHenry Counties and is home to approximately 5.29 million people, 3.95 million of whom are women. The most recent population estimates (2009) were obtained by county for the Affiliate services areas. Cook County is the most populated county in the Affiliate's service area, followed by DuPage County, Lake County, Kane County and McHenry County. With approximately 2.71 million women, Cook County also has the largest female population in the Affiliates five county service area. DuPage County has the second highest female population, followed by Lake County, Kane County, and McHenry County. Having the smallest female population in the Affiliate's service area, McHenry County also has the largest percentage of White women. Cook County, having the largest female population in the Affiliate's service area, has the largest percentage of African American women. Kane County has the largest population of Hispanic women and DuPage County has the largest population of Asian women.

Breast cancer age-adjusted incidence and mortality data (rates and counts) for the five counties (Cook, DuPage, Kane, Lake, and McHenry), from 2003 – 2007, were obtained from Thompson Reuters and National Cancer Institute (NCI) State Cancer Profiles. According to the NCI State Cancer Profiles, the United States incidence data is obtained from the CDC's National Program of Cancer Registries Cancer Surveillance System (NPCR-CSS) November 2009/January 2010 data submission and SEER November 2009 submission. The Illinois and Counties incidence data was obtained from the State Cancer Registry and the CDC's National Program of Cancer Registries Cancer Surveillance System (NPCR-CSS) November 2009/January 2010 data submission.

The incidence and mortality data obtained from the NCI State Cancer Profiles all include rates for the Hispanic population. The incidence and mortality rates on Hispanics also include all other races. The limitation of the data is that rates could not be obtained all races (White, Black, Hispanic) separately.

According to the NCI State Cancer Profiles for the 2003-2007 period, the breast cancer annual incidence rates (IR) were the highest in Lake County, with an IR of 134.4. However, Cook County has the highest IR Average Annual Count of 3,400. DuPage County has the next highest IR Average Annual Count of 649. Cook County has the highest IR Average Annual Count for all races/ethnicities. The IR Average Annual Count is the actual average number of breast cancer occurrences. The breast cancer annual mortality rates (MR) for the same time period were highest in McHenry County, with a MR of 27.1. The highest mortality count, however, was in Cook County with 802 counts. Cook County has the highest MR counts for all races/ethnicities. DuPage County has the second highest MR counts when accounting for all race/ethnicities. Due to high average annual IR and MR counts, Cook and DuPage Counties were chosen as priority areas for the Affiliate. A tremendous effect on the Continuum of Care can be made by addressing the breast cancer issues facing women in Cook and DuPage Counties.

In conducting the preliminary analysis of the service area we focused on areas with high incidence and mortality rates, noted mortality disparities, and vulnerable populations that may not have adequate access to screening and treatment. If recent data conflicted with that obtained by cancer registries and other public sources, we relied on the more recent information. Though the entire Affiliate service area is suffering acutely due to breast cancer impact, we have chosen Cook and DuPage Counties as current target areas because of their overall highest disparity rates. The specific communities we are targeting within Cook County are Beverly, Chatham, Roseland, and South Shore. The target population in these communities is African American women. The communities we are targeting in DuPage County are Lombard, Elmhurst, and Downers Grove and the target populations of interest are Hispanic and African American Women. All seven of these target areas and the populations within them were chosen due to their annual mortality rates, percentage of late-stage diagnosis and/or the presenting socioeconomic challenges.

In order to reduce the large breast health mortality disparity with African American women in Cook County and Hispanic and African American women in DuPage County, the Affiliate plans to strengthen and build capacity of existing breast health providers and grantees. A new grant program with a 2-year structure, as well as a small capacity building grant program will be created and implemented to address the aforementioned problems. The Affiliate also intends to maintain and create new strategic partnerships to better address the dire needs apparent in these communities.

**Health Systems Analysis**

Based on the quantitative findings, asset maps were made for Cook and DuPage Counties to better understand the issues concerning the Continuum of Care. These maps analyzed the Mortality Rates and Uninsurance Rates in these counties. Additionally the locations of Hospitals, Federally Qualified Health Centers, Grantees and Mammography Clinics were added to these maps. Key informants were selected from the communities on the map that had high Mortality Rates and high Uninsurance Rates. Additional partners from areas with similar demographics were chosen.

The Affiliate works with numerous community organizations and faith groups to improve breast health outcomes. In our target communities of Cook and DuPage County these partnerships and coalitions include: DuPage County Health Department, The Metropolitan Breast Cancer Task Force, Stand Against Cancer Coalition, Sisters Working It Out, and UIC Center for Excellence in Eliminating Disparities. Additionally, the Affiliate plans to create partnerships with Elmhurst Hospital, and Health Care Consortium of Illinois, and Sisters Network in order to better reach our target population.

We solicited feedback from our key informants to document the issues around the Continuum of Care. Their feedback identified the following issues: an inability to get to medical appointments, a lack of services for uninsured women, and a lack of knowledge concerning their rights. Additionally, agencies have expressed a difficulty in identifying women who need their services. Digging deeper and investigating these barriers will allow the Affiliate to create more community partnerships and encourage collaboration amongst other community organizations.

**Qualitative Data Overview**

Qualitative data was collected via surveys and key informant interviews. Two surveys were distributed to two target groups: grantees and breast health service providers. Breast cancer health service providers, including Affiliate grantees and IBCCP coordinators, completed 16 surveys.

The Affiliate also chose to conduct key informant interviews as a means to obtain a more in depth perspective about our communities of interest. Eleven key informants representing different healthcare and advocacy organizations including clinics, hospitals, and support groups in the five county service area as well as under/uninsured African American, Hispanic and Asian populations were utilized for this process. Key informants were selected using a referral sampling process where informants identified other individuals within the breast health community for interviews.

The informants revealed several types of barriers (system, personal, physical) that impeded women from obtaining annual screening and diagnostic/treatment services. System barriers, which work at the macro level where they create bureaucratic obstacles to screening and

treatment. These barriers are often a daunting task when trying to navigate to and through the healthcare system. Individuals may have the desire to obtain a mammogram or receive breast cancer treatment, but they are faced with barriers within the system and do not have appropriate access to care. This is exacerbated at the micro level where day-to-day personal barriers impede a woman's abilities to prioritize breast health. Women experience a number of personal barriers, such as family, fear and cultural beliefs, which present themselves as challenges when attempting to prioritize their breast health. Because personal barriers are experienced on a constant basis, they can be overwhelming and discourage a woman from seeking screening and treatment. This is often in conjunction with physical barriers that affect women on a daily basis but over which they do not have control. A lack of reliable or access to public transportation is a recurring theme. While some barriers are specific to certain race/ethnic groups, most are experienced by all under/uninsured women.

In addition to the numerous concerns listed above, a major problem is the lack of collaboration and cooperation between breast health organizations. As a result, the Affiliate made this a priority for our 2013-14 grant cycle.

Finally, the Affiliate can also improve its visibility and presence in many areas. A key informant revealed that the Affiliate is virtually unknown in her community and in many communities of color. Even though the Affiliate funds many programs that provide services to racially and ethnically diverse communities, the women are unaware of the purpose that we serve as a breast health resource. It was also revealed that there is confusion about the Affiliate, Breast Cancer Network of Strength and Avon because we all hold a race or have a multi-day/multi-mile walking event.

**Conclusions**

A review of demographic and breast cancer data revealed that the Affiliate's service area overall is suffering acutely from the impact of breast cancer, especially with regard to mortality rates. There are many areas and populations within our service area that are disproportionally affected by breast cancer. The Affiliate decided to focus on Cook and DuPage Counties due to high IR and MR average annual counts, percentage of late-stage diagnosis and/or the socioeconomic challenges. Target communities were chosen. In Cook County the target communities are Beverly, Chatham, Roseland, and South Shore. In DuPage County the target communities are Downers Grove, Elmhurst, and Lombard.

The quantitative analysis and findings led to gathering qualitative data from breast cancer facilities in each of the targeted areas. Solicited key informants provided a more personal and comprehensive perspective of the strengths and weaknesses in the target communities. System, personal, and physical barriers affecting the Continuum of Care in the target communities were identified.

An analysis of the Continuum of Care in our targeted communities through a review of existing community assets, legislative issues, and key informant surveys revealed a shortage of medical

providers and resources in certain areas of our target communities. Focusing on the continuum of care will ensure access into and through the breast healthcare system at each level by addressing the barriers that women seeking services encounter as well as the barriers that agencies providing those services face.

Surveys were distributed to twenty-five area mammography screening facilities, and local breast healthcare service providers in each of our five county service area and with at least one survey completed from each of selected seven target communities. The main goals of the surveys were to identify details on populations served, types of services offered, what barriers, if any, exist from the service provider. During this process, several types of barriers (system, personal, physical) that impeded women from obtaining annual screening and diagnostic/treatment services were revealed. In addition to the system, personal and/or physical barriers that may women experience that prevent them from accessing quality breast healthcare, a major problem is the lack of collaboration and cooperation between breast health organizations. Finally, it was revealed through the key informant interviews the need for the Affiliate to improve its visibility and presence in many communities of color.

The Affiliate's Board of Directors and Community Profile team convened to review the data and recommend priorities for our service area. SMART goals were developed as a result. The following priorities will be used to inform the Affiliate's grantmaking and strategic planning for the next grant period. Other considerations in determining which priorities to focus on include health care reform, state and federal programming, and fiscal decisions which may reduce access to programs that serve the uninsured.

**Affiliate Priorities**

1. Continue coalition with Komen statewide Illinois affiliates to advance public policy agenda.
2. Target African American Women in Cook County to reduce the breast health mortality disparity through strengthening and building capacity of existing breast health providers and grantees.
3. Target Hispanic and African American Women in DuPage County through strengthening and building capacity of existing breast health providers and grantees.
4. Expand education and outreach messaging from breast self awareness to incorporate legal rights, patient rights and access to available services
5. Strengthen the continuum of breast health and breast cancer care services in our 5-county service area to allow individuals to have total access to programs and services.

# Introduction

## Affiliate History

In 1982, a promise between two sisters became Susan G. Komen for the Cure® and launched a global breast cancer movement. Today, Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists fighting to save lives, empower people, ensure quality care for all and energize science to find the cures. Thanks to events like the Susan G. Komen Race for the Cure® Series, we have invested more than $1.9 billion to fulfill our promise, becoming the largest source of nonprofit funds dedicated to the fight against breast cancer in the world. For more information about Komen, breast health care and/or breast cancer, visit **www.komen.org**

The Chicagoland Area Affiliate of Susan G. Komen for the Cure® was established in 1997 and held the first Susan G. Komen Chicago Race for the Cure®. With the support of our signature fundraiser, the Komen Chicago Race for the Cure®, the Affiliate has awarded over $10 million towards the fight against breast cancer by funding grassroots breast health education and breast cancer screening and treatment projects, as well as global research. 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% of net proceeds raised are contributed to the Komen Grants Program which funds research and education programs.

