

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



SUSAN G. KOMEN®  
SOUTHEAST WISCONSIN

# Table of Contents

<b>Table of Contents</b> .....	<b>2</b>
<b>Acknowledgments</b> .....	<b>3</b>
<b>Executive Summary</b> .....	<b>5</b>
Introduction to the Community Profile Report .....	5
Quantitative Data: Measuring Breast Cancer Impact in Local Communities.....	6
Health System and Public Policy Analysis .....	9
Qualitative Data: Ensuring Community Input .....	13
Mission Action Plan .....	16
<b>Introduction</b> .....	<b>26</b>
Affiliate History .....	26
Affiliate Organizational Structure .....	28
Affiliate Service Area .....	28
Purpose of the Community Profile Report.....	30
<b>Quantitative Data: Measuring Breast Cancer Impact in Local Communities</b> .....	<b>31</b>
Quantitative Data Report.....	31
Additional Quantitative Data Exploration.....	43
Selection of Target Communities .....	46
<b>Health Systems and Public Policy Analysis</b> .....	<b>64</b>
Health Systems Analysis Data Sources .....	64
Health Systems Overview .....	65
Public Policy Overview .....	93
Health Systems and Public Policy Analysis Findings.....	102
<b>Qualitative Data: Ensuring Community Input</b> .....	<b>113</b>
Qualitative Data Sources and Methodology Overview .....	113
Qualitative Data Overview.....	119
Qualitative Data Findings .....	222
<b>Mission Action Plan</b> .....	<b>246</b>
Breast Health and Breast Cancer Findings of the Target Communities.....	246
Mission Action Plan .....	251
<b>References</b> .....	<b>261</b>

# Acknowledgments

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

**Susan G. Komen® Southeast Wisconsin (Komen SE WI) would like to extend its deepest gratitude to the Board of Directors and the following individuals who participated in the preparation of the 2015 Community Profile:**

**Dawn Anderson**  
Executive Director  
Wisconsin Breast Cancer Coalition

**Phyllis Holder, RN, MSN**  
Founder  
Sisters 4 Cure Inc.

**Carol Cameron**  
Program Manager  
WI Pink Shawl Initiative

**Pam Lyon, RN, MS, CBCN**  
Patient Navigator  
Aurora West Allis Memorial Hospital-  
Women's Pavilion

**Crystal Cepican, BSN, RN**  
Community Outreach Nurse  
Hispanic Resource Center,  
ProHealth Care

**Sarah Mroz, MPH**  
Facilitator  
Wisconsin Breast Cancer Task  
Force

**Sarah Clemens**  
WI Well Women Program  
Coordinator  
City of Racine Health Department  
and Milwaukee County

**Sue Rapp**  
Breast Cancer Survivor  
Past Board President  
Retired Principal

**Ginny Finn**  
Executive Director  
After Breast Cancer Diagnosis

**Alecka Weber, MS**  
Patient Navigator  
American Cancer Society

**A special thank you to the following individuals for their assistance with data collection and analysis:**

- Indira Vadapali, Data Analysis
- Holly Gamblin and Anna Kaufman, Health System and Public Policy Analysis
- Char Ahler, Data Collection
- Gabrielle Balestreri, Data Collection
- Omoshalewa Bamkole, Data Collection
- Elaine Rebatzke, Data Entry
- Katrina Worthan, Data Entry

Volunteers are the core foundation of any organization, its activities, community involvement and success. The individuals who volunteered to participate in interviews, forums, complete surveys, and attend the Survivor Forum demonstrated this. The Affiliate greatly appreciates their commitment. Each individual brought an additional level of knowledge and expertise

about breast cancer, the health system, and the needs of vulnerable populations throughout the Komen SE WI service area.

Komen SE WI and the Community Profile Team are indebted to all the women, health system staff, breast cancer survivors, and committed individuals from the following community organizations who shared their experiences and stories.

- Aging and Disability Resource Center of Washington County
- Casa Guadalupe
- Community Action
- Core El Centro
- Diverse and Resilient
- Columbia St. Mary's
- Goodwill Industries of Southeastern WI
- Health Care Network
- Kenosha Lifecourse Initiative for Healthy Families
- La Causa
- Love, Inc.
- Milwaukee Area Health Education Center
- Milwaukee Consortium for Hmong Health
- Milwaukee LGBT Community Center
- Muslim Community Health Center
- Nurses Affecting Change
- Partners in Pursuit of the Promise
- Philippine Health Center
- Planned Parenthood of Southeast Wisconsin
- St. Joseph's Free Clinic
- St. Francis Su Salud Program
- United Voices
- Wisconsin Association of Free & Charitable Clinics
- Women's Resource Center
- Word of Hope Ministries
- Wisconsin Well Women of City of Milwaukee
- Wisconsin Well Women of Kenosha County
- Wisconsin Well Women of Racine County
- Wisconsin Well Women of Walworth County
- Wisconsin Well Women of Washington County
- Wisconsin Well Women of Waukesha County
- Young Survivors Coalition

The knowledge gained increased the Affiliate's understanding of the barriers to breast health as well as the challenges faced by women and families impacted by breast cancer. The recommendations in this report are a result of this cumulative story. It is the hope of Komen SE WI that the 2015 Community Profile will have a positive impact on breast education, screening, and treatment in Southeast Wisconsin.

**Report Prepared by:**

**Susan G Komen® Southeast Wisconsin**

2025 W. Oklahoma Ave., Suite 116

Milwaukee, WI 53215

414-389-4882

[www.KomenSoutheastWI.org](http://www.KomenSoutheastWI.org)

Contact: Robin Luther

# Executive Summary

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

Susan G. Komen<sup>®</sup> Southeast Wisconsin (Komen SEWI) was founded in 1999 by a group of dedicated breast cancer survivors, breast health professionals, and other women of vision to provide breast health education and support services to medically underserved residents in the Southeast Wisconsin area. It is one of the largest of the more than 100 Affiliates in the Komen network and as of March 31, 2014 has raised more than \$11.3 million through donations, corporate support and fundraisers including the Komen Southeast Wisconsin Race for the Cure<sup>®</sup>.

Since its inception, Komen Southeast Wisconsin provided grants to 38 community organizations totaling over \$9.2 million and also provided over \$3.3 million to the Komen Headquarters Research Programs to help find the cures for breast cancer.

Komen SEWI's grant funding currently is focused on innovative programs that provide patient education, navigation, case management, screening, diagnostic services, and treatment. The Affiliate also funds programs that provide crucial support services including transportation and financial assistance for breast health screenings, diagnostic services, and treatment access. Past Komen grant funding included financial assistance for living expenses, as well as legal assistance to help prevent eviction and employer discrimination.

In addition to its grants program, Komen SEWI has been involved in several major city and state-wide initiatives to address the breast cancer burden. As an active member of the Wisconsin Breast Cancer Task Force (WBCTF) Komen SEWI participates in this statewide initiative convened by the Wisconsin Cancer Council and the American Cancer Society with the goal to improve breast cancer screening percentages in Wisconsin. The task force began meeting in December 2009 and brings together over 90 physicians, advocates, researchers, health educators, hospital administrators and policy experts from the local, regional and statewide organizations. Komen SEWI also is an organizational member of the Milwaukee Regional Cancer Care Network, an integrated effort of public and private partners to develop and implement a regional approach to cancer control. One priority of the Network is to increase access to care by reducing economic, geographic, cultural, and systems barriers through the development of "regional partnership networks" dedicated to breaking down local barriers.

Komen SEWI staff serves as committee members for the American Cancer Society's Community Health Workers Conference and Dia de La Mujer Latina health fair, as well as for the Medical College of Wisconsin's Cancer Center Community Advisory Board and the multiple subcommittees of the MCW Cancer Center Community Initiative. Additionally, Komen SEWI is a well-represented member in development and leadership organizations around Milwaukee such as the Agency Executive Group of Greater Milwaukee, Tempo Women Leaders of Milwaukee, and the Milwaukee Professional Fundraisers Association.

Since 2010, Komen Southeast Wisconsin has partnered with national retailer Kohl's Department Stores to fund and implement the innovative Conversations for the Cure program focused on

increasing education, driving awareness, and encouraging women to take action for their breast health.

Komen Southeast Wisconsin is located on the west shore of Lake Michigan. The region has traditionally attracted newcomers, especially from suburban Chicago and across the Midwest. The Affiliate serves a culturally and socio-economically diverse seven-county region located in Southeast Wisconsin, which includes Kenosha, Milwaukee, Ozaukee, Racine, Walworth, Washington, and Waukesha Counties. These counties vary greatly by total population, population density, socioeconomic status, access to health care, and race/ethnic composition. To meet its promise to save lives and end breast cancer forever, Komen SEWI relies on information obtained through the Community Profile process to establish priorities and guide its work in Southeast Wisconsin. The purpose of the Community Profile is to further illuminate areas of need for breast health promotion and breast cancer education, screening, treatment and support. This report intends to describe the varied breast health needs in Southeast Wisconsin as well as potential areas in which Komen SEWI's programs and funding might help advance the network's promise of ending breast cancer. Potential opportunities and areas of interest have been drawn from analyses of breast cancer statistics, policies and programs in the region that may impact breast health and exploratory, primary data collection among providers and breast cancer survivors in the region. After synthesizing data from various sources, this report presents data-driven priority areas from which the Affiliate intends to develop funding decisions for the years 2015-2019. This report provides abridged analyses of the data collected and reviewed by the Affiliate. In addition, this report will assist Komen SEWI in the following ways:

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

Komen SEWI will share this report with the community-at-large via the Komen Southeast Wisconsin website. It will also be shared with legislature, health care systems, other breast cancer organizations, and community organizations that interface with vulnerable and potentially underserved residents of Southeast Wisconsin.

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

The quantitative data for Komen Southeast Wisconsin points to needs in every county of the service area. Several counties stand out because of higher breast cancer incidence and death rates, others because of unique demographic factors. The limited size of the Affiliate makes it possible and, indeed, compels the Affiliate to proceed with an in-depth investigation of the variety of factors contributing to the different challenges faced in five areas of Southeast Wisconsin. In order to make the most efficient and effective use of resources, the Affiliate has identified and selected the following five target communities:

## **Milwaukee County**

Milwaukee County is the most populous county in Wisconsin, the 45th largest in the United States, and home to more than half of the women in the Komen Southeast Wisconsin service area. Its county seat is the City of Milwaukee, which is the largest city in the state. In terms of breast cancer age-adjusted incidence and death data, Milwaukee County sits squarely in the middle tier of the Southeast Wisconsin counties. It ranks medium low in terms of the Healthy People 2020 goals and is on track to achieve the 2020 breast health targets in four years. Milwaukee County's breast cancer incidence rate is 130.2/100,000 women - 13.3 percentage points higher than the State average(122.1) and more than 11 percentage points higher than the average for Southeast Wisconsin as a whole (116.9). Similarly, the county's age adjusted death rate is 22.6 deaths/100,000 women is higher than the average SEWI rate (21.3) and above the HP2020 goal of 20.6.

The socioeconomic and demographic data in Milwaukee County is more dramatic. Over 32 percent of the county's residents live in medically underserved areas and over 14 percent have less than a high school education. Almost one in five residents live at or below the Federal Poverty Level and alarmingly over a third of the county's residents live at or below 250 percent of the FPL.

The racial and ethnic makeup of Milwaukee County is by far the most diverse in the state. A full 29.2 percent of Milwaukee County is Black/African-American, a percentage twice as high as the national average and over four times higher than the overall Southeast Wisconsin service area average. This is a major factor for Milwaukee County due to high late-stage breast cancer incidence and the high breast cancer death rates Black/African-American women experience when compared to other races. Hispanic/Latina residents make up 12.8 percent of the county and every other race is represented in Milwaukee at percentages higher than anywhere else in the state. Nearly nine percent of the County's residents are foreign born and almost four percent are linguistically isolated. Each of Milwaukee's distinct demographic groups is shown to be at risk of challenges in terms of breast health and access to quality care.

The contrast of Milwaukee County's relatively medium low need breast cancer data with the extreme nature of its socioeconomic and demographic data faced by a diverse Milwaukee County secure it as a high need Target Community.

## **Northern Rural Region (NRR - Washington and Ozaukee Counties)**

In comparison to other counties in Komen Southeast Wisconsin's service area, the Northern Rural Region is home to some troubling quantitative data. Washington is identified as Komen SEWI's highest need county and has the Affiliates highest breast cancer death rate (24.5 deaths per 100,000 women), third highest breast cancer incidence rate (138.4/100K), and the slowest death rate trend ( -0.2 percent) making Washington County 13 years away from achieving the Healthy People 2020 breast cancer goals. Additional quantitative data also showed that Washington County has higher late-stage diagnosis rate than other SEWI counties of similar size and make up. Meanwhile, Ozaukee County carries the Affiliate's highest age-adjusted breast cancer incidence (156.2/100,000 women which is 27.9 percent higher than the national rate of 122.1), the third highest age-adjusted breast cancer death rate(23.4), and is five years away from the HP 2020 goals.

Despite this data, the NRR has very flat socioeconomic and demographic data with few exceptions. Additional data to consider in the NRR includes a large percentage of rural residents (Ozaukee 24.9 percent; Washington 30.8 percent) as well as a low proportion of Ozaukee women 50 to 74 having regular screening mammograms (77.3 percent). Although that number is higher for Washington County (92.5 percent), a wide confidence interval potentially makes that number dramatically lower.

### **Racine County**

Racine County is the third most populous county in Komen Southeast Wisconsin's service area and is home to the City of Racine which is Wisconsin's fifth largest city. This target community has the Affiliate's second highest age adjusted breast cancer death rate (24.4) which is higher than the averages for both the State of Wisconsin (21.3) and Affiliate (22.4) rates for death per 100,000 women. Racine County is also fourth in terms of breast cancer incidence in the Southeast Wisconsin service area, its age-adjusted rate of 128.7 breast cancer cases per 100,000 women is still 5.4 percent higher than the national rate of 122.1. This community is a full eight years away from reaching the Healthy People 2020 breast cancer goals.

The reported mammogram screening percentage for Racine women (78.3 percent) is among the lowest in the Affiliate's service area and well below the Affiliate Average of 82.9 percent. The confidence interval for this rate is very wide, opening the potential for the reality of even lower actual screening percentages. The county also has broader racial and ethnic diversity than average for the State of Wisconsin and is one of the more diversified counties in of the Affiliate. Racine's Black/African-American population is 12.1 percent which is 70.4 percent higher than the average for Wisconsin. The Hispanic/Latina population in Racine County is 11.3 percent which is greater than both the State (5.8 percent) and the Affiliate (9.5 percent) averages. As discussed earlier, different race and ethnicity populations can face unique breast cancer burdens and a variety of individual and systemic barrier. Other factors that indicate residents likely to bear a higher burden of breast cancer include Racine's relatively high rural population (12.3 percent), low education levels (12.3 percent under HS education), and especially notable the large portion of Racine County residents are living at or below 250 percent of the Federal Poverty Level (27.1 percent).

### **Waukesha County**

Waukesha County is Komen Southeast Wisconsin's second largest county. It is home to the city of Waukesha which is the seventh largest city in Wisconsin, but also has a 10 percent of its residents living well beyond the city boundaries in rural areas. The region has a slightly higher death rate than Wisconsin's average and a high breast cancer incidence rate when compared with the rest of the Affiliate counties. Waukesha County has the third highest breast cancer incidence rate in the Affiliate's service area at 138.6 cases per 100,000 women. This is 13.5 percent higher than the national breast cancer incidence rate of 122.1 deaths per 100,000. The county is at least three years away from attaining the Healthy People 2020 breast cancer goals.

Other quantitative data that may indicate higher breast cancer burden include a high percentage of women over the age of 40, a 14.0 percent level of residents living at or below 250 percent of the Federal Poverty Level, and according to information provided through local grantees a great deal of linguistic isolation as well as individual and systemic barriers to breast health services for Hispanic/Latina women and other identified vulnerable populations.

### **Southern Rural Region (SSR - Walworth and Kenosha Counties)**

While Kenosha and Walworth County's age-adjusted death rates as well as Kenosha's breast cancer incidence rate are the lowest in the Komen SEWI service area, careful regional analysis uncovered additional quantitative data that reveals populations and communities that are carrying far more than their share of the region's risk of breast cancer incidence and deaths. Kenosha and Walworth Counties have a combined 15 distinct census tract areas that have poverty levels far above the county average – some tracts with up to 64 percent of the residents living at or below the Federal Poverty Level. In addition the entire region is challenged with low education levels, high levels of non-insured residents, and a large percentage of population living at or below 250 percent of poverty (28.6 percent in Kenosha and 26.1 percent in Walworth). Both Kenosha and Walworth Counties also have slightly higher levels of foreign born citizens and linguistically isolated residents than the State of Wisconsin as a whole. It is very likely that this data indicates that many SSR residents are facing barriers that severely limit their access to accurate breast health information and affordable breast health services. Additionally, Walworth has one of the Affiliate's lowest mammography screening percentages at 77.4 percent. While Kenosha's percentage is much higher at 90.2 percent, the confidence interval for that rate is extremely large with a span of 40 percentage points indicating the screening could possibly be as low as 58 percent.

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

The Breast Cancer Continuum of Care (CoC) model reflects how a person would typically move through the health care system for breast care from screening to diagnosis to treatment to follow up. Education surrounds the model entire model as the foundation and is a key element to all aspects of the continuum of care. An individual ideally moves through the CoC quickly and seamlessly, receiving timely, quality care in order to have the best breast health outcomes.

When barriers exist that hinder an individual's progression through the continuum, it can contribute to poorer health outcomes. Barriers that exist in Komen Southeast Wisconsin's service area include several related to access of care within the local health systems including limited local access to services, a lack of transportation, inconvenient hours, limited language and culturally appropriate service delivery, need for financial assistance, lack of consistent breast health messages, and individual fear or mistrust of the health system. These and many other needs, gaps and barriers were explored during the Community Profile assessment.

The data collected for the health system analysis portion of the Community Profile illustrate the strengths and weakness of the health systems across the continuum of care within each of the five Komen Southeast Wisconsin Target Communities.

### **Milwaukee County**

Milwaukee County has full inventory of service providers with over 60 hospitals, community health centers, free clinics, mammography centers, and organizations within the community that provide breast health/breast cancer services along one or more points of the continuum of care. Sites are located widely throughout the Target Community. However, the health system in Milwaukee County shows weaknesses in the way specific breast health and breast cancer services are distributed. As you progress along the continuum of care, provider locations

become more clustered away from the City of Milwaukee. The majority of breast cancer services are located outside of Milwaukee County's most vulnerable areas.

Locations for screening mammograms are plentiful in the county, but comparably lacking in the county's lowest income areas mainly located within the City of Milwaukee. Mobile mammography increases access to local mammography, but the needs outpace the capacity of the county's single mobile mammography resource. Barriers increase with a lack of familiarity and trust of the larger health care systems and breast cancer service providers outside of one's neighborhood. Data revealed that few sites navigated eligible women to screening if they were being seen for a reason other than breast health. Many of the hospital and clinic sites were mainly concerned with navigating women back to screening mammograms through the use of reminder cards but some of these reminder systems did not have robust follow up with women who did not return for their yearly mammogram

There are 21 sites offering diagnostic services in Milwaukee County. Seven of these sites offer a full range of diagnostics (diagnostic mammogram, Ultrasound, Biopsy, and MRI). The health system inventory identified that the sites providing full diagnostic services were the only sites providing treatment services. These sites are predominantly located in zip codes areas of middle or high economic status. Breast cancer treatment and diagnostic services are geographically less available to Milwaukee County residents in lower socioeconomic areas. Transportation barriers to treatment and limited service hours are likely. Residents of Milwaukee County's low income zip codes are more than twice as likely to have a lack of adequate health care, inadequate support systems and no health insurance as residents in Milwaukee County's higher income zip codes. A lack of diagnostic and treatment facilities in lower income areas is likely to exacerbate this problem.

### ***Northern Rural Region (NRR - Ozaukee and Washington Counties)***

The Northern Rural Region is fortunate to have a much higher prevalence of health systems providing CBEs along with mammography than providers in other Target Communities. However, while the number of sites seems fairly extensive, the geographical reach is limited. In Washington County, the only sites for provider locations are in the middle and mid-west portion of the county. Overall there are six sites in Washington County providing CBEs four of which also provide screening mammograms. The number of screening sites is fairly large for the population of Washington County; however, the geographical reach is limited to two city centers.

In Ozaukee County, there is a concentration of continuum of care service sites falling mainly in the middle and southern eastern areas of the county. Overall, nine locations provide screening mammography in Ozaukee County. The Northern Rural Region is fortunate to have a much higher prevalence of health systems providing CBEs along with mammography than providers in other Target Communities. However, while the number of screening sites seems fairly extensive for the size of the county, the geographical reach is limited to city centers leaving large rural areas without local accessibility.

Mammography screening sites in the NNR are enhanced by the Columbia St. Mary's Mobile Mammography Coach. But while the coach increases the number of screening sites and locations, mammography sites in the region are still only around the city centers and have limited impact on the vast rural areas in this Target Community as a whole.

When assessing Washington and Ozaukee County for diagnostic and treatment resources, the inventory is less robust and unevenly distributed in the region. Residents of the Northern Rural Region have only one option for breast cancer treatment in Washington County. However, this facility is not a NBCCEDP provider so women needing to utilize WWWP or Komen funding must travel out of Washington County for those services.

Neither county in the Northern Rural Region has a Federally Qualified Health Center, but both Washington and Ozaukee Counties have a free clinic. The Washington and Ozaukee Health departments began a merger in 2015 and simultaneously increased the focus on the region's breast health needs with the help of a Komen SEWI grant.

### **Racine County**

Racine County has a relatively small health system inventory with an evident disparity of service locations. All but one of the seven sites providing screening service are located within the City of Racine which is on the far eastern side of the county. There is only one screening provider in the more rural western portion of the county. The region has one community health center and one free clinic available, both located in the City of Racine, far from the outer rural sections of Racine County. Mobile mammography is not a locally provided service in Racine County, so large areas of the county are without truly local service options. The County's available diagnostic and treatment services are limited to three providers and also very geographically slanted to the east side of the County.

The total number of service points is limited for a county as large as Racine. There may also be other factors keeping women from fully utilizing health systems that are relatively close. Transportation could be an issue even for city residents. Facility hours and limited after-hours public transportation affect access could be in play. And, while the City of Racine has good options for service along the CoC, most of the sites identified are larger provider facilities so individual barriers to service are likely including a discomfort or mistrust of hospital systems. WWWP and other funding agents are available, financial barriers may still exist for those not knowing about those resources or how to access them.

The Greater Racine County Mammography Coalition was formed to address the need for greater screening in Racine County. This Coalition is a cooperative effort between multiple community partners to educate, navigate, and ultimately screen low income, under and uninsured women in Racine County. These organizations are a combination of outreach and education organizations, health service providers with breast cancer services across the CoC, and the Racine Health Department - Wisconsin Well Women Program. The coalition efforts have contributed to an increase in mammography screening numbers from its inception to present. The Coalition demonstrated an ability to be flexible to the needs of the community by adding a west side county partner in 2014 that provided a new access point for women in the western portion of the county. Women in rural areas without involved partner organizations have few opportunities to access needed educational and navigational services. There is more work to do and perhaps additional partners to be recruited.

### **Waukesha County**

As the service area's second largest county, Waukesha County has a broad range of health system providers available including 22 CBE, 19 screening mammogram, and 17 diagnostic

service provider sites. County providers and partner organizations have close relationships creating a strong navigational network.

As complete as this inventory appears, there is still a potential weakness in the distribution of these services in this geographically large county. There is a large area with no service providers - predominantly in the southwestern quadrant of the county. Towns such as North Prairie, Dousman, Genesee Depot, Eagle Wales, and Waterville are miles from the nearest screening facility making transportation a likely barrier to breast cancer services. The lack of providers in these mainly rural areas also puts into question the availability of breast health outreach efforts providing accurate breast health information and information on available resources.

The full range of breast cancer treatment services (surgery, reconstruction, chemotherapy, and radiation) are available in five facilities located in five different cities, but all are located in the northern half of Waukesha County leaving the entire southern section of the county without local treatment options. Travel becomes an even greater barrier to the treatment portion of the CoC. Waukesha County residents living in the southern section of the county must travel considerable distances into northern Waukesha County or equal distances south into neighboring Walworth County.

### **Southern Rural Region (SSR - Kenosha and Walworth Counties)**

Assessment of the Southern Rural Region shows a small inventory of health care providers for the regions two counties, Kenosha and Walworth. The health system inventory for this Target Community consists of fifteen total providers and the distribution of these sites is very unbalanced. Residents of this SRR Target Community have few options and long distances to navigate.

There are only four sites in Kenosha County that offer screening mammograms, six facilities providing diagnostic services, and four facilities providing breast cancer treatment services. Every provider site is located on the far eastern side of the Target Community including the Federally Qualified health center with two City of Kenosha locations. Kenosha has no free clinic.

In Walworth County there are three distinct locations that provide CBEs, but only two screening mammogram providers, both located in the center of the county in the cities of Elkhorn and Lake Geneva. There are three total diagnostic service sites in the county's center but neither provides a full range of diagnostic services. Breast cancer treatment facilities number only two in Walworth County, again in the middle of the county. One provides chemotherapy and surgery, the other surgery and reconstruction. There are no service providers for radiation in Walworth County. To receive radiation a patient would need to travel either to the City of Kenosha or the City of Pleasant Prairie on the far eastern side of the Southern Rural Region or travel north into neighboring Waukesha County. The access to all breast health services in Walworth County is extremely limited especially for women in the county's predominant rural areas.

Additionally, while Kenosha and Walworth Counties show lower risk demographic and socioeconomic data overall, both counties contain multiple census tracts whose residents live in extreme levels of poverty in comparison to the rest of the residents in the Southern Rural Region and appear to bear an inequitable burden of breast cancer. Unfortunately, the location

of the available service sites does not always coincide with the location of these lowest socioeconomic population clusters.

### **Public Policy**

Regarding initiatives, Komen SEWI participates in the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) known as the Wisconsin Well Women program. Unfortunately, Wisconsin has elected not to adopt Medicaid expansion, and excludes non-citizens from enrolling in the Medicaid portion of the Wisconsin Well Women Program. For breast health and breast cancer needs, these limitations add additional stressors to those trying to access care. Komen Southeast Wisconsin has been a consistent advocate for the NBCCEDP. Using the Race for the Cure as an advocacy opportunity, the Affiliate circulates petitions calling for the continuation of Federal and State funding for the National NBCCEDP. The Affiliate also partners with other local and state organizations to closely monitor the progress and efficacy of the Wisconsin Well Woman Program as it moves through a restructuring process that was put into place in July of 2015.

While most of the Affiliate's advocacy guidance comes from Komen's Advocacy Team, Komen Southeast Wisconsin is also obligated to be informed on additional local and state issues that could specifically impact the breast health or disrupt the equity of health services of Wisconsin residents. Komen Southeast Wisconsin was proud to join other local breast cancer organization in the advocacy for and ultimate passage of the Oral Chemo Bill known as the Cancer Treatment Fairness Act.

Partnering and co-sponsorship of advocacy efforts with the WBCC and other local organizations, health systems, and key individuals in order to leverage combined voices in the fight for optimal breast health legislation enhances Komen Southeast Wisconsin's efficacy in advocacy efforts. It is through these avenues that the Affiliate can most effectively lobby Wisconsin State representatives to continue to support legislation for federal breast cancer funding, as well as continue to consider an expansion of Medicaid in Wisconsin.

Local and State issue and legislation advocacy is also strengthened by Komen Southeast Wisconsin's relationship with the Komen South Central and Komen Central Affiliates. Together the Affiliates can stay more informed of issues, present a unified voice at lobby days, and partner in co-signing petitions and letters to State representatives. All of the Komen Wisconsin Affiliates have an obligation to stay on top of local and state issues so that they can provide meaningful input back to the Komen Advocacy team for consideration when the annual Advocacy Priorities are being set.

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

To obtain the community perspective on the state of breast health in the target communities, the Community Profile Team used a variety of qualitative data collection methods.

1. **The General Population Survey** – This survey was available as both a paper and an online survey. Women responding answered a series of both close-ended questions that captured mainly demographic and socioeconomic information and open-ended questions intended to collect input on health system experiences, perceptions of barriers and motivators to breast health services, beliefs/attitudes about breast cancer, and

opinions on what could be done differently in the community to improve breast health service delivery.

2. **The Survivor Survey** – This survey was offered only online and designed to gain a more in-depth look at the themes addressed in the General Population Survey.
3. **Key Informant Interviews** – This data collection consisted primarily of one-on-one interviews designed to gather information from community organization service providers who have deep familiarity with the needs and issues faced by their target populations. Questions were mainly open ended and probing.
4. **Health Provider Survey** – This online survey collected data from providers identified in the Health System Analysis. The format consisted mainly of close-ended questions with the option of adding additional narrative to explain and/or expand on responses. The health provider survey collected information across the continuum of care. Questions addressed a range of topics including breast health services provided; ability to meet CDC guidelines; CBE and mammography recommendations; individuals in need; individuals served; assessment of barriers to screening, diagnostics, and treatment; methods used to overcome barriers; and possible collaborations.
5. **Survivor Forum** – The Forum was a one time, in-person gathering of Southeast Wisconsin breast cancer survivors. The goal of the Survivor Forum was to gather input on three topics: education, barriers, and support.
6. **Conversation for the Cure (CFTC) Data** – Komen SEWI's in-house breast health education program CFTC has a registration form and a survey that each woman is asked to fill in when participating in the program. Information collected includes ethnicity as well as the individual's reported barriers to breast cancer screening.

## Highlights of the Qualitative Data Analysis

### **All Target Communities**

- Top barriers to *screening and diagnostic services*: Fear, lack of insurance/money, lack of education, and cultural factors. Top barriers to *breast cancer treatment services*: Money, home-life, transportation, and fear
- Transportation barriers exist for rural residents & all economically vulnerable residents.
- Overall need for truly culturally sensitive delivery of all breast health services
- Providers give low scores to their current breast health education programs on their ability to lead women to breast cancer screening.
- Majority of women surveyed do not feel personally at risk of breast cancer. The majority of survivors surveyed did not feel at risk of breast cancer prior to their diagnosis.
- Call for better local neighborhood access to screening mammograms
- Call for increased collaboration between the health systems and local agencies serving vulnerable populations in order to increase access to/use of breast health services.
- Call for increased use of a Community Health Worker model as a necessary navigational bridge to the health systems.

### ***Milwaukee County***

- Call for more local services, especially screening, in lower income areas.
- Personal and systemic cultural barriers exist at every point in the continuum of care for many populations of individuals outside of the cultural mainstream.
- Over 32 percent of women under 40 never or rarely have clinical breast exams.
- Black/African-American women report lower frequency of mammogram screenings than White women.
- Black/African-American women reported more barriers to breast health services per person than White women.

### ***Northern Rural Region (Washington and Ozaukee Counties)***

- Key Informants identified additional vulnerable populations (Black/African-American, American Indian Alaskan Natives (AIAN), Asian Pacific Islanders (API), Lesbian, Gay, Bisexual, and Transgender (LGBT)) to add to those identified by health providers (rural, Hispanic/Latino, low income, underinsured, and unemployed residents).
- Transportation and distance a major barrier to rural residents
- Low annual screening percentages reported (Never or rarely screened: 72.0 percent of General Survey participants and 62.5 percent of Survivor Survey participants prior to their diagnosis.) One quarter of survivors surveyed had never had a mammogram prior to diagnosis.

### ***Racine County***

- Broad spectrum of populations identified as needing additional breast health services
- One quarter of Survivors reported rarely/never having mammograms prior to diagnosis.
- Those with incomes just above financial assistance levels are falling through the cracks.
- Lack of local access for broad areas of Racine County. No mobile mammography.
- Survivor services vastly under recognized and underutilized.

### ***Waukesha County***

- Multiple populations identified as needing additional breast health services and information. Several (including API, Hmong, Russian, mentally and physically disabled, elderly, LGBT residents) are not currently targeted by providers.
- Over 63 percent of providers feel their breast cancer education programs are only sometimes effective
- One third of 40 to 49 year olds surveyed never or rarely had a mammogram.
- Complementary survivor support services were recognized by less than ten percent of health providers surveyed.

### ***Southern Rural Region (SRR) (Walworth and Kenosha Counties)***

- Providers in the SRR Target Community reported the fewest methods of education and outreach of all Target Communities.
- Education and outreach were identified as the greatest motivator to pursuing a breast cancer screening.
- No providers reported being aware of populations being targeted for breast health services by any other organizations in the area.

- When asked if their current education and outreach programs are effective at leading women to breast cancer screenings, three quarters of providers responded ‘only sometimes’ and one quarter stated ‘rarely’.
- One third of non-White women in SRR report that they rarely or never have a mammogram.
- Key Informants and General Survey participants identified many more barriers to breast health services than were identified by SRR providers in the health system.
- No providers or survivors identified transportation as an available support service
- More than any other Target Community, Survivor Support Services were widely unrecognized as available by providers and survivors. They were also greatly underutilized by survivors.

Using the data collected in the quantitative, health system and public policy analysis, and qualitative sections, a plan of action was developed.

### **Mission Action Plan**

Eight problems have been identified for Komen Southeast Wisconsin’s Mission Action Plan based on the information uncovered in the development of the 2015 Community Profile. The problems identified address needs in all five Target Communities and have been organized into six different categories including Public Policy, Communication, Breast Health Services, Education, Grantmaking, and Survivorship.

For each problem statement, one or more priorities are stated that will help the Affiliate address or begin to address the ‘problem’ during fiscal years 2016 to 2019. Each priority is followed by objectives which are specific, measurable action items the Affiliate feels it can achieve during the upcoming fiscal years.

### **Public Policy**

**Problem:** Public policy related to breast cancer research funding, as well as the Wisconsin Well Woman Program (National Breast and Cervical Cancer Early Detection Program), the Affordable Care Act, insurance coverage, and out of pocket costs for breast cancer services greatly affect the ability of Southeast Wisconsin resident to access affordable and accessible breast health services.

**Priority 1:** Maintain optimal availability of and increase access to the Wisconsin Well Woman Program (WWWP) for eligible women in Southeast Wisconsin.

*Objective 1:* FY2016 to 2017, the Affiliate will actively monitor the restructuring of the Wisconsin Well Woman Program and advocate (through a united effort with the Wisconsin Breast Cancer Coalition, other Komen Wisconsin Komen Affiliates, and other breast health stakeholders) as needed both in person and through co-sponsored letters calling for accessible and affordable access to individualized navigation and high quality service delivery.

*Objective 2:* FY 2016 to 2019, participate as deemed necessary (in cooperation with the Breast Cancer Task Force and the Cancer Center Community Advisory Board) in the development of messaging and promotional materials to provide outreach for the Wisconsin Well Woman Program through local health systems and organizations

*Objective 3:* FY 2016 to 2019, distribute WWWP promotional messaging and materials to all Affiliate grantees and at least five partners in each Target Community for distribution.

*Objective 4:* FY2016 to 2019, disseminate WWWP promotional messaging through the Affiliate Website, social media, Conversation for the Cure programming, and all Affiliate education and outreach events.

**Priority 2:** Increase Affiliate advocacy efforts both at a local/statewide level and at a Federal level.

*Objective 1:* FY 2016 to 2019, the Affiliate will participate annually in Komen Headquarters Advocacy days in Washington D.C.

*Objective 2:* FY 2016 to 2019, the Affiliate will participate annually in the Wisconsin Breast Cancer Coalition's State Advocacy days in Madison, Wisconsin.

*Objective 3:* By FY 2018, the Affiliate will develop and conduct one Komen-sponsored Advocacy Day in Madison that is attended by at least five representatives of Komen Southeast, South Central, and Central Wisconsin.

*Objective 4:* FY 2017 to 2019, timely advocacy 'calls to action' will be posted on the Affiliate's social media outlets (including Facebook, twitter) as needed.

**Priority 3:** Increase Affiliate constituent's access to breast health advocacy issues and facilitate involvement in advocacy efforts.

*Objective 1:* FY 2016 to 2019, annual development of a timely and relevant advocacy-focused petition to be circulated at the annual Race for the Cure, signed by a minimum of 300 participants, and then submit to State legislators and/or Komen Headquarters Advocacy staff.

*Objective 2:* FY 2016 to 2019, advocacy information on the Affiliate's website will be updated quarterly.

*Objective 3:* FY 2016 to 2019, a link to constituent's current elected official contact information will be included on the Komen Southeast Wisconsin website.

*Objective 4:* FY 2017 to 2019, links to current Local, State and Federal breast health related policy information and other Wisconsin Breast Health Advocacy Group's information (including Wisconsin Breast Cancer Coalition and the Wisconsin Women's Health Alliance) on the Affiliate's website will be updated annually.

## Communication

**Problem:** Majority of individuals surveyed during the qualitative data collection could not identify a resource or organization they would turn to for information on breast health and breast cancer.

**Priority 1:** Increase community awareness of the work of Susan G. Komen Southeast Wisconsin.

*Objective 1:* FY 2016 to 2018, annual Media Campaigns launched through Kohl's Conversations for the Cure Program to deliver three million impressions to individuals residing in all five SEWI Target Communities.

*Objective 2:* FY 2016 to 2019, distribution of a quarterly Komen SEWI newsletter to all Affiliate constituents and partner organizations via email (and by mail as requested) to include sections on breast health education, research, grants and grantees, events, survivorship, and Affiliate development.

*Objective 3:* FY 2017 to 2019, at least one time annually, the Affiliate will provide Komen grantees and partner organizations with shareable social media content inviting their constituents to link to Komen SEWI's website and/or register to receive Komen SEWI's quarterly newsletter.

*Objective 4:* FY 2016 to 2019, monthly distribution of a Race e-newsletter including mission content from May to September to all current and past race participants in Affiliate data base.

*Objective 5:* FY 2016 to 2019, development of a yearly October calendar of Breast Cancer Awareness Month activities and events.

*Objective 6:* FY 2016 to 2019, annually in October (Breast Cancer Awareness Month) the Affiliate will have a presence at a large local Milwaukee County venue at which the Affiliate will host at least four special events; promote breast self-awareness and distribute at least 2,000 pieces of printed educational materials on breast health; provide information on breast cancer services and resources; celebrate local survivors; and register individuals to receive the Komen SEWI newsletter.

**Priority 2:** Increase the visibility of Komen grantees within the community in order to promote utilization of available grant programs and to enhance the awareness and understanding of local Komen Affiliate funding.

*Objective 1:* FY 2016 to 2019, the Affiliate will update spreadsheet of all grantee information and contact information on an annual basis.

*Objective 2:* FY 2017 to 2019, annually the Affiliate will create a basic word document with updated grantee information for distribution to individuals navigating women to breast health services in each Target Community. This will include, but

not be limited to all Affiliate staff, Komen grantees, Kohl's Conversation for the Cure program managers, and Wisconsin Well Woman Coordinators serving each Target Community.

*Objective 3:* FY 2018 to 2019, annually the Affiliate will create yearly grantee marketing piece for public distribution that promotes awareness and utilization of current grant programs by residents in the Affiliate's Target Community. This marketing piece will be printed and distributed to the public by Komen staff and volunteers at public health fairs, Kohl's Conversation for the Cure events, and all outreach efforts. A PDF of this document will be posted on the Affiliate website and also provided to all current grantees and partner organizations each year.

*Objective 4:* FY 2017 to 2019, at least one time per grant year, the Affiliate's Grantees will submit photographs of and/or stories about their funded programs which will be featured on the Affiliate website, Facebook page, and/or newsletter. These stories and photographs will also be offered for sharing on social media of partner organizations, local health departments, as well as with local media sources.

**Priority 3:** Improve community access to breast health and breast cancer resources.

*Objective 1:* FY2017, convene one meeting of at least two interested stakeholders from each Target Community to assess the feasibility and development of a working plan for creating an accessible, comprehensive, and up-to-date Breast Cancer Resource Guide which would be available to residents, providers, and local organizations in all Target Communities by FY 2019.

*Objective 2:* FY2017 to 2018, in cooperation with other local breast cancer agencies in each Target Community and utilizing the work plan established in Objective 1, identify and document the current holders of breast cancer resource information to begin the process of consolidating one local, comprehensive, and up-to-date Breast Cancer Resource Guide to services, products, and support in Southeast Wisconsin.

*Objective 3:* FY 2018-2019, identify and contact nonprofit organizations that have the capacity to consolidate, maintain, and/or electronically house a comprehensive Breast Cancer Resource Guide to assess their interest in and potential for taking on this project by FY 2019.

## Breast Health Services

**Problem:** In every Target Community key multiple ethnic/racial/socioeconomic populations are identified as being underserved in terms of breast health information and services. In qualitative data collection, providers and key respondents surveyed identified a gap between the organizations that understand how to access and serve these populations and the agencies or health providers who are able to provide breast health services to these residents.

**Priority 1:** Increase Affiliate collaboration with local non-medical organizations serving specific populations within each Target Community.

*Objective 1:* FY 2016 to 2017, begin to building capacity for future collaborations, the Affiliate will utilize the Community Profile to create a working local organization data base for each Target Community that will contain information on identified organizations including, but not limited to each organization's name, contact information, mission, and population served.

*Objective 2:* FY 2018 to 2019, to increase the potential for future collaborative efforts, the Affiliate's Mission Manager will make quarterly updates to the local organization data base to both add new organizations and keep existing organizational contact information current.

*Objective 3:* FY 2016 to 2019, annually the Affiliate Mission manager will meet with at least one new organization per vulnerable population identified in each Target Community (as available) to explore the opportunities to partner in the delivery of breast health information to their specific targeted populations.

**Priority 2:** Increase collaboration between local health care organizations and non-medical organizations serving vulnerable populations in each Target Community.

*Objective 1:* FY 2016 to 2019, annually meet with at least one key breast health personnel from each major health system identified in the Community Profile health system analysis in each Target Community.

*Objective 2:* FY 2016 to 2019, as deemed appropriate, initiate contact between local agencies and local health care facilities based on information gained in meetings with each partner to encourage collaborative efforts and partnering on program development and possible Komen grant funding.

**Problem:** Access to and utilization of breast cancer screening, diagnostic, and treatment services in each Target Community are negatively impacted by an interwoven myriad of barriers, both personal and systemic as indicated by the health system, public policy, and qualitative data analyses.

**Priority 1:** Assess and facilitate the ability of the Affiliate and partner organizations to provide local, accessible opportunities for increasing the health literacy of residents in all Target Communities – specifically the ability to provide opportunities that deliver

information on the importance of breast health, as well as information on finding and accessing available medical, insurance and financial resources available.

*Objective 1:* By the end of FY 2017, convene a meeting in each Target Community of local organizations and providers to discuss, prioritize, and brainstorm possible strategies for:

- Developing neighborhood events in each target community that would provide opportunities for residents to develop the skills needed to successfully find and access breast health information, services, and support resources.
- Addressing the breadth of challenges to providing truly culturally sensitive breast health services at every point in the continuum of care.
- Facilitating the utilization of Community Health workers to create a bridge from local neighborhoods into the larger health systems.

*Objective 2:* By the end of FY2019, at least one educational outreach event will be conducted in each Target Community to provide community members with information on the importance of breast health and how to find and access the medical, insurance, and financial resources available.

**Priority 2:** Increase access to local breast cancer screening for residents in the all Target Communities.

*Objective 1:* FY 2016 to 2019, identify at least two local organizations and health provider facilities in each Target Community interested in and able to host mobile mammography opportunities for the populations they serve.

*Objective 2:* FY 2016 to 2019, the Affiliate and Mobile Mammography provider will partner with at least one local organization and/or provider in each Target Community to facilitate or cohost at least one mobile mammography event annually.

*Objective 3:* FY 2016 to 2019, Kohl's Conversations for the Cure program will annually lead a minimum of 1,000 women to age appropriate breast cancer screening as measured by the return of the program's screening confirmation cards.

**Priority 3:** Address the impact of fear and denial as major barriers to breast cancer screening and diagnostic services.

*Objective 1:* FY 2017, incorporate messaging about overcoming barriers of fear and denial in the Kohl's Conversations for the Cure media campaign to hit three million views over the campaign year.

*Objective 2:* FY 2017 – 2019, include breast health and breast cancer information through the inclusion of at least one 'survivor story' that addresses fear and denial in the Komen SEWI Quarterly Newsletter, the Survivor Newsletter, and on social media at least one time annually per media.

## Education

**Problem:** Providers and Key Respondents in all Target Communities feel that current breast health education efforts are not consistently effective at leading women to screening mammograms.

**Priority 1:** Provide access to information on breast self-awareness messaging and breast cancer resources to providers in all Target Communities.

*Objective 1:* FY 2017 to 2019, host and fund a yearly educational opportunity to provide curriculum on Komen Breast Self-Awareness messaging and discuss recommended breast cancer screening guidelines. FY 2017 in Milwaukee County, FY 2018 in the Northern Rural Region, and FY 2019 in the Southern Rural Region.

*Objective 2:* FY 2017 to 2019, annually create and distribute a document of available funding resources for breast cancer screening, diagnostic, and treatment services to at least five local providers in each Target Community identified in the health system analysis to improve their working knowledge of the various referral processes and their ability to better navigate patients.

*Objective 3:* FY 2017 to 2019, incorporate in-house provider education as a recommended priority in Community Grant RFAs.

**Priority 2:** Facilitate health providers and local organizations access to and utilization of Komen SEWI's Conversation for the Cure breast self-awareness curriculum and Komen's Breast Cancer tool kits.

*Objective 1:* FY 2017 to 2019, annually the Kohl's Conversations for the Cure program staff will extend an offer to provide leader training on the presentation of breast self-awareness curriculum to individuals working within local agencies from at least 1 organization per Target Community.

*Objective 2:* FY 2016 to 2019, annually the Affiliate will offer electronic distribution of Komen breast health and breast cancer educational toolkits to every local organization in the organization data base as well as to key breast health providers at health facilities identified in the health system analysis.

**Problem:** Lack of education was identified by all key informants and providers as a major barrier to screening and diagnostic breast health services in all Target Communities.

**Priority 1:** Increase the number of opportunities for women to be educated about their personal risk of breast cancer.

*Objective 1:* In FY 2017, incorporate the understanding of personal breast cancer risk into the media campaign for Kohl's Conversations for the Cure.

*Objective 2:* In FY 2016, incorporate a focus on understanding personal risk for breast cancer into the programming messaging of Breast Cancer Awareness Month.

**Priority 2:** Increase the availability of accurate and consistent breast health and breast cancer educational opportunities in each Target Community.

*Objective 1:* FY 2016 to 2019, provide annual access to the Affiliate's Conversation for A Cure Breast Self-Awareness Curriculum (verbally, electronically, and/or in-print) to all grantees for dissemination to their clients and their health system providers.

*Objective 2:* FY 2016 to 2019, utilizing the Breast Self-Awareness curriculum of the Kohl's Conversation for a Cure program, annually provide consistent breast health and breast cancer information (verbally, electronically, and/or in-print) to a minimum of 2,500 women residing in the Affiliate's Target Communities.

*Objective 3:* By the end of FY 2016, launch of a quarterly webinar series hosted by the Affiliate and featuring a variety of breast health and breast cancer relevant topics.

### **Grantmaking**

**Problem:** Future Grantmaking must align with needs identified in the 2015 Community Profile.

**Priority 1:** Facilitate access to the grantmaking process in every Target Community.

*Objective 1:* FY 2016 to 2017, host at least one meeting in each Target Community to provide an overview of the 2015 Community Profile, provide information on Komen SEWI Grantmaking, and to provide additional opportunities for local input on the gaps, needs and barriers to breast health services.

*Objective 2:* By end of FY 2017, the Affiliate's contact spreadsheet will be updated to utilize as the data base for disseminating information on the release of Grant RFA's and grant writing workshops.

*Objective 3:* FY 2018- 2019, quarterly updates to Contact Spreadsheet to keep document current and broadly inclusive.

*Objective 4:* FY 2017 to 2019, offer a webinar format option for the annual Community Grant Writing Workshop to accommodate potential grantees unable to travel into Milwaukee County for the in-person workshop.

*Objective 5:* FY 2017 to 2019, increase access to Community Grant funding for those organizations unable or unwilling to apply for funding independently by facilitating collaborative breast health project development and Community Grant program development between local organizations and/or local health providers based on information gathered during in person meetings.

**Priority 2:** Define the priorities of Community Grant (CG) Request for Applications (RFA) for upcoming grant years to reflect the needs and gaps addressed in the 2015 Community Profile.

*Objective 1:* FY 2017 to 2019, include a CG RFA Priority related to increasing access to local and affordable screening mammograms for vulnerable populations identified in the 2015 Community Profile.

*Objective 2:* FY 2017 to 2019, include a CG RFA Priority related to increasing access to local and affordable breast cancer services for vulnerable populations identified in the 2015 Community Profile.

*Objective 3:* FY 2017 to 2019, include a CG RFA Priority related to an effort to provide accurate and standardized breast cancer information to both Target Community's residents and to health care providers.

*Objective 4:* FY 2017 to 2019, include a CG RFA Priority related to the development of targeted outreach and strategic collaborations to provide access to breast health services across the continuum of care for vulnerable populations identified in the 2015 Community Profile.

**Priority 3:** Expand the narrative of the Community Grant RFA to include references to issues addressed in the 2015 Community Profile.

*Objective 1:* FY 2017 to 2019, include references to the following in each year's Community Grant RFA:

- Awareness of barriers faced by specific populations the program intends to serve;
- Methods for navigation of eligible women to Wisconsin Well Woman Program, Badger Care Plus, and the Federal Marketplace;
- Facilitation of Health Literacy;
- Facilitation of Insurance Literacy;
- Promotion of healthy lifestyle factors;
- Delivery of truly Cultural Sensitivity programming
- Details of Community Health Worker training and expectations,
- Utilization of a Community Health Worker model,
- Ability to address the top breast health screening and diagnostic barriers of Fear, money/insurance, culture, and transportation.

**Priority 4:** Foster the growth of the Small Grant program to promote new breast health initiatives, capacity building, and program development.

*Objective 1:* FY 2016-2019, during years when small grant funding is available, meet with a minimum of two possible small grantees from each Target Community each fiscal year to explore funding possibilities.

*Objective 2:* FY 2017 to 2019, as appropriate and based on information gathered during in person meetings in Objective 1, facilitate collaborative Community Grant and/or Small Grant program development between local organizations and/or local health providers by making connections between key organizational representatives through email and/or in person introductions.

## Survivorship

**Problem:** Providers and survivors in all Target Communities report having limited awareness of and under-utilization of survivor support services.

**Priority 1:** Assess and facilitate the ability of the Affiliate and local partner organizations ability to increase local awareness and understanding of available survivor support services.

*Objective 1:* By end of FY 2017, convene an exploratory meeting of local breast cancer organizations to initiate a conversation about local survivor support services.

*Objective 2:* FY 2017, convene interested stakeholders from all Target Communities to meet and consider the development of a strategic plan that would help:

- Identify available survivor support services;
- Increase awareness of available local survivor support services to health system providers and to breast cancer patients;
- Increase provider and patient understanding of the value of the survivor support services.
- Host or co-host event(s) to honor, inform, and/or support breast cancer survivors.

**Priority 2:** Increase opportunities for Komen SEWI to provide information on breast cancer survivor support services to survivors/forever fighter constituents.

*Objective 1:* FY 2016 to 2019, distribute a monthly Survivor Newsletter to survivors in the Affiliate's data base.

*Objective 2:* FY 2016 to 2019, facilitate access to ABCD: After Breast Cancer Diagnosis's services through contact links provided in the Survivor Newsletter and on Komen SEWI social media (in particular the organization's hotline, mentoring program, and ABCD's monthly Mets Virtual Support Group).

*Objective 3:* FY 2016 to 2019, host a free, annual Metastatic Breast Cancer Symposium in Waukesha County designed and marketed to Metastatic Breast Cancer patients, their families, and their providers that feature current and relevant presentations related to the topic of Metastatic Breast Cancer.

*Objective 4:* FY 2016 to 2019, host a free, annual Survivor Luncheon In Milwaukee County that honors the Affiliate's Survivor/Mets constituents and provides a presentation on a topic of relevance to these guests.

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

# Introduction

## Affiliate History

Susan G. Komen® Southeast Wisconsin (Komen SEWI) was founded in 1999 by a group of dedicated breast cancer survivors, breast health professionals, and other women of vision to provide breast health education and support services to medically underserved residents in the Southeast Wisconsin area. It is one of the largest of the more than 114 Affiliates in the Komen network and as of March 31, 2014 has raised more than \$11.3 million through donations, corporate support and fundraisers including the Komen Southeast Wisconsin Race for the Cure®.

Since its inception, Komen Southeast Wisconsin provided grants to 38 community organizations totaling over \$8.3 million and also provided \$3 million to the Komen Headquarters Research Programs to help find the cures for breast cancer. Figure 1.1 depicts Komen SEWI yearly grant distribution from 2001 to 2014.

Komen SEWI's grant funding is focused on innovative programs that provide patient navigation, case management, screening, diagnostic services, treatment and programs that provide crucial support services including transportation and financial assistance. In the past Komen SEWI has funded meals for patients and their families and legal assistance to prevent eviction and employer discrimination.

In addition to its grants program, Komen SEWI has been involved in several major city and state-wide initiatives to address the breast cancer burden. As an active member of the Wisconsin Breast Cancer Task Force (WBCTF) Komen SEWI participates in this statewide initiative convened by the Wisconsin Cancer Council and the American Cancer Society with the goal to improve breast cancer screening percentages in Wisconsin. The task force began meeting in December 2009 and brings together over 90 physicians, advocates, researchers, health educators, hospital administrators and policy experts from the local, regional and statewide organizations. Komen SEWI also is an organizational member of the Milwaukee Regional Cancer Care Network, an integrated effort of public and private partners to develop and implement a regional approach to cancer control. One priority of the Network is to increase access to care by reducing economic, geographic, cultural, and systems barriers through the development of "regional partnership networks" dedicated to breaking down local barriers. Additionally, Komen SEWI staff serves as committee members for the American Cancer Society's Community Health Workers Conference and Dia de La Mujer Latina health fair, as well as

for the Medical College of Wisconsin's Needs, Barriers and Gaps Subcommittee of the Cancer Center Community Advisory Board. Finally, Komen SEWI is a well-represented member in



**Figure 1.1.** Susan G. Komen yearly grant distribution, 2001-2014

development and leadership organizations around Milwaukee such as the Agency Executive Group of Greater Milwaukee, Tempo Women Leaders of Milwaukee, and Milwaukee Professional Fundraisers Association.

Since 2010, Komen Southeast Wisconsin has partnered with national retailer Kohl's Department Stores to fund and implement programs focused on increasing education, driving awareness, and encouraging women to take action for their breast health. From 2009 to 2014, Kohl's and its philanthropic platform, Kohl's Cares®, donated \$3.5 million to Komen Southeast Wisconsin and committed to an additional \$2.2 million dollars in the subsequent three years. This funding contributes to the Affiliate's Community Grant program, as well as to support the Affiliate's development and deployment of the Kohl's Conversations for the Cure® (KCFTC) program.

KCFTC, a unique breast health and breast cancer educational program, offers women the opportunity to talk openly about breast cancer and the impact it can have on their lives. The goal of every Conversation is to educate women throughout Southeast Wisconsin on the four key breast self-awareness messages and encourage them to get regular breast health screenings, thereby increasing survival rates. Two full-time staff positions are funded through this program.

Kohl's will be renewing for three more years with \$2.2 million in additional funding.



Through Komen SEWI's public policy program, the Affiliate works to improve the access of low-income women to breast screening and quality treatment. Komen SEWI has worked on changing state regulations that affect women who are diagnosed with breast cancer. The Affiliate, along with the Wisconsin Breast Cancer Coalition, co-sponsored an informational town hall style meeting in February 2014 regarding the proposed changes to the National Breast and Cervical Cancer Early Detection Program across the state. In Wisconsin, this program is known as the Wisconsin Well Women Program (WWWP). Komen Southeast Wisconsin provided an extremely early response to the announcement of changes and facilitated a meeting of almost 150 concerned individuals from across the health care spectrum – giving one unified voice to everyone in the community.

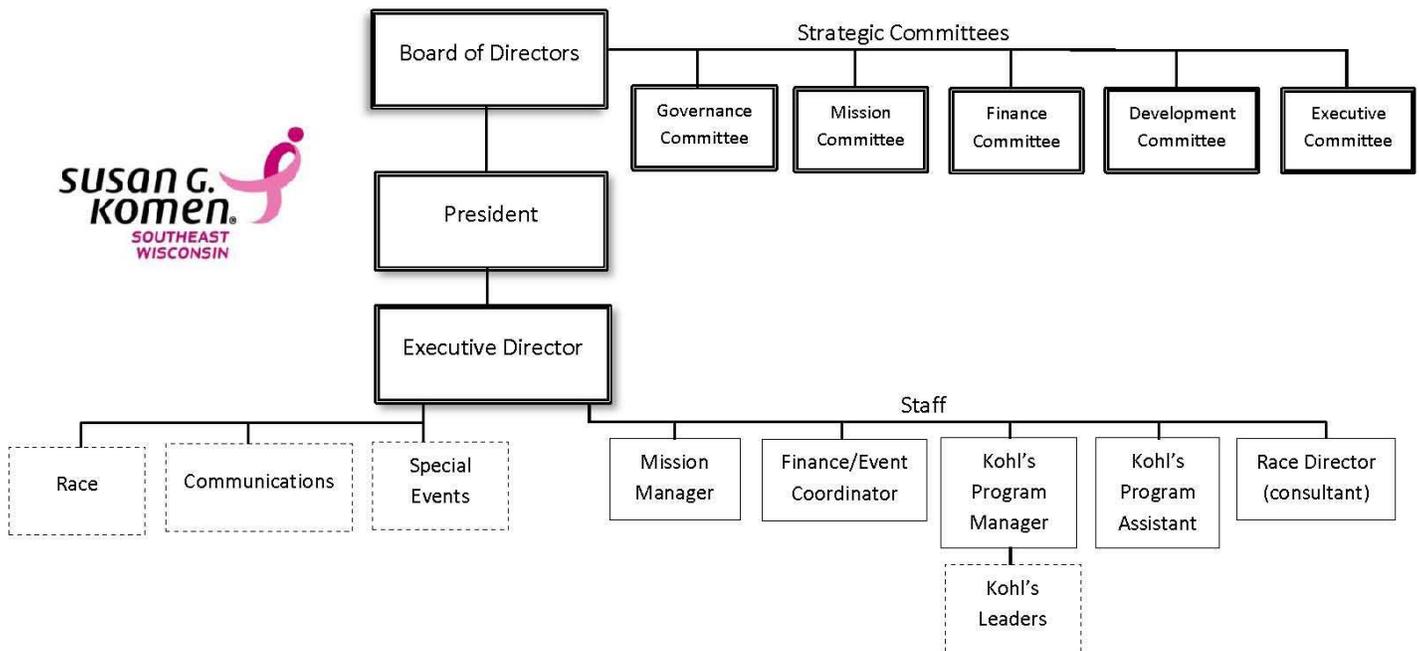
This meeting sparked further conversation and input, as well as provided content and direction to the continued lobbying to slow the changes in order to ensure that the integrity of the WWWP be preserved. The result of these unified efforts was a one-year delay on program restructure, allowing time for input from key respondents and analysis of data to inform what changes should be made and how the program could respond effectively to the needs of Wisconsin women after implementation of the Affordable Care Act.

In another major advocacy victory, SB 300, the Wisconsin Cancer Fair Treatment Act (the oral chemotherapy parity bill), passed both the Wisconsin State Senate and Assembly. Signed into law on April 3, 2014, this bill mandates that medical insurance coverage for Oral Chemotherapy be identical to coverage for traditional chemotherapy. Komen Southeast Wisconsin was on the statewide committee that worked to make this happen.

**Affiliate Organizational Structure**

Komen SEWI is based in Milwaukee, Wisconsin. Komen SEWI is incorporated as a nonprofit organization with its own Board of Directors and five Milwaukee-based full time staff, led by an Executive Director. It has a collaborative and contractual relationship with the national organization of Komen that augments the Affiliate’s fundraising, program activities and local influence. An 11 member Board of Directors is Chaired (2014 to 2016 term) by a Board President. Figure 1.2 depicts Komen SEWI’s organizational structure.

Komen SEWI is a respected resource for breast cancer information in the region. Komen SEWI staff and key volunteers consistently appear on local radio and television programs to share their opinion on emerging breast cancer issues. Komen SEWI staff also regularly participates in community and corporate events to educate audiences about breast cancer. In addition to the grants program, Komen SEWI participates in several major city and state-wide initiatives to address the breast cancer burden.



**Figure 1.2.** Susan G. Komen Southeast Wisconsin organizational chart

**Affiliate Service Area**

The State of Wisconsin has three Affiliates as depicted in Figure 1.3 below.

Komen Southeast Wisconsin is located on the west shore of Lake Michigan. The region has traditionally attracted newcomers from suburban Chicago. The Affiliate serves a culturally and socio-economically diverse seven-county region located in Southeast Wisconsin, which includes

Kenosha, Milwaukee, Ozaukee, Racine, Walworth, Washington, and Waukesha Counties. These counties vary greatly by total population, population density, socioeconomic status, access to health care, and race/ethnic composition. Refer to Table 1.1 below.

Milwaukee County is the most populous county in Wisconsin and the 45th most populous in the United States. Its county seat is the City of Milwaukee, which is also the largest city in the state. The racial makeup of the county is by far the most diverse in the state.

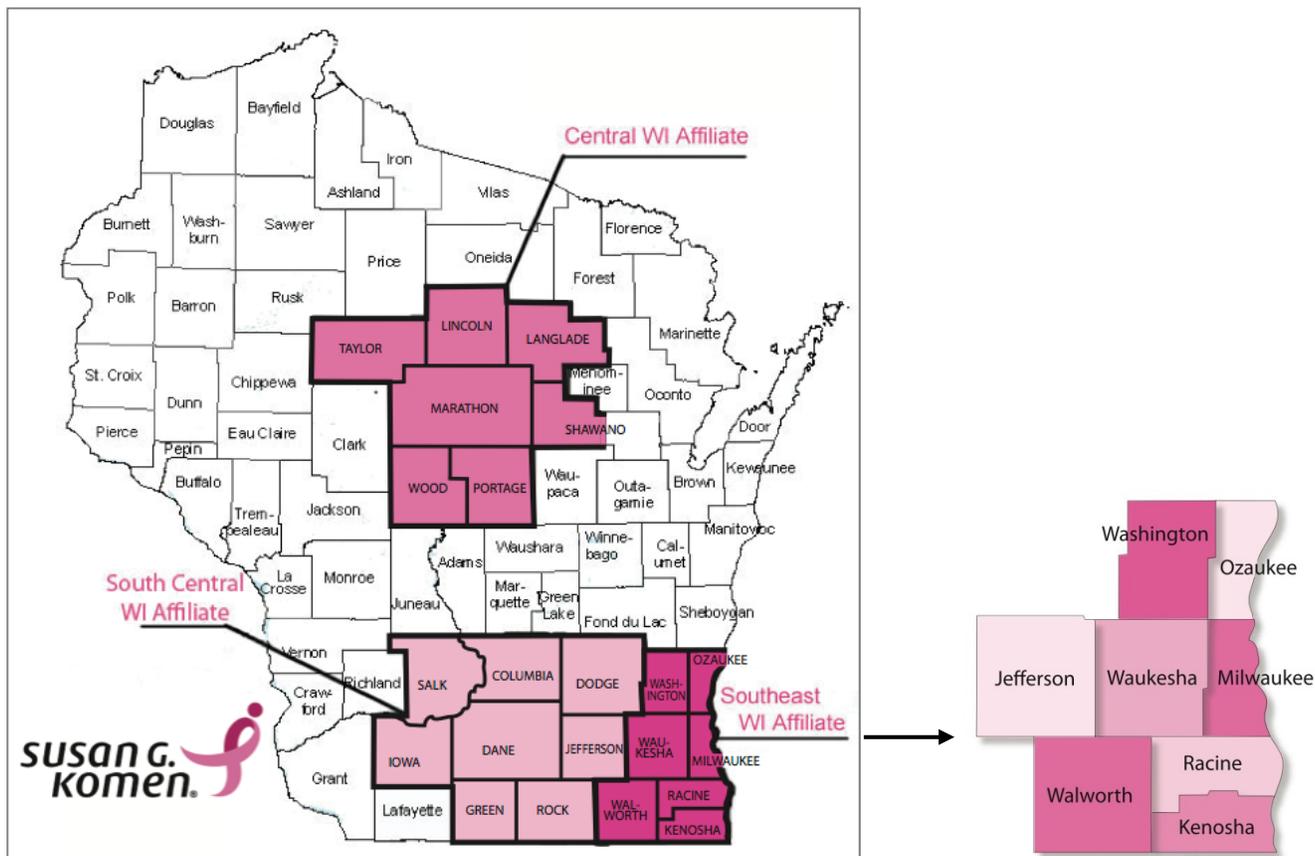


Figure 1.3. Susan G. Komen Wisconsin service area

Table 1.1. Service area demographics and socioeconomic data

County	Population	% Below Poverty Level	Median Household Income	Racial Breakdown			
				White	African-American	Hispanic/Latino	Other
Kenosha	167,757	14%	\$54,930	77.7%	7.2%	12.3%	2.8
Milwaukee	956,023	21.6%	\$43,193	65.5%	24.6%	8.8%	1.1%
Ozaukee	87,054	5.2%	\$75,457	92.7%	1.5%	2.6%	3.2%
Racine	195,041	13.3%	\$54,090	73.5%	11.6%	12.3%	2.6%
Walworth	102,945	13.4%	\$54,020	85.9%	1.2%	10.9%	2.0%
Washington	132,739	6.3%	\$66,159	93.7%	1.0%	2.9%	2.4%
Waukesha	393,843	5.4%	\$75,850	93.9%	1.4%	4.5%	.2%

Source: State and County Quick Facts, United States Census Bureau  
Data Retrieved from <http://quickfacts.census.gov/qfd/states/55000.html>

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

To meet its promise to save lives and end breast cancer forever, Komen SEWI relies on information obtained through the Community Profile process to establish priorities and guide its work in Southeast Wisconsin. The purpose of the Community Profile is to further illuminate areas of need for breast health promotion and breast cancer education, screening, treatment and support. As of 2014, the Komen SEWI Affiliate has granted over \$8.3 million to community based breast health organizations since its inception in 1999. This report intends to describe the varied breast health needs in Southeast Wisconsin as well as potential areas in which Komen SEWI's programs and funding might help advance the network's promise of ending breast cancer. Potential opportunities and areas of interest have been drawn from analyses of breast cancer statistics, policies and programs in the region that may impact breast health and exploratory, primary data collection among providers and breast cancer survivors in the region. After synthesizing data from various sources, this report presents data-driven priority areas from which the Affiliate intends to develop funding decisions for the years 2015-2019. This report provides abridged analyses of the data collected and reviewed by the Affiliate. In addition, this report will assist Komen SEWI in the following ways:

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

Komen SEWI will share this report with the community-at-large via the Komen Southeast Wisconsin website. It will also be shared with legislature, health care systems, other breast cancer organizations, and community organizations that interface with vulnerable and potentially underserved residents of Southeast Wisconsin.

# Quantitative Data: Measuring Breast Cancer Impact in Local Communities

## Quantitative Data Report

### Introduction

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

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

The following is a summary of Komen Southeast Wisconsin's Quantitative Data Report. For a full report please contact the Affiliate.

### Breast Cancer Statistics

#### Incidence rates

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

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

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

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

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

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

### **Death rates**

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

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

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

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

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

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

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

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

Population Group	Incidence Rates and Trends				Death Rates and Trends			Late-stage Rates and Trends		
	Female Population (Annual Average)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of Deaths (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)
US	154,540,194	198,602	122.1	-0.2%	40,736	22.6	-1.9%	70,218	43.7	-1.2%
HP2020	-	-	-	-	-	20.6*	-	-	41.0*	-
Wisconsin	2,841,001	3,893	116.9	-1.3%	745	21.3	-2.5%	NA	NA	NA
Komen Southeast Wisconsin Service Area	1,064,821	NA	NA	NA	281	22.4	NA	NA	NA	NA
White	865,474	NA	NA	NA	245	21.8	NA	NA	NA	NA
Black/African-American	163,605	NA	NA	NA	34	29.7	NA	NA	NA	NA
American Indian/Alaska Native (AIAN)	7,808	NA	NA	NA	SN	SN	SN	NA	NA	NA
Asian Pacific Islander (API)	27,934	NA	NA	NA	SN	SN	SN	NA	NA	NA
Non-Hispanic/ Latina	972,910	NA	NA	NA	277	22.7	NA	NA	NA	NA
Hispanic/ Latina	91,911	NA	NA	NA	5	10.3	NA	NA	NA	NA
Jefferson County – WI**	41,582	57	121.9	NA	9	19.3	-3.0%	NA	NA	NA
Kenosha County - WI	82,962	106	121.6	NA	18	19.5	-3.6%	NA	NA	NA
Milwaukee County - WI	485,207	656	130.2	NA	123	22.6	-2.9%	NA	NA	NA
Ozaukee County - WI	43,804	87	156.2	NA	14	23.4	-2.7%	NA	NA	NA
Racine County - WI	98,277	146	128.7	NA	28	24.4	-2.2%	NA	NA	NA
Walworth County - WI	50,756	73	126.1	NA	13	21.4	-3.7%	NA	NA	NA
Washington County - WI	65,532	108	138.4	NA	19	24.5	-0.2%	NA	NA	NA
Waukesha County - WI	196,701	333	138.6	NA	56	22.0	-2.9%	NA	NA	NA

\*Target as of the writing of this report.

\*\*Jefferson County will no longer be a part of the Komen Southeast Wisconsin Service Area effective April 1, 2014.

NA – data not available.

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

Data are for years 2006-2010.

Rates are in cases or deaths per 100,000.

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

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

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

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

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

Breast cancer incidence data were not available for the Komen Southeast Wisconsin service area. All seven of the Affiliate service area counties had incidence rates higher than the State of Wisconsin.

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

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

Overall, the breast cancer death rate in the Komen Southeast Wisconsin service area was similar to that observed in the US as a whole and the death rate trend was not available for comparison with the US as a whole. The death rate of the Affiliate service area was not significantly different than that observed for the State of Wisconsin.

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

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

- Washington County

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

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

Breast cancer late-stage data were not available for the Komen Southeast Wisconsin service area.

### **Mammography Screening**

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

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

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

\*As of October 2015

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

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

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

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

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

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

one. It is very unlikely that the true rate is less than the lower value or more than the higher value.

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

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

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

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
US	174,796	133,399	77.5%	77.2%-77.7%
Wisconsin	1,907	1,523	81.6%	79.3%-83.6%
Komen Southeast Wisconsin Service Area	532	442	82.9%	78.6%-86.4%
White	373	302	82.3%	77.4%-86.4%
Black/African-American	144	130	92.8%	83.5%-97.0%
AIAN	SN	SN	SN	SN
API	SN	SN	SN	SN
Hispanic/ Latina	10	6	73.4%	31.7%-94.3%
Non-Hispanic/ Latina	519	434	83.2%	79.0%-86.7%
Jefferson County – WI*	10	9	89.2%	52.0%-98.4%
Kenosha County - WI	14	12	90.2%	58.0%-98.4%
Milwaukee County - WI	335	280	81.7%	75.4%-86.6%
Ozaukee County - WI	28	20	77.3%	54.9%-90.4%
Racine County - WI	48	39	78.3%	62.2%-88.8%
Walworth County - WI	27	21	77.4%	57.3%-89.7%
Washington County - WI	33	29	92.5%	75.8%-98.0%
Waukesha County - WI	37	32	84.9%	70.4%-93.0%

\*Jefferson County will no longer be a part of the Komen Southeast Wisconsin Service Area effective April 1, 2014.

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

Data are for 2012.

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

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

The breast cancer screening proportion in the Komen Southeast Wisconsin service area was significantly higher than that observed in the US as a whole. The screening proportion of the Affiliate service area was not significantly different than the State of Wisconsin.

For the United States, breast cancer screening proportions among Blacks/African-Americans are similar to those among Whites overall. APIs have somewhat lower screening proportions

than Whites and Blacks/African-Americans. Although data are limited, screening proportions among AIANs are similar to those among Whites. Screening proportions among Hispanics/Latinas are similar to those among Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the screening proportion was not significantly different among Blacks/African-Americans than Whites. There were not enough data available within the Affiliate service area to report on APIs and AIANs so comparisons cannot be made for these racial groups. The screening proportion among Hispanics/Latinas was not significantly different than among Non-Hispanics/Latinas.

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

### **Population Characteristics**

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

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

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

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

**Table 2.4. Population characteristics – demographics**

Population Group	White	Black /African-American	AIAN	API	Non-Hispanic /Latina	Hispanic /Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
US	78.8 %	14.1 %	1.4 %	5.8 %	83.8 %	16.2 %	48.3 %	34.5 %	14.8 %
Wisconsin	89.1 %	7.1 %	1.2 %	2.6 %	94.2 %	5.8 %	49.8 %	36.0 %	15.5 %
Komen Southeast Wisconsin Service Area	80.8 %	15.6 %	0.8 %	2.8 %	90.5 %	9.5 %	48.3 %	34.4 %	14.4 %
Jefferson County – WI*	97.5 %	1.1 %	0.5 %	0.9 %	93.5 %	6.5 %	49.2 %	35.2 %	14.8 %
Kenosha County - WI	89.4 %	7.8 %	0.8 %	1.9 %	88.3 %	11.7 %	47.0 %	31.9 %	12.9 %
Milwaukee County - WI	65.9 %	29.2 %	1.1 %	3.8 %	87.2 %	12.8 %	43.7 %	31.3 %	13.3 %
Ozaukee County - WI	96.0 %	1.6 %	0.3 %	2.2 %	97.7 %	2.3 %	56.3 %	41.1 %	17.3 %
Racine County - WI	85.8 %	12.1 %	0.6 %	1.4 %	88.7 %	11.3 %	50.8 %	36.2 %	15.1 %
Walworth County - WI	97.0 %	1.4 %	0.5 %	1.1 %	90.2 %	9.8 %	49.2 %	35.4 %	15.0 %
Washington County - WI	97.0 %	1.2 %	0.4 %	1.4 %	97.5 %	2.5 %	53.4 %	37.1 %	15.5 %
Waukesha County - WI	95.1 %	1.5 %	0.4 %	3.1 %	95.9 %	4.1 %	55.0 %	39.3 %	16.4 %

\*Jefferson County will no longer be a part of the Komen Southeast Wisconsin Service Area effective April 1, 2014.

Data are for 2011.

Data are in the percentage of women in the population.

Source: US Census Bureau – Population Estimates

**Table 2.5. Population characteristics – socioeconomics**

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistic-ally Isolated	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age: 40-64)
US	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
Wisconsin	10.2 %	12.0 %	27.4 %	7.1 %	4.6 %	1.6 %	29.8 %	13.9 %	9.4 %
Komen Southeast Wisconsin Service Area	11.1 %	13.3 %	27.3 %	8.2 %	6.5 %	2.4 %	9.9 %	16.7 %	9.7 %
Jefferson County – WI*	9.9 %	9.4 %	25.4 %	7.1 %	3.9 %	1.2 %	34.1 %	0.0 %	8.8 %
Kenosha County - WI	11.7 %	11.6 %	28.6 %	9.4 %	6.4 %	1.7 %	10.7 %	15.3 %	10.0 %
Milwaukee County - WI	14.8 %	19.9 %	37.5 %	10.0 %	8.7 %	3.9 %	0.2 %	32.4 %	12.8 %
Ozaukee County - WI	4.2 %	4.7 %	13.7 %	5.5 %	4.7 %	0.9 %	24.9 %	0.0 %	5.5 %
Racine County - WI	12.3 %	11.7 %	27.1 %	8.7 %	4.8 %	1.7 %	12.3 %	10.1 %	9.5 %
Walworth County - WI	10.8 %	11.8 %	26.1 %	7.0 %	6.7 %	1.9 %	34.2 %	0.0 %	10.2 %
Washington County - WI	7.7 %	5.3 %	17.8 %	5.8 %	2.7 %	0.4 %	30.8 %	0.0 %	6.3 %
Waukesha County - WI	4.8 %	4.7 %	14.0 %	5.3 %	4.4 %	0.8 %	9.9 %	0.0 %	5.6 %

\*Jefferson County will no longer be a part of the Komen Southeast Wisconsin Service Area effective April 1, 2014.

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

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

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

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

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

### ***Population characteristics summary***

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

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

- Milwaukee County

The following county has a substantially lower income level than that of the Affiliate service area as a whole:

- Milwaukee County

### **Priority Areas**

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

Healthy People 2020 (HP2020) is a major federal government initiative that provides specific health objectives for communities and for the country as a whole. Many national health organizations use HP2020 targets to monitor progress in reducing the burden of disease and improve the health of the nation. Likewise, Komen believes it is important to refer to HP2020 to see how areas across the country are progressing towards reducing the burden of breast cancer.

HP2020 has several cancer-related objectives, including:

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

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

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

These data are used to estimate how many years it will take for each county to meet the HP2020 objectives. Because the target date for meeting the objective is 2020, and 2008 (the

middle of the 2006-2010 period) was used as a starting point, a county has 12 years to meet the target.

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

**Identification of priority areas**

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

Late-stage incidence reflects both the overall breast cancer incidence rate in the population and the mammography screening coverage. The breast cancer death rate reflects the access to care and the quality of care in the health care delivery area, as well as cancer stage at diagnosis.

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

Counties are classified as follows (Table 2.6):

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

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

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

If the time to achieve a target cannot be calculated for one of the HP2020 indicators, then the county is classified based on the other indicator. If both indicators are missing, then the county

is not classified. This doesn't mean that the county may not have high needs; it only means that sufficient data are not available to classify the county.

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

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

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

Trends can change for a number of reasons, including:

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

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

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

County	Priority	Predicted Time to Achieve Death Rate Target	Predicted Time to Achieve Late-stage Incidence Target	Key Population Characteristics
Washington County - WI	Highest	13 years or longer	NA	Rural
Racine County - WI	Medium High	8 years	NA	
Milwaukee County - WI	Medium Low	4 years	NA	%Black/African-American, poverty, medically underserved
Ozaukee County - WI	Medium Low	5 years	NA	Rural
Walworth County - WI	Medium Low	2 years	NA	Rural
Waukesha County - WI	Medium Low	3 years	NA	
Jefferson County – WI*	Lowest	Currently meets target	NA	Rural
Kenosha County - WI	Lowest	Currently meets target	NA	

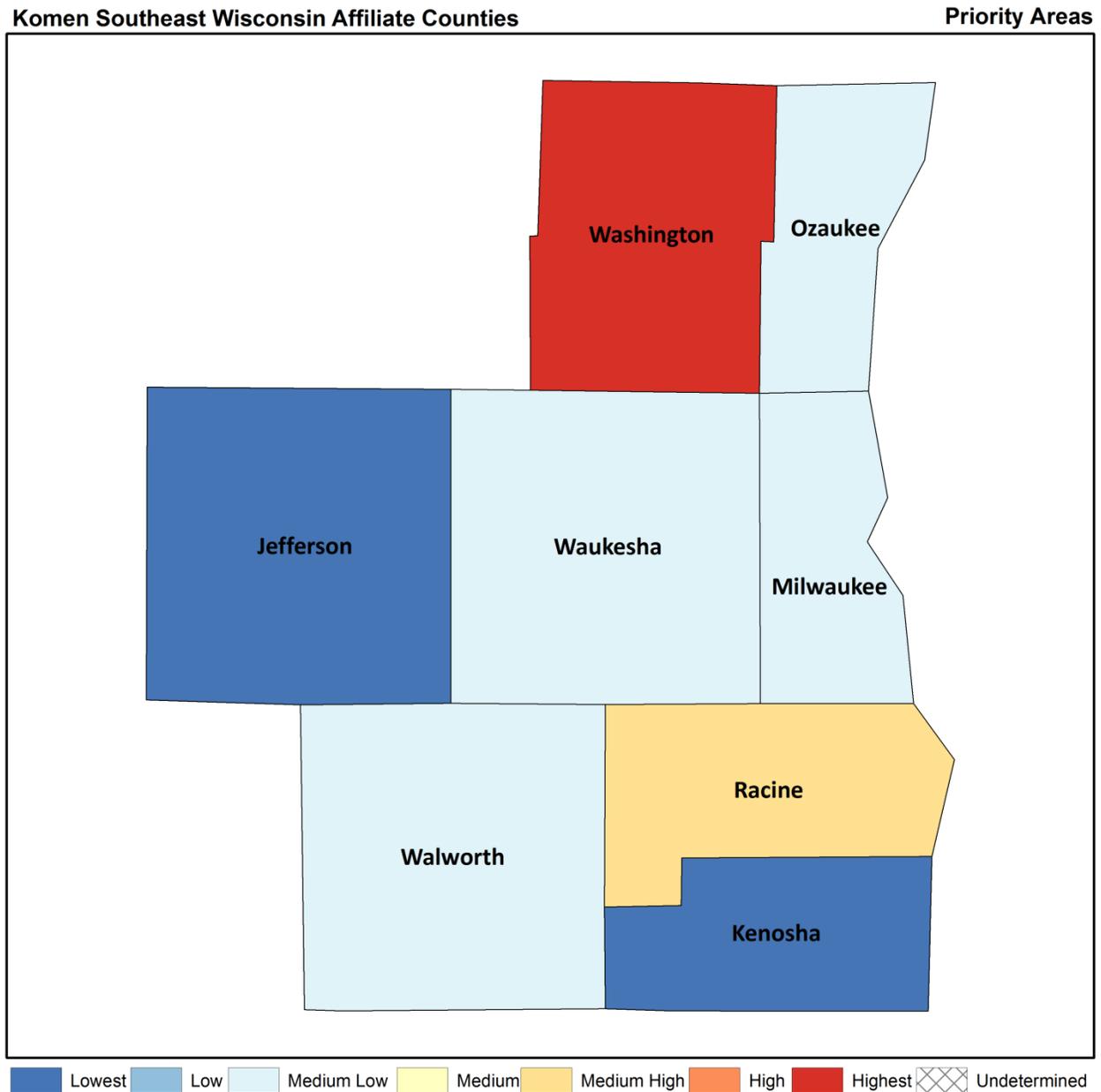
\*Jefferson County will no longer be a part of the Komen Southeast Wisconsin Service Area effective April 1, 2014.

NA – data not available.

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

### Map of Intervention Priority Areas

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



**Figure 2.1.** Intervention priorities

### Data Limitations

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

- The most recent data available were used but, for cancer incidence and deaths, these data are still several years behind.
- For some areas, data might not be available or might be of varying quality.
- Areas with small populations might not have enough breast cancer cases or breast cancer deaths each year to support the generation of reliable statistics.

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

## **Quantitative Data Report Conclusions**

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

One county in the Komen Southeast Wisconsin service area is in the highest priority category. Washington County is not likely to meet the death rate HP2020 target.

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

One county in the Komen Southeast Wisconsin service area is in the medium high priority category. Racine County is expected to take eight years to reach the death rate HP2020 target.

## **Additional Quantitative Data Exploration**

The data presented in Table 2.8 is a compilation of Vulnerable Footprint census tract information collected from the Community Commons website <http://assessment.communitycommons.org>. Community commons is an interactive mapping, networking and learning platform that utilizes available public data to create accessible maps, charts, reports, etc. Sources of public data include the US Census Bureau, the Center for Disease Control and the National Center for Education Statistics. The vulnerable footprint data highlights populations that overlap for high poverty levels and low educational attainment demographics.

The addition of Table 2.8 *Census Tracts – Southern Rural Region* drills deeper into the existing QDR to highlight pockets of high need within Kenosha and Walworth. The data reveals that while these counties appear to be low-need overall, they each have very specific population clusters that bear a higher burden of socioeconomic disadvantage. For instance, 22.0 percent of the population in Kenosha carries 49.0 percent of Kenosha County's poverty. Another example can be seen in Walworth County. While the overall county poverty level is 11.8 percent, there is one census tract of 3,505 people in which 64.8 percent live at or below the Federal Poverty Level.

This additional data compels further investigation into the breast cancer burden within these two counties that make up the Southern Rural Region Target Area. The data are limited in that it does not break down the makeup of these high need census areas beyond poverty level and education level. Further information will need to be gathered to flesh this out during Qualitative

Data collection. Combining new data from Table 2.8 with initial QDR data on rural populations (Table 2.5) and low mammography rates in Walworth (Table 2.3) will be key in guiding this investigation within the Affiliate's Southern Rural Region.

**Table 2.8.** Census tracts-Southern Rural Region

TARGET AREA	High Risk census tract #	Total Population*	% of population at or below Federal Poverty Level	# of % points above County Average	# of % points above SEWI Average	# individuals living at or below FPL	% of Population with less than a H.S. Education	# of % points above County Average	# of % points above SEWI Average	# individuals with less than a HS Education
Entire Komen SEWI Service Area		1,023,239	13.3				11.1			
Komen SEWI Southern Region										
Kenosha		163,176	11.6		-1.7	18928	11.7		0.6	19092
	3	4,851	22.34	10.74	9.04	1084	13.61	1.91	2.51	660
Kenosha County Census Tracts by Tract Number	7	5,615	22.56	10.96	9.26	1267	17.05	5.35	5.95	957
	8	3,239	22.17	10.57	8.87	718	26.83	15.13	15.73	869
	9	3,542	29.12	17.52	15.82	1031	23.78	12.08	12.68	842
	10	2,354	34.12	22.52	20.82	803	16.31	4.61	5.21	384
	11	3,472	35.32	23.72	22.02	1226	28.51	16.81	17.41	990
	13	3,918	27.67	16.07	14.37	1084	13.42	1.72	2.32	526
	16	3,184	28.6	17	15.3	911	29.68	17.98	18.58	945
	21	4,952	22.24	10.64	8.94	1101	12.34	0.64	1.24	611
Totals for Kenosha		35,127				9226				6785
		22% of the population				49% of the county's poverty				36%
										of popul.. < HS educ.
Walworth		101,370	11.8		-1.5	11962	10.8		-0.3	10948
	4	4,162	23.35	11.55	10.05	972	9.43	-1.37	-1.67	392
Walworth County Census Tracts by Tract Number	5.01	3,505	64.78	52.98	51.48	2271	0	-10.8	-11.1	0
	5.02	3,633	35.92	24.12	22.62	1305	13.18	2.38	2.08	479
	7.01	3,981	17.38	5.58	4.08	692	17.52	6.72	6.42	697
	7.02	4,720	18.77	6.97	5.47	886	13.43	2.63	2.33	634
	16.02	6,129	21.21	9.41	7.91	1300	13.6	2.8	2.5	834
Totals for Walworth		26,130				7425				3036
		26% of the population				62% of the county's poverty				28%
										of popul.. < HS educ.

\* SEWI population is female only (Komen Table 2.1), census data are for entire population

Source of total county population 2006-2010: WI Department of Health Services, <http://www.dhs.wisconsin.gov/population>

Source of Census Tract Data: Community Commons, Community Health Needs Assessment, <http://www.assessment.communitycommons.org/footprint>.

Table 2.9 entitled County Breast Cancer Incidence by Stage has been included to help clarify the nature of the breast cancer burden in Washington County, and most likely Ozaukee County as well. As stated earlier, breast cancer late-stage data were not available in the QDR for Komen Southeast Wisconsin. An online search of Wisconsin's Department of Health Informatics, Wisconsin Interactive Statistics on Health (WISH) provided new data compiled from local health system sources that adds data to the QDR regarding the breakdown of the number of Wisconsin breast cancer cases by county from 2007 to 2011 into stages of diagnosis.

These data are limited in that the reporting of this data includes “In Situ” staging which is not consistently included in the table’s State data or within other breast cancer data sources from the same time period (2007-2011). Also, while providing data on the stage of breast cancer diagnosis, Table 2.9 does not provide breast cancer late-stage incidence trends that would add clarity to data interpretation. Additionally, the data are suppressed in some categories due to small numbers.

Despite these limitations, Table 2.9 is a potentially valuable addition to the data provided in the QDR, especially for Washington County. The QDR identified Washington County as the Affiliate’s highest need community. Its high age-adjusted breast cancer incidence (138.4) and death rates (24.5) are Komen Southeast Wisconsin service area’s third and first highest respectively. Further analysis of these high need indicators are complicated by a lack of other supporting high need demographics. Table 2.5 identifies Washington County as a relatively affluent, well educated, employed, and well-insured area with little racial and ethnic diversity. The addition of Table 2.9 provides a glimpse into the possibility of a high level of late-stage diagnosis. While other counties of similar size in the Southeast Service Area had late-stage numbers that were too small to include in the data tables, Washington County tallied 26 late-stage distant/systemic breast cancer cases and another 138 regional stage diagnoses. Considering both the data from the QDR related to the rural challenges of Washington County along with the additional late-stage incidence data in Table 2.9 will provide a strong starting point for further investigation. It will also provide guidance for the development of follow up questions on breast cancer education, awareness and screening percentages. Because of geographic and demographic similarities, Washington County has been paired with Ozaukee County to make up the Northern Rural Region Target Community. The entire North Rural Region will likely benefit from the additional data shown in Table 2.9 as a variable to consider in the Affiliate’s further assessment of the region’s needs during the Qualitative Data Gathering and Analysis process of the Community Profile development.

**Table 2.9. County breast cancer incidence by stage**

Komen Southeast Wisconsin Community Profile County Breast Cancer Incidence by Stage												
			Stage at Diagnosis									
Service County	Female Population	# BC Cases 2007-2011	In Situ	%	Localized	%	Regional	%	Distant/ Systemic	%	Unknown or Unstaged	%
WISCONSIN	2,841,001	20,664	x		13,108	63.4	6107	29.6	1088	5.3	361	1.7
Kenosha	82,962	691	148	21.4	340	49.2	159	23.0	36	5.2	8	1.2
Milwaukee	485,207	4,132	856	20.7	2026	49.0	1009	24.4	209	5.1	32	0.8
Ozaukee	43,804	566	123	21.7	298	52.7	120	21.2	x		x	
Racine	98,277	933	16	18.1	476	51.0	239	25.6	x		x	
Walworth	50,756	459	95	20.7	249	54.2	93	20.3	x		x	
Washington	65,532	696	152	21.8	370	53.2	138	19.8	26	3.7	10	1.4
Waukesha	196,701	2,141	437	20.4	1128	52.7	500	23.4	68	3.2	8	0.4
<b>SEWI Total for all</b>	<b>1,023,239</b>	<b>9,618</b>	<b>1980</b>	<b>20.6</b>	<b>4887</b>	<b>50.8</b>	<b>2258</b>	<b>23.5</b>	<b>423</b>	<b>4.4</b>	<b>70</b>	<b>0.7</b>
x: data suppressed due to small numbers									<b>total includes</b>		<b>total includes</b>	

**Source:** WISH Data Query System (Wisconsin Interactive Statistics on Health), Office of Health Informatics, Division of Public Health, Wisconsin Department of Health Services. Data retrieved from <http://dhs.wisconsin.gov/wish/>. Cancer Module, accessed 5/11/2014. Table contains 2007 -2011 data

**Selection of Target Communities**

**Overview**

In order to best utilize the Affiliate’s resources, Susan G. Komen Southeast Wisconsin has thoughtfully considered the quantitative data collected in order to determine where the greatest breast cancer burden exists within the service area. The purpose of the Qualitative Data Section of the Community Profile is to identify the communities that are most likely to experience:

- Gaps in breast cancer and breast health services available
- Individual and/or systemic barriers to breast health services
- Elevated risk of breast cancer incidence
- Elevated risk of late-stage breast cancer diagnosis
- Greatest risk of breast cancer deaths

Target communities are those communities which have cumulative key indicators showing an increased chance of vulnerability to some or all of these risks.

When selecting target communities, the Affiliate considered the following information:

### **Healthy People 2020**

Healthy People 2020 is a major federal government initiative that provides specific health objectives for communities and the country as a whole. HP2020 sets goals around reducing women's death rate from breast cancer and reducing the number of breast cancers found at a late-stage. The seven counties within Komen Southeast Wisconsin's service area were analyzed to determine their progress in meeting these goals. Through this review, areas of priority scaled from lowest to highest need were identified based on the time needed to meet Healthy People 2020 targets for breast cancer.

### **Key Breast Cancer Indicators**

- Incidence rates and trends
- Death rates and trends
- Late-stage rates and trends
- Below average screening percentages

### **Key Demographic Indicators**

- Residents living below or slightly above the poverty level
- Residents living without health insurance
- Unemployment percentages
- Residents who are linguistically isolated and/or foreign born

### **Race**

#### ***Blacks/African-Americans***

While White women are at slightly higher risk of developing breast cancer, Black/African-American women are at higher risk of both late-stage breast cancer diagnosis and breast cancer deaths. According to the American Cancer Society's 2013 report on Surveillance and Health Service Research, breast cancer is the leading cancer type comprising 33 percent of all the new cancer cases in Black/African-American Women. It is also the second highest cause of all female Black/African-American cancer deaths at 19.0 percent. (American Cancer Society (ACS), 2013)

Table 2.10 shows the higher probability of cancer death among Black/African-American women despite the fact that they are less likely to develop the disease in comparison to White women.

**Table 2.10.** Blacks/African-Americans risk of developing or dying from breast cancer

Lifetime Probability (%) of Developing or Dying from Invasive Breast Cancer By Race, US, 2007-2009		
Probability of:	Developing Invasive BC	Dying from Invasive BC
<b>Black/African-American Women</b>	10.8 (1 in 9)	3.3 (1 in 31)
<b>White Women</b>	12.7 (1 in 8)	2.7 (1 in 37)

Source: American Cancer Society. Cancer Facts & Figures for African-Americans 2013-2014. Atlanta: American Cancer Society, 2013.

There is also a notable difference of death rate between Black/African-American women and White women. The American Cancer Society states that Wisconsin's age adjusted breast cancer death rate for Black/African-American women is 27.4 per 100,000 women.

(ACS, 2013)

As illustrated by Table 2.11, Black/African-American women have an overall five year survival rate (78.0 percent) that is lower than the five year survival rate of White women (90.0 percent)

When these data are further divided by stage of breast cancer diagnosis, the differences in death rates between Black/African-American and White women become even more evident. The disparity increases as breast cancer is diagnosed at later stages. With breast cancer diagnosed as occurring locally or regionally, White women's five year survival rates are 6.5 percent and 16.4 percent, respectively, higher than Black/African-American women. When a woman is diagnosed with breast cancer at a distant stages, the five year survival rates for White women is an alarming 66.7 percent higher than the five year survival rate for Black/African-American women diagnosed at the same stage of breast cancer.

**Table 2.11.** Five-year relative breast cancer survival rate (%) by race and stage\*

	Localized	Regional	Distant	All Stages
<b>Black/African-American Women</b>	93.0%	73.0%	15.0%	78.0%
<b>White Women</b>	99.0%	85.0%	25.0%	90.0%

\*Survival rates are based on patients diagnosed between 2002 and 2008 and followed through 2009.

**Source:** Howlader N, Noone AM, Krapcho M, et al., eds. *SEER Cancer Statistics Review, 1975-2009 (Vintage 2009 Populations)*. Bethesda, MD: National Cancer Institute, [http://seer.cancer.gov/csr/1975\\_2009\\_pops09/](http://seer.cancer.gov/csr/1975_2009_pops09/), based on the November 2011 SEER data submission, posted to the SEER website, April 2012; 2012.**Source:** Howlader et al, 2012.6

Making this data especially poignant is the fact that Black/African-American Women are also more likely to be diagnosed with later stages of breast cancer than White Women. Table 2.12 illustrates this disparity. While White women are 19.6 percent more likely to be diagnosed with localized breast cancer, Black/African-American women are nearly 18.8 percent more likely than White women to be diagnosed at a regional stage and 60.0 percent more likely to be diagnosed at a distant stage of breast cancer.

**Table 2.12.** Stage distributions(%) of breast cancer diagnosis in Black/African-American and White women, 2002-2008

	Localized	Regional	Distant	Unstaged
<b>Black/African-American Women</b>	51.0%	38.0%	8.0%	3.0%
<b>White Women</b>	61.0%	32.0%	5.0%	2.0%

Percentages may not total 100% due to rounding

**Source:** Howlader N, Noone AM, Krapcho M, et al., eds. *SEER Cancer Statistics Review, 1975-2009 (Vintage 2009 Populations)*. Bethesda, MD: National Cancer Institute, [http://seer.cancer.gov/csr/1975\\_2009\\_pops09/](http://seer.cancer.gov/csr/1975_2009_pops09/), based on the November 2011 SEER data submission, posted to the SEER website, April 2012; 2012.

Adding to this burden, premenopausal Black/African-American women are also at higher risk for triple-negative (ER negative, PR negative, and human epidermal growth factor receptor [HER] 2 negative) and basal-like breast cancers (Carey, Perou & Livasy, 2006). These are both very aggressive subtypes of breast cancer that are associated with higher death rates (Carey et al., 2006).

It is essential to consider all of this data that alerts the Affiliate to the elevated breast cancer risk of Black/African-American Women while completing the assessment of breast cancer need and burden in Southeast Wisconsin. The Affiliate service area has an overall Black/African-American population of 15.6 percent (Table 2.4). Both Racine and Kenosha Counties approach this population rate (12.1 and 7.8 percent, respectively) while Milwaukee County nearly doubles it (29.2 percent). During the Qualitative Data Collection, careful consideration should be given to assessing the impact of these race specific variables within each target community.

### ***American Indian and Alaska Natives (AIAN)***

The American Indian and Alaska Native population refers to anyone with original descendants from North, Central, or South America who maintains tribal affiliation or community attachment with that heritage. As shown in Table 2.1, there are 7,808 AIAN women living in the Affiliate service area.

Studies indicate that the American Indian and Alaska Native populations have a high prevalence of poor health and limited health care options (US Department of Health and Human Services (USHHS), April 2014). While cancer deaths for American Indian females is higher than the State of Wisconsin cancer death rate, it is especially concerning that AIAN individuals have cancer related hospitalizations at a lower rate than the general state population (Wisconsin Department of Health Services (WIDHS), 2014). Higher than average rates of binge drinking, obesity, and lack of physical activity further complicate the health risks of the AIAN population (WIDHS, 2014).

The American Indian and Alaska Native population trend of poor health indicators and relatively low access to health care compels further investigation into the overall breast health practices of the AIAN population. AIAN mammography screening percentages would be of particular benefit to the Affiliate needs assessment. The QDR did not provide

data for mammography screening due to small numbers. The Affiliate will benefit from investigating this population's screening behaviors during qualitative data collection. More complete screening behavior information will prove especially helpful in the assessment of AIAN breast cancer burden in Milwaukee, Ozaukee, and Waukesha Counties which are home to the largest AIAN populations in the Affiliate. In addition, thorough qualitative data investigation and health system analysis of access to affordable care, breast health information, and breast cancer services for AIAN women in the Affiliate's target communities is also essential to assessing the full impact of breast cancer on this vulnerable population.

### ***Asian Pacific Islanders (API)***

The Asian Pacific Islander population in Southeast Wisconsin (2.8 percent) is slightly higher than the population rate in Wisconsin (2.6 percent) (Table 2.4). There are 27,934 women of Asian descent living in the Komen Southeast Wisconsin service area (Table 2.1). Milwaukee County has the Affiliate's highest percentage of API residents (3.8 percent). Local API women have ancestral roots in a wide range of places including the Far East, Southeast Asia, or the Indian Subcontinent including Cambodia, China, India, Japan Korea Malaysia, Pakistan, the Philippine Islands, Laos, Thailand and Vietnam (WIDHS, 2014).

The Asian population is extremely heterogeneous. Asian women are varied in culture, values, languages, religions, and traditions. This variety is important to note as it complicates the ability to provide culturally appropriate access to breast health information and breast cancer services. Linguistic challenges are an issue for Asian women and the Affiliate should strive to understand the variety within that challenge. Across the country, the percentage of adults that are not fluent in English varies by sub-group: 23.0 percent of Asian Indians, 24.0 percent of Filipinos, 50.0 percent of Chinese, and 62.0 of Vietnamese do not speak English in their home (WIDHS, 2014).

In general, the Wisconsin Asian population has low socioeconomic risk. Eighty-six percent have a high school diploma and 50.0 percent hold a bachelor degree compared to the national average of 28.0 percent (WIDHS, 2014). Wisconsin Asian households have the highest median income of all races (US Census, 2010) and are 93.0 percent likely to have insurance coverage (USHHS, 2014). However, mammography screening percentages are suppressed in the QDR due to low numbers and warrant further investigation to gain a clearer picture of breast service awareness and access by API women. Additionally, the high probability of linguistic isolation and cultural/religious barrier to breast health information are major factors that need to be uncovered through further qualitative investigation. The Affiliate is obligated to provide more clarity regarding the impact these barriers have on the availability of and/or access to accurate breast health information, prevalence of mammography screening, and access of breast cancer services for Asian women of all cultures in the target communities.

## **Ethnicity**

### ***Hispanic/Latino***

Hispanic/Latinos are the second largest and fastest growing minority racial and ethnic population in Wisconsin (WIDHS, 2014). In Southeast Wisconsin, the Hispanic/Latina population is 9.5 percent, well above the 5.8 percent of Hispanic/Latina residents in Wisconsin as a whole (Table 2.4). Hispanic/Latino individuals live in all of the seven Southeast Wisconsin counties. In total 91,911 Hispanic/Latina women reside in Komen Southeast Wisconsin's service area (Table 2.1). While Milwaukee County is well above the State and Affiliate percentages with a 12.8 percent Hispanic/Latina population, even the two Affiliate counties with the lowest Hispanic/Latina population, Ozaukee and Washington, still have respectively 2.3 and 2.5 percent Hispanic/Latina residents.

Several factors contribute to increased health risks for the Hispanic/Latino population. Nationally, Hispanic/Latinos have the highest uninsured percentages of any racial or ethnic group (US Census, 2011). In 2010, 30.7 percent of the Hispanic/Latino population was not covered by health insurance, as compared to 11.7 percent of the non-Hispanic White population (US Census, 2011).

In Wisconsin, Hispanic/Latino individuals are consistently less insured than the general population. In a Wisconsin Family Health Survey, Hispanic/Latino nearly a quarter of the respondents (23.0 percent) reported being uninsured, a rate nearly four times higher than the percentage uninsured in the total Wisconsin Population (WIDHS, 2014). Many Hispanic/Latino women are also at increased health risk due to language/ cultural barriers and a lack of access to preventive care (US Census, 2011).

The QDR shows that Hispanic/Latina women in Southeast Wisconsin have the lowest percentage of Mammography screening (Table 2.3) of all racial and ethnic groups. Their screening percentage of 73.4 percent is not only lower than the State and National levels, it also has a confidence interval of over 60 points that indicates a realistic possibility that the actual percentage of women having mammography screenings could be much lower.

Komen Southeast Wisconsin is charged with uncovering the barriers affecting breast health for the large population of Hispanic/Latina women in its service area. Focusing on issues including linguistic isolation, cultural norms affecting access to breast health information and breast cancer screening, immigration status, insurance coverage will assist the Affiliate in fleshing out the service needs and barriers to those service that are disproportionately affecting Hispanic/Latina women. This assessment is essential in every Southeast Wisconsin target community.

## **Population Concentration**

While Komen Southeast Wisconsin only serves seven of the 72 counties in the state, the Affiliate's reach is substantial when considering that 37.4 percent of the women living in the State of Wisconsin reside in the Affiliate's Southeast Wisconsin service area (Table 2.1). Equally notable is the fact that four of the state's most populous cities are located within the Affiliate's service boundary (Milwaukee, Kenosha, Racine, and Waukesha) (Table 2.13).

**Table 2.13.** Wisconsin’s most populated cities

Rank	Municipality	Population (2010 Census)	County
1	Milwaukee	594,833	Milwaukee
2	Madison	233,209	Dane
3	Green Bay	104,057	Brown
4	Kenosha	99,218	Kenosha
5	Racine	78,860	Racine
6	Appleton	72,623	Outagamie
7	Waukesha	70,718	Waukesha

Source: American Fact Finder, United States Census Bureau, US Department of commerce.  
Data Retrieved from <http://factfinder2.census.gov/faces/tableservices>

## Lifestyle

The following are all lifestyle variables that contribute to an individual’s level of risk for breast cancer and/or affect their access to breast health information and services. As such, each of these factors warrants exploration as part of the qualitative data collection process in all of the Affiliates Target Populations.

### ***Lesbian, Gay, Bisexual, Transgender (LGBT) Community***

While accurate LGBT population data are incomplete because main sources of data about people living in the United States do not collect sexual orientation data, it is essential that the analysis of Komen Southeast Wisconsin target communities include efforts to gather information related to the risks and barriers faced by women identifying as Lesbian or Bisexual.

Several factors put lesbian and bisexual women at higher risk for breast cancer. Lesbian and gay women are (US HHS, Office on Women’s Health, 2011):

- Less likely to be pregnant thereby reducing their opportunities for the hormonal releases that accompany pregnancy and breast feeding and is thought to lower a woman’s risk of breast cancer and other cancers
- More likely to lack health insurance (especially bisexual women)
- Less likely to get routine mammograms and clinical breast exams
- More likely to experience discrimination and/or bad experiences with health care.

### **Healthy Weight**

Maintaining a healthy weight through diet and exercise is a healthy lifestyle choice that is tied to lowering an individual’s risk of breast cancer. In 2012, Wisconsin’s adult obesity rate was 29.7 percent, up from 20.9 percent in 2003 and from 11.8 percent in 1990. Wisconsin’s 2012 obesity rate is ranked 15th highest in the country (WIDHS, Division of Public Health, 2012).

The high rate of overweight and obesity for Wisconsin adults as shown in Table 2.14 and Table 2.15, suggest weight is a health indicator that warrants consideration and further study in the Qualitative Data Gathering and Analysis for every Target Community.

**Table 2.14.** Prevalence of overweight, obesity and total overweight (overweight or obesity) for Wisconsin adults by race/ethnicity, 2004 – 2006

	White	Black/ African American	Asian	American Indian	Hispanic/Latino
<b>% Overweight</b>	38.0	32.9	30.6	35.0	37.2
<b>% Obese</b>	24.6	34.4	9.4	40.2	29.4
<b>Total %</b>	62.6	67.2	40.1	75.1	66.6

Source: 2004-2006 Behavioral Risk Factor Surveillance System, Bureau of Health Information and Policy, Division of Public Health, Wisconsin Department of Health Services.

**Table 2.15.** Overweight/Obesity Percentiles for Wisconsin Women by Age Group

Age	16-29	30-39	40 -49	50-59	60-69	70+
<b>% Overweight</b>	22.0	28.9	30.1	30.0	37.2	36.1
<b>% Obese</b>	16.1	21.7	26.1	29.3	28.0	20.3

Source: "The State of Obesity - Wisconsin" from F as in Fat 2013 [PDF]; F as in Fat Project, Trust for America's Health and the Robert Wood Johnson Foundation.

### ***Alcohol consumption***

Multiple studies have linked the consumption of alcohol to an increase in breast cancer risk. For each alcoholic drink consumed per day, an individual's risk of breast cancer increases about 7.0 percent (Barone, Yeh & Collins, 2011). Studies show that women who consume two to three drinks increase their relative risk of breast cancer a full 20.0 percent (Barone et al, 2011).

This increased risk is due at least in part to a change in the way estrogen is metabolized by the body when alcohol is consumed. Drinking increases estrogen levels which in turn increases the risk of breast cancer (Yanghyan, Colditz, & Collins, 2011) (Del Giudice, Fantus & Ezzat, 1998) (Eliassen, Tworoger, Mantzoros, Pollak & Hankinson, 2007). Alcohol consumption also reduces the amount of folic acid. Folic acid is key to the copying and repair of DNA. Low folic acid levels may increase the likelihood that errors will occur in the natural division of cells in the body. Such errors can begin the process of a cell becoming cancerous (Eliassen, Colditz & Rosner, 2006) (Ahn, Schatzkin & Lacey, 2007).

Alcohol consumption in Wisconsin is self-reported at rates higher than any other state in the country. As shown in Table 2.16 adults in Wisconsin have noticeably higher rates of binge drinking (24.0 percent), current alcohol use (69 percent), and heavy drinking (8.0 percent) than the average national rates. The per capita consumption of alcohol is also one of the highest in the nation at nearly three gallons per person (USHHS, National Institute on alcohol Abuse and Alcoholism, 2005).

**Table 2.16.** Alcohol use among adults, Wisconsin and the United States, 2006

	<b>Current Use</b>	<b>Binge Drinking*</b>	<b>Heavy Drinking</b>
<b>Wisconsin</b>	69.0%	24.0%	8.0%
<b>United States</b>	55.0%	15.0%	5.0%

\* Binge drinking is defined as five or more drinks on one occasion, one or more times in the past 30 days  
Source: Behavioral Risk Factor Survey, Bureau of Health Information and Policy, Division of Public Health, Department of Health Services; Behavioral Risk Factor Surveillance System, US Centers for Disease Control and Prevention.

All of Wisconsin's racial and ethnic groups have a higher average of alcohol consumption of that seen nationally. Percentages by race/ethnicity is as follows – White (69.0 percent), Hispanic/Latino (67.0 percent), American Indian (65.0 percent), Asians (57.0 percent), and Black/African-American (48.0 percent)(WIDHS, WI Epidemiological Profile on Alcohol and other drug use, 2012). The relationship of alcohol to breast cancer risk is particularly relevant for a Wisconsin Komen Affiliate. The high statewide rate of alcohol consumption puts Wisconsin's women at higher overall risk of breast cancer. Alcohol consumption is certainly a lifestyle factor that warrants further exploration and analysis in all of the Komen Southeast Wisconsin target communities.

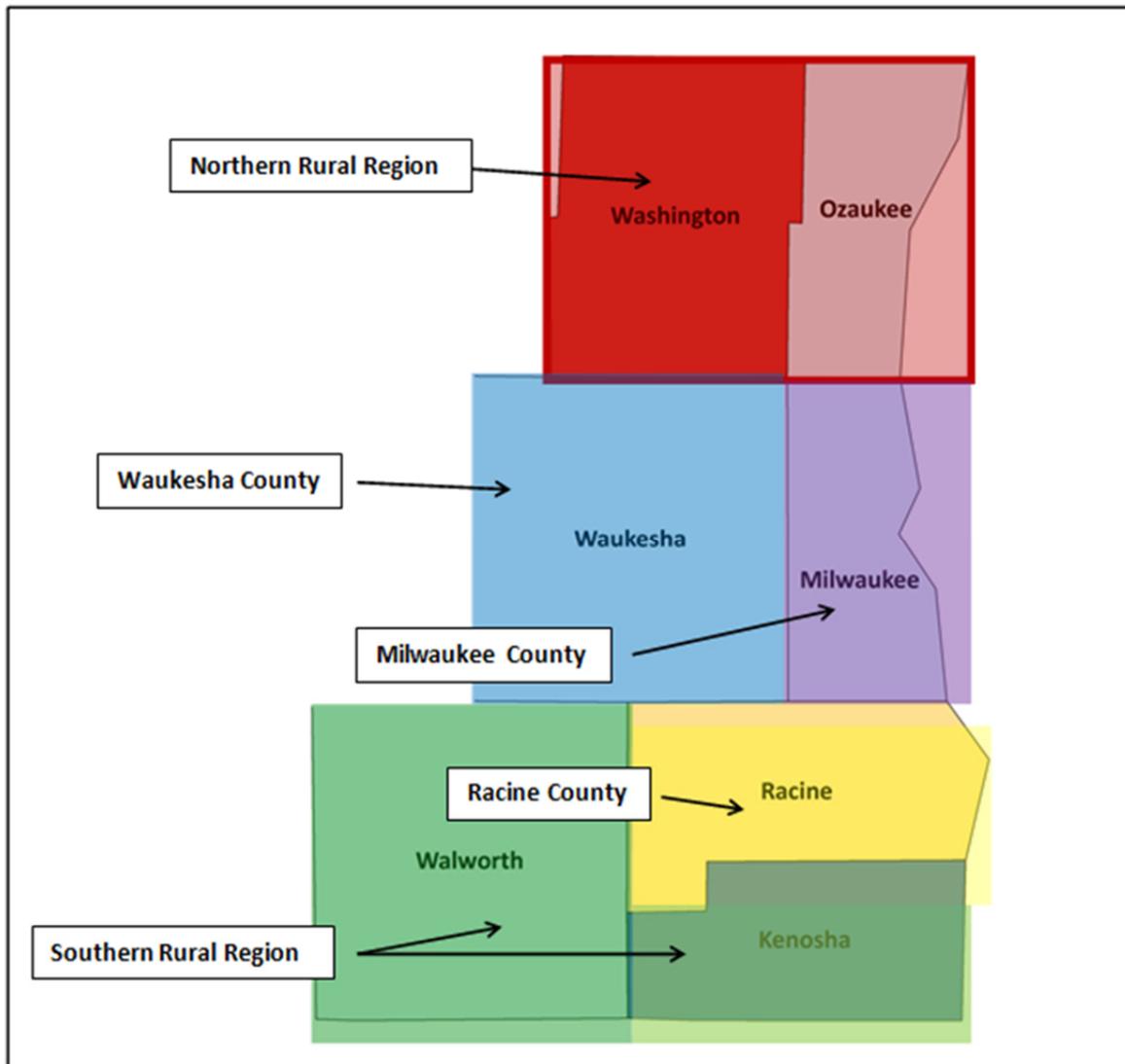
### **Target Communities**

By illuminating the highest need counties and populations in the service area, the 2015 Community Profile will enable Komen Southeast Wisconsin to facilitate positive impact by:

1. Identifying the counties and populations for which extensive qualitative data collection is indicated in order to drill down to more fully understand the specific challenges faced by that Target Community, as well as the circumstances and realities that exist.
2. Focusing strategic efforts of Komen southeast Wisconsin on key areas of need in these Target Communities
3. Developing specific goals and measurable objectives to guide the Affiliate's primary mission, education and advocacy work over the course of the next four years.
4. Creating integrated Grant Funding priorities to inform applicants in the development of Community Grant and Small Grant applications, as well as to guide grant reviewers in the selection and ranking of Community Grant proposals.

The quantitative data for Komen Southeast Wisconsin points to needs in every county of the service area. Several counties stand out because of higher breast cancer incidence and death rates, others because of unique demographic factors. The limited size of the Affiliate makes it possible and, indeed, compels the organization to proceed with an in-depth investigation of the variety of factors contributing to the different challenges faced in five areas of Southeast Wisconsin. In order to make the most efficient and effective use of resources, Komen Southeast Wisconsin has identified and selected the following five target communities (Figure 2.2) :

- Milwaukee County
- Northern Rural Region (Washington and Ozaukee Counties)
- Racine County
- Waukesha County
- Southern Rural Region (Walworth and Kenosha Counties)



**Figure 2.2.** Susan G. Komen Southeast Wisconsin selected Target Communities  
2015 Community Profile

### **Milwaukee County**

Milwaukee County is an urban county located centrally within the Komen Southeast Wisconsin service area. The county is bordered by Lake Michigan on the east, and Ozaukee, Waukesha, and Racine Counties on the north, west, and south. Milwaukee County is home to the city of Milwaukee, Wisconsin’s largest municipality. As shown in Table 2.13 above, the population of the City of Milwaukee alone is greater than the total population in the next five largest Wisconsin cities. Milwaukee County’s 485,207 women represent a full 47.4 percent\* of the women residing in Komen Southeast Wisconsin’s service area. (\*Note: total Affiliate female population is 1,023,239 after removing the population of Jefferson County which is no longer in the Komen Southeast Wisconsin service area).

Milwaukee County’s population density and demographic diversity alone warrant its selection as a target community. As shown in Table 2.17, Milwaukee County is home to 57.8 percent to 92.0 percent of the Southeast Wisconsin population identified within each of the listed demographics. For instance, 65.1 percent of people have incomes at or below 250 percent of the Federal Poverty

Level in the Affiliate’s service area live in Milwaukee County. An alarming 92.0 percent of Milwaukee’s residents live in medically underserved areas.

**Table 2.17.** Demographic analysis of Milwaukee compared to entire SEWI service area

Milwaukee County Demographic Analysis as a Percentage of the Entire Southeast Wisconsin Service Area													
	Female Population	Percent with Income below 100% Poverty	Percent with Income below 250% Poverty	% with Less than HS Education	Percent Unemployed	Percent Foreign Born	Percent Linguistically Isolated	Percent Medically Underserved	Percent Uninsured	Percent Black/African-American	Percent AIAN	Percent API	Percent Hispanic/Latino
<b>All SEWI Counties</b>	1,023,291	13.3	27.3	11.1	8.2	6.5	2.4	16.7	9.7	15.6	0	2.8	9.5
#		13609	27936	11358	83911	66514	24559	17089	99260	159635	81	28652	9721
<b>Milwaukee</b>	485,207	19.9	37.5	14.8	10	8.7	3.9	32.4	12.8	29.2	1	3.8	12.8
#		96556	18195	71811	48521	42213	18923	15720	62106	141680	53	18438	6210
<b>Milwaukee as a percentage of entire SEWI</b>	47.4	70.9	65.1	63.2	57.8	63.5	77.1	92.0	62.6	88.8	65.2	64.4	63.9

Table 2.17 information compiled with data from Table 2.1 and Table 2.5

Milwaukee County’s 485,207 women (Table 2.1) represent the most diverse population in Southeast Wisconsin. With the exception of White residents, people of every race are living in Milwaukee County at percentiles higher than that of the state and SEWI averages. Milwaukee County is rich in racial diversity, but with this comes more vulnerable population statistics that show 3.9 percent of its residents are linguistically isolated, and 8.7 percent are foreign born. All of these percentages are substantially higher than the Affiliate service area’s averages (Table 2.5).

Similarly, ethnic diversity is also more prevalent in Milwaukee County than the rest of the Affiliate service counties. Table 2.4 shows that Hispanic/Latina individuals comprise 12.8 percent of Milwaukee County’s population. This is more than twice as high as the Hispanic/Latina population for the State of Wisconsin (5.8 percent) and more than thirty percent higher than the Hispanic/Latina population of the Affiliate service area (9.5 percent).

Especially of note, 29.2 percent of Milwaukee County is Black/African-American, a percentage twice as high as the national average and over four times higher than the overall Southeast Wisconsin service area average (Table 2.4). This is a major factor for Milwaukee County due to high late-stage breast cancer incidence and the high breast cancer death rates Black/African-American women experience when compared to other races.

Table 2.18 gives a quick reference to the stage of diagnosis for the 4132 cases of breast cancer in Milwaukee County between 2007 and 2011. Five percent of these cases were listed as late-stage. If considering only invasive breast cancer (removing the in-situ cases), that percentage rises to nearly 6.5 percent. The high population of Black/African-American women in Milwaukee County compels the Affiliate to investigate what kind of population distribution exists in later-staged breast cancer diagnoses as well as in breast cancer deaths.

**Table 2.18.** Female breast cancer incidence by stage – Milwaukee County

Year	Stage at Diagnosis					
	All stages	In Situ	Localized	Regional	Distant/ Systemic	Unknown
2007-2011	4132	856	2026	1009	209	32

Source: Wisconsin Department of Health Services, Division of Public Health, Office of Health Informatics. Wisconsin Interactive Statistics on Health (WISH) data query system, <http://dhs.wisconsin.gov/wish/>. Cancer Module accessed May 2014.

Every race and ethnic group has its own challenges in terms of breast cancer incidence and deaths as well as access to quality care. The cumulative effects of those challenges faced by a diverse Milwaukee County secure it as a high need Target Area and points to a need for extensive and equally diverse qualitative data collection.

In terms of breast cancer age-adjusted incidence and death data, Milwaukee County sits squarely in the middle tier of the Southeast Wisconsin counties (Table 2.1). It ranks medium low in terms of the HP2020 goals and is on track to achieve the 2020 targets in four years (Table 2.7). Milwaukee County's breast cancer incidence rate (130.2) is 13.3 percentage points higher than the State average (122.1) and more than 11 percentage points higher than the average for Southeast Wisconsin as a whole (116.9) (Table 2.1). Similarly, the county's age adjusted death rate is 22.6. This is equal to the National rate but higher than the average SEWI rate (21.3) and above the HP2020 goal of 20.6 deaths per 100,000 people (Table 2.1).

The contrast of Milwaukee County's relatively medium low need breast cancer data with the extreme nature of the demographic data in Table 2.16 mandates careful investigation into likely disparity of the breast cancer burden within Milwaukee County. Questions must be raised and answered about income variation, pockets of poverty, as well as individual and systemic barriers to breast health/breast cancer services in order to uncover and illuminate an accurate depiction of the state of Breast Cancer in Milwaukee County for its many diverse residents.

### **Northern Rural Region (Washington and Ozaukee Counties)**

Washington and Ozaukee are adjacent rural counties in the northern portion of the service area. Washington is situated directly west of Ozaukee County and they share that middle border completely. Their northern and southern borders align to form a rectangle that is the entire north portion of the Southeast Wisconsin service area. Largely rural in nature, the city of West Bend (ranked Wisconsin's 25<sup>th</sup> largest) is the most populous within the region's boundary. While differing in their county need level designation, Washington and Ozaukee County have a great number of geographical, demographic, and breast cancer factors in common which support the merger of these two counties to form a single Northern Rural Region.

### **Washington County and Ozaukee County Similarities**

Komen Southeast Wisconsin has combined Washington and Ozaukee Counties to form one Northern Region Target Area. A major factor in this decision was the extremely similar demographics that these two counties share in nearly every category. This suggests that there are likely similar challenges and causes behind their higher than service-area average rates of breast cancer incidence and deaths.

### *Highly rural communities*

Ozaukee County has a 24.9 percent rural population, more than two times the SEWI average. Washington's rural population is 30.8 percent, slightly higher than Wisconsin's percentage of rural population (29.8) and over three times higher than the Affiliate service area's 9.9 percent (Table 2.5). While there are several small city centers in each county, Washington and Ozaukee Counties also share the feature of being two of three SEWI service area counties that lie furthest from a major population center.

### *Aging population*

Washington and Ozaukee also share the similarity of being home to more women aged 40 years and over than average for the SEWI Affiliate service area, as well as for the State of Wisconsin and the country as a whole. Mammography screening percentages for women 50 to 74 are low for Ozaukee women at 77.3 percent, but high for Washington County women at 92.5 percent (Table 2.3). However, the data for each county has wide confidence intervals that necessitate the need for further investigation of accurate mammography screening percentages throughout the Northern Rural Region.

### *Socioeconomic Factors*

Both Washington and Ozaukee County are consistently ranked in the lowest third of the Affiliate's counties for percentages on all socioeconomic demographics (i.e. poverty, no insurance, medically underserved, racial/ethnic diversity, less education, low screening percentages –Table 5). These demographics are indicators that often accompany communities and/or populations with poor breast health statistics. The only exception to this for the Northern Rural Regions is a higher than average percentage for rural population.

There are many factors that warrant the selection of this Northern Rural Region as a target community. Washington County was identified in the QDR as Komen Southeast Wisconsin's single highest need county in the Affiliate's service area (Table 2.7). This county is the furthest off track on meeting the Healthy People 2020 goals. Washington County has the Affiliate's worst breast cancer death rate trend at -0.2 percent (Table 2.1). This rate indicates slow change toward the HP2020 goals and puts the county a full 13 years away from achieving the target of 20.6 BC deaths per 100,000 women (Table 2.7). While Ozaukee ranks as a medium low need county with a breast cancer death rate trend that is on track to meet the 2020 goals in five years, other data points to the need for further exploration of this county. Ozaukee carries the Affiliate's highest age-adjusted breast cancer incidence in Southeast Wisconsin at a rate of 156.2 cases per 100,000 women. This rate is 27.9 percent higher than the national rate of 122.1 (Table 2.1).

Washington County's age adjusted breast cancer death rate is the highest of the Southeast Wisconsin Counties (24.5) and is above both the national (22.6) and State of Wisconsin (21.3) rates (Table 2.1). The county also stands out as having the Affiliate's third highest age-adjusted breast cancer incidence rate at 138.4 deaths per 100,000 women. This rate is 13.3 percent higher than the national rate of 122.1 percent. Ozaukee County has the third highest age-adjusted breast cancer death rate in Komen Southeast Wisconsin's service area. Ozaukee County's 23.4 breast cancer deaths per 100,000 women are higher than both the State of Wisconsin's rate of 21.3 and the SEWI rate of 22.4. Ozaukee's breast cancer death rate trend

is again the Affiliate's third lowest at -2.7 percent, although this rate is better than the State average of -2.5 percent (Table 2.1) and puts Ozaukee five years out for achieving the HP2020 breast cancer death rate targets (Table 2.7).

A final consideration is illustrated in Table 2.9, *County Breast Cancer Incidence by Stage*. Washington County's late-stage breast cancer diagnosis is 3.7 percent. While this is not an unusually high percentage for a county, there may be significance in this number when compared to other counties in the Affiliate's SEWI service area. Washington County was the only one of SEWI's smaller counties to have enough late-stage incidence data to count. Three counties (Ozaukee, Racine and Walworth) had suppressed data for this category (under five cases), while Washington County presented with 26 cases in the same 2007 to 2011 time frame.

In comparison to other counties in Komen Southeast Wisconsin's service area, both counties comprising the Northern Rural Region (Washington and Ozaukee) are in the highest tier for breast cancer incidence rate, death rate, and death rate trends (Table 2.1). Conversely, these two counties are both at relatively low risk in terms of socioeconomic variables. Their similar rural profiles suggest transportation and/or access may be factors in their relatively high breast incidence and death rates. A health systems review will analyze the availability of services in this region. Higher population age, questionable actual screening percentages, and the consideration of late-stage diagnoses data from Table 2.9 present as possible causes for elevated incidence and death data within this region and warrant further investigation. It is clear that careful and thorough qualitative data collection and analysis is needed in this Northern Rural Region to further illuminate the root causes of the area's high breast cancer incidence and death burden.

### **Racine County**

Racine County is located on the east central portion of the Komen Southeast Wisconsin Service area bordered by Lake Michigan to the east, Milwaukee County to the north, Walworth County to the west, and Kenosha County to the south. Racine County is the third most populous county in Komen Southeast Wisconsin's service area and is home to the City of Racine which is Wisconsin's fifth largest city.

The QDR ranks Racine as a medium high priority county making it the Affiliate's second highest need county (Table 2.7). Racine County has Komen Southeast Wisconsin's second highest age adjusted breast cancer death rate (24.4) which is higher than both the State of Wisconsin (21.3) and Affiliate (22.4) rates for death per 100,000 women. Accompanying this, Table 2.1 shows that Racine also has the second slowest breast cancer rate trend in Southeast Wisconsin and that the breast cancer deaths in Racine are falling at a rate of -2.2 percent. As further illustrated by Table 2.7, this means that Racine is not projected to reach the Healthy People 2020 target rate of 20.6 deaths per 100,000 women for a full eight years.

While Racine County ranks fourth in terms of breast cancer incidence in the Southeast Wisconsin service area, its age-adjusted rate of 128.7 breast cancer cases per 100,000 women is still 5.4 percent higher than the national rate of 122.1 (Table 2.1). There are several additional factors that indicate need in Racine County. The reported mammogram screening percentage for women aged 50 to 74 at 78.3 percent is among the lowest in the Affiliate's service area and well below the Affiliate Average of 82.9 percent (Table 2.3). The confidence

interval for this percentage is very wide, opening the potential for the reality of even lower actual screening percentages. These factors warrant further qualitative investigation into screening behavior in Racine County.

Racine County also has broader racial and ethnic diversity than average for the State of Wisconsin and is one of the more diversified counties in of the Affiliate. Racine's Black/African-American population is 12.1 percent which is 70.4 percent higher than the average for Wisconsin. The Hispanic/Latina population in Racine County is 11.3 percent which is greater than both the State (5.8 percent) and the Affiliate (9.5 percent) percentages (Table 2.4). As discussed earlier, different race and ethnicity populations can face unique breast cancer burdens and a variety of individual and systemic barriers. Qualitative data for Racine County must drill down into what specific challenges are present.

Additionally, Table 2.5 shows that in comparison to the Affiliate as a whole, Racine County has a slightly higher rural population (12.3 percent), as well as a greater number of people with less than a High School Education (12.3 percent). A large portion of Racine County residents are living at or below Federal Poverty Markers (26.1 percent). Qualitative data will allow the Affiliate to delve further into these socioeconomic factors to determine who in Racine is carrying the highest burden of breast cancer and how that is contributing to the high breast cancer incidence and death data. The Health System Analysis will also be essential to clarify what service gaps may exist in this target community.

### **Waukesha County**

Waukesha County is Komen Southeast Wisconsin's second largest county. It is located on the west side of the service area and shares its eastern border with Milwaukee County. The County is bordered on the north by Washington County, the south by both Racine and Walworth Counties, and shares its western border with Jefferson County which is part of Komen South Central Wisconsin.

Waukesha County is both rural and urban. It is home to the city of Waukesha which is the seventh largest city in Wisconsin. In addition to a good sized urban presence, the County also has nearly 10 percent of its residents living well beyond the city boundaries in rural areas (Table 2.5).

Identified as one of the Affiliate's four medium low risk counties, Waukesha County warrants selection as a target community for several reasons. While its age-adjusted breast cancer death rate of 22.0 deaths per 100,000 women is below the Wisconsin average, Waukesha County still has a slightly higher death rate than Wisconsin's average of 21.3 (Table 2.1). According to the QDR, Waukesha County is on track to reach HP 2020 Goals in three years (Table 2.7) with a Death Rate Trend of -2.9 percent (Table 2.1). Of concern, however, is Waukesha County's relatively high breast cancer incidence rate when compared with the rest of the Affiliate counties. In fact, Waukesha County has the third highest breast cancer incidence rate at 138.6 cases per 100,000 women. This is 13.5 percent higher than the national breast cancer incidence rate of 122.1 deaths per 100,000 (Table 2.1).

The staged breast cancer incidence data shown in Table 2.19 provides a starting point for further investigation into Waukesha County's relatively high breast cancer incidence rate.

**Table 2.19.** Female breast cancer incidence by stage – Waukesha County

Year	Stage at Breast Cancer Diagnosis					
	All stages	In Situ	Localized	Regional	Distant/Systemic	Unknown
2007-2011	2141	437	1128	500	68	8

Source: Wisconsin Department of Health Services, Division of Public Health, Office of Health Informatics. Wisconsin Interactive Statistics on Health (WISH) data query system, <http://dhs.wisconsin.gov/wish/>. Cancer Module accessed May 2014.

While socioeconomic factors in Waukesha County are not especially different than the rest of the service area, 14.0 percent of the County population is living at or below 250 percent of the Federal Poverty Level (Table 2.5). This factor could help explain the elevated breast cancer incidence data. The population of women over the age of 40 is higher in Waukesha County as compared to Wisconsin averages (Table 2.4). Additionally the mammogram screening percentage is 84.9 percent, close to the State of Wisconsin percentage, however the confidence interval for this percentage is broad and could indicate far lower actual screening behaviors (Table 2.3). While the majority of Waukesha County residents are White, 4.1 percent of its residents are Hispanic/Latina (Table 2.4). A current Waukesha County Komen Southeast Wisconsin grantee has uncovered a great deal of linguistic isolation as well as individual and systemic barriers to breast health services for Hispanic/Latina women. Investigation into the possibility of similar circumstances within the County's 3.1 percent Asian and Pacific Islander residents is warranted as well, especially considering that Waukesha County is the second most prevalent county of API residence in the Affiliate's service area.

While on the surface much of the socioeconomic and race/ethnic diversity data for Waukesha appears fairly flat, there is good reason to believe great need exists for many residents.

Careful Qualitative Data collection and analysis are essential to illuminate the breast cancer burden of Waukesha's most vulnerable residents. A thorough Health System Analysis is also warranted to identify possible gaps that may exist in the availability of and access to breast cancer screening, diagnostic, and treatment services.

### **Southern Rural Region (Walworth and Kenosha Counties)**

Walworth and Kenosha County combine to make up the Affiliate's final target community - Southern Rural Region. Both counties are located on the far south end of Southeast Wisconsin's service area with each of their southern boundaries on the border between Wisconsin and Illinois. Walworth sits west of Kenosha. Its east border is shared by Kenosha and Racine Counties. Walworth shares most of its northern border with Waukesha County while the rest borders Jefferson County, a service area of neighboring Komen South Central Wisconsin. Kenosha is located on the far southeast corner of Wisconsin. Its east border is along Lake Michigan and its northern border is shared with Racine County.

Besides location, Walworth and Kenosha share many similarities that warrant their combination into one region. As illustrated in Table 2.7, Kenosha and Walworth Counties rank as low and medium low risk areas respectively. Table 2.1 shows that Kenosha and Walworth County's age-adjusted death rates as well as Kenosha's breast cancer incidence rate are the lowest in the

Komen SEWI service area. While Walworth's age-adjusted breast cancer Incidence Rate is slightly higher than the area average, these two counties appear to be at lowest risk within Southeast Wisconsin (Table 2.1). Demographically, Kenosha and Walworth also appear in relatively good standing. With the exception of rural population measures, all of the data for these two counties in Table 2.5 present close to or below the Southeast Wisconsin Service Area averages.

However, additional data provided in Table 2.8 illuminates specific areas of concern in both Kenosha and Walworth County. These two counties have a combined 15 distinct census tract areas in which the extremely high levels of poverty and low levels of education are far above the poverty levels and low education levels found in the counties as a whole. These pockets of poverty must be assessed carefully in the Qualitative Data collection and analysis. Careful regional analysis including an emphasis on these high need areas may reveal populations and communities that are carrying far more than their share of the region's risk of breast cancer incidence and death. It is also very likely that these high risk census tract areas are home to individuals facing barriers that severely limit their access to accurate breast health information and affordable breast health services.

Also worth noting is that while most of the Southern Rural Region's socioeconomic factors are comparable to percentages throughout Komen Southeast Wisconsin's service area, there are a few stand-out areas of need in this Southern Rural Region. Both Kenosha and Walworth Counties have slightly higher levels of foreign born citizens and linguistically isolated residents than the State of Wisconsin as a whole. Both are also challenged with a large percentage of population living at or below 250 percent of poverty (28.6 percent in Kenosha and 26.1 percent in Walworth) and both counties have higher percentiles of residents without health insurance than Wisconsin as a whole (Table 2.5). All of these factors warrant further investigation through qualitative data collection and analysis to determine the effects on the Southern Rural Region's breast cancer burden.

Kenosha and Walworth also have higher rural populations than the Affiliate as a whole. Walworth County has the Affiliate's highest percentage of rural resident at 34.2 percent which is more than three times the rural residency percentage of 9.9 percent for the entire Affiliate service area (Table 2.5). Higher rural population can be tied to greater likelihood of service access and transportation challenges. Kenosha County rural population is at 10.7 percent which is just slightly higher than the service area rate but may still indicate that many residents could be facing similar challenges. While qualitative investigation should strive to understand the needs of this population, questions also need to be asked in the Health System Analysis to determine whether the 15.3 percent medically underserved population in Kenosha (Table 2.5) is related to rural residency and/or the result of other service gaps and barriers.

Percentages for mammography screening also warrant additional examination throughout the Southern Rural Region. Walworth has one of the Affiliate's lowest mammography screening percentages at 77.4 percent. Kenosha's mammography percentage is much higher at 90.2 percent; however the confidence interval for that screening percentage is extremely large with a span of 40 percentage points indicating the screening could possibly be as low as 58 percent. (Table 2.3)

Information gathered during qualitative data collection will help develop an accurate picture of how the demographics of the region may be imposing challenges that are affecting access to breast health and breast cancer services. A fuller understanding of the Southern Rural Region's poverty pockets, possible rural transportation issues, linguistic challenges, potentially low screening practices, access barriers and service gaps will result in a strong analysis of the burden of breast cancer on this Target Community. A robust Health System Analysis will identify gaps in service in the Southern Rural Counties and further assist in assessing the breast cancer burden in this target community.

# Health Systems and Public Policy Analysis

The purpose of the Health Systems and Public Policy Analysis (HSPPA) section is to enable Komen Southeast Wisconsin to gain an understanding of the health systems, the available breast health/ breast cancer services, and the partner organizations and resources within each of its five selected target communities. The HSPPA is also an opportunity to gather information on the federal/state-level public policy issues and efforts that affect those communities.

Completing the health system analysis gives the Affiliate a good sense of existing resources, as well as service gaps within each Target Community.

## **Health Systems Analysis Data Sources**

Multiple sources were utilized to identify service providers, details of services provided, current state and Federal legislation and policy, and the organizational information contained in this health system analysis.

Primary data sources include:

### **Continuum of Care Resources**

- Mammography Centers  
<http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMQSA/mqsa.cfm>
- Hospitals  
<https://data.medicare.gov/Hospital-Compare/Hospital-General-Information/v287-28n3>
- Local Health Departments  
<https://www.naccho.org/about/lhd/>
- Community Health Centers  
[https://findahealthcenter.hrsa.gov/Search\\_HCC.aspx](https://findahealthcenter.hrsa.gov/Search_HCC.aspx)
- Free Clinics  
<http://www.nafclinics.org/clinics/search>

### **Quality of Care Resources**

- American College of Surgeons Commission on Cancer  
[http://datalinkds.facs.org/cpm/CPMAApprovedHospitals\\_Search.htm](http://datalinkds.facs.org/cpm/CPMAApprovedHospitals_Search.htm)
- American College of Radiology Centers of Excellence  
<http://www.acr.org/Quality-Safety/Accredited-Facility-Search>
- American College of Surgeons Nat'l Accreditation Program for Breast Centers  
<http://napbc-breast.org/resources/find.html>
- National Cancer Institute Designated Cancer Center  
<http://www.cancer.gov/researchandfunding/extramural/cancercenter/find-a-cancer-center>

### **Additional informational resources**

- [www.wha.org](http://www.wha.org)
- Wisconsin Comprehensive Cancer Control Plan 2010-2015
- [www.CitizenActionWi.org](http://www.CitizenActionWi.org) (Wisconsin DHS BadgerCare Plus enrollment data)
- Health system websites
- Google searches health facilities, service providers, and survivor services
- Partner Organization's websites and personal communications
- Verbal leads from identified service facilities
- Information provided from local health departments

- Information provided by Wisconsin Breast Cancer Coalition
- Phone calls/interviews with specific health facilities and community organizations
- UW Extension County online resource guides

### **Data collection and review process**

A major portion of the health system analysis consisted of completing an inventory of all breast cancer programs and services in the target areas. The result of this work was the development of a comprehensive Health System Inventory that documents every health system facility and organization, as well as the breast health and/or breast cancer services they provide within each of Komen Southeast Wisconsin's five target communities. From this inventory, facilities have been mapped to illustrate the distribution of these services and to identify the resources (or lack thereof) in each community.

The inventory provides an excellent opportunity to access Komen Southeast Wisconsin's current partnerships and collaborations, as well as identify and begin to foster potential new relationships that will help further the Affiliate's mission in the communities of greatest need within its service area.

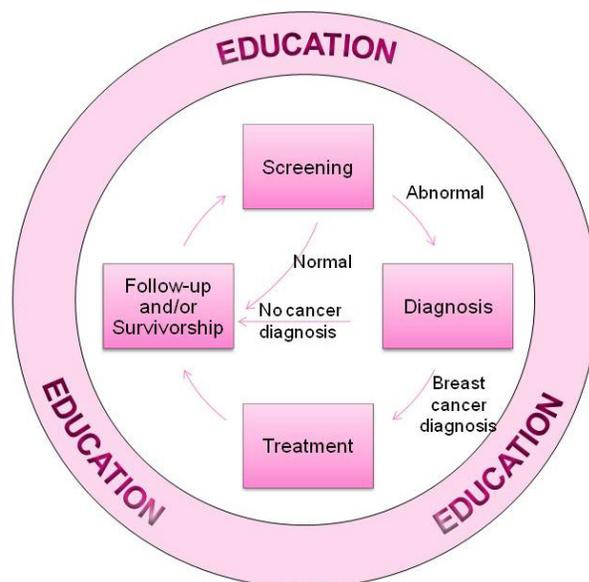
Komen Southeast Wisconsin utilized the resulting asset maps, provider service and program data to further analyze each Target Community in terms of its current ability to provide optimal breast health and breast cancer care to its residents. Analysis included identifying potential strengths as well as gaps, needs and limitations in the health care system that affect a woman's health as she transitions through breast cancer screening, diagnosis, treatment, and survivor support services. Availability of services was measured in terms of number of providers, level of service quality, and accessibility of these services to the Target Community residents.

Insight gained through the health system analysis will be considered in conjunction with the quantitative data to guide the Affiliate's collection of qualitative data by further illuminating specific topics to explore and whom to approach for such information.

### **Health Systems Overview**

The health systems analysis tells the story of the breast cancer continuum of care and the delivery of health care in the community. Its key components are education, screening, diagnosis, treatment, follow-up, and survivorship services.

The Breast Cancer Continuum of Care (CoC) is a model that shows how a woman typically moves through the health care system for breast care (Figure 3.1). A woman would ideally move through the CoC quickly and seamlessly, receiving timely, quality care in order to have the best outcomes. Education can play an important role throughout the entire CoC.



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

While a woman may enter the continuum at any point, ideally a woman would enter the CoC by getting screened for breast cancer – with a clinical breast exam or a screening mammogram. If the screening test results are normal, she would loop back into follow-up care, where she would get another screening exam at the recommended interval. Education plays a role in both providing education to encourage women to get screened and reinforcing the need to continue to get screened routinely thereafter.

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

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

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

at a recommended interval after treatment ends, or for some, during treatment (such as those taking long term hormone therapy).

There are often delays in moving from one point of the continuum to another – at the point of follow-up of abnormal screening exam results, starting treatment, and completing treatment – that can all contribute to poorer outcomes. There are also many reasons why a woman does not enter or continue in the breast cancer CoC. These barriers can include things such as lack of transportation, system issues including long waits for appointments and inconvenient clinic hours, language barriers, fear, and lack of information - or the wrong information (myths and misconceptions). Education can address some of these barriers and help a woman progress through the CoC more quickly.

### **Health system strengths and weaknesses**

The data collected for the health system analysis portion of the Community Profile illustrate the strengths and weakness of the health systems across the continuum of care within each of the five Komen Southeast Wisconsin Target Communities. Points of service (screening, diagnostic, treatment, support/survivorship services) have been mapped within individual Target Communities providing a visual story of the availability of each portion of the continuum of care to residents. A strong health system will provide multiple points of access at locations that are convenient to residents; a weaker system will have few points of access with geographical challenges to health care access. These strengths and weaknesses can be analyzed along each portion of the CoC.

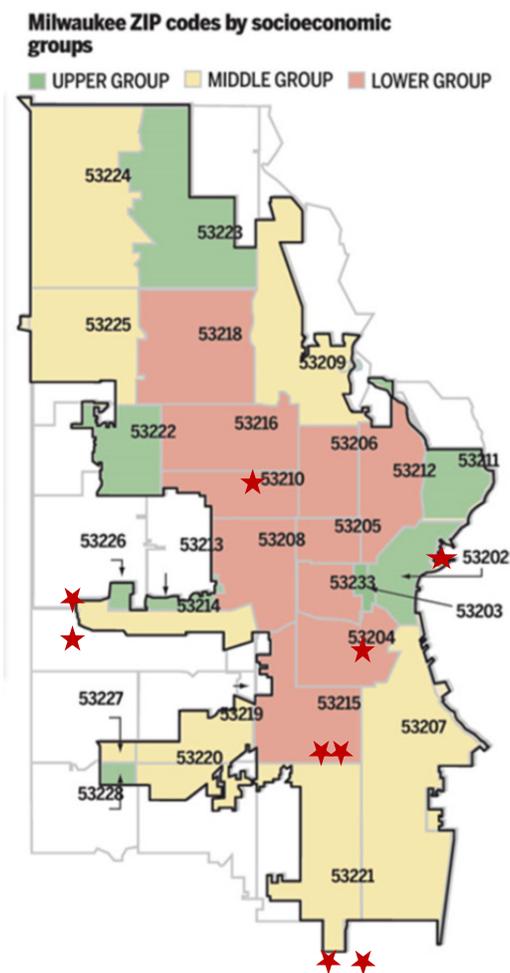
### ***Milwaukee County***

An analysis of Milwaukee County must begin with the recognition that the county is unique among the Affiliate's Target Communities. As shown in the quantitative data analysis, Milwaukee County is home to more than half of the women in the Komen Southeast Wisconsin service area, has the most racially and diverse population, and the highest levels of poverty. A full 92.0 percent of the residents in Milwaukee County reside in a medically underserved area and 37.5 percent are living at or below 250 percent of the Federal Poverty Level. Non-White residents of every race and ethnicity reside in Milwaukee numbers higher than both the state and Komen Southeast Wisconsin regional percentages.

US Census 2010 data shows that there are 258,126 Black/African-American residents in Milwaukee County and 237,993 Black/African-American residents in the City of Milwaukee. This means that 92.2 percent of Milwaukee County's Black/African-American residents live in the city. Since Black/African-American women have both higher late-stage breast cancer diagnosis and higher breast cancer death rates than White women, it is essential that breast cancer services are optimally available and accessible to these women. The most accessible and trusted health services are those offered in a woman's own neighborhood in their own neighborhood.

Milwaukee County also has a great disparity in the distribution of wealth across its neighborhoods. This income disparity must also be taken into account when analyzing the location of breast cancer points of service in the county. Figure 3.2 shows the breakdown of the majority of Milwaukee County by zip codes and socioeconomic status. The map highlights the county areas in and around the City of Milwaukee. Every low socioeconomic zip code within Milwaukee County is located within the City of Milwaukee. The upper and middle income zip

codes lie mainly on the outer edges of this map and continue out to the perimeter of Milwaukee County.



Note: Red stars indicate sites offering both full breast cancer diagnostic and treatment services in Milwaukee County  
 Source: Secondary Data Report, Summary of secondary data sources related to health in Milwaukee County 2012-13, Milwaukee Health Care Partnership.

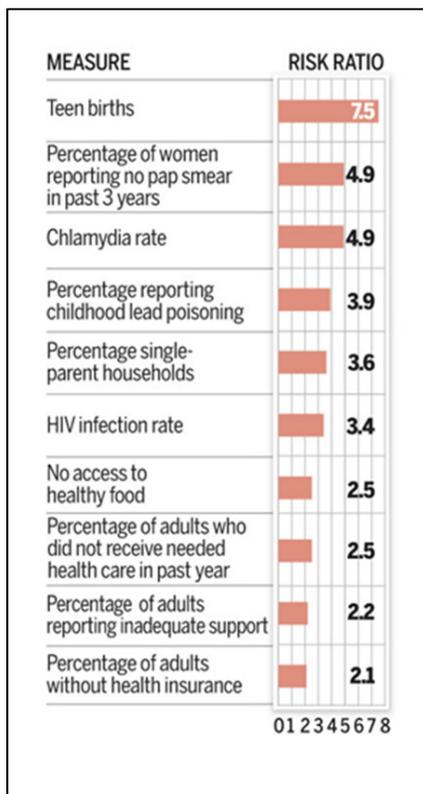
**Figure 3.2.** City of Milwaukee and portions of Milwaukee County, socioeconomic groups by zip code

A 2014 report by the University of Wisconsin -Milwaukee Employment and Training Institute put into context the economic disparities problem in Milwaukee County. Figure 3.4 illustrates the health consequences of being poor in Milwaukee County.

Based on US Census 2010 population numbers and the socioeconomic data in Table 2.5, of the population in Southeast Wisconsin 65.1 percent of those individuals earning under 250 percent of the federal poverty level reside in Milwaukee County. The risk ratios shown in Figure 3.4 potentially affect the vast majority of women in the City of Milwaukee. Risks are highest for residents in the lowest socioeconomic zip codes. Residents of Milwaukee County’s low income zip codes are more than twice as likely to have a lack of adequate health care, inadequate support systems and no health insurance as residents in Milwaukee County’s higher income zip codes. A lack of diagnostic and treatment facilities in lower income areas is likely to exacerbate this problem.

Figure 3.3 also reveals that women in lower socioeconomic groups in Milwaukee County are nearly five times more likely to not have had a pap smear in the past three years. It seems

likely that women who are not being guided to regular screening pap smears are also not being guided to regular screening mammograms.



Source: Secondary Data Report, Summary of secondary data sources related to health in Milwaukee County 2012-13, Milwaukee Health Care Partnership.

**Figure 3.3.** Risk ratios in Milwaukee County for lowest socioeconomic groups

Overall, Milwaukee County has a full inventory of service providers (Figure 3.4). There are over 60 hospitals, community health centers, free clinics, mammography centers, and organizations within Milwaukee County that provide breast health/breast cancer services along one or more points of the continuum of care. Sites are located widely throughout the Target Community. However, the health system in Milwaukee County shows weaknesses in the way specific breast health and breast cancer services are distributed. As you progress along the continuum of care, provider locations become more clustered away from the City of Milwaukee.

Navigation to services is a strength throughout Milwaukee County. Nearly every site identified offers some level of navigation to screening, most offer navigation to diagnostics, and all diagnostic sites offer navigation to treatment. At the screening level, however, there may be room for improvement. While some health system respondents indicated that navigation to screening was a regular part of their interaction with the women they serve, there were several who more typically offered navigation to screening assistance only when their client initiated the topic of breast health. Few sites navigated eligible women to screening if they were being seen for a reason other than breast health. Many of the hospital and clinic sites were mainly concerned with navigating women back to screening mammograms through the use of reminder cards. Most of these reminder systems did not have robust follow up with women who did not return for their yearly mammogram.

Fifteen sites in Milwaukee County regularly offer clinical breast exam (CBE) screening, but only four of these facilities also offer screening mammograms. Of the four, one is a hospital

(Columbia St. Mary's), two are clinics that have regular visits from the Columbia St. Mary's Mobile Mammography Coach, and the last is the City of Milwaukee Health Department which, unlike most health departments, has an onsite clinic with mammography capability. The majority of locations providing screening mammograms did not supplement that diagnostic screening with an accompanying CBE.

There are 36 sites within Milwaukee County providing screening mammograms. Eleven of these sites are located in the lowest socioeconomic zip codes. Four of these sites are clustered within a mile of each other on the south side of the city creating basically only eight distinct site locations for screening mammograms in the county's lowest income areas.

According to the US Census Bureau 2010, Milwaukee County's poorest zip codes are 53204, 53205, and 53206 with median household incomes of \$22,602 to \$26,297. CBEs are offered at seven sites in these zip codes – five in 53204 and two in 53205. Two of these sites also offer the only screening mammograms in these areas - the City of Milwaukee Health Department and the Walker's Point Clinic that utilizes the Columbia St. Mary's Mobile Mammography Coach. No breast cancer screenings are offered in the 53206 zip code neighborhood.

The Columbia St. Mary's Mobile Mammography Coach is the only mobile unit currently in regular use in Milwaukee County. It has scheduled visits to five Milwaukee County clinic locations. Three are in the City of Milwaukee and two are in neighboring suburbs. Mobile mammography improves the access to screening mammograms in Milwaukee County's more vulnerable neighborhoods, but at the rate it is currently used does not sufficiently provide equity to screening access for all Milwaukee County women. There are more than twice as many options for breast cancer screening mammograms in the suburban areas of Milwaukee County as there are in the City of Milwaukee.

There are 21 sites offering diagnostic services in Milwaukee County. Nine of these sites only offer diagnostic mammograms and three others only offer diagnostic mammograms and ultrasound. Seven sites offer the full range of diagnostic services including diagnostic mammogram, biopsy, MRI, and ultra sound. The other two sites are located on the same hospital campus (St. Francis) and offer all of these services between them.

The health system inventory identified that the sites providing full diagnostic services were also the only sites providing treatment services. These sites (indicated with red stars in Figure 3.3) are predominantly located in zip codes areas of middle or high economic status.

Wheaton Franciscan's St. Joseph Hospital is the most notable exception to diagnostic and treatment facilities being located in higher income zip codes. St Joseph's is located in the 53210 zip code and is most accessible from zip code 53206 which, according to the US Census Bureau is the poorest zip code in Milwaukee County.

Other exceptions include Aurora St. Luke and Wheaton Franciscan St. Francis hospitals which are both located on the south side of the City of Milwaukee on the very perimeter of the lower socioeconomic 53215 zip code neighborhood.

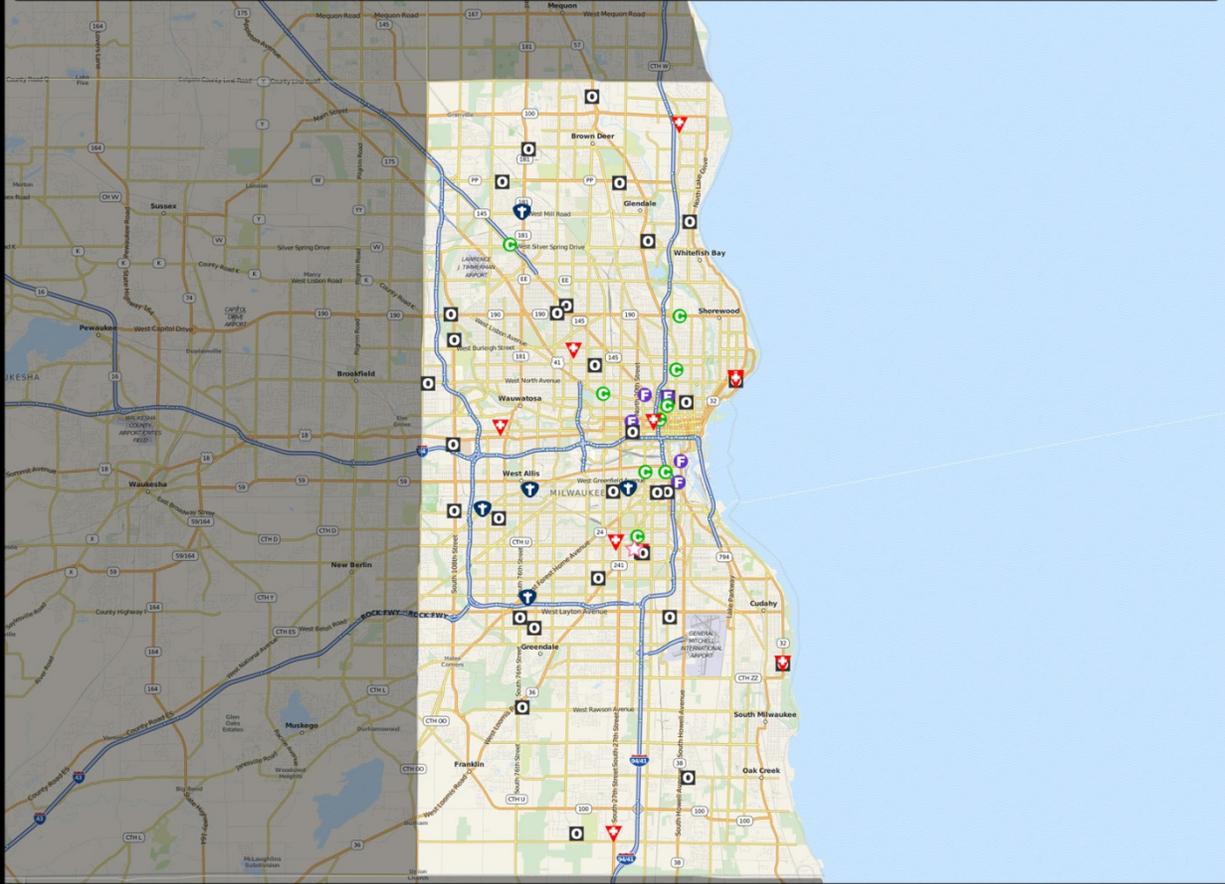
Breast cancer treatment and diagnostic services are geographically less available to Milwaukee County residents in lower socioeconomic areas. Transportation barriers to treatment and limited service hours are likely. It is also important to assess the Target Community for the effects of individual barriers related to the lack of familiarity and trust with larger health care

systems and breast cancer service providers outside of one's neighborhood. Because the majority of breast cancer services are located outside of Milwaukee County's most vulnerable areas, it is also essential for Komen Southeast Wisconsin to investigate the sophistication of the navigation systems in place in smaller facilities and organizations. The quality of this navigation greatly impacts a provider's ability to assist individuals in one area of the county in successfully accessing diagnostic and treatment services in another area of the county.

There are a limited number of health system led breast cancer support groups in Milwaukee County and most of them are located in the same facilities providing diagnostic and treatment services. Three support groups are located in low socioeconomic zip codes, one in the middle, and two in the high socioeconomic zip codes. Counseling, diet/exercise programs, and complementary therapies are all available, but not widespread in Milwaukee County. However, survivorship services can certainly be seen as a strength for Milwaukee County. The After Breast Cancer Diagnosis (ABCD) organization plays an extremely vital role in supporting the mind, spirit, and body of all Milwaukee County breast cancer survivors regardless of income or location. ABCD's Helpline and its One-on-One Mentoring Program provide equal access to support for survivors throughout Milwaukee County. Individualized service maximizes ABCD's ability to educate, support and navigate every breast cancer they assist. Organizations such as Komen, ABCD, American Cancer Society (ACS) and others work together to provide services, information, and navigation to women along all points of the breast cancer continuum of care to local resources available in Milwaukee County.

# Milwaukee County

 Hospital	 Community Health Center	 Other
 Free Clinic	 Department of Health	 Affiliate Office



## Statistics

Total Locations in Region: 68

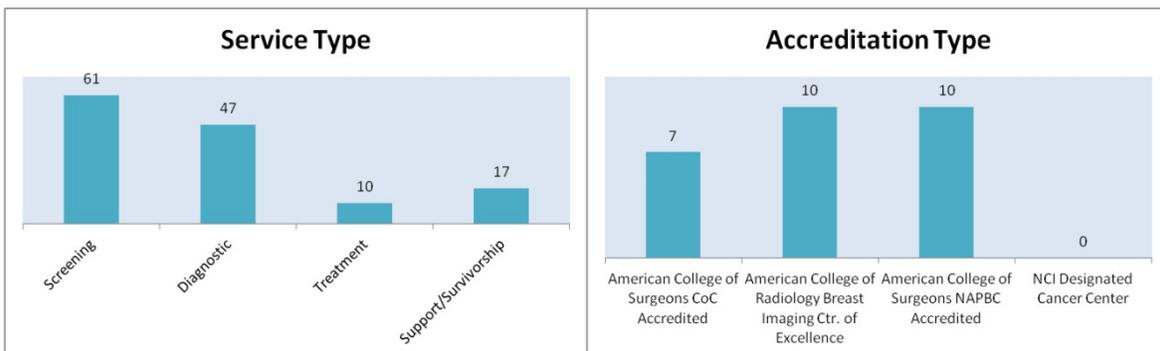


Figure 3.4. Breast cancer services available in Milwaukee County

### ***Northern Rural Region (Ozaukee and Washington Counties)***

Assessment in the Northern Rural Region is especially important in light of the fact that both of its counties, Washington and Ozaukee, indicate some of the highest needs in the Komen Southeast Wisconsin's service area. Demographically, the region seems at low risk so an investigation of the strengths and weaknesses of the health system in the Northern Rural Region is essential to help identify the factors that make this Target Community at such high risk. The area as a whole has an inventory of twenty service providers. However, provider locations are clustered within a limited number of city centers.

Washington County has the highest age-adjusted breast cancer death rate and the third highest age-adjusted breast cancer incidence rate in the Affiliate's service area. It is a full 13 years away from achieving the Healthy People 2020 target of 20.6 BC deaths per 100,000 women. The county also appears to have a greater number of late-stage breast cancer diagnosis than other similarly sized counties in Southeast Wisconsin.

In Washington County, the only sites for provider locations are West Bend (mid-county) and Harford (mid-west county) (Figure 3.5). Overall there are six sites in Washington County that provide CBEs. Of these, four sites also provide screening mammograms in the county. The number of screening sites is fairly large for the population of Washington County; however, the geographical reach is limited to two city centers.

When assessing Washington County for diagnostic and treatment resources, the inventory is less robust. Centrally located Froedtert's St. Joseph Community Hospital in West Bend offers full diagnostic services; however, Froedtert is not a Wisconsin Well Woman or Komen SEWI's Kohl's Southeast Wisconsin Breast Health Assistance Fund Provider. Women utilizing funding from either of these programs can receive diagnostic services in Washington County's Aurora facilities. The Aurora Medical Center in Hartford (center western location) offers full diagnostic services between its two closely neighboring facilities. The Aurora Medical Center in West Bend offers just diagnostic mammogram and ultrasound.

Residents of the Northern Rural Region have only one option for breast cancer treatment in Washington County. Froedtert's St. Joseph Hospital in West Bend offers the full range of breast cancer treatments from surgery and reconstruction to chemotherapy and radiation. Women needing to utilize WWWP or Komen funding must travel out of Washington County for those services.

Neighboring Ozaukee County carries the Affiliate's highest age-adjusted breast cancer incidence, the third highest age-adjusted breast cancer death rate, and is five years out for achieving the HP2020 breast cancer death rate targets. While not as prevalent as Washington County, Ozaukee also has a relatively high number of late-stage breast cancer diagnoses when compared to Komen SEWI's other Target Communities.

In Ozaukee County, there is a concentration of continuum of care service sites in Mequon, Cedarburg, Grafton, Saukville and Port Washington, all located along the expressway system. These sites fall mainly in the middle and southern eastern areas of the county. Overall, Ozaukee County has eight sites providing CBEs and nine locations that provide screening mammography. Similar to Washington County, an impressive seven sites provide both screening services. The Northern Rural Region is fortunate to have a much higher prevalence

of health systems providing CBEs along with mammography than providers in other Target Communities. However, while the number of sites seems fairly extensive, the geographical reach is limited as pointed out previously.

Contributing to the high number of mammography screening sites is Columbia St. Mary's (CSM) Mobile Mammography Coach. CSM expanded its outreach and mobile program into Ozaukee County with the help of a Komen grant in 2013. This has added three screening mammogram sites to the county at CSM clinics in Saukville, Grafton, and Cedarburg. While increasing the number of screening sites and locations, mammography sites in Ozaukee County are still only found in the southeastern areas and, thus have limited impact on the vast rural areas in this Target Community as a whole.

Diagnostic and treatment resources in Ozaukee County are less robust. Columbia St. Mary Hospital in Mequon and Aurora Medical group in Grafton (both on the county's southern border) offer full diagnostic services. Aurora Medical Center in east Mequon offers all diagnostic services except MRI. Partial diagnostic services potentially require patients to seek additional services at another day requiring additional scheduling, travel, and time.

The options for breast cancer treatment in Ozaukee County are even more limited with full treatment options only available at Columbia St. Mary Hospital in Mequon located on the far southern edge of the county. Breast cancer treatment is also available at two Aurora systems in Ozaukee County. Surgery and reconstruction services are available at the Aurora Medical Center in Grafton while chemotherapy and radiation are provided at the nearby Aurora Cancer Care Center.

While neither county in the Northern Rural Region has a Federally Qualified Health Center, both Washington and Ozaukee Counties do have free clinics. Washington County's Dr. James E. Albrecht Free Clinic is located in West Bend and Ozaukee County's Huirus Family Ozaukee Community Health Clinic is in Mequon. Both of these clinics are located in two of the most populated city centers in the Target Community. So, while valuable, they are providing service alongside the other existing health services. Neither provides convenient access to residents in the more rural regions of the Target Communities. The Huirus Family Clinic is located on the far southern edge of Ozaukee County and the Albrecht Clinic, although more central, is miles away from rural residents in both counties.

Both counties in the Northern Rural Region also have health departments. Again, each is located in a city center - Washington County in West Bend and Ozaukee County in Port Washington. Each county also has a Wisconsin Well Women (WWW) coordinator working at the local health department to assist low income, under and uninsured women receive financial assistance through the WWW program. These coordinators and other health department staff are tuned into the needs of their counties and provide breast cancer navigation to screening and diagnostic services. Limited time, staff, and resources in addition to the coordinator's city-center office location put limits on the both health departments' ability to affect the breast health of more outlying rural regions.

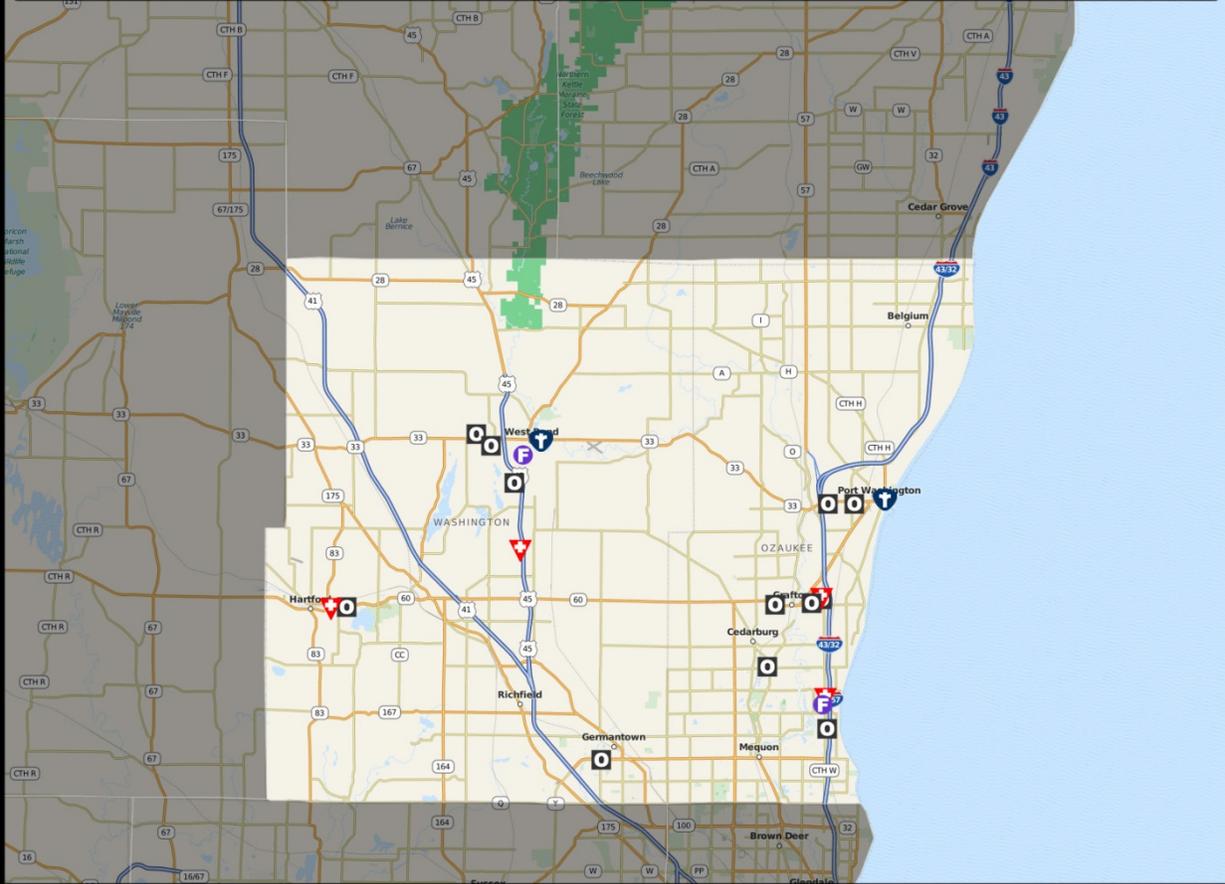
Navigation to services is a strong component of the health systems in the Northern Rural Region. Free clinics, health departments, and the majority of screening facilities basically all provide navigation to screening and diagnostics. Those facilities providing diagnostic services

provide especially strong, individualized navigation to treatment. In order to begin to understand the high need statistics of this Target Community, the nature of navigation to screening must be further investigated.

Kohl's Conversations for the Cure (CFTC) has an emerging presence in the Northern Rural Region holding about five conversation events in 2013 -14. However, there were no local leaders available in this region until late 2014 when three CFTC leaders were trained in Washington County, greatly increasing the capacity of the program. The continuing challenge for the Northern Rural Region, as with the other service providers, is to get services into the non-city areas of the region. A thoughtful expansion of CFTC in the Northern Rural Region has the potential to make a large impact.

# Northern Rural Region

	Hospital		Community Health Center		Other
	Free Clinic		Department of Health		Affiliate Office



## Statistics

Total Locations in Region: 20

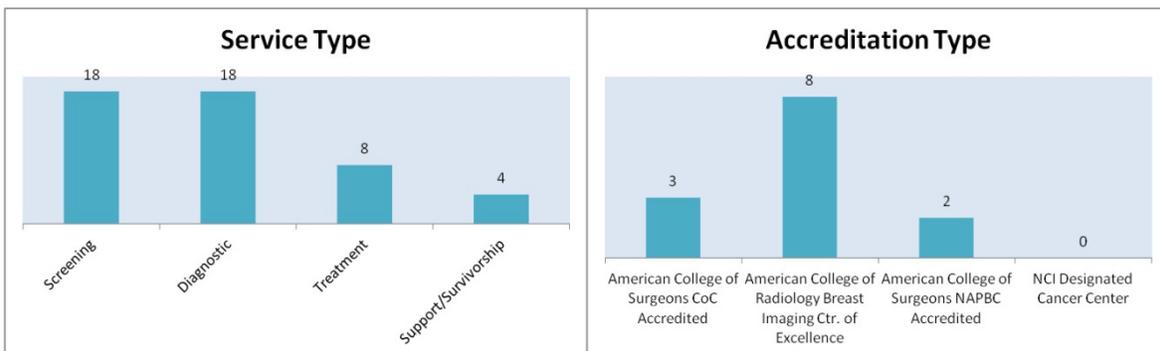


Figure 3.5. Breast cancer services available in Northern Rural Region

## ***Racine County***

Racine County has a relatively small health system inventory with an evident disparity of service locations (Figure 3.6). Racine County has seven locations for a woman to receive a clinical breast exam and six locations for women to obtain screening mammograms. However all but one of the sites providing service are located within the City of Racine which is on the far eastern side of the county. There is one location, Burlington Memorial Hospital located in the Southwestern part of the county, which offers both CBEs and screening mammograms. Women living in rural parts of the county need to travel to Burlington or Racine to receive screenings, a distance that could be over 30 miles. The Health Care Network and the Racine Community Health Center offer free or low-cost screenings to women with no insurance. The Wisconsin Well Woman Program also provides financial assistance to qualifying women for screening and diagnostic services within Racine's major health systems. An option that seems to be lacking in Racine County is mobile mammography, as no services were found. Mobile service could be a great equalizer in Racine County's otherwise unbalanced breast cancer screening scenario.

Racine County is Komen Southeast Wisconsin's second highest need community in terms of Healthy People 2020 goals. Racine County breast cancer death rate is higher than the state rate and the Affiliate rate as a whole. Breast cancer deaths for the county are falling slowly and Racine is not expected to reach preferred target rate for breast cancer deaths for eight years. All of this seems likely to be related to the fact that Racine has one of the Affiliate's lowest mammography rates and the limited availability of screening in the county may be suspected of playing a role.