The Affiliate's Community-Based Grants Program is made possible through outstanding support from our signature fundraisers, such as the Susan G. Komen Chicagoland Race for the Cure®, Dancing with Chicago Celebrities, other local events, individual donations and the generous support of corporate sponsors. In 2010, the Affiliate funded approximately $1.38 million to local non-profit breast health care organizations that share our mission to save lives and end breast cancer forever. For additional information on the Chicagoland Area Affiliate of Susan G. Komen for the Cure, please visit **www.komenchicago.org**

## Organizational Structure

Komen Chicagoland Area Affiliate is part of an Affiliate Network of Susan G. Komen for the Cure that exists in 122 cities and communities in the United States along with three established international Affiliates in Italy, Germany, and Puerto Rico. The Affiliate is a 501(c)3, locally operated not for profit organization and governed by a 13-member volunteer Board of Directors. We rely on the time, talents, and treasures of hundreds of committed volunteers to make it possible for us to be a leader in the fight against breast cancer in the Chicagoland Area.

Below is the current organizational structure of the Affiliate including Board members, Affiliate staff, strategic partnerships, and operational committees.

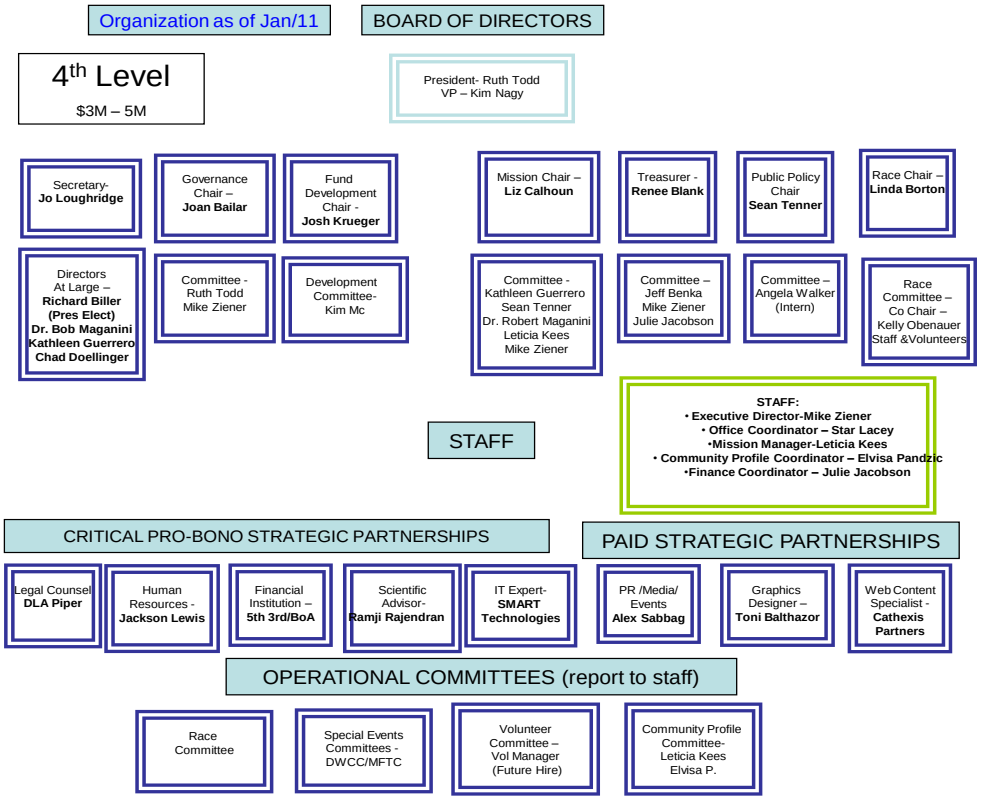



***Figure 1.*** *Chicagoland Area Affiliate of Susan G. Komen for the Cure® Organizational Structure*

**Description of Service Area**

The Affiliate serves a large and diverse geographic area that is located on the south western coast of Lake Michigan to include Cook, DuPage, Kane, Lake and McHenry Counties in Illinois. These five counties cover over 2,850 square miles and range from urban areas to suburban and more rural, agricultural areas. According to the 2009 County Population Estimates of the U.S. Census Bureau, half of the population in the five county service area is female (50.1%). This amounts to approximately 3.95 million women that can benefit from breast cancer education, screening, and treatment. According to the 2009 County Population Estimates of the U.S. Census Bureau, of the nearly 4 million women in the service area, 65.8% are White, 19% are Hispanic, 8.9% are African American, 5.6% are Asian, and 1.7% are of other races.

The largest amount of women in the service area reside in Cook County, and approximately 15.5% of them are uninsured. Cook County is also home to the largest city in the State of Illinois. With approximately 2.7 million residents, Chicago is also the largest city in the Midwest

and an epicenter of economic and cultural activity. Metropolitan Chicago, also called Chicagoland, is an expansion of the city boundaries to include the surrounding neighborhoods and is home to nearly 9.8 million people. Chicagoland includes the city of Chicago and all of Cook County, as well as eight counties in Illinois and three counties in Indiana. The Illinois counties are Lake, McHenry, DuPage, Kane, Kendall, Grundy, Will and Kankakee. The Indiana counties consist of Lake, Porter and LaPorte.

DuPage County is the second most populated county in the Affiliate service area. With nearly one million persons living in DuPage County, 50.4% are female. Of these women, 4.9% are currently uninsured and in dire need of services. Lake County is the third most populated county in the Affiliate service area, followed by Kane County and McHenry County. Like Cook and DuPage Counties, Lake, Kane and McHenry have female populations of approximately 50% of the total population. Kane County has a 7.4% female uninsured rate, followed by Lake County at 6.3% and McHenry County at 4.7%.

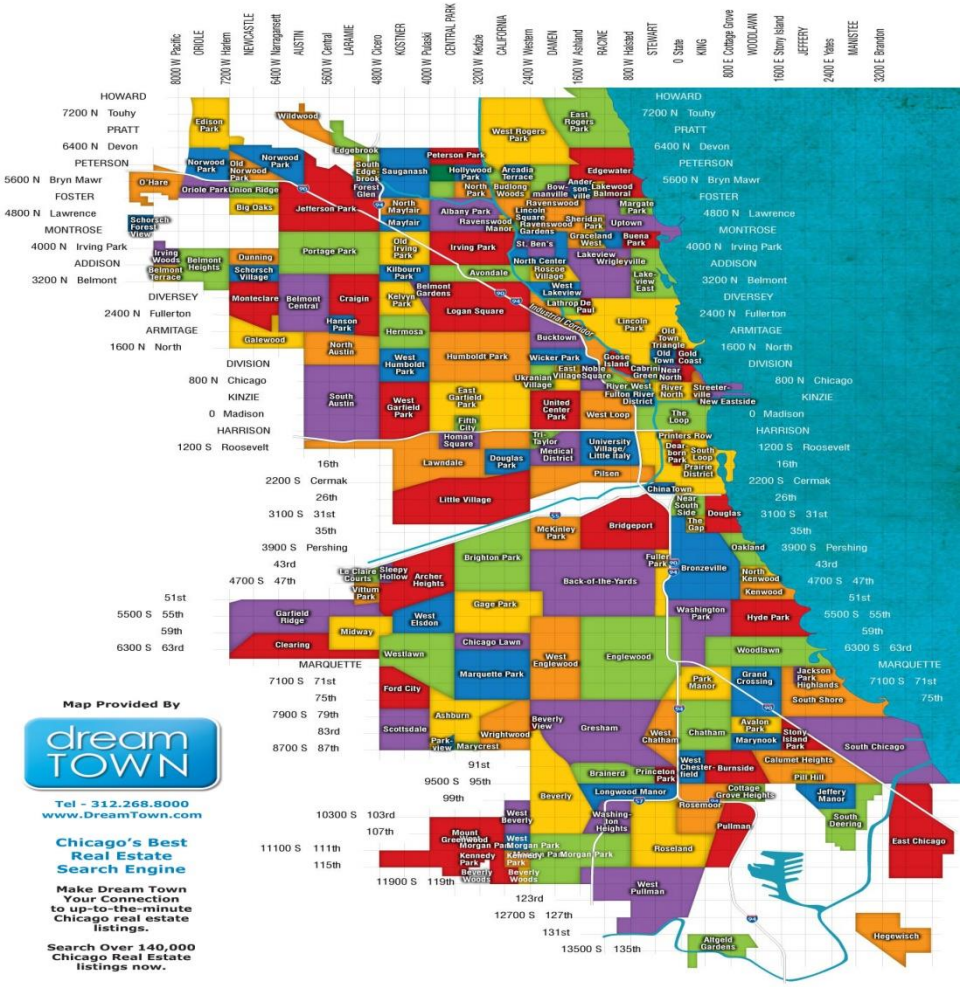



***Figure 2.*** *Metropolitan Chicago*

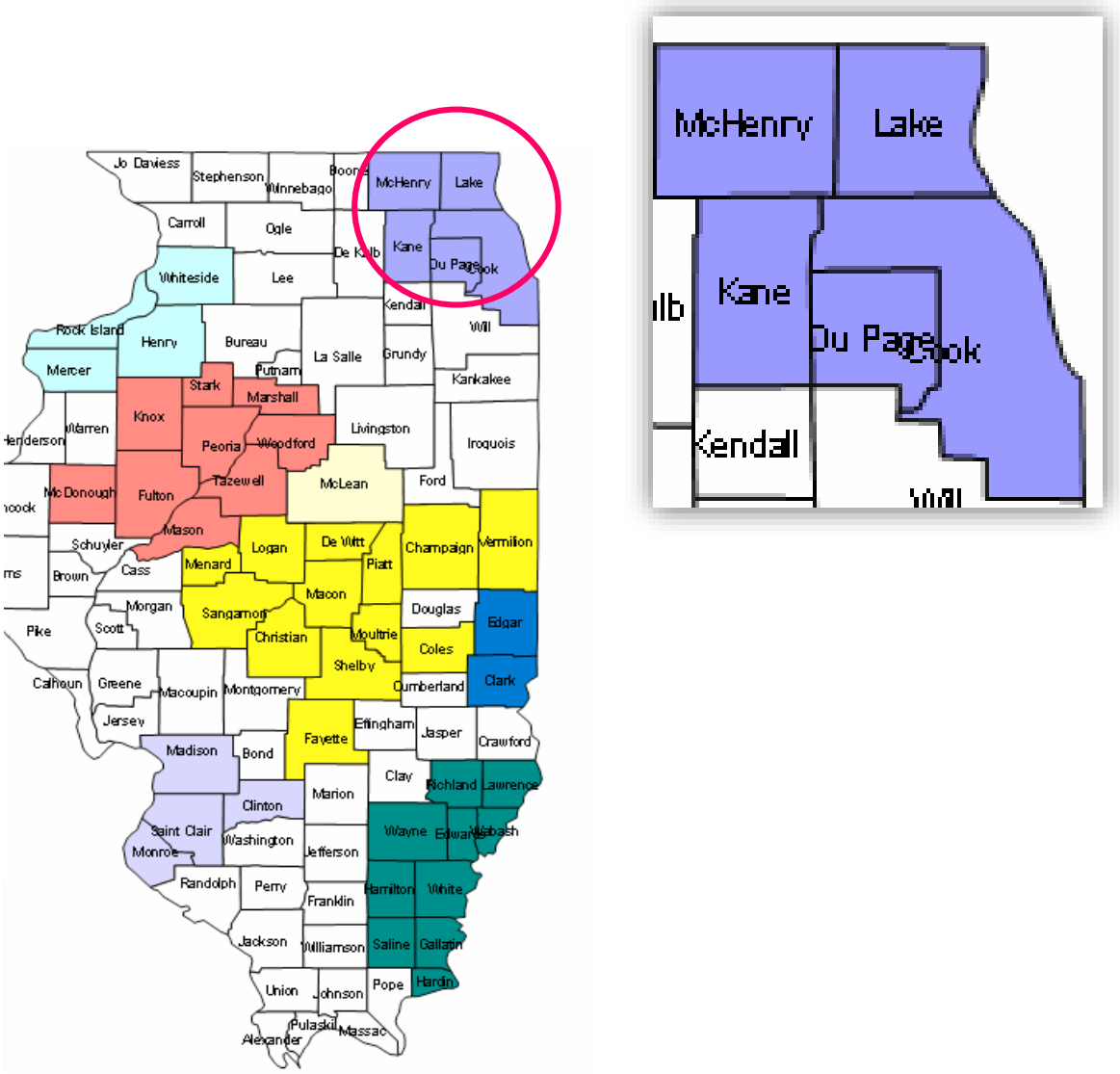



***Figure 3.*** *Komen Affiliate Service Area: Chicagoland Area*

**Purpose of the Report**

The *2011 Community Profile* provides an overview of the breast health issues facing the Affiliate's service area. A community profile, also called a community needs assessment, is a picture of the community, specifically looking at breast health and breast cancer.

The primary intent of the *2011 Community Profile* process undertaken by the Affiliate was to better understand the community we serve. According to the Susan G. Komen for the Cure Community Profile Guidebook, a quality Community Profile guarantees that mission and non-mission work is targeted and non-duplicative. In addition, the Community Profile should allow the Affiliate to:

- Establish focused Community-Based Grant priorities
- Establish focused community education needs
- Strengthen sponsorship and fundraising efforts by allowing the Affiliate to tell the story about breast cancer and breast healthcare needs in our service area
- Drive public policy efforts
- Establish directions for marketing and outreach
- Align the Affiliate's strategic and operational plan
- Drive inclusion efforts in the community

# Breast Cancer Impact in Affiliate Service Area

**Data Sources and Methodology Overview:**

Demographics data used in this report were obtained from the US Census Bureau, Population Estimates Program. The most recent population estimates (2009) were obtained by county for the Affiliate services areas (Cook, DuPage, Kane and Lake Counties). Breast cancer age-adjusted incidence and mortality data (rates and counts) for the service area were obtained from National Cancer Institute (NCI) State Cancer Profiles and Thomson Reuters.

According to the NCI State Cancer Profiles, the United States incidence data is obtained from the CDC's National Program of Cancer Registries Cancer Surveillance System (NPCR-CSS) November 2009/January 2010 data submission and SEER November 2009 submission.

The symbol (§) in the incidence data in Table 3, denotes data that was not provided because it did not meet USCS data quality standards for one or more years during the rate period of data collection. The limitation to this data is that 4% of the US population was not yet represented in the United States cancer Statistics.

The mortality data was provided by the National Vital Statistics System public use data file. SEER*Stat software was used by the NCI to calculate the death rates. Racial Rate ratios of Blacks and Whites (B/W) and Hispanics and Whites (H/W) were calculated by dividing the rates of Blacks over the rates of Whites and the rates of Hispanics over the rates of Whites respectively.

The all race, White and Black incidence and mortality data obtained from the NCI State Cancer Profiles include Hispanic while the Hispanics rates include any race. The limitation is that data could not be obtained for Whites, Blacks and Hispanics alone. ArcMap version 9.3, ESRI ArcGIS software was used to map the breast cancer incidence rates, mortality rates and rate ratios for Cook, DuPage, Kane and Lake Counties (Appendix A and B).

**Overview of the Affiliate Service Area:**

The Affiliate service area includes Cook, DuPage, Kane, Lake, and McHenry counties in Illinois. The five county service area contains approximately 3.95 million women.

<u>Demographics</u>

Table 1 shows race/ethnicity for the service area by county. Cook and DuPage Counties, target communities for the Affiliate, have the overall highest percentages across all demographic categories listed.

| County/Region | 2009 Total Population** | 2009 Female† | | 2009 Female Population† | | | | |
|---|---|---|---|---|---|---|---|---|
| | | Population | % | % White | % Black | % Hispanic | % Asian | % Other |
| Cook | **5,287,037** | **2,714,038** | **51.3%** | 44.9% | **25.5%** | 23.2% | 5.9% | 1.8% |
| DuPage | 932,541 | 470,054 | 50.4% | 71.6% | 4.8% | 12.6% | **10.1%** | 1.6% |
| Kane | 511,892 | 252,709 | 49.4% | 61.9% | 5.7% | 28.5% | 3.3% | 1.8% |
| Lake | 712,567 | 354,632 | 49.8% | 66.5% | 7.1% | 19.6% | 6.0% | 2.0% |
| McHenry | 320,961 | 159,518 | 49.7% | 83.9% | 1.3% | 11.3% | 2.7% | 1.1% |
| Illinois | 12,910,409 | -- | -- | -- | -- | -- | -- | -- |
| Service Area | -- | 3,950,951 | 50.1% | 65.8% | 8.9% | 19.0% | 5.6% | 1.7% |

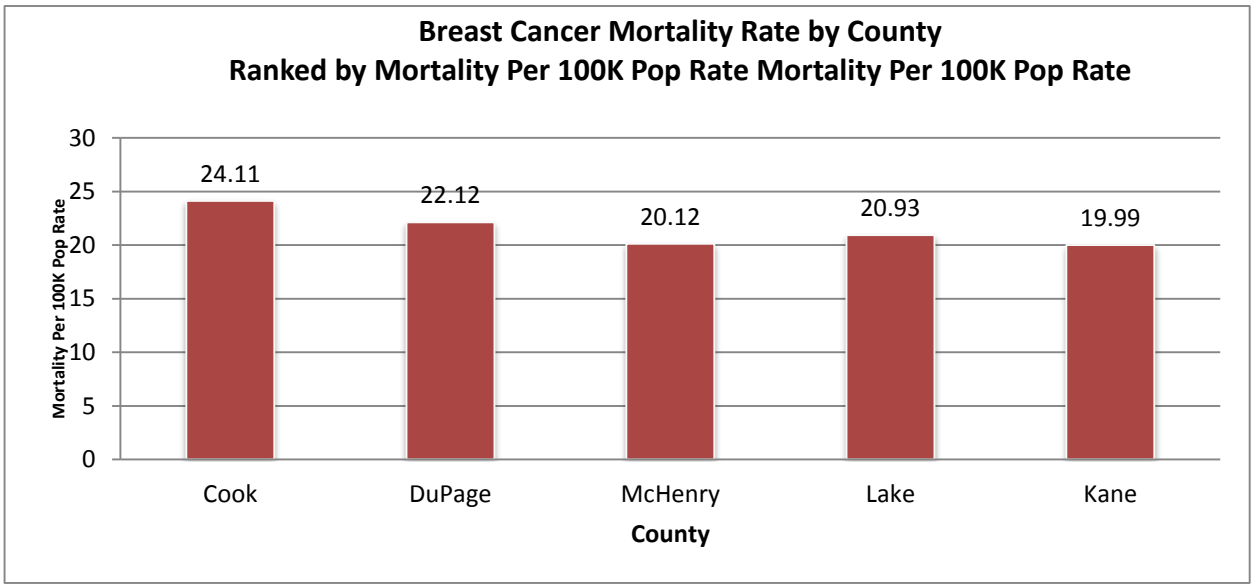
*2009 County Population Estimates (July 1, 2009) U.S. Census Bureau

†Healthcare Business of Thomson Reuters 2009

***Table 1**. Female Population by Race/Ethnicity per County, Chicagoland Area Affiliate of Susan G. Komen for the Cure®, 2009*

Moratality rates by county

In figure 4, we see the breast cancer mortality rate by county in the Affiliate Service area. Cook County and DuPage County have the highest moratlity rate out the five county service area. Between Cook and DuPage County, Cook County has the higher moratality rate.




Source: Thomson Reuters 2009

***Figure 4.** Mortality Rates by County in Komen Chicagoland Area*

Uninsurance

Since 2009, we have seen a dramatic increase in the number of women between the ages of 16-64 that are uninsured. The variance is quite noticeable. Areas of concern are highlighted. Although Kane County has the highest percentage of uninsured women, Cook County has the highest number of women uninsured. The difference in count of uninsured women in Cook County is alarming when compared to the rest of the service area, especially because it is the County with the lowest median household income.

| County | Uninsured Women, 18-64 * | | All Ages in Poverty † | | Median Household Income † |
|---|---|---|---|---|---|
| | % | Estimated # | % | Estimated # | |
| Cook | 16.8% | **669,992** | **14.8%** | **828,626** | $54,559 |
| DuPage | 12.5% | 79,838 | 5.8% | 61,041 | $77,040 |
| Kane | 17.7% | 59,847 | 9.0% | 47,635 | $66,834 |
| Lake | 16.9% | 69,956 | 7.6% | 53,026 | $78,617 |
| McHenry | 14.4% | 32,399 | 5.2% | 21,119 | $79,656 |
| Illinois | 15.8% | 1,670,278 | 11.9% | 1,671,343 | $54,141 |
| United States | NA | NA | 13.0% | 42,868,163 | $50,740 |

*2007 Small Area Health Insurance Estimates (SAHIE), U.S. Census Bureau

†2009 Small Area Income & Poverty Estimates, U.S. Census Bureau

***Table 2.*** *Poverty Level, Household Income, and Uninsured Status by County, Chicagoland Area Affiliate Service Area, 2008*

Uninsurance and mortality rates

Figure 5 and Figure 6 are maps portraying the number of mortalities due to breast cancer in communities in DuPage and Cook Counties.