The Racine County Mammography Coalition was formed to address the need for greater screening in Racine County. This Coalition is a cooperative effort between six community partners to educate, navigate, and ultimately screen low income, under and uninsured women in Racine County. These organizations are a combination of outreach and education organizations, health service providers with breast cancer services across the CoC, and the Racine Health Department - Wisconsin Well Women Program.

While the statistics for Racine County are not yet ideal, the coalition efforts have contributed to the increase in mammography screening numbers from its inception to present. There is more work to do and perhaps additional partners to be recruited. The Coalition has demonstrated an ability to be flexible to the needs of the community. In 2014 a change was made to add a partner in Burlington that provided a new access point for women in the western portion of the county.

The education role that the coalition plays is critical. The outreach organizations each specialize in reaching their specific demographic and conveying breast self-awareness to women in Racine County. Women in rural areas without nearby health system sources have few opportunities to access this kind of information.

If an abnormal finding is detected on a screening requiring further diagnostic testing, women in Racine County must travel to one of the area hospitals: Wheaton Franciscan All Saints, Aurora Health Center, or Burlington Memorial. Health facilities in the Target Community that do not offer diagnostic services navigate women to these services, often through the Wisconsin Well Woman Program. The Well Woman Coordinator for Racine is the Project Director of the Racine

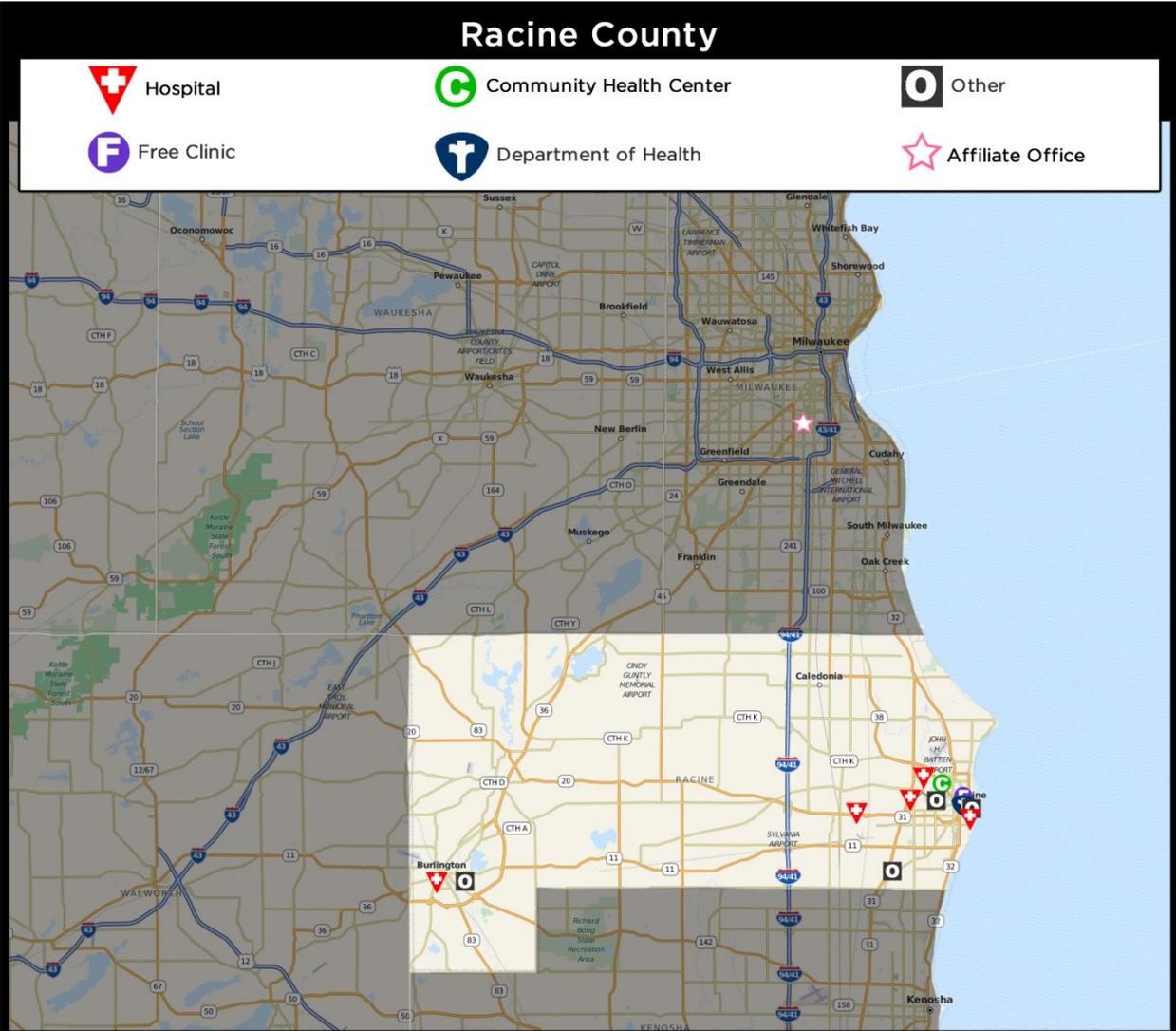
County Mammogram Coalition. Women are efficiently navigated to diagnostic service however those services are, as before, very geographically slanted to the east side of the County. Burlington Memorial is once again the only provider in the more rural western portion of the county.

Three hospitals are also the only providers for the full spectrum of breast cancer treatment services in Racine County – Wheaton Franciscan All Saints and Aurora Health Center are both in the City of Racine, Burlington Memorial Hospital is in the southwest section of the County. Wheaton Franciscan has a satellite office that is dedicated to plastic and reconstructive surgery. The Health Care Network and the Racine Community Health Center are able to navigate patients into these services from their locations. The fewest services are offered in the support section of the CoC, but Burlington Memorial and Aurora Health Center offer the full spectrum except for end of life care, and legal/financial services. These limited locations point to suspecting transportation issues.

Wheaton Franciscan does have general support with support groups and complementary therapies available. This is a weakness with Racine's services, as women living in rural areas would have to travel a distance to utilize support services available. Although not directly located in Racine County, After Breast Cancer Diagnosis can provide essential individualized support services to Racine County breast cancer survivors via their 24 hour hotline and by carefully matching survivors to a one-on-one support mentor.

Despite the clustering of service facilities nearest to city of Racine, transportation could still be an issue even for city residents. Facility hours and after hours public transportation access could be in play. There may be other factors keeping women from fully utilizing health systems that are relatively close. Diagnostics and treatment and the majority of screenings are taking place in large hospital systems. Individual barriers to service could include a discomfort or mistrust of hospital systems. While WWW and other funding agents are available, financial barriers may still exist for those not knowing about those resources or how to access them.

The number of service points is limited for a county as large as Racine. While the City of Racine has many options for service along the CoC, most of the sites identified are larger provider facilities. There is only one community center and one free clinic available. Once again they are both located in the City of Racine, far from the outer rural sections of Racine County.



### Statistics

Total Locations in Region: 12

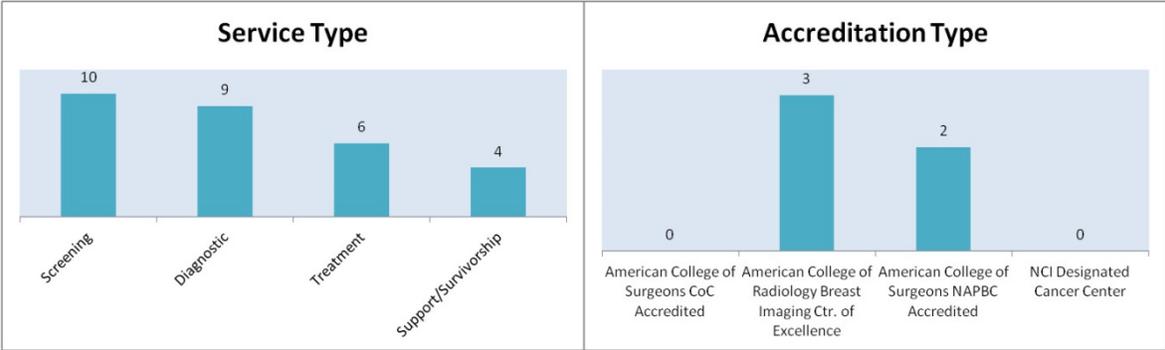


Figure 3.6. Breast cancer services available in Racine County

## **Waukesha County**

As the service area's second largest county, Waukesha County has a broad range of health system providers available (Figure 3.7). There are five hospitals in Waukesha, three free clinics, a FQHC community health center, two unique support service providers, and a number of additional resources.

Navigation in Waukesha County is consistently available within the health care systems. The Wisconsin Well Woman Program is an active navigator to screening and diagnostic services for low income women in the Target Community where over 14 percent of the population lives below 250 percent of the Federal Poverty Level. ProHealth Care's Hispanic Resource Center actively provides outreach and education in order to identify low income, under and uninsured Hispanic/Latina women to navigate to screening mammograms. Their goal is to increase mammography rates among the county's 4.1 percent Hispanic/Latina population, but their services are open to all women.

In total, there are 22 sites that provide screening CBEs. Of these facilities, 17 also provide screening mammograms. There are 19 facilities in all providing screening mammograms in this Target Community. These numbers are extremely high in comparison to the rest of the Komen Southeast Wisconsin service area counties. Facilities are predominantly present in four major areas of the county and are mostly situated along the path of the major freeway systems that cut through Waukesha County.

In general, service site distribution is very broad. Of the three free clinics, one is in the City of Waukesha (Central east border area), one is in Menomonee Falls (far northeast corner) and the third is in Oconomowoc (far northwest corner). There is a FQHC community health center in the City of Waukesha. Additional sites providing screening, at least some level of diagnostic and, in some cases, treatment services are located in other Waukesha County city centers including Brookfield, Mukwanago, Summit, Muskego, Pewaukee and New Berlin.

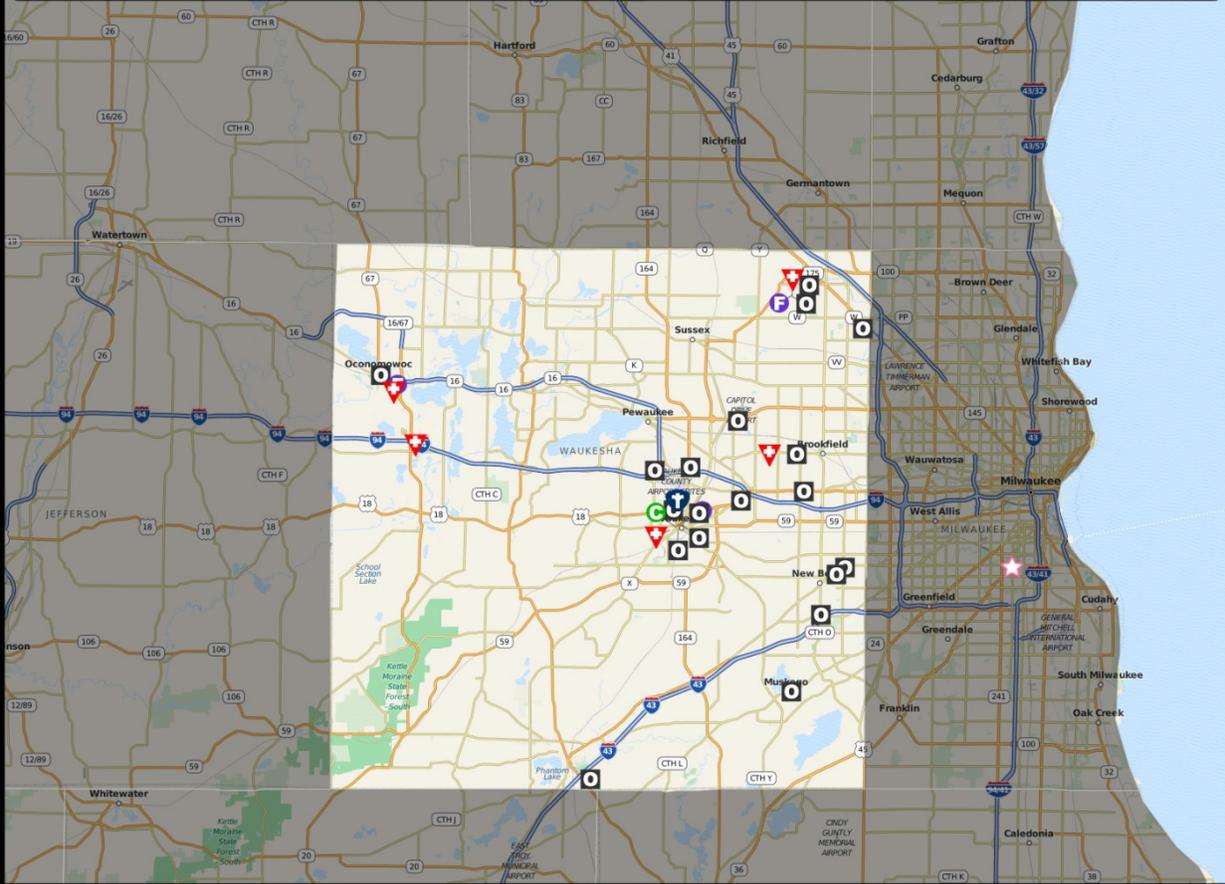
As complete as this inventory appears, there is still a potential weakness in the distribution of these services in this geographically large county. There is a large area with no service providers - predominantly in the southwestern quadrant of the county. Towns such as North Prairie, Dousman, Genesee Depot, Eagle Wales, and Waterville are miles from the nearest screening facility making transportation and may be a barrier to breast cancer services. The lack of providers in these mainly rural areas also puts into question the availability of breast health outreach efforts providing accurate breast health information and information on available resources.

Waukesha County has 17 sites providing diagnostic services. There are six providers offering a spectrum of diagnostic services including Diagnostic mammograms, biopsy, Ultrasound, and MRI's in Waukesha, Menomonee Falls, Oconomowoc, and Summit. Another two associated facilities provide full diagnostic service in Brookfield as well (Elmbrook Hospital and Pavlic Center). Six providers in various city centers offer diagnostic mammograms and ultrasound, the free clinic in Waukesha provides ultrasounds. The remaining two facilities offer diagnostic mammograms, ultrasound, and the addition of either MRI (Waukesha) or biopsy (Menomonee Falls). Women have a wide variety of resources to choose from for diagnostic screening, but the same potentially troubling distribution pattern appears in the site locations of the diagnostic portion of the CoC as appeared with screening sites.

The full range of breast cancer treatment services (surgery, reconstruction, chemotherapy, and radiation) are available in five facilities located in five different cities – Menomonee Falls, Waukesha, Brookfield, Summit and Oconomowoc. For treatment services, the distribution of facilities is entirely in the northern half of Waukesha County leaving the entire southern section of the county without local treatment options. Travel becomes a barrier to the treatment portion of the CoC. Waukesha County residents living in the southern section of the county must travel considerable distances into northern Waukesha County or equal distances south into neighboring Walworth County.

# Waukesha County

+ Hospital     
 C Community Health Center     
 O Other  
F Free Clinic     
 + Department of Health     
 ☆ Affiliate Office



## Statistics

Total Locations in Region: 29

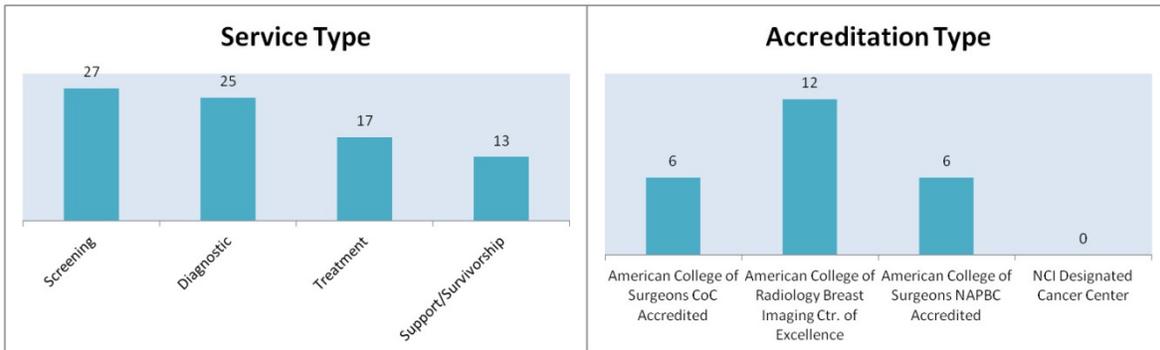


Figure 3.7. Breast cancer services available in Waukesha County

### ***Southern Rural Region (Kenosha and Walworth Counties)***

Assessment of the Southern Rural Region shows a small inventory of health care providers for the regions two counties, Kenosha and Walworth (Figure 3.8). The health system inventory for this Target Community consists of fifteen total providers and the distribution of these sites is very unbalanced. Additionally, while Kenosha and Walworth Counties show lower risk demographics overall, both counties contain multiple census tracts whose residents live in extreme levels of poverty in comparison to the rest of the residents in the Southern Rural Region. It is especially important to compare the location of the available service sites with the location of these lowest socioeconomic population clusters.

*In Kenosha County* there are five facilities that offer CBEs. Four of them are located in the City of Kenosha and the fifth is in nearby Pleasant Prairie. There are only four sites in Kenosha County that offer screening mammograms. Only two of these sites (one in the City of Kenosha and the other in Pleasant Prairie) are sites that also offer CBEs. The two other Kenosha County sites offering screening mammograms are both located in the City of Kenosha.

There are six facilities providing diagnostic services in Kenosha County. United's Kenosha Medical Center and Aurora Medical Center both provide full diagnostic services (diagnostic mammogram, ultrasound, biopsy, and MRI) in the City of Kenosha. St. Catherine's Hospital in the City of Pleasant Prairie also provides full diagnostic services. The Aurora Cancer Care in the City of Kenosha provides only diagnostic mammograms. There are also two imaging centers located in the City of Kenosha. Kenosha Radiology provides all diagnostic services and MH Imaging provides ultrasound and MRI. Every facility are all located on the far eastern side of the Target Community .

Treatment Services are offered at four facilities within Kenosha County. An individual can receive the full range of treatment services including surgery, reconstruction, chemotherapy, and radiation at St. Catherine's Hospital in Pleasant Prairie. In the City of Kenosha, Aurora Medical Center provides surgery and reconstruction and the Aurora Cancer Center provides chemotherapy and radiation . United's Kenosha Medical Center provides surgery and reconstructive services only.

Kenosha County has a health department located in the City of Kenosha, alongside the majority of the county's other service providers. Kenosha's health department is unique in that there is a nurse on site and is able to provide screening CBEs. The Wisconsin Well Woman Program is also housed out of the health department providing strong service and financial navigation for low income and under/uninsured women.

Kenosha County does not have a free clinic, but does have an FQHC called the Kenosha Community Health Center (KCHC). KCHC has two City of Kenosha locations and offers a full range of health services including CBEs and navigation to additional breast health services.. A 2012-13 Komen Grantee, KCHC has a strong commitment to and presence in Kenosha County. Both KCHC sites are located in the City of Kenosha so there is no FQHC presence in the western portion of Kenosha County.

Support services are limited in Kenosha County. While financial services are provided at all the health facilities that offer breast cancer diagnostics and treatment, other support services are more sporadic. St. Catherine's in Pleasant Prairie provides side effect management, personal

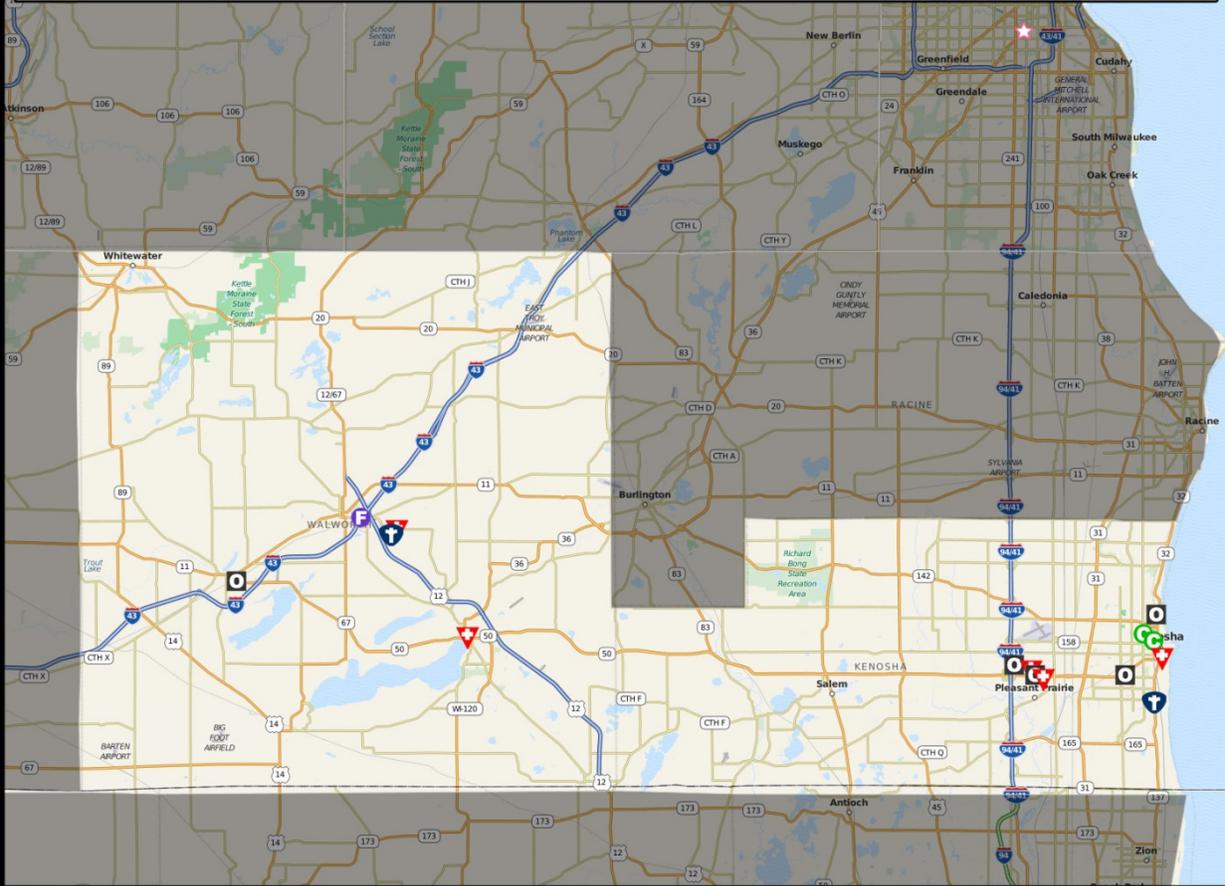
counseling, and the only provider support group in Kenosha County. United Medical Center has counseling services available while Aurora's Cancer Care Center in the City of Kenosha offers side effect management, some exercise/nutrition options, and is the only site that reported providing complementary therapies.

*In Walworth County* there are three distinct locations that provide CBEs – health providers in Lake Geneva and Elkhorn, and Planned Parenthood in Delavan. There are only two providers for screening mammograms in Walworth County. Both are located in the center of the county in the cities of Elkhorn and Lake Geneva. Walworth's screening service sites are few and the distribution of these facilities weakens access to screening services even further for women in the county's predominant rural areas. Racine County to the north offers an additional central screening location in Burlington, but the distance to screening facilities remains sizeable for a large portion of the Target Communities' residents.

There are three diagnostic service sites in Walworth County. Aurora Lakeland Hospital in Elkhorn provides the full range of diagnostic services (screening mammography, ultrasound, biopsy and MRI). Mercy Hospital in Lake Geneva offers diagnostic mammogram, ultrasound and biopsy but does not provide MRI's. The only other diagnostic service provider in Walworth County is the Open Arms Free Clinic in Elkhorn where women can receive only diagnostic ultrasounds. The access to diagnostic services is extremely limited and once again residents of this Target Community have few options and long distances to navigate.

# Southern Rural Region

Hospital  
 Community Health Center  
 Other  
 Free Clinic  
 Department of Health  
 Affiliate Office



## Statistics

Total Locations in Region: 15

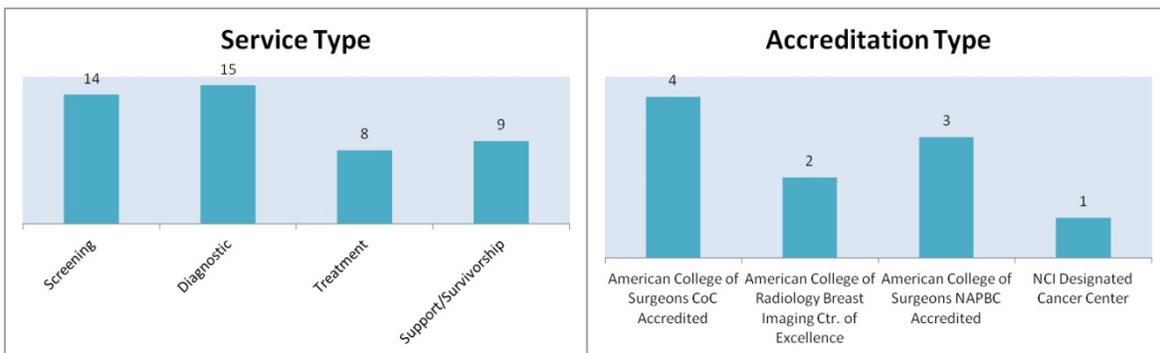


Figure 3.8. Breast cancer services available in Southern Rural Region

## **Mission Related Partnerships**

Komen Southeast Wisconsin strongly believes and relies on the power of partnerships. The Affiliate is proud to stand as a strong local leader and understands the importance of working side by side with other organizations whose missions are similar in the fight to end breast cancer forever.

There are a number of key Mission related partnerships in place across the entire Komen Southeast Wisconsin service area that are beneficial to the work in every Target Community.

### ***Partners for all Target Communities include:***

#### ***Breast Cancer Education, Awareness and Outreach Partners***

***Kohl's Conversations for the Cure (CFTC) - Komen*** Southeast Wisconsin is fortunate to have a strong partnership with Kohl's Cares allowing the Affiliate to provide an in-house breast cancer education program to its entire service area. Kohl's Conversations for the Cure is a program that provides educational sessions where women can talk openly about breast cancer and the potential impact it can have on their lives. The goal of these sessions is to encourage women to get regular breast health screenings, thereby increasing survival rates throughout Southeast Wisconsin. The program director and Program Assistant work to train leaders within the community as well as identify potential events and venues at which to hold Conversations. The Affiliate utilizes CFTC to dramatically expand its outreach and education potential in all Target Communities. In addition, the CFTC Breast Self Awareness curriculum is shared with all Komen grantees.

**Wisconsin Breast Cancer Task Force (WBCTF)** - The WBCTF is convened by the Wisconsin Comprehensive Cancer Control Program and its partnership organization, the Wisconsin Cancer Council, in collaboration with Wisconsin Well Woman Program and the American Cancer Society. The goal of the Task Force is to improve breast cancer screening percentages in Wisconsin. Komen Southeast Wisconsin benefits from connections made with WBCTF's more than 90 representatives of local, regional and statewide organizations and is active on both the public education and provider outreach teams.

**Milwaukee Regional Cancer Care Network (MRCCN)**- Initiated through the Center for Urban Population Health + Partnerships for Healthy Milwaukee, MRCCN is an integrated effort of public and private partners to develop and implement a statewide approach to cancer control. The Network provides a forum for people across the CoC to work together to improve the accessibility, quality, effectiveness, and efficiency of cancer care to improve patients/co-survivors lives.

**American Cancer Society(ACS)** – ACS is a nationwide, community-based, voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service. Komen SEWI and the American Cancer Society staff are strong supporters of each other's overlapping mission events and initiatives.

**Area Health Education Centers (AHEC)** – Federally and State funded health professions education and outreach program that seeks to improve access to quality health care by developing community-based health professions training programs and enhancing health

education resources across the state. One of AHEC's program goals is to partner with local organizations in a variety of outreach activities to improve the health of the community.

### ***Treatment Partners***

**Marshfield Mobile Mammography Program** – Marshfield Clinic, a highly respected health system in Wisconsin, has built a strong mobile screening mammography program and has been in contact with Komen Southeast Wisconsin to partner in an effort to expand their program into Southeast Wisconsin. As of August 2014, the program has three mammography coaches. One also houses equipment to measure bone density and another is also able to offer primary care services. Efforts are underway to utilize the Marshfield resources with the goal of expanding the availability of screening mammograms in Komen's service areas. The coach offers great potential for the Kohl's Conversation for a Cure Program as well as broad use in future Komen Small and Community Grant Program.

### ***Financial Assistance Partners***

**The Kohl's Southeast Breast Health Assistance Fund and the Wisconsin Women's Health Foundation** - Kohl's continues its strong support of Komen Southeast Wisconsin as the partnering funder of this grantee administered Komen fund. The Wisconsin Women's Health Foundation provides effective, efficient administration of this fund as well as compassionate customer service to under and uninsured women under 400 percent of the Federal Poverty Level. The fund helps provides financial assistance for breast cancer screening and diagnostic services as well as access funding for breast cancer survivors. The fund is a collaborative partner of all Komen Community Grantees.

**The Wisconsin Well Woman Program (WWWP)** - WWWP is the state program for the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). WWWP provides preventive health screening services to women at 250 percent of the the Federal Poverty Level who have little or no health insurance coverage. Well Woman pays for screening mammogram, diagnostic mammograms, and additional diagnostic tests. Women diagnosed with breast cancer can necessary financial assistance through the WWWP's Medicaid funding arm. The program is administered by the Wisconsin Department of Health Services, Division of Public Health, and is available in all of Komen's service counties.

**Local health departments** – Each county in Wisconsin is required to provide community health services through a local Health Department. Each of Komen SEWI's service counties has at least one local Health Department. In addition to providing community based health information and services, the local health departments are the agencies that house the Wisconsin Well Woman Coordinators who are essential in navigating low income, under and uninsured women to affordable breast cancer screening, diagnostic, and treatment services.

### ***Survivorship Services Partners***

**After Breast Cancer Diagnosis (ABCD)** - ABCD's mission is to provide free, personalized information and one-to-one support to people who are affected by breast cancer. While science searches for a cure, ABCD complements the work of health care providers by serving as a reliable, accessible and highly personalized resource for breast cancer patients and their loved ones.

ABCD is headquartered in Glendale within Milwaukee County and provides unparalleled individualized support services. Komen and ABCD share founding roots and have a strong mission partnership that adds strength to each organization. ABCD provides essential support services in every Target Community and, in fact, now provides support on a national level through the expansion of its help line in 2013. The services of ABCD's staff and organization are critically helpful to the advancement of Komen Southeast Wisconsin's mission

**Stillwaters Cancer Support Services** – Counseling center providing individual and family counseling, Support groups, workshops, Caregiver support, as well as breast cancer information and resources to individuals affected by a cancer diagnosis. All services are provided free of charge to anyone seeking assistance. Stillwaters is located within the Waukesha County Target Community, but also regularly provides services at health care facilities throughout the Komen Southeast Wisconsin service area and has office space in Milwaukee County within ABCD and The Harry and Rose Sampson Family Jewish Community Center.

**Young Survivor Coalition** – YSC connects, educates, and supports young women affected by breast cancer.

**FORCE** - national nonprofit organization with a strong local ambassador devoted to hereditary breast and ovarian cancer. FORCE's mission includes support, education, advocacy, awareness, and research specific to hereditary breast and ovarian cancer. Their programs serve anyone with a BRCA mutation or a family history of cancer.

#### ***Advocacy Partners***

**Wisconsin Breast Cancer Coalition** – WBCC brings Wisconsin voices together to stand up and speak out about breast cancer. They are a statewide organization recognized as the premier resource on breast cancer policy issue. WBCC provides education on issues and makes alliances with organizations including Komen Southeast Wisconsin, and advocates for legislative action that supports equal and optimal breast health for all Wisconsin women.

There are many additional existing key Mission related partnerships and collaborations already in place at the Affiliate that are specific to one or more of the Target Communities. Many are long standing and others are newly begun with the potential of being developed into effective working relationships. A few are older relationships that Komen Southeast Wisconsin will rekindle to explore current partnering opportunities. The following summary of these partner organizations illustrates that the development of Komen's organizational networking has, up to this point, varied widely by county.

#### **Mission Partners by Target Community**

##### ***Partners in Milwaukee***

As the most populated County in Komen Southeast Wisconsin's service area and the location of both the Affiliate office and the annual Race for the Cure, Milwaukee County is home to many existing mission related partner organizations. The need for breast health and breast cancer services in Milwaukee County is great and the following partner organizations have been and will continue to be strong partners to the Affiliate in making strides against breast cancer in this Target Community.

*Partners for the Promise* (a Komen Grantee) and *Nurses Affecting Change* are two such organizations that have a large impact in the City of Milwaukee by providing no cost Clinical Breast Exams to thousands of low income, un/under insured women in the City of Milwaukee.

The *Milwaukee Health Department* is one of the most effective partners for eliminating barriers to screening for Women in the City of Milwaukee. Besides providing effective and caring coordination of the Well Woman Program in Wisconsin's largest city, the health department also has an onsite clinic that provides both CBEs and screening mammograms. Their location in the 53204 zip code neighborhood places them squarely in the most impoverished area of Milwaukee County.

*Wisconsin Well Woman Program* – In addition to the Milwaukee WWW program, Milwaukee County has its own WWW coordination. As mentioned earlier, WWW is integral to eliminating barriers to breast cancer screenings for low income, un/under insured women and is one of the Affiliate's most valued partners. WWW is a key partner to Komen Southeast Wisconsin's Grant Program and an essential collaborating partner with every Komen grantee.

The *Columbia St. Mary's Mobile Mammography Coach* plays a fundamental role in bringing mammography into areas of Milwaukee County that are in need a service providers. The coach has routine schedules at five Milwaukee County health clinics expanding their service capacity from CBEs to screening mammography. Especially impressive is that Columbia St. Mary Health System has chosen to have the mobile coach serve clinics beyond those within their own health system. In addition to clinic visits the coach also has regularly scheduled visits to corporations in Milwaukee County making regular screening mammography more convenient for their employees. The coach also provides mammography service for many local organizations in Milwaukee County such as Pink Shawls and the Muslim Community Health Center (through Komen grantee Medical College of Wisconsin)

*The Wisconsin Pink Shawls Initiative* mission is to reduce breast cancer in American Indian communities through education, advocacy and service and to increase the number of American Indian women accessing screening opportunities. Komen has a great partner in Pink Shawls as a major arm of the Conversations for the Cure program, as well as a consistent mission partner in all Komen Affiliate events and initiatives.

Komen Southeast Wisconsin also has important partners in its current and former Milwaukee County grantees including:

- African-American Outreach Program - Wheaton Franciscan St. Joseph's
- Su Salud Program – Wheaton Franciscan St. Francis
- Milwaukee Health Services Inc.
- Medical College of Wisconsin
- 16<sup>th</sup> Street Community Health Clinic
- Milwaukee LGBT Community Center
- Planned Parenthood
- Word of Hope Ministries

Newer mission relationships that have potential for strong future collaborations include:

- Core El Centro
- UW Milwaukee – Zilber School of Public Health

- Gerald Ignace Indian Health Center
- YMCA of Milwaukee
- Salvation Army clinic

### ***Partners in Northern Rural Region***

Columbia St. Mary's Mobile Mammography Program – This Milwaukee based program has extended its reach into Ozaukee County (the eastern half of the Northern Rural Region and delivers regularly scheduled mammography opportunities to multiple locations in the county, including Germantown, Mequon, and Grafton.

### ***Partners in Waukesha***

*Hispanic Resource Center* – Operated by Waukesha Pro Health, this center uses a community health worker and outreach model to support the needs of Hispanic/Latina females in the Waukesha County area, encouraging these individuals to obtain mammograms at regular intervals.

*Stillwaters Cancer Support Services* – Headquartered in Waukesha, this community-based, not-for-profit agency exists to serve persons with cancer and those who love them. Stillwaters nurtures, supports and encourages healing of the whole person; mind, body and spirit by providing professional psychological, social and emotional support services that complement the efforts of medical professionals and other cancer organizations. Stillwaters' services include professional counseling for individuals and families, professionally facilitated support groups, workshops and grief services. All services are provided at no cost.

### ***Partners in Racine***

*Racine Mammography Coalition* – A unique collaboration between multiple organizations and health systems in Racine County. Each organization provides outreach and education in line with their individual mission. Women are navigated to mammograms at the health system most convenient to them. Partners include the Wisconsin Well Women Program, the Burlington Transitional Living Center, The Jane Cremer Foundation, Wheaton Franciscan All Saints Hospital System, All Saints Bosom Buddy Program, Aurora Health Care Center, and the Health Care Network.

### ***Partners in Kenosha***

*Kenosha Community Health Center (KCHC)* - A Federal free clinic established in 1995, KCHC addresses the financial, cultural, and language barriers that prevent access to health care. As a not-for-profit charitable organization, KCHC provide affordable and quality primary medical, dental and behavioral health care. KCHC prioritizes the delivery of breast health information and navigating individual to breast cancer screenings, diagnostic, and treatment services.

### ***New Potential Mission Partners by Target Community***

The Community Profile compels the Affiliate to also explore new potential partnerships and collaboration opportunities that will help Komen Southeast Wisconsin address the needs found within its Target Communities. Completing the Health System inventory provided a unique opportunity to interface with dozens of service providers across the entire service area. This assessment also had the added benefit of providing insight into the work being done at hospitals, clinics, and organizations throughout Komen Southeast Wisconsin's five Target Communities. Connections made during this portion of the Community Profile resulted in

numerous introductions to potential new partners for future collaborations and/or future community Grant applicants.

A purposeful online search also uncovered multiple potential partners in the Affiliate service area as a whole, as well as within each Target Community. Partnerships provide the potential to create new avenues to the continuum of care, especially for low income, under and uninsured individuals. It is essential that both Komen Southeast Wisconsin and current/future grantees make diligent efforts to seek out and collaborate with government, community and private organizations that have the potential to provide the connections and resources to make the Affiliate's Community Grant and Small Grant programs optimally successful and effective. New connections made during the health system inventory assessment will be fostered into new partnerships. These connections included key individuals at community health clinics, free clinics, support services, as well as breast cancer navigators and providers throughout the health systems.

Other promising partnerships that could benefit all Target Communities include:

- Local health department employees/nurses/www navigators,
- Rural Policy Research Institute
- Planned Parenthoods – numerous locations throughout the target communities
- Local YMCA's,
- Senior centers,
- Neighborhood associations,
- UW extension offices,
- Wisconsin Women's Business Initiative

Additional partnership potential with specific organizations should be explored within each Target Community. While the following list is by no means all inclusive, some examples of new possible partner organizations for Komen Southeast Wisconsin as well as for its Community Grant recipients include:

#### **Milwaukee County**

- Outreach Community Health Center
- Progressive Community Health Center
- Goodwill industries
- Milwaukee African-American Nurses Association, Inc.
- Center for Urban Population Health

#### **Northern Rural Region**

- Washington County Local Nutrition Assistance Programs
- The Washington County Association for Home and Community Education, Inc. -
- WAHCE a nonprofit educational organization comprised of local clubs in Washington County. The organization is unique in that the members extend the information they receive from the University faculty and other reliable sources to the membership.
- Washington County Community Development Educator - works with local government, civic organizations, and help communities respond to new challenges and opportunities
- Aging & Disability Resource Center - West Bend, Washington County
- Domestic Violence Center - Washington

- Organizers of the Annual Free Family Event in Washington
- Ozaukee Kacmarcik Education Resource Center - A consumer health library, part of the health information network of the Columbia St. Mary's Medical Libraries.

### **Racine County**

- Racine/Kenosha Chapter - National African-American Nurses Association
- Urban League of Racine and Kenosha, Inc.
- Racine Friendship Clubhouse
- Women's Resource Center
- N.A.A.C.P. (National Association for the Advancement of Colored People)
- Aging and Disability Resource Center of Racine County (ADRC)
- Racine Interfaith Coalition (RIC)
- Volunteer Center of Racine
- Voces de la Frontera - A Wisconsin nonprofit that educates workers about their employment rights and organizes to protect and improve the quality of life for low-wage and immigrant workers. They promote grassroots leadership and community and workplace organizing as a strategy to achieve their goals, and operate workers' centers in Milwaukee and Racine
- Big Sisters of Greater Racine
- Burlington Community Education Department
- City of Racine Community Centers
- Lesbian, Gay, Bisexual and Transgender (LGBT) Center of SE Wisconsin
- Love, Inc. is a network of churches and individuals working together to identify and assess the needs of families and individuals and direct them to the appropriate resources. Their goal is to help families and individuals help themselves.
- We are Racine Advocacy Community Center
- Family Service of Racine
- HOPES Center of Racine, Inc.
- HALO, Inc.
- The Homeless Assistance Leadership Organization
- The Salvation Army
- Hispanic Roundtable
- Women's Resource Center

### **Waukesha**

- The Waukesha County Association for Home and Community Education, Inc. (WA-HCE) is a nonprofit educational organization comprised of local clubs in Waukesha County. The organization is unique in that the members extend the information they receive from the University faculty and other reliable sources to the membership and community.
- Family Living Programs presented on various topics by Family Living Educator Waukesha County UW-Extension
- Food Pantry of Waukesha County, Inc.
- The Women's Center, Inc.

### **Southern Rural Region**

- Kenosha – Aging and disability Resource Center

- Urban League of Racine and Kenosha, Inc.
- Carthage College
- University of Wisconsin Parkside
- Kenosha Community Action Agency
- Agape House – Walworth
- Bethel House – Walworth
- Family Resource Coalition of Walworth County

## **Public Policy Overview**

Understanding current issues, legislation, and resulting public policies that affect Wisconsin residents is essential to effective advocacy for optimal and equitable breast health and breast cancer care within the state. Susan G. Komen plays a key advocacy role nationally for the development and preservation on quality breast health legislation and policy. Komen Southeast Wisconsin is obligated to assist in that national advocacy as well as stay attuned to and address issues of specific importance to fighting breast cancer in the local communities.

### **National Breast and Cervical Cancer Early Detection Program (NBCCEDP)**

The Centers for Disease Control and Prevention (CDC) provides low-income, uninsured, and underserved women access to timely, high-quality screening and diagnostic services through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). Also through the NBCCEDP, uninsured women under age 65 who are diagnosed with cervical or breast cancer (may) have access to full Medicaid benefits under the Breast and Cervical Cancer Prevention and Treatment Act of 2000.

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP), known in Wisconsin as the Wisconsin Well Woman program (WWW), is administered through WI DHS, the Division of Public Health with funding from the Centers for Disease Control and Prevention (CDC). This program applies to women aged 45-64 at or below income 250 percent of the poverty level. WWW has served 72,000 women since 1994, utilizing the services of 1,060 providers around the state. Eligible women enroll through a county or tribal local coordinating agency.

Without access to breast cancer early detection programs, many uninsured women are forced to delay or forego screening, leading to later diagnoses. This delay can mean that a woman will not seek care until the cancer has spread beyond the breast, making it much harder and costlier to treat, and deadlier. Uninsured women with breast cancer have up to a 50 percent higher risk of dying than insured women. This causes the Well Woman Program to be vital to Wisconsin, as it provides screening services to low-income women with little or no health insurance coverage.

There are currently local coordinators in each of Wisconsin's 72 counties, and separate coordinator for the City of Milwaukee, and a small network of tribal coordinators. Each applicant must meet medical and non-medical eligibility, for which there are separate criteria. While individuals are able to check their eligibility through the Medicaid website [www.access.wisconsin.gov](http://www.access.wisconsin.gov), most women enrolling in the Wisconsin Well Woman Program work personally with their local coordinating agency's staff. The WWW program provides

individualized attention and excellent follow up to ensure that every woman entering the program is navigated thoughtfully and correctly into the continuum of care.

As of October 2014, there are over 1,000 providers in Wisconsin that work cooperatively with the Wisconsin Well Woman Program. Health care providers who provide services through the Well Woman Program must be Medicaid certified, and sign a Provider Participation Agreement. They are reimbursed at the allowable Medicaid rate. Screening activity and diagnostic reporting forms with the appropriate billing claims are sent electronically through the ForwardHealth Portal or by hard copy.

Through the NBCCEDP, uninsured women under age 65 who are diagnosed with cervical or breast cancer may have access to full Medicaid benefits under the Breast and Cervical Cancer Prevention and Treatment Act of 2000. A woman who has enrolled in Wisconsin Well Woman through a Well Woman Program Local Coordinating Agency and is in need of breast or cervical cancer treatment can be transferred to Medicaid coverage through Wisconsin's Well Woman Medicaid program. Women currently enrolled in Wisconsin's Family Planning Only Services are also eligible for coverage under the Wisconsin Well Woman Medicaid program.

To meet eligibility requirements a woman must be:

- Under age 65
- A United States citizen or qualifying immigrant
- A Wisconsin resident
- Diagnosed with breast or cervical cancer, or a precancerous condition of the cervix
- In need of treatment for the breast or cervical cancer, or a precancerous condition of the cervix, as identified by the Wisconsin Well Woman Program, or Family Planning Only Services plans diagnosing provider
- Not covered by private or other public health insurance for treatment of breast or cervical cancer

Women who are enrolled in the Wisconsin Well Women Program and receive a breast cancer diagnosis work with their local Well Woman coordinator to gain access into the Wisconsin Well Woman Medicaid Program. The local WWW representative becomes the liaison between the woman and the Medicaid program. They also facilitate navigation to treatment within a provider health system. WWW representatives provide individualized customer care and follow through creating a personalized and efficient bridge between the WWW program and the transition into the continuum of care with a specific provider. Most hospital systems in Southeast Wisconsin have oncology (and often breast cancer specific) navigators that will work with local WWW representatives to assume navigational responsibility within their health system for a woman enrolled into the WWW Medicaid Program.

Currently, the Affiliate is a stakeholder with the Wisconsin Well Woman Program. They have a shared vision and mission of increasing breast cancer screenings and eliminating barriers to screening and diagnostic services for low income and under/uninsured women. Komen SEWI's Community Grant recipients, more often than not, have a direct relationship with the WWW program. The Wisconsin Well Woman program is the first source of funding for screening and diagnostic breast services for Komen grantees. Every Community Grant program in recent years has secured a written letter of collaboration with WWW and interfaces with their county specific WWW provider to secure financial services for individuals in their programs. These

relationships have most often developed to the extent that Komen grantees can actually assist in completing and submitting enrollment paperwork for the Wisconsin Well Women program making the accessibility of this funding optimal for their clients. This relationship is extremely important in programmers' efforts to eliminate cultural, individual, and systemic barrier to breast cancer screenings.

At the Affiliate office, Komen Southeast Wisconsin staff members have established strong open lines of communications with most coordinators of the Wisconsin Well Women Program in the service counties. This has been key to developing a mutual understanding of services, fostering responsive working relationships, and strengthening the commitment to continue advocacy for the NBCCEDP program by the Affiliate.

### **Wisconsin Comprehensive Cancer Control Coalition**

The Wisconsin Comprehensive Cancer Control Program (WCCCP) and its partnership arm, the Wisconsin Cancer Council, work to engage public, private and community partners to develop, implement and promote a statewide approach to cancer control. The vision is for a healthier Wisconsin by reducing the impact of cancer.

The breast cancer objectives for the Wisconsin Comprehensive Cancer Control Coalition include reducing the death rate from 23.4 to 19.7 per 100,000 and the breast cancer incidence rate from 122.7 to 113.0 per 100,000 by 2015 (Cancer Control Plan 2010-2015). They also aim to increase the percent of women aged 40 and older who have had a mammogram in the last two years.

Komen Southeast Wisconsin was a contributing organization in the development of the Wisconsin Comprehensive Cancer Control Plan 2010-2015. The Affiliate maintains a regular relationship with the WCCCP through membership in its partnership organization, the Wisconsin Cancer Council, as well as through regular Affiliate executive director and staff attendance and participation with WCCCP's subgroup, the Breast Cancer Task Force.

Komen Southeast Wisconsin will continue to strengthen its role in the Wisconsin Cancer Coalition. Active membership and involvement in the Breast Cancer Task Force will be paramount in pursuing ways to address cross-cutting breast cancer issues of mutual concern to Komen and the broader network of WCCCP stakeholders. Komen will provide a voice on both the educational and provider outreach committees of this organization. Komen will also continue to be a contributing source for development of the Cancer Control Plans for the State of Wisconsin. The Affiliate will further strengthen this partnership by utilizing the Cancer Control Plan as a resource to improve its ability to fulfill its mission of providing quality service, empowering individuals, and ending breast cancer forever.

CCC Plan recommendations that could strengthen the work of the Affiliate include:

- Create a local level action plan to eliminate barriers to cancer screenings.
- Provide community based educational forums to address specific and unique needs of cancer survivors.
- Work with health systems to improve health literacy resources for patients.
- Advocate for legislation to increase funding for survivorship services, research and surveillance.
- Advocate for the completion of advance care documents for all cancer patients.

- Advocate for full funding of the WI Cancer Reporting System.

### **The Affordable Care Act**

The Affordable Care Act (ACA) is a federal government program intended to broaden the access to quality health services and coverage for all Americans. The ACA has many provisions that will affect breast health care access and quality.

### **Medicaid and Insurance**

Wisconsin is one of twenty three states that chose not to expand Medicaid through federal funding allocated through the Affordable Care Act. Medicaid in Wisconsin has three arms, namely *Well Woman Medicaid* (for women diagnosed with breast or cervical cancer), *EBD Medicaid* (serving low income Elderly, Blind, and Disabled Wisconsin Residents), and *Badgercare Plus*.

Federal money for Medicaid expansion would have extended Medicaid coverage to individuals earning up to 133 percent of the Federal Poverty Level. Since Wisconsin opted not to expand Medicaid, individuals and families earning above 100 percent of the FPL are no longer eligible for Medicaid, but can now apply for and purchase private health insurance through the Federal Marketplace or other insurance sources.

As of April 1, 2014, the following people are able to enroll in BadgerCare Plus:

- An adult with income at or below 100 percent of the Federal Poverty Level (FPL).
- A pregnant woman with income at or below 300 percent of the FPL.
- A child (under age 19) with household income at or below 300 percent of the FPL.

According to the Wisconsin DHS Badgercare Plus enrollment website in 2014, the number of parents/caretakers that have become ineligible for BadgerCare Plus since implementation of the ACA is 7,938. Wisconsin's Badgercare Plus was expanded to include childless adults previously unable to access Medicaid. So while individuals with incomes between 100 percent-133 percent FPL became ineligible for BadgerCare Plus, a new category of childless adults has now become eligible.

A preliminary look at this data for Milwaukee County reveals that in 2014 between May and June, 3,655 previously un-enrolled childless adults were added to Medicaid, with a total of 34,697 new Badgercare Plus childless adult enrollees since the changes went into effect. As of June 2014, the Medicaid enrollment for Badgercare Plus was at 226,424 individuals, up 25,123 people since the eligibility changes were put into effect. The overall enrollment for all Wisconsin Medicaid programs was at 310,678. The Department of Health services estimated that there were approximately 44,000 childless adults who could be newly enrolled in Badgercare Plus. This mean there are roughly 10,000 residents who have yet to enroll.

The US 2010 Census revealed there was an estimated 412,000 Wisconsinites without health insurance. Between the October 1, 2013 and March 31, 2014 enrollment period, 139,815 of those uninsured individuals selected a plan from Federal Marketplace. While coverage has expanded, there are still large numbers of Wisconsin residents that remain uninsured.

The Affiliate must continue to be aware of the insurance issues facing residents of Southeast Wisconsin. Health insurance is paramount in obtaining needed health care services, and those

who lack insurance are less likely to get timely and appropriate care. Women with low incomes that are no longer eligible for Medicaid but decide they cannot afford to purchase marketplace coverage find themselves caught in a coverage gap that puts their health at risk.

### ***Implications of ACA on state NBCCEDP eligibility and utilization***

The Affordable Care Act has implications on state NBCCEDP (Wisconsin Well Women Program) eligibility and utilization. The ACA was cited as the impetus for a proposed major restructuring of Wisconsin Well Woman. Planning for a new system of service provision began at in late 2013.

In November of 2014, the Wisconsin Department of Health Services (DHS) Division of Public Health detailed the proposed changes to the program in a document titled Wisconsin Well Woman Program – New Model Proposal, Recommendations from Local Health Work Group, The changes consist of two proposed models for replacing the 72 local coordinating agencies with regional coordinators. In addition, the existing provider contracts would be terminated, and Federally Qualified Health Centers, rural health clinics, outpatient clinics, and larger health systems by sub contract will be targeted for new provider contracts. The proposal is to have a “model of multi-jurisdictional groupings.”

Originally, the changes were to be effective July 1, 2014. This timeline was adjusted by NBCCEDP (with the advocacy help of Wisconsin Komen Affiliates, the Wisconsin Breast Cancer Coalition, and the united voices of breast cancer organizations, health systems, breast cancer, community advocates, and service providers) and changes have been delayed for a period of one year to allow for transition into the restructured program. The new provider network and the final service coordination model is targeted to begin July 1, 2015.

The State WWW director’s office stated that this structural change is in part due to the large number of providers which hinders the CDC’s ability to fulfill its requirement of Professional Development and Site visits. A reduction in provider sites will need to be carefully monitored to see if it impacts the availability of resources or presents any new barriers to services, especially for lower income residents in less populated rural regions. Even if the WWW meets its standard of a service location within 50 miles, transportation issues could come into play for many low income women and many working women.

The other justification for the WWW restructuring was an anticipated decline in enrollment due to the mandatory breast cancer screening provisions in the Affordable Care Act. Even as WWW enrollees are navigated to ACA marketplace coverage, they are still likely to experience a gap in coverage if they are required to have any diagnostic breast cancer screenings. WWW should anticipate filling this need.

Also, although many women will be able to drop out of WWW because of ACA mandated coverage of screening mammography, there are thousands of low income, uninsured Wisconsin women that can and should be newly enrolled into the WWW program. According to Komen Advocacy, even with current funding the NBCCEDP serves less than one-third of eligible women and, most importantly, the program will continue to serve less than one-third of eligible even with increased screening coverage provided by the Affordable Care Act.

As of 2014, the Wisconsin Well Woman Program coordinators are under mandate from the DHS to suspend all outreach efforts. This could potentially result in an unnecessary net drop in enrollment numbers as women leave the program but no concurrent efforts are being made to identify and enroll eligible women that don't know about or don't have access to the program. The likely result is that enrollment numbers will not accurately represent the actual breast health needs in Southeast Wisconsin. The Affiliate can be a voice to create awareness of this issue, as well as a potential funding agent for programs actively seeking out previously un-enrolled eligible women and providing them with a path to life saving breast cancer screening.

As the Affordable Care Act continues to roll out, the implications for Wisconsin women will be more and more obvious. A recent issue affecting affordability of Marketplace coverage has surfaced that could potentially leave even more Wisconsin residents caught uninsured in a gap between inaccessible Medicaid coverage and prohibitive costs of individual insurance coverage. A recent court case has challenged whether the federal government can subsidize premiums for individuals enrolled in Marketplace plans in the 33 states (including Wisconsin) without a state run Marketplace. As 85.0 percent of those currently enrolled in the Marketplace plans are receiving premium subsidies, a prohibition on federal premium subsidies would make it difficult for Wisconsin residents to afford coverage. This would eliminate covered screening mammograms for women in this situation driving them back to screening coverage through Wisconsin Well Woman Program. More distressingly, this could exacerbate the problem of women diagnosed with breast cancer being able to afford private insurance through the marketplace, leaving them uninsured for life saving treatment options.

### ***Implications of ACA for health care providers***

The ACA has had both positive and negative effects on safety net funding. In theory, if the ACA were fully implemented then all US citizens and legal residents would have insurance coverage, dramatically reducing the need for clinics to focus on serving the uninsured. If those clinics are able to get reimbursed by insurers for care provided, then they would have new sources of revenue to support operations. Marketplace plans are instructed to have adequate provider networks and to incorporate safety net providers in the area. The ACA increased Medicaid payments to 100 percent of Medicare payment levels for primary care services through 2014.

The ACA also has a series of provisions related to health care workforce development, designed to place primary care residents in community settings, including FQHCs. The ACA increased funding by \$11 billion for community health centers and by \$1.5 billion for National Health Service Corps over five years (effective fiscal year 2011); and established new programs to support school-based health centers.

The ACA does dramatically reduce both Medicaid and Medicare Disproportionate Share Hospital (DSH) payments, under the assumption that there would be a substantial reduction in the number of uninsured patients. This aspect of the ACA will be problematic in states such as Wisconsin that do not expand Medicaid, as they are likely to see a much smaller reduction in the uninsured percentages for poor adults in their states.

There are also some changes to the health care workforce as a result of the ACA that could have implications for women's health and how they receive care and treatment for breast health care. There is a provision that increases Medicaid payments to primary care physicians to no less than 100 percent of the Medicare rate in 2013 and 2014. The federal government covers

the cost of the higher payments. There is also a state option of enrolling Medicaid beneficiaries with chronic conditions into a health home. The health homes would be composed of a team of state-designated health professionals and would provide a comprehensive set of medical services, including care coordination (AAMC Center for Workforce Studies, 2010).

### ***Implications of ACA for the Affiliate***

Implementation of the ACA also has implications for the Affiliate, as more uninsured women will be choosing a health plan through the federal marketplace, which will be offering mammograms without cost-sharing. In the most optimistic scenario, the need for Komen funded breast cancer screenings would decrease allowing those funds to be shifted to services further along on the Continuum of Care (diagnostic, treatment, and support). In this scenario most women would have insurance that covers screening, Komen programs could assist in finding funding for diagnostic services and potentially satisfying insurance co-pays, and the remaining costs of necessary treatments would be covered by individual insurance. Additional local Komen dollars could then be pushed more fully into education and support services.

Any large movement of women into the marketplace creates the potential of shifting the priority of Komen funding away from screening and into diagnostic and/or access to treatment services. Funding that would help offset the financial burden encountered with an abnormal screening result for women with or without insurance.

A more likely scenario is that the ACA will successfully increase coverage for screening mammograms for a very substantial number of women, but there will still be thousands of Wisconsin women who will remain uninsured. It is estimated that even after full ACA enactment, the Wisconsin Well Women program would still only be able to provide coverage to less than a third of eligible women. Lack of insurance is a big barrier to women receiving an annual mammogram and the Affiliate can help by funding programs that work to close that gap.

To prepare for changes in the health care landscape, Komen Southeast Wisconsin can best respond to the enactment of the ACA by initiating and fostering partnerships with organizations that use best practice methods in new and creative ways to deliver outreach/education that would lead women to breast cancer screenings - most importantly women who have previously not been served and may be more difficult to identify and serve than in recent years. As many previously served individuals find their way to insurance coverage in the marketplace, the challenge to the Affiliate may ultimately be to facilitate the development of programs that can reach a new audience of women who have never been in the continuum of care.

### **Affiliate's Public Policy Activities**

Susan G. Komen is the voice for the 2.9 million breast cancer survivors and those who love them, working to ensure that the fight against breast cancer is a priority among policymakers in Washington, D.C., and every State Capitol across the country.

The Affiliate's mission is to translate the Komen promise to end breast cancer forever into action at all levels of government to discover and deliver the cures.

Komen has worked for years at a national and local level to protect breast cancer screening and research funding and to advance breast health and cancer care policy at the federal and state levels. As an Affiliate, Komen Southeast Wisconsin works to advocate for the priorities

established by the organization as a whole. These priorities are developed yearly with input from local Affiliates, relevant national Komen staff, and selected individuals from the Komen Advocates in Science program.

Susan G. Komen Advocacy Priorities include:

- Protecting federal and state funding for the **National Breast and Cervical Cancer Early Detection Program (NBCCEDP)**, to ensure all women have access to potentially lifesaving breast cancer screening;
- Ensuring continued federal investment in **cancer research** through the National Institutes of Health (NIH), National Cancer Institute (NCI) and Department of Defense (DOD), to discover and deliver the cures;
- Requiring insurance companies provide **coverage for oral anti-cancer drugs** on a basis that is no less favorable than what's already provided for intravenously-administered chemotherapy, to protect patients from high out-of pocket costs; and
- Expanding **Medicaid coverage** to ensure the availability of the full-range of breast health services to low-income women, including cancer screening, diagnostics and treatment.

In order to advocate for these priorities it is essential that Komen Southeast Wisconsin be informed of and forge relationships with elected officials at all levels in the state. Locally, advocacy efforts are aimed at the Wisconsin State Governor, as well as representatives of the Senate and House of Representative at both the Federal and State level.

While Komen Southeast Wisconsin's service area includes all or parts of districts 1, 4, 5 and 6, the Affiliate also strives to work with fellow Wisconsin South Central and Central Komen Affiliates in order to cooperatively maintain contact with all Federal and State Representatives throughout the state and to present a united front in advocating for the advancement of breast health related legislation.

A local partner organization, the Wisconsin Breast Cancer Coalition, is a key resource for keeping up to date on issues of breast health issues and legislation most pertinent to Wisconsin and the southeastern service area. Partnering and co-sponsorship of advocacy efforts with the WBCC and other local organizations, health systems, and key individuals fighting for optimal breast health legislation enhances Komen Southeast Wisconsin's efficacy in advocacy efforts. There are several examples of Komen SEWI public policy activities that stand out.

Of major concern in 2014 was the announcement of proposed changes to the structure of the Wisconsin Well Woman Program – Wisconsin's structure for the Federal NBCCEDP. Komen, both nationally and locally, considers the NBCCEDP a credible and crucial point of service for low income, under and uninsured women. Major changes in the Wisconsin Well Woman Program seem likely as state level mandates initiated a restructuring of the NCCEDP delivery model in Wisconsin. Proposed changes called for service coordination to be more regionally based. The plan calls for a reduction in the number of local coordinators from 72 (one per county) down to between six and 15 (one full time or multiple part time staff per region.). It has also been proposed that the number of providers be reduced to a handful of larger health

systems. These health system providers will be supplemented by selected service providers at local FQHC's, free and sliding scale community clinics, and health departments.

In 2014, Komen Southeast Wisconsin strongly advocated for this Komen priority service in Wisconsin. In March of 2014, Komen Southeast Wisconsin and the Wisconsin Breast Cancer Coalition co-sponsored a town hall style meeting to address the concerns around the restructuring of the Wisconsin Well Women Program. The Director of the WWW was invited and agreed to be present to speak and be available for questions. Komen invited key individuals from all areas of breast cancer services – advocates, WWW providers, grantees, health system administrators, health provider, and breast cancer organizational leaders. Over 50 people attended this several hour long meeting co-hosted by Komen and WBCC. Follow up was in the form of co-signed letters to Wisconsin elected representative, the Governor, and State Departments. The changes proposed for implementation on 7/1/14 were pushed back to 7/1/15 to allow for more careful consideration of the restructure. Komen continues to monitor the progress of this restructure.

In August 2014, Komen Southeast Wisconsin was invited to participate in a round table discussion initiated by the State Department of Health. The Affiliate utilized this opportunity to add it's voice to other key organizations and individuals advocating for a careful and thoughtful restructuring process for the Wisconsin Well Woman Program.

Komen Southeast Wisconsin has been and will continue to be a strong voice for the careful development and oversight of the WWW restructure. It is in the best interest of the women of Wisconsin to maintain the high level of support and services provided through the Well Woman Program. The Affiliate will continue to work with local coordinators to make sense of changes occurring and advocate most powerfully for a best practices solution to the reorganizational challenges. Komen Southeast Wisconsin has a developing relationship with the director of the Well Woman Program and will leverage that relationship to stay as intimately involved as possible with the transition into a new phase of service delivery.

Using its strong connections with partner organizations in Southeast Wisconsin, Komen has and will continue to play a central advocacy role in facilitating a united show of support for the Well Woman Program as well as mutual concern for and interest in its future viability. As a state with multiple Affiliates, it is also important that Affiliates partner and work together when collaborating with state or regional NBCCEDP directors. It is imperative that the Wisconsin Komen Affiliates act as a united front with the same message as it relates to breast cancer, especially when there are issues that affect the entire state. The Affiliate will continue to advocate with and for the NBCCEDP as a centerpiece program of women's health in Wisconsin.

The Affiliate also strengthens its relationship with NCCEDP because of Susan G. Komen's advocacy of issues also recommended by this governmental program. One such recommendation is the passage of the Cancer Treatment Fairness Act that provides equity for oral chemotherapy. Komen Southeast Wisconsin joined other local breast cancer organization in carefully following the progress of and advocating for the passage of this Oral Chemo Bill. The Affiliate cosigned advocacy efforts aimed at state representatives and the Governor. After a three year struggle, the Cancer Treatment Fairness Act was signed into law in Wisconsin on April 3, 2014 and will take effect in January 2015.

Additionally, the Affiliate regularly uses its local Race for the Cure as an opportunity to advocate for the priorities set out by the National Komen Advocacy team. In the last several years, petitions were developed by the Komen SEWI Mission Manager with the assistance of Komen's Advocacy team and their resources asking for support of the continuation of Federal and State funding for the National NBCCED, as well as continued NIH funding for cancer research. Utilizing volunteers, these petitions are circulated at the RFTC. Hundreds of signatures are gathered and then sent to the National Komen Advocacy team to use to demonstrate support for continued strong Federal funding of breast cancer screening services and continued Federal funding of breast cancer research.

Komen Southeast Wisconsin will continue to stay aware of important breast cancer issues and advocate to the best of the Affiliate's ability for legislation that creates public policy that is optimal for the breast health of women in Southeastern Wisconsin and beyond. The Affiliate will continue to look for new opportunities and partnerships that will expand capacity to serve Southeast Wisconsin. Komen Southeast Wisconsin intends to:

- Take a lead role in staying on top of the restructuring of the Wisconsin Well Woman program to ensure the program remains a vital and viable resource for Wisconsin women.
- Participate alongside Komen South Central and Central Affiliates, the Affiliate will participate in Lobby days to advocate for optimal breast health legislation in Wisconsin.
- Pursue local city government proclamations and recognition of breast cancer issues in order to raise awareness of the need for lifesaving breast cancer services in southeast Wisconsin.
- Continue to explore the possibility of expanding the Affiliate northward to include more counties in the service area.

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

Komen Southeast Wisconsin's intent is to analyze the findings of the Health System Inventory and Public Policy Analysis as accurately as possible. Investigation into points of service were extensive and exhaustive. Information compiled on the many aspects in the Public Policy section were assessed thoroughly through written documents, online sources and personal interviews. Development of the Health Systems and Public Policy Analysis was done carefully and to the best of the Affiliate's ability, but as in any human endeavor there is the possibility of error.

The possible limitations of the information gathered could include any of the following:

- Completed template may have missed some breast health/cancer providers
- Information about services provided by the health care providers is inaccurate
- Providers were included that do not provide services related to the continuum of care
- Health care services not in the continuum of care were excluded (e.g.. education, outreach)
- Information could become outdated
- Information gathered by interviews could have inaccuracies

## **Target Communities – Health System and CoC Needs and Potential Partners**

Komen Southeast Wisconsin must carefully assess the potential impact the service gaps and inequities indicated in the Health System Overview may have on the delivery of breast health and breast cancer services. It is essential that these services are optimally available and accessible to all women, preferably right in their own neighborhoods. The following analysis identifies areas of concern for individuals in each of the Affiliate's target communities that can be explored further through qualitative data collection. Fostering existing and developing new partnership will be essential to the Affiliate's ability to make a meaningful impact in each of its five target communities.

### ***Milwaukee County***

More than half the women in the Komen Southeast Wisconsin reside in Milwaukee County, so it is not surprising to find over 60 widely scattered sites providing breast health/breast cancer services along varying number of points in the Continuum of Care. However, despite the high number of total service providers, Milwaukee County has weaknesses in the way breast health and breast cancer services are distributed that appear to be directly related to the county's great disparity in its distribution of wealth. Every low socioeconomic zip code within Milwaukee County is located within the City of Milwaukee and currently there are over twice as many options for breast cancer screening mammograms in the suburban areas of Milwaukee County as there are in the City of Milwaukee. While mobile mammography improves the access to mammograms in Milwaukee County's more vulnerable neighborhoods, at the rate it is used currently it does not sufficiently provide equity to screening access for all women in Milwaukee County. Breast cancer diagnostic and treatment services are also geographically less available to Milwaukee County residents in lower socioeconomic areas. Transportation to treatment and a lack of convenient service hours are likely barriers to services. Lack of neighborhood sites also points to possible barriers related to the lack of familiarity and trust with larger health care systems and breast cancer service providers outside of one's neighborhood. There are health consequences to being poor in Milwaukee County and the lack of diagnostic and treatment facilities in lower income areas likely exacerbate this problem. Milwaukee's Black/African-American community is disproportionately affected by these risk factors putting their breast health in jeopardy. Milwaukee County is also home to the highest percentage of non-White racial and ethnic groups in the Affiliate service area. The Affiliate must assess the impact of low income risk factors and countywide inequities in breast cancer service access on all potentially vulnerable populations.

Komen Southeast Wisconsin has a great opportunity to be a facilitator for the development of more best practice programs in areas of the Milwaukee County Target Community that have low access to breast health services. Improvements of breast cancer services in Milwaukee County will require aggressive development of relationships with all types of service providers on the ground to expand the Affiliate's Community Grant and Small Grant programs into areas of highest need. The existing health system disparity also compels the Affiliate to look for opportunities to add more site-based screening mammogram options through mobile mammography, especially at sites already offering CBEs in high risk neighborhood.

Demographic challenges and an unbalanced delivery of breast cancer services emphasize the importance of further qualitative data collection to fully analyzing the breast cancer needs and gaps in Milwaukee County. With additional clarification of breast cancer burden in Milwaukee

County, Komen Southeast Wisconsin can play an important role in advocating for the development of additional diagnostic and treatment services in lower socioeconomic areas. Komen Southeast Wisconsin has developed many strong partnerships in Milwaukee County. The Affiliate's Community Grant Program has forged relationships with Milwaukee's major health systems. Komen SEWI has also developed important working relationships with numerous other organizations including partnerships with After Breast Cancer Diagnosis, the American Cancer Society, the Milwaukee Regional Cancer Care Network, Pink Shawls, the University of Wisconsin-Milwaukee, the Zilber School of Public Health, Milwaukee Health Department, Milwaukee Area Health Education Centers, Partners for the Promise, Nurses Affecting Change, Sisters 4 Cure, and many others.

Komen Southeast Wisconsin continually seeks out new partnerships with organizations in every part of Milwaukee County. The needs are great in this Target Community. Strong partnerships with a variety of organizations not only develop future Komen grantees, but also helps make connections between organizations in the county that create opportunities to foster collaborative efforts that can optimize the impact of breast health programs throughout Milwaukee County.

### ***Northern Rural Region***

The Northern Rural Region is made up of Washington County and Ozaukee County, two of the Affiliate's highest need counties. In addition to being in the top third of the Affiliate's counties with the highest breast cancer incidence and death rates, the Northern Rural Region also bears higher late-stage breast cancer diagnoses than is typically seen in other Target Communities with counties that have a similar number of residents. The puzzle in the Northern Rural Region is that despite these statistics, the demographics of both of its counties seem to be low risk in terms of income, education, employment, and insurance.

The health system analysis pointed to a region that, although containing twenty breast cancer service providers, has an unbalanced distribution with all provider locations clustered within a limited number of city centers. The region's Continuum of Care service sites are concentrated directly off of the major expressway routes, located in a handful of small city centers, and clustered mainly in the region's southern areas. This situation leaves very large, mainly rural areas of the Target Community without any breast cancer services at all. Mobile mammography service has only slightly expanded screening services in Ozaukee County, since even these added locations are all found in the southeastern areas of the Northern Rural Region and have little new impact on increasing service availability for the vast rural areas in the rest of the Target Community.

Even the free clinics and health departments are located in the Region's city centers alongside the other existing health services. The Northern Rural Region has no convenient access to breast health services for its more rural residents. While Wisconsin Well Women has a strong community presence in the Northern Rural Region Target Community, limited time, staff, and resources make it difficult for the health departments to affect the breast health of residents in the more outlying rural regions. Navigation to services at every stage of the CoC is a relatively strong component of the health system in the Northern Rural Region. Although not located equitably, screening service sites are numerous. The region's diagnostic and treatment inventory, though, is much less robust making access to these services less than optimal for even a larger portion of the Region.

On first glance the obvious barrier to service appears to be transportation and ease of access. This seems likely but deserves further investigation since socioeconomic data for the Northern Rural Region indicate a relatively affluent, well educated, employed, and well-insured population with little racial and ethnic diversity that likely has access to adequate transportation. To understand the full story of this Target Community, Komen Southeast Wisconsin must identify and develop new partnerships with local community organizations that that can help illuminate all the factors contributing to the high breast cancer risk.

Possible factors that should be considered are:

- The impact of transportation and rural residency on accessing breast health services.
- The presence of isolated high risk demographic groups concentrated or spread throughout the region that are masked by the low risk demographics of the broader community.
- The presence of non-White racial and ethnic groups that are possibly culturally isolated and medically underserved.
- A lack of educational resources in the city and/or rural regions to inform women of the necessity of regular breast cancer screenings.
- A lack of outreach and education programs that drive women to breast cancer screenings both in the larger city centers and in the rural regions.
- A lack of insurance.
- A shortage of breast cancer services available during convenient time frames for working women living in an area requiring greater travel time.
- The presence of any regional, cultural, or individual barriers to breast health unique to women living in this Target Community.

Komen Southeast Wisconsin has limited partnerships in the Northern Rural Region. Development of additional breast cancer programs and breast cancer service sites requires the Affiliate and its grantees to establish new partnerships with community organizations, churches, neighborhood associations, and businesses. The health departments of both Washington and Ozaukee County are potential future partners for this Target Community. As the roles of Well Women Coordinators change, health department staff could provide great guidance or direct assistance in program development for the communities they know so well. Partnerships with mobile mammography providers Columbia St. Mary's and Marshfield Clinic should also be explored for the Northern Rural Region.

### ***Racine County***

Racine County is Komen Southeast Wisconsin's second highest need community in terms of Healthy People 2020 with a breast cancer death rate that is higher than both the state rate and the Affiliate rate as a whole. Breast cancer deaths rates are falling slowly and Racine is not expected to reach preferred target rate for breast cancer deaths for eight years. There are many factors that could be playing a role in this situation.

In addition to Racine County's relatively small health system inventory for a county its size, it is especially important to note that the county's health system sites are located either on the far eastern side or the far western side of the county. Limited options for breast cancer screenings, diagnostics, treatment, and/or support services for women living in rural parts of Racine County result in the need to travel a distance that could be over 30 miles to receive any breast health

service at all. Quantitative data sites low mammography rates and the disparate availability of service sites must be suspected of playing a role. Limited geographic locations point strongly to the need to fully identify barriers due to transportation issues as well as trust or comfort issues arising from a lack of truly local health facilities.

Despite the clustering of service facilities nearest to City of Racine, transportation must also be investigated as an issue even for city residents. Limited facility hours, after hours public transportation access, even a lack of sidewalks could be possible barriers to service. There may be other factors keeping women from fully utilizing health systems that are relatively close. While the City of Racine has multiple options for service along the CoC, most of the sites identified are larger hospital systems. Barriers to service could also include a personal or cultural discomfort or mistrust of the hospital systems.

With the County's one community health center and one free clinic both located far from the outer rural sections of Racine County, financial barriers are possible. While WWW and other funding agents are available to provide financial assistance to qualifying women for screening, diagnostic, and even treatment services, financial barriers may still exist for those not knowing about those resources or how to access them.

The Racine County Mammography Coalition, a strong Komen SEWI partner, is actively addressing the need for increased screening in Racine County by cooperatively providing education, navigation, and ultimately screening for low income, under and uninsured women in Racine County. The coalition has improved the number of women receiving mammography screenings, but there is more work to do. Additional partners may help in this effort. As the Wisconsin Well Woman Program is restructured, the Racine Health Department may also take on new roles in the provision of breast health in the County. Collaborations with other city and county resources could help stretch services further into the rural regions of the county.

Additional partnerships in Racine County are critical to the ability of Komen SEWI to make an impact on the health equity in this Target Community. The Affiliate must strive to make new partnerships with community organizations in all parts of Racine County to determine how to best access underserved populations in both the City of Racine and in rural Racine County. Developing new partnerships specifically in the county's middle and western would greatly enhance Komen SEWI's reach into this Target Community. Such partnerships could help provide new geographic points of access for underserved women in the more rural areas of Racine County. These partnerships could also enhance the ability of women in rural areas without nearby health system sources to have greater access quality breast health information. The addition of mobile mammography providers could also help close the gap of service for rural women as well. Both the Marshfield Clinic and Columbia St. Mary's could be considered potential partners in this Target Community.

Many potential partners are available and a systematic exploration of their missions and goals would be a good first step in addressing the need for increased screening that is exacerbated by the inequitable locations of service sites. These organizations could be vetted for their ability to provide services including education, outreach, and navigation, as well as more direct access services such as transportation in the form of rides or financial assistance for rides to service delivery sites. A working list of possible partners includes: Urban League of Racine and Kenosha, Inc., Racine Friendship Clubhouse, Women's Resource Center, N.A.A.C.P., Aging

and Disability Resource Center of Racine County , Racine Interfaith Coalition, Volunteer Center of Racine, Voces de la Frontera, Big Sisters of Greater Racine, Burlington Community Education Department, City of Racine Community Centers, LGBT Center of SE Wisconsin, Love, Inc., We are Racine Advocacy Community Center, Family Service of Racine, HALO, Inc., The Homeless Assistance Leadership Organization, The Salvation Army, and the Hispanic Roundtable.

### ***Waukesha County***

As the service area's second largest county, Waukesha County has a broad range of health system providers available. Unfortunately, it also has a high rate of breast cancer incidence in comparison to the rest of the Southeast counties. As complete as Waukesha County's health inventory appears, there is still a potential weakness in the distribution of these services in this geographically large county. There is a large rural area of Waukesha County (predominantly located in the southwestern quadrant of the county) with no service providers for any portion of the CoC. Facilities providing treatment services are located entirely in the northern half of Waukesha County creating an even larger inequity. Obviously travel must be further investigated as a barrier to services for the rural residents in these areas of the Target Community. Komen SEWI will need to gather qualitative data that can examine the role site distribution plays as a contributing factor to breast cancer in Waukesha County.as a contributing factor

Komen SEWI must partner with organizations in Waukesha to address the broader inequities caused by the absence of service facilities in outlying rural areas of the Target Community. Developing additional mobile mammography program partnerships could be an ideal way to begin to close the service gaps for the geographic regions lacking providers in Waukesha County. Marshfield Clinic's Mobile Mammography Program would be ideally suited to this county. Great potential exists in the development of alternate screening locations. The services of the Waukesha Health Department would also be helpful in providing knowledgeable guidance into the needs of the Target Community. Komen SEWI should foster that relationship to fully explore what the health department has to offer as a strong consulting partner or, perhaps, as a grantee.

Cultural barriers must also be considered. In this predominately White, English speaking county the cultural barriers to breast health services for the county's Hispanic/Latino and API populations could be especially difficult to overcome. An awareness of who is living where in relationship to health system locations is also important to consider. Geographic challenges could exacerbate existing cultural and socioeconomic barriers.

Komen Southeast Wisconsin already has a strong partnership with Waukesha ProHealth's Hispanic Resource Center. The center itself has developed many community partners. ProHealth's focus on Hispanic/Latina women can continue to grow through the continued development of partnerships. Komen SEWI should continue to identify resources to learn more about other relatively large non-White racial populations in Waukesha County.

Waukesha County is as rich in community organizations as it is in the number of health care providers. Community organizations may be the key to spreading the work of health systems out into the communities or assisting individuals with access to the health systems. One new Komen SEWI partner, Tricia's Troops provides financial assistance to cancer survivors in

multiple ways. This relationship can be developed further to understand the organization's ability to help address the disparate access to health services in Waukesha County.

Waukesha County is also home to Stillwaters Cancer Support Services providing survivor support services at no cost to individuals in this Target Community and farther afield. Komen can utilize the strength of organizations such as Stillwaters as a starting point for forming new partnerships in the Target Community. Organizations such as The Waukesha County Association for Home and Community Education, Family Living Programs, Waukesha County UW-Extension, Food Pantry of Waukesha County, The Waukesha Women's Center, and others are all potential partners in the effort to fight breast cancer in Waukesha County.

### ***Southern Rural Region (Kenosha and Walworth Counties)***

The Southern Rural Region Target Community Health System Inventory only consists of only sixteen entries, but it is the distribution of these facilities that seems to be the most important factor in the analysis of this Target Community. Residents of the Southern Rural Region Target Community have few options and many have long distances to travel to reach locations that provide breast cancer services. Access to diagnostic and treatment services is extremely limited. In Kenosha County, every site that provides any type of breast health services is located on the far east side of Kenosha County in the City of Kenosha or in Pleasant Prairie. This leaves the western portion of Kenosha County without any service provider sites. Walworth County residents have especially limited options. Diagnostic mammogram, ultrasound and biopsy can be found only in Lake Geneva and MRI's only in Elkhorn. Surgery and Reconstruction services are only available in Lake Geneva and chemotherapy and surgery services are only available in Elkhorn. There are no service providers for radiation in Walworth County. To receive radiation a Walworth resident would need to travel to the City of Kenosha on the furthest east side of the Southern Rural Region or travel north into neighboring Waukesha County.

This disparity is noticeable even in the availability of basic breast cancer screening services. Because of the unbalanced concentration of service sites, the distance to screening facilities is sizeable for a large portion of the Target Community residents. This could also point to an access problem for basic breast cancer information that is vital in motivating women to overcome the barriers to getting screened in the first place.

In addition to concerns over transportation and lack of service sites, the quantitative data for Southern Rural Region illuminated areas of extreme poverty in both Kenosha and Walworth Counties. The location of service sites line up well in the more vulnerable areas of Kenosha County, but less favorably in Walworth County. In Kenosha County, the census tracts at-risk were mainly clustered on the eastern border. This is fortunate because all the resources in Kenosha County are clustered on the east side of the county. Community partnership will be essential in developing programs that can identify and serve the at-risk population especially in the high poverty census tracts. Pockets of high poverty do not line up as closely with available service sites in Walworth County. Lowest income populations are located near Lake Geneva and Delavan where there are some service providers, but also in Whitewater in the upper northwest corner area of the Target Community where there are no service providers.

Currently the Affiliate's partnerships in Kenosha County consist mainly of a well-developed working relationship with the Kenosha Community Health Center (KCHC). KCHC is strongly

dedicated to improving the health of Kenosha residents and has begun to develop partnerships with local organizations to make in-roads into both Black/African-American and Hispanic/Latino residents. The Affiliate can further develop its partnership with KCHC and possibly assist them in making ties out into the community. It will take many strong partnerships to reach individuals throughout the Southern Rural Region and to overcome the barrier to services due to an inequity of geographic as well as financial access.

Kenosha and Walworth Counties each have a health department that could be a valuable partner with Komen SEWI. The on-site nurse and availability of CBEs in the Kenosha Health Department greatly increases that County's ability to maximize breast health services for the County's residents. Kenosha has a FQHC Kenosha Community Health Center, but no free clinic. Conversely, Walworth has a free clinic, but no FQHC. Both offer great partnering opportunities and connections to underserved people in the Southern Rural Region. Komen Southeast Wisconsin must begin to collaborate with these organizations, as well as develop other partnership in the Southern Rural Region Target Community as a whole as a first step to find ways to effectively connect at-risk individuals into a somewhat limited CoC range of services providers whose services are not distributed uniformly across this Target Community.

### **Partnerships**

As modeled by Susan G. Komen, partnerships hold the key to making great strides forward in fulfilling the Komen mission of ending breast cancer forever. The Affiliate's strong Community Grant program has already enabled Komen SEWI to forge effective and ever growing partnerships with its numerous grantee organizations. Komen Southeast Wisconsin also has and will continue to work diligently to develop strong collaborative ties with other hard working breast cancer organizations in the southeast Wisconsin service area and across the state. Every partnership strengthens Komen SEWI as an organization and increases the Affiliate's ability to advance its mission. Komen grantees are encouraged to develop partnerships as well to benefit their programs and increase the efficacy of the Komen grant program as a whole. As shown throughout this document, Komen Southeast Wisconsin is dedicated to nurturing the partnerships it has made as well as actively seeking new partnerships that will make the Affiliate and its grantees better able to serve the women of Southeast Wisconsin. Many potential Target Community partnership opportunities have been identified in this document and many more exist. The challenge is to uncover them, facilitate connections between organizations, and leverage those relationships to foster the most effective Community and Small Grants possible. On a broader level, Komen Southeast Wisconsin also depends on partners outside of its work in Targeted Communities. Partnering with fellow Komen Wisconsin Affiliates, South Central and Central Wisconsin, strengthens the Affiliate's ability to be a leading advocacy voice and breast cancer organization of excellence within the State of Wisconsin. Partnering with Komen Affiliates in the North Central Region help the Affiliate streamline service delivery, share resources, and develop best practice grant programs.

A lack of breast cancer service facilities in one's community is likely to minimize their exposure to breast cancer education, as well as hinder their access to breast cancer services. Komen SEWI's Kohl's Conversations for a Cure Program will play an integral part in maximizing the educational resources and greater breast health awareness provided to women in the City of Milwaukee, as well as throughout southeast Wisconsin. Local efforts to prioritize high-quality navigation in smaller service facilities and organizations will serve an equally important role in

reducing barriers to screening, diagnostic, and treatment services in facilities outside of a woman's neighborhood.