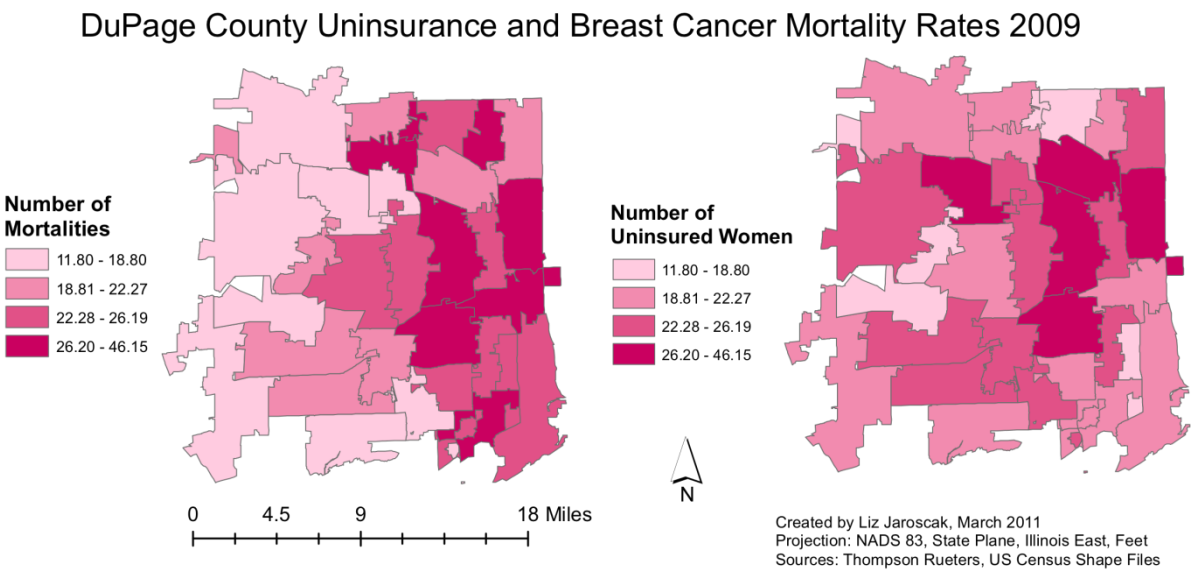
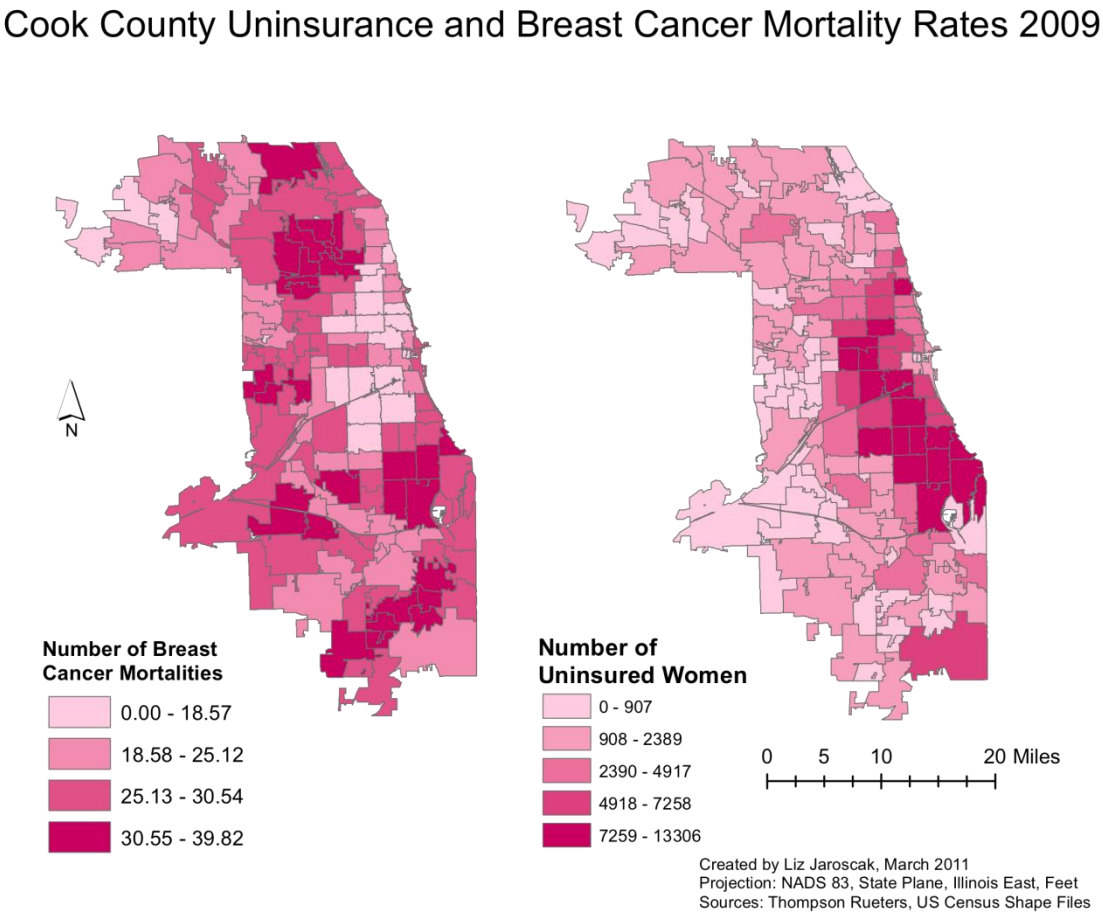



***Figure 5.*** DuPage County Uninsurance and Breast Cancer Mortality Rates, 2009




Source: Thompson Rueters 2009 and US Census Bureau, 2009

***Figure 6.*** Cook County Uninsurance and Breast Cancer Mortality Rates, 2009

Incidence rates

Incidence rates provide the number of new cases per population in a given time period. In Table 3, we observe that the incidence rates for all races (131.2), Whites (134.9) and Hispanics (114.7) in DuPage County were higher than the US and Illinois rates. Cook County had higher IR average annual counts than the other counties. Both DuPage and Cook Counties are target communities for the Affiliate.

Rate ratios (RR) of the incident rates were calculated by dividing one incidence rate by another incidence rate, it informs us of racial/ethnic health disparities in the cancer rates. (For example, the Black/White incidence RR was obtained by dividing the incidence rate of Blacks by the incidence rate of Whites. If the RR < 1, the incidence rates for Whites are greater than that of Blacks. If the RR = 1 the incidence rates for Blacks and Whites are the same. If RR > 1, the incidence rates for Blacks is greater than Whites). Concerning the incidence RR in Table 3, Cook County had a RR similar to 1 for Black/White while the RR for the rest of the counties were less than 1. Hispanics/White RR for all the counties were also less than 1. Areas of concern are highlighted.

| | All Race | | White | | Black | | Hispanic | | B/W | H/W |
|---|---|---|---|---|---|---|---|---|---|---|
| Region | IR* | Counts† | IR* | Counts† | IR* | Counts† | IR* | Counts† | RR | RR |
| United States | 120.6 | § | 121.8 | § | 114.7 | § | 89.3 | § | - | - |
| Illinois | 126.6 | 8492 | 123.6 | 7101 | 119.1 | 1112 | 84.7 | 403 | - | - |
| Cook | 117.7 | 3400 | 118.1 | 2366 | 119 | 874 | 79.9 | 267 | 1.01 | 0.68 |
| DuPage | 131.2 | 649 | 134.9 | 595 | 112.5 | 15 | 114.7 | 27 | 0.83 | 0.85 |
| Kane | 129.6 | 272 | 130.5 | 254 | 111.9 | 11 | 80 | 25 | 0.86 | 0.61 |
| Lake | 134.4 | 448 | 136.2 | 405 | 107.3 | 20 | 61.2 | 18 | 0.79 | 0.45 |

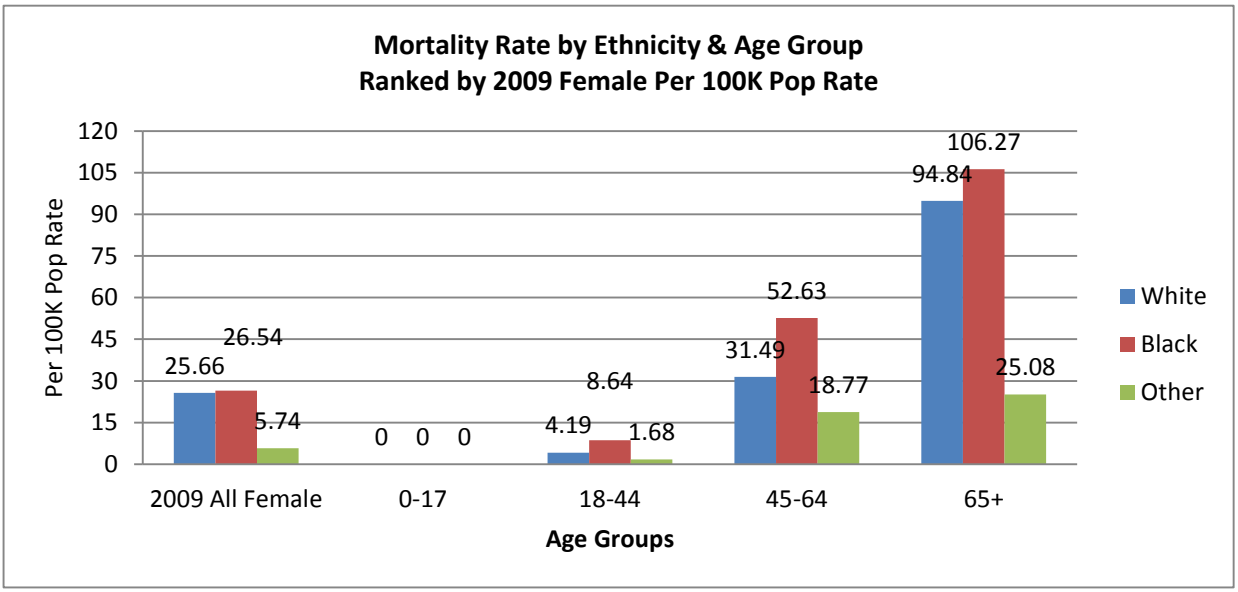
Source: National Cancer Institute (NCI) State Cancer Profiles.

All races, Whites and Blacks rates include Hispanic while Hispanic includes any race.
*Annual Incidence Rate over rate period - cases per 100,000
†Average Annual Count
§ Data that was not provided because it did not meet USCS data quality standards for one or more years during the rate period of data collection.
IR – Incidence Rate; B/W – Black/White Rate Ratio; H/W – Hispanic/White Rate Ratio; RR – Rate Ratio

***Table 3.*** *Incidence Rates (cases per 100,000) for Breast Cancer, Illinois (2003-2007), Age-Adjusted*

Mortality, late stage diagnosis, screening percentages

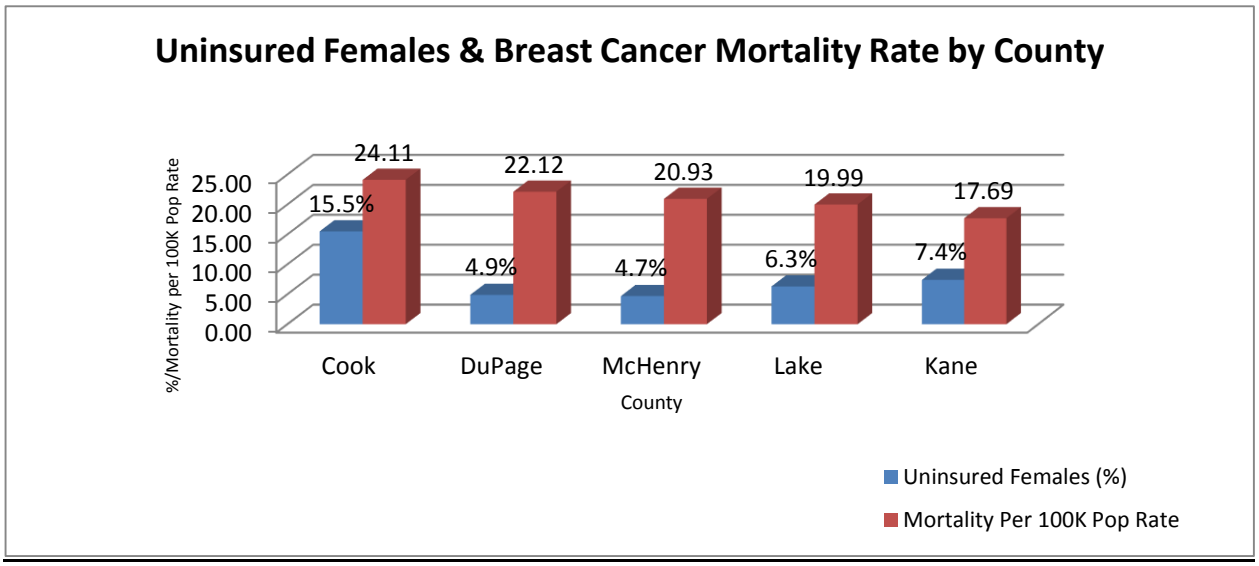
Mortality rate is the number of deaths per population in a given time period. Figure 7 shows the mortality rates by ethnicity and age for the State of Illinois. Mortality rates for African Americans are higher for all age groups and the state average. In the 18-44 and 45-64 age groups, the mortality rates are almost double the mortality rates for Caucasians. The 65 and above age group's mortality rates are disproportionately higher across all age groups and race/ethnicity.




*Source: Thomson Reuters, 2009*

***Figure 7:*** *Breast Cancer Mortality Rate by Age Group in Illinois (cases per 100,000)*

Figure 8 shows uninsured female rates compared to mortality rates by county in the Affiliate service area. Cook County has the highest percentage of uninsured females and the highest mortality rate in the Affiliate Service Area. DuPage County has the second highest when considering uninsured rates and mortality rates together. Kane and Lake Counties have higher uninsured rates compared to DuPage County, but their mortality rates, while of important consideration, are lower than those of DuPage County.




Source: Thomson Reuters, 2009

***Figure 8:*** *Uninsured Females & Breast Cancer Mortality Rate (cases per 100,000) by County*

Table 4 below shows the percentage of women 40 years of age and older who have ever 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. This data shows that White women were most likely to have ever received a mammogram.

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

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

Source: Illinois Behavioral Risk Factor Surveillance System, 2008

***Table 4.*** *Mammography Utilization (women who have ever received a mammogram) by Race/Ethnicity and Education, Females Ages 40 Years and Over, 2008*

Table 5 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.

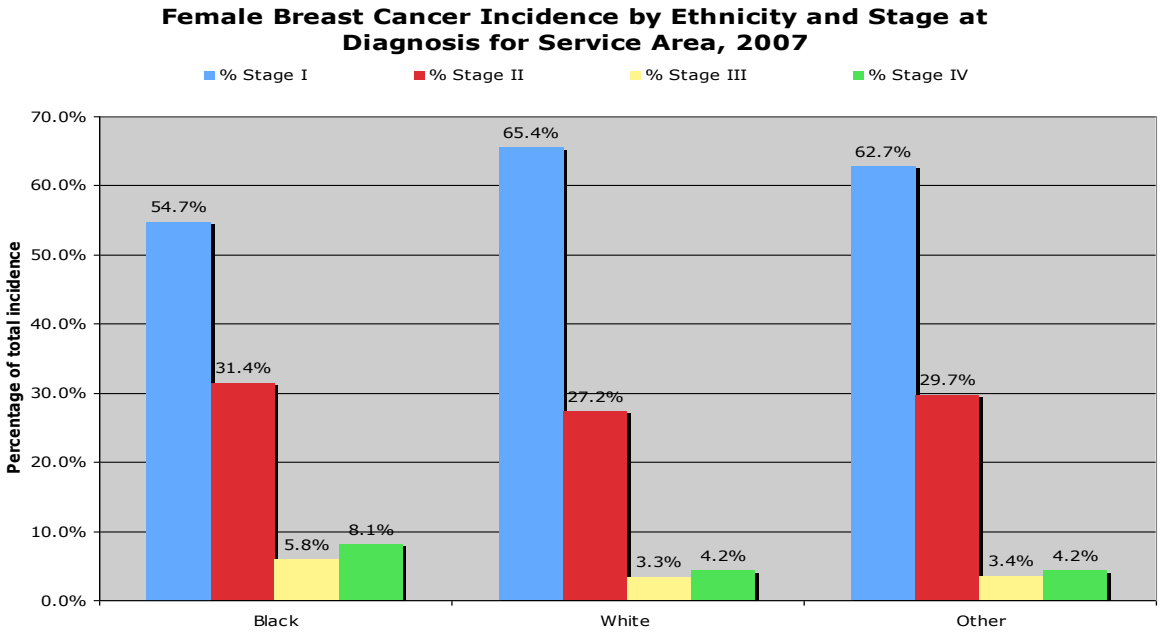
At the county level, the City of Chicago (Cook County, IL) had the largest amount of women who have never received a mammogram. However, due to their small sample size, the data shows McHenry County having the highest prevalence or percentage. Suburban Cook County had the highest amount of women whom had not received a mammogram **in the last 12 months.**

| Area | Total Number of Women | Count | Prevalence (%) | Confidence Interval (%) |
|---|---|---|---|---|
| **Have never had a mammogram (Women 40+)** | | | | |
| Chicago | 139,172 | 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% |
| **No Mammogram in the last 12 months (Women 40+)** | | | | |
| Chicago | 518,040 | 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% |

Source: 2007-2009 Illinois Behavioral Risk Factor Surveillance System

***Table 5.*** *Mammography Utilization for Females 40 Years of Age and Older by County, Chicagoland Affiliate Service Area, 2007-2009*

Finally, Figure 9 shows the breast cancer stage of diagnosis by service area. African American and White women had higher incidence and mortality rates in the Affiliate service area when compared to the state of Illinois; however, Hispanic women in the service had lower incidence and mortality rates. Sixty-one percent of women were diagnosed with breast cancer at Stage 1, 29% were at Stage 2, 4% were at Stage 3, and nearly six percent of women were diagnosed at Stage 4.




Source: Illinois Department of Public Health, 2009

***Figure 9**. Breast Cancer Stage at Diagnosis for the Service Area, All Females, 2000-2007*

**Communities of Interest:**

The preliminary analysis of our service area based on breast cancer and demographic statistics guided the choice of our communities of interest. We focused on areas with high incidence and mortality rates, noted mortality disparities, and vulnerable populations that may not have adequate access to screening and treatment. If recent data conflicted with that obtained by cancer registries and other public sources, we relied on the more recent information. Coupled with the availability of programs and services, the demographic and cancer statistics found that we want to examine Cook and DuPage Counties further.

*Cook County*

Cook County (IL) has the highest female breast cancer mortality rate in 2007 for our service area, of 26.5/100,000 women.[i] When we look at the mortality rates by race/ethnicity, however, alarming disparities reveal themselves. Cook County's mortality rate is 39.7/100,000 for Black women, whereas it is 24.4/100,000 for White women. [ii] Within Chicago, the female breast cancer mortality rate was 116% higher for Black women compared to White women.

The City of Chicago was the only region to provide data by race for mammography utilization; of the White women surveyed, 48.5% had had a mammogram, compared to 51.5% who responded that they did not. In contrast, 68.3% of the Black women surveyed responded that

they had received a mammogram. While a disparity does not present itself with this data, the stage at diagnosis information by race/ethnicity shows that Black women are diagnosed at Stage IV nearly twice as often as White women across our service area. [iii] We were unable to obtain meaningful data on Latinas' utilization of screening.

*DuPage County*

DuPage County (IL) has the second highest incidence rate in our service area. According to 2007 data, DuPage County's female breast cancer mortality rate is also alarming. More surprising to us, however, was that DuPage County's mortality rate is 53.3/100,000 for Black women and only 26/100,000 for White women. We also wanted to learn more about the rates for Latinas, since DuPage, Kane, and Lake have such growing Hispanic populations, but the data we obtained is not reliable.

Another concern for the Affiliate is utilization of mammography services. Chicago has one of the highest rates of women reporting never having had a mammogram (11.1%).[iv] DuPage County (IL) had the second highest percentage of women 40 years and older reporting not having had a mammogram in the past 12 months at 38%.

**Conclusions:**

Demographic data shows that Cook County has the largest population among the five counties in our service area, and it also has the highest number of women over 40 years. This is five times more compared to the rest of the counties in the Affiliate's service areas.

The incidence rates showed that at the time of diagnosis White women had higher incidence rates than those for Blacks and Hispanics in most counties except for Cook County where the incidence rates for Black women were similar to those of the White women. The mortality rate results were different. There were insufficient mortality data for Hispanics in 3 of the counties. The mortality rates for Black women were higher than those for the White women. The RR were greater than 1 (especially for Black/White) in the mortality data while the incidence RR were below 1 indicating a racial/ethnic health disparities in the mortality data. This shows more new cases in White women but more deaths in Black women likely reflecting a survival disadvantage in black women.

These results raise the question of why Black women have a higher mortality rate than their counterparts? Some of the issues that need to be evaluated are: clinical and prognostic characteristics, standards of treatment achieved, treatment adherence and socio-cultural influences on treatment, and health behaviors post diagnosis.

Qualitative and quantitative studies are recommended to examine factors that affect the survival of minority women, in particular African American women with breast cancer.

We also looked at stage of diagnosis by race/ethnicity because these disparities lead to the inequity in mortality rates. Black women are diagnosed at later stages and die more often from the disease, even though their incidence rates are lower. We relied on the estimates provided by the Healthcare Business of Thomson Reuters data to analyze stage at diagnosis, although it is limited to Black, White, and Other, as shown in Figure 9. When we looked at each county in the service area, the stage at diagnosis rates were consistently disparate, suggesting that this issue affects each county.

The data for Hispanics is quite low and may not be accurate. We learned that many of the Hispanic residents in our service area are migrant workers who often return to their country of origin after a couple of years. The system loses track of women who are diagnosed here but then move away.

We are concerned about access to breast health services for the vulnerable populations in our service area. When we look at poverty levels and rates of insurance in each county, we want to ensure that women are able to get the services they need

## Health Systems Analysis of Target Communities

**Overview:**

**The Continuum of Care**

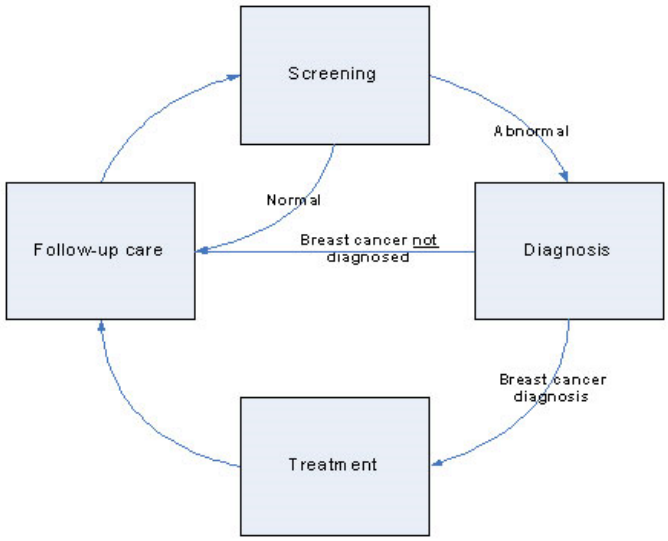



***Figure 10.*** *The Continuum of Care*

The Continuum of Care for breast health encompasses education, outreach, screening and treatment. To truly reduce disparities in our community we must ensure that all women know the facts on breast health, have access to outreach programs to aid them in finding all pertinent resources, can get annual screenings regardless of their income and insurance status, and once diagnosed they have the ability to receive the treatment they require. Barriers at any stage of this continuum perpetuates the breast health disparities our service areas currently face; such as an inability to get to medical appointments, a lack of services for uninsured women, and a lack of knowledge concerning their rights. Additionally, agencies have expressed a difficulty in identifying women who need their services. A Health Systems Analysis of the Affiliate Service Area allows us to identify all the barriers along the continuum of care to determine funding priorities, and to determine which partnership collaborations will have the most impact.