Additionally, the limited number of health system led breast cancer support groups in the majority of Komen SEWI's Target Communities causes concern for inequity in the delivery of survivor services. One of Komen SEWI's strongest partners in the service area is the Milwaukee based organization After Breast Cancer Diagnosis (ABCD). ABCD's Helpline and One-on-One mentoring program reach beyond Milwaukee County and provide equal access to support services for survivors throughout Southeast Wisconsin. Individualized service maximizes ABCD's ability to educate, support and navigate every breast cancer survivor they assist regardless of their income or where they live. Increased collaboration with ABCD and Komen Southeast Wisconsin grantees should be fully explored.

Komen Southeast Wisconsin is especially proud to have established strong relationships with these groups, as well as other hard working breast cancer organizations such as the Wisconsin Breast Cancer Task Force, the Wisconsin Breast Cancer Coalition, the American Cancer Society, the Milwaukee Regional Cancer Care Network, Pink Shawls, Cancer Treatment Centers of America, Partners for the Promise, Nurses Affecting Change, the Sister's Network, Wisconsin Well Woman Program, Wisconsin Women's Health Foundation, and so many others. Each organization's mission is unique, but they all share the goal of fighting breast cancer in southeast Wisconsin. Strong connections between Komen SEWI and these organizations will lead to better results in advancing every organization's work to fight breast cancer, serve women in need, support survivors, find the cures, and ultimately end breast cancer forever.

### **The Impact of Public Policy on Breast Health Care**

Public policy can be generally defined as a system of laws, regulatory measures, courses of action, and funding priorities concerning a given topic put into effect by a governmental entity or its representatives. The state of breast health care for Wisconsin women is directly tied to the public policy decisions made by local, state, and federal government representatives. Public policy can determine the types of breast health services available, the extent of the services provided, and the support given for accessing services. Public policy often mandates programs and funding that help states and local communities assess and address a common issue. Cancer is a public health challenge for the entire country and, as such, can be efficiently addressed as a priority of the Federal Government.

Both the National Breast and Cervical Cancer Early Detection Program's Wisconsin Well Woman Program and the National Center for Disease Control and Prevention's support of the development of the Comprehensive Cancer Control Plan are excellent examples of government programs put into effect to support the breast health of residents of Wisconsin. The passage of the Affordable Care Act (ACA) is an example of Public Policy working on broad scale reform of the health system.

Optimal breast health for residents of Wisconsin is dependent on conscientious legislative action that is part of a breast health supportive Public Policy. It is essential for individuals as well as organizations such as Komen Southeast Wisconsin to advocate for optimal and equitable breast health and breast cancer care within the state. This is accomplished by urging State and Federal Representative to support public policy that sets the stage for:

- Robust programs that make breast health a priority,

- State aid that ensures equitable access to breast cancer screening and diagnostic services,
- High quality, best practice breast cancer services for all residents,
- Health care landscape that values the breast health of the individual over the financial gains of health care systems and insurance providers, and
- Dedicated and tireless funding of breast cancer research

### **Affiliate's Policy Work**

Susan G. Komen is the voice for the 2.9 million breast cancer survivors and those who love them, working to ensure that the fight against breast cancer is a priority among policymakers in Washington, D.C., and every Capitol across the country. Komen Southeast Wisconsin is the representative of that voice locally.

### ***Komen Advocacy Priorities***

Komen Southeast Wisconsin is proud to join the other 116 US Affiliates in providing a unified front in the support of Susan G. Komen's Advocacy Priorities. Health equity for breast health and breast cancer issues is of great importance in Wisconsin. Komen Southeast Wisconsin has been a major voice in preserving the essential work of the local NBCCEDP Wisconsin Well Woman Program (WWW).

Komen Southeast Wisconsin, in partnership with Wisconsin Breast Cancer Coalition, co-sponsored a town hall style meeting to address the concerns around the restructuring of the Wisconsin Well Women Program. Gail Johnson, the Director of the WWW agreed to be present to both speak and answer questions. Komen organized and facilitated the meeting, inviting key individuals from all areas of breast cancer services – advocates, WWW coordinators, grantees, health system administrators, health providers, and breast cancer organizational leaders, and fellow Wisconsin Komen Affiliates. Over 50 people attended this several hour long meeting allowing them to express their concern with the nature of the restructuring, the speed at which changes were occurring, a lack of clear communication from the State, and the absence of effort to gather input from key stakeholders of the WWW program.

Rigorous follow up in the form of phone calls, personal contacts, and co-signed letters to Wisconsin's elected state representatives, the Governor, and State's department heads assisted in pushing back implementation of the proposed changes from 7/1/14 to 7/1/15 to allowing for input from local coordinators, health systems, and key organizations. Komen SEWI was included in resulting information gathering sessions hosted by the Wisconsin Department of Health Services. Communication has been more forthcoming from the State, and the nature and details of the restructure are being more carefully considered. The Affiliate will continue to monitor the progress and impact of this restructure and continue to take a role to ensure the NBCCEDP remains a vital and viable resource for Wisconsin women.

Komen Southeast Wisconsin has been a consistent advocate for the NBCCEDP. Using the Race for the Cure as an advocacy opportunity, the Affiliate circulates petitions calling for the continuation of Federal and State funding for the National NBCCEDP. This not only results in petitions that can be sent to representatives in the Senate and House of Representatives, it also provides an opportunity to educate Komen's supporters about the existence and value of the WWW program.

Komen Southeast Wisconsin was also proud to join other local breast cancer organization in the advocacy for and ultimate passage of the Oral Chemo Bill known as the Cancer Treatment Fairness Act. The Affiliate cosigned advocacy efforts aimed at state representatives and the Governor. After a three year struggle, the Cancer Treatment Fairness Act was signed into law in Wisconsin on April 3<sup>rd</sup>, 2014 and will take effect on January, 2015.

A local partner organization, the Wisconsin Breast Cancer Coalition, is a key resource for keeping up to date on issues of breast health issues and legislation most pertinent to Wisconsin and the southeastern service area. Partnering and co-sponsorship of advocacy efforts with the WBCC and other local organizations, health systems, and key individuals fighting for optimal breast health legislation enhances Komen Southeast Wisconsin's efficacy in advocacy efforts. It is through these avenues that the Affiliate can most effectively lobby Wisconsin State representatives to continue to support legislation for federal breast cancer funding, as well as continue to consider an expansion of Medicaid in Wisconsin.

### ***Awareness of issues and legislation***

While most of the Affiliate's advocacy guidance comes from Komen's Advocacy Team, Komen Southeast Wisconsin is also obligated to be informed on additional local and state issues that could specifically impact the breast health or disrupt the equity of health services of Wisconsin residents. This is an area that benefits from partnership with the Wisconsin Breast Cancer Coalition and other local cancer and breast cancer organizations to, once again, advocate in a united and powerful voice. A 2014 issue warranting attention is Senate Bill 632. There is a strong effort underway advocating for protection from potential breast cancer causing chemicals by opposing the passage of this bill which would eliminate local governments' ability to regulate or restrict air or water quality by ways of permits, licenses, and state regulations. Local and State issue and legislation advocacy is also strengthened by Komen Southeast Wisconsin's relationship with the Komen South Central and Komen Central Affiliates. Together the Affiliates can stay more informed of issues, present a unified voice at lobby days, and partner in co-signing petitions and letters to State representatives. All of the Komen Wisconsin Affiliates have an obligation to stay on top of local and state issues so that they can provide meaningful input back to the Komen Advocacy team for consideration when the annual Advocacy Priorities are being set.

### ***Local Affiliate impact***

Komen Southeast Wisconsin has the resources and support to be a leading expert in the fight against breast cancer in its Southeastern service area. The Affiliate will continue to have a strong and widespread community presence in order to promote broad awareness of the need for strong programs fighting breast cancer in Southeast Wisconsin.

This type of leadership compels the Affiliate to constantly look for partnership opportunities with organizations throughout Southeastern Wisconsin, facilitate working connections between community organizations and health services, lead advocacy efforts for optimal breast health in Wisconsin, take an active role in local and state organizations such as the Breast Cancer Task Force and the Wisconsin Cancer Coalition, provide accurate and accessible breast cancer education to the community, and be diligent in promoting the development of best practice breast cancer programs to optimize the use of grant funding dollars.

# Qualitative Data: Ensuring Community Input

## Qualitative Data Sources and Methodology Overview

### **Methodology**

Komen SEWI utilized qualitative data collection to gather input on the perspective of people living and working in Southeast Wisconsin in order to develop a more comprehensive assessment of the breast health needs and issues facing the Target Communities. A deeper understanding of the community's attitudes, beliefs and behaviors about disparities, access to services, utilization of services, quality of care, and additional breast health and breast cancer issues provides insight into the possible gaps and needs identified in earlier data collection.

Breast health and breast cancer issues revealed by the Quantitative Data Findings and the Health System Analysis laid the foundation for developing qualitative assessment questions in several categories:

Education/Awareness - How are health systems providing breast health education in their Target Communities? Who needs and who has access to accurate and culturally appropriate breast health and breast cancer information in each Komen SEWI Target Community? Are current education and outreach programs in the community effective at leading women to breast cancer screenings?

Breast Cancer Screening - Are there gaps between breast cancer screening guidelines and health providers' usage of guidelines? Between guidelines and reported frequency of CBE and screening mammograms? Does personal perception of breast cancer risk have an impact on screening behavior?

Barriers - What are the factors that are preventing, discouraging or inhibiting women in each Target Community from accessing and/or following through with breast cancer screenings? With diagnostic services? With breast cancer treatment services? Are there socioeconomic and/or demographic indicators tied to identified barriers? Are health providers able to provide access to timely coordinated care across the CoC for breast health services?

Survivorship - What can providers reveal about the availability of survivor support services? Do breast cancer survivors feel a need to talk about their breast cancer and whom do they choose to speak with? How do survivors find out about support services? What support services are survivors aware of, how often do they utilize them, and which services are seen as most valuable?

Solutions – What can be done to reduce the gaps and barriers identified?

In an effort to gather input from the perspective of a variety of sources, the Affiliate selected six different tools for data collection:

1. **The General Population Survey** – This survey was available as both a paper and an online survey. It consisted of a series of close-ended questions that captured mainly demographic and socioeconomic information and open-ended questions intended to

collect input on health system experiences, perceptions of barriers and motivators to breast health services, beliefs/attitudes about breast cancer, and opinions on what could be done differently in the community to improve breast health service delivery. The General Survey was offered only to women and although it did not specifically target breast cancer survivors, it did include an area to self-identify as a survivor.

In-person data collection was accomplished through the efforts of Komen staff and multiple volunteers. The survey targeted women only, but the in-person nature of collection allowed staff and volunteers to steer data collection more specifically to women of mammogram age (ages 40 and older). Collection sites were selected based on their ability to draw a wide sample of residents from a given area and, in several cases, their ability to provide access to individuals representing specific demographics.

Paper surveys were returned to the Affiliate office where additional volunteers entered each survey's responses into a manual entry port allowing them to be added to the data collected by the online General Population Survey.

The online General Population Survey was identical in content to the paper surveys, but was created on SurveyMonkey. SurveyMonkey was selected for its ease of use, variety of question formats, and data analysis capabilities. The General Population Survey was made available on the Komen SEWI website and by links in an eBlast reaching over 30,000 individuals from the Affiliate's data base. Partner organizations were also provided a pre-written email template which they could forward to their constituents that would link interested individuals to the survey.

- 2. The Survivor Survey** – This survey was developed in SurveyMonkey and offered only online. It was designed to gain a more in-depth look at the themes addressed in the General Population Survey. The format consisted of a combination of open-ended and close-ended questions that gathered input ranging from pre-diagnosis (risk perception, barriers to screening, education), to diagnostic and treatment (stage of diagnosis, movement through the health system, additional barriers) to support systems (access, availability, and timeliness of support services). The Survivor Survey also collected socioeconomic and demographic information that would allow the Affiliate to sort the data collected.

Like the General Population Survey, the Survivor Survey was made available online through the Komen SEWI website, by eBlast to the Affiliate's data base, and also included as a link on the email template sent to partner organizations. Individuals receiving these emails were given the option of taking either the General Population Survey or the Survivor Survey. A brief description of each was provided along with an estimate of time needed to complete the task. This option allowed breast cancer survivors to give input through either survey format. A limited number of emails containing a link to just the Survivor Survey was also sent to a list of identified breast cancer survivors. All responses from the Survivor Survey went directly into the online SurveyMonkey Collector.

- 3. Key Informant Interviews** – This data collection consisted primarily of one-on-one interviews designed to gather information from community organization service providers

who have deep familiarity with the needs and issues faced by their target populations. Questions were mainly open ended and probing. Responses were transposed into a SurveyMonkey so that the data could be more easily accessed and analyzed.

The majority of key informant interviews were conducted in-person or via conference call by Komen's Mission Manager. This provided a consistency to the delivery of questions and the recording of data. The interview followed the questions laid out in a SurveyMonkey format. Responses were typed verbatim into the survey's manual data collection link. Accuracy was checked by reading back responses and summarizing the information provided by the interviewees frequently during the interview process.

Key informant interviews were also completed by a handful of interviewees online through the *Community Organization Survey* collection tool on SurveyMonkey. These responses were provided by people unable to schedule a personal interview. In these cases, data were entered directly by the key informants into SurveyMonkey through a web link collector. Because the collection formats were identical, the online input was easily added to the data collected during the in-person key informant interviews.

4. **Health Provider Survey** – This online survey was created in SurveyMonkey and designed to collect data from providers identified in the Health System Analysis. In order to be respectful of the time restraints faced by survey respondents, the format consisted mainly of close-ended questions with the option of adding additional narrative to explain and/or expand on responses. The health provider survey was fairly extensive with the intention of collecting information across the continuum of care. Questions addressed a range of topics including breast health services provided; ability to meet CDC guidelines; CBE and mammography recommendations; individuals in need; individuals served; assessment of barriers to screening, diagnostics, and treatment; methods used to overcome barriers; and possible collaborations.

The Affiliate identified one team member to organize and track the delivery and completion of the health provider surveys. This individual made initial phone calls and emails to introduce the survey and explain its purpose to the desired respondents. This was followed up with an email providing the web link, as well as an outlook calendar reminder to complete the survey within a desired time frame. Compliance with this request was tracked and follow-up emails and phone calls were made as needed to encourage individuals to take time to provide input from their health facility.

5. **Survivor Forum** – The Forum was a one time, in-person gathering of Southeast Wisconsin breast cancer survivors. The goal of the Survivor Forum was to gather input on three topics: education, barriers, and support. Participants were invited for dinner, given a brief overview of the purpose of the Forum, provided with a paper list of the evening's topics and sub-questions, and then randomly divided into three equal sized groups and assigned to a topic area for their first discussion.

Within each topic, two to three questions were posed to initiate feedback. The groups rotated to each of the topic areas, spending approximately 30 minutes discussing each topic. Each topic discussion was facilitated by one discussion leader and one scribe. The leaders were chosen for their ability to facilitate good discussion and their

knowledge of the topic. The Conversation for the Cure Program Manager led the discussion on Education, Komen SEWI's Executive Director led the Barrier Discussion, and partner organization ABCD - After Breast Cancer Diagnosis's Executive Director led the discussion on Support Services. To ensure that information would be recorded accurately and easily, the forum chose scribes who were also very familiar with the topics – respectively the CFTC Program Assistant, a Komen Board Member and past Race Chair, and the Affiliate's Mission Manager.

Topic questions were written on large sheets of paper viewable by the whole group. The topic leaders posed each question, probed for further elaboration on responses, and strived to ensure fairly equal input from all participants. The scribes recorded the participant's responses on the paper sheets, regularly checking for accuracy with the group.

6. **Conversation for the Cure (CFTC) Data** – Komen SEWI's in-house breast health education program CFTC has a registration form and a survey that each woman is asked to fill in when participating in the program. Responses were recorded by conversation leaders into a SurveyMonkey. Some data from April 2013 to January 2015 were in a useable format for qualitative analysis:  
General participant responses to questions regarding barriers to screening and new information learned through the CFTC Program  
Barriers to screening responses from Hispanic/Latina participants

The use of multiple data collection tools allowed Komen SEWI to triangulate its data findings. Triangulation is a process of validating data by comparing the results found in the study of one phenomenon by two or more data collection methods. The weakness of one data collection method can be clarified by the use of other collection source(s) investigating the same query.

The ability to compare one data source to another was especially important to the qualitative analysis in the 2015 Community Profile. Komen SEWI's identification of five Target Communities encompassing its entire service area accurately reflected the needs recognized in the quantitative and health system analysis, but came with some inherent barriers to successful qualitative data collection and analysis. There was a great deal of new ground to break in this endeavor. The Affiliate's partnerships are very strong in Milwaukee County, but modest or non-existent in other Southeast Wisconsin counties. In Kenosha, Ozaukee, Racine, and Waukesha partnerships are limited, but do include some strong relationships with current and past Komen SEWI grantees. Until the end of 2014, the Affiliate had few if any partnerships in either Walworth or Washington Counties. Komen SEWI chose to utilize all six of the data collection methods described above in each Target Community in an effort to compensate for possible shortcomings in the utilization of any one or more methods in a particular Target Community.

### **Sampling**

Each data collection method was chosen and utilized for its ability to gather input from specific groups of respondents within each Target Community. The respondents were targeted for their ability to illuminate the issues and needs that surfaced in the quantitative and health system data analysis. The methods of data sampling varied between collection tools.

## **Surveys**

Surveys were chosen as an important sampling tool for gathering input on the perceived barriers to and gaps in breast health services. Individuals targeted for responses included breast cancer survivors, women of mammogram age, health system providers, as well as a broad cadre of women from the larger population. Wherever possible, the Affiliate also hoped to capture some input through these surveys from vulnerable populations identified in each Target Community. While the types of surveys varied in content and audience, the Affiliate utilized emergent sampling design with all of the surveys in order to assess its progress collecting qualitative data and attempt to add to the sample size as needed.

The General Population Survey was used as a collection tool to ask women, mainly of mammogram age, to answer questions about breast health awareness, mammogram rates, barriers to breast health service, motivators to increase screening behaviors, and gaps in the health system. The Affiliate's goal was to achieve a large enough survey response from each Target Community to achieve high confidence levels for specific queries even when dissecting the data by socioeconomic and demographic variables. Sampling for the General Population Survey was mainly by convenience and was emailed to every individual in the Affiliate's data base, shared with members of local other community organizations, and made accessible to women throughout Southeast Wisconsin through links to all the Affiliate's social media including website, Facebook, and Twitter. Paper versions of the general survey were made available to women at local malls and general health fairs capitalizing on the availability of a broad audience. Ideally the Affiliate wished to be able to collect data from individuals that appeared to bear the greatest burden of breast cancer in each of its five Target Communities as identified in the quantitative and health system analyses. To facilitate this, the Affiliate also utilized the paper version of the general survey to do purposive sampling at clinics, work places, grocery stores, and community events known or expected to draw individuals of specific demographic and socioeconomic populations.

The target audience for the Survivor Survey was breast cancer survivors, of any gender and at any point in their breast cancer journey, residing in each Target Community. Survivors were chosen as a target population for their ability to speak first hand on the barriers and gaps experienced over the course of their breast cancer diagnosis and treatment. In order to achieve a high level of participation, the Survivor Survey was distributed in several ways targeting individuals in the Komen SEWI database (purposive sampling), recipients of assistance through the Komen SEWI Breast Health Assistance Fund (purposive sampling), through outreach on the Affiliate's Facebook and Twitter posts, and by emails to partner organizations. Non-probability purposive sampling was attempted, drawing survey recipients from known groups of breast cancer survivors. .

The Health Provider Survey was strictly purposive data sampling. Because the number was not overwhelming in any of the identified Target Communities, the Affiliate began with the comprehensive list of providers developed during the Health System Analysis and attempted to survey every facility identified in each Target Community. The goal was for 100 percent compliance to try to gain a full picture of the needs and issues surrounding breast health services from the perspective of individuals working in each of the Target Community's various health facilities.

The final survey based sample utilized by Komen SEWI was the existing Conversation for the Cure (CFTC) program data. These data were collected by convenience sampling with responses provided by women filling in the required registration and survey forms that were part of the CFTC Program they attended. As collected, this data only provided the opportunity to analyze a small amount of input in relationship to specific population characteristics. One exception to this was a pool of data collected strictly from Hispanic/Latina women throughout Southeast Wisconsin which could help confirm ideas found in other data collection tools and illuminate the needs of and barriers facing Hispanic/Latina women.

### ***Key Informant Interviews***

Key Informant Interviews allowed the Affiliate to gain further insight on populations suspected of higher than average vulnerability based on the quantitative and health system findings within each Target Community. Key Informant Interview participants were purposively selected. Identification of potential partners earlier in the development of the Community Profile provided the Affiliate with a starting point from which to select respondents, especially in less familiar counties. A list of possible interviewees was developed as Komen SEWI identified multiple organizations within each Target Community that targeted specific populations likely to experience barriers to breast health services. Speaking with key staff members from these organizations, as well as partners from current and past grant programs, gave the Affiliate insight on populations that would likely be under represented in the General Population Survey, but whom the Affiliate considered necessary to learn about in order to gain a better understanding of the needs in each Target Community. Not surprisingly, snowball sampling also occurred as interviewees assisted the Affiliate in identifying other key stakeholders that could provide further input.

### ***Survivor Forum***

The Survivor Forum provided data from a separate unique group of respondents. Komen SEWI leveraged its relationships with ABCD, Sisters4Cure, Young Survivor Coalition, Conversations for the Cure, Wisconsin Women's Health Foundation, Hispanic Resource Center, and Partners for the Promise/Nurses Affecting Change to recruit as random of a sample of participants as possible to attend the Forum. Individuals from each of these organizations were invited to extend an invitation to the Survivor Forum to breast cancer survivors in their network. The goal was to gather a room with a diverse group of individuals in hopes of achieving a broad range of perspectives. The only common denominators between participants were being a breast cancer survivor and living in Southeast Wisconsin. While not a perfect random sample generator, this method did fill the Forum with women whose age, race, income level, and county of residence varied widely.

### ***Ethics***

The confidentiality of all respondents and the appropriate use of data gathered are of utmost importance to the Komen SEWI Affiliate. All qualitative data collected has been archived by Komen SEWI as Excel data spreadsheets and Word files with all personal data removed.

***Surveys*** – No names or identifying information were collected within the surveys. Participation was strictly voluntary and respondents were given the option of not answering any question (with the exception of 'county of residence').

**Key Informant Interviews** – All Key Informant Interviews were conducted confidentially. Pre-interview clarification was given relating the purpose and future use of the information gathered and verbal agreement was secured. Interviewees were informed that the statements they made were understood to be their own opinions and observations and that the Affiliate held no expectation of their accuracy. Interviewees were informed that no content specifically referencing an individual or organization in the Community Profile would be specifically referenced in the narrative and that all direct quotes (although included anonymously) would be shown to the respondent for their approval prior to the publication of the Community Profile.

**Survivor Forum** – All participation was purely optional and voluntary. No personal data were attached to any of the input collected. No formal list of participants was collected.

**Conversations for the Cure Data** – Data are kept per the program requirements of the CFTC Program Grant. All personal information is strictly confidential. All CFTC data utilized for the Community Profile did not contain personal data.

### **Qualitative Data Overview**

While the format of Komen SEWI's original data varied by collection method, a large amount of data were initially gathered either online or, in some cases, by manual entry into SurveyMonkey. All paper survey data were inputted and merged with the identically formatted online survey data. The Affiliate chose to work with SurveyMonkey(SM) for many reasons, especially convenience, affordability and ease of access - even for beginners with little to no previous data collection experience. Through SM, Komen SEWI was able to custom design each survey and collect input through open and close ended formats utilizing text, ranking, and multiple choice questions. While open-ended questions provided the bulk of the surveys' narrative responses, comment sections allowed participants to expand on their responses to close-ended questions. These responses were easily gathered within SM and provided the Affiliate with a wealth of additional descriptive narrative to reference in its analysis of the data collected.

SurveyMonkey's text analysis ability provided a good starting point for mining data from the surveys' open-ended questions. Key words were collected and confirmed within the raw data. Words were combined into categories and similar categories were combined to create a manageable group of themes for each open-ended question. Ultimately, the data collected from the General Population Survey, Survivor Survey, Key Informant Interviews, and Conversations for the Cure ended up ready for analysis in Microsoft Excel format- a good choice for the Affiliate due to its ease of accessibility, its pivot table data manipulation capabilities, and its fairly strong data charting and graphing tools. The actual data mining of open-ended questions was completed by developing formulas in Excel. Each spreadsheet was labeled and fine tuned to facilitate the use of pivot tables to compare data within each Target Community.

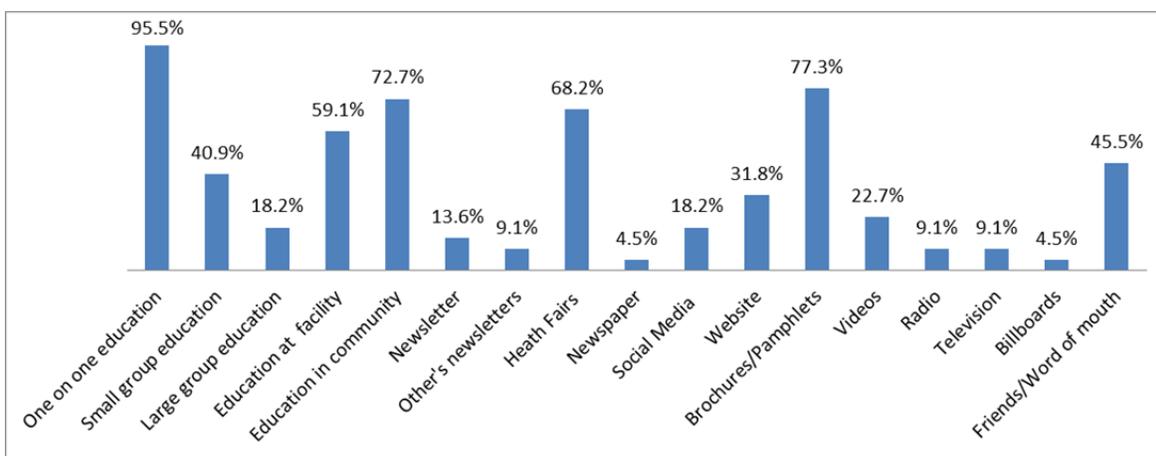
The Survivor Forum input was recorded verbatim, archiving the responses in each of the three discussion areas. Individual responses were recorded as accurately as possible to reflect the original content of the statements and confirmed for accuracy by the participants. For ease of reference, these responses were then transcribed into a Microsoft Word file, categorized by topic and sub-questions. Themes were identified in each category in a written analysis of the data providing supportive narrative for the data collected through other methods.

## Milwaukee County

Data collection for Milwaukee County allowed for the exploration of many questions within this Target Community on the topics of education, barriers, access and quality of care within the health system, as well as survivorship issues. The General Population Survey gathered responses from 256 individuals. The Survivor Survey brought in 81 responses. The Health Provider Survey had 27 respondents representing every major health system in Milwaukee County in addition to responses from providers at local free clinics and FQHC's. The Affiliate was able to compare data sets from all the collection methods.

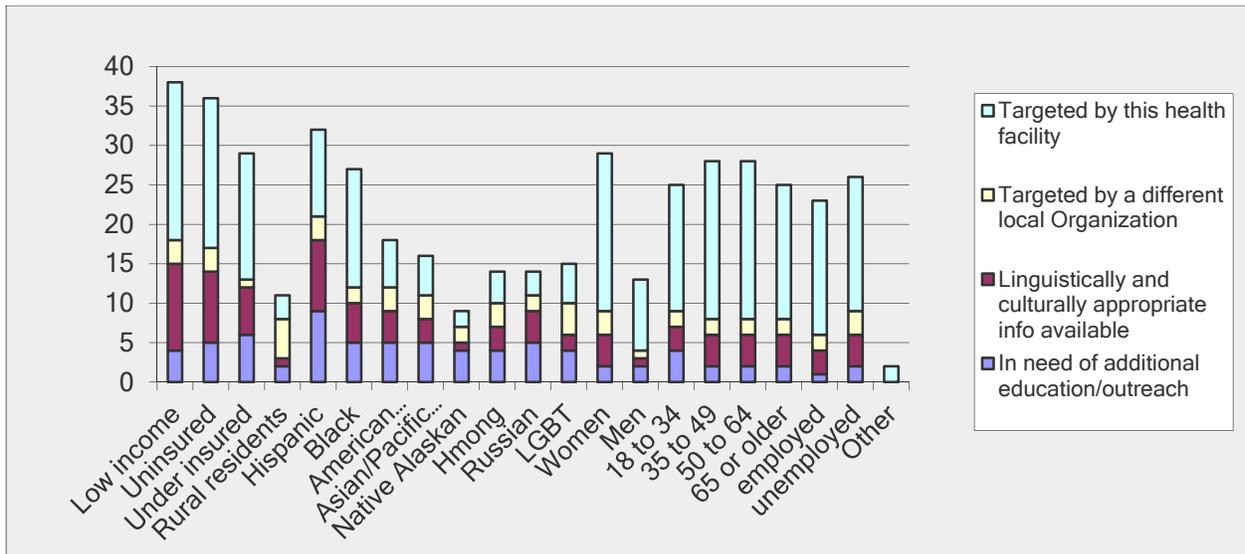
### Education and Outreach

The Health Provider Survey results confirm that outreach to provide breast health education and outreach was both a priority for service providers and a necessity for a wide variety of populations within Milwaukee County. Providers indicated that the health system utilizes a broad collection of methods to provide breast health education as shown in the Figure 4.1 below. The most common methods identified by providers are personalized one-on-one education, brochures, health fairs, and small and large group education. Many providers stated that their facility took their breast health education programs into the community and nearly half said that their outreach and education programs relied on getting information out through friends or others by word of mouth.



**Figure 4.1.** Milwaukee County health facility education/outreach services – Health provider survey

Figure 4.2 illustrates the availability as well as the need for breast health educational services in Milwaukee County. Health Provider Survey respondents recognize and target a broad selection of individuals from a wide range of demographics and socioeconomic variables. Key Informant Interviews in Milwaukee County identified the presence of individuals from additional distinct populations including disabled individuals (both mentally and physically), the homeless, and those transitioning from incarceration or recovering from drug and/or alcohol problems. Key Informants and health providers surveyed agreed that every population group identified needed additional education and outreach services.

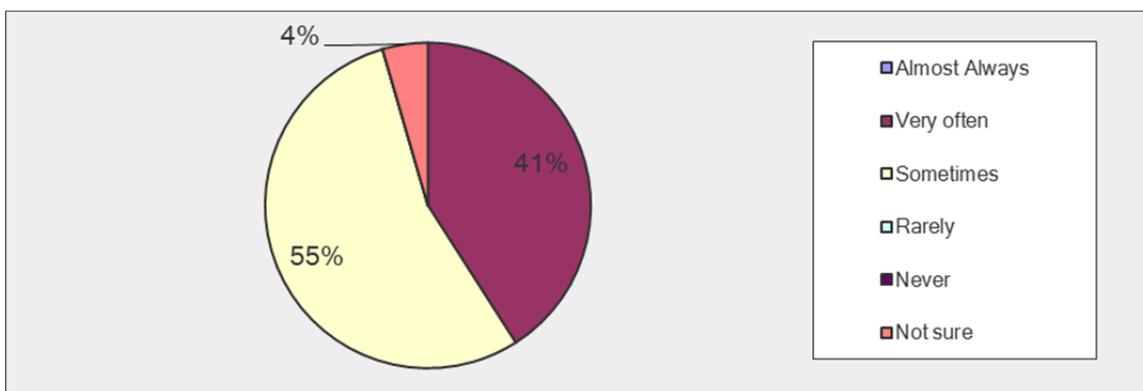


**Figure 4.2.** Population groups in need of breast health education – Health provider survey

Data from all sources showed a call for continued improvements in outreach and education. A local health facility navigator stated a need for “*more active community outreach to underserved populations.*” Others concurred stating “*we are continuing to work to serve all residents of the county*” and “*we will continue to seek effective partners in outreach to impoverished women.*”

While most survivors surveyed felt breast cancer information was available, few thought the information was effective or culturally sensitive. These thoughts were further echoed by the key informants and health providers that indicated while breast health education/outreach programs and materials are available, additional information and services are needed.

When asked to evaluate the effectiveness of breast health education and outreach in the Target Community moving women to breast cancer screening. Where 1 represents ‘never’ and 5 is ‘almost always’, health providers rated the effectiveness of current education efforts in Milwaukee County a 3.4, a solid C-plus grade (Figure 4.3).



**Figure 4.3.** Answers to the question: “In your opinion, do you think current education or awareness programs in your community are successful at getting women to be screened for breast cancer?” – Health provider survey

### Breast Cancer Screening

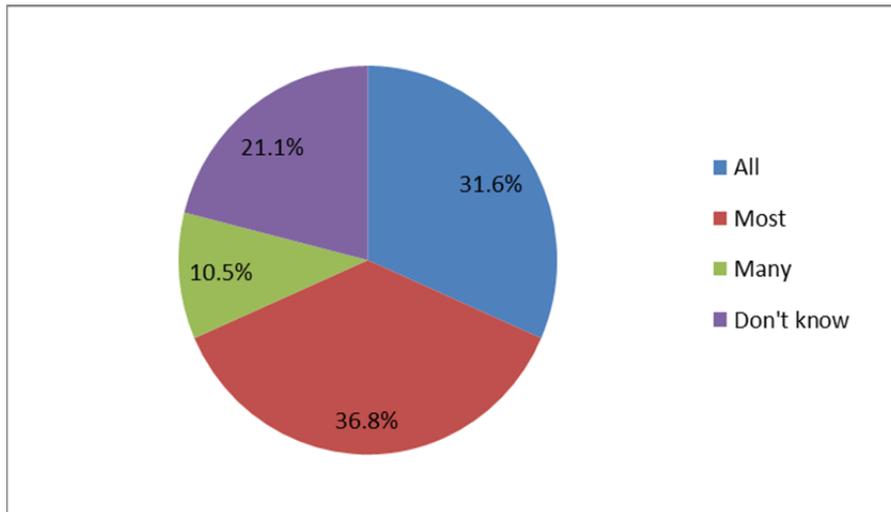
A full 76.5 percent of providers reported that their health system recommended yearly clinical breast exams and 11.8 percent of providers recommend CBEs every two years. 93.8 percent recommended beginning this screening at age 20. The remaining respondents reported providers used a different guideline or were not aware of their health system's recommendations for CBEs.

Milwaukee County women that participated in the General Population Survey showed that nearly three quarters reported having a yearly CBE (Table 4.1). However, when these data are broken down, the CBE frequency for women under 40 is markedly lower than this average and more than twice as many women under 40 never or rarely have CBEs than women over 40. It is also notable that the percentage of Black/African-American women 40 and older reporting a CBE within the past year is considerably less than percentage of White women 40 and older.

**Table 4.1.** Frequency of CBEs by percentage - Milwaukee County general survey

	% 1 yr or less	% 2 yrs or less	% 3 yrs or less	Longer than 3 years	% Never had a CBE	% Don't know what a CBE is	Combine: Don't know, > 3 and never	# number of women surveyed
All Women	73.4	12.1	1.2	5.1	7.8	0.4	13.3	256
Women under 40	55.7	10	1.4	7.1	24.3	1.4	32.9	70
Women 40+	80.1	12.9	1.1	4.3	1.6	0.0	5.9	186
Black/African-American Women	71.6	11.2	1.5	7.5	7.5	0.7	15.7	134
Black/African-American Women <40	56.4	12.8	0.0	5.1	23.1	2.6	30.8	39
Black/African-American Women 40+	77.9	10.5	2.1	8.4	1.1	0.0	9.5	95
White Women	77.7	11.7	1.0	1.9	7.8	0.0	9.7	103
White Women <40	57.7	7.7	3.8	7.7	23.1	0.0	30.8	26
White Women 40+	84.4	13.0	0.0	0.0	2.6	0.0	2.6	77

For screening mammograms, 88.9 percent of providers in Milwaukee County reported that their health system recommends the American Cancer Society's screening guidelines of yearly mammograms. Only about five percent recommended screening every two years. The remaining respondents reported providers used a different guideline or were not aware of their health system's recommendations for the frequency of mammogram screening. A full 94.4 percent recommend beginning at age 40 And 5.6 recommend beginning at age 50 which is the recommendation of the United States Preventive Service's Task Force. Figure 4.4 provides data on how often providers felt that these internal guidelines were being followed by providers in their health system.



**Figure 4.4.** Percentage of providers thought to follow their health system's screening guidelines – Health provider survey

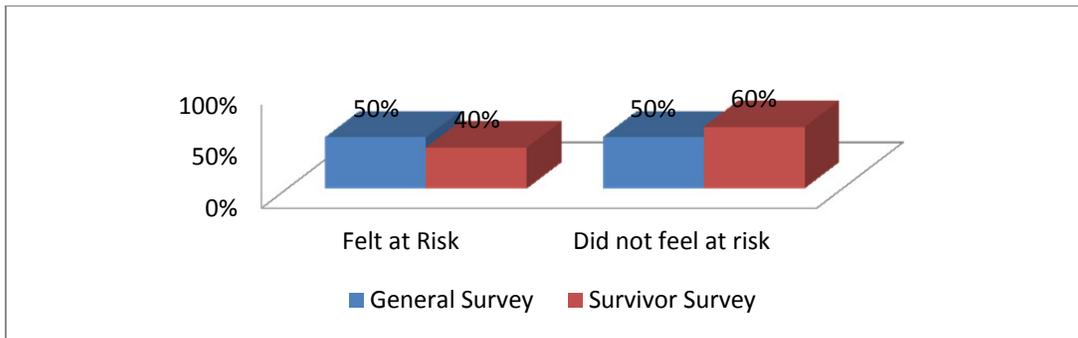
Table 4.2 provides data on the frequency of mammogram screenings for Milwaukee County women forty years and older responding to the General Population Survey. Of these women, the majority had a mammogram in the past one or two years. There is, however, a sizeable percentage of women who had either never had a mammogram or whose last mammogram was more than two years ago. Black/African-American women reported having a mammogram within the past one or two years at a lower percentage than White women. It is also notable that Black/African-American women and women in lower income brackets are well above the average percentages for having infrequent or no screening mammograms.

**Table 4.2.** Frequency of screening mammogram- General population survey

	% 1 yr or less	% 2 yrs or less	% > than 2 years	Never had a mammogram	Total of >2 yrs + never	Total # of women responding
All women 40+	76.3	10.2	7.0	6.5	13.4	186
Black/African-American Women 40+	72.6	10.5	9.5	7.4	16.8	95
White women 40+	87.8	4.9	2.4	4.9	7.3	41
Low income <50K	71.6	11.0	9.2	8.3	17.4	109
Low income <30K	72.4	13.8	10.3	3.4	13.8	58
Low income <20K	75.0	10	10	5.0	15.0	40
Underinsured	78.6	11.9	4.8	4.8	9.5	42

### **Perception of Risk**

A specific discussion of perception of risk is warranted as it appears to be tied to screening frequency, late-stage diagnosis, and breast health education. The data in Figure 4.5 shows the breakdown of the responses to the question “Do you feel at risk for breast cancer?” in the General Population Survey as well as the responses to a similar question in the Survivor Survey “Before your diagnosis, did you feel at risk for breast cancer?” More than half of respondents said they did not feel they were at risk for breast cancer.



**Figure 4.5.** Perception of breast cancer risk – General population survey and survivor survey

When compared to screening frequency, perception of **being at risk** is related to a higher percentage of annual screenings (Table 4.3). Conversely, the perception of **not being at risk** is often related to individuals screening only every two years and those never screening or screening less than every two years.

**Table 4.3.** Mammogram percentage by age and perception of risk – General population survey

	How long since your last Mammogram?							Total Mamms
		1 year or less	% 1 year or less	2 years or less	% 2 years or less	> 2 years or never	% > 2 years or never	
Age by Perception of BC Risk Milwaukee Women over 40	<b>40 to 49</b>	51	76.1	4	6.0	12	17.9	67
	No	28	41.8	3	4.5	6	9.0	37
	Yes	23	34.3	1	1.5	6	9.0	30
	<b>50 to 59</b>	53	70.7	12	16.0	10	13.3	75
	No	18	51.4	11	14.7	6	8.0	35
	Yes	35	87.5	1	1.3	4	5.3	40
	<b>60 to 69</b>	31	91.2	1	2.9	2	5.9	34
	No	11	32.4	1	2.9	2	5.9	14
	Yes	20	58.8		0		0	20
	<b>70 plus</b>	7	70	2	20	1	10	10
No	4	40	2	20	1	10	7	
Yes	3	30	0	0	0	0	3	

This connection was strengthened by a similar data from the Survivor Survey that showed the majority of women who rarely or never received a mammogram before their diagnosis also *did not* feel a personal risk of breast cancer prior to diagnosis.

Survivor Survey data also showed a possible connection to perception of risk when compared to stage of breast cancer diagnosis. Twice as many Milwaukee County survivors diagnosed at stage I indicated they *did* feel at risk for breast cancer than those who *did not* perceive they were at risk (Table 4.4). Conversely, for those with stage 2 and 3 diagnoses, a noticeably higher percentage of individuals reported that they *did not* feel at risk for breast cancer prior to their diagnosis compared to those who did perceive they were at risk (X).

**Table 4.4.** Late-stage diagnosis in relation to perception of risk - Survivor survey

	Stage I	% No to Yes	Stage II	% No to Yes	Stage III	% No to Yes	Stage IV	% No to Yes	total stage 3 and 4	% of Y/N stage 3 and 4
At Risk – NO	8	33.3	19	79.2	7	77.8	2	58.1	9	64.3
At Risk – YES	16	66.7	5	20.8	2	22.2	3	41.9	5	35.7
Total	24		24		9		5		14	

Data regarding risk perception further correlated with education in an unanticipated way. A survivor’s pre-cancer risk perception was compared to how knowledgeable that survivor felt about breast cancer before being diagnosed. Table 4.5 illustrates that nearly half of Milwaukee County Survivors who felt they were informed or somewhat informed about breast cancer ALSO *did not* perceive themselves as being at risk for breast cancer prior to their diagnosis.

**Table 4.5** Risk perception compared to knowledge about breast cancer – Survivor survey

	Did you <b>feel at risk</b> for BC before your diagnosis?		Education to Risk Disconnect	
	No	Yes		
Did you <b>feel informed</b> about BC before your Diagnosis?	No	9	5	Out of 75 Breast Cancer Survivors:
	Somewhat	9	3	9 (12%) somewhat informed but did not feel at risk of bc
	Yes	27	22	27 (36%) informed but did not feel at risk of bc

**Barriers to Breast Health Services**

The General Population Survey data identified eight major barriers to breast cancer screening for Milwaukee County women. The most frequently identified barriers were insurance, fear, time, and money across all populations (Table 4.6). Some results are especially striking including the Among many of the survey respondents, fear as a barrier was identified at a higher frequency. Worth noting is the relatively low percentages given to pain as a barrier. Data mining for fear did not include the concept of pain, including instead fear of diagnosis, the unknown, the health system, and fear of admitting something is wrong. Black/African-American and White women in Milwaukee County indicated the same categories as their top four barriers, the order of these barriers differ as well as the frequency at which they are chosen (Table 4.6).

Table 4.6 also illustrates some major differences in the frequency at which barriers were identified by Black/African-American and White women in Milwaukee County. While selecting the same categories in their top four barriers, the order of these barriers differ as well as the frequency at which they are chosen. Black/African-American women identified barriers more frequently than White women overall. Black/African-American respondents identified an average of 0.93 per person while White women identified an average of 0.66 per person.

**Table 4.6.** Percentages of barriers to screening – General population survey

	Total Responses	Cultural -Religious	Support	Pain	Insurance	Transportation	Money	Time	Fear
All Respondents	256	8.2	4.3	7.8	23.8	3.9	16.4	17.2	22.3
Survivors	47	8.5	0.0	8.5	36.2	4.3	21.3	14.9	23.4
Black/African-American Women	134	4.5	3.0	7.5	23.1	3.7	9.7	14.9	27.6
White Women	103	11.7	4.9	6.8	24.3	3.9	24.3	20.4	16.5
API	1	100.0	0.0	100.0	0.0	0.0	0.0	100.0	100.0
AINA	8	12.5	25.0	0.0	50.0	0.0	25.0	12.5	0.0
Other	10	10.0	0.0	20.0	10.0	10.0	20.0	10.0	20.0
Non-White respondents	153	5.9	3.9	8.5	23.5	3.9	11.1	15.0	26.1
Hispanic/Latino	14	14.3	7.1	14.3	21.4	7.1	28.6	21.4	14.3
income <50K	156	9.6	3.8	9.0	21.2	5.1	12.2	15.4	22.4
income <30K	89	6.7	2.2	6.7	19.1	5.6	11.2	15.7	27.0
income <20K	61	6.6	0.0	8.2	11.5	3.3	11.5	8.2	32.8
Under or uninsured	53	11.3	3.8	11.3	35.8	3.8	18.9	17.0	24.5
Age - Under 40	70	11.4	4.3	2.9	14.3	4.3	7.1	17.1	17.1
Age - Over 40	186	7.0	4.3	9.7	27.4	3.8	19.9	17.2	24.2

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

Survivor Survey data indicated that respondents felt that insurance, money, and fear were the top three barriers to breast cancer screening. Unlike the General Population Survey, survivors indicated that education was also a prominent barrier to breast cancer screening across multiple populations (Table 4.7).

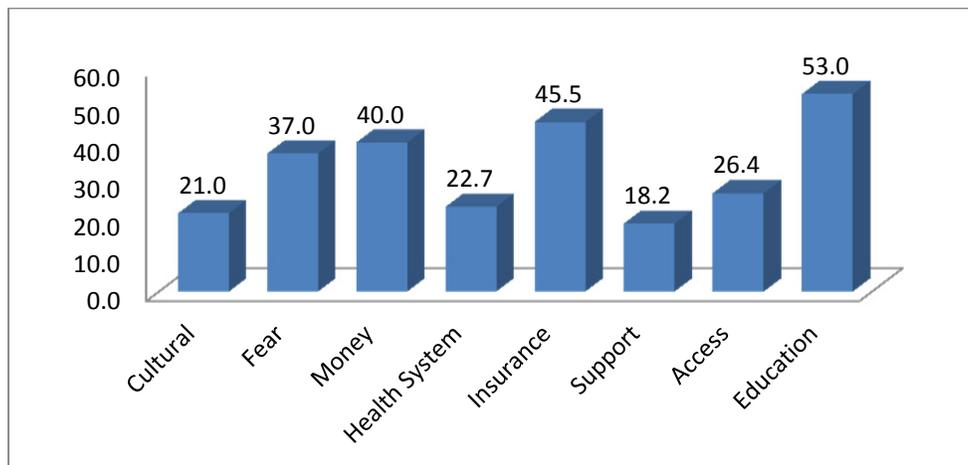
**Table 4.7.** Barriers to breast cancer screenings by population characteristics - Survivor survey

From 81 Survivor Survey Respondents	Fear	Support	Education	Time	Money	Insurance	Pain	Transportation	Cultural - Religious
All Respondents	16	1	10	6	17	21	2	3	3
Black/African-American	3	0	3	0	2	5	0	0	0
White	12	1	6	6	11	13	2	3	3
Age Under 40	2	0	2	0	1	2	0	0	1
Age 40 plus	14	1	8	6	16	19	2	3	2

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

The Health Provider Survey (Figure 4.6) for Milwaukee County identified barriers and rated them as either minor, moderate, or major. Health providers indicated education was the greatest screening barrier in Milwaukee County (Figure 4.6). Echoing similar General Population and

Survivor Survey results, insurance, money, and fear were the next highest barriers. It is notable that three new categories were also identified frequently - access, the health system itself, and cultural barriers (including language barriers and related health literacy barriers, cultural beliefs, and a broad lack of culturally sensitive health services in addition to religious barriers). The scope of cultural barriers was illustrated by one respondent's statement that *"we still do not place enough emphasis on cultural and language barriers...these can be huge obstacles to breast cancer screening and treatment."*



Note: Barriers were given points- Minor (1), Moderate (3), and Major (5) each time the barrier was chosen. Barriers were then grouped by category and each category was scored by totaling the points earned by the barriers chosen. The numbers attached to each of the categories shown are averages of the points earned by the specific barriers making up that category.

**Figure 4.6.** Barriers to screening Milwaukee County - Health provider survey

Key Informant Interviewees indicated culture, education, fear, and insurance as top barriers (Table 4.8). One interviewee emphasized the importance of education stating that *"the barrier at the root of the problem is a lack of knowledge in the community. Lack of knowledge of specific health concerns such as breast health, breast cancer screening recommendations, and lack of knowledge of how to access services."* Another, speaking on cultural barriers faced by her clients reflected that there is *great "hesitance, shyness even. I see a reluctance to mammography because many feel that mammograms are culturally inappropriate."* One respondent expressed a common sentiment that for smaller isolated populations it is *"difficult to find and difficult to gather information – it takes a lot of outreach and follow up to overcome their barriers – this can be a long process."*

One common theme in most Key Informant Interviews was the impact of 'social factors' on access to screening mammograms for populations targeted by the interviewee's organization. These included mental illness, lack of social acceptance, homelessness, physical disability, drug or alcohol use, and more general issues such as unemployment, poverty, and housing difficulties.

Several key interviewees provided input on the effect barriers have on screening percentages. One individual who provides breast health education to Hispanic/Latina women in Milwaukee County revealed that at least three quarters of the participants in her community outreach events targeting women over 40 year old have never had a mammogram. She cited insurance and cultural barriers as the major causes for these low rates. Another respondent whose program targets Asian Pacific Island women (40 years and older) of different ethnic

backgrounds stated that nearly three quarters of API women in this program have either never had a mammogram or have not had a screening in the past five years. This interviewee indicated the top barriers as insurance, language/cultural barriers, transportation, and fear.

**Table 4.8.** Barriers to breast cancer screening in Milwaukee County- Key informant interviews

	Fear	Time	Money	Transportation	Insurance	Pain	Education	Support	Cultural Religious
All Responses	14	7	7	7	8	3	14	4	15

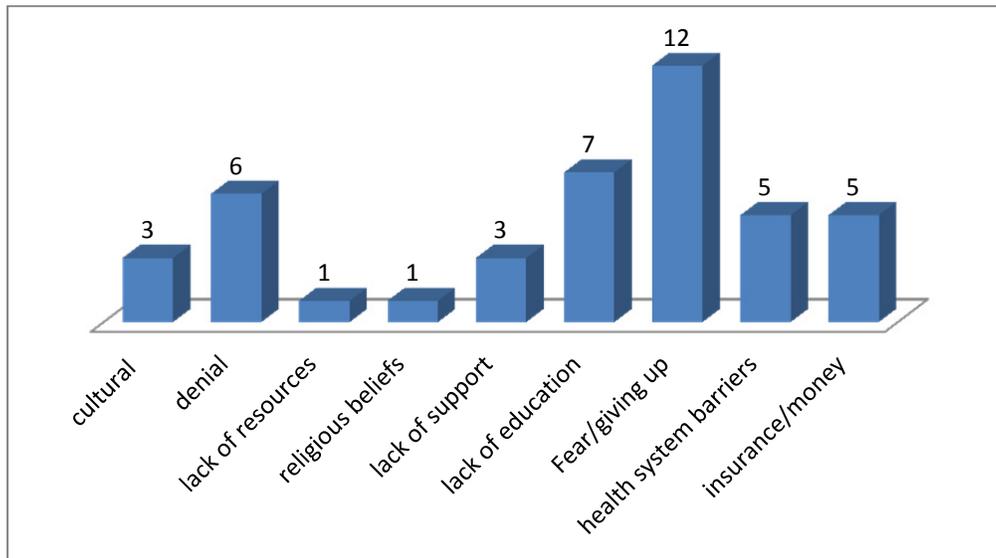
Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

Cultural barriers warrant additional attention as they were noted repeatedly in Key Respondent interviews. While the Health Provider Survey data indicated that providers are aware of cultural barriers and are beginning to take steps to address them, key interviewees were adamant that more progress needs to be made in order to achieve health equity (equal access and delivery of health services) for all residents of Milwaukee County. Key Informant Interviewees gave a strong voice to the opinion that there are major barriers at all levels of breast health services for individuals whose primary language is not English, as well as anyone who is seen as out of the cultural mainstream. The interviewees pointed to a system-wide lack of culturally and situationally sensitive materials and service delivery.

One interviewee expressed concern for great vulnerability faced by individuals who are outside of the mainstream. *“There is an inherent level of uncertainty and sometimes shame in not knowing how to or not feeling able to overcome barriers to services. This creates an imbalance of power that not only negatively affects access to services, but also represses the degree to which these inequities are reported by the individuals affected.”*

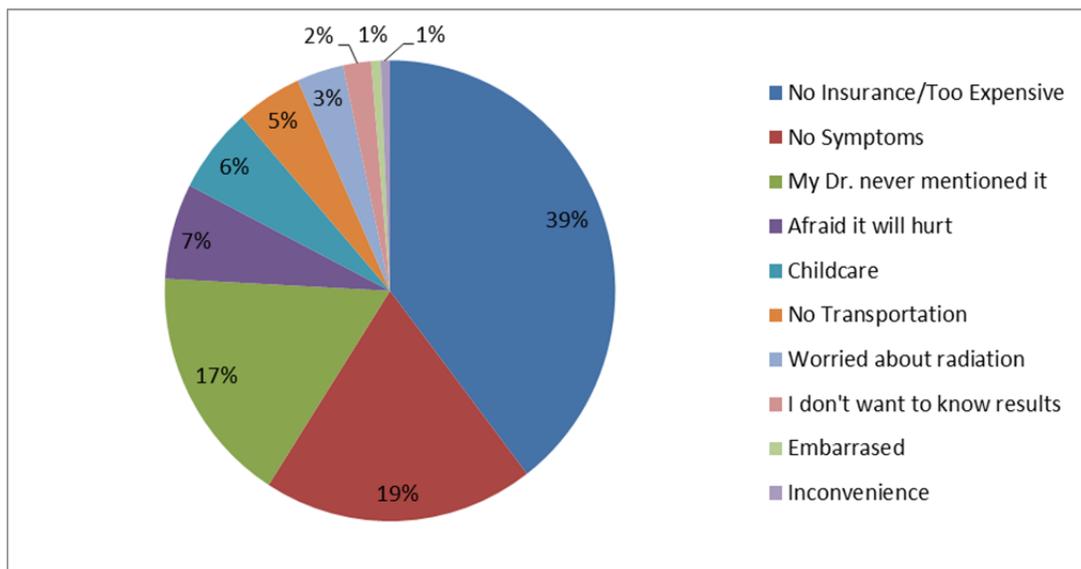
Many informants pointed to a systemic *“lack of knowledge of cultural customs in order to offer services in a culturally appropriate or acceptable way.”* One community health worker working mainly with Hispanic/Latina women, echoed the broader sentiment of most key interviewees that the scope of barriers faced by her clients was not simply linguistic challenges when she explained that Milwaukee County is *“very segregated and hostile to immigrant populations - people are often nervous to leave their own neighborhoods. Racism is a big factor - not feeling like you belong or have the right to move around affects people’s lives so deeply”*. Another health professional with a long history of community involvement calls the array of barriers faced by Milwaukee County’s most vulnerable populations *“a rampant problem. The system lacks a true understanding of individual’s right which often causes an abuse of individual’s rights just because they are culturally/linguistically different. For example, bilingual efforts cannot simply be putting something in Spanish. The goal must be deliberate to deliver services at the same standard for all populations and the health systems must align with other organizations to get services necessary to bridge cultural/language needs or at least be upfront that they are not filling this need.”*

Responses from the Survivor Forum found that fear and education were top barriers as well as denial, insurance/money and the health system itself (Figure 4.7).



**Figure 4.7.** Barriers to breast cancer screening -Survivor forum

Data from 2013 – 2014 Conversation for the Cure Program Hispanic/Latina participants indicated that insurance and money were top barriers, but a large percentage of participants also reported that they do not pursue screening because they have no symptoms or because their doctor did not instruct them to get screened (Figure 4.8).



**Figure 4.8.** Barriers to screening – Hispanic/Latina CFTC Participants 2013 - 2014

### Barriers to Diagnostic and Treatment Services

Health providers indicated that the populations facing major impediments to diagnostic and treatment services are those who are low income, under and uninsured, and unemployed (Table 4.9) . A number of additional population groups were also identified as likely to experience some difficulty accessing and following through with breast cancer diagnostic and treatment services.

**Table 4.9.** Populations experiencing diagnostic and treatment barriers - Health provider survey

Population Group Experiencing Barriers	Barriers to Diagnostic Service			Barriers to Treatment Service		
	Minor Problem	Moderate Problem	Major Problem	Minor Problem	Moderate Problem	Major Problem
Low income individuals	4	5	7	3	2	8
Uninsured individuals	6	3	7	4	1	8
Under insured	2	5	7	2	2	8
Rural residents	1	1	1	1	1	1
Hispanic/Latina	4	3	3	3	3	3
Black/African-American	1	3	3	1	3	3
American Indian	0	1	1	0	1	1
Asian/Pacific Islander	0	0	1	0	0	1
Alaska Native	1	0	0	1	0	0
Hmong	0	1	1	0	1	1
Russian	0	0	1	0	0	1
Lesbian women	2	0	0	2	0	0
Transgender individuals	0	0	1	0	0	1
People w/ young children	1	1	0	1	1	0
20 to 44 year olds	3	3	1	3	3	1
65 or older	2	1	1	1	1	1
employed	3	0	0	3	0	0
unemployed	0	5	2	0	4	3

Health providers felt barriers that affected access to and follow through with breast cancer diagnostic services were insurance/money, fear, education/awareness, and culture (Table Y). While barriers to treatment services were insurance/money remains first, fear is second, and education/awareness is third, but personal barriers emerged as the fourth most commonly cited barrier (Table 4.10).

**Table 4.10.** Barriers to diagnostic and treatment services – Health provider survey

Diagnostic Services			Barriers	Treatment Services		
minor	moderate	major		minor	moderate	major
			<b>Cultural</b>			
2	2	3	Cultural beliefs	2	3	2
3	0	2	Religious beliefs	3	0	2
2	2	2	Lack of culturally sensitivity	2	1	2
1	2	2	Language Barriers	1	1	2
			<b>Fear</b>			
3	5	5	Fear of having breast cancer	4	4	2
3	3	4	Fear of procedure(s)	2	1	5
2	5	4	Fear/distrust of medical system	1	5	3
3	0	1	Fear of neighborhood	3	0	1
			<b>Insurance/Money</b>			
2	2	6	Low Income	0	3	6
1	4	6	Lack of Insurance	0	2	7
0	3	7	Out of medical pocket costs	0	3	6
			<b>Education/Awareness</b>			
3	4	3	Not aware of the importance	2	4	2
2	5	2	Unaware of services available	2	3	2
2	3	1	Don't know where to go	2	2	1
2	3	2	Don't know how to access	2	2	2
2	1	2	Lack of support services	2	2	2
			<b>Personal</b>			
1	2	1	Lack of family support	2	2	1
3	1	2	Need for Childcare	2	0	3
0	3	2	Can't get off Work	0	2	3
2	3	1	Too draining	1	4	1
			<b>Health System</b>			
2	4	3	No Primary Care provider	2	2	2
2	2	0	Long waiting lists	2	2	0
3	0	1	Lack of providers	2	1	1
0	3	2	Distance to facility	0	3	2
2	3	1	Lack of navigation services	1	3	1
1	2	2	Limited service hours	1	2	1

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

Key interviewees indicated lack of education was the top barrier for all population groups (Table 4.11). Money and fear were the next most frequently identified barriers, with insurance and cultural/religious barriers also appearing prominently (Table 4.11).

**Table 4.11.** Barriers to diagnostic breast cancer services – Key informant interviews- Milwaukee County

	Fear	Time	Money	Transportation	Insurance	Pain	Education	Support	Cultural - Religious
All Responses	13	3	10	3	4	1	23	4	5
Hispanic/Latina	7	2	4	2	2	1	12	1	4
Black/African-American	6	0	3	1	1	0	8	1	2
Asian/Pacific Islander	2	1	3	0	0	0	4	1	0
American Indian	1	0	1	0	0	0	3	0	0
Low income	8	2	8	2	3	1	13	3	3
Under or uninsured	8	2	8	2	3	1	13	3	3
LGBT population	2	0	1	0	2	0	4	1	0

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

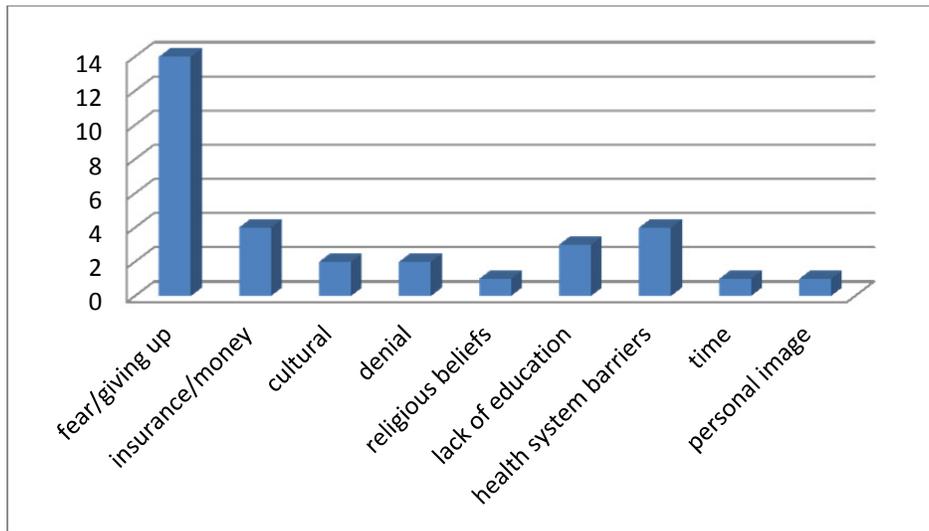
Key interviewees indicated that money (out of pocket health expenses as well as general living expenses) was the top barrier to accessing treatment services (Table 4.12). Transportation issues emerged as a close second confirming that travel becomes a greater burden as appointment frequency increases during breast cancer treatment (Table 4.12). Fear, time, support were also cited often.

**Table 4.12.** Barriers to breast cancer treatment services – Key respondents Milwaukee County

	Fear	Time	Money	Transportation	Insurance	Pain	Education	Support	Cultural - Religious
All Responses	9	4	13	8	0	0	4	6	5
Hispanic/Latina	5	4	7	5	0	0	1	4	3
Black/African-American	2	2	4	4	0	0	0	3	2
Asian/Pacific Islander	1	0	3	2	0	0	0	0	1
American Indian	1	1	2	2	0	0	0	0	1
Low income	5	2	8	6	0	0	3	3	3
Under or uninsured	5	2	8	7	0	0	3	3	3
LGBT population	1	1	2	0	0	0	1	1	0

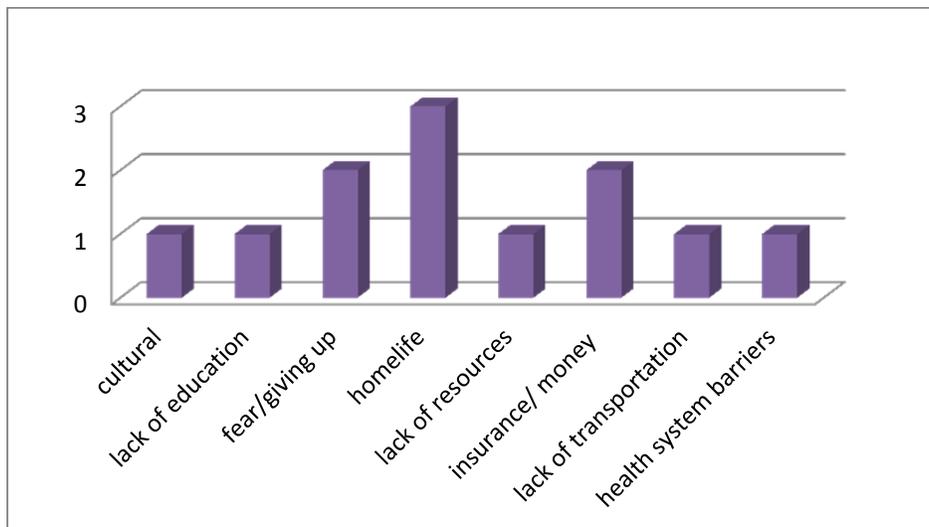
Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

Survivor Forum participants identified fear or a desire to ‘give up’ as, by far, the main reason an individual would not pursue or follow through with recommended diagnostic tests to determine if they have breast cancer (Figure 4.9). Insurance/money concerns, health system barriers, and education emerged as other top diagnostic barrier themes.



**Figure 4.9.** Barriers to breast cancer diagnostic testing – Survivor forum

The Survivor Forum participants identified homelife, which included the need to support and care for a family, the need to continue working in order to afford housing and life expenses, and the tendency to put the well being of others ahead of their own, as the top barrier to breast cancer treatment (Figure 4.10). Insurance/money and fear were also identified as top barriers. Survivor Forum participant’s strongly stated that transportation issues were a greater barrier to treatment than to screening or diagnostic services because of an *“increased need for travel due to multiple chemo or radiation appointments.”* The challenges of public transportation were also said to be *“exacerbated by the physical stress of riding when you do not feel well.”*



**Figure 4.10.** Barriers to Breast Cancer Treatment – Survivor Forum

***Insurance as a barrier***

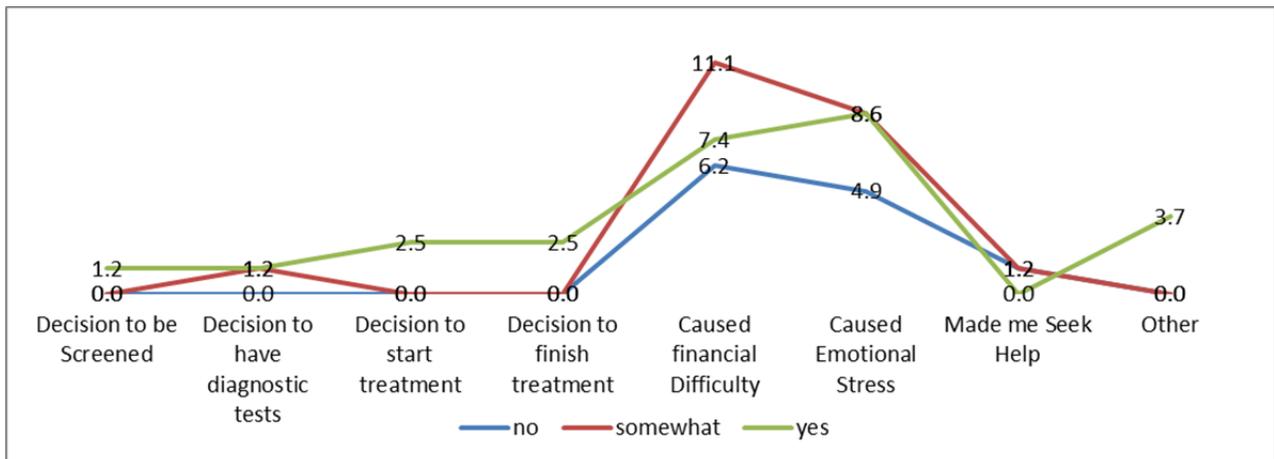
The recognition of insurance as a major deterrent to breast health services across the continuum of care by all respondents warrants additional consideration of this barrier. Being under or uninsured affects the majority of Milwaukee County’s most vulnerable populations, as well as many residents with few other barriers to service. Inadequate insurance is a big factor in an individual’s ability and decision to pursue breast cancer services at all points on the continuum of care. Those who are unable to obtain insurance due to residency status or

financial barriers are put at a severe disadvantage in accessing breast health services. But, this barrier can also affect those with insurance, as recognized in this comment by a Health Survey respondent, “our experiences have shown that low-income **underinsured** individuals often have a harder time accessing services than those without insurance altogether.”

Survivor Forum participants noted that insurance was a barrier for those who could not find and/or afford coverage, but also a major deterrent to treatment for those who had coverage but could not afford the expense of high deductibles or those whose prescription coverage was inadequate.

Survivor Survey responses provided data that further illuminates the negative effect inadequate insurance can create ranging from affecting one’s decision to be screened to causing financial and emotional stress (Figure 4.11). Comments from the Survivor Survey give insight into the burden inadequate insurance adds to a breast cancer diagnosis. One woman related “(my insurance) covered a lot, but I’m still paying medical bills from last year. Diagnostics and treatment are expensive ... I often refer to my chest as ‘the million dollar chest’ and it’s not far from the truth. Insurance just didn’t cover enough. There was such a big deductible to meet before full coverage.”

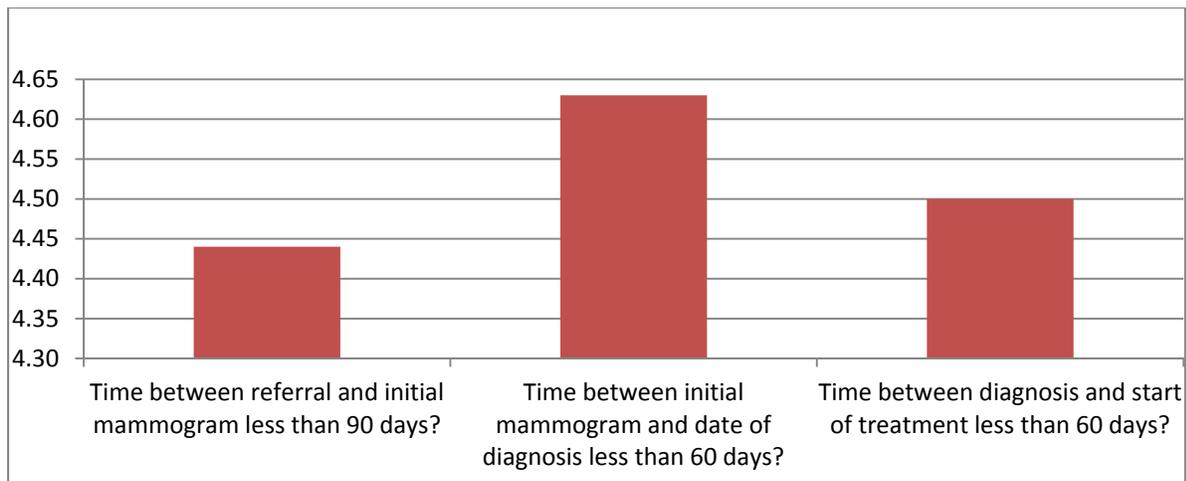
Other Survivor Survey respondents with adequate insurance confirmed the importance of that coverage to their well being. “Cancer treatment is ridiculously expensive. One neulasta shot was nearly \$12,000, and I needed a shot after each chemo treatment; add the chemo, the MD visits, the surgery, and follow up labs and without medical insurance I would have been financially devastated.”



**Table 4.11.** Effects of inadequate insurance – Milwaukee County survivor survey

**Timeliness of Breast Health Services**

Health Provider Survey respondents were confident that the majority of their breast health services were being offered efficiently and well within the Center for Disease Control guidelines. Where ‘always’ equals 5, ‘usually’ equals 4, and ‘often’ equals 3, a summary of these scores are shown in Figure 4.12.

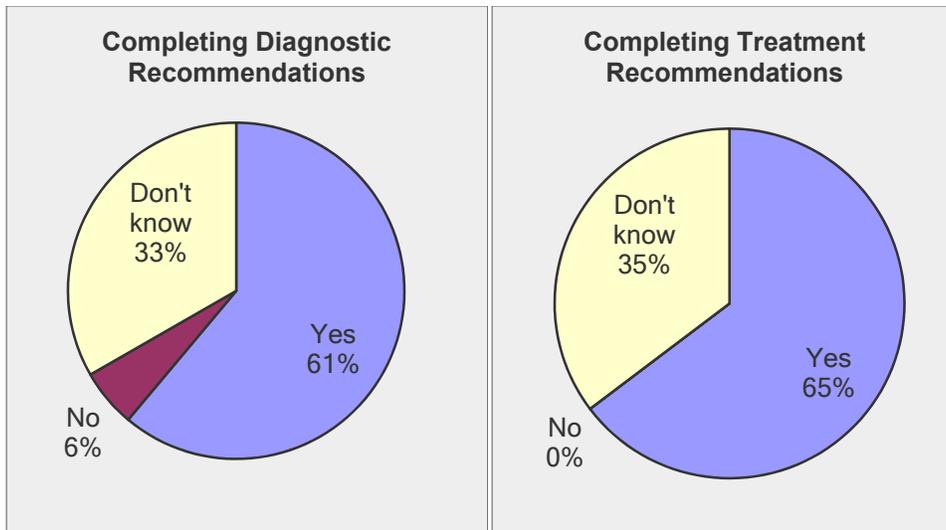


**Figure 4.12.** Milwaukee County health systems meeting CDC guidelines

Most survivors thought they moved through the health system at an optimal pace, but a handful perceived that they experienced delays in receiving timely diagnostic testing. *“The time it takes to get results of test is way too long,”* said one. *“I felt that the wait was lengthy between each step of the diagnostic process.”* Another survivor explained that she *“had to insist on getting the ultrasound follow up - my MD, the RNs and even the schedulers tried to talk me out of getting the ultrasound.”* These delays were all perceived as problems stemming from the health system.

In contrast, a full quarter of the Survivor Survey respondents reported delays in breast cancer treatment. Of these responses, more than half of delays came from complications with the breast cancer treatment itself. Insurance and money each were cited for nearly a quarter of the reasons for treatment delay. About a tenth of these delays were related to responsibilities at home, and the rest were cited as a health system delay or transportation difficulty.

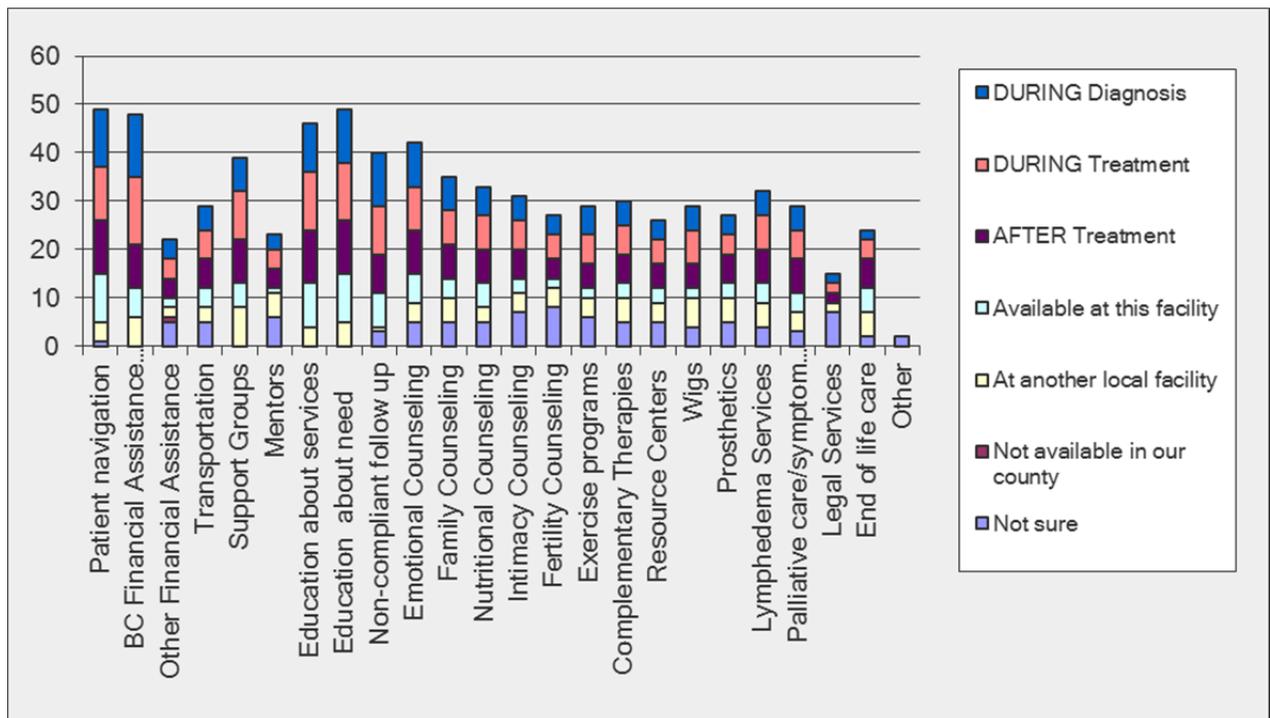
The data in Figure 4.13 shows there may be more to learn about the impact of barriers to diagnostic and treatment barriers. The Health Provider Survey reveals that a little over half of providers say they know if patients are completing recommended diagnostic tests or breast cancer treatment, but that the rest don’t know or are unsure.



**Figure 4.13.** Are patients compliant with diagnostic and treatment recommendations

### Survivor Support Services

Health Provider Survey data in Figure 4.14 shows respondents identified a broad range of possible survivor support services available along the entire continuum of care. Patient Navigation, financial assistance for breast cancer expenses, and education about the need for breast cancer services were the most frequently reported source of support. Mentors, financial assistance for non-medical expenses, and transportation support were the least frequently reported support options. In twenty out of twenty four support services identified, a handful of providers were unsure of the availability of service.



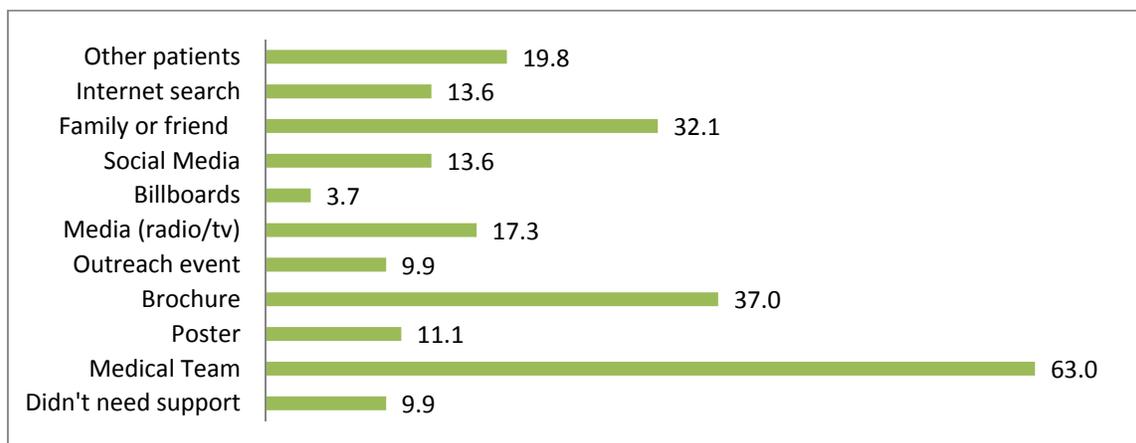
**Figure 4.14.** Support services availability and timing - Health provider survey

While most respondents to the Survivor Survey said they encountered no barriers to survivor support services, some survivors voiced their frustration about the barriers they had to finding and accessing valuable support services (Table 4.12).

**Table 4.12.** Survivor statements regarding barriers to support services – Survivor survey

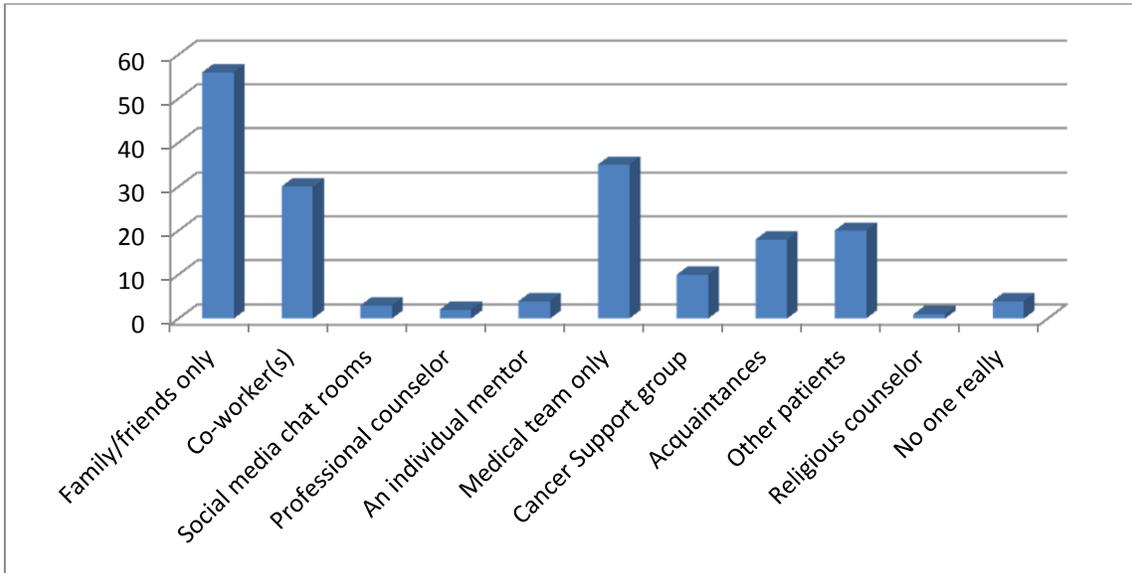
There were no support services available to me at the time of my breast cancer diagnosis
I was not aware of most of the programs listed in this question
There are no support groups on the east side of Milwaukee
At my time of diagnosis, I was told there was no support available for women my age.
Financially, once you are done with treatments you are no longer able to get financial help. Sometimes that is when you need it too for other things. You're trying to get back on your feet and the bills just keep coming in.
I had a personal barrier to support service...my husband (is ill) and I am his care giver. He can not be left alone.

Survivors overwhelmingly indicated their first source of information was their medical team (Figure 4.13). Other common sources of information identified included brochures, family and friends, and other breast cancer patients (Figure 4.13). About 10 percent of breast cancer survivors responding to the Survivor Survey stated they did not feel they needed support services.



**Figure 4.13.** Support service information – Survivor survey by percentage

When survivors who participated in the survey were asked “who do you talk to about your breast cancer,” a handful reported that they really spoke with no one about their cancer (Figure 4.14). Most respondents indicated they had several people or groups they could turn to when they wanted to discuss their cancer (Figure 4.14). More often cancer survivors reported that their main confidants were close family and friends and their medical team. Less frequently reported were co-workers, other breast cancer patients, acquaintances, and support groups.



**Figure 4.14.** Who do you talk to about your breast cancer – Survivor survey

Of 81 total breast cancer survivors that participated in the survey, less than half stated they had knowledge of any specific service available and considerably fewer reported utilizing services. The most frequently recognized support services were support groups, mentoring, counseling, and nutritional support, but usage of these was even low (Table 4.13). Mentoring had the highest number of individuals recognizing it as an ‘especially valuable’ service (Table 4.13). Other support services were not recognized as being available by the majority of those surveyed (Table 4.13).

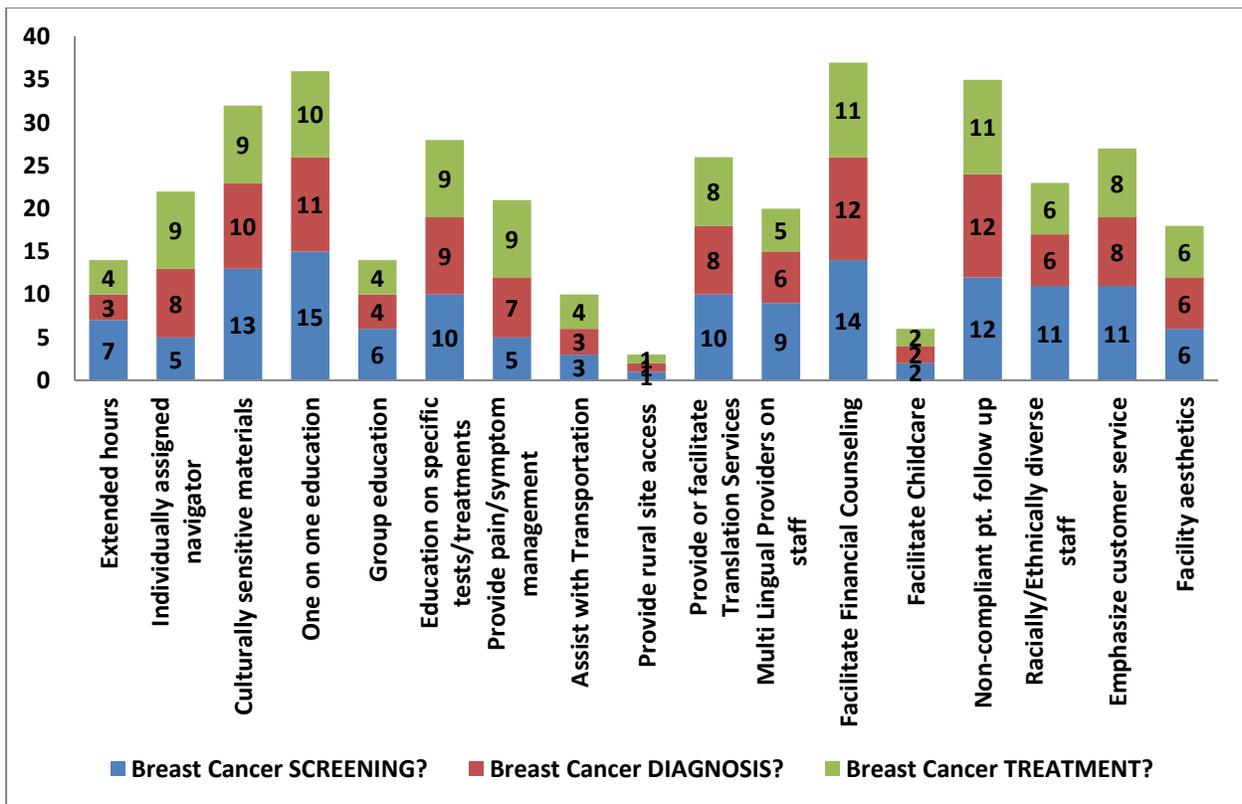
**Table 4.13.** Survivor support services: What, when, and how important – Survivor survey

	support groups	one on one mentoring	Ind. Counseling	Group counseling	Religious Counseling	Financial Support	Fertility Support	Intimacy Support	Legal Counseling	Palliative Care	End of Life Planning
<b>Available</b>	48	30	33	30	21	16	7	7	6	7	8
<b>Used before treatment</b>	0	1	2	0	0	0	0	0	0	0	0
<b>Used during treatment</b>	10	15	8	2	4	6	1	0	0	0	0
<b>Used after treatment</b>	8	5	3	0	1	3	0	1	0	0	0
<b>Especially Valuable</b>	5	10	3	0	4	6	1	0	0	0	0
	Yoga	Massage	Reiki	Meditation	Acupuncture	Exercise Program	Nutritional Support				
<b>Available</b>	10	8	5	7	6	14	25				
<b>Used before treatment</b>	0	0	0	0	0	0	0				
<b>Used during treatment</b>	4	3	1	5	3	8	10				
<b>Used after treatment</b>	2	3	0	5	0	10	5				
<b>Especially Valuable</b>	3	1	1	5	1	9	5				

**Solutions- What Can Be Done**

Each participant surveyed or interviewed by Komen SEWI was asked to offer solutions to confronting the barriers they identified to breast cancer screening, diagnostics, and treatment.