**Methodology:**

Based on the breast cancer disparities due to annual mortality rates, percentage of late-stage diagnosis and/or the socioeconomic challenges faced by communities in Cook and DuPage Counties, asset maps were made. These maps analyzed the Mortality Rates and Uninsurance Rates in these counties. Locations of Hospitals, Federally Qualified Health Centers (FQHCs), Grantees and Mammography Clinics were added to these maps. The target communities in Cook County include: Chatham, Roseland, South Shore and Beverly. The target communities in DuPage County include: Elmhurst, Lombard and Downers Grove.

Key informants were selected from the target communities that had high Mortality Rates and high Uninsurance Rates. Additional Komen partners from areas with similar demographics were chosen. We endeavored to conduct focus groups with these targeted community groups. However, a major limitation arose when the consultant that we selected to conduct the focus groups relocated during the project. As a result we were unable to do focus groups, and chose to turn our interview questionnaires into a survey.

**Overview of Community Assets:**

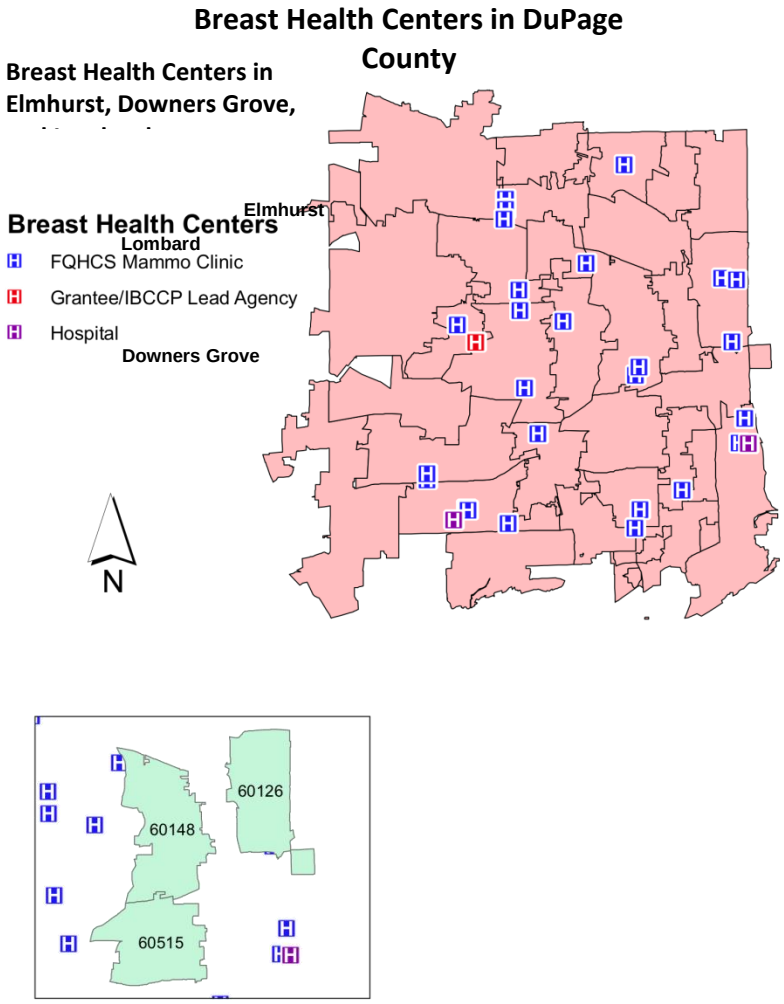
*Existing Partnerships and Coalitions*

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

- **DuPage County Health Department-** The DuPage County Health Department is an Illinois Breast and Cervical Cancer Program (IBCCP) agency that provides breast cancer screenings for low income uninsured primarily minority women. Grant money from the Affiliate funds staff, a nurse and Hispanic case manager, to support the increased caseload and additionally it funds direct breast health services for the women screened.
- **The Metropolitan Chicago Breast Cancer Task Force (MCBCTF)** - a group of dedicated community leaders, advocates, and professionals concerned with the growing breast cancer mortality 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 Komen nationals has provided initial funding for the Task Force for its Quality Consortium. The local affiliate has been involved with Task Force governance, as well as coordinating outreach events and state policy initiatives. As we continue to fine-tune our scope, the Task Force we will be more strategically aligned with agenda of the Chicagoland Area Affiliate.
- **Stand Against Cancer Coalition** – Led by a Chicagoland Area Affiliate grantee, Access Community Health Network, the Stand Against Cancer Coalition engages numerous faith-based institutions and community health center partners in outreach and education activities with the goal of linking minority women to a medical home so that women have a regular source for breast screenings. The Affiliate has been a funder of these services.
- **Sisters Working It Out** - Through their Sister's Working it Out…Health Advocacy in Motion program they serve underserved African American women in the Woodlawn and Englewood communities by training women to become health educators and health advocates within their communities. This outreach program receives funding from the Affiliate**.**
- **UIC Center for Excellence in Eliminating Disparities** - is a university wide resource for minority health and health disparities research at the University of Illinois at Chicago. They are conducting research on health disparities and developing effective strategies for improving these disparities. The Affiliate has an ongoing relationship with the center.

Breast Health Center locations in DuPage and Cook Counties

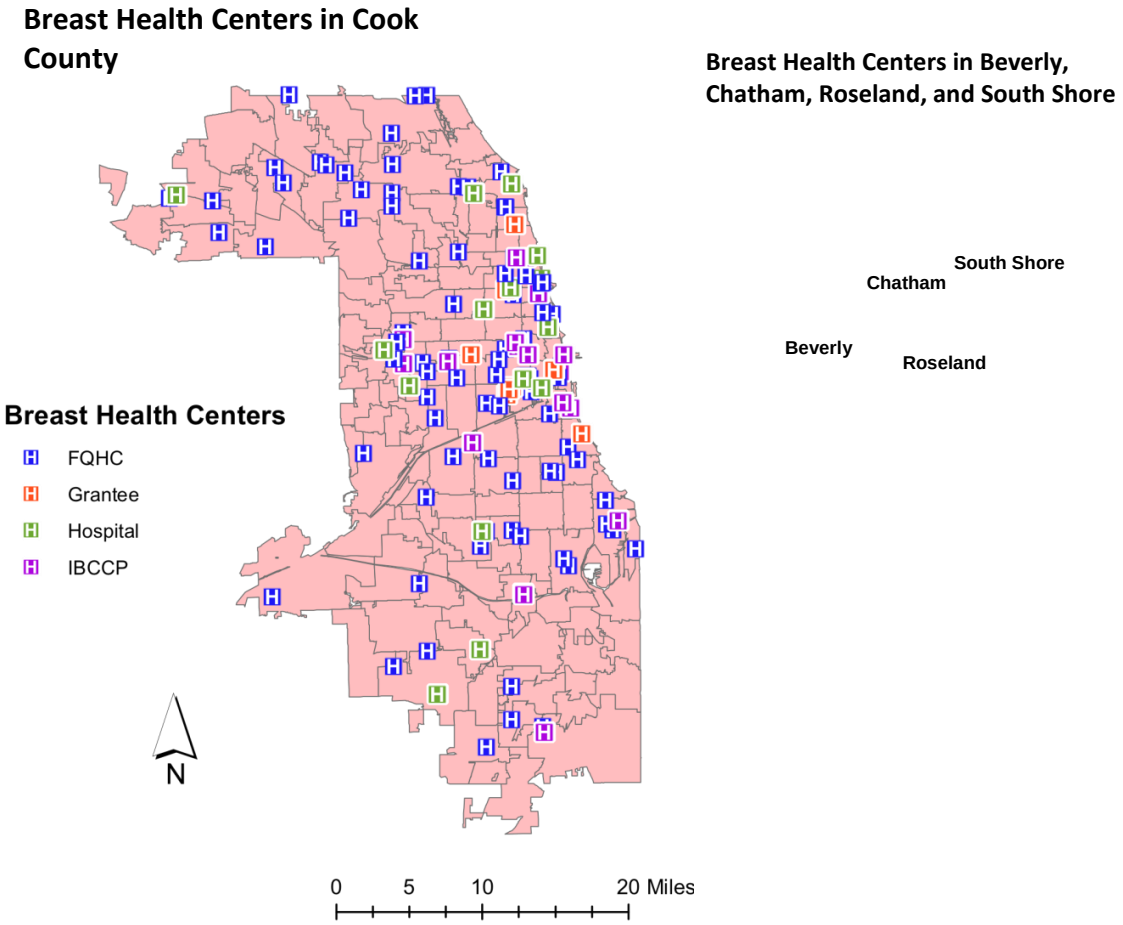
Below is a detailed mapping of all Breast Health Centers found in DuPage County. The Breast Health Centers are a mixture of FQHCs, Affiliate grantee organizations, hospitals, and IBCCP agencies. While there appears to be a wealth of breast healthcare facilities located in DuPage County, the selected target communities of Elmhurst, Downers Grove and Lombard appear to be resource poor, with only on FQHC mammography clinic located within an 8 mile radius.




Source: Google and US Census Bureau, 2009

***Figure 11.*** *DuPage County Breast Health Centers, 2011*

Below is a detailed mapping of all Breast Health Centers found in Cook County. The Breast Health Centers are a mixture of FQHCs, several Affiliate grantee organizations, hospitals, and IBCCP agencies. While there appears to be a wealth of breast healthcare facilities located in Cook County, the selected target communities of Beverly, Chatham, Roseland and South Shore appear to be resource poor, with only two FQHC mammography clinics located within a 10 mile radius.




Source: Google and US Census Bureau, 2009

***Figure 12.*** *Cook County Breast Health Centers, 2011*

*Potential Partnerships*

The Affiliate has several opportunities to deepen existing partnerships and create the venues to lead and coordinate policy and service coordination efforts. We recognize that there are many smaller community-based organizations working in these areas with whom we can partner.

- **Elmhurst Hospital** - currently the Affiliate is working on a partnership with Elmhurst Hospital, which is in one of our target areas. This hospital is a great resource in that community, and has recently opened a new imaging center.
- **Health Care Consortium of Illinois** - is committed to developing and maintaining targeted, community-based, integrated health and human service delivery systems which increase the well-being of individuals, families and communities throughout Illinois by means of advocacy, awareness and action.
- **Sisters Network** - a community-based organization comprised of African American breast cancer survivors. Their goal is to work with other survivors, communities and health care professionals to fight against breast cancer and provide support for breast cancer survivors.

*IBCCP*

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 age 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.

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. The third issue is eligibility restrictions; women above 200 percent of the poverty level are not eligible, treatment coverage is limited to documented Illinois residents, and women below 34 require special approval for coverage. IBCCP is an integral part of Illinois' public health infrastructure, addressing part of a wider need and thus requiring consistent funding, an increased number of participating

providers, and a restructuring of eligibility requirements.