Health providers reported that the most frequent actions being taken by Milwaukee County health systems to confront screening, diagnostic, and treatment barriers were one-on-one education, financial counseling, and providing culturally sensitive materials, and following up with non-compliant patients (Figure 4.15).



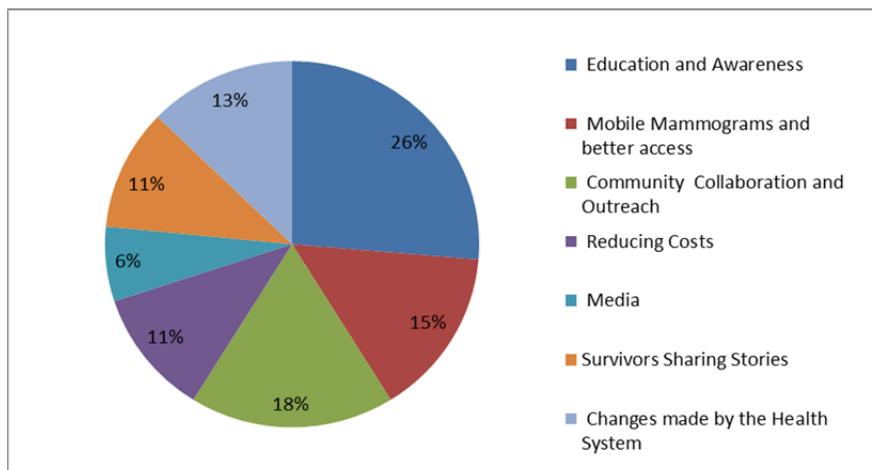
**Figure 4.15.** Confronting barriers to screening, diagnostics and treatment in the health system

Health Provider Survey offered many ideas for reducing some of the barriers to breast health services identified in the health system and within the broader community (Table 4.14). Respondents' comments focused mainly on affordability, access and education.

**Table 4.14.** Ideas for reducing barriers – Milwaukee County health providers

Offer screening services onsite to improve compliance
Facilitate access to resources for those who fall 'just above' income guidelines
Provide affordable insurance for everyone
Automatically refer self-pay patients to a financial counselor
More community programs providing CBEs and education out in the community
Increase the availability of navigators to work with every woman
Health systems should consider providing transportation
More sources of financial support for expenses such as housing, utilities, food, etc.
Mobile Mammography services - free for un/underinsured low income women
Make diagnostic and treatment services more affordable
Provide quality education to dispel myths about breast cancer and mammograms
More education and more action!

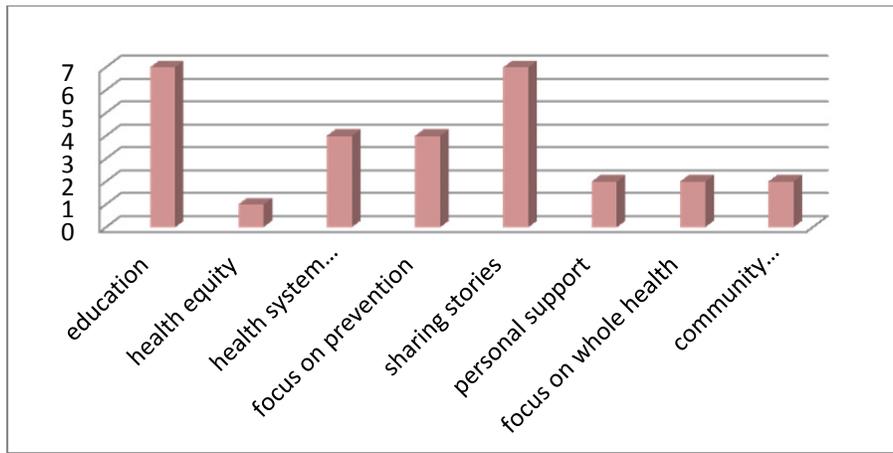
Breast cancer education and awareness was the most frequently selected choice by the General Population Survey respondents, followed by better local access to services with an emphasis on mobile mammography, community collaborations to improve outreach, and reducing costs (Figure 4.16).



**Figure 4.16.** Removing barriers to breast cancer services – General population survey

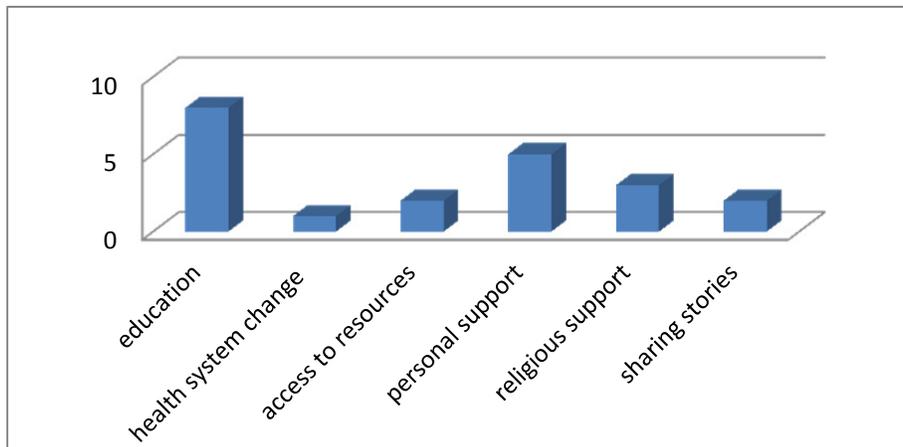
Participants of the Survivor Forum also shared their ideas for eliminating barriers to breast cancer screening, diagnostics and treatment services. One strong message that Survivor Forum participants emphasized was a conviction that health equity in general and better breast health in particular can only come out of a community-wide, grassroots effort that shifts the paradigm of the health system to one that focuses on prevention and the whole health of each individual. This viewpoint was shared by the majority of Forum participants and was seen as the most basic and necessary solution to moving individuals, especially those in vulnerable populations bearing a heavier burden of breast cancer and other disease, to a point of increased health literacy, equitable access to quality medical care and services, and, ultimately, to better overall health.

Providing broadly available breast health education and the idea of breast cancer survivors sharing their stories to inspire others into action were the two most prevalent solutions offered to increasing screening percentages for Milwaukee County women (Figure 4.17). There was also an emphasis on the need for changes in the health system such as providers increasing their awareness of and interest in the needs of patients, strong guidance to screening and understanding family history, health systems allowing patients to bring along a support person, and the ability to change doctors if necessary.



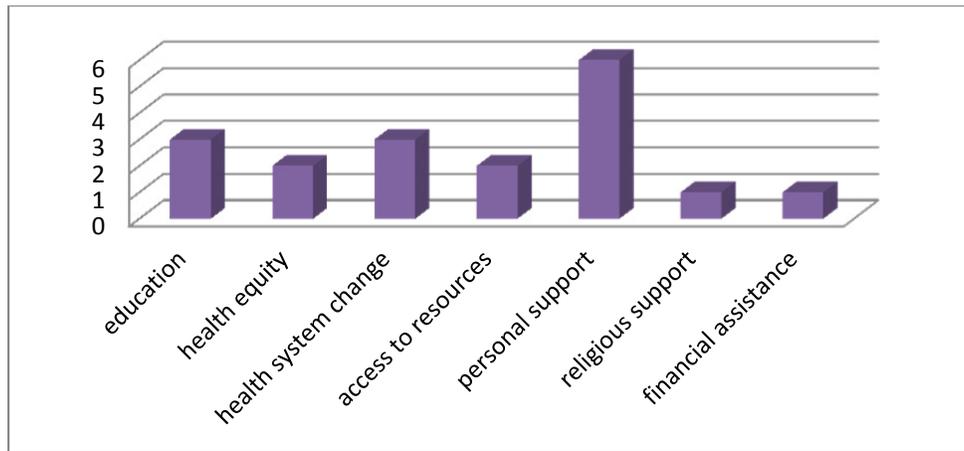
**Figure 4.17.** Solutions to breast cancer screening barriers - Survivor forum

Forum participants recognized education again as the most important element to breaking down diagnostic barriers (Figure 4.18). Support was a strong second and included a range of interventions from the emotional support of friends and family, community and religious support groups or individuals, and support in finding needed resources. Respondents also emphasized the positive effect of breast cancer survivors sharing their stories with others to increase the understanding of the importance of following through with recommended diagnostic tests.



**Figure 4.18.** Solutions to breast cancer diagnostic barriers- Survivor forum

Personal support was seen as the most vital way of eliminating barriers to the access or follow through of breast cancer treatment (Figure 4.19). Participants' comments on this topic included various practical, emotional, and informational support sources including strong advocates or mentors, informational resources, financial support, help with daily living and transportation. The need for better breast cancer education and changes in the health system were also strongly stressed.



**Figure 4.19.** Solutions to breast cancer treatment barriers - Survivor forum

Key Informants indicated that education, collaboration, affordability and an emphasis on facilitating easier access to service by utilizing community health workers and focusing on providing culturally sensitive, individualized service delivery would assist in closing the gaps in the health system for the community’s most vulnerable populations (Table 4.15).

**Table 4.15.** Ideas for reducing barriers and achieving health equity – Key informant interviews

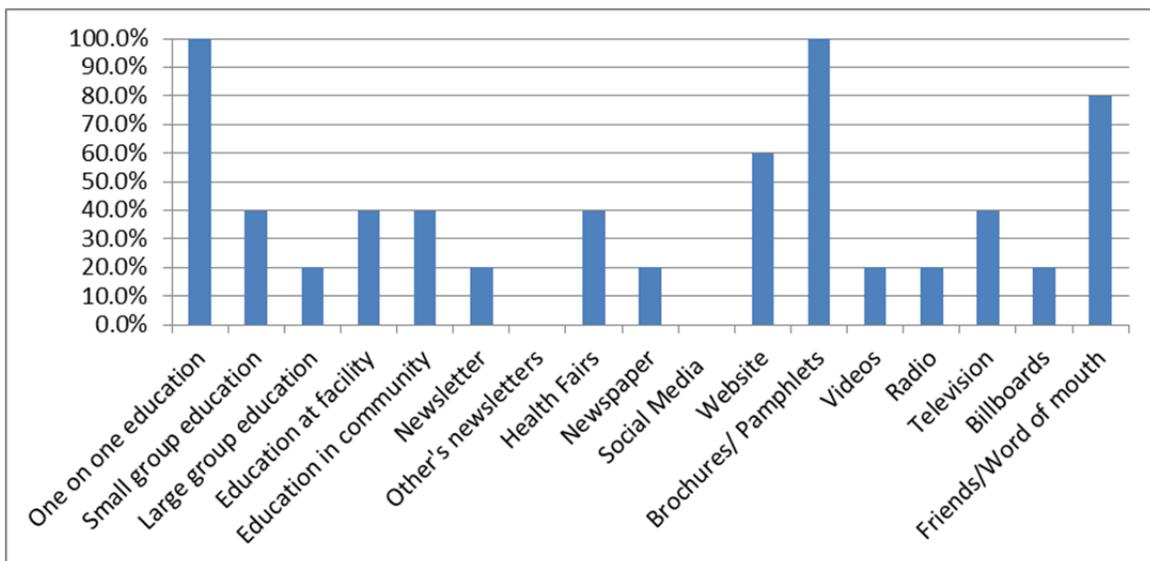
Milwaukee County
Go to where people are, show big effort, and don't let ignorance scare us away from doing the good work
Practice 'talk back" to assess how what you say to a patient is interpreted
Align with other organizations to get all necessary services needed to bridge barriers
Community Health Worker model - information from someone 'like you' builds bridges to the health system
Make screening and prevention less complicated - normalize the idea of breast cancer screenings
Give individuals ways to disclose sexual orientation to providers
Give individuals ways to express their concerns or report inequitable treatment
Prioritize a bilingual and culturally diverse health provider staff
Invite other cultures into the process of determining how the health system should work
Keep up public and private funding for screenings and breast cancer care
Work with people and think out of the box
Assume a learner's posture and let people tell you what will serve them best
Infiltrate the communities with people from the same community in order to get the work done
Give individuals specific questions to ask provider
Broaden people's understanding that you need to take active role in health
Provide transportation
Provide follow up calls to see if individuals went to appointments, treatments
Perform a thorough needs assessment to guide programming ideas
Struggle and apologize, struggle and apologize and eventually get this right

## Northern Rural Region

The Affiliate anticipated a challenge for data collection in the Northern Rural Region (NRR) Target Community consisting of Washington and Ozaukee Counties. Personal surveys proved fairly difficult to collect. There were 31 respondents to the General Population Survey. The Health Provider Survey, although returning only six responses did represent all the major health providers in the NRR as well as the free clinic. Additional health providers along with respondents from 14 individual organizations provided a solid data base through Key Informant Interviews. Triangulation of data for the NRR Target Community allowed for themes to be identified even though some data collection methods were less than optimally effective.

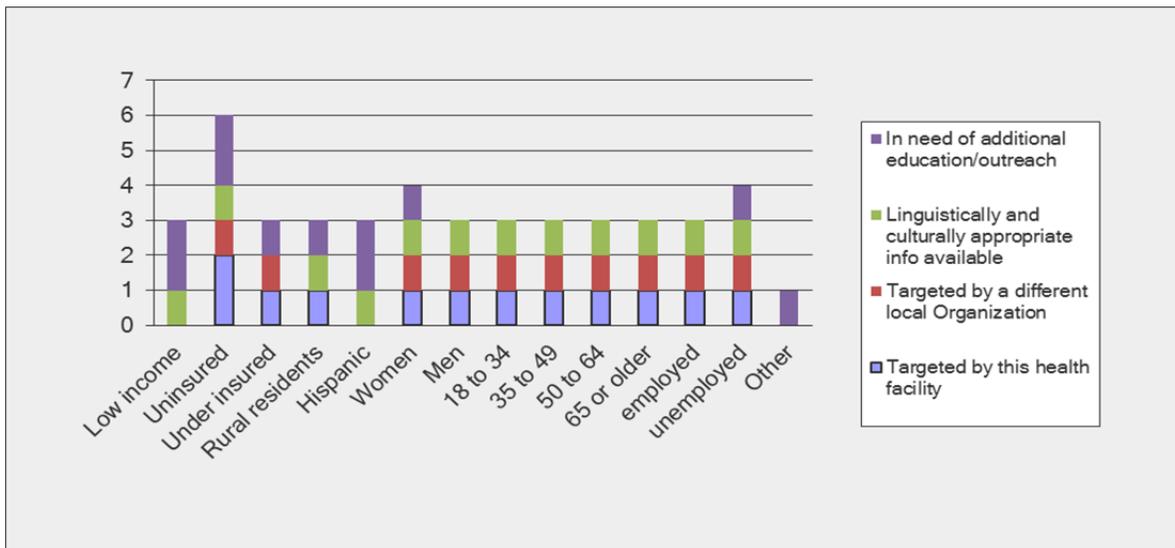
### Education and Outreach

The Health Provider Survey and Key Respondent Interviews confirm that outreach to provide breast health education and outreach is a priority for service providers and a necessity for a variety of populations within the Northern Rural Region. As shown in Figure 4.20, the health system utilizes a variety of methods to provide breast health education. One on one education and brochures were used by all respondents and word of mouth and website information were other top outreach methods.



**Figure 4.20.** Health system methods of providing breast health education and outreach

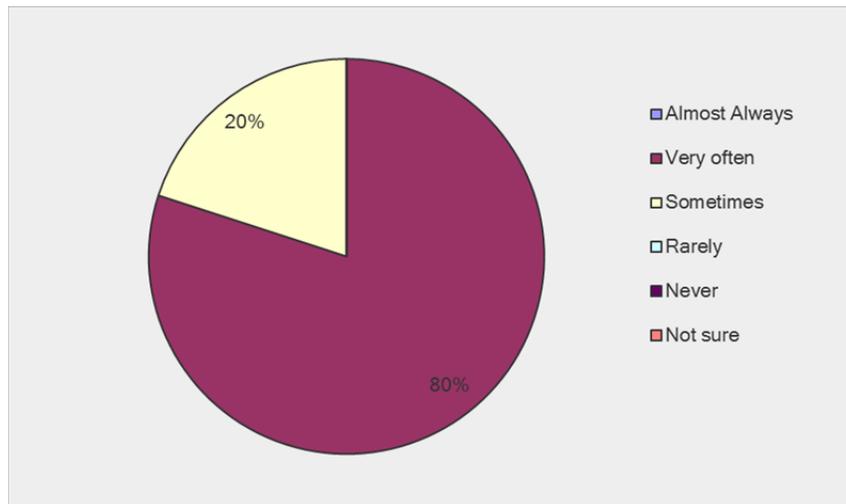
Respondents to the Health Provider Survey were asked to identify the populations in the Northern Rural Region that were targeted for breast health education, indicate if culturally appropriate information was available for those populations, and identify populations needing additional services. Figure 4.21 shows recognition of additional service needs for low income and under and uninsured individuals, rural residents, Hispanic/Latina residents, and the unemployed. Respondents indicated that education and outreach was targeted at the majority of these populations. However, while recognizing the need, this health provider data did not list any targeted outreach for the community's Hispanic/Latina population.



**Figure 4.21.** Populations in need of breast health education/outreach – Health provider survey

Key Informant Interviews confirmed the need for breast health information to the populations identified by the health system, especially those with low incomes, inadequate insurance, and/or rural residencies. The interviewees also gave firsthand accounts of the need for breast health education by Hispanic/Latina residents in the Northern Rural Region. Their connections to other vulnerable populations in this Target Community also allowed these key responders to identify definitive breast health education and outreach needs for population groups that did not appear in the health system data including individuals living in the NRR community who identify as Black/African-American, Asian Pacific Islanders, American Indians, and Lesbian, bisexual or transgender.

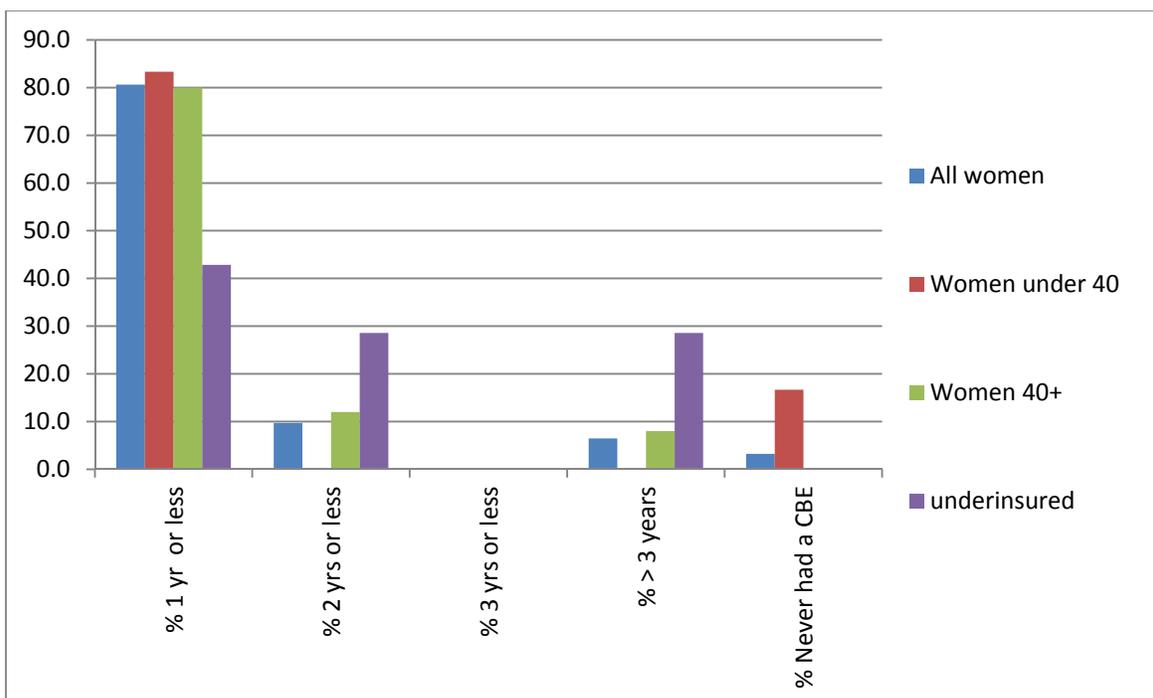
Figure 4.22 shows that health providers surveyed had mixed feelings about the ability of current education or awareness programs in the community to lead women to breast cancer screenings. On a scale of 1 to 5, with 5 being 'always' and 1 being 'never,' these respondents scored education and outreach effectiveness in the Northern Rural Region as a 3.8 which translates into a B minus grade.



**Figure 4.22.** Answers to the question: “In your opinion, do you think current education or awareness programs in your community are successful at getting women to be screened for breast cancer?” – Health provider survey

### **Breast Cancer Screening**

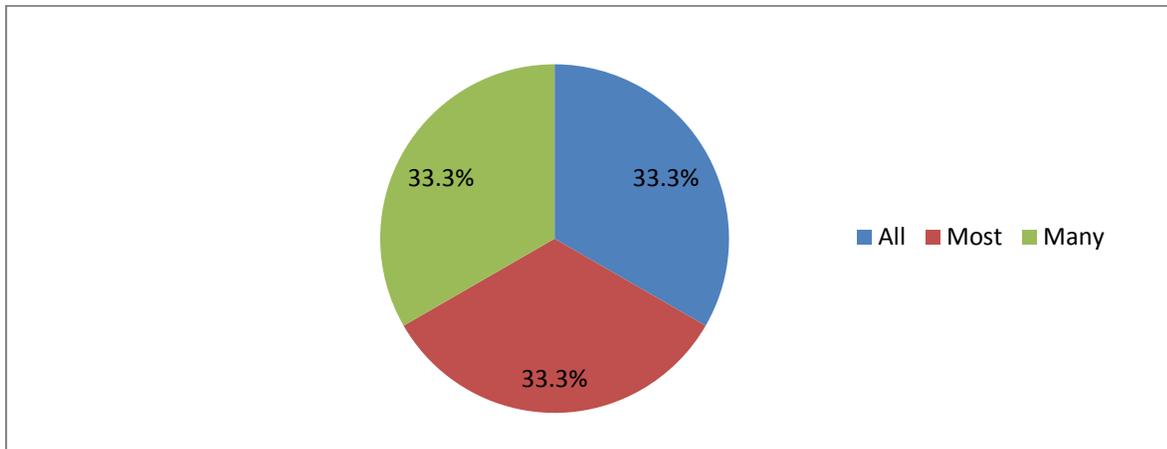
One third of the Health Provider Survey respondents reported that their health system recommended CBEs every three years and the other two third recommended yearly screening. All respondents stated their guidelines recommended this screening begin at age 20. According to the General Population Survey data shown in Figure 4.23, the majority of respondents reported having a CBE within the past year. Women under 40 years of age and women with less than adequate insurance were far more likely to infrequently or never have a CBE.



**Figure 4.23.** CBE frequency in Northern Rural Region – General survey respondents

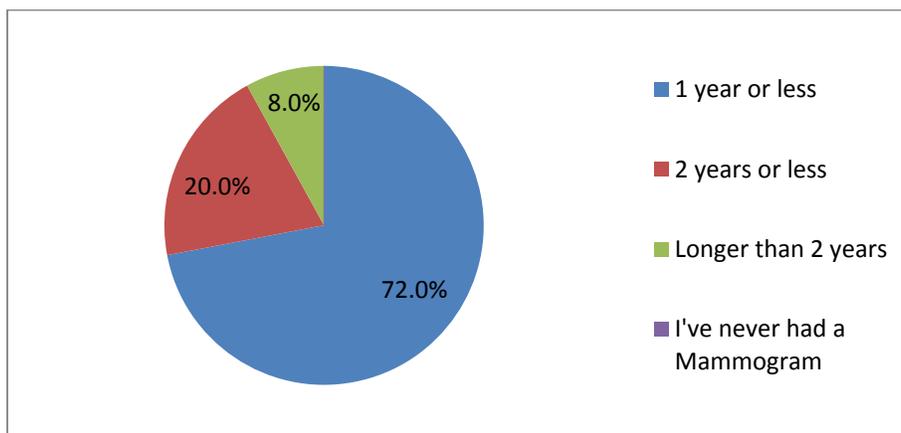
All Health Provider Survey respondents stated that their Health System recommended yearly screening mammograms. Two thirds recommended screening beginning at age 40 and the other third recommended screenings beginning at age 50.

Figure 4.24 shows that, in the opinions of those surveyed, the consistency of providers following these guidelines varied. When asked if the guidelines they reported were followed by providers in their health system, survey responses were split equally between 'always', 'usually', and 'often'. In addition, while all health systems reported the use of screening reminders for mammograms, two thirds of respondents were unsure if the effectiveness of those reminders was tracked.



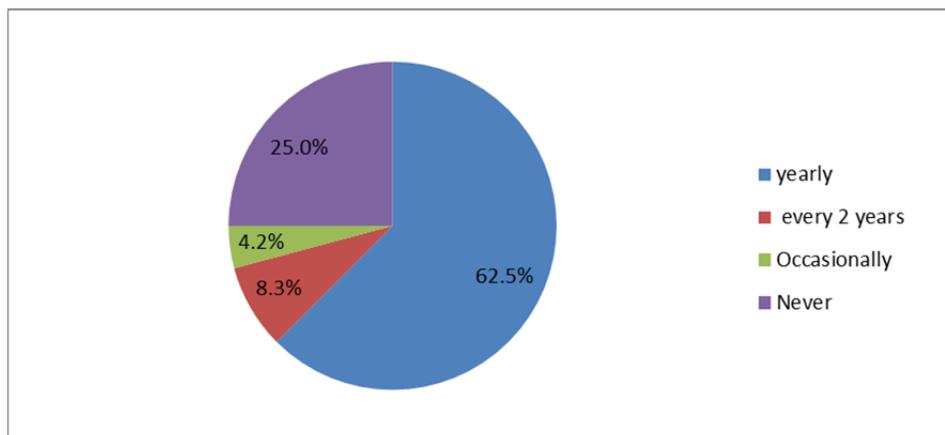
**Figure 4.24.** Percentage of providers thought to follow their health system's screening guidelines – Health provider survey

Data from the General Population Survey in Figure 4.25 shows that nearly three quarters of respondents 40 or older had a mammogram within the past year and an even greater number had been screened within the past two years. However, when broken down by age group, the frequency of mammograms trended more toward every two years for women between the ages of 40 to 49. In this age bracket less than half had a mammogram in the past year



**Figure 4.25.** Screening mammogram frequency for NNR - General population survey

The Survivor Survey data in Figure 4.26 illustrates a different picture for the frequency of mammograms prior to diagnosis for these respondents. Less than two thirds of survivors surveyed reported yearly screening and close to a third stated they had never or only occasionally had a screening prior to diagnosis.



**Figure 4.26.** Mammography frequency prior to breast cancer diagnosis – Survivor survey

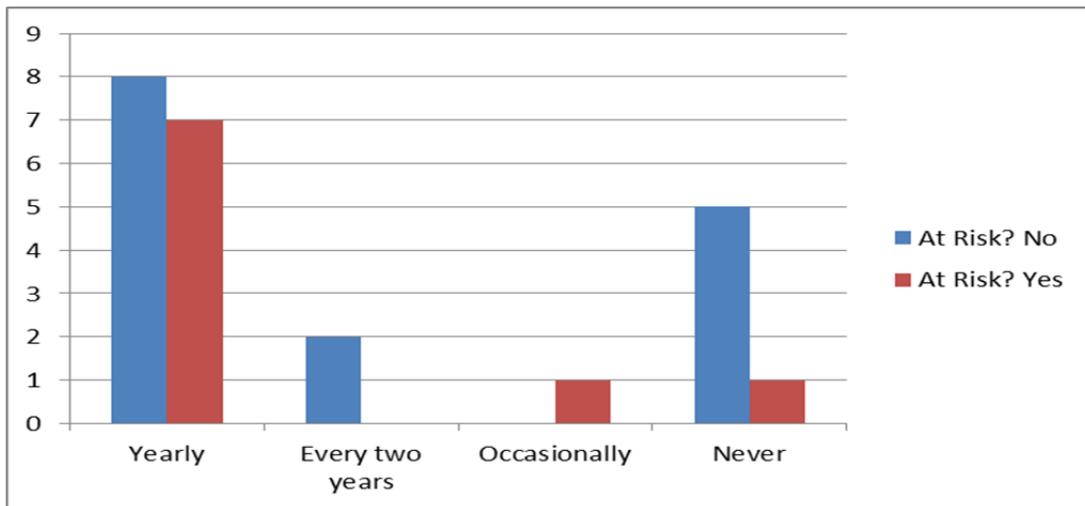
### Perception of risk

Perception of Risk warrants separate discussion as a factor related to screening frequency, late-stage diagnosis, and education. Table 4.17 shows data from the General Population Survey comparing a woman’s perception of risk to her screening frequency. Mammogram frequency for those women who *do not* perceive themselves at risk for breast cancer was lower than for those who do perceive a risk in the 40 to 49 age bracket. Of women who screened less frequently at every two years, only one quarter felt at risk of breast cancer. A similar trend appeared with 60 to 69 year olds.

**Table 4.17.** Mammogram frequency compared to perception of breast cancer risk – General population survey

		How long since your last Mammogram?					
		≤ 1 year	% ≤ 1 year	≤ 2 years	% ≤ 2 years	> 2 years	% > 2 years
Age by Perception of BC Risk Northern Rural Region over 40	<b>40 to 49</b>	<b>3</b>	<b>42.9</b>	<b>4</b>	<b>57.1</b>		<b>0.0</b>
	No		0.0	3	42.9		0.0
	Yes	3	42.9	1	14.3		0.0
	<b>50 to 59</b>	<b>10</b>	<b>90.9</b>		<b>0.0</b>	<b>1</b>	<b>9.1</b>
	No	5	45.5		0.0		0.0
	Yes	5	45.5		0.0	1	9.1
	<b>60 to 69</b>	<b>5</b>	<b>71.4</b>	<b>1</b>	<b>14.3</b>	<b>1</b>	<b>14.3</b>
	No	2	28.6	1	14.3		0.0
Yes	3	42.9		0.0	1	14.3	

Figure 4.27 shows collaborating data which compares the mammogram frequency before diagnosis to the perception of breast cancer risk before diagnosis for respondents from the Survivor Survey. For women never having a screening mammogram prior to diagnosis the majority did not feel that they were at risk for breast cancer.



**Figure 4.27.** Mammogram frequency before diagnosis vs. perception of risk for breast cancer – Survivor survey

Table 4.18 shows a further break down of Survivor Survey data comparing perception of risk prior to diagnosis to the stage at which a survivor was diagnosed. Survivors at diagnosed at stages 1 or 4 had fairly equal numbers feeling at risk and not feeling at risk of breast cancer. A noticeably higher percentage of survivors diagnosed at stage 2 and stage 3 did not feel that they were at risk for breast cancer prior to their diagnosis.

**Table 4.18.** Perception of breast cancer risk before diagnosis vs. stage of diagnosis – Survivor survey

	Stage 0 or I	% No to Yes	Stage II	% No to Yes	Stage III	% No to Yes	Stage IV	% No to Yes	Total	% total Y/N	total stage 2 and 3	% of Y/N stage 2 and 3
<b>At Risk - NO</b>	4	44.4	5	71.4	5	83.3	1	50.0	15	62.5	10	76.9
<b>At Risk - YES</b>	5	55.6	2	28.6	1	16.7	1	50.0	9	37.5	3	23.1
<b>Total</b>	5		7		6		2		24		13	

Data regarding risk perception further correlated with education in an unanticipated way. A survivor’s pre-cancer risk perception was compared to how knowledgeable that survivor felt about breast cancer before being diagnosed. Table 4.19 illustrates that more than half of the survivors who felt they were informed or somewhat informed about breast cancer also *did not* perceive themselves as being at risk for breast cancer prior to their diagnosis.

**Table 4.19.** Perception of risk vs. education on breast cancer - Survivor survey

		Did you feel at risk for BC before your diagnosis?		Education to Risk Disconnect	
		No	Yes		
Did you feel informed about BC before your diagnosis?	No	1	0	Out of 24 Breast Cancer Survivors:	
	Somewhat	5	2	5 (20.8%)	felt <i>somewhat informed</i> but did not feel at risk of bc
	Yes	9	7	9 (37.5%)	felt <i>informed</i> but did not feel at risk of bc

**Barriers to Breast Cancer Screening**

Respondents to the Health Provider Survey reported that individuals in the community (including those who were under or uninsured, low income unemployed, rural residents, and/or Hispanic/Latina) all faced minor or moderate barriers to screening as shown in Table Y. Insurance/money and access were seen as moderate barriers, while fear, time, and education emerged as top minor barriers. One respondent summarized the impact of financial barriers this way “*We can educate people in our community about what they need but if they are unable to pay for the service, it is not going to happen.*”

**Table 4.20.** Barriers to breast cancer screening – Health provider survey

	Minor Barrier to screening	Moderate Barrier	Major Barrier
Fear of having breast cancer	2	0	0
Fear of procedure(s)	1	0	0
Can't get off work	2	0	0
Language Barriers	0	0	0
Low Income	0	1	0
No Primary Care provider	0	1	0
Limited service hours	1	0	0
Lack of Insurance	0	1	0
Out of medical pocket costs	0	2	0
Need for Childcare	1	0	0
Can't get off Work	1	0	0
Unaware of services available	0	1	0
Don't know where to go for services	0	1	0
Don't know how to access service	0	1	0
Not aware of need for or importance of service	2	0	0
Too emotionally or physically draining	1	0	0

Table 4.21 shows the themes identified in the Key Informant Interviews regarding barriers to screening. Cultural-religious barriers, money, insurance, and fear topped the list for all respondents. Interviewees reported that screening barriers are impacting additional population groups in the Target Community including Blacks/African-Americans, Asian Pacific Islanders, American Indians, lesbian/bisexual/transgender women.

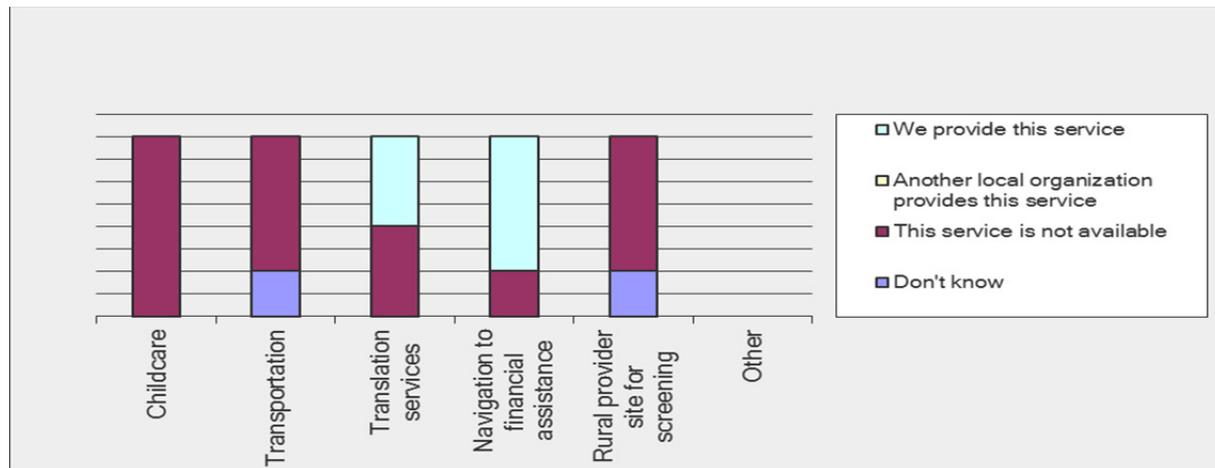
**Table 4.21.** Barriers to Breast Cancer Screening – Key Respondent Interviews for NRR

	Fear	Time	Money	Transportation	Insurance	Pain	Education	Support	Cultural - Religious
All Responses	8	6	8	5	8	2	6	3	9
Hispanic/Latina	5	4	3	4	3	1	4	1	4
Black/African-American	2	1	1	1	2	0	2	0	1
Asian/Pacific Islander	1	1	2	1	1	0	1	0	2
American Indian	1	1	1	1	1	0	1	0	1
LGBT population	1	0	1	0	2	0	1	1	0

Note: The All response section of the table is coded to identify the top four barriers (red -1, orange-2, yellow-3, and green-4)

Health Provider Survey respondents indicated that some financial barriers to screening are being addressed. All respondents were aware of and utilized the Wisconsin Well Woman Program. A third utilized the resources of the Komen’s Breast Health fund and two referenced the availability of charity care within their hospital system.

When asked to identify other sources of assistance to breast cancer screening, three quarters of providers reported providing navigation to financial assistance and half reported that translation services were available. No respondents reported that childcare, transportation for screening, or rural screening access points are available. (Figure 4.28)



**Figure 4.28.** Additional assistance to breast cancer screening access – Health provider survey

**Barriers to Diagnostic and Treatment services**

The Health Provider Survey data reveals providers’ views on who is having problems accessing breast cancer diagnostic (Table 4.22) or treatment (Table 4.23) services and the degree to which these problems are affecting that population. The identical data in these tables shows providers recognize minor problems for the area’s rural community and moderate problems for

low income, inadequately insured residents, unemployed and Hispanic/Latina residents in accessing both diagnostic and treatment services.

**Table 4.22.** Problems accessing breast cancer diagnostic services - Health provider survey

	Minor Problem	Moderate Problem	Major Problem
Low income individuals	0	1	0
Uninsured individuals	0	2	0
Under insured	0	1	0
Rural residents	1	0	0
Hispanic	0	1	0
unemployed	0	1	0

**Table 4.23.** Problems accessing breast cancer treatment services - Health provider survey

	Minor Problem	Moderate Problem	Major Problem
Low income individuals	0	1	0
Uninsured individuals	0	2	0
Under insured	0	1	0
Rural residents	1	0	0
Hispanic	0	1	0
unemployed	0	1	0

Specific barriers to diagnostic services identified by Health Provider Survey respondents are provided in Table 4.24. Insurance, out of pocket costs, and distance to a screening site were seen as moderate barriers. Fear, time restraints, and childcare are the minor barriers to breast cancer diagnostic services identified by health providers.

**Table 4.24.** Barriers to breast cancer diagnostic services – Health provider survey

	Minor	Moderate	Major
Fear of having breast cancer	1	0	0
Fear of procedure(s)	1	0	0
Can't get off work	1	0	0
Limited service hours	1	0	0
Lack of Insurance	0	1	0
Out of medical pocket costs	0	1	0
Need for Childcare	1	0	0
Can't get off Work	1	0	0
Distance to facility	0	1	0

Health Provider Survey data in Table 4.25 shows the same distribution for barriers to breast cancer treatment services as it did for diagnostic services. Distance, insurance, and out of pocket medical cost are again seen as the most pressing barriers.

**Table 4.25.** Barriers to breast cancer treatment - Health provider survey

	Minor Barrier	Moderate Barrier	Major Barrier
Fear of procedure(s)	1	0	0
Can't get off work	1	0	0
Distance to facility	0	1	0
Limited service hours	1	0	0
Lack of Insurance	0	1	0
Out of medical pocket costs	0	1	0
Need for Childcare	1	0	0
Can't get off Work	1	0	0

Key Informants working closely with vulnerable populations in NRR expanded on this data. Their input shown in Table 4.26. adds cultural/religion, support, and education as major barriers to diagnostic services and identifies multiple populations bearing the burden of these barriers. Education was reported most frequently across all populations as a barrier to breast cancer diagnostic tests. One interviewee working with a range of low income and uninsured individuals in the community related that *“the more testing you need, the more complicated the health literacy needs are. This creates a bigger gap than there was for a simpler screening procedure.”* She goes on to state that if an individual does not have a strong support system, education barriers they are facing can be further complicated by fear. *“The more complicated the issue is, the more fear there is and the less likely it is that an individual will be asking the right questions”* needed to understand the diagnostic services recommended.

**Table 4.26.** Barriers to diagnostic breast cancer services - Key informant interviews

	Fear	Time	Money	Transportation	Insurance	Pain	Education	Support	Cultural - Religious
All Responses	4	3	5	0	3	0	8	5	2
Hispanic/Latina	2	1	3	0	1	0	4	3	1
Black/African-American	0	0	1	0	0	0	1	0	0
Asian/Pacific Islander	1	1	2	0	0	0	2	1	0
American Indian	0	0	1	0	0	0	1	0	0
White	0	1	2	0	1	0	2	1	0
Other Race	0	0	1	0	0	0	1	0	0
Low income	4	3	6	1	4	0	9	5	2
Under or uninsured	4	3	5	0	3	0	8	5	2
LGBT population	1	0	1	0	2	0	3	1	0

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

While those interviewed acknowledged that earlier barriers identified were still in play, interviewees felt the major barriers to breast cancer treatment are money and transportation.

(Table 4.27). Transportation, while largely absent as a screening or diagnostic barrier in this data sample earlier, was strongly recognized as an impediment to treatment by all identified population groups. Support and education barriers were also noted as barriers for most populations and a consistent recognition of the presence of cultural or religious barriers was recognized, especially for Hispanic/Latina residents. Once again key informants identified a broader spectrum of populations affected by barriers than was reported in the Health Provider Survey.

**Table 4.27.** Barriers to breast cancer treatment by population – Key respondent interviews

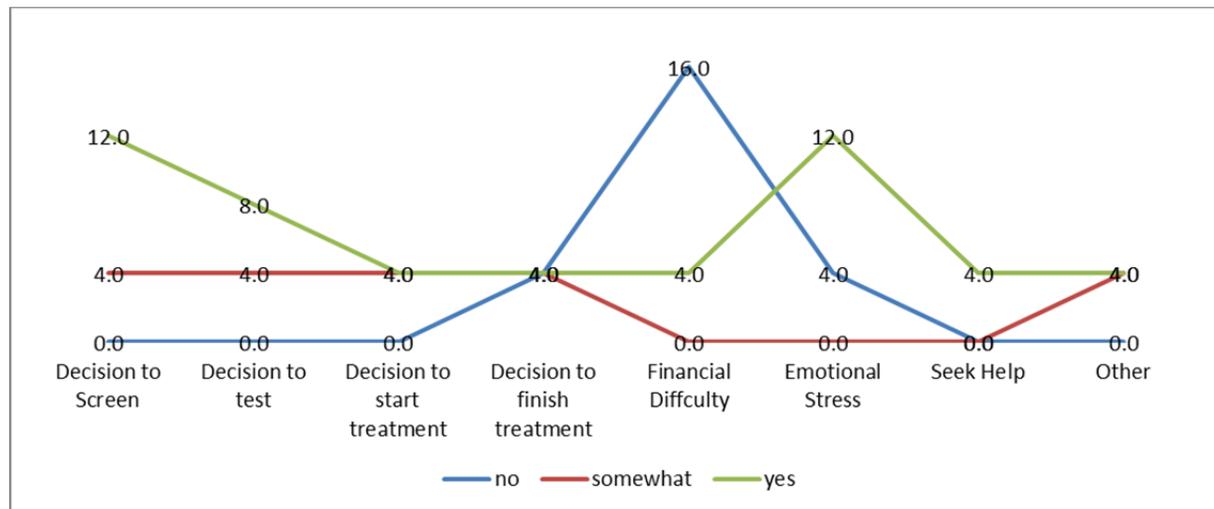
	Fear	Time	Money	Transportation	Insurance	Pain	Education	Support	Cultural - Religious
All Responses	1	2	10	4	0	2	3	3	3
Hispanic/Latina	0	2	4	3	0	1	1	2	2
Black/African-American	0	1	2	1	0	0	0	1	0
Asian/Pacific Islander	0	0	2	2	0	0	0	0	0
American Indian	0	0	1	1	0	0	0	0	0
White	0	0	2	2	0	1	0	0	1
Other Race	0	0	1	1	0	0	0	0	0
Low income	0	1	6	3	0	2	2	1	2
Under or uninsured	0	1	5	4	0	1	2	1	2
LGBT population	0	1	2	0	0	0	1	1	0

One interviewee’s statements illustrated that a myriad of factors are in play when a cancer diagnosis is made. *“Once someone has understanding that treatments is needed and that it is important to follow through, there are still barriers of finances and questions of where to go for assistance. There are so many questions - language barriers are especially hard at this point. Plus lots of financial worries, there is no Well Women available at the treatment point for undocumented women.”* Another respondent’s comments reflect a common theme that *“one challenge for a lot of people is that even if they can get the treatment, they have a lack the support that enables them to continue their life at home - single moms, children to care for, low income - who can help support them in everyday life? A lot of individuals are more likely to forfeit treatment before forfeiting the essential things like working and caring for family. This is complicated more by the fact that a treatment also can make someone feel sicker before they are better.”*

**Insurance as a barrier**

Insurance was identified as a barrier along the entire continuum of care by respondents of all surveys and interviews and so warrants further discussion. Figure 4.29 shows data from the Survivor Survey that illustrates the negative impact that insurance has on accessing and following through with breast cancer services all along the continuum of care, as well as the

emotional and financial toll it causes. The greatest impact of inadequate insurance was causing emotional stress and affecting the initial decision to pursue breast cancer screening.



**Figure 4.29.** Effects of inadequate insurance by percent – Survivor survey Northern Rural Region

Many survivors commented on their experiences with insurance. *“There were so many additional expenses that were not covered. (Breast cancer) is a very expensive disease.”* One survivor related that *“co-pay and loss of work time put us in financial difficulties. Also, I would have needed to pay Cobra if not back to work in three months so I went back to work with my PICC line in place. I could have benefited from more time off.”* This survivor illustrated the challenge of dealing with insurance issues during breast cancer... *“100 percent coverage of all expenses would have been the ideal. I was in no psychological condition to be making financial decisions or to be dealing with coverage during that health crisis.”*

### **Timeliness of Breast Health Services**

One hundred percent of Health Provider Survey respondents reported that their facilities always meet CDC guidelines for timeframes between referral to mammogram, mammogram to diagnosis, and diagnosis to treatment. Three quarters of Health Provider Survey respondents reported they were able to tell if a patient was following diagnostic recommendations and two thirds stated they knew if treatment recommendations were being followed. Formal tracking of this compliance was cited by half of respondents with the other half unsure if such tracking tools were in place.

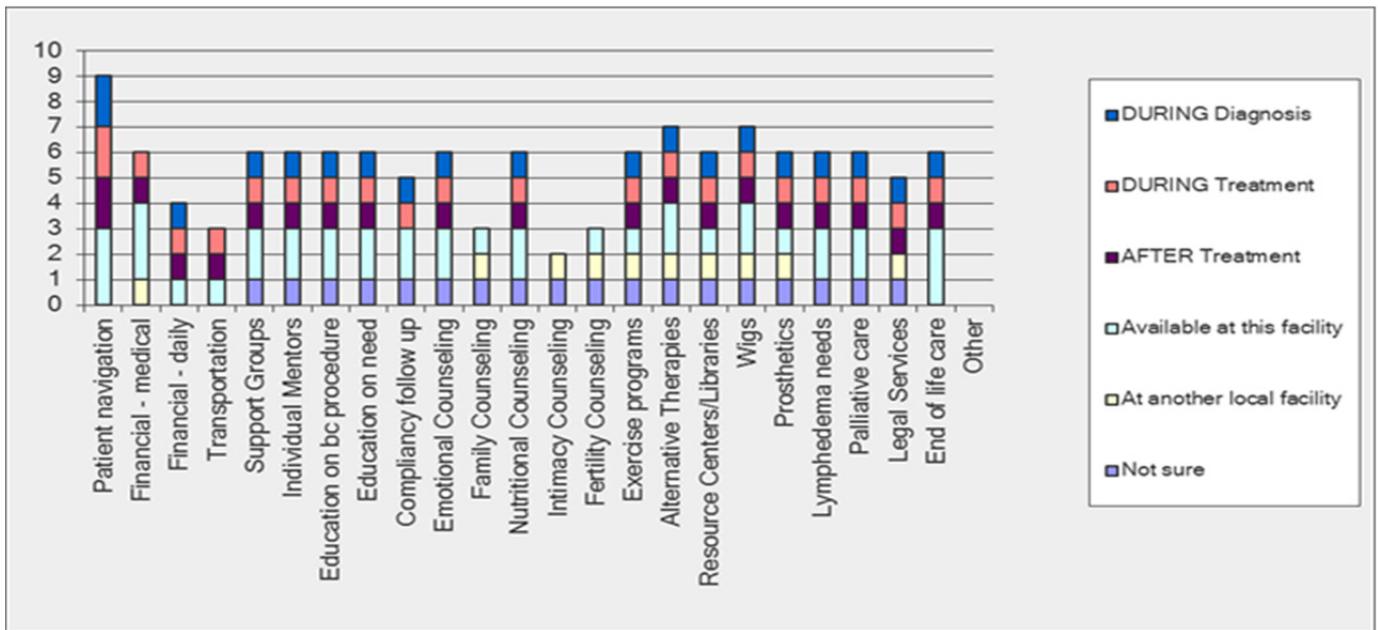
While not identifying a time frame, four of the 25 breast cancer survivors surveyed from the Northern Rural Region reported experiencing delays to diagnostic and treatment services (Table 4.28). Three of the four diagnostic delays and both of the treatment delays were stated as caused by the health system. One survivor spoke of being misdiagnosed for 10 months, *“Doctors, nurses, and lactation specialists did not recognize my symptoms.”* Another cited *“bureaucratic missteps and incorrect orders”* that caused her to seek treatment elsewhere. The third spoke of an unresponsive doctor that *“simply handed me a book about breast cancer.”* One key respondent related having experience with clients that have *“had a mammogram and had a terrible time with the waiting period between the initial mammogram and a call back appointment - so they don’t want to go through that again.”*

**Table 4.28.** Delays to Breast Health Services – Survivor Survey Northern Rural Region

Barriers to Diagnostic Services	Options Given	Any Barriers to Treatment	Health System Delay	Personal Delay
Yes	Yes	No	No	Yes
Yes	No	No	No	No
Yes	Yes	Yes	Yes	No
Yes	Yes	Yes	Yes	No

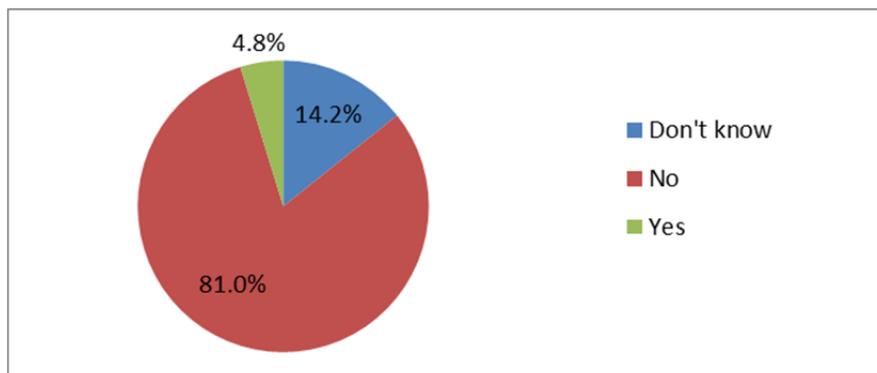
**Survivor Support Services**

Health Provider Survey data in Figure 4.30 shows respondents identified a broad range of possible services available. The majority of providers reported that support services were offered all along the continuum of care. Patient Navigation was the most frequently reported source of support. It is notable; however, that for 18 of the 23 support services listed there were at least some respondents that were ‘not sure’ if that service was available.



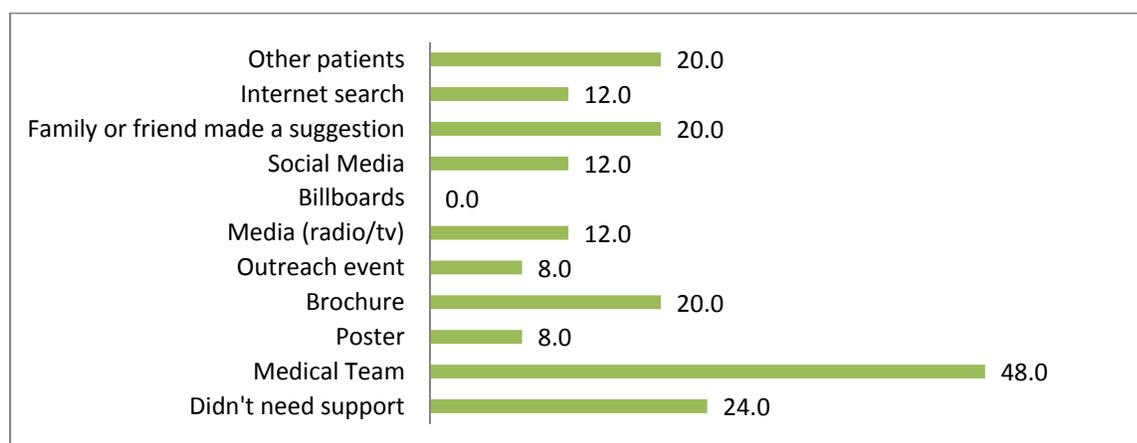
**Figure 4.30.** Support services available – Health provider survey

Survivor Survey data indicated that while the majority of respondents did not indicate any barriers to support services, nearly a fifth reported a barrier or were unsure (Figure 4.31).



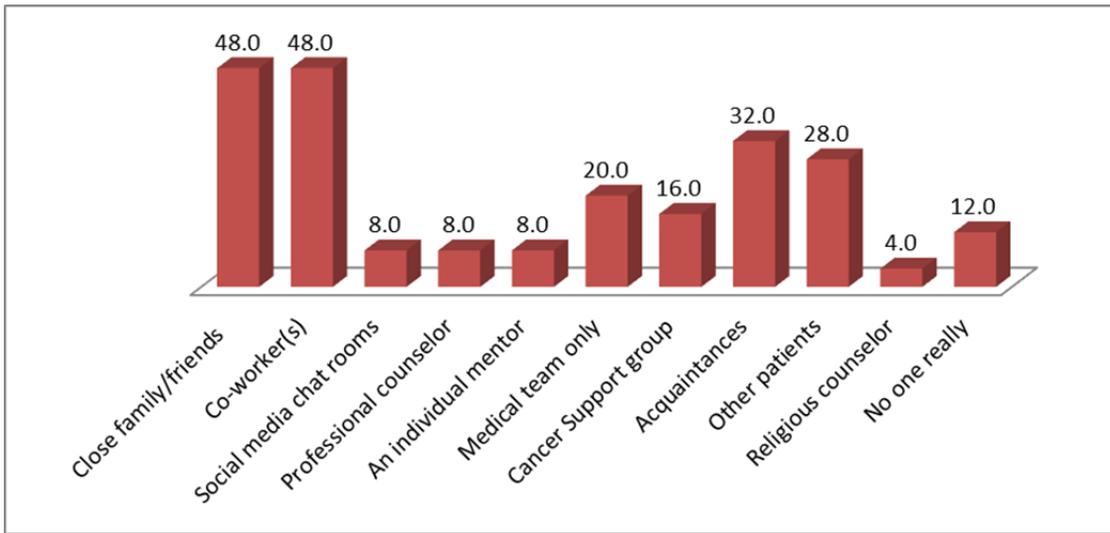
**Figure 4.31.** Survivors reporting barriers to support services

Additional data (Figure 4.32) shows that almost a quarter of Survivor Survey respondents did not feel they needed any support. Of those seeking services, about half learned about service availability from their medical team. The other top sources of this information were other patients, family/friends, and brochures.



**Figure 4.32.** Sources used to learn about support services – Survivor survey

Most survivors surveyed reported talking about their diagnosis with others (Figure 4.33). Friends/family and co-workers were mentioned most frequently, but other patients, and even acquaintances were also strong outlets. Smaller percentages used more formalized resources such as support groups, counselors, or mentors.



**Figure 4.33.** Who do you talk to about your breast cancer – Survivor survey

The Survivor Survey data in Table 4.29 indicates a low awareness of the availability of support services and an even lower access and usage of those services. The most recognized service was support groups. Less than a third of respondents were aware of mentoring or individual counseling services, and even fewer were aware of available group, religious, or fertility counseling. Only three of the 25 surveyed were aware of financial services although all that were aware of it utilized those services

Awareness and usage of alternative support therapies was also very low. With the exception of limited use of exercise and nutrition programs, there was almost no use of these alternate therapies.

**Table 4.29.** Survivor awareness and utilization of available support services

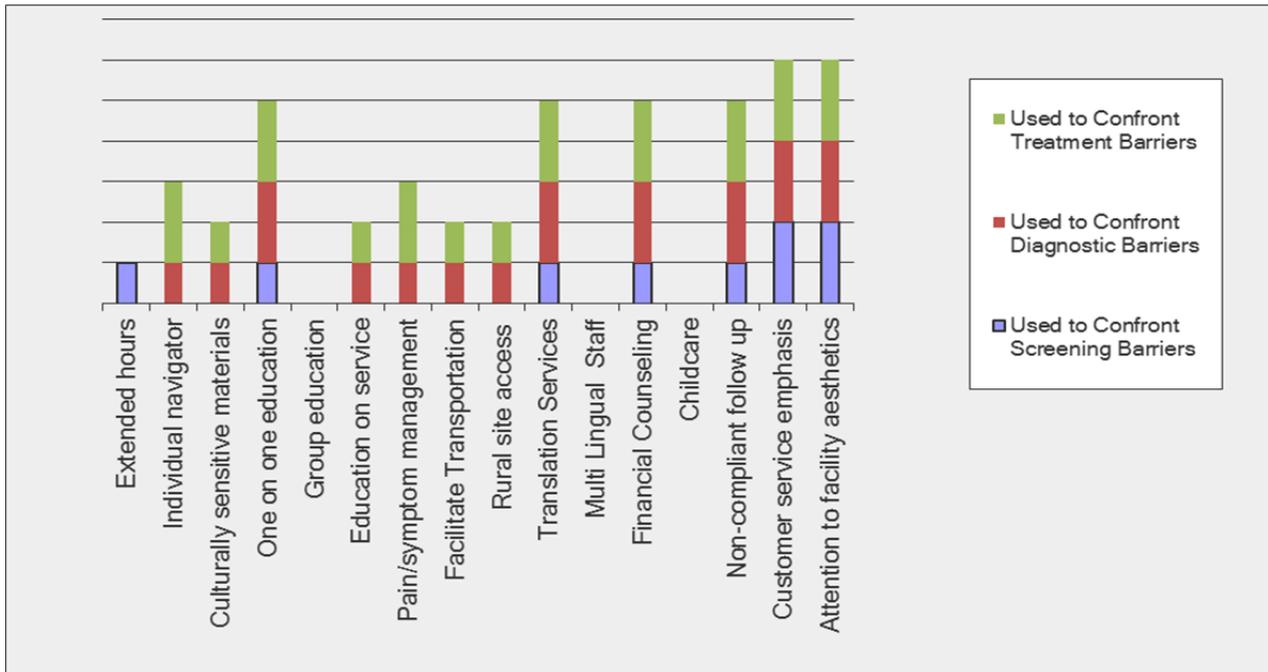
	support groups	one on one mentoring	Ind. Counseling	Group counseling	Religious Counseling	Financial Support	Fertility Support	Intimacy Support	Legal Counseling	Palliative Care	End of Life Planning
<b>Available</b>	12	7	7	5	5	3	1	0	0	0	0
<b>Used before treatment</b>	1	1	1	0	1	1	0	0	0	0	0
<b>Used during treatment</b>	2	1	1	0	1	1	0	0	0	0	0
<b>Used after treatment</b>	4	1	1	0	1	2	0	0	0	0	0
<b>Especially Valuable</b>	1	1	1	0	0	0	0	0	0	0	0

	Yoga	Massage	Reiki	Meditation	Acupuncture	Exercise Program	Nutritional Support
<b>Available</b>	2	5	1	2	1	4	5
<b>Used before treatment</b>	0	0	0	0	0	1	3
<b>Used during treatment</b>	0	0	0	0	1	1	3
<b>Used after treatment</b>	1	0	0	0	0	2	2
<b>Especially Valuable</b>	0	0	0	0	0	1	1

**Solutions- What Can Be Done**

The Health Provider Survey data in Figure 4.34 shows ways in which health providers are currently attempting to mitigate the effects of barriers to breast health services across the continuum of care. Current efforts to minimize barriers to screening include extended hours, one on one education, some translation services, reminder systems, and some financial counseling. Missing from this infrastructure of fighting barriers to screening are rural access sites, culturally sensitive materials, multi-cultural staff, facilitation of transportation or childcare, and individualized navigation. Diagnostic and treatment barriers are reportedly being addressed on all of these fronts with the exception of extended hours, facilitation of childcare, and multi-cultural staffing.



**Figure 4.34.** Methods used to confront barriers to breast health services – Health provider survey

Key Informant Interviews provided a large amount of input (Table 4.30) that supports and expands on the solutions promoted by health providers to reduce barriers and promote more equal access to breast cancer services across the continuum of care for the Target Community’s most vulnerable populations.

**Table 4.30.** Ideas for reducing barriers to breast health services – Key informant interviews

Work for increased health literacy for patient and their entire family to create better support system
Take a more holistic view on health. Preventative rather than a quick fix band aid approach
Facilitate collaboration between groups
Increase awareness of available programs for providers and for the public
Increase use of mobile mammography for rural residents and people with less access to health systems
Increase education on access to services - what they are, where they are, and how to get them
Make screening and prevention less complicated Need to simplify systems and structures,
Capitalize on cultural community spirit to leverage better support within a population group
Expand resources such as financial assistance and transportation options
Personal attention is key, individualized service is most effective
Utilize community health workers to help bridge individuals to the health system
Increase breast cancer education for community and for providers
Increase awareness that the majority of breast cancer is not hereditary
Provide truly bilingual culturally sensitive services at all points of breast health services

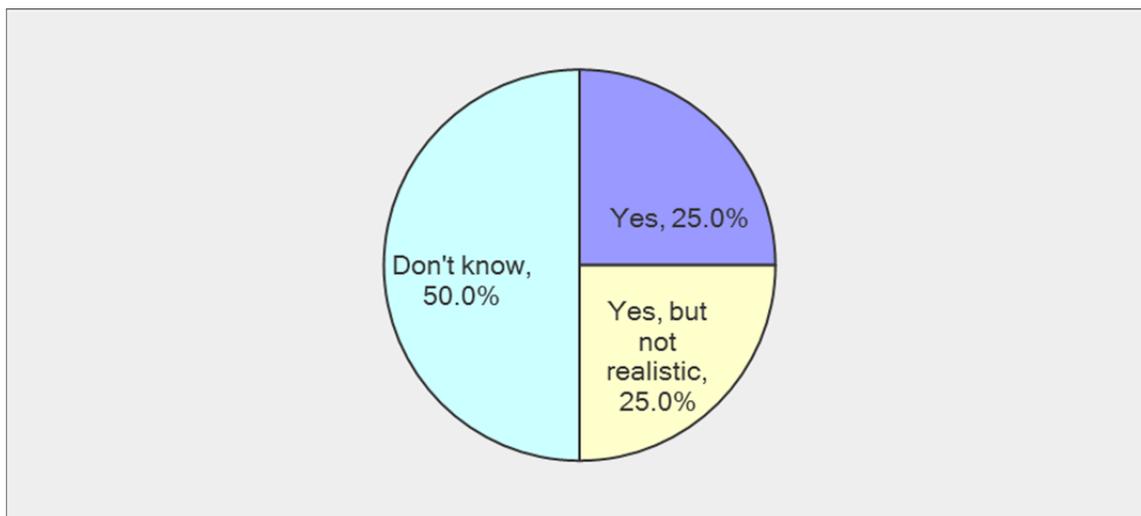
## Collaboration

Key Informant Interview data in Table 4.31 indicates that nearly three quarters of those interviewed felt that breast health could fit into the scope of their organization’s mission. There was a strong sense that some element of breast health service could be either facilitated or directly provided by the respondent’s organization.

**Table 4.31.** Does breast health fit into the mission of your organization – Key informant interviews

# of respondents	Does Breast Health fit into the mission of your organization?				Could your organization facilitate or directly provide some type of breast health service to the people you serve?			
	Yes	%	Possibly	%	facilitate	%	directly provide	%
14	10	71.4	1	7.1	9	64.3	8	57.1

Figure 4.35 shows that a quarter of the Health Provider Survey respondents also saw this type of collaborative effort possible. Another quarter liked the idea of collaborations, but felt that they may be unrealistic. The remaining providers stated they didn’t know if such collaborative efforts were possible.



**Figure 4.35.** Are collaborations possible with other local organizations – Health provider survey

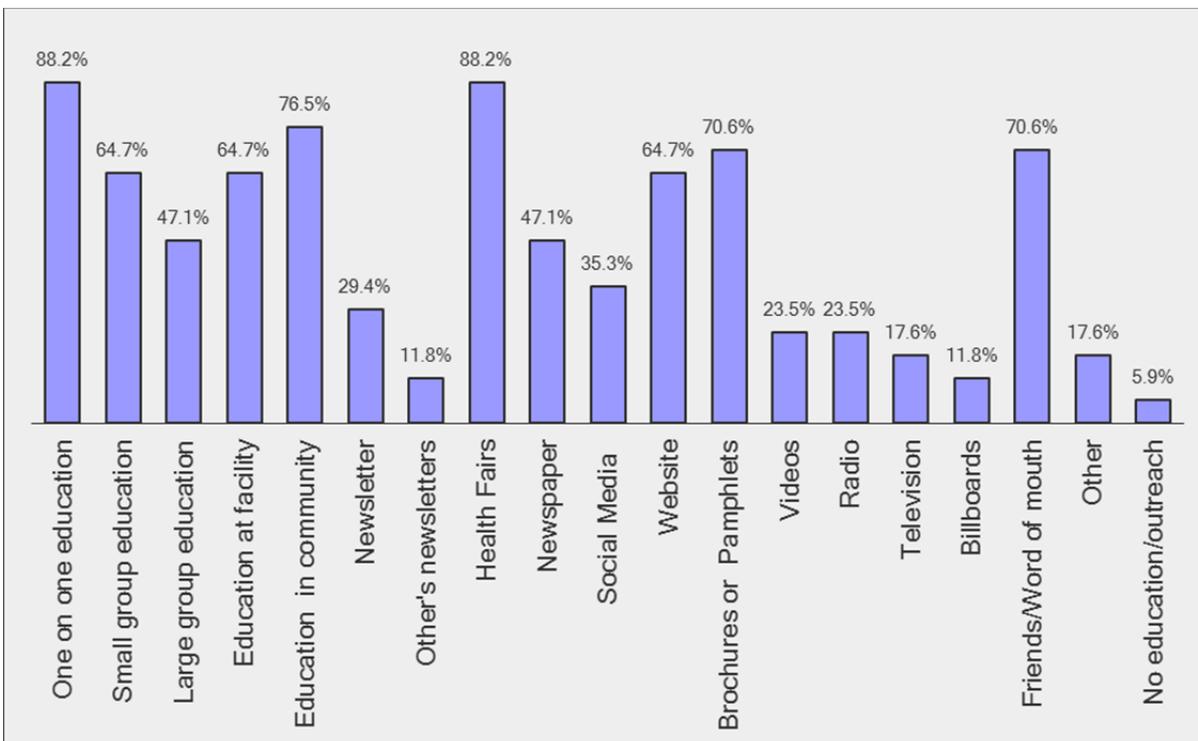
## Racine County

For a variety of reasons, including staff and volunteer limitations, the Racine County Target Community proved the weakest in data gathering. The General Population Survey returned only nine responses and the Survivor Survey only eight. While this level of data collected is not strong enough to paint a truly accurate picture of the nature of breast health services in Racine County, these surveys do provide backup data for the stronger Health Provider Survey. Seventeen respondents to this survey provided 100 percent representation of the full spectrum of health providers in this Target Community. Nineteen additional Key Informant Interviews round out this data collection. While the voices of individuals from this community are

underrepresented, there is a strong representation from the perspectives of the individuals who are providing health services and from other organizational leaders who have in depth knowledge of the needs and issues of the populations they serve.

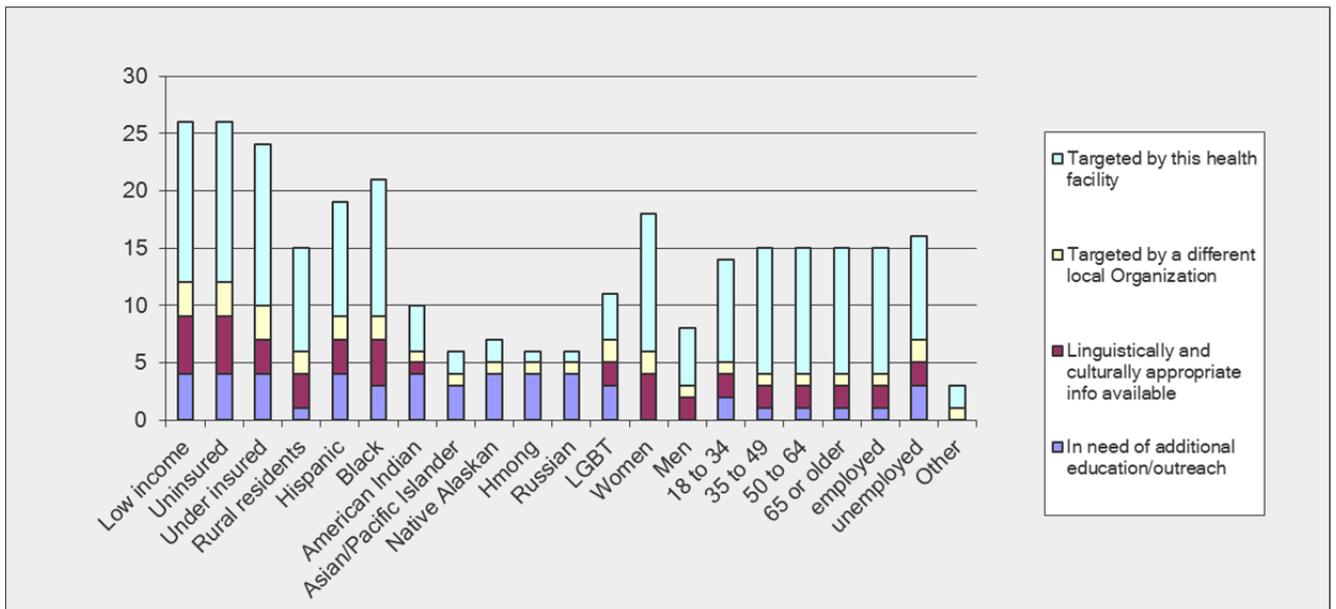
### Education and Outreach

Education and Outreach methods are diverse in Racine County’s health system. Health Provider Survey respondents identified 18 different means currently used to provide breast health education and awareness messages (Figure 4.36). One on one education and health fairs were cited most frequently. Education within the community, brochures, word of mouth, in-house education, small group education, and health system website were also reported as being used by more than half of providers



**Figure 4.36.** Methods of breast health education and outreach – Health provider survey

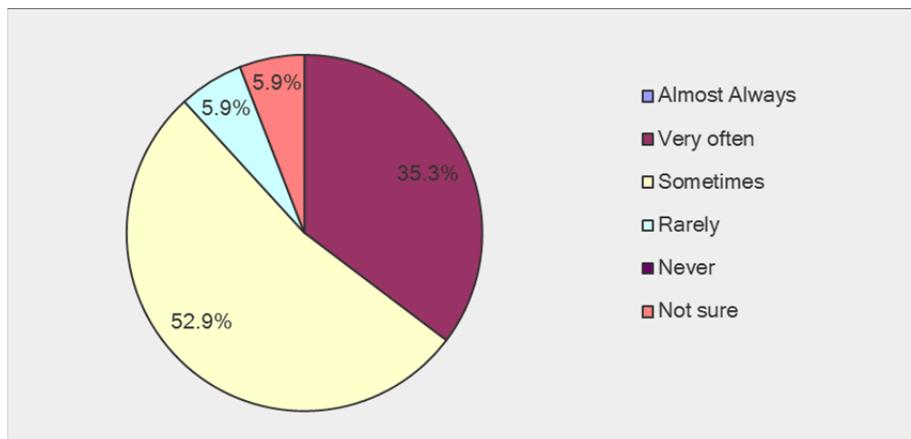
Health providers identified numerous populations in Racine County that were in need of breast health education (Figure 4.37). Each group identified was targeted by at least one provider. Individuals with low incomes, employment issues, or inadequate insurance were targeted most frequently. There was also strong identification of education/outreach efforts targeting Hispanic/Latina and Black/African-American individuals. Populations including American Indians, Asian Pacific Islanders, Hmong, Russian, and LGBT individuals were rarely targeted, but were *not* seen as having linguistically or culturally appropriate information available to them. All identified populations were seen as needing additional education and outreach.



**Figure 4.37.** Populations in need of breast health education/outreach - Health provider survey

Key Informant Interviews in Racine County echoed the educational needs of the populations above. They also identified the presence of disabled residents (both mentally and physically) and their need for increased access to breast health education. One respondent’s comments especially emphasized the importance of education. *“Education eliminates barriers. We need to serve more people and personal education almost always results in better compliance.”*

When asked to evaluate the effectiveness of current breast health education and outreach in the Target Community, provider responses varied from very often to rarely (Figure 4.38). Where 1 represents ‘never’ and 5 represents ‘almost always’, providers rated the effectiveness of current education efforts in Racine County as a 3.3 which translates to a grade of C plus.

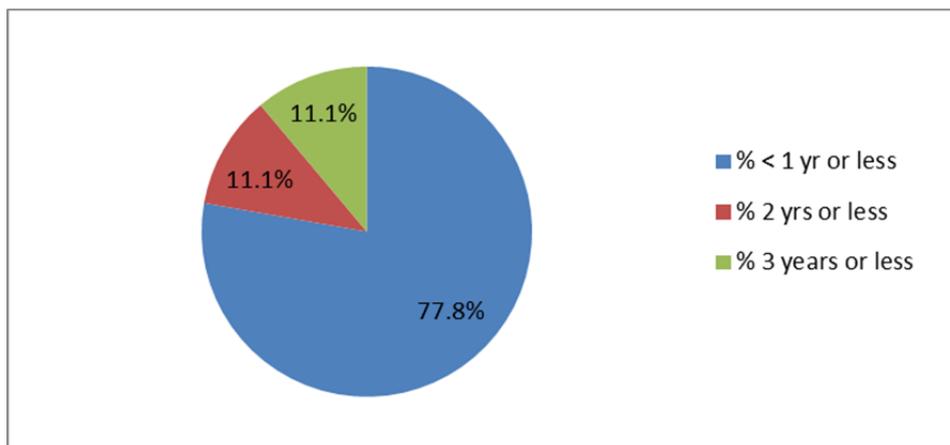


**Figure 4.38.** Answers to the question: “In your opinion, do you think current education or awareness programs in your community are successful at getting women to be screened for breast cancer?” – Health provider survey

### Breast Cancer Screening

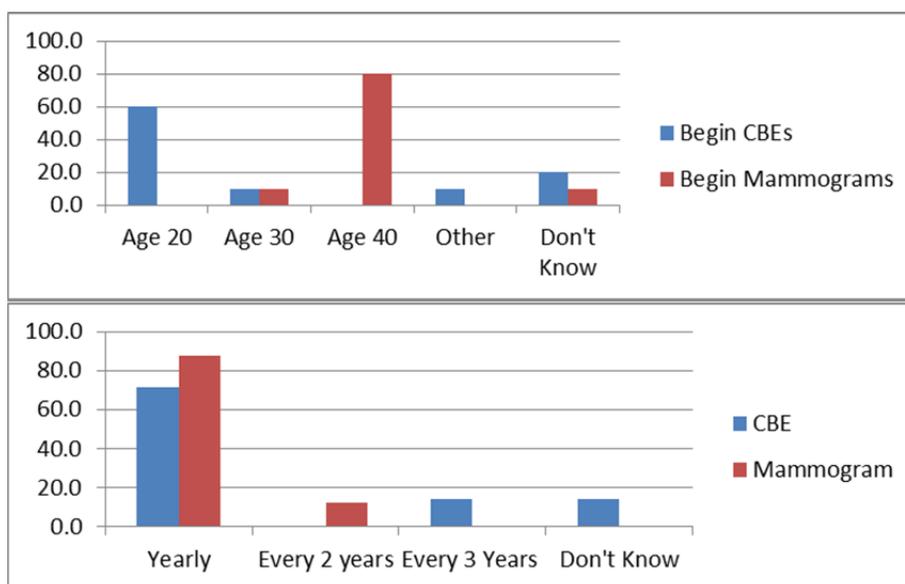
The Health Provider Survey showed that nearly three quarters of providers stated that their health system recommended yearly CBEs. Over half recommend beginning CBEs at age 20.

Figure 4.39 shows that three quarters of those in the General Population Survey had a CBE within the past year and that all respondents had been screened within the past three years or less.



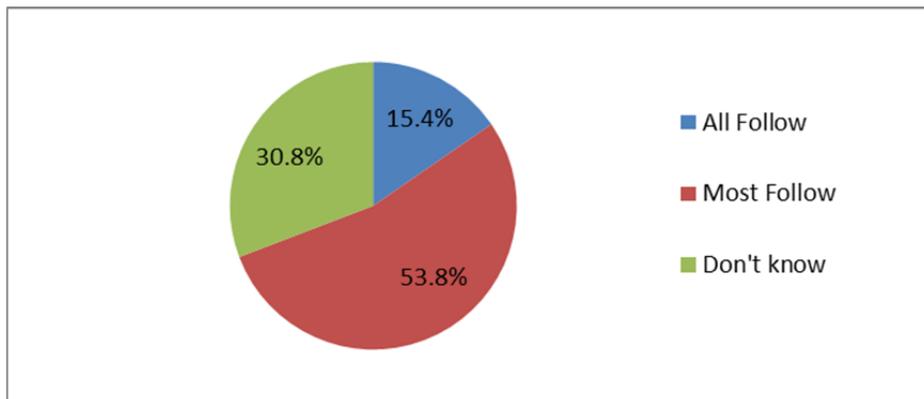
**Figure 4.39.** Frequency of clinical breast exams – General population survey

The vast majority of providers reported that their health system recommends yearly screening mammograms (Figure 4.40). Four of five recommend beginning at age 40, one in five at age 30.



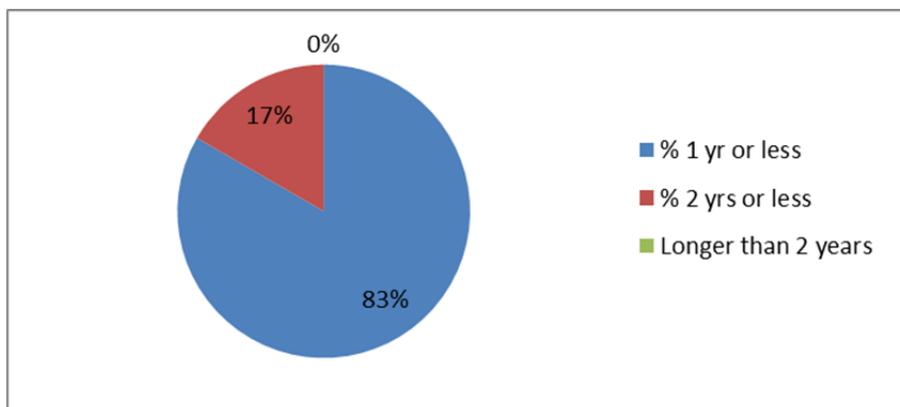
**Figure 4.40.** Provider guidelines for breast cancer screenings – Health provider survey

Only a small percent of Health Provider Survey respondents felt that that the health providers in their systems were following the recommended guidelines for screening (Figure 4.41). About half stated that 'most' follow the guidelines and about a third did not know if guidelines are followed.



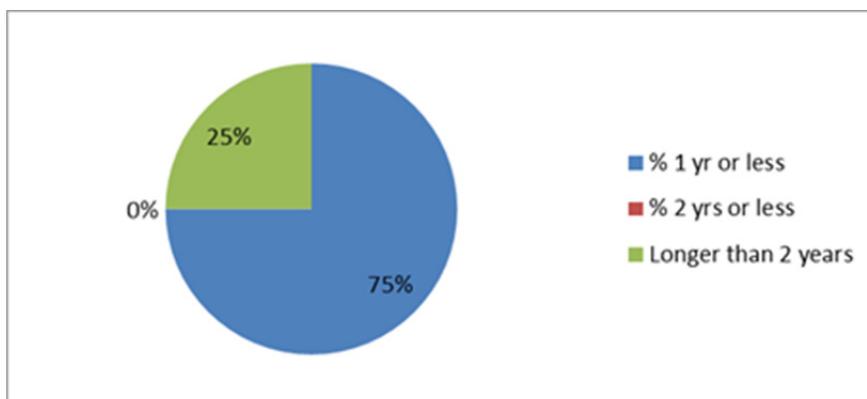
**Figure 4.41.** Percentage of providers thought to follow their health system's screening guidelines – Health provider survey

All Racine County women responding to the General Population Survey had a screening mammogram within the past two years (Figure B).



**Figure 4.42.** Mammogram frequency – General population survey-Racine County

Survivor Survey data showed a somewhat lower mammography frequency before diagnosis for the survivors responding (Figure 4.43). While three quarters reported yearly mammograms, the other quarter reported that they had screenings only occasionally prior to their breast cancer diagnosis.



**Figure 4.43.** Mammogram frequency prior to diagnosis – Survivor survey

### Perception of risk

A separate discussion of perception of risk is warranted as it appears to be tied to screening frequency, late-stage diagnosis, and breast health education. Almost three quarters of the General Survey respondents felt they were at risk for breast cancer. Survivor Survey respondents had a much lower perception of risk prior to their diagnosis. A full 87.6 percent of these survivors *did not* feel they were at risk of breast cancer prior to their diagnosis. In addition, of the survivors surveyed who felt they were informed about breast cancer, only one felt they were personally at risk for the disease before their diagnosis (Table 4.32).

**Table 4.32.** Perception of risk vs. feeling informed about breast cancer – Survivor survey

		Did you feel at risk for BC before your diagnosis?		Education to Risk Disconnect	
		No	Yes		
Did you feel informed about BC before your diagnosis?	No	1	0	Out of 8 Breast Cancer Survivors:	
	Somewhat	2	0	2 (25%) women	felt <i>somewhat informed</i> but did not feel at risk of bc
	Yes	4	1	4 (50%) women	felt <i>informed</i> but did not feel at risk of bc

Data in Table 4.33 compares the perception of risk for breast cancer to the stage at which the Survivor Survey respondents were diagnosed. This sample as a whole had a very low perception of risk. It is notable that out of eight respondents, only one felt at risk for breast cancer before her diagnosis and that individual was the only respondent diagnosed at stage 0.

**Table 4.33.** Perception of breast cancer risk by stage of diagnosis

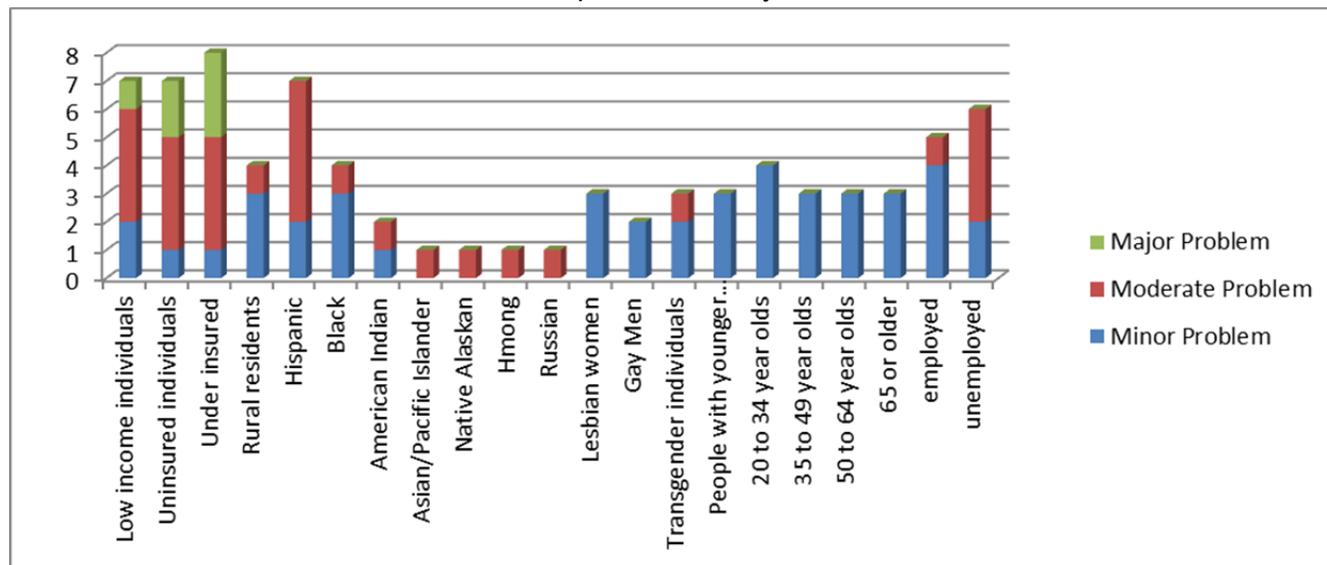
	Stage 0 and 1	% No to Yes	Stage II	% No to Yes	Stage III	% No to Yes	Stage IV	Total	% total Y/N
At Risk - NO	4	80.0	1	100.0	2	100.0	0	7	87.5
At Risk - YES	1	20.0		0		0	0	1	12.5
Total	1		1		2			8	

One Key Informant interviewee who provides breast health education directly in the community confirms that there is often a disconnect with being exposed to breast cancer information and truly understanding the messages. She emphasized the need for accurate and available education by saying “*we need to educate individuals in all walks of life – not just the ‘at risk’ populations. Don’t assume professional women or even health providers understand breast health info fully. Most people do not have good breast health information. It is usually necessary to educate women a few times to really get (accurate breast health) messages across and make screening a regular behavior.*”

### Barriers to Screening

Figure 4.44 contains data from the Health Provider Survey that shows the populations providers report as likely to experience difficulty in accessing breast cancer screening. Low income and under or uninsured individuals were identified as experiencing major problems accessing breast cancer screenings. Hispanic/Latina and unemployed individuals were also identified frequently as having minor or moderate access issues. There were many others identified as experiencing barriers to screening but far fewer providers seemed aware of these populations.

**Figure 4.44.** Populations affected by barriers to breast cancer screening – Health provider survey



Health Provider Survey respondents went on to identify the items listed in Table 4.34 as the barriers to breast cancer screenings affecting the populations identified. Divided into degree of impact, the most frequently identified barriers are highlighted in yellow. Money/insurance, fear, and cultural/religious barriers were shown to have the greatest negative impact.

**Table 4.34. Barriers to screening – Health provider survey**

	Minor Barrier	Moderate Barrier	Major Barrier
<b>Cultural/Religious</b>			
Cultural beliefs	3	1	0
Religious beliefs	3	0	0
Language Barriers	2	0	2
Culturally sensitive services	1	0	0
<b>Fear</b>			
Fear of having breast cancer	3	3	0
Fear of procedure(s)	4	1	0
Fear of medical system	4	1	0
Fear of neighborhood	1	0	0
<b>Money/Insurance</b>			
Low Income	2	1	1
Lack of Insurance	1	2	1
Out of pocket medical costs	0	3	2
<b>Personal</b>			
Need for Childcare	2	1	0
Can't get off work	2	1	0
<b>Education/Awareness</b>			
Unaware of services	2	1	1
Don't know where to go	2	0	1
Don't know how to access	2	1	1
Not aware of importance	2	1	0
<b>Health System</b>			
Lack of navigation	1	0	2
Lack of support services	0	0	1
No Primary Care provider	2	1	2
Limited service hours	1	1	0
Long waiting lists	0	0	1
Distance to facility	0	1	0

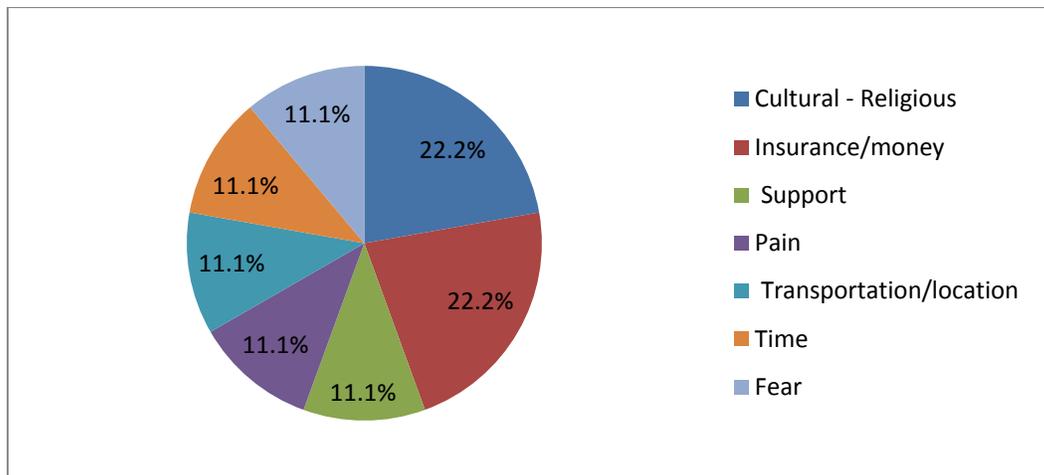
Key Informant Interviews echoed barriers recognized by the health providers. Interviewees identified education as the most impactful barrier, citing lack of knowledge about breast cancer risk and the need for screening; confusion on where and how to access screening; and a lack of insurance literacy (Table 4.35). Insurance was the next most frequently cited barriers with references to inadequate insurance; no insurance; high premiums, co-pays and deductibles; and lack of access to insurance. Cultural barriers were also selected frequently by interviewees citing language barriers; a lack of truly culturally accessible and appropriate information and services; a tendency to only seek medical care when sick; and a strong inclination to care for others before oneself. Transportation was seen as a barrier specifically for those in rural areas, individuals dependent on public transportation, or those whose circumstances make leaving their residence a factor such as disabled individuals, seniors, or people in transitional living situations.

**Table 4.35.** Barriers to breast cancer screening – Key informant interviews

	Fear	Time	Money	Transportation	Insurance	Pain	Education	Support	Cultural/Religious
All Responses	9	6	7	7	10	2	12	3	10
Hispanic/Latina	6	5	3	7	5	2	8	1	6
Black/African-American	3	3	1	4	4	0	5	0	3
Asian/Pacific Islander	1	1	2	1	1	0	2	1	3
American Indian	2	2	1	2	2	0	2	0	2
Other Race	1	1	1	1	1	0	1	0	1
Low income	5	5	4	8	5	2	9	3	7
Under or uninsured	6	5	5	8	6	2	9	3	8
LGBT population	1	0	1	0	2	0	1	1	0

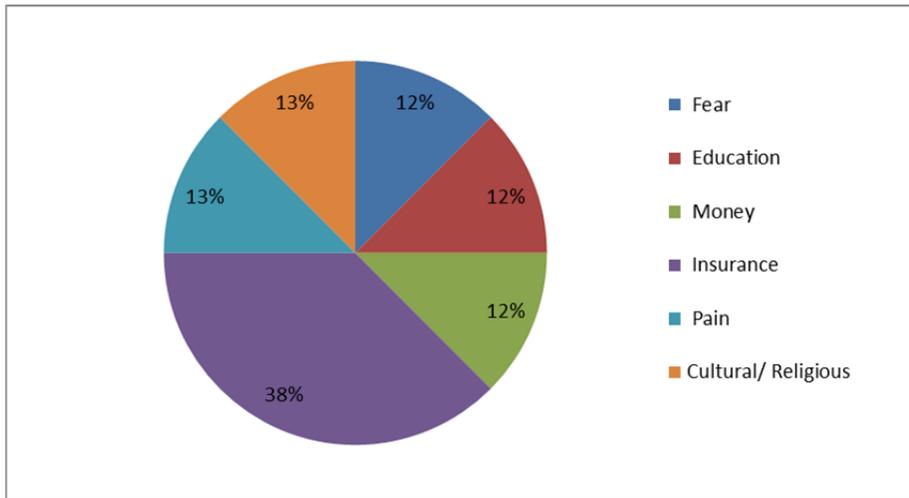
Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

General Population Survey data in Figure 4.45 provides corroboration to some of the barriers to screening identified by providers and key informants. Money/insurance and cultural/religious barriers were identified as screening barriers most frequently.



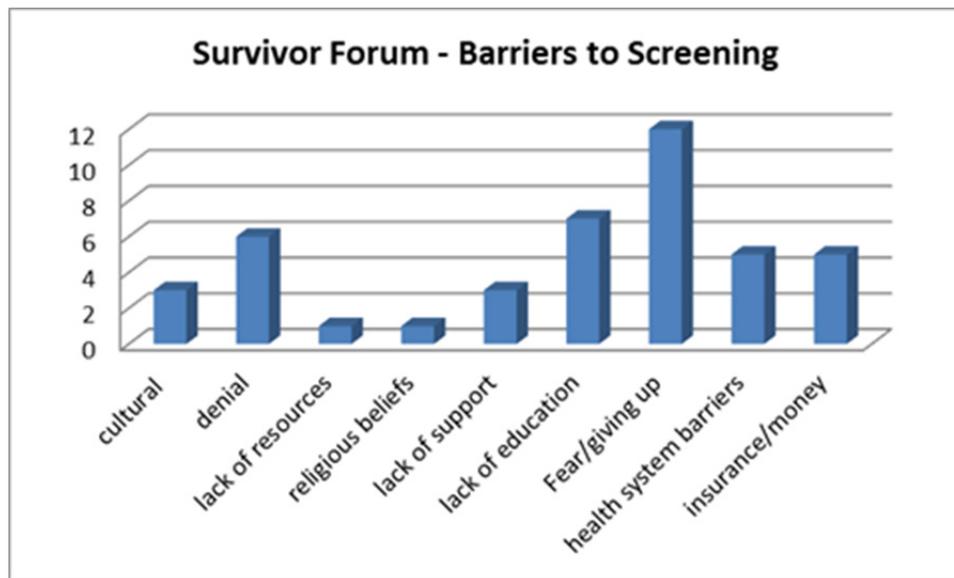
**Figure 4.45.** Barriers to screening in Racine County - General population survey

Figure 4.46 shows that themes emerging from the Survivor Survey data are also in line with the provider and key interview data. Survivors responding identified insurance, pain, and cultural/religious barriers as the top barriers to screening.



**Figure 4.46.** Barriers to screening – Racine County survivor survey

The multiple themes that emerged from the small respondent samples of the General Population and Survivor Surveys are strengthened by additional data on barriers to screening from the Survivor Forum. Fear was the most frequently cited barrier in the Survivor Forum data shown in Figure 4.47. Forum participants stated the ideas of ‘giving up’ and denial were also intimately related to the role fear plays in keeping women from screening mammograms. Other top barriers to screening identified in the Survivor Forum were education and insurance.



**Figure 4.47.** Barriers to screening – Survivor forum

***Barriers to Diagnostic and Treatment Services***

Health providers indicated that the populations facing the most frequent and impactful barriers to both diagnostic and treatment services are those who are low income, under and uninsured, rural, Hispanic/Latina, Black/African-American, and unemployed (Table 4.36). Employed individuals were also identified as having major barriers to breast cancer treatment most due to insurance and/or income related reasons. Providers also cited numerous other populations as experiencing at least minor barriers to breast cancer diagnostics and treatment.

**Table 4.36.** Populations experiencing problems accessing breast cancer diagnostic and treatment services

	BC Diagnostic Access			BC Treatment Access		
	Minor Problem	Moderate Problem	Major Problem	Minor Problem	Moderate Problem	Major Problem
Low income	1	4	1	1	5	1
Uninsured	0	5	1	1	4	1
Under insured	0	4	3	1	3	3
Rural residents	1	2	0	2	1	0
Hispanic/Latina	1	5	0	2	3	1
Black/African-American	2	1	0	3	0	0
American Indian	1	0	0	1	0	0
Asian Pacific Islander	1	0	0	1	0	0
Alaska Native	1	0	0	1	0	0
Hmong	1	0	0	1	0	0
Russian	1	0	0	1	0	0
Lesbian women	2	0	0	2	0	0
Gay Men	1	0	0	1	0	0
Transgendered	2	0	0	2	0	0
With young children	2	0	0	2	0	0
20 to 34 year olds	2	0	0	2	0	0
35 to 49 year olds	2	0	0	2	0	0
50 to 64 year olds	2	0	0	2	0	0
65 or older	2	0	0	2	0	0
employed	3	1	0	3	0	1
unemployed	1	4	0	1	4	0

Note: This table is color coded. Red = major or frequent moderate barriers, orange = moderate or frequent minor barriers, yellow = frequent minor barriers, green = less frequent minor barriers

Health Provider Survey respondents also identified the barriers they perceived impacting access to and follow through for both diagnostic testing and breast cancer treatment services. Table 4.37 shows that the top diagnostic barriers were identified as insurance/money, fear, cultural or religious barriers, and elements related to the health system including distance to the facility. Providers identified the top barrier to treatment services as fear followed by cultural/religious barriers, insurance/money, as well as personal barriers such as time and childcare issues.

**Table 4.37. Barriers to diagnostic and treatment services – Health provider survey**

	Access to Diagnostic Services				Access to Treatment Services		
	Minor Barrier	Moderate Barrier	Major Barrier		Minor Barrier	Moderate Barrier	Major Barrier
<b>Cultural - Religious</b>							
Cultural beliefs	2	1	0		3	1	0
Religious beliefs	2	0	0		3	0	0
Language Barriers	1	0	2		1	0	2
<b>Fear</b>							
Fear of cancer	2	4	0		2	3	1
Fear of procedure	3	0	0		2	0	1
Fear of medical system	1	2	0		1	2	0
Fear of neighborhood	1	0	0		1	0	0
<b>Insurance/Money</b>							
Lack of Insurance	1	2	0		1	2	0
Low Income	1	2	0		1	1	0
Out of pocket medical costs	0	1	3		1	0	2
<b>Personal</b>							
Need for Childcare	0	1	0		0	0	1
Can't get off work	2	1	0		3	0	0
<b>Access/Awareness</b>							
Unaware of services	0	1	0		0	0	0
Don't know how to access	0	1	0		0	0	0
Lack of support services	0	1	0		0	0	0
<b>Health System</b>							
Limited service hours	0	1	0		1	0	0
Lack of navigation services	0	1	1		0	0	1
No Primary Care provider	1	2	0		1	1	0
Long waiting lists	0	1	0		0	0	0
Lack of providers	0	1	0		0	0	0
Distance to facility	0	1	0		0	1	0

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4). Each category was weighted by impact (5-major, 3-moderate, 1- minor) and averaged in order to compare category scores.

Key Informant Interviews identified seven barrier themes that impact access to and follow through of diagnostic testing. Table 4.38 shows that education was the top barrier identified followed by fear, money, and support. Lack of support, transportation issues, cultural barriers, and time constraints were also themes of diagnostic barriers that were common in interview responses, especially in relationship to more specific population groups.

**Table 4.38.** Barriers to diagnostic services by population – Key respondent interviews

	Fear	Time	Money	Transportation	Insurance	Pain	Education	Support	Cultural - Religious
All Responses	11	2	8	3	3	0	18	4	3
Black/African-American	3	0	2	1	1	0	5	0	1
Hispanic/Latina	6	1	3	2	1	0	9	2	2
API	2	1	3	0	0	0	3	1	0
American Indian	1	0	1	0	0	0	2	0	0
Under/uninsured	8	2	6	3	1	0	12	4	2
Low income	8	2	6	3	1	0	12	4	2
LBGT	1	0	1	0	2	0	3	1	0

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

Barriers to treatment services identified through Key Informant Interviews showed a different balance. Education, while still mentioned, dropped off and barriers of money, time, fear, and transportation were seen as most impactful (Table 4.39).

Money barriers cited included both out-of-pocket medical costs and everyday living expenses. Respondents noted that there is great stress in worrying about being able to afford the care needed. One respondent related that even if someone has access to treatment, the bigger challenge is the *“lack of support that enables them to continue their life at home. Single moms, children to care for, low income, underinsured - who can help support their everyday life? Individuals are more likely to forfeit treatment before forfeiting the essential things like working and caring for family. This is complicated even more by the fact that a treatment also can make someone feel sicker before they are better.”* There was specific concern for *“people who qualify for some services but not for total charity care - certain income levels are falling through the cracks. A lot of times someone’s assets (such as having a home) disqualifies them for charity care even though their income is low enough to qualify for WWW or other assistance.”*

Transportation was stated as a barrier to treatment far more often than it was as a barrier to screening or diagnostic services. *“Transportation for treatment is a different story,”* said one respondent. *“Medical sites are further away and there is a much higher frequency of times of transport. Access to bus or taxi services is key for women in this situation who don’t have access to a car.”* Another respondent added that public transportation is especially difficult when you are feeling sick. The on-going nature of breast cancer treatment was also stated as exacerbating time barriers to services.

Cultural barriers were noted consistently for Hispanic/Latina individuals and other populations whose cultural experiences did not coincide with the mainstream culture of the county. Language barriers and finding truly culturally sensitive services were stated as huge barriers for many. Several key respondents related that many of their clients faced discrimination that affected their everyday life and their ability to access services in an equitable way. One interviewee stated that many people from immigrant populations often felt the need to “go

home” after a cancer diagnosis. Without culturally accessible treatment, “they often can’t find good treatment options or may stop treatments before completion.” Another stated that “cancer treatment is so harsh - most people follow through, but undocumented populations are often more isolated and find less resources available making it very difficult to get to places and to do anything as invasive as breast cancer treatment.”

While fear was cited as a top barrier to treatment in interviews, it is interesting to note that pain was not cited as a barrier that key respondents felt held people back from breast cancer treatment. Fear of cancer itself, fear of how breast cancer affected family life, fear of the unknown, and fear of the health system were elements mentioned in regards to fear as a barrier.

**Table 4.39.** Barriers to treatment services by population – Key informant interviews

	Fear	Time	Money/Insurance	Transportation	Pain	Education	Support	Cultural - Religious
All Responses	4	7	11	6	0	3	2	4
Hispanic/Latina	2	5	4	5	0	1	2	2
Black/African-American	1	3	3	4	0	0	1	1
Asian/Pacific Islander	1	0	3	2	0	0	0	1
American Indian	1	1	2	2	0	0	0	1
Low income	3	5	7	5	0	2	1	3
Under or uninsured	3	5	7	6	0	2	1	3
LGBT	0	1	2	0	0	1	1	0

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

### **Insurance as a barrier**

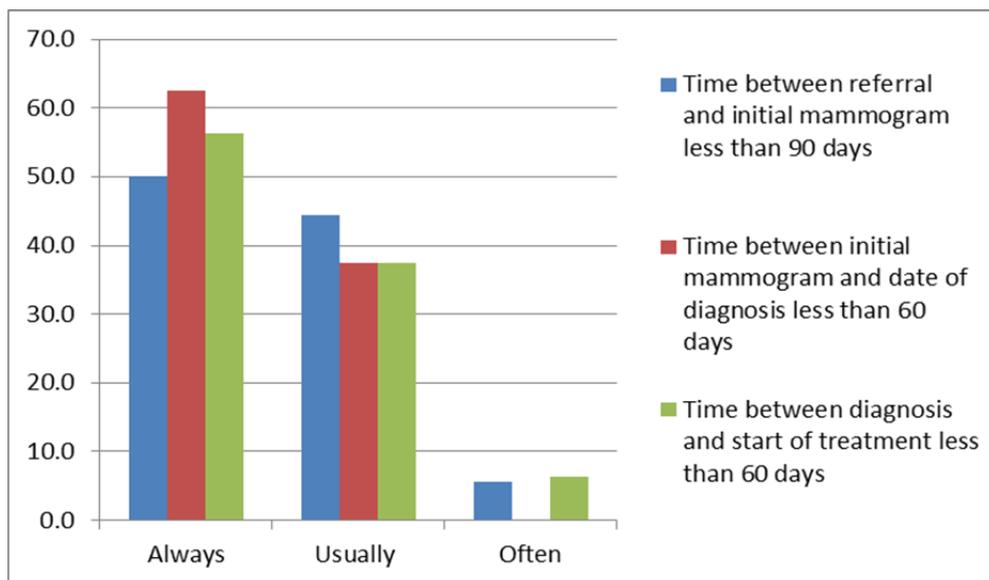
Inadequate insurance is consistently cited by all respondents as a major barrier to breast cancer services across the continuum of care and warrants additional consideration. The impact of inadequate insurance affects a broad range of individuals including those insured with large deductibles, co-pays, and coinsurance; individual’s unable to find affordable insurance even in the public marketplace; undocumented individuals who do not qualify for coverage; and immigrants who may find screening and diagnostic coverage through the Well Woman Program, but do not qualify for Well Women to cover their breast cancer treatment.

Respondents to the Survivor Survey had many negative experiences to relate. One survivor was “left with very large bills. My drugs cost over \$800 a month, which I was partially reimbursed later, but had to come up with it up front.” Or from another women who stated that “for me, it was money. I had two surgeries on my private insurance that racked up huge medical bills. I was being harassed so badly despite paying several hundred dollars a month paying off bills and even more for medications.” Key respondents echoed this concern for their clients who experienced difficulty accessing or affording insurance coverage. One respondent working in a free clinic setting relates that “cost is by far the biggest barrier to receiving all breast cancer

services. For those without insurance, we can partner with local hospitals but once someone doesn't qualify for Well Woman or for the health system's charitable program, there are very few options left for helping."

### Timeliness of Breast Health Services

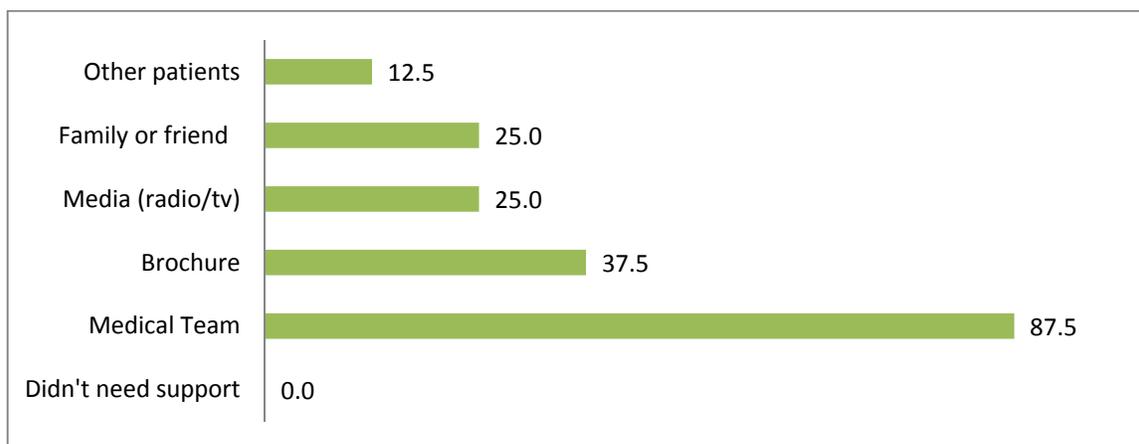
Health Provider Survey data (Figure 4.48) shows that providers in Racine County reported their health systems are able to provide services either 'always' or 'usually' within the recommended CDC Guidelines. Survivor Survey data indicated no delays to service supporting the time efficiency of the health system.



**Figure 4.48.** Ability to meet CDC guidelines for breast cancer service delivery – Health provider survey

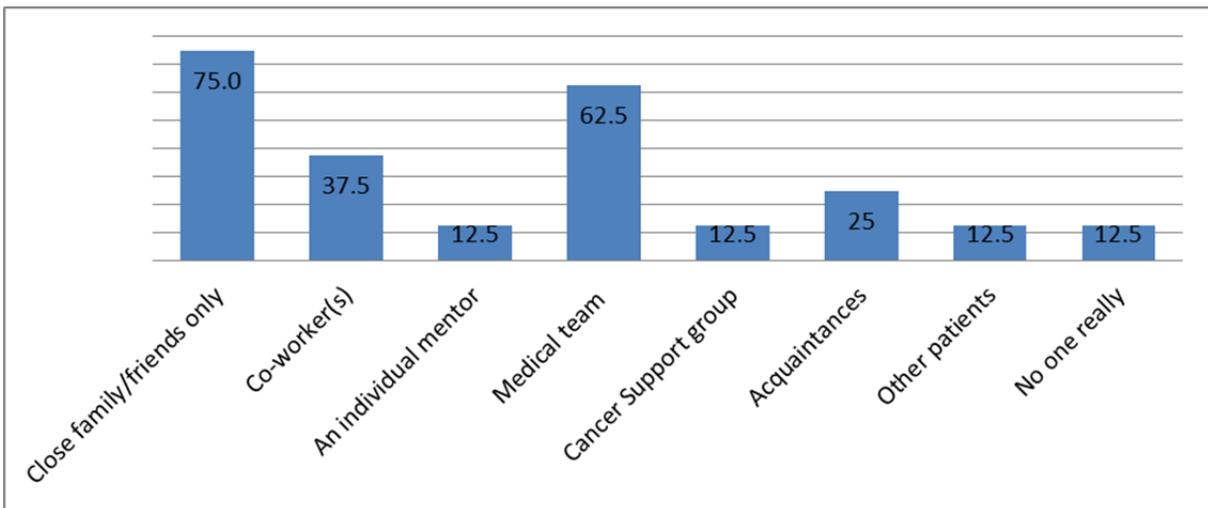
### Survivor Support Services

The majority of survivors surveyed in Racine County reported that they found out about survivor support services mainly through their medical team. Other top sources of information included brochures, local media, and family or friends (Figure 4.49).



**Figure 4.49.** Sources of information on support services – Racine County survivor survey

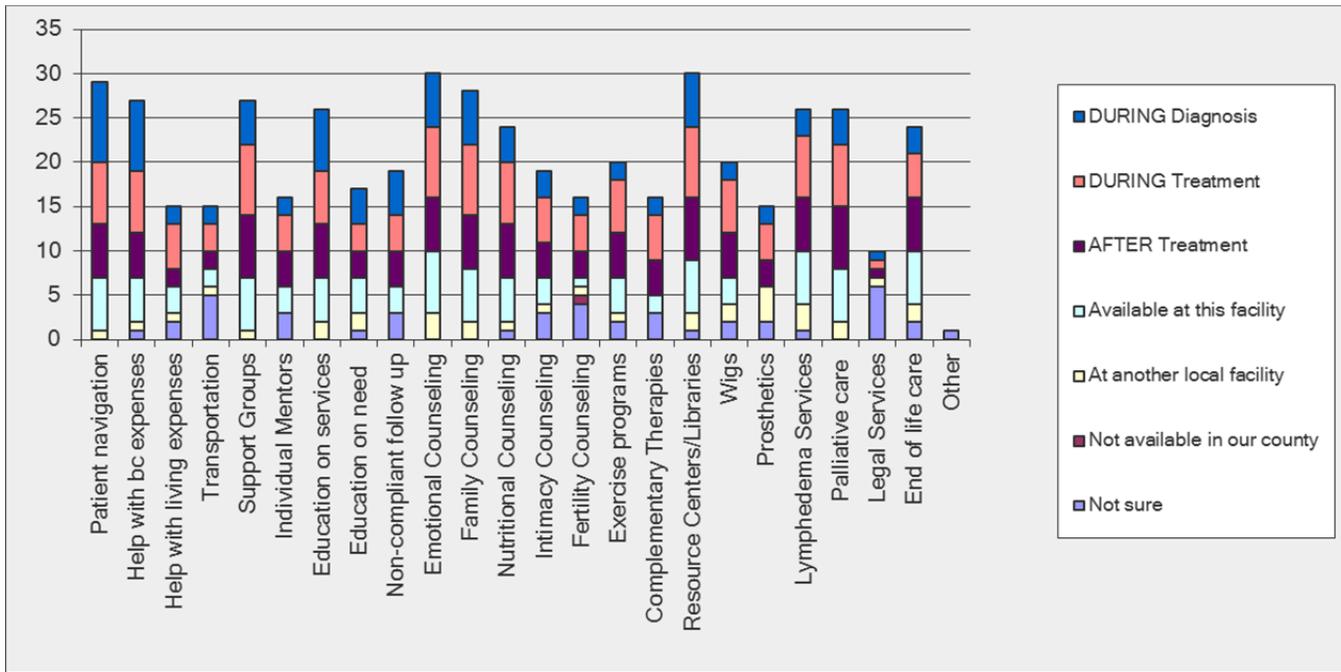
Figure 4.50 data shows that most survivors choose to find people to talk with about their breast cancer. Most frequently, survivors reported talking with their friends and family or their medical team, but a quarter of the respondents or more are also talking with co-workers and acquaintances.



**Figure 4.50.** Who do you talk with about breast cancer – Racine County survivor survey

Only one survivor surveyed in Racine County reported experiencing barriers to support services. Interestingly, this individual was also the only respondent to state that she was aware of survivor services and the only one to utilize any of them. When commenting on the barriers to support encountered, this survivor said she found no programs for her in Racine County but was *“thankful to be able to drive to Gilda’s Club Madison for exceptional support.”*

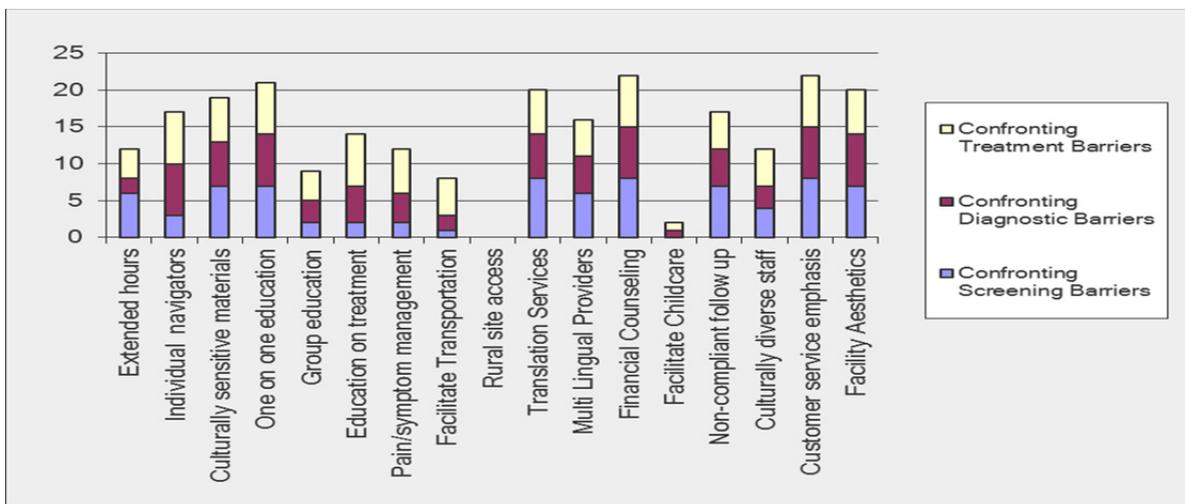
The data from the Health Provider Survey in Figure 4.51 shows a different picture. Providers report a range of support services available with most seen as available in more than one health facility. There were, however several providers that noted they were unsure of the availability of almost every support service listed.



**Figure 4.51.** Support services availability and timing - Health provider survey

**Solutions- What Can Be Done**

Providers identified current initiatives in their health systems to mitigate barriers to breast cancer screening, diagnostic, and treatment services as shown in Figure 4.52 below. Efforts range from providing translation services and culturally appropriate materials, to extended service hours. Financial counseling, individualized education, and improved customer service were most frequently identified along every point of the continuum of care. No single effort was identified by more than half of the respondents. Efforts mentioned far less frequently, particularly in regards to reducing screening barriers, were rural access sites (no responses), facilitating childcare, individualized navigators, and a culturally diverse staff.



**Figure 4.52.** Efforts to minimize barriers to breast cancer service – Health provider survey

Health providers recognize the need for more to be done. Their comments in Table 4.38 provide a sample of their ideas for increasing access to all aspects of breast cancer service. These statements reflect an agreement that there is need for increased outreach to find those

individuals less likely to receive services and awareness that some populations of individuals in the county are not receiving optimal service. There is also a strong call for more consistency in breast health messaging and information.

**Table 4.38.** Ideas for reducing barriers - Health provider survey

Targeted information to the Hispanic/Latina Population
Better identification of risk
Clarification of confusing screening guidelines
Better understanding of treatment options - especially decrease the overuse of prophylactic contralateral mastectomy
Initiation of 'Screening Days' featuring pampering services for women
More outreach to local businesses
More educational targeting of churches and schools with appropriate educational content

Table 4.39 contains key informant comments on what could be done in the Target Community to decrease barriers to breast health services and foster health equity in Racine County. These include suggestions for collaboration between community groups and local health providers; concerted efforts to make services culturally sensitive and appropriate for individuals outside of the mainstream culture; accurate and widely available community based breast health education; and for the simplification of processes for accessing breast cancer screening, diagnostic, and treatment services and assistance.

**Table 4.39. Reducing the impact of barriers and promoting health equity –  
Key informant interviews**

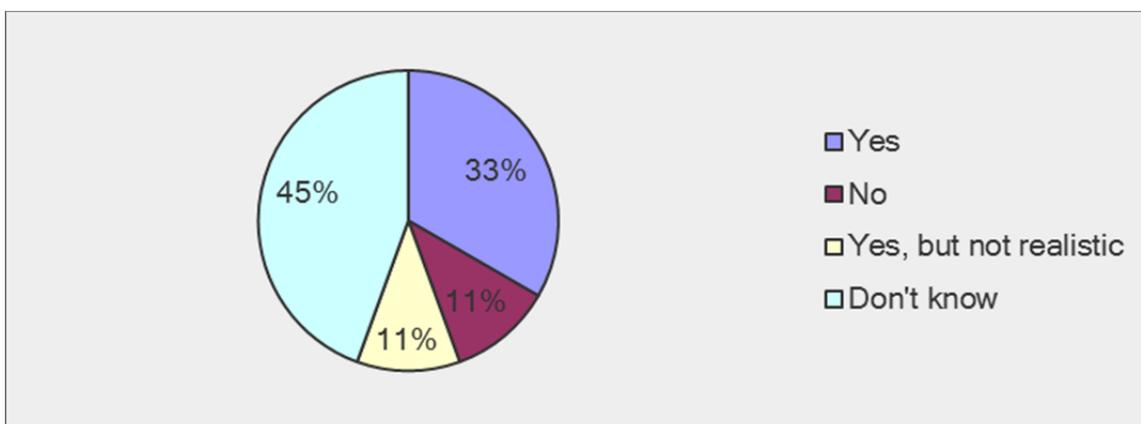
Collaborative efforts between groups. Work in partnership to help people with finances and access to services.
Increase awareness of available programs for providers and for the public.
Promote the WI Cancer Council 5 year plan - especially for increasing screening and provider based service.
Need to have mobile mammography available for rural areas, others who have a hard time accessing services.
More use of wrap around programs and services especially for childcare and transportation.
Health systems must align with other organizations to get people the services necessary to bridge cultural and language needs. Can't assume to understand an entire culture - must keep services individually attuned.
More education programs that help women understand their risks and to be aware of 'their normal'
Community workers must do the best they can to help breast cancer patients - put counseling into place, provide a positive perspective, and try to create some sort of support system to help with child care, transportation, and family care so that the individual is allowed to be sick without repercussions.
Simplify systems and structures, and make care more personalized by paying attention to people's needs, customer service. Remember that people are easily dissuaded from prevention services.
Educate people on access to services - what they are, where they are, and how to get them.
Need additional promotion of mammograms as the normal thing to do - normalize the screening to increase rates - take a step back from promoting mammograms strictly through the stories of women who have been diagnosed.
Be sure programs and services are in a person's own language - translation is essential.
Provide programs closer to home, they will be more successful in a familiar environment - places of worship, local gathering places, familiar health centers, etc.
Take a broad holistic perspective with a preventative focus.
Provide more support for a system of Community Health Workers. Utilize CHWs to increase trust and provide navigation that will bridge the way into the health system. Strive for less classism and less racism.
Expand available programs that provide assistance such as transportation options and financial assistance
Make sure medical providers have good breast health information on risk and helping women know breast cancer signs to watch for. Increased awareness of young survivors and the elevated risks of breast cancer for Black/African-American women.
The goal is health equity. Need a targeted plan to reach populations that are underserved, not just pink awareness.
Need workforce that is experienced at working with people from other cultures and who know the need for options - SENSITIVITY is key. Bilingual efforts cannot simply be putting something in Spanish. Must let people tell you what will serve them best in order to get more buy in from that individual and that population.
Provide scheduling for or actually do diagnostic testing right when the mammograms present as abnormal.
Transportation services are needed, especially to chemo or radiation - no reliable available transportation is currently available. Transportation for screening will increase rates and eliminate so many cancelled appointments.

Table 4.40 shows that the majority of key informants see ways to fit breast health services into their organizations with over half stating the ability to facilitate or directly provide some level of service.

**Table 4.40.** Breast health services in local organizations – Key informant interviews

# of respondents	Does Breast Health fit into the mission of your organization?				Could your organization facilitate or directly provide some type of breast health service to the people you serve?			
	Yes	%	Possibly	%	facilitate	%	directly provide	%
19	15	78.9	1	5.3	13	68.4	11	57.9

A good portion of Health Provider Survey respondents in Racine County also show a willingness to collaborate with other organizations and agencies to find better solutions to breast health in the Target Community (Figure 4.53). A third of respondents stated that collaborations would be possible. Nearly half don't know, but are not closed to the idea of collaborations.



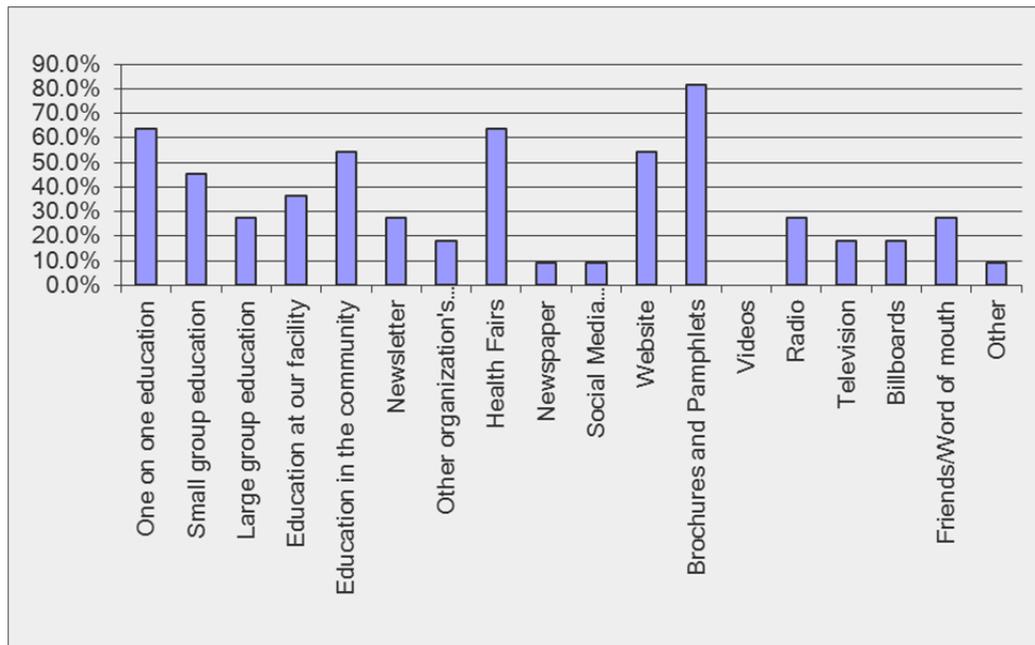
**Figure 4.53.** Are collaborations possible with other organizations – Health provider survey

### Waukesha County

Waukesha County was fairly well represented through all data collection tools. The General Survey gathered 85 responses. Also fairly strong, the Affiliate gathered 41 responses to the Survivor Survey. Waukesha County's Health Provider Survey data provided good content for the triangulation of data; however, this survey was answered by 12 respondents representing only about one half of the county's major health systems. Free clinic and FQHC responses provided a broad scope of responses and all of the respondents generally answered the majority of the survey questions fully. Key Respondent Interviews were held with 17 individuals from local community organizations that work to serve vulnerable populations in the Waukesha County Target Community. Conversation for the Cure and the Survivor Forum provided additional data to help reinforce trends that were found.

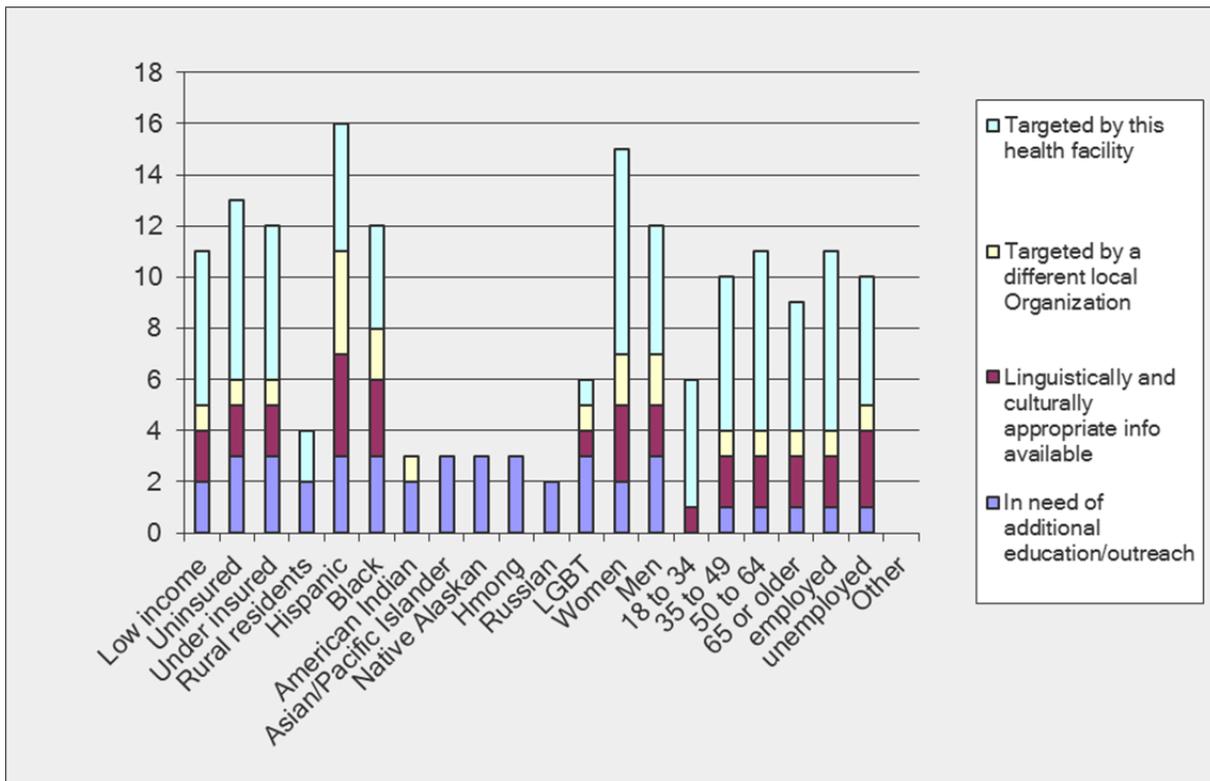
## Education and Outreach

Figure 4.41 shows that Waukesha County health providers utilize many methods to provide breast health education and outreach to the community. Top methods used were identified as brochures, health fairs, one on one education, and websites.



**Figure 4.54.** Methods of education and outreach – Health provider survey

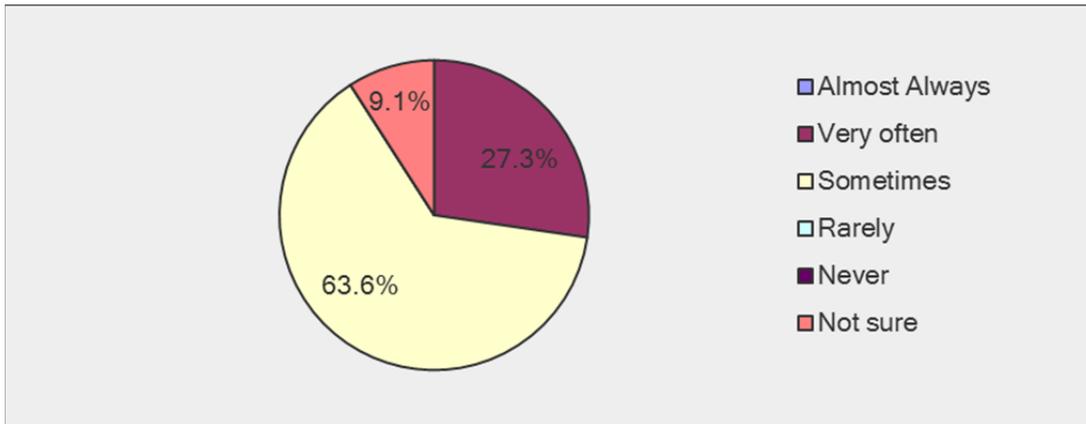
Providers also recognized multiple populations in need of additional education and outreach. American Indians, Asian Pacific Islanders, Hmong, and Russian immigrants were identified as needing education, but no respondents stated that their health system targeted any of these individuals (Figure 4.55). The most targeted populations included low income individuals, under or uninsured residents, and the unemployed.



**Figure 4.55.** Populations in need of breast health education and outreach – Health provider survey

Key informants corroborated the need for service for the populations identified by the Health Provider Survey respondents, but expanded that list to include additional populations including the homeless, individuals with mental and/or physical handicapped, those in transitional living situations, and the elderly. General health literacy education and breast health education in particular were seen as major needs for all populations. Limited school education levels were also recognized as a factor complicating an individual’s overall ability to access to health education.

Health providers were asked to rate the effectiveness of current breast health education and outreach programs in the community at leading women to regular breast cancer screening. Figure 4.56 shows that most respondents felt the current systems for educating people on breast cancer were only sometimes effective. With ‘almost always’ being a 5 and ‘never’ being a 1, Waukesha County health providers rated the cumulative effectiveness of their programs and others as a 3.3 which is a grade of C plus.



**Figure 4.56.** Answers to the question: “In your opinion, do you think current education or awareness programs in your community are successful at getting women to be screened for breast cancer?” – Health provider survey

The importance of education was supported by data from an open ended question in the General Population Survey. When asked what they felt motivated them to pursue a breast cancer screening, five themes were identified, but education was by far the top factor selected by survey respondents (Table 4.41).

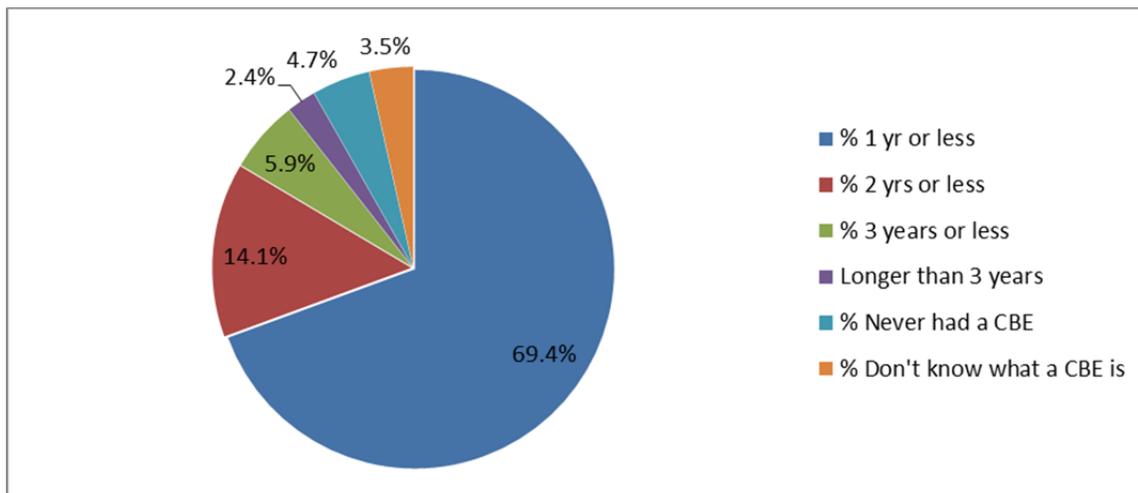
**Table 4.41.** Factors motivating breast cancer screening – General survey Waukesha

	# responding	Efforts from the Health System	Education and Awareness	Knowing Others with BC	Experiencing Problems	Advertisement or Social Media
All Responses	85	7	30	24	9	9
Survivors	25	4	11	7	2	2
Black/African-American Women	2	1	2	0	1	1
White Women	71	4	23	19	8	8
API	2	0	0	1	0	0
AINA	4	2	3	3	0	0
Other	6	0	2	1	0	0
Non-White	14	3	7	5	1	1
Hispanic/Latina	7	1	4	1	1	1
income <50K	27	0	10	4	3	3
income <30K	11	0	3	2	0	0
income <20K	9	0	3	2	0	0
Under /uninsured	8	0	4	0	1	1
Age - Under 40	19	1	8	9	3	3
Age- Over 40	66	6	22	15	6	6

### Breast Cancer Screening

More than half of surveyed health providers stated that their health system guidelines recommend yearly clinical breast exams (CBEs). About two thirds report recommending CBEs begin at age 20 and the other third reported 30 as the starting age.

Nearly seventy percent of the Waukesha County women in the General Population Survey indicated that they had a CBE within the last year or less (Figure 4.57). About ten percent reported waiting longer than three years or had never had a CBE. A small percentage of women did not recognize the term clinical breast exam.



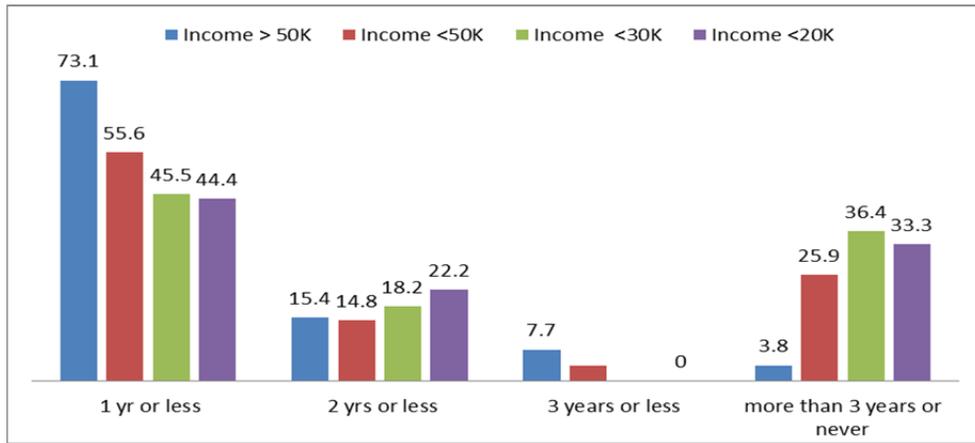
**Figure 4.57.** Frequency of CBE screening – Waukesha County General population survey

When broken down further in Table 4.42, the data indicates that while a high percentage of women reported having a clinical breast exam within three years, less than seventy percent of women 40 or older were having yearly CBEs which are in alignment with Komen breast self-awareness messaging and ACS recommended screening frequency for this age group.

**Table 4.42.** CBE frequency by population groups – Waukesha County general survey

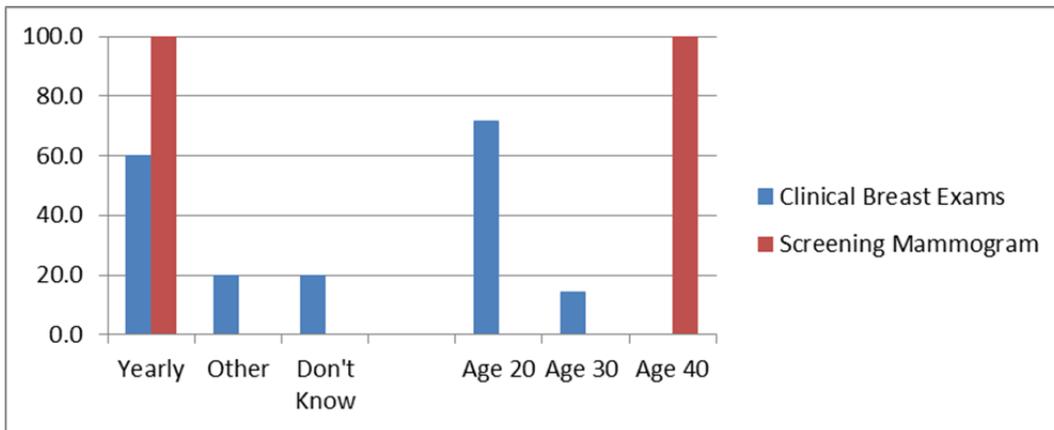
	% 1 yr or less	% 2 yrs or less	% 3 years or less	% more than 3 years	% Never had a CBE	% Don't know what a CBE is	Combine: Don't know, > 3 and never
All women	69.4	14.1	5.9	2.4	4.7	3.5	10.6
Women under 40	73.7	10.5	5.3		10.5		10.5
Women 40+	68.2	15.2	6.1	3.0	3.0	4.5	10.6

Lower income appears to correlate with lower screening frequency as seen in Figure 4.58. In the general population, the percentage of women waiting more than three years or never having a CBE is about ten percent. That percentage increases to over 25 percent for women in lower income brackets.



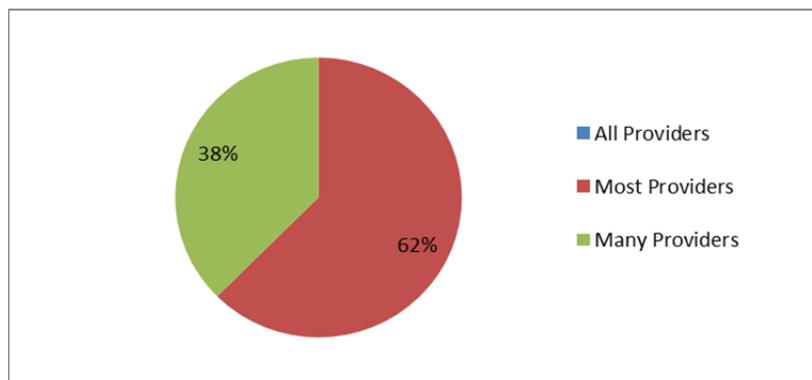
**Figure 4.58.** CBE frequency by income – Waukesha County general population survey

One hundred percent of those providers responding to the Health Provider Survey stated that their guidelines for a screening mammogram were yearly beginning at age 40 (Table 4.59).



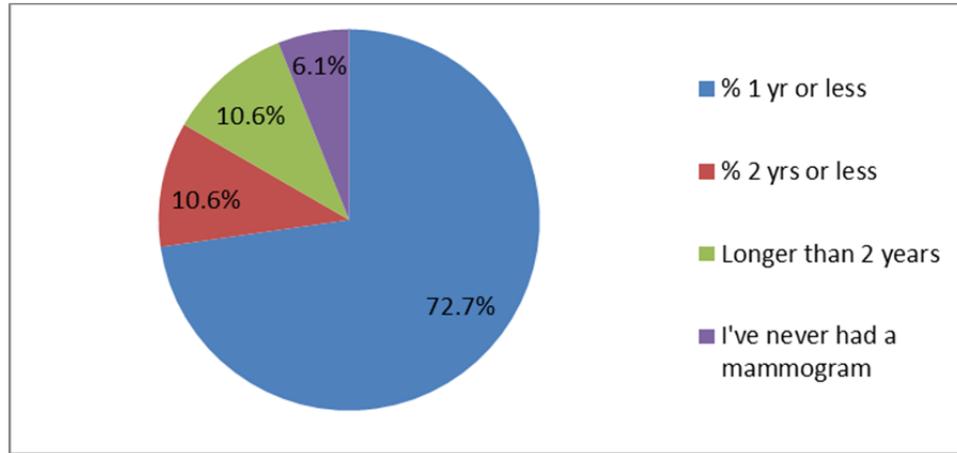
**Figure 4.59.** Recommendations for frequency and initial age of breast cancer screening – Health provider survey

As shown in Figure 4.60 no providers reported that their health system’s recommended screening age and frequency guidelines were followed by all of their providers. On a scale of 1 to 5 where 5 means all providers and 1 means no providers following internal guidelines, Waukesha County providers scored a 3.6 which translates to a grade of B minus.



**Figure 4.60.** Percentage of providers thought to follow their health system’s screening guidelines – Health provider survey

Nearly three quarters of women responding to the General Population Survey reported having a screening mammogram within the past year and over eighty percent had been screened in the past two years or less (Figure 4.61). It is notable that mammogram frequency for women surveyed between the ages of 40 to 49 year olds was much lower. Over thirty percent of these women had waited longer than three years or had never had a screening mammogram.



**Figure 4.61.** Mammogram frequency for women 40 and over – Waukesha County general population survey

***Perception of risk***

Perception of risk warrants individual discussion as a factor related to screening frequency and education. Over forty percent of Waukesha County women responding to the General Survey did not feel they were personally at risk for breast cancer. Table 4.43 compares the frequency of mammograms for Waukesha County women 40 years and older to their perception of their breast cancer risk. A pattern emerges that correlates these two variables. As highlighted in yellow, those having mammograms more frequently were disproportionately represented by women who stated they *did* feel at risk for breast cancer. Women having mammograms less frequently were often disproportionately represented by those who stated they *did not* feel at risk for breast cancer.

**Table 4.43.** Mammogram frequency vs. perception of risk –  
Waukesha County general population survey

		How long since your last Mammogram?							
			≤ 1 year	% ≤ 1 year	≤ 2 years	% ≤ 2 years	> 2 years or never	% > 2 years or never	Total
<b>Age by Perception of BC Risk</b> <b>Country over 40</b>	<b>Waukesha</b>	<b>40 to 49</b>	10	62.5	1	6.3	5	31.3	16
		No	3	18.8	1	6.3	1	6.3	5
		Yes	7	43.8		0	4	25.1	11
		<b>50 to 59</b>	18	81.8	1	4.5	3	14.6	22
		No	9	40.9	1	4.5	3	13.6	13
		Yes	9	40.9		0		0	9
		<b>60 to 69</b>	16	69.6	4	17.4	3	13.0	23
		No	4	17.4	2	8.7		0	6
		Yes	12	52.2	2	8.7	3	13.0	17
		<b>70 or over</b>	4	80	1	20		0	5
		No		0	1	20			1
		Yes	4	25.0		0			4

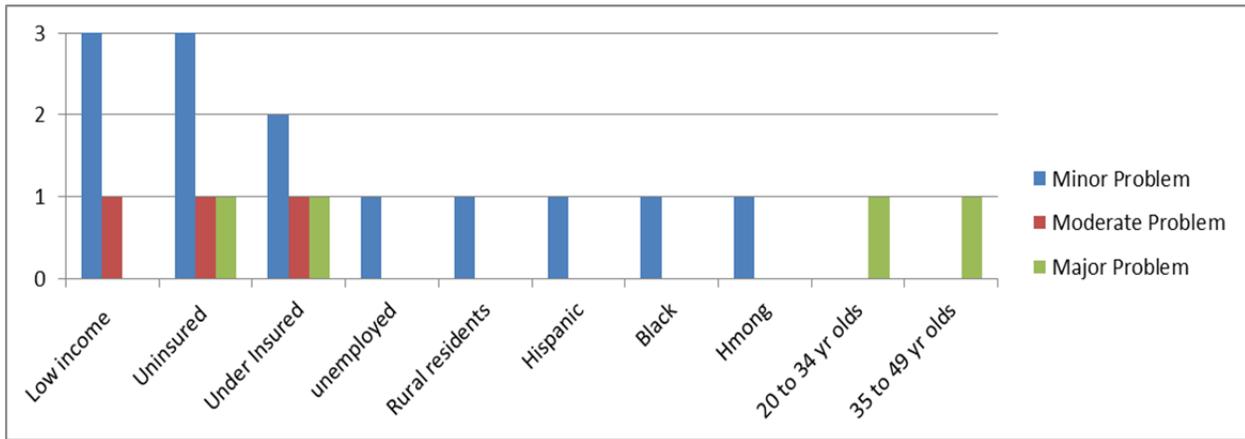
Survivor Survey data in Figure 4.62 shows a similar trend. Nearly two thirds of survivors surveyed *did not* feel at risk for breast cancer prior to their diagnosis. Especially notable is that while nearly two thirds of these survivors felt at least somewhat knowledgeable about breast cancer before their diagnosis, most still did not recognize a personal risk of breast cancer.

		Feel at risk for BC before your diagnosis?		Education to Risk Disconnect	
		No	Yes		
<b>Feel informed about BC before your Diagnosis?</b>	No	1	1	Out of 34 Breast Cancer Survivors:	
	Somewhat	6	2	6 (17.6%)	somewhat informed + not at risk
	Yes	15	9	15 (44.1%)	informed + not at risk

**Figure 4.62.** Knowledge of breast cancer vs. risk of breast cancer – Survivor survey

**Barriers to Screening**

Health Provider Survey respondents identified 10 distinct population groups (Figure 4.63) that they felt experienced barriers to breast cancer screening. Low income residents and those under and insured were identified most frequently. The majority of barriers these populations faced were seen as minor, although individual respondents did identify some populations experiencing moderate and major barriers.



**Figure 4.63.** Populations affected by barriers to screening – Health provider survey

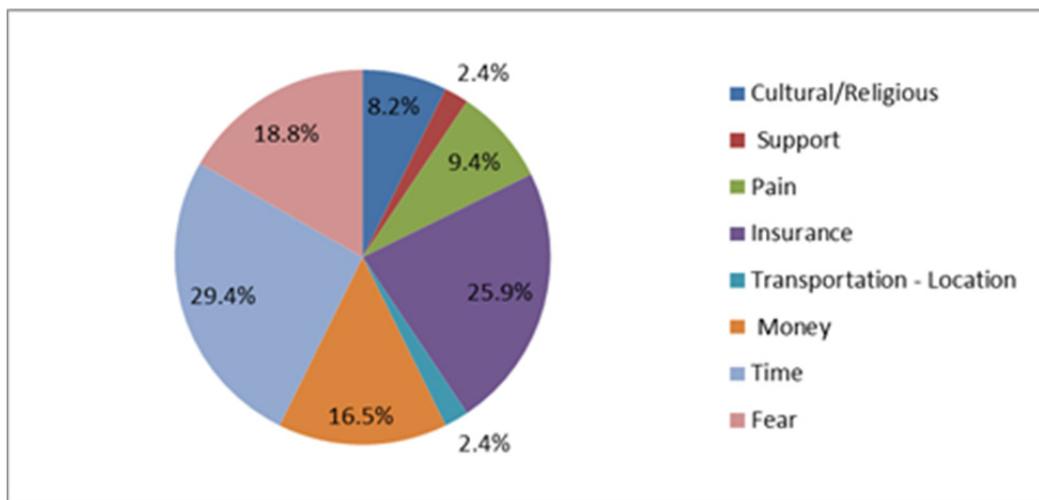
Health providers reported a range of screening barriers of varying impact was present in the community (Table 4.44). A lack of breast health education and awareness was recognized most frequently as the most impactful barrier to screening, with money/insurance and fear cited as close seconds. Cultural/religious barriers, although mainly identified by health providers as minor barriers, were recognized frequently.

**Table 4.44.** Barriers to screening and their degree of impact– Health provider survey

	Minor Barrier	Moderate Barrier	Major Barrier
<b>Cultural/Religious</b>			
Cultural beliefs	3	0	0
Religious beliefs	2	0	0
Lack of culturally sensitive services	1	0	0
Language Barriers	1	1	0
<b>Fear</b>			
Fear of having breast cancer	2	2	1
Fear of procedure(s)	2	3	0
Fear/distrust of medical system	0	1	2
Fear of neighborhood	1	0	0
<b>Money/Insurance</b>			
Low Income	2	1	1
Lack of Insurance	1	0	1
Out of medical pocket costs	3	1	1
<b>Education/Awareness</b>			
Unaware of services available	0	1	2
Don't know where to go for services	0	1	1
Don't know how to access service	2	1	2
Not aware of need for or importance of service	3	0	2
<b>Personal</b>			
Lack of family support	1	0	0
Too emotionally/physically draining	1	1	0
Need for Childcare	2	0	0
Can't get off work	3	0	0

Note: This table is color coded. Red = major or frequent moderate barriers, orange = moderate or frequent minor barriers, yellow = frequent minor barriers, green = less frequent minor barriers

The General Population Survey data in Figure 4.64 shows the themes that emerged for barriers to screening. Time, insurance, fear, and money barriers were cited most frequently. New themes of pain and transportation also emerged in this data set as additional barriers recognized in Waukesha County.



**Figure 4.64.** Barriers to screening – Waukesha County general population survey

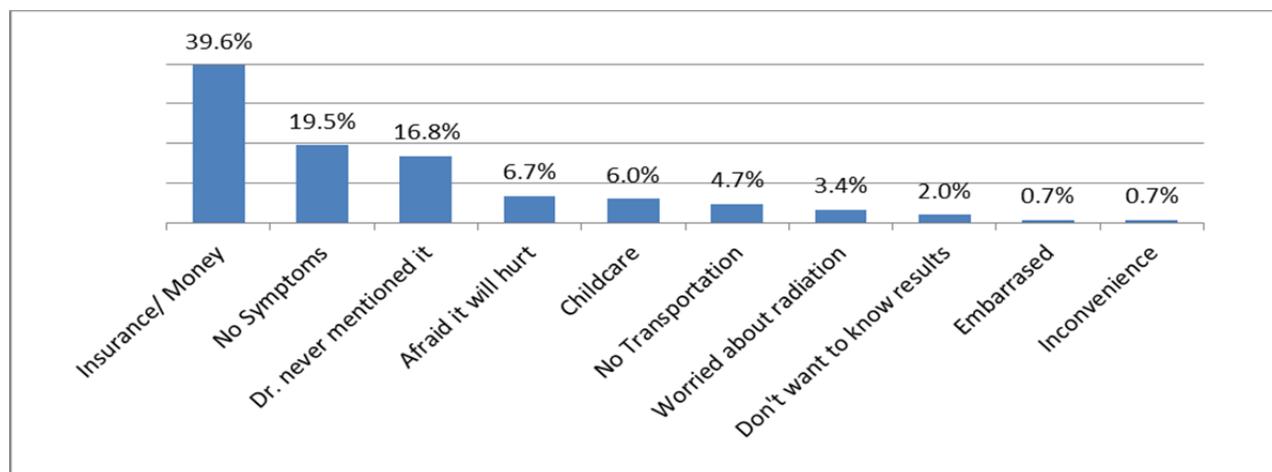
Table 4.45 shows a percentage breakdown of the screening barriers that emerged from the General Population Survey. Time, insurance, money and fear were shown to impact every population to varying extents. Although the frequency of responses was smaller for other barriers, they are not to be overlooked especially in instances where a specific population selects a screening barrier at a higher percentage than the overall survey group (such as cultural, support and transportation barriers).

**Table 4.45.** Barriers to breast cancer screening by populations – General population survey

	Cultural - Religious	Support	Pain	Insurance	Transportation - Location	Money	Time	Fear
All Respondents	8.2	2.4	9.4	25.9	2.4	16.5	29.4	18.8
White Women	7.0	2.8	9.9	25.4	0	14.1	29.6	16.9
Non-White Women	14.3	0	7.1	28.6	14.3	28.6	28.6	28.6
Hispanic/Latina	14.3	14.3	0	28.6	0	28.6	28.6	14.3
Women 40+	6.1	3.0	6.1	24.2	3.0	19.7	30.3	3.0
Women under 40	15.8	0	21.1	31.6	0	5.3	26.3	36.8
Survivors	12.0	4.0	0	24.0	4.0	20	28.0	8.0
Don't feel at risk	5.6	0	11.1	22.2	2.8	11.1	27.8	5.6
Do feel at risk	10.2	4.1	8.2	28.6	2.0	20.4	30.6	28.6
Inadequate insurance	0	12.5	0	62.5	0	37.5	37.5	12.5
Income <50K	3.7	0	14.8	29.6	3.7	14.8	29.6	7.4
Income <30K	0	0	9.1	9.1	9.1	0	18.2	0
Income <20K	0	0	11.1	11.1	11.1	0	11.1	0

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

Conversations for the Cure (CFTC) data from Hispanic/Latina women participating in the program supports the presence of multiple barriers for this population (Figure 4.65) and gives additional depth to data for Hispanic/Latina women in the General Population Survey. Insurance and money are major barriers emerging from both data sources. The existence of fear and transportation barriers is also corroborated. Two new barriers in the CFTC data ('having no symptoms' and 'doctor never mentioned it') support the presence of education barriers, both for Hispanic/Latina women and providers. They also are indicative of cultural barriers and a possible lack of culturally sensitive breast health information and services available.



**Table 4.65.** Barrier to screening – Hispanic/Latina program participants- CFTC 2013-14

Survivor Survey data in Table 4.46 supports the barriers recognized by health providers and General Population Survey participants. Survivors reported barriers across nine different themes. Time, money, fear were cited most frequently. Women 40 and older cited a wider range of barriers impacting access to breast cancer screenings than women under 40.

**Table 4.46.** Barriers to screening – Waukesha County survivor survey

	Fear	Support	Education	Time	Money	Insurance	Pain	Transportation	Cultural -Religious
Target community	12.2	2.4	9.8	14.6	14.6	7.3	7.3	2.4	7.3
Age Under 40	33.3	0.0	33.3	33.3	0.0	0.0	33.3	0.0	0.0
Age 40 +	10.5	2.6	7.9	13.2	15.8	7.9	5.3	2.6	7.9

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

Key informant interviewees in Waukesha County recognized many barriers to breast cancer screening. Education was cited as the top barrier for almost every population group referenced in the data and was mentioned most frequently by respondents in regards to low income and inadequately insured populations, as well as Hispanic/Latina and Black/African-American women (Table 4.47) Cultural/religious barriers were seen as having an almost equally large

impact on individuals' ability to access breast cancer screening. Money, transportation and insurance were also recognized as top barriers.

**Table 4.47. Barriers to screening – Key respondent interviews**

	Fear	Time	Money	Transportation	Insurance	Pain	Education	Support	Cultural - Religious
All Responses	5	5	7	7	7	1	9	4	9
Hispanic/Latina	4	3	2	4	3	1	5	0	3
Black/African-American	2	2	1	2	2	0	3	0	1
Asian/Pacific Islander	1	1	2	1	1	0	2	1	3
American Indian	1	1	1	1	1	0	1	0	1
White	1	1	2	2	2	0	1	1	1
Low income	2	3	5	5	3	1	6	4	5
Under or uninsured	3	3	6	5	4	1	6	4	6
LGBT population	1	0	1	0	2	0	1	1	0

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

**Barriers to Diagnostic and Treatment services**

The Health Provider Survey data in Table 4.48 shows the populations that providers identified as experiencing some degree of barriers to breast cancer diagnostic and treatment services. Uninsured individuals were the only group thought to experience major diagnostic barriers, but every population was identified as experiencing some degree of problems accessing breast cancer diagnostics. Major barriers to breast cancer treatment were reported for low income, under or uninsured, and Hispanic/Latina residents. Once again, the majority of populations identified were perceived to face at least minor barriers to treatment services.

**Table 4.48.** Populations with treatment and diagnostic services barriers –  
Health provider survey

	Problems Accessing Diagnostics			Problems Accessing Treatment		
	Minor Problem	Moderate Problem	Major Problem	Minor Problem	Moderate Problem	Major Problem
Low income individuals	2	1	0	2	0	1
Uninsured individuals	3	1	1	2	1	1
Under insured	2	2	0	2	1	1
Rural residents	1	0	0	1	0	0
Hispanic/Latina	1	1	0	1	0	1
Black/African-American	1	1	0	1	0	0
Hmong	1	0	0	1	0	0
20 to 34 year olds	0	2	0	0	1	0
35 to 49 year olds	0	2	0	0	1	0
50 to 64 year olds	0	1	0	0	0	0
65 or older	0	1	0	0	0	0
employed	0	1	0	0	0	0
unemployed	1	1	0	1	0	0

Note: This table is color coded. Red = major or frequent moderate barriers, orange = moderate or frequent minor barriers, yellow = frequent minor barriers, green = less frequent minor barriers

Health Provider Survey data in Table 4.49 identifies the barriers recognized by health providers and indicates the extent to which those barriers are affecting individuals in Waukesha County. Health provider recognize insurance/money as the biggest barriers to both diagnostic and treatment services with the impact of this barrier increasing as a patient moves from diagnostic testing to breast cancer treatment. The other most recognized barriers to breast cancer diagnostic services were education, fear and systemic barriers within the health system itself. The remaining top breast cancer treatment barriers were also education, fear, and health system barriers, but personal barriers were also recognized as impacting an individual's ability to both access and continue recommended breast cancer treatment services.

**Table 4.49. Barriers to diagnostic and treatment services and their impact – Health provider survey**

	Barriers to Diagnostic Services			Barriers to Treatment Services		
	Minor Barrier	Moderate Barrier	Major Barrier	Minor Barrier	Moderate Barrier	Major Barrier
<b>Cultural/Religious</b>						
Cultural beliefs	1	1	0	2	1	0
Religious beliefs	2	0	0	2	0	0
Lack of culturally appropriate services	1	0	0	1	0	0
Language barriers	1	0	0	1	0	0
<b>Fear</b>						
Fear of breast cancer	2	1	1	2	1	0
Fear of procedure(s)	1	2	0	1	1	1
Fear of medical system	0	1	2	0	1	1
Fear of neighborhood	1	0	0	1	0	0
<b>Money/Insurance</b>						
Low Income	2	1	1	2	1	3
Lack of Insurance	1	0	1	1	0	2
Out of pocket costs	1	2	1	1	1	2
<b>Education/Awareness</b>						
Unaware of services	0	1	1	0	1	1
Don't know where to go	0	1	1	0	1	1
Don't know how to access service	1	1	2	1	0	2
Not aware of importance	2	0	1	1	0	1
<b>Personal</b>						
Lack of family support	1	0	0	1	0	0
Too draining	1	1	0	1	1	0
Need for childcare	1	0	0	0	1	0
Can't get off work	0	2	0	0	1	1
<b>Health System</b>						
Lack of navigation	0	1	0	0	1	0
No Primary Care provider	1	1	0	1	1	0
Lack of support services	0	1	0	0	1	0
Limited service hours	0	2	0	0	1	1
Long waiting lists	1	0	0	1	0	0
Lack of providers	0	1	0	0	1	0
Distance/transportation	2	0	0	1	0	1

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4). Each category was weighted by impact (5-major, 3-moderate, 1- minor) and averaged in order to compare category scores.

Key Informant Interview data provides supporting information on the barriers to breast health diagnostic services for vulnerable residents of Waukesha County. Table 4.50 indicates that interviewees recognized lack of education as the primary barrier to diagnostic services selecting it most frequently for nearly every population identified. Fear, money, and lack of support were stated as the other top barriers to diagnostic services. Key informants tended to speak more in terms of money as opposed to insurance, so while insurance barriers did not emerge as frequently in the data, money issues were often cited as a result of inadequate insurance coverage.

One key informant’s comments illustrate how intertwined these barriers can be, *“The more testing you need the more complicated the health literacy needs are – this creates a bigger gap than a simpler screening procedure. If a person does not have full ability to understand what is being said, access to accurate information may be limited. These individuals are not likely to be supported by people that are any more aware of what questions need to be asked or what feedback is required, so they don’t get the additional informational or access support they need. And the more complicated this gets, the more fear there is and the less likely it becomes that person will ask the right questions.”*

**Table 4.50.** Barriers to diagnostic services - Key respondent interviews

	Fear	Time	Money	Transportation	Insurance	Pain	Education	Support	Cultural -Religious
All Responses	9	1	7	1	3	0	15	4	2
Hispanic/Latina	4	0	1	0	1	0	6	1	2
Black/African-American	2	0	1	0	1	0	3	0	1
Asian/Pacific Islander	2	1	3	0	0	0	3	1	0
American Indian	0	0	1	0	0	0	1	0	0
White	1	0	2	1	1	0	1	1	0
Other Race	0	0	1	0	0	0	1	0	0
Low income	6	1	5	1	2	0	9	4	2
Under or uninsured	6	1	5	1	2	0	9	4	2
LGBT population	1	0	1	0	2	0	3	1	0

Key Informant Interview data in Table 4.51 suggest the emergence of a different set of barriers in regards to breast cancer treatment. While education was still seen as a barrier, the treatment barrier most frequently mentioned was money. A lack of insurance was acknowledged as a major root cause for problems, but the respondents most typically reference these issues as money barriers. Transportation was the next top barrier at the treatment level of the continuum of care. One respondent’s comment reflects the consensus of many, *“Transportation becomes a major issue at treatment - frequent trips are difficult for the population we serve.”*

The other top treatment barriers interviewees reported were fear, time, and education closely followed by support and cultural/religious barriers. Respondents cited instances of people resisting treatment due to religious barriers calling their breast cancer *“God’s Plan.”* Numerous references were also made to cultural tendencies of prioritizing family needs above one’s own health needs.

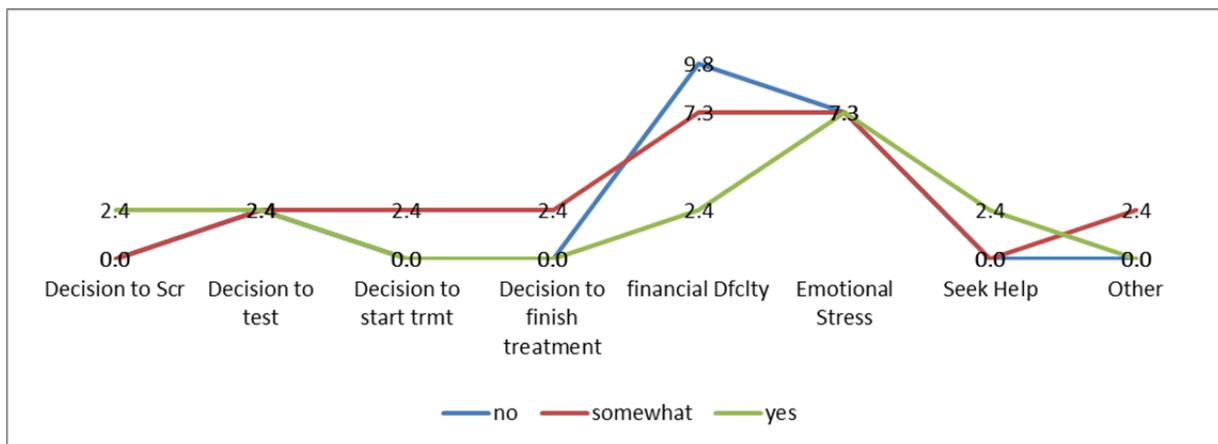
Important to note is that most key informants indicated that barriers have a major impact on the populations they serve at all points across the continuum of care. Interviewees stressed that there are deep pockets of individuals in Waukesha County who are extremely limited in their access to resources and services.

**Table 4.51. Barriers to Treatment Services – Key Respondent Interviews**

	Fear	Time	Money	Transportation	Pain	Education	Support	Cultural -Religious
All Responses	4	4	11	5	1	4	3	3
Hispanic/Latina	0	2	3	3	0	1	2	1
Black/African-American	0	1	2	2	0	0	1	0
Asian/Pacific Islander	1	0	3	2	0	0	0	1
American Indian	0	0	1	1	0	0	0	0
White	1	0	2	2	1	1	1	0
Other Race	0	0	1	1	0	0	0	0
Mainly women	1	1	1	1	0	0	0	1
Low income	2	2	6	4	1	3	2	3
Under or uninsured	2	2	6	5	1	3	2	3
LGBT population	0	1	2	0	0	1	1	0

**Insurance as a barrier**

Additional consideration of insurance barriers is warranted. Data from all collection sources indicate that insurance looms large as a barrier to all levels of breast health services. Figure 4.66 illustrates the effects of inadequate insurance as reported by the respondents to the Waukesha County Survivor Survey. Financial difficulty, emotional stress, and impact on screening and treatment services were all noted by many respondents. One Waukesha County survivor gave an idea of the impact a lack of insurance coverage can cause when she comment, “within two years of my first diagnosis, I was re-diagnosed with a second type of breast cancer. It left me with staggering medical bills. I was off of work for six full months.”



**Figure 4.66. Effects of inadequate insurance on breast cancer survivors**

**Timliness of Breast Health Services**

All respondents to the Health Provider Survey reported that their facilities were 100 percent compliant in providing screening mammograms at the CDC guidelines of within 90 days of a referral. Compliance with guidelines for diagnostic and treatment services were ‘always’ met according to of the majority of respondents. On a scale of 1 to 5 with ‘always’ being a 5,

'usually' a 4 and 'never' a 1, Waukesha County health providers give themselves an overall score of 4.9 which is a solid A grade (Figure 4.67).

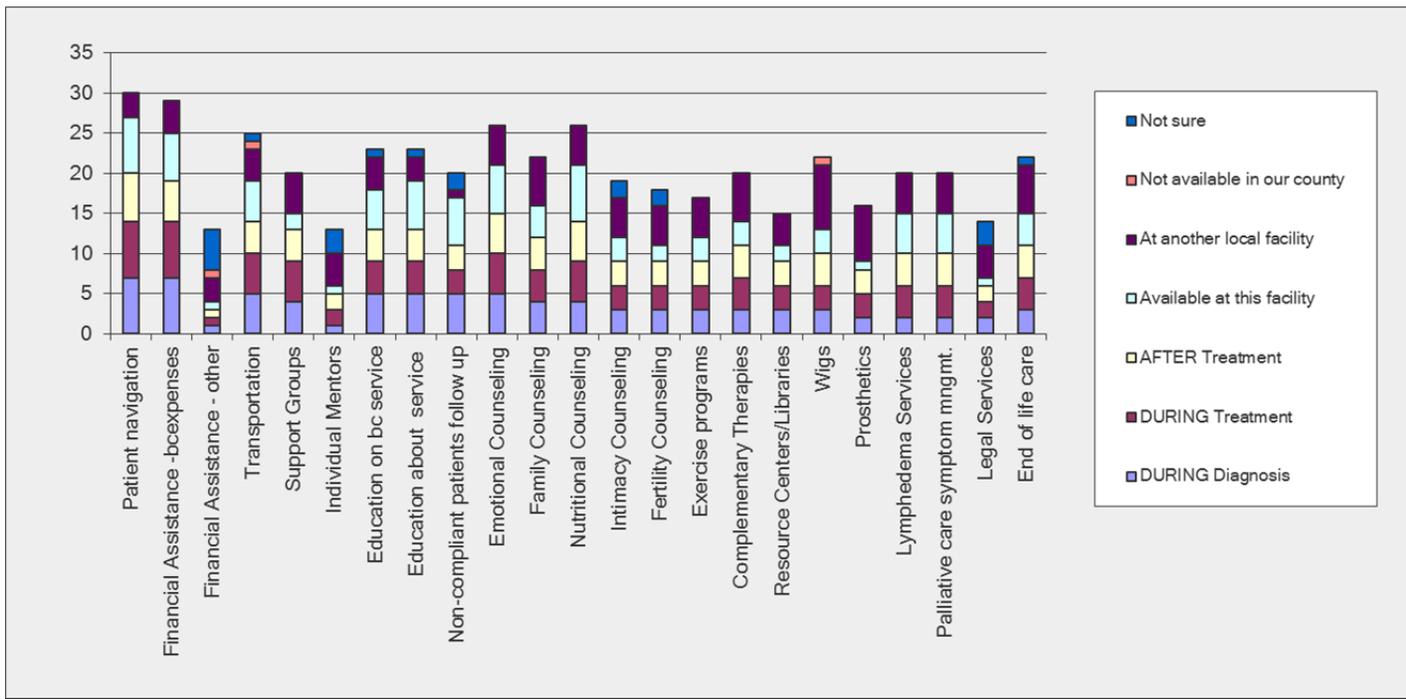


**Figure 4.67.** Health system compliance with CDC guidelines – Health provider survey

Receiving services within the CDC time guidelines does not necessarily mean that individuals do not still have a sense of delays in breast health services. About a fifth of Waukesha County survivors reported that they had experienced some delays in diagnostic services and most of those reported delays in treatment services as well. One survivor cited personal delays due to both emotional and physical reactions. Others felt their diagnostic and treatment services were delayed due to problems within the health system including insurance hold ups, referral delays, inaccurate testing, and one instance of communication breakdowns within a survivor's health team. It is notable that these survivors reported experiencing a great deal of angst because of these delays regardless of the actual timeframe involved. This is reflected in the comments of one woman who simply stated *"the process was just too long."*

### **Survivor Support Services**

Health Provider Survey data in Figure 4.68 shows respondents identified a broad range of possible survivor support services available along the entire continuum of care. Patient navigation and financial assistance for breast cancer expenses were the most frequently reported source of support. Aside from these services, no more than five of the seventeen providers responding identified any one particular service before, during, or after breast cancer treatment. Mentors and financial assistance for non-medical expenses related to breast cancer were the least frequently reported support options.