**Legislative Issues and Komen's role:**

The Affiliate is committed to continuing its vigorous public policy campaign to help reduce the toll of the disease on Illinois women. We collaborate with all Illinois Affiliates to ensure that we have a statewide strategy to create public policy change.

On October 21, 2010 the Metropolitan Chicago Breast Cancer Task Force held a "Day of Action" to Save Women's Lives. They released a report from the Chicago Breast Cancer Quality Consortium, which reported that many Chicago Hospitals are not meeting breast cancer quality standards. Additionally that day the Task Force held a Rally and March in support of increased funding for the IBCCP, which is severely underfunded. In 2009, only 13% of eligible women were seen with a budget of $20.6 million. In 2010, Illinois cut the IBCCP budget by $3.5 million until the Task Force worked to ensure the budget was restored to $20.6 million. The Metropolitan Chicago Breast Cancer Task Force, a Komen-funded organization which consists of the region's leading breast cancer researchers, breast cancer organizations, care providers, advocates and survivors documented shocking differences in the mortality rates of black and white women in Chicagoland.

On March 8, 2011, the Affiliate along with the other Illinois Affiliates announced their campaign to pass Illinois House Bill 1191. This bill will ensure that qualified patients who are enrolled in clinical trials have coverage for medical costs related to them. House Bill 1191 will also make sure that qualified patients in health plans have coverage for routine care costs during the clinical trial.

For cancer patients, the benefits of participating in a clinical trial include the following:

- Participants have access to promising new approaches that are often not available outside the clinical trial setting.
- The approach being studied may be more effective than the standard approach.
- Participants receive regular and careful medical attention from a research team that includes doctors and other health professionals.
- Participants may be the first to benefit from the new method under study.
- Results from the study may help others in the future.

Additionally, the Affiliate is working to pass Illinois House Bill 1825. This bill requires private health insurance plans to cover oral chemotherapy at the same rate as IV chemotherapy.

**Findings from key informant surveys:**

The key informant interviews show that there are numerous barriers to ensuring everyone has access to the continuum. In addition to the numerous concerns listed below a major problem is

the lack of collaboration and cooperation between breast health organizations. As a result the Affiliate made this a priority for their 2011-2012 grant cycle.

The responses from the key informant surveys include:

- A major barrier is "getting women to facilities can be difficult even when the facilities have IBCCP programs and mammography and breast ultrasounds onsite."
- Many women who are least likely to be getting regular services report being unemployed. They are under or uninsured and unable to pay for breast health screenings.
- "Women least likely to receive effective breast health services earn on average between $5,000 and $10,000 a year, have limited education and live in an urban community."
- "There are limited resources for women who are uninsured or underinsured. The statewide services that do exist have many barriers to accessing services."
- Every Woman Counts! Program, the state IBCCP program, Stand Against Cancer program, Sisters Embracing Life, and A Silver Lining Foundation are financial assistance programs in the community that help women access breast health services.
- "Even some women who have health insurance do not get regular screenings because they feel that even if they were diagnosed they would not be able to afford to take time off work or fear losing their jobs if they had time to take off from work for treatment."
- "A large part of the problem with women not accessing breast health services is lack of knowledge of their legal rights and benefits. Often times women of low or moderate incomes do not know that they have the legal right to take time off of work for diagnosis and treatment. Additionally, many people do not know how to navigate managed care, apply for government benefits, or how health care reform laws affect them. By providing people with the necessary knowledge and tools to advocate for themselves we can improve the current health care system."
- "More organizations need to come together and collaborate and make a joint effort to enhance the quality of life for these women, who are not even aware if they have anything, wrong with them."
- "The current health care systems are quite complex."
- "Sometimes the challenge is finding the women in the community (getting them to come to [our facility] make the appointment)."
- "The IBCCP system is quite slow and complex. Little communication exists with providers. In addition, the city does not respond to partnership offers fast enough."
- "Due to the current economic crisis, many are unemployed, but much of the Lesbian, Bisexual and Transgendered community does not have access to insurance, due to lack of partner benefits through the workplace."
- "IBCCPP has been incredibly helpful at assisting us with providing women in the [LGBT] Community with access to services. Stand Against Cancer has also been a supportive means to provide service to the community.
- "We are always looking to do more outreach and education amongst other healthcare providers so that patients can feel safe anywhere they go, and they don't have to be limited to out clinic as a resource. We'd like the opportunity to be able to do that more often."

**Conclusions:**

An analysis of the Continuum of Care in our targeted communities through a review of existing community assets, legislative issues, and key informant surveys revealed a shortage of medical providers and resources in certain areas of our target communities. Even in areas with medical resources, many women still cannot access necessary screening and care. To the end, the Illinois Breast and Cervical Cancer Program (IBCCP) had proven somewhat successful, and in collaboration with the Affiliate grant-making program, have made great strides in reaching specific populations. It would be valuable to expand the outreach worker program model to other health departments in specific areas of the state. Additionally, in most counties, IBCCP infrastructures exist to enroll and navigate more eligible women through the screening process, but lack necessary funding to reach their full potential and screen all eligible women. The Affiliate has made it a priority to create a small grants program focused on building the capacity of these programs.

Focusing on the continuum of care will ensure access into and through the breast healthcare system at each level by addressing the barriers that women seeking services encounter as well as the barriers that agencies providing those services face. As previously mentioned those barriers include lack of state funding, lack of access for women to access state funded services, an inability to identify potential clients, and the complexity of the overall system. Partnerships and collaboration between the Affiliate and community agencies as well as among the community agencies themselves will help reduce many of these barriers. To ensure this occurs the Affiliate will continue to actively advocate for Breast Health legislation such as House Bill 1191 and House Bill 1825. Additionally we will work to find innovative ways to create collaborations among our community partners and continue to seek new partnerships in our target communities.

## Breast Cancer Perspectives in the Target Communities

**Methodology**:

*Survey*

Two surveys were developed using Survey Monkey, an online survey development, collection, and analysis tool. Emails with a link to the surveys were sent to five Affiliate grantee representatives, 25 area mammography screening facilities, and local breast healthcare service providers in each of our five county service area and with at least one survey completed from each of selected seven target communities. The main goals of the surveys were to identify details on populations served, types of services offered, what barriers, if any, exist from the service provider. This allowed us the ability to gauge breast health priorities for each group.

Twenty respondents were asked for recommendations of the types of programs they think would help improve the delivery of breast health services in the current system. Respondents were also asked for suggestions of strategies that could be utilized to improve knowledge of, access to, and use of breast health services.

*Key Informant Interviews*

A revised version of the Komen for the Cure Key Informant Questionnaire was used in identifying information related to the Continuum of Care, such as: health issues, sources of breast health information, barriers to screening and treatment, method of payment for services, the healthcare system, causes of gaps in treatment, advocacy, and recommendations for future action. Revisions were made based on suggestions from the Community Profile Steering Committee to identify barriers specific to screening and treatment.

The questionnaire was distributed electronically to 11 key informants representing different healthcare and advocacy organizations including clinics, hospitals, and support groups in the five county service area as well as under/uninsured African American, Hispanic and Asian populations. Key informants were selected using a referral sampling process where informants identified other individuals within the breast health community for interviews.

A major limitation in the qualitative data collection was the fact that the consultant we selected to conduct the focus groups relocated during the project. As a result, we were unable to do focus groups, and chose to turn our interview questionnaires into a survey.

**Review of Qualitative Findings:**

*Surveys*

More than 50% of the respondents, and in some cases over 80%, indicated they would be interested in:

- Networking opportunities with other providers
- Information about breast cancer resources
- Professional education

A large majority of the respondents also believed that the following services are most beneficial to breast cancer patients:

- Financial assistance
- Patient navigation
- Support groups

Financial assistance was also the need that was most referenced in the responses to the open-ended question asking providers about the greatest needs in their communities:

*"The financial assistance offered is helping women access breast health services; however, medical expenses can be daunting. And not all hospitals are offering."*

*"The city government is extremely complex. I am not sure the IBCCP program is moving women quickly enough through the system. Our contract to provide services has been in their legal department for 7 months!"*

*"Funding resources that are provided in a type of "block grant" with fewer silos of funding…absolutely need to provide accountability and broad parameters, but also need to acknowledge that women don't present to us requiring only breast health services—they have other chronic health, mental health or social health needs that interfere with them receiving optimal breast care. Comprehensive, universal health coverage which addresses, but is not limited to breast health issues."*

*Key Informants*

The key informant interviews showed that there are numerous barriers to ensuring everyone has access to the continuum. The eleven key informants were selected from a diverse group, representing different healthcare and advocacy organizations including clinics, hospitals, and support groups in the five county service area as well as under/uninsured African American, Hispanic and Asian populations. Key informants were selected using a referral sampling process where informants identified other individuals within the breast health community for interviews. The informants revealed several types of barriers that impeded women from obtaining annual screening and diagnostic/treatment services. System barriers typically work at the macro level where they create bureaucratic obstacles to screening and treatment.

Individuals may have the desire to obtain a mammogram or receive breast cancer treatment, but they are faced with barriers within the system and do not have appropriate access to care. This is exacerbated at the micro level where day-to-day personal barriers impede a woman's abilities to prioritize breast health. Because personal barriers are experienced on a constant basis, they can be overwhelming and discourage a woman from seeking screening and treatment. This is often in conjunction with physical barriers that affect women on a daily basis but over which they do not have control. While some barriers are specific to certain race/ethnic groups, most are experienced by all under/uninsured women.

System Barriers

Under/uninsured women described overwhelming bureaucratic obstacles in signing up for Medicaid, scheduling a mammogram, and understanding different program eligibility criteria. Providers have expressed their frustration with the lack of clarity for determining federal poverty levels (e.g. 150% vs. 200%). In addition, the Medicaid income review process occurs every six months. These eligibility and renewal challenges were compounded by a long process to obtain insurance coverage to begin with. As a result, women often experience long periods of no coverage during and after treatment for breast cancer. Additionally, some women experienced problems obtaining pain management medication due to limits imposed by rules from assistance programs and Medicaid. Several women also complained about not receiving any information about clinical trials.

However, in DuPage County, where screening and treatment facilities are limited and breast cancer incidence is high, a key informant interview revealed that the team at DCHD sees the high incidence as a success to their programs rather than an issue that needs to be addressed. Also, they feel that the mortality rates for the minorities in their county are skewed due to the small sample size and that they fall in line with national trends.

Personal Barriers

At the family level, women are often needed to financially and emotionally provide for their households, regardless of pain or a breast cancer diagnosis. As a result, women often had to prioritize work over scheduling/attending appointments because they could not afford to miss a day of work. Many under/uninsured women are hourly workers with no benefits, so they do not have paid time off. Because quality free clinics are not always in their communities, especially in rural areas, a mammogram can take an entire day.

For other women, fear of finding breast cancer and /or pain of treatment encouraged the use of excuses such as "I don't have time", "I'll go later", I don't have a family history" and "I'm too young to get cancer". These excuses were often supported by false beliefs and misinformation about breast cancer related to age or initial screening, necessity of post-operative chemotherapy, breast size, and frequency of mammography.