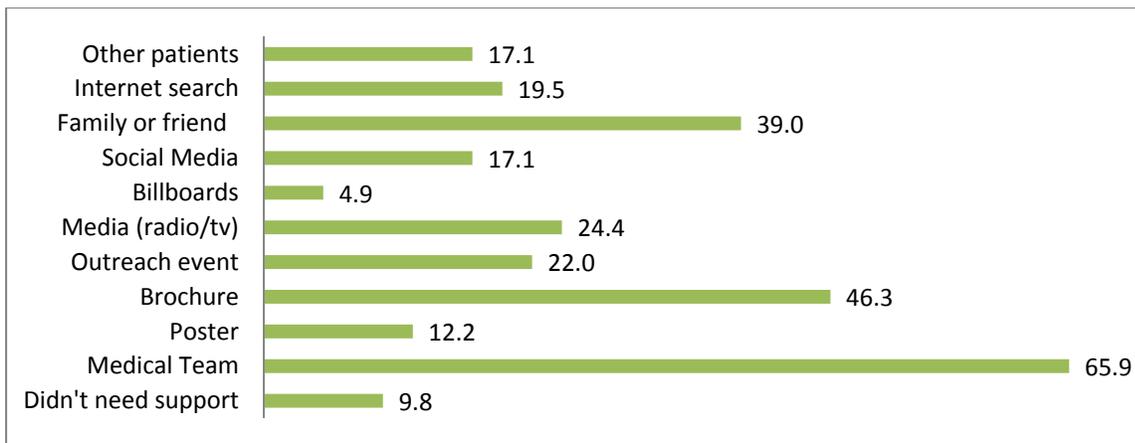
**Figure 4.68.** Support services available what, where, and when – Health provider survey

The majority of Waukesha County breast cancer survivors surveyed reported that they did not experience any barriers to support services (Figure 4.69).



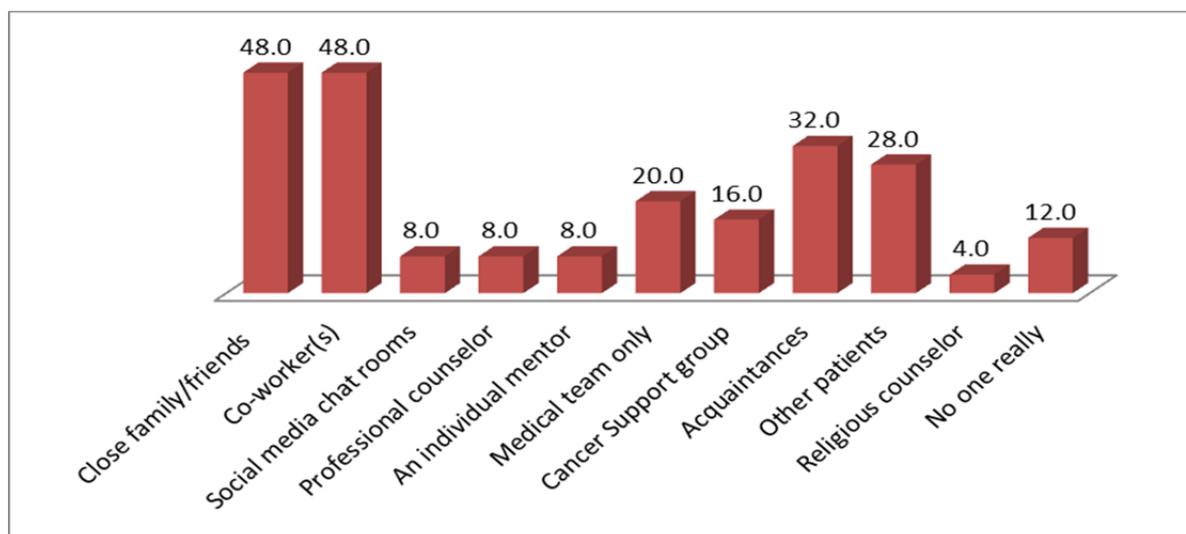
**Figure 4.69.** Percentage of survivors who experienced barriers to support services – Waukesha County

Figure 4.70 Survivor Survey data indicates that the majority of survivors were able to get information about available survivor services from multiple sources. The most frequent source for this information was the medical team, brochures, and friends and family. About ten percent of survivors did not feel a need for support services.



**Figure 4.70.** Source of Information for Support Services – Waukesha Survivor Survey

The Survivor Survey data shown in Figure 4.71 illustrates that most Waukesha County survivors are interested in having an outlet to talk to about their breast cancer experiences. Although some indicated that they do not talk with anyone about their breast cancer, nearly half of respondents reported talking with family, friends, and co-workers. Acquaintances and other survivors were also frequently mentioned as people with whom survivors shared their experiences. Very few survivors reported talking with counselors or mentors.



**Figure 4.71.** Outlets for talk about your breast cancer - Waukesha County Survivor Survey

Survivor Survey respondents had fairly good awareness of support services that provided an outlet for this willingness to talk about their breast cancer. Table 4.52 shows that more than half were aware of available support groups and a quarter were aware of mentoring services. More than a third of those surveyed knew about exercise and nutrition programs. Utilization of these services, however, lagged well behind awareness. The support services most utilized were nutritional and exercise programs, mentoring, and individual counseling each used by around a third of respondents. Only a handful of survivors made use of any other survivor support services.

**Table 4.52.** Support services utilized – Waukesha County survivor survey

	Support groups	One on one mentoring	Individual Counseling	Group counseling	Religious Counseling	Financial Support	Fertility Support	Intimacy Support	Legal Counseling	Palliative Care	End of Life Planning
Available	24	22	17	14	11	9	4	5	2	3	4
Used before treatment	1	3	3	2	2	0	0	0	0	0	0
Used during treatment	5	7	6	2	5	1	0	0	0	0	0
Used after treatment	3	3	3	1	1	0	1	0	0	0	1
Especially Valuable	5	4	5	1	2	1	0	0	0	0	0
	Yoga	Massage	Reiki	Meditation	Acupuncture	Exercise Program	Nutritional Support				
Available	7	7	1	7	6	16	15				
Used before treatment	1	1	0	1	0	2	3				
Used during treatment	4	3	0	3	2	6	9				
Used after treatment	1	3	0	1	0	7	3				
Especially Valuable	4	3	0	3	1	8	3				

**Solutions- What Can Be Done**

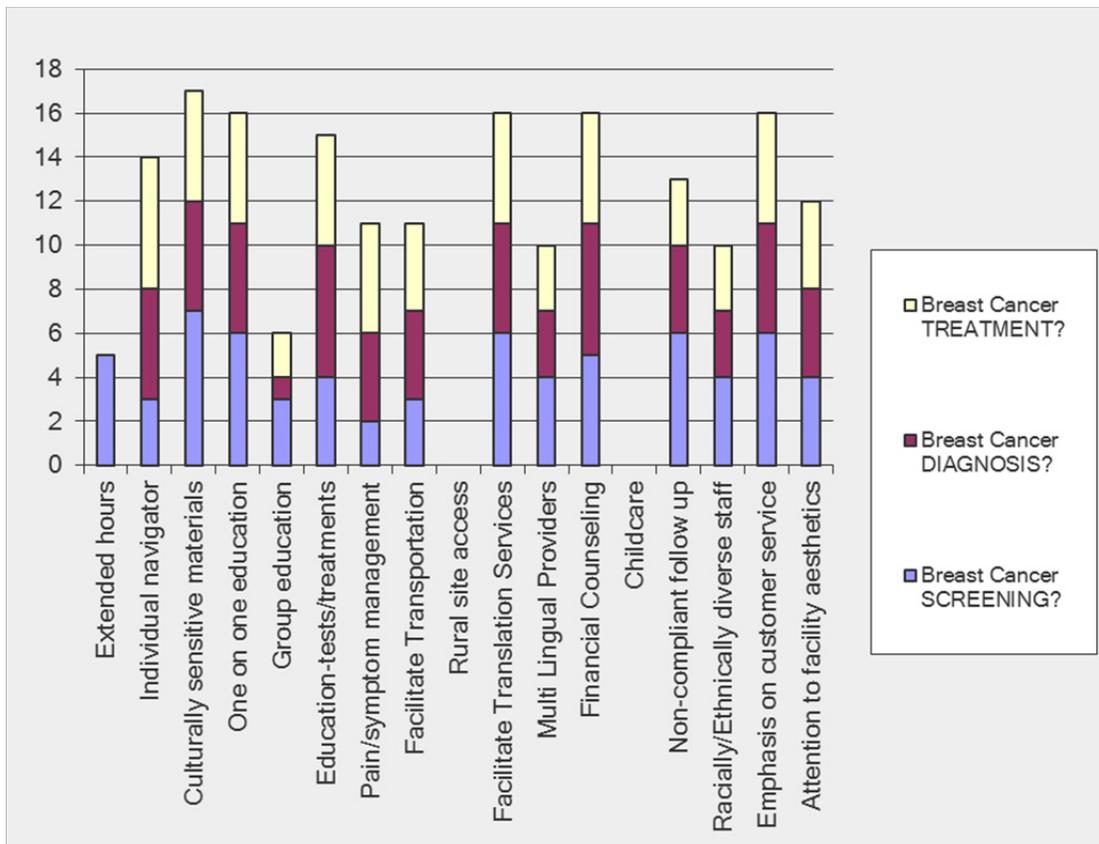
Data collected from all sample groups provided themes of what individuals felt was needed to overcome barriers and reduce service gaps for breast health in Waukesha County. Table 4.53 is data from the General Population Survey on reducing screening barriers. Education emerges as the top solution in every population. Reducing costs, survivors sharing stories, and making changes within the health system were other top suggestions. There was much consensus on the need for collaboration between local agencies and consistent calls for mobile mammography or other means of increasing access to services.

**Table 4.53.** Reducing screening barriers – General population survey Waukesha County

	Total Responding	Education and Awareness	Mobile Mammograms and better access	Community Collaboration and Outreach	Reducing Costs	Media	Survivors Sharing Stories	Changes made within the Health System
All Responses	85	17	6	6	9	5	9	7
Survivors	25	6	1	3	2	1	3	0
White Women	71	13	6	4	8	4	7	7
Non-White	14	4	0	2	1	1	2	0
Hispanic/Latina	7	1	0	1	1	1	2	0
Age under 40	19	4	1	0	1	0	0	2
Age 40 and over	66	13	5	6	8	5	9	5
Under or uninsured	8	1	1	1	2	0	1	1

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

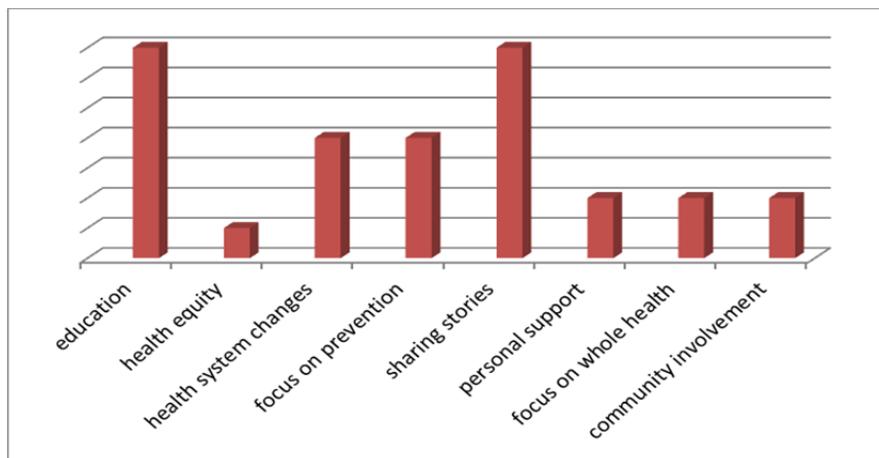
Figure 4.72 provides data on a broad range of provider suggestions for reducing barriers to screening as well as diagnostic and treatment services. Education, more culturally sensitive materials and translation services, financial counseling, and additional attention to customer service were frequently suggested as solutions at every level of breast health service delivery.



**Figure 4.72.** Overcoming screening, diagnostic, and treatment barriers -Health provider survey

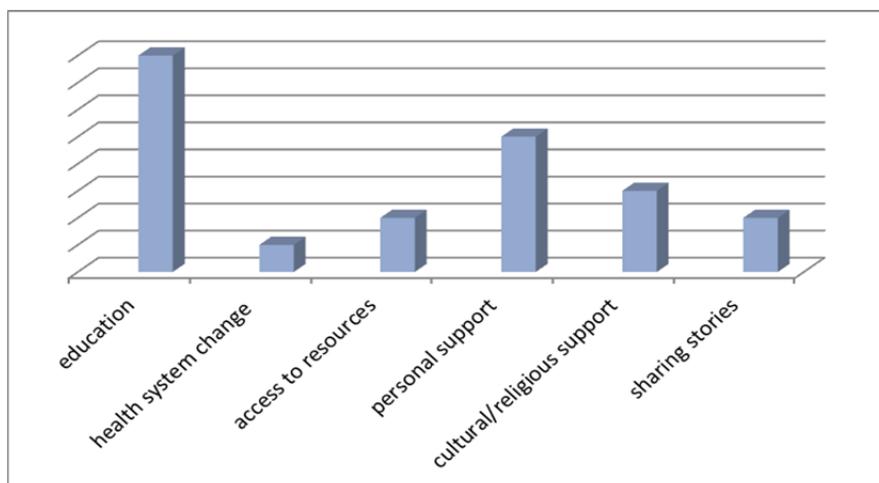
Survivor Forum data provides corroboration to other data with suggested solutions for closing gaps and eliminating barriers to breast health services. Throughout the Forum discussion there was a strong overarching call for a shift to a preventative and whole health focus within the community as the optimal way to truly address existing barriers and promote more equitable access to breast health services at all points on the continuum of care.

While providing eight identified themes, Survivor Forum participants most frequently mentioned education and survivors sharing stories as solutions for overcoming screening barriers (Figure 4.73).



**Figure 4.73.** Solutions to screening barriers – Survivor forum

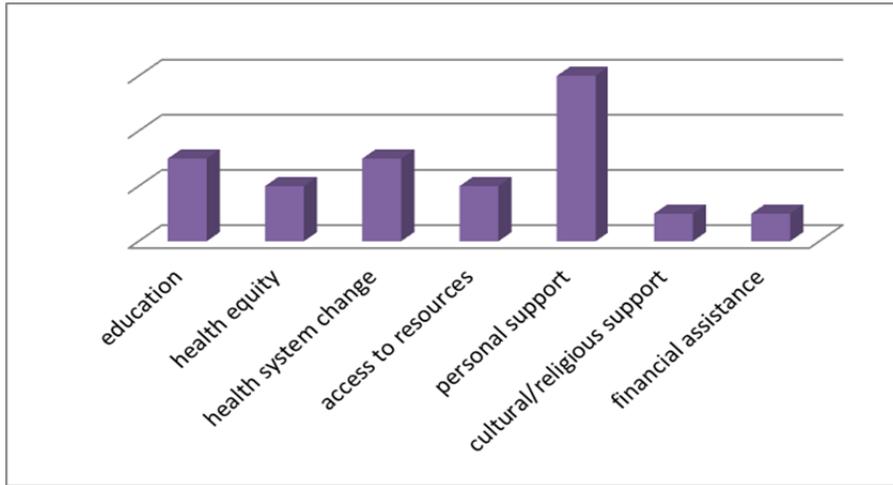
The most suggested solution to diagnostic barriers from Forum participants was again education, but the need for support was also seen as especially important. Personal support, culturally and religiously sensitive support, and support for accessing services all emerged as major themes for overcoming barriers to diagnostic services (Figure 4.74).



**Figure 4.74.** Solutions to Diagnostic Barriers - Survivor Forum

Several strong themes emerged as solutions to barriers and inequities at the breast cancer treatment stage in the continuum of care (Figure 4.75). Support was seen as the most important element. Survivor Forum participants called for an increase of personal support, as

well as greater efforts to support individuals through culturally sensitive services and increased assistance in finding access to resources. The participants also saw great need for changes in the health system in order to achieve equitable access to breast cancer treatment for everyone in the community.



**Figure 4.75.** Solutions to treatment barriers - Survivor forum

Key Informant Interview participants also provided insight on ways to positively impact access to all levels of breast health services. Their comments in Table 4.54 are a sample of ways these interviewees felt barriers could be reduced for the vulnerable populations that they serve.

**Table 4.54. Reducing the impact of barriers and promoting health equity –  
Key informant interviews**

Test materials to use for increasing awareness, encourage screening and healthy behaviors.
Facilitating collaboration between groups. Health system needs to find ways to find people where they live and recruit other community support organizations to help with the costs and other challenges.
Utilize Mobile Mammography.
Work to overcome barriers such as fear, lack of knowledge, cultural barriers by providing quality breast health education to everyone.
Don't make assumptions about people. Work to understand people and meet them with services where they are.
Educate individuals about how to find and access to breast health services and support services.
Need to provide full support after diagnosis - breast cancer is hard on everyone - even harder on people who can't afford food, rent, etc. Find a way to make sure there is funding to cover people's medical and living expenses.
Focus on prevention. Provide breast health information as part of a broader preventative health focus.
More culturally sensitive educational programs in own language - translation is essential. Programs closer to home will be more successful.
Focus on providing resources such as transportation options, financial assistance.
Need to get the word clearly to people that BC is not a death sentence, must be persistent on getting people to follow through. Clearly lay out the pros/cons of screenings and treatment and promote good attitudes for women with BC.
Personalized service has the best results. A lot of people need some 'hand holding' to start with. Begin where the woman is at, helps them proceed through the health system and then works to empower them with good information and plans.
Utilize a Community Health Worker Model.
Promote a better understanding of the why's of breast cancer, the risk factors, and the environmental component.
Must have bilingual and culturally diverse staff - the goal must be deliberate to deliver services at the same standard for all populations.
Put a premium on developing trust. Give support from start to finish in financial assistance, culturally sensitive services, side effect management and help bearing treatment.
Lots of community outreach, education, and funding.

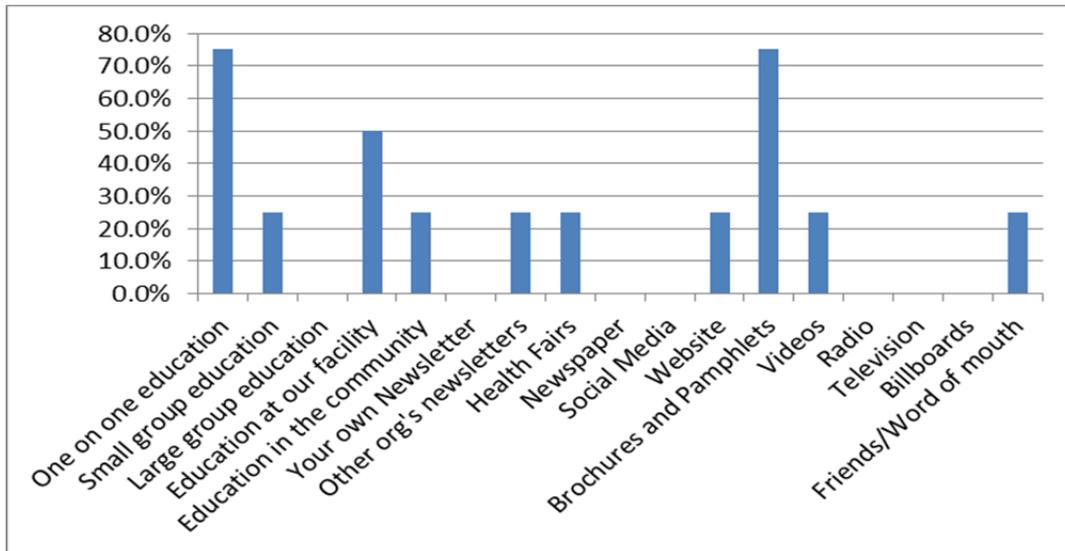
**Southern Rural Region**

Although the Affiliate had limited partnerships established in the Southern Rural Region (SRR), data collection for this Target Community was fairly strong. The General Survey collected 90 responses. The Health Provider survey had 10 respondents representing all the major health systems in Kenosha and Walworth Counties, as well at the FQHC and the free clinic. The Survivor Survey was not a strong source of data on its own but has the potential to validate data results of the other collection methods. The Affiliate also conducted 21 Key Respondent Interviews with individuals from organizations serving a variety of populations in the Southern Rural Region and this input further strengthened the data sources in this Target Community.

**Education and Outreach**

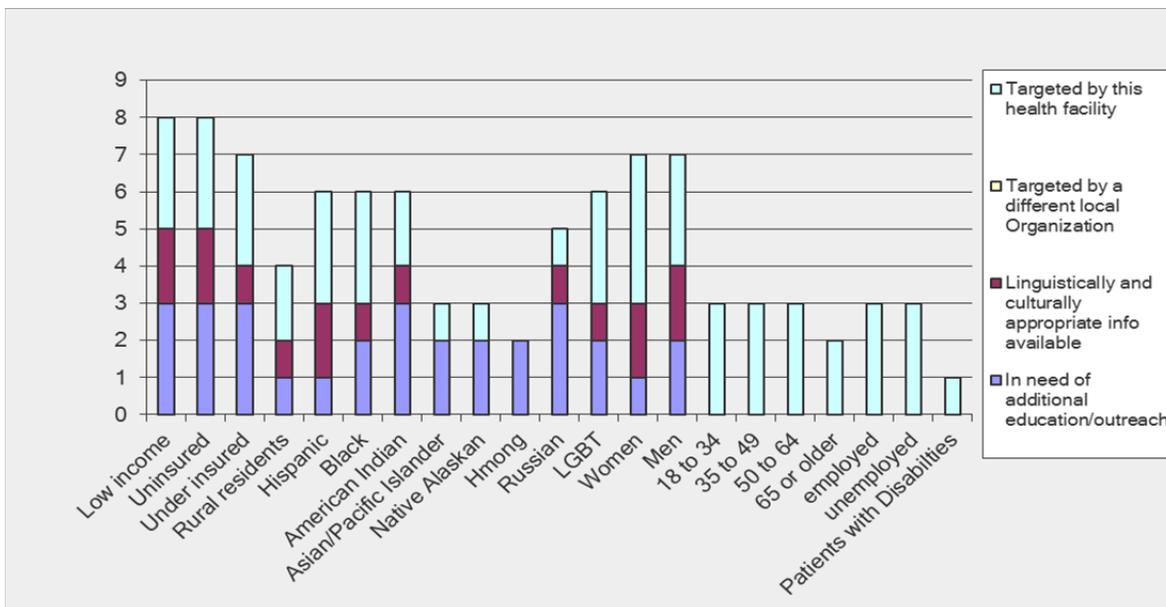
Respondent to the Health Provider Survey identified ten methods utilized to provide education and outreach in the Southern Rural Region as shown in Figure 4.76. The most common

methods reported were one on one education, and the availability of brochures, and pamphlets. Half of the providers indicated that education was provided within their facility.



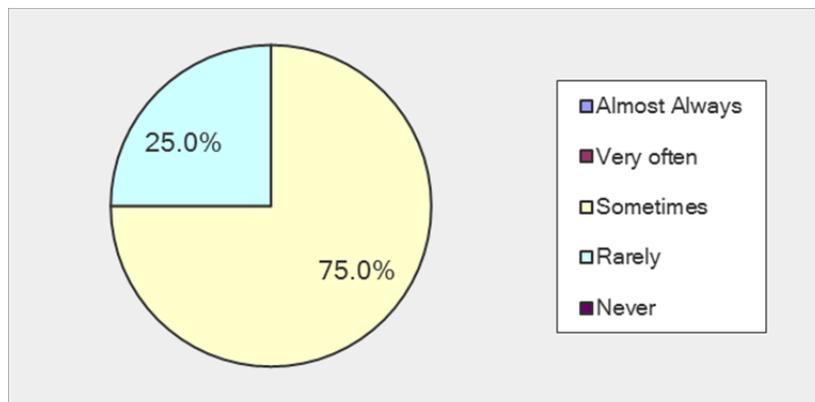
**Figure 4.76.** Education and outreach methods – Health provider survey

Health providers identified many populations that they feel need breast health services and show that they have efforts in place to target most of these groups (Figure 4.77). The Hmong population stands out as needing service but not yet being targeted for service. The data shows a strong recognition of the need for additional education and outreach for all populations identified. In fact, for several populations seen as being targeted for service, there is an equal or greater response for their need for additional services. One provider felt compelled to add a comment that she “*would like to see the African-American community targeted. There is a great need for education in the community.*” The data also indicates that providers feel that some culturally appropriate information is available, but missing for several populations.



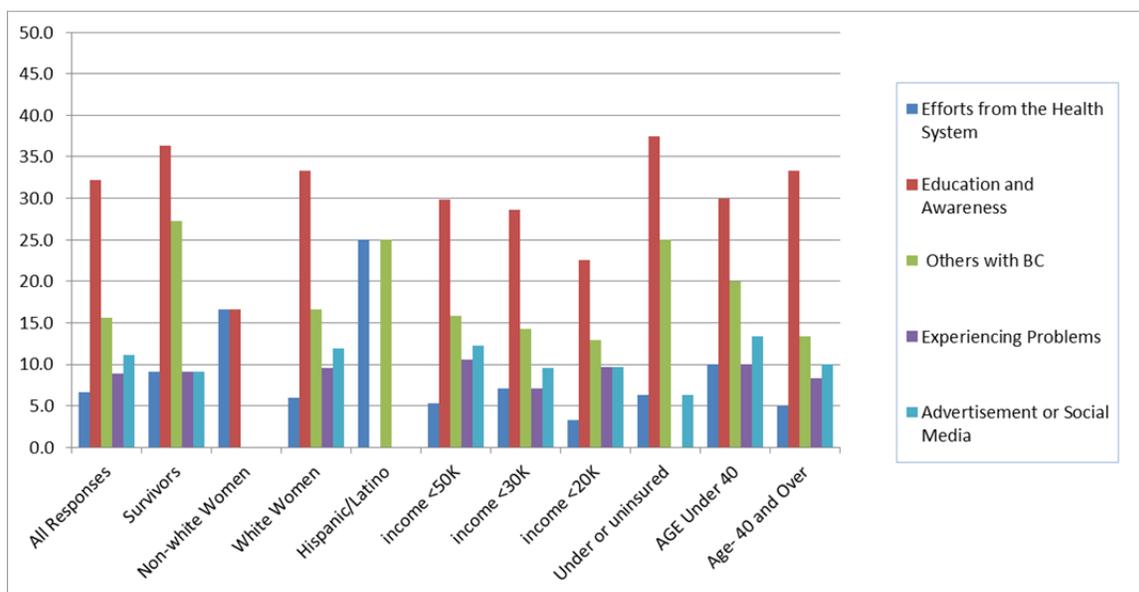
**Figure 4.77.** Populations in need of breast health services – SSR health provider survey

When asked about the ability of current education efforts in the Southern Rural Region to get women to have a breast cancer screening, three quarters of respondents stated they were 'sometimes' effective and the other quarter felt current programs were 'rarely' effective (Figure 4.78). On a scale of 1 to 5 where 5 is almost always effective, 4 is very often, 3 is sometimes, 2 is rarely, and 1 is never, providers rated the Southern Rural Region programs a 2.75. This translates into a grade of C minus.



**Figure 4.78.** Effectiveness of current education/outreach – SSR health provider survey

The General Population Survey offers data (Figure 4.79) that supports the importance of available and effective breast health information. Respondents across all populations reported that education/awareness is by far the greatest motivator to getting a breast cancer screening. The next most frequent response was knowing someone with breast cancer which is directly related to the idea of awareness as a motivator.

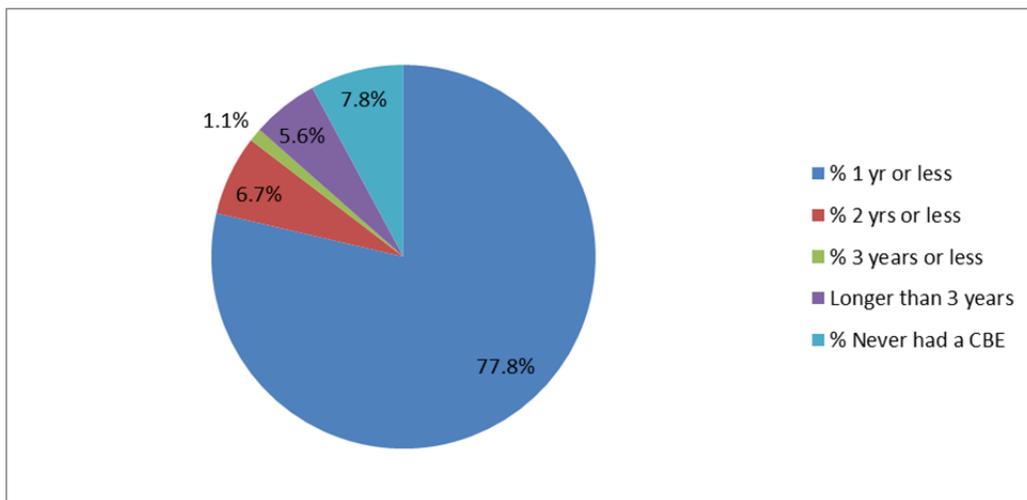


**Figure 4.79.** Motivators to screening - General population survey

### Breast Cancer Screening

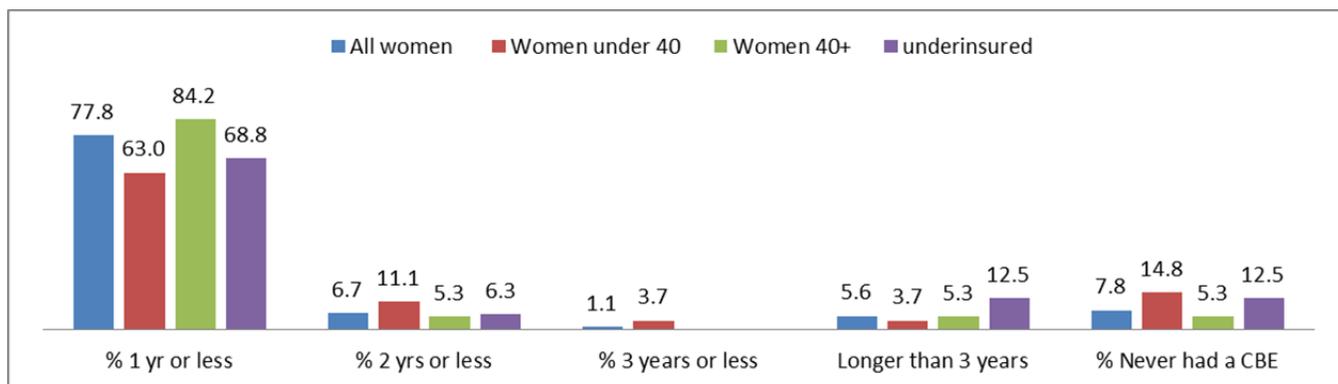
Every Health Provider Survey participant stated that their health system recommended clinical breast exams yearly beginning at age 20. Data in Figure 4.80 shows that over three quarters of

the General Population Survey respondents reported having a CBE in the past year. Slightly more than a tenth had either never had a CBE or had waited more than three years.



**Figure 4.80.** CBE frequency for Southern Rural Region – General population survey

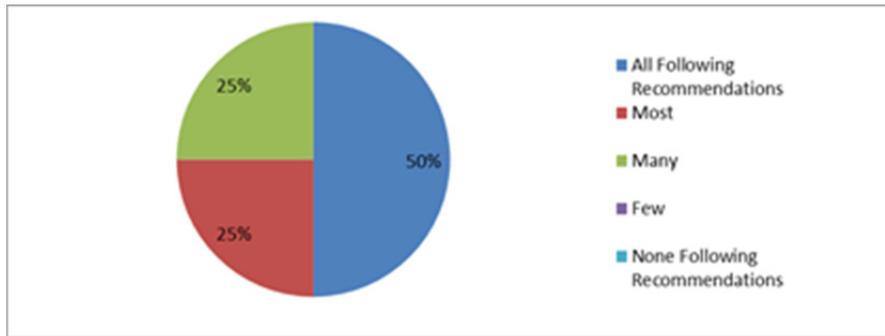
Figure 4.81 shows CBE frequency data by age group and for women reporting inadequate insurance. Yearly CBEs are less common for those under 40 than for those 40 and older. Women who feel underinsured are also less likely to have yearly CBEs than the sample as a whole. Underinsured women and women under 40 are also much more likely to report never having a CBE or not having one in over three years.



**Figure 4.81.** CBE frequency by age and for those underinsured – General population survey

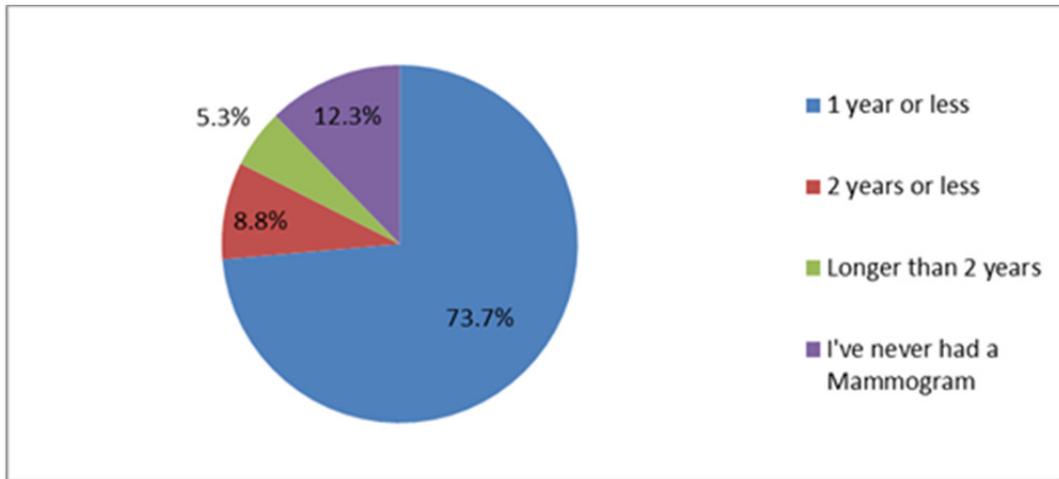
Every Health Provider Survey respondent stated that their health system recommends screening mammograms beginning at age 40. Two thirds of these respondents said yearly mammograms were the standard and the other third reported every two years as the recommendation.

Figure 4.82 shows the percentage of providers that the survey respondents felt followed their health system internal breast cancer screening recommendations. Half felt all providers followed recommendations while the other half reported that in their experience either ‘most’ or ‘many’ provider followed recommendations.



**Figure 4.82.** Percentage of providers thought to follow their health system’s screening guidelines – Health provider survey

Figure 4.83 shows data on the frequency at which respondents of the Southern Rural Region General Survey reported having screening mammograms. Three quarters of women 40 and older had a mammogram within the past year. Slightly under a fifth of respondents reported either not being screened in over two years or never having a screening mammogram.



**Figure 4.83.** Screening mammogram frequency – SSR general population survey

While the sample size was small for non-White women in the Southern Rural Region, Table 4.55 shows that this population’s screening mammogram frequency was noticeably lower than that of White women. Non-White women reported never or rarely having a screening mammogram much more frequently than their White neighbors and nearly twice as often than reported by all respondents. A similar disparity is seen when the data are compared by income.

**Table 4.55.** Frequency of screening mammograms by age and income –  
General population survey

	% 1 year or less	% 2 years or less	Longer than 2 years	Never had a mammogram	Combine: % >2 and never
All women 40+	73.7	8.8	5.3	12.3	17.5
White women 40+	80.0	6.7	6.7	6.7	13.3
Non-White women 40+	66.7		33.3		33.3
low income <50K	73.7	7.9	7.9	10.5	18.4
low income <30K	70.4	11.1	7.4	11.1	18.5
Low income <20K	68.4	10.5	5.3	15.8	21.1

**Perception of Risk**

A separate discussion of perception of risk is warranted as it appears to be tied to screening frequency, breast health education, and possibly late-stage diagnosis. Two thirds of General Population Survey participants 40 years and older indicated that they *do not* feel at risk for breast cancer. This perception of risk appears to correlate with their frequency of screening mammograms as shown in Table 4.56. Highlighted in yellow are several instances where a perception of risk predicts more frequent screening and where no perception of risk accompanies those having less frequent screenings. This is especially apparent for 40 to 49 year olds who have never had a screening mammogram. None of these women perceived a personal risk of breast cancer before their diagnosis.

**Table 4.56.** Frequency of screening mammograms vs. perception of risk for breast cancer –  
General population survey

		How long since your last Mammogram?								Grand Total
		≤ 1 year	% ≤ 1 year	≤ 2 years	% ≤ 2 years	> 2 years	% > 2 years	Never	% Never	
Age by Perception of BC Risk Southern Rural Region over 40	<b>40 to 49</b>	8	57.1	0	0	1	7.1	5	35.7	14
	No	6	42.9		0	1	7.1	5	35.7	12
	Yes	2	14.3		0		0		0	2
	<b>50 to 59</b>	13	81.3	1	6.3	1	6.3	1	6.3	16
	No	6	37.5	1	6.3		0	1	6.3	8
	Yes	7	43.8		0	1	6.3		0	8
	<b>60 to 69</b>	11	73.3	2	13.3	2	13.3	0	0	15
	No	4	26.7	2	13.3	2	13.3			8
	Yes	7	46.7		0		0			7
	<b>70 +</b>	7	70	2	20	0	0	1	10	10
	No	5	50	2	20		0	1	10	8
	Yes	2	20	0	0		0			2

Five out of six SRR respondents to the Survivor Survey *did not* feel at risk for breast cancer prior to their diagnosis. Surprisingly, four of these women also stated they *did* feel informed about breast cancer prior to diagnosis (Table 4.57).

**Table 4.57.** Perception of risk vs. feeling educated about breast cancer - Survivor survey

	Did you feel at risk for BC before your diagnosis?			Education to Risk Disconnect	
		No	Yes		
Did you feel informed about BC before your Diagnosis?	No	1	0	Out of 6 Breast Cancer Survivors:	
	Somewhat	0	0	0	felt <i>somewhat informed</i> but did not feel at risk of bc
	Yes	4	1	4 (66.7%)	felt <i>informed</i> but did not feel at risk of bc

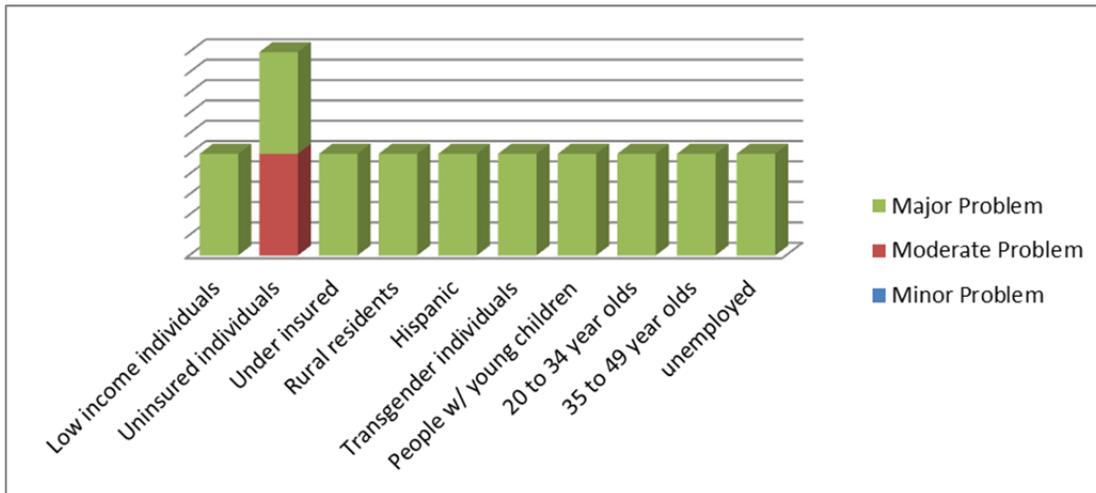
While the data are too limited to draw any conclusions linking an individual’s perception of risk to their stage of diagnosis, further study may be warranted on this connection. Of the three respondents diagnosed at stage 2, only one felt at risk of breast cancer (Table 4.58). The one survivor diagnosed at stage 3 did not feel at risk and was also in the group that reported having mammograms only occasionally.

**Table 4.58.** Late-stage diagnosis as related to the perception of risk

	Stage II	% No to Yes	Stage III	% No to Yes	Stage IV	% No to Yes	Total	% total Y/N	total stage 3 and 4	% of Y/N stage 3 and 4
At Risk – NO	2	66.7	1	100	0	0	3	75.0	1	100
At Risk – YES	1	33.3	0	0	0	0	1	25.0	0	0

### Barriers to Screening

Figure 4.84 shows the populations health providers reported as likely to experience difficulty in accessing breast cancer screening. While not as extensive as the populations providers recognized as needing increased education and outreach, all populations identified were reported to experience major barriers. The populations identified were low income, under and uninsured, and unemployed individuals, as well as rural and Hispanic/Latina residents, transgendered individuals, parents of young children and those in age brackets not captured by Wisconsin Well Woman funding. While providers did identify Hispanic/Latina residents as experiencing barriers to breast cancer screening, they did not identify any other populations by race.



**Figure 4.84.** Populations affected by barriers to breast cancer screening – Health provider survey

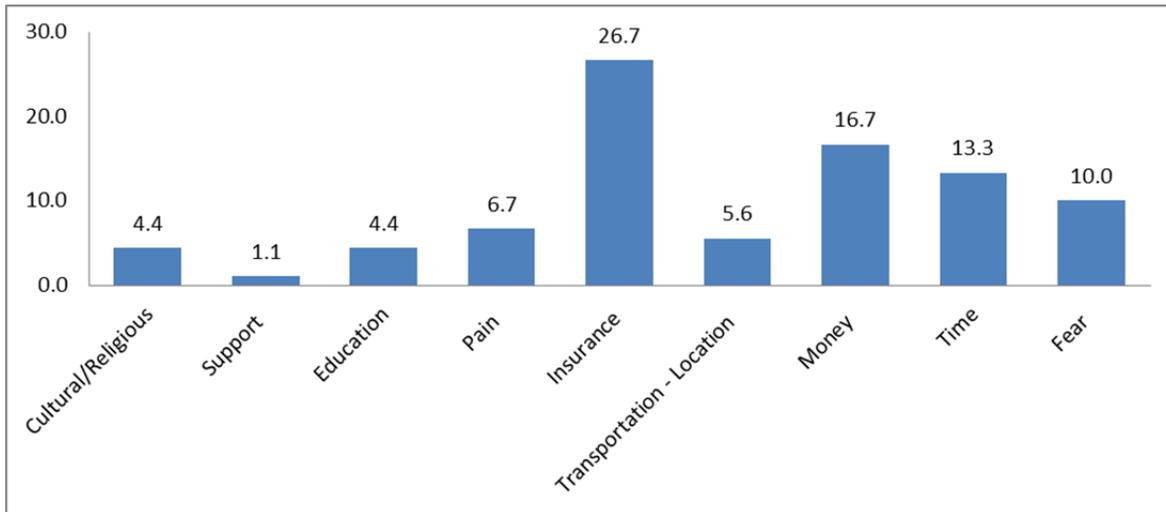
Table 4.59 provides the data on the types of screening barriers providers felt existed in the community and the extent to which each barrier is seen as a problem. All barriers identified were thought to be either of moderate or major concern. No providers listed any of these barriers as a minor problem for those affected. Providers identified major barriers related to insurance/money and to the health system. A lack of childcare was also identified as a major screening barrier. Moderate barriers were cited across all six of the identified barrier themes.

**Table 4.59.** Barriers to screening and impact - SRR Health provider survey

	Barriers to Screening		
	Minor Barrier	Moderate Barrier	Major Barrier
<b>Cultural Religious</b>			
Cultural beliefs	0	1	0
Religious beliefs	0	1	0
Language Barriers	0	1	0
Lack of cultural sensitivity	0	1	0
<b>Fear</b>			
Fear of breast cancer	0	1	0
Fear of procedure(s)	0	1	0
Fear of medical system	0	1	0
<b>Insurance / Money</b>			
Lack of Insurance	0	1	1
Low Income	0	0	1
Out of pocket costs	0	1	1
<b>Personal</b>			
Can't get off Work	0	0	0
Lack of family support	0	1	0
Need for Childcare	0	0	1
<b>Education / Awareness</b>			
Unaware of services	0	2	0
Don't know where to go	0	1	0
Don't know how to access	0	2	0
Not aware of importance	0	1	0
<b>Health System</b>			
No primary care doctor	0	0	1
Lack of navigation	0	1	0
Lack of support services	0	1	0
Limited service hours	0	0	1
Long waiting lists	0	1	0
Lack of providers	0	1	0
Distance to facility	0	0	1

Note: This table is color coded with red = major barrier and orange = moderate barrier

Data in Figure 4.85 shows the nine themes that emerged from the General Population Survey in an open-ended question about barriers to screening. Insurance was mentioned most frequently followed by money, time, and fear.



**Figure 4.85.** Barriers to screening – Southern Rural Region general population survey

Data in Table 4.60 breaks down the responses of the General Population Survey into a variety of socioeconomic and demographic populations. Sample size is small for non-White individuals and Hispanic/Latina individuals but provides a starting point for further investigation. Sample sizes, although not at ideal confidence level rates, were much larger for individuals in income brackets under \$50,000.

Education was the barrier cited most frequently by all population groups. Money, time and fear were the next most frequently identified screening barriers overall. Specific populations show some variance in the screening barriers they identified as most impactful. For instance fear was selected by respondents under 40 years of age more often than by the survey group as a whole. Transportation and money barriers were more prevalent for individuals with lower incomes, and those who report feeling at risk for breast cancer reported higher percentages than average for almost all barrier themes.

**Table 4.60.** Barriers to screening, percentage by population group - General population survey

	Cultural - Religious	Support	Education	Pain	Insurance	Transportation - Location	Money	Time	Fear	total respondents
All Respondents	4.4	1.1	4.4	6.7	26.7	5.6	16.7	13.3	10.0	90
White Women	3.6	1.2	4.8	7.1	25.0	6.0	15.5	14.3	10.7	84
Non-White Women	16.7	0	0	0	50.0	0	33.3	0	0	6
Hispanic/Latina	25.0	0	0	25.0	25.0	0	0	25.0	25.0	4
Women 40+	3.3	0	3.3	10	26.7	5.0	13.3	13.3	8.3	60
Women under 40	6.7	3.3	6.7	0	26.7	6.7	23.3	13.3	13.3	30
Survivors	0	0	9.1	0	27.3	0	18.2	9.1	18.2	11
Don't feel at risk of bc	4.1	0	6.1	12.2	16.3	8.2	14.3	10.2	12.2	49
Do feel at risk of bc	5.6	2.8	2.8	0	41.7	2.8	19.4	19.4	8.3	36
Inadequate insurance	0	0	18.8	0	50.0	6.3	43.8	12.5	6.3	16
Income <50K	5.2	1.7	5.2	6.9	36.2	6.9	20.7	12.1	6.9	58
Income <30K	4.8	2.4	4.8	9.5	26.2	9.5	19.0	11.9	4.8	42
Income <20K	6.5	3.2	3.2	0	22.6	6.5	12.9	16.1	6.5	31

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

Key Informant Interview data in Table 4.61 adds clarity to the screening barriers faced by vulnerable populations in the Southern Rural Region Target Community. In addition to identifying nine barrier themes, interviewees also confirmed the presence of a variety of populations facing barriers to screening in this community. Education was thought to be the most prominent barrier to screening for nearly every population identified. Insurance, cultural/religious barriers, money, transportation, and fear also were mentioned very frequently.

**Table 4.61. Barriers to screening - Key informant interviews**

	Fear	Time	Money	Transportation	Insurance	Pain	Education	Support	Cultural - Religious
All Responses	9	6	10	10	11	3	14	5	11
Hispanic/Latina	4	5	3	7	4	1	7	1	5
Black/African-American	3	4	3	6	3	1	6	2	4
Asian/Pacific Islander	1	1	2	1	1	0	1	0	2
American Indian	2	2	1	2	2	0	2	0	2
White	2	1	4	3	3	0	4	3	1
Other Race	1	1	1	1	2	0	1	0	2
Low income	5	4	7	9	5	3	10	4	7
Under or uninsured	6	4	7	7	6	3	9	3	8
LGBT population	1	0	1	0	2	0	1	1	0

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

### Barriers to Diagnostic and Treatment Services

Few Health Provider Survey respondents identified barriers to breast health diagnostic and treatment services. However, those responding noted that insurance and money barriers had moderate impact on access to diagnostic and treatment services.

Key informants identified nine themes of barriers to diagnostic services (Table 4.62). Lack of education was recognized as the biggest barrier to diagnostic services for every population identified. Fear was the second most frequently cited barrier for the majority of populations. Interviewees spoke of a fear of cancer itself, fear of what might happen to family or job situations if breast cancer was found, and in some cases fear of the health system itself. Money was the third most frequently cited barrier most often related to a concern of not being able to manage daily living expenses if breast cancer was found. Insurance was not cited nearly as often but it is notable that many key respondents expressed a barrier that was related to insurance in terms of money.

**Table 4.62.** Barriers to diagnostic services - Key informant interviews

	Fear	Time	Money	Transportation	Insurance	Pain	Education	Support	Cultural - Religious
All Responses	12	2	11	3	5	1	21	6	2
Hispanic/Latina	6	0	4	1	1	0	8	2	2
Black/African-American	5	0	4	2	1	0	7	1	1
Asian/Pacific Islander	1	1	2	0	0	0	2	1	0
American Indian	1	0	1	0	0	0	2	0	0
White	2	0	4	2	2	0	4	2	0
Other Race	1	0	1	0	0	0	2	0	0
Low income	9	2	8	3	2	1	14	6	2
Under or uninsured	7	2	6	2	2	1	12	5	2
LGBT population	1	0	1	0	2	0	3	1	0

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

Key Respondent Interviews also identified nine major themes for barriers to breast cancer treatment (Table 4.63). Money and transportation were the most impactful barriers to breast cancer treatment for vulnerable population groups in the Target Community. Money issues were seen as related to inadequate insurance as well as the inability to continue working and bringing in an income during breast cancer treatment. Populations that are already living under stressful conditions, especially financially, were seen as likely to have difficulty prioritizing breast cancer treatment. One respondent stated that an *“individual is more likely to forfeit treatment before forfeiting the essential things like working and caring for family.”*

Interviewees also stressed a great increase in transportation barriers at the treatment phase of the continuum of care. They recognized that *“transportation becomes a major issue at treatment - frequent trips are difficult.”* While most respondents felt transportation was at least achievable for accessing breast cancer screening, transportation to frequent breast cancer treatment appointments (such as regular chemotherapy or daily radiation therapy) could be extremely stressful and sometimes impossible for many individuals, especially those with low incomes in every demographic group.

While not affecting every population group, key informants stated adamantly that cultural barriers were a major barrier to treatment for many individuals, especially those less familiar with westernized medicine and those who are linguistically isolated. Health equity issues were most often cited in relationship to a lack of truly culturally sensitive service for those outside the cultural mainstream.

**Table 4.63.** Barriers to treatment services - Key respondent interviews

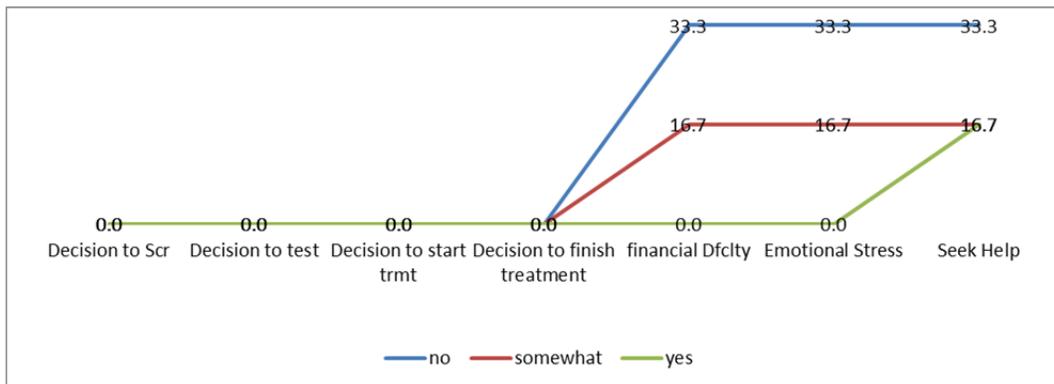
	Fear	Time	Money	Transportation	Insurance	Pain	Education	Support	Cultural - Religious
All Responses	6	5	15	9	0	5	5	5	3
Hispanic/Latina	2	2	4	6	0	0	2	3	2
Black/African-American	3	1	4	6	0	1	2	2	1
Asian/Pacific Islander	0	0	2	2	0	0	0	0	0
American Indian	1	1	2	2	0	0	0	0	1
White	1	0	4	3	0	2	1	2	0
Other Race	1	0	2	1	0	0	0	0	0
Low income	4	4	10	7	0	4	4	4	3
Under or uninsured	3	4	9	7	0	4	3	2	3
LGBT population	0	1	2	0	0	0	1	1	0

Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

### Insurance as a barrier

Insurance and money issues related to inadequate insurance were common denominators to barriers from screening to treatment and warrant additional discussion. While no survivors surveyed decided not to receive services based on insurance issues alone, there were reports of insurance creating financial difficulty and emotional stress, as well as driving people to seek outside help (Figure 4.86). One Survivor Survey participant related the financial stress she experienced during her breast cancer treatment, *“The ‘specialist’ co pays were \$35 each visit. You have to see the specialist each time you have a chemo treatment. The Breast MRI's were not covered. There were three of them at \$750 each. The insurance company said they were not necessary.”* Another survivor related that *“insurance only covered \$2500 of my costs, nothing for cancer. I owe the hospital over \$75,000.”*

One health provider commented that often the “‘working poor’ had the most challenges in accessing services, *“Patients on Medicaid, Medicare, and SSI often have better access to services than individuals who don’t qualify for those programs, but cannot afford insurance or do not have adequate insurance to cover their costs.”*



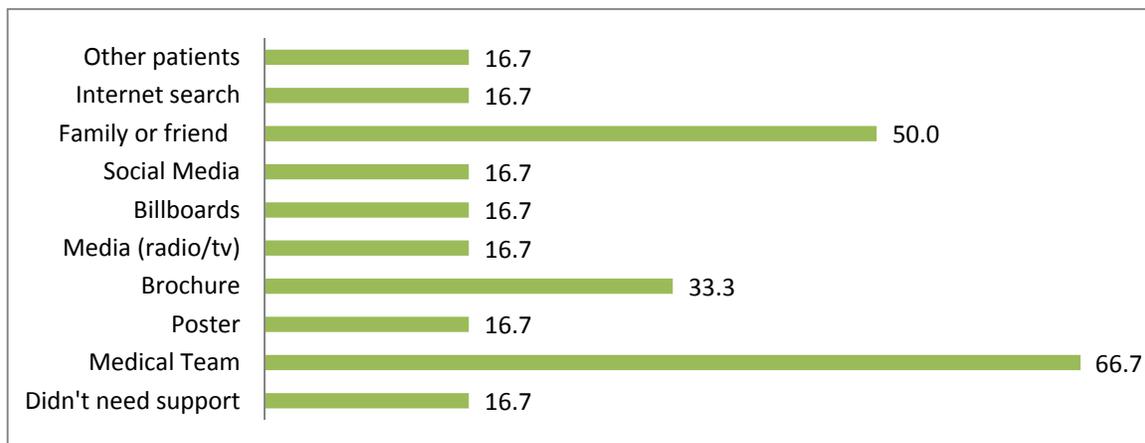
**Figure 4.86.** Effects of inadequate insurance on breast cancer survivors by percent – Survivor survey

### Timeliness of Breast Health Services

CDC guidelines allow 90 days between referral and mammogram, 60 days between mammogram and date of diagnosis, and 60 between diagnosis and the beginning of treatment. Of the health providers responding to the Health Provider Survey, two thirds felt that breast cancer services were 'always' provided within the guidelines set out by the CDC while the other third felt these guidelines were rarely met. According to these perceptions on a scale of 1 to 5 (never-1, rarely-2, sometimes -3, often-4, and always- 5) the SRR Target Community would score a 4.0 or a grade of B. This extreme range of responses, however, warrants further investigation.

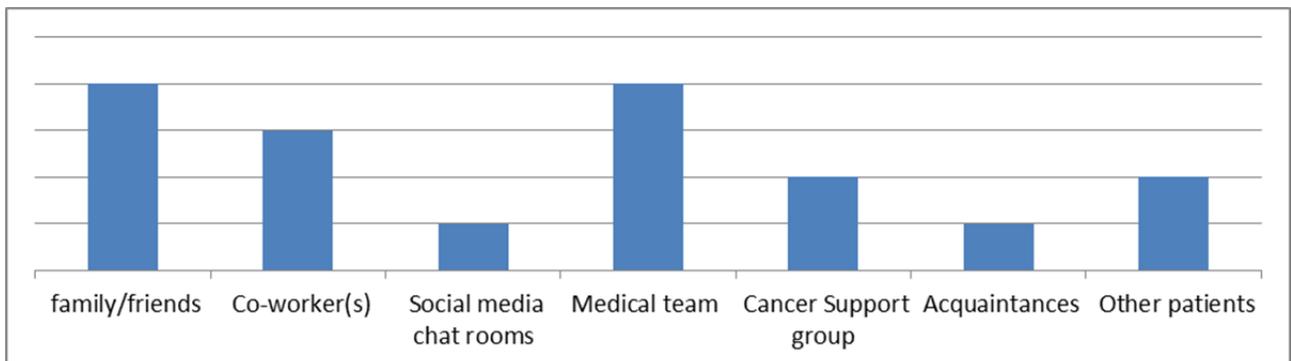
### Survivor Support Services

Survivor Survey respondents reported that they learned about available survivor support services in many ways. The most frequent sources of information were the survivor's medical team, family and friends, and informational brochures (Figure 4.87).



**Figure 4.87.** Sources of information on survivor support services – Survivor survey

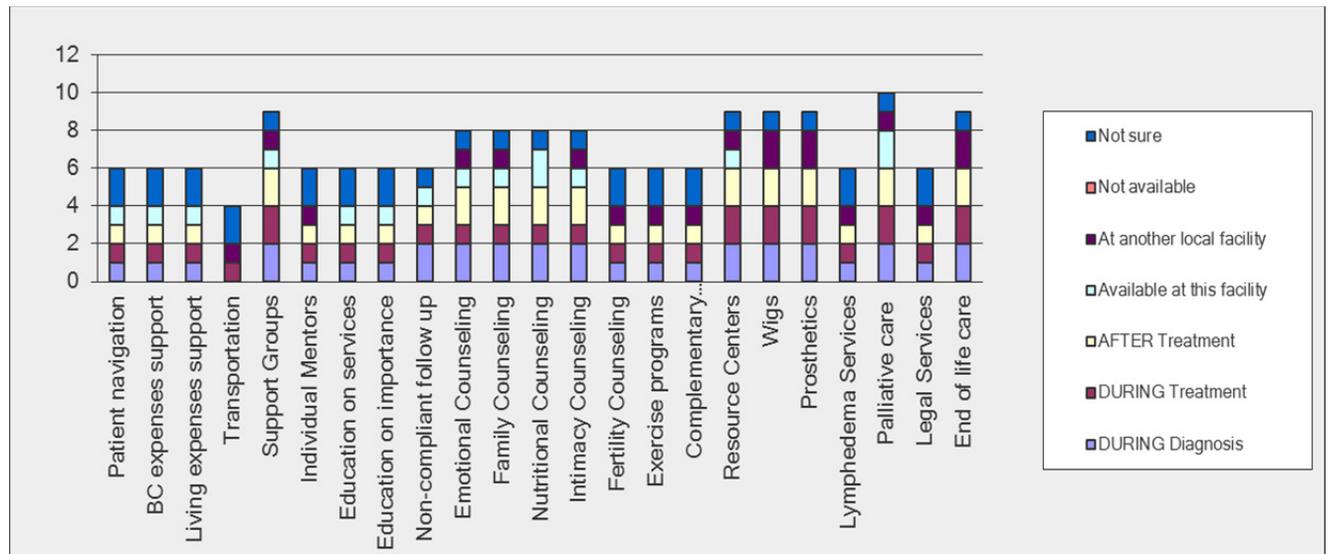
As shown in Figure 4.88, all Survivor Survey data show that all respondents reported having at least one outlet that they talked to about their breast cancer. Respondents reported that they spoke about their breast cancer most frequently with their medical team, family and friends, and co-workers.



**Figure 4.88.** Who do you talk with about your breast cancer – Survivor survey

Health Provider Survey data in Figure 4.89 shows that two thirds of health providers feel that adequate support services are available in the Target Community and the other third is unsure. Health providers have some awareness of support services available in the community, but

infrequently reported that the service is available at their facility. There is some recognition of services available at other local facilities but this is also fairly uncommon. While no survivor support service was listed as not available, most of the services listed had more respondents not sure of the availability of that service than the number able to identify where services could be found.



**Figure 4.89.** Support services available what, where, and when – Health provider survey

Survivor Survey data in Table 4.64 show that respondents were most aware of traditional therapies such as support groups, mentoring, and individual counseling. These services, however, were rarely utilized. There was less awareness of complementary therapies and services such as yoga, meditation and acupuncture. Exercise and nutritional programs were the most utilized of all services identified.

**Table 4.64.** Awareness and utilization of support services – Survivor survey

	Support groups	one on one mentoring	Ind. Counseling	Group counseling	Religious Counseling	Financial Support	Fertility Support	Intimacy Support	Legal Counseling	Palliative Care	End of Life Planning
Available	4	4	4	3	1	2	1	1	1	1	1
Used before treatment	1	0	0	0	0	0	0	0	0	0	0
Used during treatment	1	1	0	1	0	2	0	0	0	0	0
Used after treatment	1	0	1	0	0	0	1	0	0	0	0
Especially Valuable	1	0	0	1	0	2	0	0	0	0	0
	Yoga	Massage	Reiki	Meditation	Acupuncture	Exercise Program	Nutritional Support				
Available	0	2	0	0	1	3	3				
Used before treatment	0	0	0	0	0	0	0				
Used during treatment	0	1	0	0	0	1	3				
Used after treatment	0	1	0	0	1	3	0				
Especially Valuable	0	0	0	0	0	1	0				

**Solutions- What Can Be Done**

Survey respondents and key informants all offered ideas for eliminating barriers and closing the gaps in breast health services recognized in the Target Community. Table 4.65 shows seven themes mined from open ended responses in the General Population Survey. Education/awareness, community collaboration, use of media, and reducing costs were seen as the most important factors for eliminating barriers to breast cancer screening.

**Table 4.65.** Eliminating barriers to screening by population – General population survey

	Total Responding	% Education and Awareness	% Mobile Mammograms and better access	% Community Collaboration and Outreach	% Reducing Costs	% Use of Media	% Survivors Sharing Stories	% Changes within the Health System
All Responses	90	13.3	2.2	12.2	10	12.2	7.8	10
Survivors	11	18.2	0	9.1	9.1	0	9.1	9.1
White Women	84	14.3	2.4	13.1	8.3	10.7	8.3	10.7
Age under 40	30	16.7	6.7	23.3	13.3	13.3	6.7	13.3
Age 40 and over	60	11.7	0	6.7	8.3	11.7	8.3	8.3
Under or uninsured	16	18.8	6.3	25.0	12.5	18.8	6.3	6.3
income <50K	57	15.8	3.5	15.8	12.3	17.5	10.5	12.3
income <30K	42	16.7	4.8	19.0	11.9	21.4	9.5	11.9
income <20K	31	16.1	3.2	19.4	9.7	16.1	9.7	9.7

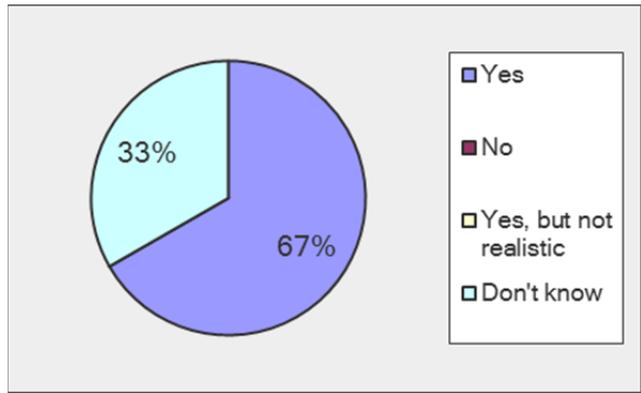
Note: Table is coded to identify each groups top four barriers (red -1, orange-2, yellow-3, and green-4)

Health provider comments in Table 4.66 reflect ideas for eliminating barriers across the entire continuum of care. There is a strong call for better access to service and adequate support especially for those with financial barriers.

**Table 4.66.** Solutions to breast health barriers - Health provider survey

Utilize mobile mammography vans that come to the patients,
Strive to remove barriers and fill gaps wherever possible
Provide transportation / gas cards
Additional help for those at risk of falling between the gaps. May just be able to afford care, but choose not to because they have other more pressing financial needs.
More funding available for all women
More providers volunteering to complete screening exams

Supporting the General Population survey theme of a need for increased collaboration between local agencies, two-thirds of the Health Provider Survey Respondents felt that collaborations would be possible and desirable in an effort to improve breast health for the Southern Rural Region (Figure 4.90). Respondents recognized time, staffing, and funding issues as factors that may need to be overcome in order for this to happen. Distance from and awareness of other organizations were also noted as barriers. The other one-third of health providers responded that they were unsure of the ability to collaborate with other agencies. These respondents included competition for the same patient base as an issue complicating collaboration.



**Figure 4.90.** Collaboration between health systems and other local organizations

Key informants responded positively to the possibility of working collaboratively with other agencies in the community. Eighteen of the nineteen respondents stated a willingness to take on a portion of providing or facilitating breast health services for the population they serve. Collaboration is a common theme in their comments below (Table 4.67) that capture interviewees' ideas on what needs to be done to overcome barriers and close the breast health gaps that prevent equity of service for many in their Target Community.

**Table 4.67.** Thoughts on reducing barriers and closing gaps - Key informant interviews

Increase awareness and share information about available programs for providers and for the public.
Facilitating collaboration between groups.
Collaborative connections to help with finances plus collaborative between agencies using CHWs to help overcome access barriers. Need more support for CHWs to help women right in their communities.
More availability of wrap-around services for things like childcare and transportation.
Need to educate individuals in all walks of life, sometimes multiple times. Don't assume anyone, even professionals or providers, understands breast health info fully -MOST people do not have good information.
Need resources to cover what insurance does not. Need better health insurance literacy.
Both Hispanic/Latina and Black/African-American populations transportation is huge. Need a volunteer transportation service - with bilingual drivers.
Incorporate faith into education to overcome religious barriers. It's ok to pray about breast cancer, Just want people to pray in the doctor's office.
Listen to the people in the community to learn what they need.
Need education beyond 'get a mammogram' to education that says 'what happens when you have breast cancer.'
Need to serve more people with good education. Many barriers are eliminated by education alone.
Transportation options are needed.
Use Community Health Workers to help remove barriers and navigate people to breast health services.
Women must be educated to recognize their risk for breast cancer.
Overcoming barriers is tricky - need health care support and insurance reform to continue to grow. Need to get the word out that insurance is available and preventative screenings can be provided.
Promote the use of mobile mammography. Find ways to make screening access easier.
Translation services broadly available and culturally sensitive.
Increased community outreach. Partnerships with the health department.
Gas cards are a constant on going need for people in Walworth County – these would be the best incentive.
Work with local organizations to get all the services necessary working together.

## **Qualitative Data Findings**

### **Limitations of the Qualitative Data**

Susan G. Komen of Southeast Wisconsin acknowledges the limitations of the data utilized in creating this report. The authors of this report further recognize the potential for human error in working with the data gathered for this Community Profile. The Affiliate makes no claim as to the accuracy of this report and intends it to be used only as a guide to begin to understand the gaps and barriers to breast health services in Southeast Wisconsin.

### **General Limitations and benefits**

- Convenience samples not necessarily representative of the broader public.
- Purposive sampling potentially skewed by respondents and collection sites chosen.
- Poor response rates especially in counties in which the Affiliate has few if any conflicts.

- Small sample sizes unable to accurately represent the broader population.
- Low response rates leading to low confidence levels and higher margins of error.

### ***Key Respondent Interviews limitations***

- No assurance of selecting the “right” informants and the right balance of informants.
- Possible absence of other key respondent with different perspective from same area.
- All respondents are weighted equally which may not accurately reflect the community.
- Difficult to mine, compare, and analyze interview data.
- Interviewer may distort information during transcription.
- Interviewee bias due to a pre-conception of what is wanted/desired by interviewer.

### ***Survivor Forum Limitations***

- Quality of responses dependent on discussion facilitation skills.
- Different levels of participation may inaccurately represent some views over others.
- Difficult to mine and analyze open ended data.
- Difficult to generalize forum data to the larger population.
- Not able to attach data to demographic and socioeconomic variables.
- Possible misrepresentation of participants – non participants may have different ideas.
- Possible misinterpretation of questions by participants.
- Possible misinterpretation of responses in transcription.

### ***Online Surveys***

- No opportunity to clarify questions.
- Limited response rates, hard to get representative sample size.
- Inability to control who responds.
- Unintended or limited responses due to flawed question wording.
- Language/cultural barriers – limited ability to collect data from non-English speaking.
- Literacy barriers –those with limited reading/writing skills under or misrepresented.
- Skewed representation by utilization of Affiliate data base and social media.
- Over representation of individuals aware of Komen and/or breast health messages.
- Distorted answers based on perception of what Affiliate ‘wants’ people to say.
- Small data set of health providers requires 100 percent participation.
- Participant time limitations affect the completeness of in depth surveys.
- Close ended questions – less accurate of individual’s actual opinions.
- Open ended questions – time consuming, subject to interpretation.
- Data mining distortions possible due to the perceptions of those analyzing data and generating data themes.

### ***In-Person Surveys***

- Audience determined by where the Affiliate was allowed to survey, attempts at purposive sampling are limited by ability to access to different collection sites.
- Time and staff limitations.
- Surveyor may inadvertently lead or influence answers.
- Distorted answer based on what respondent thinks the collector wants them to say.
- Open ended questions and longer survey formats require more patience and time which possibly limits answer quality or causes some individuals not to participate.

- Absence of hard to reach populations in survey responses.
- Data mining distortions due to misinterpretation or error in category identification.

### **Public Policy and Insurance Issues – All Target Communities**

Data from every collection source identified insurance and money as a major barriers to breast cancer services across the continuum of care for every Target Community identified by Komen SEWI. Eliminating these barriers is essential for improving screening percentages, facilitating compliance with diagnostic and treatment recommendations, and achieving health equity for all residents in southeast Wisconsin.

Eliminating financial barriers compels a call to action in three areas: increased **availability** of resources, increased **awareness** of resources, and increased **access** to resources. Komen Southeast Wisconsin must be a community leader in the advocacy of policy that directly affects individual access to and affordability of breast health services. This will involve direct Affiliate action in regards to both the continued roll out of the Affordable Care Act and the efficacy of the NBCCEDP Wisconsin Well Woman program.

#### ***Affordable Care Act***

- Support of navigation of women to the marketplace as possible at every point of contact in the CoC.
- Advocacy for the expansion of Medicaid coverage in Wisconsin.
- Increased insurance literacy efforts to ensure women are aware of available screening coverage and understand the limits of this coverage.
- Awareness of populations that cannot or will not utilize the Marketplace and navigation of those individuals to other resources.

#### ***NBCCEDP Wisconsin Well Woman (WWW) Program***

- Continued monitoring of and input to changes to the WWW program structure.
- Careful assessment of the effects of these changes on women and on local breast health programs and initiatives.
- Advocacy for steady or increased funding for the WWW program.
- Advocacy for highest levels of customer service and outreach within the WWW program.
- Dedicated outside outreach efforts to identify new women qualified for WWW services.
- Dedicated outside navigation of new women into the WWW program.

#### ***Komen Southeast Wisconsin Breast Fund***

The Affiliate is compelled by the data to continue to assess its ability to help eliminate financial barriers to screening, diagnostics, and treatment through the Komen Southeast Wisconsin Breast Fund. As of 2015 the fund provides last source coverage for screening and diagnostic services, as well as access coverage for co-pays, deductibles, co-insurance, premiums, medications, transportation, childcare, and numerous breast cancer related supplies.

Elements to consider in relation to the breast health fund:

- Continued funding to help eliminate financial barriers screening and diagnostic services.
- Continued funding to help eliminate financial barriers to breast cancer treatment.
- Regular assessment of items covered through access funding.

- Continued navigation of women to this fund – through the Affiliate, grantees and other sources.
- Continued efforts to recruit and maintain health care providers to the fund.
- Continued efforts to minimize administrative costs related to the fund
- Consideration of efforts to broaden funding sources for the Fund

**Milwaukee County**

<b>Education and Awareness</b>		
<p><b>How are health systems providing breast health education?</b></p>	<p><b>Who needs and who has access to accurate and culturally appropriate breast health and breast cancer information?</b>  <i>(1 - targeted, 2 - somewhat targeted, 3 not targeted, 4 - additional info needed)</i></p>	<p><b>Are current education/outreach programs in the community effective at leading women to breast cancer screenings?</b>  <i>(Scale: 1-never, 2-rarely, 3 - sometimes, 4 - Very Often, 5 - Almost Always)</i></p>
<p><b>Top responses included:</b></p> <ul style="list-style-type: none"> <li>• One on one education</li> <li>• Brochures/Pamphlets</li> <li>• Education within the community</li> <li>• Health Fairs</li> <li>• Education in health facilities</li> <li>• Word of mouth</li> <li>• Small group education</li> </ul>	<ul style="list-style-type: none"> <li>• Low income (1,4)</li> <li>• Under and uninsured (1,4)</li> <li>• Rural Residents (2,4)</li> <li>• Hispanic/Latina (1,4)</li> <li>• Black/African-American (1,4)</li> <li>• API (2,4)</li> <li>• AI/AN (2,4)</li> <li>• Russia(2,4)</li> <li>• LGBT (2,4)</li> <li>• Unemployed (1,4)</li> <li>• Young women (1,4)</li> </ul>	<p>Providers answering:</p> <p>Almost Always – 0%</p> <p>Very Often – 41%</p> <p>Sometimes – 55%</p> <p>Rarely – 0%</p> <p>Never – 0%</p> <p>Unsure – 4%</p> <p>Score: 3.4 or a grade of C-plus</p>
<b>Breast Cancer Screening</b>		
<p><b>Are there gaps between breast cancer screening guidelines and health providers' usage of guidelines?</b></p>	<p><b>Providers reported their health system recommendations:</b></p> <p>Clinical Breast Exams</p> <ul style="list-style-type: none"> <li>• Yearly – 76.5%</li> <li>• Every two years – 11.8%</li> <li>• Start at age 20 – 93.8%</li> </ul> <p>Screening Mammograms</p> <ul style="list-style-type: none"> <li>• Yearly – 88.9%</li> <li>• Every two years – 5.6%</li> <li>• Start at age 40 – 94.4%</li> <li>• Start at age 50 – 5.6%</li> </ul>	<p><b>Guidelines were thought to be followed by:</b></p> <ul style="list-style-type: none"> <li>• All providers – 31.6%</li> <li>• Most providers – 36.8%</li> <li>• Many providers – 10.5%</li> <li>• Not Sure – 21.1%</li> </ul>

Are there gaps between breast cancer screening guidelines and reported frequency of Clinical Breast Exams?	Are there gaps between screening guidelines and reported frequency of screening mammograms?	Does personal perception of breast cancer risk have an impact on screening behavior?
<p><b>Surveyed frequency of Clinical Breast Exams:</b></p> <p><b>Within one year</b></p> <ul style="list-style-type: none"> <li>All women – 73.4%</li> <li>Women &lt;40 – 56.4%</li> <li>Women 40plus – 80.1%</li> <li>Black/African-American women – 71.6 %</li> <li>White women – 77.7 %</li> </ul> <p><b>Cumulative within 2 years or less</b></p> <ul style="list-style-type: none"> <li>All women – 85.5%</li> <li>Women &lt;40 – 65.7%</li> <li>Women 40plus – 93.0%</li> <li>Black/African-American women – 82.8%</li> <li>White women – 89.4%</li> </ul> <p><b>Cumulative within 3 years or less</b></p> <ul style="list-style-type: none"> <li>All women – 86.7%</li> <li>Women &lt;40 – 67.1%</li> <li>Women 40plus – 94.1%</li> <li>Black/African-American women – 83.3%</li> <li>White women – 90.4%</li> </ul> <p><b>Longer than 3 years or never</b></p> <ul style="list-style-type: none"> <li>All women – 13.3%</li> <li>Women &lt;40 – 32.9%</li> <li>Women 40plus - 5.9%</li> <li>Black/African-American women – 15.7%</li> <li>White women – 9.7%</li> </ul>	<p><b>Surveyed frequency of Screening Mammograms:</b></p> <p><b>Within 1 year</b></p> <ul style="list-style-type: none"> <li>All women - 76.3%</li> <li>Black/African-American women – 72.6%</li> <li>White women – 87.8%</li> </ul> <p><b>Within 2 years</b></p> <ul style="list-style-type: none"> <li>All women – 86.5%</li> <li>Black/African-American women – 83.1%</li> <li>White women – 91.7%</li> </ul> <p><b>Longer than 2 years or never</b></p> <ul style="list-style-type: none"> <li>All women – 13.4%</li> <li>Black/African-American women – 16.8%</li> <li>White women – 7.3%</li> <li>Income &lt;\$50K – 17.4%</li> </ul>	<p><b>General Population Survey</b></p> <ul style="list-style-type: none"> <li>don't feel at risk - 50%</li> <li>do feel at risk – 50.0%</li> </ul> <p><i>Had a screening mammograms within the past year( Age 50 to 69)</i></p> <ul style="list-style-type: none"> <li>Feel at risk- 65.5%</li> <li>Don't feel at risk – 35.4%</li> </ul> <p><i>Had a mammogram more than 2 years ago or never (Age 50 to 69)</i></p> <ul style="list-style-type: none"> <li>Feel at risk – 33.3%</li> <li>Don't feel at risk – 66.7%</li> </ul> <p><b>Survivor Survey – feelings <u>prior</u> to diagnosis</b></p> <ul style="list-style-type: none"> <li>don't feel at risk – 60.0%</li> <li>do feel at risk – 40.0%</li> </ul> <p>The majority of survivors who rarely or never had mammograms before their diagnosis did not feel at risk of breast cancer.</p> <p>Two third of survivors diagnosed at stage 1 felt at risk of breast cancer before their diagnosis.</p> <p>Only one fifth of survivors diagnosed at stage 2 or 3 felt at risk of breast cancer prior to their diagnosis.</p> <p>Nearly half of survivors surveyed <i>did feel informed</i> about breast cancer and also <i>did not feel at risk</i> of breast cancer before their diagnosis.</p>

<b>Barriers</b>		
<b>What factors prevent, discourage or inhibit women from accessing and/or following through with...</b>		
<b>...breast cancer screenings?</b>	<b>...breast cancer diagnostic services?</b>	<b>...breast cancer treatment services?</b>
<p><b>Top barriers identified by:</b></p> <p>Health Provider Survey</p> <ul style="list-style-type: none"> <li>• Education, Insurance, money, fear</li> </ul> <p>General Population Survey</p> <ul style="list-style-type: none"> <li>• Insurance, fear, time, money</li> </ul> <p>Key Informant Interviews</p> <ul style="list-style-type: none"> <li>• Cultural, education, fear, insurance</li> </ul> <p>Survivor Survey</p> <ul style="list-style-type: none"> <li>• Insurance, money, fear, education</li> </ul> <p>Survivor Forum</p> <ul style="list-style-type: none"> <li>• Fear/Giving up, education, denial</li> </ul>	<p><b>Top barriers identified by:</b></p> <p>Health Provider Survey</p> <ul style="list-style-type: none"> <li>• Insurance/money, fear, education, cultural</li> </ul> <p>Key Informant Interviews</p> <ul style="list-style-type: none"> <li>• Education, fear, money, cultural</li> </ul> <p>Survivor Forum</p> <ul style="list-style-type: none"> <li>• Fear/giving up, insurance/money, health system, education</li> </ul>	<p><b>Top barriers identified by:</b></p> <p>Health Provider Survey</p> <ul style="list-style-type: none"> <li>• Insurance/money, fear, education, personal</li> </ul> <p>Key Informant Interviews</p> <ul style="list-style-type: none"> <li>• Money, transportation, fear, support</li> </ul> <p>Survivor Forum</p> <ul style="list-style-type: none"> <li>• Homelife, fear, insurance/money, transportation</li> </ul>
<b>Are there socioeconomic and/or demographic indicators tied to identified barriers?</b>	<b>Are health providers able to provide access to timely coordinated care across the continuum of care for breast health services?</b>	
<p>Black/African-American women identified barriers more frequently than White women.</p> <p>Key informants stressed the impact of personal and systemic cultural barriers at every point in the continuum of care individuals outside of the cultural mainstream.</p> <p>Hispanic/Latina participants in the Conversation for the Cure program introduced two additional screening barriers – ‘no symptoms’ and ‘my doctor did not tell me to get screened.’</p> <p>Individuals who are under or uninsured are very likely to have difficulty accessing care, especially diagnostic and treatment services.</p> <p>Refer to barrier tables for more information on specific populations.</p>	<p>Providers were confident that the majority of their breast health services were being offered efficiently and well within the Center for Disease Control guidelines.</p> <p>(Scale: 5 =always, 4= usually, 3 = often, 2 = equals rarely, 1 = never)</p> <p>Referral to Mammogram in 90 days: Score 4.44</p> <p>Mammogram to diagnosis 60 days: Score 4.63</p> <p>Diagnosis to treatment 60 days Score 4.50</p>	<p>A handful of survivors reported delays to breast cancer diagnostic services, but a full quarter of survivors reported delays to treatment.</p> <ul style="list-style-type: none"> <li>• Half = treatment complications</li> <li>• Quarter = insurance/money issues</li> <li>• Quarter = home, transportation and health system</li> </ul>

Survivorship		
<p><b>What can providers reveal about the availability of survivor support services?</b></p>	<p><b>Most commonly noted services:</b></p> <ul style="list-style-type: none"> <li>• Patient navigation</li> <li>• Financial Assistance w/ BC expenses</li> <li>• Education</li> </ul> <p><b>Least identified services included:</b></p> <ul style="list-style-type: none"> <li>• Financial Assistance for living expenses impacted by breast cancer</li> <li>• Mentors</li> <li>• Transportation</li> <li>• Complementary Therapies</li> </ul>	<p>Every support service identified was reported to be available during diagnosis, as well as during and after breast cancer treatment.</p> <p>In twenty out of twenty four survivor support services identified, there were providers stating they were unsure if that support service was available.</p>
<p><b>Do breast cancer survivors feel a need to talk about their breast cancer and whom do they choose to speak with?</b></p>	<p><b>How do survivors find out about support services?</b></p>	
<p><b>Top responses include:</b></p> <ul style="list-style-type: none"> <li>• Friends and Family</li> <li>• Medical Team</li> <li>• Co-Workers</li> <li>• Other patients</li> <li>• Acquaintances</li> </ul>	<p><b>Top responses include:</b></p> <ul style="list-style-type: none"> <li>• Medical Team 63.0%</li> <li>• Brochures 37.0%</li> <li>• Friends/Family 32.1%</li> <li>• Other patients 19.8%</li> </ul>	
<p><b>What support services are survivors aware of, how often do they utilize them, and which services are seen as most valuable?</b></p>	<p><b>Most Aware of:</b></p> <ul style="list-style-type: none"> <li>• Support Groups</li> <li>• Individual Counseling</li> <li>• Mentoring</li> <li>• Group Counseling</li> <li>• Nutritional Programs</li> <li>• Religious Counseling</li> </ul> <p><b>Most Utilized:</b></p> <ul style="list-style-type: none"> <li>• Support Groups</li> <li>• Mentoring</li> <li>• Exercise Programs</li> <li>• Nutrition Programs</li> </ul>	<p><b>Most Valued:</b></p> <ul style="list-style-type: none"> <li>• Mentoring</li> <li>• Exercise Program</li> </ul> <p>No services were recognized by more than half of those surveyed</p> <p>No service was utilized by more than half of those aware of them, and most were utilized by very few survivors</p> <p>Complementary therapies were very underutilized by survivors.</p>

Solutions		
<p><b>What can be done to reduce the gaps and barriers identified?</b></p>	<p><b>Top responses from Survivor Forum for overcoming...</b></p> <p>Screening Barriers:</p> <ul style="list-style-type: none"> <li>Education, Sharing Stories</li> </ul> <p>Diagnostic Barriers:</p> <ul style="list-style-type: none"> <li>Education, Personal Support</li> </ul> <p>Treatment Barriers:</p> <ul style="list-style-type: none"> <li>Personal Support, Health System Changes, Education</li> </ul> <p>Forum Participants emphasized a need to shift the health system paradigm to a community based, prevention focused model of wellness in order to truly achieve equal access to and delivery of breast health services for everyone.</p>	<p><b>Key Informant Interviewees ideas included:</b></p> <ul style="list-style-type: none"> <li>Utilization of the Community Health Worker Model</li> <li>Prioritizing cultural accessibility by diversifying staff, assessing materials, inviting input from other cultures in determining how the health system should work</li> <li>Make screening and prevention less complicated, normalize screening</li> <li>More collaboration both between health systems and with other organizations</li> <li>Increased public and private funding</li> </ul>
<p><b>General Population Suggestions:</b></p> <ul style="list-style-type: none"> <li>Increased Education</li> <li>Community Collaboration</li> <li>Better access including Mobile Mammography</li> </ul> <p><b>Top Health Provider Suggestions:</b></p> <ul style="list-style-type: none"> <li>More Education and CBEs out in the community.</li> <li>Increased Mobile Mammography and on-site screening services.</li> <li>More personalized navigation to funding and to services.</li> <li>Affordable insurance for all – extra help for those who fall just above funding income guidelines.</li> <li>Provide transportation</li> </ul>		