In addition, cultural beliefs and norms often dictated women's attitudes towards screening and treatment. For many women, talking about breasts would be inappropriate and was discouraged in family and social settings. Undressing in front of others was discouraged, thus mammography is considered an immodest activity. Furthermore, some women believe that a higher spiritual power would ultimately take care of their health concerns, so there would be no need to obtain a biopsy after an abnormal screening or receive a mastectomy in the case of an operable malignancy. For other women, pain related to personal health would be a distraction from their expected roles as household caretakers, mothers, and wives. This perceived sense of duty causes women to believe that they would be a burden on their families if they spent money on healthcare or had to miss time in order to obtain a mammogram or have a follow-up with a physician.

These feelings all contributed to feelings of emotional distress within many women. Some blame themselves for their positive diagnosis and feel that they have a genetic weakness that they could now potentially pass on to their daughters and granddaughters. Others feel resentment over lack of support that they receive from physicians, medical personnel, and even their own family members. Because many women are unaware of breast cancer support groups in their communities, they feel isolated and helpless.

Physical Barriers

Many key informants shared stories illustrating the extensive difficulties their patients face going to mammography and treatment locations. Most low-income and undocumented women, for example, do not own cars so they are dependent upon others for rides to clinics. Most women rely upon the public transportation system which they find limited and unreliable, in the outlying counties. Routes and frequency of stops are greatly reduced after hours and on the weekends which are often the only times that women are able to schedule appointments because of work. Public transportation is nonexistent in predominately rural areas, such as McHenry County, so women in this area rely heavily on the services from volunteers and nurse navigator programs.

**Conclusions:**

Surveys were distributed to twenty-five area mammography screening facilities, and local breast healthcare service providers in each of our five county service area and with at least one survey completed from each of selected seven target communities. The main goals of the surveys were to identify details on populations served, types of services offered, what barriers, if any, exist from the service provider. This gave us the ability to gauge breast health priorities for each group. Key informants were asked for recommendations of the types of programs they think would help improve the delivery of breast health services in the current system. Respondents were also asked for suggestions of strategies that could be utilized to improve knowledge of, access to, and use of breast health services.

A major limitation in the qualitative data collection was the fact that we were unable to conduct focus groups. Therefore, our data collection was limited to key informant interviews and surveys to breast cancer facility provider.

In addition to the numerous concerns listed above, a major problem is the lack of collaboration and cooperation between breast health organizations. As a result the Affiliate made this a priority for its 2012-13 grant cycle. The Affiliate can also improve its visibility and presence in many areas. A key informant revealed that the Affiliate is virtually unknown in her community and in many communities of color. Even though the Affiliate funds many programs that provide services to racially and ethnically diverse communities, the women are unaware of the purpose that we serve as a breast health resource. It was also revealed that there is confusion about the Affiliate, Breast Cancer Network of Strength and Avon because we all hold a race downtown or have a multi-day/multi-mile walking event.

Although we had a good experience with collecting data from the providers, it is imperative to receive input from more breast healthcare providers. We recognize that their work is demanding and the level of coordination that it takes to convene several providers is time-consuming; however, we feel that the level of input that might come from a group interaction would be invaluable to this process.

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

**Review of the Findings:**

The Community Profile process completed by the Affiliate included a review of breast cancer statistics and demographics for the entire service area with comparative analysis by county, a health systems analysis, and a qualitative data review. All of this data was taken into consideration in determining the priorities for the Affiliate's 2011 Community Profile. The Affiliate compiled a list of IBCCP providers, health departments, FQHCs, current grantees, and mammography screening facilities and then performed an asset mapping of the resources to determine their distribution throughout its service area. The Affiliate then surveyed grantees, mammography screening facilities, and local breast healthcare service providers in the area to assess the needs about what the funding priorities should be for the Affiliate. Additional data analysis is being completed to look at the higher incidence and mortality rates that exist in more affluent communities, where access to services may not be a barrier. These analyses may further define future funding and programmatic priorities for the Affiliate.

The findings of the Community Profile reinforce the the Affiliate's efforts to focus on the service areas where there is the highest rates of breast cancer incidence and mortality.

**Conclusions:**

A review of demographic and breast cancer data revealed that the Affiliate's service area overall is suffering acutely from the impact of breast cancer, especially with regard to mortality rates. In addition, there are many areas and populations within our service area that are disproportionally affected by breast cancer. The Affiliate decided to focus on two counties and communities as current target areas due to annual mortality rates, percentage of late-stage diagnosis and/or the socioeconomic challenges faced by the following areas:

- Cook County
  - Beverly, Chatham, Roseland, and South Shore
- DuPage County
  - Lombard, Elmhurst, and Downers Grove

Analysis of the programs and services in these areas revealed a shortage of medical providers and resources. However, even in areas filled with medical resources, many women still cannot access necessary screening and care. The targeted communities face different challenges when it comes to medical providers and resources. Chatham, Roseland, South Shore and Beverly have many healthcare systems and hospitals; yet women are not accessing care and underinsured and uninsured women do not know about existing free screening programs. Lombard, Elmhurst and Downers Grove lack medical providers in their towns, however many women have found ways to access the IBCCP program in DuPage County. The IBCCP program works well for those who currently utilize it, but there are great opportunities to build capacity

and strengthen the program. Additionally, more funding is necessary for the IBCCP program to screen more eligible women.

Cook County has the highest mortality rate in our service area. In particular, African American women are being diagnosed at much later stages and are dying are at much higher rates. A mirror situation can be found in DuPage County. DuPage County also has an alarmingly low rate of mammography utilization by the most at risk populations. Meaningful data on Hispanic women is not available for either Cook or DuPage Counties and this presents a real concern. Therefore, the Affiliate is focusing on the communities within these two counties that present the most pressing problems in order to reduce the disparities and reach those in the most dire state.

The statistics, programs and services findings led to gathering qualitative data from breast cancer facilities in each of the targeted areas. The key informants provided a more personal and comprehensive perspective of the strengths and weaknesses in difficult communities. An overwhelming amount of bureaucratic obstacles from different programs are imposing hard to overcome system barriers to women seeking services. A deeper understanding of personal and physical barriers such as access to care, fear, and personal and cultural attitudes and beliefs were also revealed through key informant discussions.

**Action Plan:**

The Affiliate's Board of Directors and Community Profile team convened to review the data and recommend priorities for the Affiliate service area. The following priorities will be used to inform the Affiliate's grantmaking and strategic planning for the next grant period. Other considerations in determining which priorities to focus on include health care reform, state and federal programming, and fiscal decisions which may reduce access to programs that serve the uninsured.

<u>Affiliate Priorities</u>

1. Continue coalition with Komen Illinois Affiliates to advance statewide public policy agenda.
2. Target African American Women in Cook County to reduce the breast health mortality disparity through strengthening and building capacity of existing breast health providers and grantees.
3. Target Hispanic and African American Women in DuPage County through strengthening and building capacity of existing breast health providers and grantees.
4. Expand education and outreach messaging from breast self awareness to incorporate legal rights, patient rights and access to available services.
5. Strengthen the continuum of breast health and breast cancer care services in our 5-county service area to allow individuals to have total access to programs and services.

**Affiliate Action Plan:**

**Priority 1**
**Continue coalition with Komen Illinois Affiliates to advance state-wide public policy agenda.**

Objective 1.1: Convene with Komen Illinois Affiliates in one meeting per year to discuss legislative and outreach concerns and to ensure a strategic alignment on our shared public policy initiatives for each Affiliate.

Objective 1.2: Participate in monthly conference calls to gain input from local grantees, public policy coalition members, and Komen Advocacy Alliance regarding progress on legislative actions to be responsive to the needs of our constituents from the breast health community.

Objective 1.3: Work with the Metropolitan Chicago Breast Cancer Task Force through quarterly meetings to create a strategic plan to ensure alignment on our shared public policy agendas in the Chicagoland area as well as throughout Illinois by December 2011.

**Priority 2**
**Target African American Women in Cook County to reduce the breast health mortality disparity through strengthening and building capacity of existing breast health providers and grantees.**

Objective 2.1: By April 2012, implement a new grant structure consisting of a 2-year Community Grant program that will provide funding to organizations in Cook County, specifically in the Chatham, Roseland, South Shore, and Beverly neighborhoods, which address system, personal, and physical barriers.

Objective 2.2: By April 2012, create and implement small capacity building grants program to provide technical assistance to community-based organizations to increase their impact in Cook County, specifically in the Chatham, Roseland, South Shore, and Beverly neighborhoods.

Objective 2.3: By December 2011, participate in two meetings to maintain relationship with the University of Illinois at Chicago (UIC) and increase our knowledge and understanding of the need for quality continuum of care in target areas by evaluating survivorship and post-diagnostic management and care to inform our grant-making priorities

Objective 2.4: By December 2012, participate in four meetings to maintain relationship with the University of Illinois at Chicago (UIC) and increase our knowledge and understanding of the need for quality continuum of care in target areas by evaluating survivorship and post-diagnostic management and care to inform our grant-making priorities.

**Priority 3**
**Target Hispanic and African American Women in DuPage County through strengthening and building capacity of existing breast health providers and grantees.**

Objective 3.1: By April 2012, implement a new grant structure consisting of a 2-year Community Grant to provide grants to organizations that provide services in DuPage County in Lombard, Elmhurst and Downers Grove that specifically address system, personal, and physical barriers.

Objective 3.2: By April 2012, create and implement a small capacity building grants program to provide technical assistance to community-based organizations to increase their impact in DuPage County, specifically Lombard, Elmhurst, and Downers Grove.

Objective 3.3: Establish relationships by partnering with two local organizations to provide breast self-awareness education and outreach by December 2011.

Objective 3.4: Host one grant writing orientation and training in DuPage County to encourage 5% increase in grant applications from this county by September 2011.

Objective 3.5: Host one grant writing orientation and training in DuPage County to encourage 5% increase in grant applications from this county by September 2012.

Objective 3.6: Collaborate with the DuPage County Health Department, the only IBCCP lead agency in DuPage County, through creating a Public Relations campaign and having two discussions surrounding barriers to care by December 2011.

**Priority 4**
**Expand education and outreach messaging from breast self-awareness to incorporate legal rights, patient rights and access to available services.**

Objective 4.1: Work with the Cancer Legal Resource Center to compile data for accurate messaging by January 2012.

Objective 4.2: Create and distribute collateral that incorporates the new breast self-awareness, legal rights, patient rights and access to available services messaging to all grantees by June 2012.

Objective 4.3: By December 2012, host two networking sessions for grantees to educate them on the expanded education and outreach messaging that will incorporate the Susan G. Komen breast self-awareness information with the legal rights, patient rights and access to available services to ensure that they are communicating the appropriate Komen messaging.

**Priority 5**
**Strengthen the continuum of breast health and breast cancer care services in our 5-county service area to allow individuals to have total access to programs and services.**

Objective 5.1: By June 2012, determine how many coalitions are needed in Cook County and where they would be the most effective.

Objective 5.2: Partner with the Metropolitan Chicago Breast Cancer Task Force to create targeted outreach to breast health and breast cancer organizations in Cook County in order to establish relationships for the Quality of Care coalitions by December 2012.

Objective 5.3: Establish Quality of Care coalitions by hosting two (2) meetings by December 2013.

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[i] Healthcare Business of Thomson Reuters © 2007
[ii] NCI State Profiles, 2001-2005
[iii] Healthcare Business of Thomson Reuters © 2007
[iv] Illinois Behavioral Risk Factor Surveillance System, 2004-2006