## Northern Rural Region

Education and Awareness		
<p><b>How are health systems providing breast health education?</b></p>	<p><b>Who needs and who has access to accurate and culturally appropriate breast health and breast cancer information?</b></p> <p><i>(1 - targeted, 2 - somewhat targeted, 3 not targeted, 4 - additional info needed)</i></p>	<p><b>Are current education/outreach programs in the community effective at leading women to breast cancer screenings?</b></p> <p><i>(Scale: 1-never, 2-rarely, 3 - sometimes, 4 - Very Often, 5 - Almost Always)</i></p>
<p><b>Top responses included:</b></p> <ul style="list-style-type: none"> <li>One on one education</li> <li>Brochures/Pamphlets</li> <li>Friends/Word of Mouth</li> <li>Websites</li> </ul>	<p><b>Health Providers recognized:</b></p> <ul style="list-style-type: none"> <li>Low income (3,4)</li> <li>Under and uninsured (1,4)</li> <li>Rural Residents (2,4)</li> <li>Hispanic/Latina (3,4)</li> <li>Unemployed (1,4)</li> </ul> <p>Key Informants added Black/African-American, AIAN, API, LGBT populations as groups not often targeted and in need of additional resources.</p>	<p>Providers answering:</p> <p>Almost Always – 0%</p> <p>Very Often – 80%</p> <p>Sometimes – 20%</p> <p>Rarely – 0%</p> <p>Never – 0%</p> <p>Unsure – 0%</p> <p>Score: 3.8 or a grade of B-Minus</p>

Breast Cancer Screening		
<p><b>Are there gaps between breast cancer screening guidelines and health providers' usage of guidelines?</b></p>	<p><b>Providers reported their health system recommendations:</b></p> <p>Clinical Breast Exams</p> <ul style="list-style-type: none"> <li>Yearly – 66.7%</li> <li>Every three years – 33.3%</li> <li>Start at age 20 – 100.0%</li> </ul> <p>Screening Mammograms</p> <ul style="list-style-type: none"> <li>Yearly – 100.0%</li> <li>Start at age 40 – 67.7%</li> <li>Start at age 50 – 33.3%</li> </ul>	<p><b>Guidelines were thought to be followed by:</b></p> <ul style="list-style-type: none"> <li>All providers – 33.3%</li> <li>Most providers – 33.3%</li> <li>Many providers – 33.4%</li> </ul>
<p><b>Are there gaps between breast cancer screening guidelines and reported frequency of Clinical Breast Exams?</b></p>	<p><b>Are there gaps between screening guidelines and reported frequency of screening mammograms?</b></p>	<p><b>Does personal perception of breast cancer risk have an impact on screening behavior?</b></p>
<p><b>Surveyed frequency of Clinical Breast Exams:</b></p> <p><b>Within one year</b></p> <ul style="list-style-type: none"> <li>All women – 80.6%</li> <li>Women &lt;40 – 83.3%</li> <li>Women 40plus – 80.0%</li> <li>Under Insured – 42.9%</li> </ul> <p><b>Cumulative within 2 years or less</b></p> <ul style="list-style-type: none"> <li>All women – 90.3%</li> <li>Women &lt;40 – 83.3%</li> <li>Women 40plus – 92.0%</li> <li>Under Insured – 71.5%</li> </ul> <p><b>Longer than 3 years or never</b></p> <ul style="list-style-type: none"> <li>All women – 9.7%</li> <li>Women &lt;40 – 16.7%</li> <li>Women 40plus – 8.0%</li> <li>Under Insured – 28.6%</li> </ul>	<p><b>Surveyed frequency of Screening Mammograms:</b></p> <p><b>Within 1 year</b></p> <ul style="list-style-type: none"> <li>All women – 72.0%</li> <li>Underinsured – 71.4%</li> </ul> <p><b>Cumulative Within 2 years</b></p> <ul style="list-style-type: none"> <li>All women – 92.0%</li> <li>Under Insured – 100%</li> </ul> <p><b>Longer than 2 years or never</b></p> <ul style="list-style-type: none"> <li>All women – 8.0%</li> <li>Under Insured - 0</li> </ul> <p><b>Very different results were found for the frequency of screening mammograms prior to diagnosis reported by survivors:</b></p> <ul style="list-style-type: none"> <li>Yearly – 62.5%</li> <li>Every Two Years – 8.3%</li> <li>Occasionally – 4.2%</li> <li>Never – 25.0%</li> </ul>	<p><b>General Population Survey</b></p> <ul style="list-style-type: none"> <li>don't feel at risk – 42.3%</li> <li>do feel at risk – 57.6%</li> </ul> <p>Of those who had a screening mammograms within the past year( Age 40 to 49)</p> <ul style="list-style-type: none"> <li>Feel at risk- 100.0%</li> <li>Don't feel at risk – 0%</li> </ul> <p>Had a mammogram within the past 2 years (Age 40 to 49)</p> <ul style="list-style-type: none"> <li>Feel at risk – 25.0%</li> <li>Don't feel at risk – 75.0%</li> </ul> <p><b>Survivor Survey – feelings prior to diagnosis</b></p> <ul style="list-style-type: none"> <li>don't feel at risk – 62.5%</li> <li>do feel at risk – 37.5%</li> </ul> <p>The majority of survivors who rarely or never had mammograms before their diagnosis more than 80 percent <i>did not</i> feel at risk of breast cancer.</p> <p>Percent of survivors who <i>did not feel at risk</i> of breast cancer prior to their diagnosis at :</p> <ul style="list-style-type: none"> <li>Stage 1 – 44.4%</li> <li>Stage 2 – 71.4%</li> <li>Stage 3 – 83.3%</li> </ul> <p>More than half of survivors <i>did feel informed</i> about breast cancer and also <i>did not feel at risk</i> of breast cancer before their diagnosis.</p>

Barriers		
What factors prevent, discourage or inhibit women from accessing and/or following through with...		
...breast cancer screenings?	...breast cancer diagnostic services?	...breast cancer treatment services?
<p><b>Top barriers identified by:</b></p> <p>Health Provider Survey</p> <ul style="list-style-type: none"> <li>Insurance/money, access, fear, education</li> </ul> <p>Key Informant Interviews</p> <ul style="list-style-type: none"> <li>Cultural, money, insurance, fear</li> </ul> <p>Survivor Forum</p> <ul style="list-style-type: none"> <li>Fear/Giving up, education, denial</li> </ul>	<p><b>Top barriers identified by:</b></p> <p>Health Provider Survey</p> <ul style="list-style-type: none"> <li>Insurance/money, fear, time, distance, childcare</li> </ul> <p>Key Informant Interviews</p> <ul style="list-style-type: none"> <li>Education, money, support</li> </ul> <p>Survivor Forum</p> <ul style="list-style-type: none"> <li>Fear/giving up, insurance/money, health system, education</li> </ul>	<p><b>Top barriers identified by:</b></p> <p>Health Provider Survey</p> <ul style="list-style-type: none"> <li>Insurance/money, fear, time, distance, childcare</li> </ul> <p>Key Informant Interviews</p> <ul style="list-style-type: none"> <li>Money, transportation, time</li> </ul> <p>Survivor Forum</p> <ul style="list-style-type: none"> <li>Homelife, fear, insurance/money, transportation</li> </ul>
<p><b>Are there socioeconomic and/or demographic indicators tied to identified barriers?</b></p>	<p><b>Are health providers able to provide access to timely coordinated care across the continuum of care for breast health services?</b></p>	
<p>Health literacy is an especially large barriers for individuals who are linguistically isolated, but also for many individuals the further along the CoC they have needs.</p> <p>Even when able to receive treatment, individuals with vulnerable life situations lack support structures to do so successfully.</p> <p>Inadequate insurance in the NRR is impacting low income/ under insured women's decision to get bc screening.</p> <p>Transportation, especially to treatment services, is a barrier for nearly all recognized populations in the NRR.</p>	<p>Every surveyed providers was confident that the majority of their breast health services were being offered efficiently and well within the Center for Disease Control guidelines:</p> <ul style="list-style-type: none"> <li>Referral to Mammogram in 90 days</li> <li>Mammogram to diagnosis 60 days</li> <li>Diagnosis to treatment 60 days</li> </ul>	<p>About a fifth of survivors reported delays in the delivery of diagnostic and treatment services. The majority of delays were attributed to the health system.</p>
Survivorship		
<p><b>What can providers reveal about the availability of survivor support services?</b></p>	<p><b>Most commonly noted service:</b></p> <ul style="list-style-type: none"> <li>Patient Navigation</li> <li>Financial Assistance for bc services</li> <li>End of life care</li> </ul> <p><b>Least identified services included:</b></p> <ul style="list-style-type: none"> <li>Transportation</li> <li>Family Counseling</li> <li>Intimacy and Fertility Support</li> </ul>	<p>While a range of support services were identified along the continuum of care, no service was reported by more than a third of providers</p> <p>For the majority of survivor support services identified, there were providers that stated they were unsure if that support service was available.</p>

<p><b>Do breast cancer survivors feel a need to talk about their breast cancer and whom do they choose to speak with?</b></p>	<p><b>How do survivors find out about support services?</b></p>	
<p><b>Top responses include:</b></p> <ul style="list-style-type: none"> <li>• Family/Friends – 48.0%</li> <li>• Co-workers – 48.0%</li> <li>• Acquaintances – 32.0%</li> <li>• Other Patients – 28.0%</li> </ul>	<p><b>Top responses include:</b></p> <ul style="list-style-type: none"> <li>• Medical Team – 48.0%</li> <li>• Other Patients – 20.0%</li> <li>• Family/Friends – 20.0%</li> <li>• Brochures – 20.0%</li> </ul>	
<p><b>What support services are survivors aware of, how often do they utilize them, and which services are seen as most valuable?</b></p>	<p><b>Most Aware of:</b></p> <ul style="list-style-type: none"> <li>• Support Groups</li> <li>• Mentoring</li> <li>• Individual Counseling</li> </ul> <p><b>Most Utilized:</b></p> <ul style="list-style-type: none"> <li>• Support Groups</li> <li>• Nutritional Programs</li> <li>• Financial Counseling</li> <li>• Exercise Programs</li> </ul> <p><b>Most Valued:</b></p> <ul style="list-style-type: none"> <li>• Support Groups</li> <li>• Mentoring</li> <li>• Individual counseling</li> <li>• Exercise</li> <li>• Nutrition</li> </ul>	<p>Only half surveyed knew about support services and about a quarter were aware of other services 'most known'. Very few survivors were aware of the majority of survivor support services.</p> <p>The majority of those surveyed did not experience barriers to survivor support services, but an extremely small number of survivors reported utilizing any services.</p> <p>Complementary therapies were very underutilized with only 2 reports of use (1 yoga and 1 acupuncture)</p> <p>Nutritional support had the highest number of those aware of the service actually use it.</p>
<p><b>Solutions</b></p>		
<p><b>What can be done to reduce the gaps and barriers identified?</b></p>	<p><b>Top responses from Survivor Forum for overcoming...</b></p> <p>Screening Barriers:</p> <ul style="list-style-type: none"> <li>• Education, Sharing Stories</li> </ul> <p>Diagnostic Barriers:</p> <ul style="list-style-type: none"> <li>• Education, Personal Support</li> </ul> <p>Treatment Barriers:</p> <ul style="list-style-type: none"> <li>• Personal Support, Health System Changes, Education</li> </ul> <p>Forum Participants emphasized a need to shift the health system paradigm to a community based, prevention focused model of wellness in order to truly achieve equal access to and delivery of breast health services for everyone.</p>	<p><b>Key Informant Interviewees ideas included:</b></p> <ul style="list-style-type: none"> <li>• Increased education on bc facts, health literacy, and on access to services</li> <li>• Provide truly bilingual culturally sensitive services at all points of breast health services</li> <li>• Expand transportation and financial options</li> <li>• Utilize Community Health Workers</li> <li>• More collaboration both between health systems and with other organizations</li> <li>• Take a more wholistic approach to health care</li> <li>• Individualize service</li> <li>• Help rural residents with more access points including mobile mammography</li> </ul>
<p><b>Health providers reported many ways they are trying to reduce barriers. Methods cited most frequently were:</b></p> <p><b>Screening-</b></p> <ul style="list-style-type: none"> <li>• Better customer service</li> <li>• Aesthetic improvements</li> </ul> <p><b>Diagnostic and Treatment –</b></p> <ul style="list-style-type: none"> <li>• Education</li> <li>• Financial Counseling</li> <li>• Translation Services</li> <li>• Patient Follow up</li> <li>• Better customer service</li> <li>• Aesthetic improvements</li> </ul> <p><b>Just Treatment</b></p> <ul style="list-style-type: none"> <li>• Navigation</li> <li>• Pain/symptom management-</li> <li>• Education</li> </ul>		

**Racine County**

<b>Education and Awareness</b>		
<p><b>How are health systems providing breast health education?</b></p>	<p><b>Who needs and who has access to accurate and culturally appropriate breast health and breast cancer information?</b>  <i>(1 - targeted, 2 - somewhat targeted, 3 not targeted, 4 - additional info needed)</i></p>	<p><b>Are current education/outreach programs in the community effective at leading women to breast cancer screenings?</b>  <i>(Scale: 1-never, 2-rarely, 3 - sometimes, 4 - Very Often, 5 - Almost Always)</i></p>
<p>Top responses included:</p> <ul style="list-style-type: none"> <li>• One on one education</li> <li>• Health Fairs</li> <li>• Education in the Community</li> <li>• Brochures/Pamphlets</li> <li>• Word of Mouth</li> <li>• Education within Facility</li> <li>• Website</li> </ul>	<ul style="list-style-type: none"> <li>• Low income (1,4)</li> <li>• Under and uninsured (1,4)</li> <li>• Rural Residents (1,4)</li> <li>• Hispanic/Latina (1,4)</li> <li>• Black/African-American (1,4)</li> <li>• API (2,4)</li> <li>• AI/AN (2,4)</li> <li>• Russia(2,4)</li> <li>• LGBT (2,4)</li> <li>• Unemployed (1,4)</li> <li>• Young women (1,4)</li> </ul> <p>Key respondents added disabled individual as needing services</p>	<p><b>Providers answering:</b></p> <p>Almost Always – 0%            Very Often – 35.4%            Sometimes – 52.9%            Rarely – 5.9%            Never – 0%            Unsure – 5.9%</p> <p>Score: 3.3 or a grade of C-plus</p>
<b>Breast Cancer Screening</b>		
<p><b>Are there gaps between breast cancer screening guidelines and health providers' usage of guidelines?</b></p>	<p><b>Providers reported their health system recommendations:</b></p> <p>Clinical Breast Exams</p> <ul style="list-style-type: none"> <li>• Yearly – 83.4%</li> <li>• Every three years – 16.6%</li> <li>• Start at age 20 – 87.5%</li> <li>• Start at age 30 – 12.5%</li> </ul> <p>Screening Mammograms</p> <ul style="list-style-type: none"> <li>• Yearly – 83.4%</li> <li>• Every two years – 16.6%</li> <li>• Start at age 30 – 11.1%</li> <li>• Start at age 40 – 88.9%</li> </ul>	<p><b>Guidelines were thought to be followed by:</b></p> <ul style="list-style-type: none"> <li>• All providers - 15.4%</li> <li>• Most providers - 53.8%</li> <li>• Many providers - 30.8%</li> </ul>

Are there gaps between breast cancer screening guidelines and reported frequency of Clinical Breast Exams?	Are there gaps between screening guidelines and reported frequency of screening mammograms?	Does personal perception of breast cancer risk have an impact on screening behavior?
<p><b>Surveyed frequency of Clinical Breast Exams:</b></p> <p><b>Within one year</b></p> <ul style="list-style-type: none"> <li>All women – 77.8%</li> </ul> <p><b>Cumulative within 2 years or less</b></p> <ul style="list-style-type: none"> <li>All women – 88.9%</li> </ul> <p><b>Cumulative within 3 years or less</b></p> <ul style="list-style-type: none"> <li>All women – 100.0%</li> </ul>	<p><b>Surveyed frequency of Screening Mammograms:</b></p> <p><b>Within 1 year</b></p> <ul style="list-style-type: none"> <li>All women - 83.0%</li> </ul> <p><b>Cumulative within 2 years</b></p> <ul style="list-style-type: none"> <li>All women – 100.0%</li> </ul> <p><b>Longer than 2 years or never</b></p> <ul style="list-style-type: none"> <li>All women – 0%</li> </ul> <p><b>Frequency of screening mammograms for survivors prior to diagnosis:</b></p> <p><b>Within 1 year</b></p> <ul style="list-style-type: none"> <li>All women - 75.0%</li> </ul> <p><b>Cumulative within 2 years</b></p> <ul style="list-style-type: none"> <li>All women – 75.0.0%</li> </ul> <p><b>Longer than 2 years or never</b></p> <ul style="list-style-type: none"> <li>All women – 25.0%</li> </ul>	<p><b>General Population Survey</b></p> <ul style="list-style-type: none"> <li>don't feel at risk – 22.2%</li> <li>do feel at risk – 77.8%</li> </ul> <p>Very different results were found in the Survivor Survey –</p> <p><b>Feelings prior to diagnosis</b></p> <ul style="list-style-type: none"> <li>don't feel at risk – 87.6%</li> <li>do feel at risk – 12.4%</li> </ul> <p>Three quarters of survivors surveyed <i>did feel informed</i> about breast cancer and also did <i>not feel at risk</i> of breast cancer before their diagnosis.</p> <p>Key informant working in breast health education cited a disconnect between being exposed to breast cancer information and truly understanding the message.</p>

<b>Barriers</b>		
<b>What factors prevent, discourage or inhibit women from accessing and/or following through with...</b>		
...breast cancer screenings?	...breast cancer diagnostic services?	...breast cancer treatment services?
<p><b>Top barriers identified by:</b></p> <p>Health Provider Survey</p> <ul style="list-style-type: none"> <li>Money/insurance, fear, cultural</li> </ul> <p>General Population Survey</p> <ul style="list-style-type: none"> <li>Money/insurance, cultural</li> </ul> <p>Key Informant Interviews</p> <ul style="list-style-type: none"> <li>Education, insurance, cultural, transportation</li> </ul> <p>Survivor Survey</p> <ul style="list-style-type: none"> <li>Insurance, pain, cultural</li> </ul> <p>Survivor Forum</p> <ul style="list-style-type: none"> <li>Fear/Giving up, education, denial</li> </ul>	<p><b>Top barriers identified by:</b></p> <p>Health Provider Survey</p> <ul style="list-style-type: none"> <li>Insurance/Money, fear, cultural, health system</li> </ul> <p>Key Informant Interviews</p> <ul style="list-style-type: none"> <li>Education, fear, money, support</li> </ul> <p>Survivor Forum</p> <ul style="list-style-type: none"> <li>Fear/giving up, insurance/money, health system, education</li> </ul>	<p><b>Top barriers identified by:</b></p> <p>Health Provider Survey</p> <ul style="list-style-type: none"> <li>Fear, Insurance/Money, cultural, personal</li> </ul> <p>Key Informant Interviews</p> <ul style="list-style-type: none"> <li>Money, time, fear, transportation</li> </ul> <p>Survivor Forum</p> <ul style="list-style-type: none"> <li>Homelife, fear, insurance/money, transportation</li> </ul>

<p><b>Are there socioeconomic and/or demographic indicators tied to identified barriers?</b></p>	<p><b>Are health providers able to provide access to timely coordinated care across the continuum of care for breast health services?</b></p>	
<p>Key informants stressed the impact of personal and systemic cultural barriers at every point in the continuum of care individuals outside of the cultural mainstream.</p> <p>Transportation barriers to treatment services were particularly impactful for Hispanic/Latina, Black/African-American, Low Income, and the inadequately insured.</p> <p>Low income residents and those with inadequate insurance coverage are vulnerable to barriers caused by lack of money for everyday expenses when undergoing diagnostic and treatment services. These barriers are also experienced by those without strong support systems in place.</p> <p>Those with incomes just above financial assistance levels are falling through the cracks.</p> <p>Refer to barrier tables for more information on specific populations.</p>	<p>Racine County providers felt their breast health services were either 'always' or 'usually' offered efficiently and well within the Center for Disease Control guidelines.</p> <p>(Scale: 5 =always, 4= usually, 3 = often, 2 = equals rarely, 1 = never)</p> <p>Referral to Mammogram in 90 days: Score 4.44</p> <p>Mammogram to diagnosis 60 days: Score 4.63</p> <p>Diagnosis to treatment 60 days Score 4.50</p>	
<p><b>Survivorship</b></p>		
<p><b>What can providers reveal about the availability of survivor support services?</b></p>	<p><b>Most commonly noted services:</b></p> <ul style="list-style-type: none"> <li>• Patient Navigation</li> <li>• Emotional and Family Counseling</li> <li>• Resource Centers</li> </ul> <p><b>Least identified services included:</b></p> <ul style="list-style-type: none"> <li>• Complementary Therapies</li> <li>• Help with living expenses</li> <li>• Transportation</li> <li>• Mentoring</li> </ul>	<p>Every support service identified was reported to be available during diagnosis, as well as during and after breast cancer treatment.</p> <p>In eighteen out of twenty four survivor support services identified, there were providers stating they were unsure if that support service was available.</p>
<p><b>Do breast cancer survivors feel a need to talk about their breast cancer and whom do they choose to speak with?</b></p>	<p><b>How do survivors find out about support services?</b></p>	
<p><b>Top responses include:</b></p> <ul style="list-style-type: none"> <li>• Family and friends – 75.0%</li> <li>• Medical Team – 62.5%</li> <li>• Co-workers – 37.5%</li> </ul>	<p><b>Top responses include:</b></p> <ul style="list-style-type: none"> <li>• Medical Team - 87.5%</li> <li>• Brochures - 37.5%</li> <li>• Family or friend - 25.0%</li> <li>• Media – 25.0%</li> </ul>	

<p><b>What support services are survivors aware of, how often do they utilize them, and which services are seen as most valuable?</b></p>	<p>This area needs more investigation</p> <p>Survivor Support Services were vastly under recognized and under utilized by those survivors surveyed.</p> <p>Only one survivor reported experiencing barriers to support services. This individual was also the only respondent to state that she was aware of survivor services and the only one to utilize any of them. The services she utilized were not in Racine County.</p>
---	--

**Solutions**

<p><b>What can be done to reduce the gaps and barriers identified?</b></p>	<p><b>Top responses from Survivor Forum for overcoming...</b></p> <p>Screening Barriers:</p> <ul style="list-style-type: none"> <li>• Education, Sharing Stories</li> </ul> <p>Diagnostic Barriers:</p> <ul style="list-style-type: none"> <li>• Education, Personal Support</li> </ul> <p>Treatment Barriers:</p> <ul style="list-style-type: none"> <li>• Personal Support, Health System Changes, Education</li> </ul> <p>Forum Participants emphasized a need to shift the health system paradigm to a community based, prevention focused model of wellness in order to truly achieve equal access to and delivery of breast health services for everyone.</p>	<p><b>Key Informant Interviewees ideas included:</b></p> <ul style="list-style-type: none"> <li>• Provide mobile mammography options especially for rural residents</li> <li>• Increased culturally sensitive materials and services</li> <li>• Normalize breast cancer screening</li> <li>• More collaboration both between health systems and with other organizations</li> <li>• Utilize more Community Health Workers and wrap around services</li> <li>• Increased assistance programs for transportation and financial help</li> <li>• Focus on specifically targeting the County's underserved residents</li> </ul>
<p><b>Top Health Provider Suggestions:</b></p> <ul style="list-style-type: none"> <li>• Target information to Hispanic/Latina residents</li> <li>• Clarify confusing screening guidelines</li> <li>• Provide more information on treatment options</li> <li>• More outreach and education to area businesses and through local schools and churches</li> <li>• Additional outreach programs such as 'Screening Days'</li> <li>• Better identification of risk</li> </ul>		

**Waukesha County**

<b>Education and Awareness</b>		
<p><b>How are health systems providing breast health education?</b></p>	<p><b>Who needs and who has access to accurate and culturally appropriate breast health and breast cancer information?</b>  <i>(1 - targeted, 2 - somewhat targeted, 3 not targeted, 4 - additional info needed)</i></p>	<p><b>Are current education/outreach programs in the community effective at leading women to breast cancer screenings?</b>  <i>(Scale: 1-never, 2-rarely, 3 - sometimes, 4 - Very Often, 5 - Almost Always)</i></p>
<p><b>Top responses included:</b></p> <ul style="list-style-type: none"> <li>• Brochures/Pamphlets</li> <li>• Health Fairs</li> <li>• One on one education</li> <li>• Education in the Community</li> <li>• Websites</li> </ul>	<ul style="list-style-type: none"> <li>• Low income (1,4)</li> <li>• Under and uninsured (1,4)</li> <li>• Rural Residents (2,4)</li> <li>• Hispanic/Latina (1,4)</li> <li>• Black/African-American (1,4)</li> <li>• API (3,4)</li> <li>• Hmong (3,4)</li> <li>• AI/AN (3,4)</li> <li>• Russia(3,4)</li> <li>• LGBT (2,4)</li> <li>• Unemployed (1,4)</li> <li>• Young women (1,4)</li> </ul> <p>Key informants added mentally and physically disabled, the elderly, and those in transitional living situations as populations in need of targeted breast health services and information.</p>	<p>Providers answering:                      Almost Always – 0%                      Very Often – 27.3%                      Sometimes – 63.6%                      Rarely – 0%                      Never – 0%                      Unsure – 9.1%</p> <p>Score: 3.3 or a grade of C-plus</p>
<b>Breast Cancer Screening</b>		
<p><b>Are there gaps between breast cancer screening guidelines and health providers' usage of guidelines?</b></p>	<p><b>Providers reported their health system recommendations:</b></p> <p>Clinical Breast Exams</p> <ul style="list-style-type: none"> <li>• Yearly – 60.0%%</li> <li>• Other/Don't know-40.0%</li> <li>• Start at age 20 – 71.4%%</li> <li>• Start at age 30 – 14.3%</li> </ul> <p>Screening Mammograms</p> <ul style="list-style-type: none"> <li>• Yearly – 100.0%</li> <li>• Start at age 40 – 100.0%</li> </ul>	<p><b>Guidelines were thought to be followed by:</b></p> <ul style="list-style-type: none"> <li>• All providers – 0%</li> <li>• Most providers – 62.0%</li> <li>• Many providers – 38.0%</li> </ul>

Are there gaps between breast cancer screening guidelines and reported frequency of Clinical Breast Exams?	Are there gaps between screening guidelines and reported frequency of screening mammograms?	Does personal perception of breast cancer risk have an impact on screening behavior?
<p><b>Surveyed frequency of Clinical Breast Exams. There was consistency for women of all ages:</b></p> <ul style="list-style-type: none"> <li>• Within one year – 69.4%</li> <li>• Cumulative within 2 years or less – 83.5%</li> <li>• Cumulative within 3 years or less – 89.4%</li> <li>• Longer than 3 years or never – 10.6%</li> </ul> <p><b>Lower incomes correlated with less frequent CBEs</b></p> <p>Percent of women who have waited more than 3 years or never had a CBE:</p> <ul style="list-style-type: none"> <li>• Income &lt; \$50 K – 25.9%</li> <li>• Income &lt; \$30 K – 36.4%</li> <li>• Income &lt; \$20 K - 33.3 %</li> </ul>	<p><b>Surveyed frequency of Screening Mammograms:</b></p> <ul style="list-style-type: none"> <li>• Within 1 year – 72.7%</li> <li>• Cumulative Within 2 years – 83.3%</li> <li>• Longer than 2 years or never- 16.7%</li> </ul> <p>Mammogram frequency for Waukesha County women between 40 to 49 years old was notable.</p> <ul style="list-style-type: none"> <li>• Within one year - 62.5%</li> <li>• Within two years - 6.2%</li> <li>• 2 years or never - 31.3%</li> </ul>	<p><b>General Population Survey ages 40 to 69:</b></p> <ul style="list-style-type: none"> <li>• don't feel at risk – 39.3%</li> <li>• do feel at risk – 60.7%</li> </ul> <p><i>Had a screening mammograms within the past year</i></p> <ul style="list-style-type: none"> <li>• Feel at risk- 63.6%</li> <li>• Don't feel at risk – 36.4%</li> </ul> <p><b>Survivor Survey – feelings <u>prior</u> to diagnosis</b></p> <ul style="list-style-type: none"> <li>• don't feel at risk –65.7%</li> <li>• do feel at risk – 34.3%</li> </ul> <p>Over 61 percent of survivors surveyed <i>did feel informed</i> about breast cancer and also <i>did not feel at risk</i> of breast cancer before their diagnosis.</p>

**Barriers**

**What factors prevent, discourage or inhibit women from accessing and/or following through with...**

...breast cancer screenings?	...breast cancer diagnostic services?	...breast cancer treatment services?
<p><b>Top barriers identified by:</b></p> <p>Health Provider Survey</p> <ul style="list-style-type: none"> <li>• Education, Insurance/money, fear, cultural</li> </ul> <p>General Population Survey</p> <ul style="list-style-type: none"> <li>• Time, Insurance, fear, money</li> </ul> <p>Key Informant Interviews</p> <ul style="list-style-type: none"> <li>• Education, cultural, money, transportaion</li> </ul> <p>Survivor Survey</p> <p>Time, money, fear</p> <p>Survivor Forum</p> <ul style="list-style-type: none"> <li>• Fear/Giving up, education, denial</li> </ul>	<p><b>Top barriers identified by:</b></p> <p>Health Provider Survey</p> <ul style="list-style-type: none"> <li>• Insurance/money, education, fear, health system barriers</li> </ul> <p>Key Informant Interviews</p> <ul style="list-style-type: none"> <li>• Education, fear, money, lack of support</li> </ul> <p>Survivor Forum</p> <ul style="list-style-type: none"> <li>• Fear/giving up, insurance/money, health system, education</li> </ul>	<p><b>Top barriers identified by:</b></p> <p>Health Provider Survey</p> <ul style="list-style-type: none"> <li>• Insurance/money, education, fear, health system and personal barriers</li> </ul> <p>Key Informant Interviews</p> <ul style="list-style-type: none"> <li>• Money, transportation, fear, time, education</li> </ul> <p>Survivor Forum</p> <ul style="list-style-type: none"> <li>• Homelife, fear, insurance/money, transportation</li> </ul>

<p><b>Are there socioeconomic and/or demographic indicators tied to identified barriers?</b></p>	<p><b>Are health providers able to provide access to timely coordinated care across the continuum of care for breast health services?</b></p>	
<p>Key informants stressed the impact of personal and systemic cultural barriers at every point in the continuum of care individuals outside of the cultural mainstream.</p> <p>Hispanic/Latina participants in the Conversation for the Cure program introduced two additional screening barriers – ‘no symptoms’ and ‘my doctor did not tell me to get screened.’</p> <p>Refer to barrier tables for more information on specific populations.</p>	<p>Every provider surveyed was confident that the majority of their breast health services were always being offered efficiently and well within the Center for Disease Control guidelines.</p> <p>Referral to Mammogram in 90 days: Mammogram to diagnosis 60 days: Diagnosis to treatment 60 days</p>	<ul style="list-style-type: none"> <li>• About a fifth of survivor reported experiencing delays to diagnostic and treatment services.</li> <li>• All but one survivor cited health system and insurance as the cause for the delays</li> </ul>
<p><b>Survivorship</b></p>		
<p><b>What can providers reveal about the availability of survivor support services?</b></p>	<p><b>Most commonly noted services:</b></p> <ul style="list-style-type: none"> <li>• Patient navigation</li> <li>• Financial assistance w/ BC expenses</li> <li>• Emotional counseling</li> <li>• Nutritional programs</li> <li>• Transportation</li> </ul> <p><b>Least identified services included:</b></p> <ul style="list-style-type: none"> <li>• Financial Assistance for living expenses impacted by breast cancer</li> <li>• Mentors</li> <li>• Resource Center</li> </ul>	<p>Every support service identified was reported to be available during diagnosis, as well as during and after breast cancer treatment.</p> <p>For every one of the twenty four survivor support services identified, there were providers that reported being unsure if that support service was available.</p>
<p><b>Do breast cancer survivors feel a need to talk about their breast cancer and whom do they choose to speak with?</b></p>	<p><b>How do survivors find out about support services?</b></p>	
<p><b>Top responses include:</b></p> <ul style="list-style-type: none"> <li>• Friends and Family -48.0%</li> <li>• Medical Team – 48.0</li> <li>• Acquaintances – 32.0</li> <li>• Other Patients – 28.0%</li> </ul>	<p><b>Top responses include:</b></p> <ul style="list-style-type: none"> <li>• Medical Team 65.9%</li> <li>• Brochures 46.3%</li> <li>• Friends/Family 39.0%</li> <li>• Media 24.4%</li> </ul>	

<p><b>What support services are survivors aware of, how often do they utilize them, and which services are seen as most valuable?</b></p>	<p><b>Most Aware of:</b></p> <ul style="list-style-type: none"> <li>• Support Groups</li> <li>• Mentors</li> <li>• Individual Counseling</li> <li>• Exercise Programs</li> <li>• Nutritional Programs</li> </ul> <p><b>Most Utilized:</b></p> <ul style="list-style-type: none"> <li>• Nutritional Programs</li> <li>• Exercise Programs</li> <li>• Mentors</li> <li>• Individual Counseling</li> </ul>	<p><b>Most Valued:</b></p> <ul style="list-style-type: none"> <li>• Exercise Program</li> <li>• Support Groups</li> <li>• Individual Counseling</li> </ul> <p>Only Support Groups and Mentor services were recognized by more than half of those surveyed</p> <p>No service was utilized by more than about a third of those surveyed</p> <p>Complementary therapies were recognized by less than 10 percent of those surveyed.</p>
---	---	---

**Solutions**

<p><b>What can be done to reduce the gaps and barriers identified?</b></p>	<p><b>Top responses from Survivor Forum for overcoming...</b></p> <p>Screening Barriers:</p> <ul style="list-style-type: none"> <li>• Education, Sharing Stories</li> </ul> <p>Diagnostic Barriers:</p> <ul style="list-style-type: none"> <li>• Education, Personal Support</li> </ul> <p>Treatment Barriers:</p> <ul style="list-style-type: none"> <li>• Personal Support, Health System Changes, Education</li> </ul> <p>Forum Participants emphasized a need to shift the health system paradigm to a community based, prevention focused model of wellness in order to truly achieve equal access to and delivery of breast health services for everyone.</p>	<p><b>Key Informant Interviews ideas included:</b></p> <ul style="list-style-type: none"> <li>• Utilization of the Community Health Worker Model</li> <li>• Prioritizing cultural accessibility by insuring bilingual services and a diversified staff</li> <li>• Personalized navigation</li> <li>• More collaboration both between health systems and with other organizations</li> <li>• Increased public and private funding</li> <li>• Use of mobile mammography</li> <li>• Focus on prevention</li> </ul>
<p><b>General Population Suggestions:</b></p> <ul style="list-style-type: none"> <li>• Better education, reducing costs, share survivor stories, and making changes to the health System</li> </ul> <p><b>Top health provider Initiatives for reducing barriers:</b></p> <ul style="list-style-type: none"> <li>• Improved cultural sensitivity of information and services</li> <li>• Emphasis on education</li> <li>• Provide Financial Counseling</li> <li>• Emphasis on customer service</li> </ul>		

## Southern Rural Region

Education and Awareness		
<p><b>How are health systems providing breast health education?</b></p>	<p><b>Who needs and who has access to accurate and culturally appropriate breast health and breast cancer information?</b> (1 - targeted, 2 - somewhat targeted, 3 not targeted, 4 - additional info needed)</p>	<p><b>Are current education/outreach programs in the community effective at leading women to breast cancer screenings?</b> (Scale: 1-never, 2-rarely, 3 - sometimes, 4 - Very Often, 5 - Almost Always)</p>
<p><b>Top responses included:</b></p> <ul style="list-style-type: none"> <li>One on one education</li> <li>Brochures</li> <li>Education within the health facility</li> </ul> <p>Providers in the SRR Target Community reported the fewest methods of education and outreach of all target communities.</p> <p>General Population Survey respondents across many populations all reported that education and outreach programs were their greatest motivator to receive breast cancer screenings.</p>	<ul style="list-style-type: none"> <li>Low income (1,4)</li> <li>Under and uninsured (1,4)</li> <li>Rural Residents (1,4)</li> <li>Hispanic/Latina (1,4)</li> <li>Black/African-American (1,4)</li> <li>API (2,4)</li> <li>AI/AN (1,4)</li> <li>Russia(1,4)</li> <li>Hmong (3,4)</li> <li>LGBT (2,4)</li> <li>Unemployed (1)</li> <li>Young women (1)</li> <li>Seniors (1)</li> <li>Patients w/ disabilities (1)</li> <li></li> </ul> <p>No providers reported knowing about populations being targeted for service by any other organization.</p>	<p>Providers answering:</p> <p>Almost Always – 0% Very Often – 0% Sometimes – 75.0%% Rarely – 25.0%% Never – 0%</p> <p>Score: 2.75 or a grade of C-minus</p> <p>This is the lowest score of all Target Communities in SEWI</p>
Breast Cancer Screening		
<p><b>Are there gaps between breast cancer screening guidelines and health providers' usage of guidelines?</b></p>	<p><b>Providers reported their health system recommendations:</b></p> <p>Clinical Breast Exams</p> <ul style="list-style-type: none"> <li>Yearly – 100.0%</li> <li>Start at age 20 – 100.0%</li> </ul> <p>Screening Mammograms</p> <ul style="list-style-type: none"> <li>Yearly – 66.7%</li> <li>Every two years – 33.3%</li> <li>Start at age 40 – 100.0%</li> </ul>	<p><b>Guidelines were thought to be followed by:</b></p> <ul style="list-style-type: none"> <li>All providers – 50.0%</li> <li>Most providers – 25.0%</li> <li>Many providers – 25.0%</li> </ul>

Are there gaps between breast cancer screening guidelines and reported frequency of Clinical Breast Exams?	Are there gaps between screening guidelines and reported frequency of screening mammograms?	Does personal perception of breast cancer risk have an impact on screening behavior?
<p><b>Surveyed frequency of Clinical Breast Exams.</b></p> <p><i>Age and insurance appear to be related to frequency.</i></p> <p><b>Within one year</b></p> <ul style="list-style-type: none"> <li>• All women – 77.8%</li> <li>• Women &lt;40 – 63.0%</li> <li>• Women 40plus – 84.2%</li> <li>• Inadequate insurance– 68.8%</li> </ul> <p><b>Cumulative within 2 years or less</b></p> <ul style="list-style-type: none"> <li>• All women – 83.9%</li> <li>• Women &lt;40 – 74.1%</li> <li>• Women 40plus – 89.5%</li> <li>• Inadequate insurance– 75.1%</li> </ul> <p><b>Cumulative within 3 years or less</b></p> <ul style="list-style-type: none"> <li>• All women – 85.0%</li> <li>• Women &lt;40 – 77.8%</li> <li>• Women 40plus – 89.5%</li> <li>• Inadequate insurance-75.1%</li> </ul> <p><b>Longer than 3 years or never</b></p> <ul style="list-style-type: none"> <li>• All women – 14.5%</li> <li>• Women &lt;40 – 22.2%</li> <li>• Women 40plus - 10.5%</li> <li>• Inadequate insurance- 25.0%</li> </ul>	<p><b>Surveyed frequency of Screening Mammograms:</b></p> <p><i>Non-White women and those with incomes \$20 were more likely to never or rarely have a screening mammogram.</i></p> <p><b>Within 1 year</b></p> <ul style="list-style-type: none"> <li>• All women - 73.7%</li> <li>• White women – 80.0%</li> <li>• Non-White – 66.7%</li> <li>• Income &lt;\$50K – 73.7%</li> <li>• Income &lt;\$30K – 70.4%</li> <li>• Income &lt;\$20K – 68.4%</li> </ul> <p><b>Cumulative within 2 years</b></p> <ul style="list-style-type: none"> <li>• All women – 82.5%</li> <li>• White women- 86.7%</li> <li>• Non-White- 66.7%</li> <li>• Income &lt;\$50K – 81.6%</li> <li>• Income &lt;\$30K – 81.5%</li> <li>• Income &lt;\$20K – 78.9%</li> </ul> <p><b>Longer than 2 years or never</b></p> <ul style="list-style-type: none"> <li>• All women – 17.5%</li> <li>• White women – 13.3%</li> <li>• Non-White – 33.3%</li> <li>• Income &lt;\$50K – 18.4%</li> <li>• Income &lt;\$30K – 18.5%</li> <li>• Income &lt;\$20K – 21.1%</li> </ul>	<p><b>General Population Survey</b></p> <ul style="list-style-type: none"> <li>• don't feel at risk – 57.6%</li> <li>• do feel at risk – 42.4%</li> </ul> <p><i>Had a screening mammograms within the past year( Age 50 to 69)</i></p> <ul style="list-style-type: none"> <li>• Feel at risk- 58.3%%</li> <li>• Don't feel at risk – 41.7%</li> </ul> <p><i>Had a mammogram more than 2 years ago or never (All ages)</i></p> <ul style="list-style-type: none"> <li>• Feel at risk – 18.2%</li> <li>• Don't feel at risk – 81.8%</li> </ul> <p><b>Survivor Survey – feelings prior to diagnosis</b></p> <ul style="list-style-type: none"> <li>• don't feel at risk – 83.3%</li> <li>• do feel at risk – 16.7%</li> </ul> <p><i>Two thirds of survivors surveyed did feel informed about breast cancer and also did not feel at risk of breast cancer before their diagnosis.</i></p> <p><i>Two of three survivors diagnosed at stage 2 did not feel at risk of bc before diagnosis.</i></p> <p><i>Only survivor diagnosed at stage 3 did not feel at risk and had mammograms only occasionally.</i></p>

<b>Barriers</b>		
<b>What factors prevent, discourage or inhibit women from accessing and/or following through with...</b>		
<b>...breast cancer screenings?</b>	<b>...breast cancer diagnostic services?</b>	<b>...breast cancer treatment services?</b>
<p><b>Top barriers identified by:</b></p> <p>Health Provider Survey</p> <ul style="list-style-type: none"> <li>Insurance/money, health system barriers, lack of childcare</li> </ul> <p>General Population Survey</p> <ul style="list-style-type: none"> <li>Insurance, money, time, fear</li> </ul> <p>Key Informant Interviews</p> <ul style="list-style-type: none"> <li>Education, Cultural, Insurance, money, transportation</li> </ul> <p>Survivor Forum</p> <ul style="list-style-type: none"> <li>Fear/Giving up, education, denial</li> </ul>	<p><b>Top barriers identified by:</b></p> <p>Health Provider Survey</p> <ul style="list-style-type: none"> <li>Insurance, money</li> </ul> <p>Key Informant Interviews</p> <ul style="list-style-type: none"> <li>Education, fear, money</li> </ul> <p>Survivor Forum</p> <ul style="list-style-type: none"> <li>Fear/giving up, insurance/money, health system, education</li> </ul>	<p><b>Top barriers identified by:</b></p> <p>Health Provider Survey</p> <ul style="list-style-type: none"> <li>Insurance and money</li> </ul> <p>Key Informant Interviews</p> <ul style="list-style-type: none"> <li>Money, transportation, cultural</li> </ul> <p>Survivor Forum</p> <ul style="list-style-type: none"> <li>Homelife, fear, insurance/money, transportation</li> </ul>
<b>Are there socioeconomic and/or demographic indicators tied to identified barriers?</b>		<b>Are health providers able to provide access to timely coordinated care across the continuum of care for breast health services?</b>
<p>Fear was selected by respondents under 40 years much more often than by any other respondents</p> <p>Transportation and money barriers were more prevalent for individuals with lower incomes.</p> <p>Those who report feeling at risk for breast cancer reported higher percentages than average for almost all barrier themes.</p> <p>Key informants and General Population survey respondent identified far more barriers than health providers identified.</p>		<p>Two thirds of providers felt their health system's breast health services were always provided within the CDC guidelines. The other third felt these guidelines were rarely met.</p> <p>The wide range of provider scores warrants further investigation</p> <p>(Scale: 5 =always, 4= usually, 3 = often, 2 = equals rarely, 1 = never)</p> <p>Referral to Mammogram in 90 days: Score 4.0</p> <p>Mammogram to diagnosis 60 days: Score 4.0</p> <p>Diagnosis to treatment 60 days: Score 4.0</p>
<b>Survivorship</b>		
<b>What can providers reveal about the availability of survivor support services?</b>	<p><b>Most commonly noted services:</b></p> <ul style="list-style-type: none"> <li>Emotional, family, intimacy counseling and support groups</li> <li>Nutritional Programs</li> <li>Resource center, wigs, prosthetics</li> <li>Palliative care and end of life services</li> </ul> <p>Every support service identified was Seen as available by at least one provider except for transportation.</p>	<p><b>Least identified services included:</b></p> <ul style="list-style-type: none"> <li>Transportation</li> <li>Mentors</li> <li>Educational Services</li> <li>Navigation</li> <li>Financial Assistance for BC and non BC expenses</li> <li>Exercise programs</li> <li>Complementary Therapies</li> </ul> <p>All twenty four identified survivor support services had respondents report they were unsure of that service's availability.</p>

<b>Do breast cancer survivors feel a need to talk about their breast cancer and whom do they choose to speak with?</b>		<b>How do survivors find out about support services?</b>	
<b>Top responses include:</b> <ul style="list-style-type: none"> <li>• Medical Team</li> <li>• Family/Friends</li> <li>• Co-Workers</li> </ul>		<b>Top responses include:</b> <ul style="list-style-type: none"> <li>• Medical Team - 66.7%</li> <li>• Family or friends – 50.0%</li> <li>• Brochures – 33.3%</li> </ul>	
<b>What support services are survivors aware of, how often do they utilize them, and which services are seen as most valuable?</b>		<b>Most Aware of:</b> <ul style="list-style-type: none"> <li>• Support Groups</li> <li>• Mentoring</li> <li>• Individual Counseling</li> <li>• Group Counseling</li> <li>• Exercise Programs</li> </ul>	<b>Most Valued:</b> <ul style="list-style-type: none"> <li>• Financial Support</li> <li>• Exercise Programs</li> <li>• Support Groups</li> <li>• Group Counseling</li> </ul> <p>Survivor Support Services were widely unrecognized as available and utilized infrequently.</p> <p>Many of the complementary therapies (including yoga, Reiki, and meditation) were not seen as available by any survivors</p>
<b>Solutions</b>			
<b>What can be done to reduce the gaps and barriers identified?</b>	<b>Top Health Provider Suggestions:</b> <ul style="list-style-type: none"> <li>• Increased Mobile Mammography and on-site screening services.</li> <li>• Provide transportation and gas cards</li> <li>• More funding for all women</li> <li>• Special attention to those who miss funding guidelines but still cannot afford or justify expense of services</li> <li>• More volunteers to give screening exams</li> </ul>	<b>Key Informant Interviewees ideas included:</b> <ul style="list-style-type: none"> <li>• Increased awareness of available breast health related programs and services for providers and the public.</li> <li>• Facilitate collaboration between groups, increase community outreach and work with the local health department</li> <li>• More wrap-around services in the community that provide childcare, transportation, etc.</li> <li>• Multiple opportunities for breast health information for all members of the Target Community from every walk of life.</li> <li>• Easier screening access including Mobile Mammography</li> </ul> <p>Increased culturally sensitive materials, services, translators, and providers.</p>	
<b>General Population Suggestions:</b> <ul style="list-style-type: none"> <li>• Increase education and awareness programs</li> <li>• Community Collaborations</li> <li>• Use of media</li> <li>• Reduce Costs</li> <li>• Make changes within the health system</li> </ul>			

The qualitative data findings help illuminate the nature of the breast cancer burden faced by individuals in each Target Community and give voice to the individuals that live and work there. Consideration of this information in combination with the analysis of previous quantitative data, the health system identification, and current public policy issues provides the Affiliate with a strong base from which to understand the gaps in and barriers to breast cancer services in Southeast Wisconsin.

# Mission Action Plan

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

### **Summary of the findings from the Quantitative Data Report**

Quantitative data analysis laid the foundation for the Komen Southeast Wisconsin (SEWI) Affiliate's selection of its five Target Communities for the 2015 Community Profile. Table 5.1 illustrates that SEWI counties are consistently over the state average for breast cancer Incidence and death rate, and with only one exception, off track for hitting Healthy People 2020 breast cancer goals. The table also highlights specific demographic and socioeconomic areas of concern in each of the five target communities.

**Table 5.1.** Summary of quantitative highlights by Target Community

	TARGET COMMUNITIES							IN COMPARISON TO:	
	Milwaukee	Northern Rural Region:			Waukesha	Southern Rural Region:		State of Wisconsin	SEWI
		Washington	Ozaukee	Racine		Kenosha	Walworth		
<b>Breast Cancer Incidence Rate per 100,000 women</b>	130.2	138.4	156.2 worst in SEWI	128.7	138.6	121.6	121.6	116.9	N/A
<b>Breast Cancer Death Rate per 100,000 women</b>	22.6	24.5 worst in SEWI	23.4	24.4	22.0	19.5	21.4	21.3	22.4 White-21.8 Black- 29.7
<b>progress toward HP2020 Breast Health Goals</b>	4 years off target	13 years off target	5 years off target	8 years off target	3 years off target	meets target	2 years off target	BC death rate HP2020 goal = 20.6	N/A
Federal Poverty Level									
≤ 250% FPL	37.5%			27.1%		28.6%	26.1%	27.4%	27.3%
≤ 100% FPL	19.9%			11.7%		11.6%	11.8%	12.0%	13.3%
Rural Residency		30.8%	24.9%	12.3%	9.9%	10.7%	34.2%	29.8%	9.9%
Racial/Ethnic Diversity	*								
% Black	29.2%			12.1%		7.8%		7.1%	15.6%
% Hispanic	12.8%			11.3%	4.1%	11.7%	9.8%	5.8%	9.5%
%AIAN	1.1%			0.6%		0.8%	0.5%	1.2%	0.8%
%API	3.8%		2.2%		3.1%	1.9%		2.6%	2.8%
Foreign Born	8.7%		4.7%			6.4%	6.70%	4.6%	6.5%
Linguistically Isolated	3.9%			1.7%		1.7%	1.9%	1.6%	2.4%
Medically Underserved	32.4%			10.1%		15.3%		13.9%	16.7%
Percent of Women over 40			56.3%	50.8%	55.0%		49.2%	49.8%	48.3%
Other Factors	Home to over 47% of SEWI female residents	Higher than average late stage diagnosis			Higher than average late stage diagnosis	Poverty pockets identified	Poverty Pockets Identified		

It is worth noting that Komen SEWI service area is the most densely populated area in the state. Over 37 percent of Wisconsin's female residents live in Southeast Wisconsin. In addition, quantitative data shows that all five of the Affiliate's Target Communities have two challenges in common, weight and alcohol consumption. As discussed in the Quantitative Data Analysis, both weight gain at certain ages and excessive alcohol use put individuals at an increased risk of breast cancer. Between 40 to 75 percent of Wisconsin adults are classified as overweight or obese – White (62.6), Black/African-American (67.2), Asian (40.1), American Indian (75.1), and Hispanic/Latina (66.6). Alcohol consumption in Wisconsin is self-reported at higher percentages than any other state in the country including binge drinking (24.0 percent), alcohol use (69.0 percent), and heavy drinking (8.0 percent).

### ***Summary of the findings from the Health Systems and Public Policy Analysis***

The Public Policy Analysis provided further insight into common needs within all of Komen Southeast Wisconsin's Target Communities.

- Absence of Medicaid expansion is detrimental to the affordability of insurance for those at 101 to 133 percent of the Federal Poverty Level (FPL).
- The success of the Affordable Care Act requires the support of navigation to the marketplace at every point of contact in the continuum of care.
- Increased efforts to promote health insurance literacy are needed to ensure individuals understand and make best use of their insurance coverage.
- Attention is needed to reduce or eliminate the burden of out of pocket costs incurred from diagnostic breast cancer testing and/or breast cancer treatment that is deemed necessary after an insurance covered screening mammogram.
- Greater awareness is needed of populations that cannot or will not utilize the marketplace in order to navigate those individuals to other resources such as the Wisconsin Well Woman Program.
- Inability of Wisconsin Well Woman Program to do outreach activities negatively affects awareness of and enrollment in the program for otherwise qualified women.
- Lowered enrollment in the Wisconsin Well Woman Program could affect future state and federal funding of this critical financial assistance program.
- As of 2015, the restructure of the Wisconsin Well Woman Program has resulted in some remaining coverage gaps in many areas of the state and potentially long travel distances, especially for rural residents. Changes are still being rolled out at the time this document was created and there are currently questions about how the new structure will operate, how program information will be publicized, and how confusion created during the restructure will be addressed.

The Health Systems Analysis provided insight into potential needs and gaps within each of Komen Southeast Wisconsin's Target Communities. Table 5.2 summarizes the services offered in each Target Community.

**Table 5.2. Health system analysis overview by Target Community**

Target Communities	Screening Sites			Diagnostic Sites								Treatment Sites					Mobile coach ?	HSA Highlights and Site Distribution			
	CBE	mammography	Both (overlap)	Total Diagnostic	All Services	Diag. mamm, US & Biopsy	Diag. mam, US, MRI	DiagMamm and US	US, Biopsy, MRI	Biopsy and MRI	Ultrasound & MRI	Diag. Mamm Only	US only	MRI Only	Total Treatment	All Services			Surgery & Reconst.	Chemo & Radiation	Surgery and Chemo
Milwaukee County	15	36	4	21	7		4		1		9			9	6	1	1	1		Yes	Multiple service sites, but with a small number of exceptions distribution is largely in ring outside the City of Milwaukee. 2x's options for mammos in suburbs. Local service access, especially Diagnostic and treatment services, are less available in lower Socioeconomic areas
Northern Rural Region	14	13	11	5										4	2	1	1			Y/N	All service sites clustered around city centers leaves large travel/access burden for rural residents. No FQHC, 1 free clinic per county.
Washington	6	4	4	4	1	1		1	1					1	1					No	All providers located only in mid or midwest county in two city centers. The one provider offering both diagnostic and treatment services is <b>not</b> a WI Well Woman provider
Ozaukee	8	9	7	3	2	1								3	1	1	1			Yes	Most Mammo sites also offer CBE. All service sites only in the middle and SE sections of the county
Racine	7	6	4	5	3	2								4	3	1				No	Small Health Service inventory. Majority of sites on far east side of county. One far Southwest site available. Great travel burden on rural residents. Racine Mammo Coalition benefits coordinated services.
Waukesha	22	19	17	17	6	2	1	6				1	1	5	5					No	Many provider options but southwest area has no service sites. Services clustered in city centers in East, NE, and far NW areas. Treatment sites limited to northern half of county. 3 free clinics
Southern Rural Region	8	6		9	5	1				1	1	1		7	1	3	1	1	1	No	Small Service inventory with only 15 total providers. One FQHC in Kenosha, 1 free clinic in Walworth.
Kenosha	5	4	2	6	4					1	1			4	1	2	1			No	All far east side. Poverty pocket in service full area, but no service site for mid or west county residents.
Walworth	3	2	1	3	1	1						1		3	1			1	1	No	All services clustered only in center of county, only 1 of 3 poverty pockets with services. No radiation available in county.

**Summary of findings from the Qualitative Data**

Qualitative data collection provided the Affiliate with a perspective of people living and working in Southeast Wisconsin giving a deeper understanding of the community's attitudes, beliefs and behaviors about disparities, access to services, utilization of services, quality of care, and additional breast health and breast cancer issues. Qualitative Data Analysis allows the Affiliate to develop a more comprehensive assessment of the breast health needs and issues facing the Target Communities and provides insight into the possible gaps and needs identified in the Quantitative, Health System, and Public Policy Analyses. Below is a summary of key qualitative data findings common to all Target Communities followed by highlights of finding within each Target Community.

## **All Target Communities:**

### **Barriers**

- Top barriers to screening and diagnostic services: Fear, lack of insurance/money, lack of education, and cultural factors. Top barriers to breast cancer treatment services: Money, home-life, transportation, and fear.
- Transportation barriers exist for rural residents & all economically vulnerable residents.
- Personal and systemic cultural barriers found at every point in the continuum of care for individuals outside of the cultural mainstream.
- Overall need for truly culturally sensitive delivery of all breast health services.

### **Education**

- Widespread call for prevention focused, community based health education.
- Multiple populations identified as needing additional breast health education.
- Providers report the majority of SEWI health systems follow clinical breast exam and mammogram screening recommendations in alignment with Susan G. Komen breast self-awareness messaging and the American Cancer Society screening guidelines, but also report large gaps in the numbers of providers adhering to the system's guidelines.
- Providers give low scores to their current breast health education programs on their ability to lead women to breast cancer screening.
- Majority of women surveyed do not feel personally at risk of breast cancer. The majority of survivors surveyed did not feel at risk of breast cancer prior to their diagnosis.
- Survivors diagnosed at stage 1 more often perceived a personal risk of breast cancer prior to diagnosis than those diagnosed at stage 2 and 3.

### **Access**

- Call for better local neighborhood access to screening mammograms.
- Call for increased collaboration between the health systems and local agencies serving vulnerable populations in order to increase access to/use of breast health services.
- Call for increased use of a Community Health Worker model as a necessary navigational bridge to the health systems.

### **Survivorship**

- Awareness of breast cancer survivor support services was limited and utilization of these services was minimal. The medical team is the main source for information on survivor support services.

## **Qualitative Highlights of each Target Community**

### **Milwaukee County**

- Call for more local services, especially screening, in lower income areas.
- Personal and systemic cultural barriers exist at every point in the continuum of care for individuals outside of the cultural mainstream.
- Over 32 percent of women under 40 never or rarely have clinical breast exams.
- Black/African-American women report lower frequency of mammogram screenings than White women.

- Screening mammogram within 1 year – White: 87.8, Black/African-American 72.6.
- Screening mammogram within two years – White: 91.7, Black/African-American 83.1.
- Black/African-American women reported more barriers to breast health services per person than White women.

### **Northern Rural Region (Washington and Ozaukee Counties)**

- Key Informants identified additional vulnerable populations (Black/African-American, American Indian Alaskan Natives (AIAN), Asian Pacific Islanders (API), Lesbian, Gay, Bisexual, and Transgender (LGBT)) to add to those identified by health providers (rural, Hispanic/Latina, low income, underinsured, and unemployed residents).
- Transportation and distance a major barrier to rural residents.
- Low annual screening percentages reported (Never or rarely screened: 72.0 percent of General Survey participants and 62.5 percent of Survivor Survey participants prior to their diagnosis.) One quarter of survivors surveyed had never had a mammogram prior to diagnosis.

### **Racine County**

- Broad spectrum of populations identified as needing additional breast health services.
- One quarter of Survivors reported rarely/never having mammograms prior to diagnosis.
- Those with incomes just above financial assistance levels are falling through the cracks.
- Lack of local access for broad areas of Racine County. No mobile mammography.
- Survivor services vastly under recognized and underutilized.

### **Waukesha County**

- Multiple populations identified as needing additional breast health services and information. Several (including API, Hmong, Russian, mentally and physically disabled, elderly, LGBT residents) are not currently targeted by providers.
- Over 63 percent of providers feel their breast cancer education programs are only sometimes effective.
- One third of 40 to 49 year olds surveyed never or rarely had a mammogram.
- Complementary survivor support services were recognized by less than ten percent of health providers surveyed.

### **Southern Rural Region (SRR) (Walworth and Kenosha Counties)**

- Providers in the SRR Target Community reported the fewest methods of education and outreach of all Target Communities.
- Education and outreach were identified as the greatest motivator to pursuing a breast cancer screening.
- No providers reported being aware of populations being targeted for breast health services by any other organizations in the area.
- When asked if their current education and outreach programs are effective at leading women to breast cancer screenings, three quarters of providers responded 'only sometimes' and one quarter stated 'rarely'.
- One third of non-White women in SRR report that they rarely or never have a mammogram.

- Key Informants and General Survey participants identified many more barriers to breast health services than were identified by SRR providers in the health system.
- No providers or survivors identified transportation as an available support service
- More than any other Target Community, Survivor Support Services were widely unrecognized as available by providers and survivors. They were also greatly underutilized by survivors.

## **Mission Action Plan**

Eight problems have been identified for Komen Southeast Wisconsin's Mission Action Plan based on the information uncovered in the development of the 2015 Community Profile. The problems identified address needs in all five Target Communities and have been organized into six different categories including Public Policy, Communication, Breast Health Services, Education, Grantmaking, and Survivorship.

For each problem statement, one or more priorities are stated that will help the Affiliate address or begin to address the 'problem' during fiscal years 2016 to 2019. Each priority is followed by objectives which are specific, measurable action items the Affiliate feels it can achieve during the upcoming fiscal years.

### **Public Policy**

**Problem:** Public policy related to breast cancer research funding, as well as the Wisconsin Well Woman Program (National Breast and Cervical Cancer Early Detection Program), the Affordable Care Act, insurance coverage, and out of pocket costs for breast cancer services greatly affect the ability of Southeast Wisconsin resident to access affordable and accessible breast health services.

**Priority 1:** Maintain optimal availability of and increase access to the Wisconsin Well Woman Program (WWWP) for eligible women in Southeast Wisconsin.

*Objective 1:* FY2016 to 2017, the Affiliate will actively monitor the restructuring of the Wisconsin Well Woman Program and advocate (through a united effort with the Wisconsin Breast Cancer Coalition, other Komen Wisconsin Komen Affiliates, and other breast health stakeholders) as needed both in person and through co-sponsored letters calling for accessible and affordable access to individualized navigation and high quality service delivery.

*Objective 2:* FY 2016 to 2019, participate as deemed necessary (in cooperation with the Breast Cancer Task Force and the Cancer Center Community Advisory Board) in the development of messaging and promotional materials to provide outreach for the Wisconsin Well Woman Program through local health systems and organizations.

*Objective 3:* FY 2016 to 2019, distribute WWWP promotional messaging and materials to all Affiliate grantees and at least five partners in each Target Community for distribution.

*Objective 4:* FY2016 to 2019, disseminate WWWP promotional messaging through the Affiliate Website, social media, Conversation for the Cure programming, and all Affiliate education and outreach events.

**Priority 2:** Increase Affiliate advocacy efforts both at a local/statewide level and at a Federal level.

*Objective 1:* FY 2016 to 2019, the Affiliate will participate annually in Komen Headquarters Advocacy days in Washington D.C.

*Objective 2:* FY 2016 to 2019, the Affiliate will participate annually in the Wisconsin Breast Cancer Coalition's State Advocacy days in Madison, Wisconsin.

*Objective 3:* By FY 2018, the Affiliate will develop and conduct one Komen-sponsored Advocacy Day in Madison that is attended by at least five representatives of Komen Southeast, South Central, and Central Wisconsin.

*Objective 4:* FY 2017 to 2019, timely advocacy 'calls to action' will be posted on the Affiliate's social media outlets (including Facebook, twitter) as needed.

**Priority 3:** Increase Affiliate constituent's access to breast health advocacy issues and facilitate involvement in advocacy efforts.

*Objective 1:* FY 2016 to 2019, annual development of a timely and relevant advocacy-focused petition to be circulated at the annual Race for the Cure, signed by a minimum of 300 participants, and then submit to State legislators and/or Komen Headquarters Advocacy staff.

*Objective 2:* FY 2016 to 2019, advocacy information on the Affiliate's website will be updated quarterly.

*Objective 3:* FY 2016 to 2019, a link to constituent's current elected official contact information will be included on the Komen Southeast Wisconsin website.

*Objective 4:* FY 2017 to 2019, links to current Local, State and Federal breast health related policy information and other Wisconsin Breast Health Advocacy Group's information (including Wisconsin Breast Cancer Coalition and the Wisconsin Women's Health Alliance) on the Affiliate's website will be updated annually.

### **Communication**

**Problem:** Majority of individuals surveyed during the qualitative data collection could not identify a resource or organization they would turn to for information on breast health and breast cancer.

**Priority 1:** Increase community awareness of the work of Susan G. Komen Southeast Wisconsin.

*Objective 1:* FY 2016 to 2018, annual Media Campaigns launched through Kohl's Conversations for the Cure Program to deliver three million impressions to individuals residing in all five SEWI Target Communities.

*Objective 2:* FY 2016 to 2019, distribution of a quarterly Komen SEWI newsletter to all Affiliate constituents and partner organizations via email (and by mail as requested) to include sections on breast health education, research, grants and grantees, events, survivorship, and Affiliate development.

*Objective 3:* FY 2017 to 2019, at least one time annually, the Affiliate will provide Komen grantees and partner organizations with shareable social media content inviting their constituents to link to Komen SEWI's website and/or register to receive Komen SEWI's quarterly newsletter.

*Objective 4:* FY 2016 to 2019, monthly distribution of a Race e-newsletter including mission content from May to September to all current and past race participants in Affiliate data base.

*Objective 5:* FY 2016 to 2019, development of a yearly October calendar of Breast Cancer Awareness Month activities and events.

*Objective 6:* FY 2016 to 2019, annually in October (Breast Cancer Awareness Month) the Affiliate will have a presence at a large local Milwaukee County venue at which the Affiliate will host at least four special events; promote breast self-awareness and distribute at least 2,000 pieces of printed educational materials on breast health; provide information on breast cancer services and resources; celebrate local survivors; and register individuals to receive the Komen SEWI newsletter.

**Priority 2:** Increase the visibility of Komen grantees within the community in order to promote utilization of available grant programs and to enhance the awareness and understanding of local Komen Affiliate funding.

*Objective 1:* FY 2016 to 2019, the Affiliate will update spreadsheet of all grantee information and contact information on an annual basis.

*Objective 2:* FY 2017 to 2019, annually the Affiliate will create a basic word document with updated grantee information for distribution to individuals navigating women to breast health services in each Target Community. This will include, but not be limited to all Affiliate staff, Komen grantees, Kohl's Conversation for the Cure program managers, and Wisconsin Well Woman Coordinators serving each Target Community.

*Objective 3:* FY 2018 to 2019, annually the Affiliate will create yearly grantee marketing piece for public distribution that promotes awareness and utilization of current grant programs by residents in the Affiliate's Target Community. This marketing piece will be printed and distributed to the public by Komen staff and volunteers at public at health fairs, Kohl's Conversation for the Cure events, and all

outreach efforts. A PDF of this document will be posted on the Affiliate website and also provided to all current grantees and partner organizations each year.

*Objective 4:* FY 2017 to 2019, at least one time per grant year, the Affiliate's Grantees will submit photographs of and/or stories about their funded programs which will be featured on the Affiliate website, Facebook page, and/or newsletter. These stories and photographs will also be offered for sharing on social media of partner organizations, local health departments, as well as with local media sources.

**Priority 3:** Improve community access to breast health and breast cancer resources.

*Objective 1:* FY2017, convene one meeting of at least two interested stakeholders from each Target Community to assess the feasibility and development of a working plan for creating an accessible, comprehensive, and up-to-date Breast Cancer Resource Guide which would be available to residents, providers, and local organizations in all Target Communities by FY 2019.

*Objective 2:* FY2017 to 2018, in cooperation with other local breast cancer agencies in each Target Community and utilizing the work plan established in Objective 1, identify and document the current holders of breast cancer resource information to begin the process of consolidating one local, comprehensive, and up-to-date Breast Cancer Resource Guide to services, products, and support in Southeast Wisconsin.

*Objective 3:* FY 2018-2019, identify and contact nonprofit organizations that have the capacity to consolidate, maintain, and/or electronically house a comprehensive Breast Cancer Resource Guide to assess their interest in and potential for taking on this project by FY 2019.

### **Breast Health Services**

**Problem:** In every Target Community key multiple ethnic/racial/socioeconomic populations are identified as being underserved in terms of breast health information and services. In qualitative data collection, providers and key respondents surveyed identified a gap between the organizations that understand how to access and serve these populations and the agencies or health providers who are able to provide breast health services to these residents.

**Priority 1:** Increase Affiliate collaboration with local non-medical organizations serving specific populations within each Target Community.

*Objective 1:* FY 2016 to 2017, begin to building capacity for future collaborations, the Affiliate will utilize the Community Profile to create a working local organization data base for each Target Community that will contain information on identified organizations including, but not limited to each organization's name, contact information, mission, and population served.

*Objective 2:* FY 2018 to 2019, to increase the potential for future collaborative efforts, the Affiliate's Mission Manager will make quarterly updates to the local organization

data base to both add new organizations and keep existing organizational contact information current.

*Objective 3:* FY 2016 to 2019, annually the Affiliate Mission manager will meet with at least one new organization per vulnerable population identified in each Target Community (as available) to explore the opportunities to partner in the delivery of breast health information to their specific targeted populations.

**Priority 2:** Increase collaboration between local health care organizations and non-medical organizations serving vulnerable populations in each Target Community.

*Objective 1:* FY 2016 to 2019, annually meet with at least one key breast health personnel from each major health system identified in the Community Profile health system analysis in each Target Community.

*Objective 2:* FY 2016 to 2019, as deemed appropriate, initiate contact between local agencies and local health care facilities based on information gained in meetings with each partner to encourage collaborative efforts and partnering on program development and possible Komen grant funding.

**Problem:** Access to and utilization of breast cancer screening, diagnostic, and treatment services in each Target Community are negatively impacted by an interwoven myriad of barriers, both personal and systemic as indicated by the health system, public policy, and qualitative data analyses.

**Priority 1:** Assess and facilitate the ability of the Affiliate and partner organizations to provide local, accessible opportunities for increasing the health literacy of residents in all Target Communities – specifically the ability to provide opportunities that deliver information on the importance of breast health, as well as information on finding and accessing available medical, insurance and financial resources available.

*Objective 1:* By the end of FY 2017, convene a meeting in each Target Community of local organizations and providers to discuss, prioritize, and brainstorm possible strategies for:

- Developing neighborhood events in each target community that would provide opportunities for residents to develop the skills needed to successfully find and access breast health information, services, and support resources.
- Addressing the breadth of challenges to providing truly culturally sensitive breast health services at every point in the continuum of care.
- Facilitating the utilization of Community Health workers to create a bridge from local neighborhoods into the larger health systems.

*Objective 2:* By the end of FY2019, at least one educational outreach event will be conducted in each Target Community to provide community members with information on the importance of breast health and how to find and access the medical, insurance, and financial resources available.

**Priority 2:** Increase access to local breast cancer screening for residents in the all Target Communities.

*Objective 1:* FY 2016 to 2019, identify at least two local organizations and health provider facilities in each Target Community interested in and able to host mobile mammography opportunities for the populations they serve.

*Objective 2:* FY 2016 to 2019, the Affiliate and Mobile Mammography provider will partner with at least one local organization and/or provider in each Target Community to facilitate or cohost at least one mobile mammography event annually.

*Objective 3:* FY 2016 to 2019, Kohl's Conversations for the Cure program will annually lead a minimum of 1,000 women to age appropriate breast cancer screening as measured by the return of the program's screening confirmation cards.

**Priority 3:** Address the impact of fear and denial as major barriers to breast cancer screening and diagnostic services.

*Objective 1:* FY 2017, incorporate messaging about overcoming barriers of fear and denial in the Kohl's Conversations for the Cure media campaign to hit three million views over the campaign year.

*Objective 2:* FY 2017 – 2019, include breast health and breast cancer information through the inclusion of at least one 'survivor story' that addresses fear and denial in the Komen SEWI Quarterly Newsletter, the Survivor Newsletter, and on social media at least one time annually per media.

## **Education**

**Problem:** Providers and Key Respondents in all Target Communities feel that current breast health education efforts are not consistently effective at leading women to screening mammograms.

**Priority 1:** Provide access to information on breast self-awareness messaging and breast cancer resources to providers in all Target Communities.

*Objective 1:* FY 2017 to 2019, host and fund a yearly educational opportunity to provide curriculum on Komen Breast Self-Awareness messaging and discuss recommended breast cancer screening guidelines. FY 2017 in Milwaukee County, FY 2018 in the Northern Rural Region, and FY 2019 in the Southern Rural Region.

*Objective 2:* FY 2017 to 2019, annually create and distribute a document of available funding resources for breast cancer screening, diagnostic, and treatment services to at least five local providers in each Target Community identified in the health system analysis to improve their working knowledge of the various referral processes and their ability to better navigate patients.

*Objective 3:* FY 2017 to 2019, incorporate in-house provider education as a recommended priority in Community Grant RFAs.

**Priority 2:** Facilitate health providers and local organizations access to and utilization of Komen SEWI's Conversation for the Cure breast self-awareness curriculum and Komen's Breast Cancer tool kits.

*Objective 1:* FY 2017 to 2019, annually the Kohl's Conversations for the Cure program staff will extend an offer to provide leader training on the presentation of breast self-awareness curriculum to individuals working within local agencies from at least 1 organization per Target Community.

*Objective 2:* FY 2016 to 2019, annually the Affiliate will offer electronic distribution of Komen breast health and breast cancer educational toolkits to every local organization in the organization data base as well as to key breast health providers at health facilities identified in the health system analysis.

**Problem:** Lack of education was identified by all key informants and providers as a major barrier to screening and diagnostic breast health services in all Target Communities.

**Priority 1:** Increase the number of opportunities for women to be educated about their personal risk of breast cancer.

*Objective 1:* In FY 2017, incorporate the understanding of personal breast cancer risk into the media campaign for Kohl's Conversations for the Cure.

*Objective 2:* In FY 2016, incorporate a focus on understanding personal risk for breast cancer into the programming messaging of Breast Cancer Awareness Month.

**Priority 2:** Increase the availability of accurate and consistent breast health and breast cancer educational opportunities in each Target Community.

*Objective 1:* FY 2016 to 2019, provide annual access to the Affiliate's Conversation for A Cure Breast Self-Awareness Curriculum (verbally, electronically, and/or in-print) to all grantees for dissemination to their clients and their health system providers.

*Objective 2:* FY 2016 to 2019, utilizing the Breast Self-Awareness curriculum of the Kohl's Conversation for a Cure program, annually provide consistent breast health and breast cancer information (verbally, electronically, and/or in-print) to a minimum of 2,500 women residing in the Affiliate's Target Communities.

*Objective 3:* By the end of FY 2016, launch of a quarterly webinar series hosted by the Affiliate and featuring a variety of breast health and breast cancer relevant topics.

## Grantmaking

**Problem:** Future Grantmaking must align with needs identified in the 2015 Community Profile.

**Priority 1:** Facilitate access to the grantmaking process in every Target Community.

*Objective 1:* FY 2016 to 2017, host at least one meeting in each Target Community to provide an overview of the 2015 Community Profile, provide information on Komen SEWI Grantmaking, and to provide additional opportunities for local input on the gaps, needs and barriers to breast health services.

*Objective 2:* By end of FY 2017, the Affiliate's contact spreadsheet will be updated to utilize as the data base for disseminating information on the release of Grant RFA's and grant writing workshops.

*Objective 3:* FY 2018- 2019, quarterly updates to Contact Spreadsheet to keep document current and broadly inclusive.

*Objective 4:* FY 2017 to 2019, offer a webinar format option for the annual Community Grant Writing Workshop to accommodate potential grantees unable to travel into Milwaukee County for the in-person workshop.

*Objective 5:* FY 2017 to 2019, increase access to Community Grant funding for those organizations unable or unwilling to apply for funding independently by facilitating collaborative breast health project development and Community Grant program development between local organizations and/or local health providers based on information gathered during in person meetings.

**Priority 2:** Define the priorities of Community Grant (CG) Request for Applications (RFA) for upcoming grant years to reflect the needs and gaps addressed in the 2015 Community Profile.

*Objective 1:* FY 2017 to 2019, include a CG RFA Priority related to increasing access to local and affordable screening mammograms for vulnerable populations identified in the 2015 Community Profile.

*Objective 2:* FY 2017 to 2019, include a CG RFA Priority related to increasing access to local and affordable breast cancer services for vulnerable populations identified in the 2015 Community Profile.

*Objective 3:* FY 2017 to 2019, include a CG RFA Priority related to an effort to provide accurate and standardized breast cancer information to both Target Community's residents and to health care providers.

*Objective 4:* FY 2017 to 2019, include a CG RFA Priority related to the development of targeted outreach and strategic collaborations to provide access to breast health services across the continuum of care for vulnerable populations identified in the 2015 Community Profile.

**Priority 3:** Expand the narrative of the Community Grant RFA to include references to issues addressed in the 2015 Community Profile.

*Objective 1:* FY 2017 to 2019, include references to the following in each year's Community Grant RFA:

- Awareness of barriers faced by specific populations the program intends to serve;
- Methods for navigation of eligible women to Wisconsin Well Woman Program, Badger Care Plus, and the Federal Marketplace;
- Facilitation of Health Literacy;
- Facilitation of Insurance Literacy;
- Promotion of healthy lifestyle factors;
- Delivery of truly Cultural Sensitivity programming
- Details of Community Health Worker training and expectations,
- Utilization of a Community Health Worker model,
- Ability to address the top breast health screening and diagnostic barriers of Fear, money/insurance, culture, and transportation.

**Priority 4:** Foster the growth of the Small Grant program to promote new breast health initiatives, capacity building, and program development.

*Objective 1:* FY 2016-2019, during years when small grant funding is available, meet with a minimum of two possible small grantees from each Target Community each fiscal year to explore funding possibilities.

*Objective 2:* FY 2017 to 2019, as appropriate and based on information gathered during in person meetings in Objective 1, facilitate collaborative Community Grant and/or Small Grant program development between local organizations and/or local health providers by making connections between key organizational representatives through email and/or in person introductions.

## Survivorship

**Problem:** Providers and survivors in all Target Communities report having limited awareness of and under-utilization of survivor support services.

**Priority 1:** Assess and facilitate the ability of the Affiliate and local partner organizations ability to increase local awareness and understanding of available survivor support services.

*Objective 1:* By end of FY 2017, convene an exploratory meeting of local breast cancer organizations to initiate a conversation about local survivor support services.

*Objective 2:* FY 2017, convene interested stakeholders from all Target Communities to meet and consider the development of a strategic plan that would help:

- Identify available survivor support services;

- Increase awareness of available local survivor support services to health system providers and to breast cancer patients;
- Increase provider and patient understanding of the value of the survivor support services.
- Host or co-host event(s) to honor, inform, and/or support breast cancer survivors.

**Priority 2:** Increase opportunities for Komen SEWI to provide information on breast cancer survivor support services to survivors/forever fighter constituents.

*Objective 1:* FY 2016 to 2019, distribute a monthly Survivor Newsletter to survivors in the Affiliate's data base.

*Objective 2:* FY 2016 to 2019, facilitate access to ABCD: After Breast Cancer Diagnosis's services through contact links provided in the Survivor Newsletter and on Komen SEWI social media (in particular the organization's hotline, mentoring program, and ABCD's monthly Mets Virtual Support Group).

*Objective 3:* FY 2016 to 2019, host a free, annual Metastatic Breast Cancer Symposium in Waukesha County designed and marketed to Metastatic Breast Cancer patients, their families, and their providers that feature current and relevant presentations related to the topic of Metastatic Breast Cancer.

*Objective 4:* FY 2016 to 2019, host a free, annual Survivor Luncheon In Milwaukee County that honors the Affiliate's Survivor/Mets constituents and provides a presentation on a topic of relevance to these guests.

# References

- American Cancer Society. (2013). Cancer Facts & Figures for African-Americans 2013-2014. *Cancer Facts and Statistics*. Retrieved from <http://www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acs-036921.pdf>.
- Ahn J, Schatzkin A, Lacey JV Jr, et al. (2007) Adiposity, Adult Weight Change, and Postmenopausal Breast Cancer Risk. *Archives of Internal Medicine*. 167(19):2091-102.
- Barone BB, Yeh HC, Snyder CF, et al. (2008). Long-Term All-Cause Mortality in Cancer Patients with Preexisting Diabetes Mellitus: A Systematic Review and Meta-Analysis. *JAMA*. 300(23):2754-64.
- Carey LA, Perou CM, Livasy CA, et al. (June 7, 2006). Race, Breast Cancer Subtypes, and Survival in the Carolina Breast Cancer Study. *Journal of the American Medical Association*. 295(21):2492-2502.
- Del Giudice ME, Fantus IG, Ezzat S, et al. (1998). Insulin and Related Factors in Premenopausal Breast Cancer Risk. *Breast Cancer Research and Treatment*. 47:111-20.
- Eliassen AH, Tworoger SS, Mantzoros CS, Pollak MN, Hankinson SE. (2007). Circulating Insulin and C-Peptide Levels and Risk of Breast Cancer among Predominately Premenopausal Women. *Cancer Epidemiology, Biomarkers and Prevention*. 16(1):161-4.
- Eliassen AH, Colditz GA, Rosner B, et al. (2006). Adult Weight Change and Risk of Postmenopausal Breast Cancer. *Journal of the American Medical Association*. 296(2):193-201.
- HP 2020. Healthy People 2020. US Department of Health and Human Services. December 2, 2010. Available online at <http://www.healthypeople.gov/2020/about/> (accessed 8/2/2013).
- Li CI, Malone KE, Daling JR. (July 2002). Differences in Breast Cancer Hormone Receptor Status And Histology By Race And Ethnicity Among Women 50 Years Of Age And Older. *Cancer Epidemiol Biomarkers*. 11(7):601-607.
- National Center for Health Statistics, Centers for Disease Control and Prevention. (April 2012). Mortality - All COD, Aggregated With State, Total US (1969-2009) as provided by the Surveillance, Epidemiology, and End Results (SEER) Program data base. Retrieved at <http://www.seer.cancer.gov/data>.
- SEER Summary Stage. Young, J.L. Jr., Roffers, S.D., Ries, L.A.G., Fritz, A.G., Hurlbut, A.A. (eds). *SEER Summary Staging Manual - 2000: Codes and Coding Instructions*, National Cancer Institute, NIH Pub. No. 01-4969, Bethesda, MD, 2001. Available online at <http://seer.cancer.gov/tools/ssm/> (accessed 8/2/2013).
- Susan G. Komen. (2014). Susan G. Komen Southeast Wisconsin quantitative data report: 2014. Dallas, TX: Author.

Susan G. Komen. (2014, March 15). Breast cancer statistics. Retrieved from <http://ww5.komen.org/BreastCancer/Statistics.html#NativeAmerican> (no longer active)

Wisconsin Department of Health Services. (2008) Wisconsin Epidemiological Profile on Alcohol and Other Drug Use. Retrieved from <http://www.dhs.wisconsin.gov/stats/pdf/acoholconsumption2008.pdf>.

Wisconsin Department of Health Services. (January 2008). American Indians in Wisconsin. *Wisconsin Department of Health Services Minority Health Report 2001-2005*. Retrieved from <https://www.dhs.wisconsin.gov/minority-health/population/amind-pop.htm>.

Wisconsin Department of Health Services. (January 2008) Asian Americans in Wisconsin. *Wisconsin Department of Health Services Minority Health Report 2001-2005*. Retrieved from <https://www.dhs.wisconsin.gov/minority-health/population/asian-pop.htm>.

Wisconsin Department of Health Services. (January 2008). The Health of Racial and Ethnic Populations of Wisconsin: 2001-2005. *Wisconsin Department of Health Services Minority Health Report 2001-2005*. Retrieved at <https://www.dhs.wisconsin.gov/publications/p4/p45716.pdf>.

Wisconsin Department of Health Services. (January 2014) *Healthiest Wisconsin 2020 Baseline and Health Disparities Report*. Retrieved at <http://www.dhs.wisconsin.gov/publications/PO/p00522.pdf>.

Wisconsin Department of Health Services, Division of Public Health. (2008). Obesity, Nutrition, and Physical Activity in Wisconsin. *Nutrition, Physical Activity and Obesity Program and Wisconsin Partnership for Activity and Nutrition*. Retrieved at <https://www.dhs.wisconsin.gov/publications/p0/p00009.pdf>.

US Census Bureau. (August 2008). Income, Poverty and Insurance Coverage in the United States. *Current Population Reports: Consumer Income*. Retrieved at <https://www.census.gov/prod/2008pubs/p60-235.pdf>.

US Centers for Disease Control and Prevention Department of Health Services Bureau of Health Information and Policy, Division of Public Health. (December 2010) Adult Obesity Facts. *Behavioral Risk Factor Survey Behavioral Risk Factor Surveillance System*. Retrieved at <http://www.cdc.gov/obesity/data/adult.html>.

US Department of Health and Human Services National Institutes of Health. (September 2009). Per Capita Ethanol Consumption for States, Census Regions, and the United States, 1977-2007. *National Institute on Alcohol Abuse and Alcoholism Division of Epidemiology and Prevention Research Alcohol Epidemiologic Data System*. Retrieved at <http://pubs.niaaa.nih.gov/publications/surveillance87/CONS07.pdf>.

US Department of Health and Human Services. (June 2014). Profile: Asian Americans. *Office of Minority Health Minority Population Profiles*. Retrieved at <http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=63>.

US Department of Health and Human Services. (December 2013). Social Determinants of Health. *National Center on Minority Health and Health Disparities Initiative*. Retrieved at <http://www.nimhd.nih.gov/recovery/goSocialDeterm.asp>.

US Department of Health and Human Services. (July 2012). Lesbian and Bisexual Health Fact Sheet. *Office of Women's Health ePublications*. Retrieved from <http://womenshealth.gov/publications/our-publications/fact-sheet/lesbian-bisexual-health.html>.

Yaghjian L, Colditz GA, Collins LC, et al. (2011) Mammographic Breast Density and Subsequent Risk of Breast Cancer in Postmenopausal Women According to Tumor Characteristics. *Journal of the National Cancer Institute*. 103(15):1179-89.