

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



SUSAN G. KOMEN®
CENTRAL WISCONSIN

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- Marathon County Health Department
- Aspirus Wausau Hospital
- Taylor County Health Department
- Bridge Community Health Clinic

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Executive Summary

Introduction to the Community Profile Report

Susan G. Komen Central Wisconsin: Affiliate History

The Central Wisconsin Affiliate was granted affiliation by Susan G. Komen® in December 2006 and announced to the public January 3, 2007. This followed a thorough application process that began in 2004. The planning committee was a group of dedicated and determined individuals who had a vision to make a difference in Central Wisconsin and to bringing the foundation's mission to end breast cancer through the advancement of research, education, screening and treatment to seven counties. Today the Affiliate still carries on their passion, insight and hard work that continues to make the Affiliate thrive.

In 2014, the Affiliate held its 5th annual Race for the Cure®. The Affiliate has received the "Best Fundraising event" award from "The City Pages" in the years 2012 and 2013. The City Pages is a local free weekly news and arts Publication for the Greater Wausau area.

Since its inception, Komen Central Wisconsin has remained an all-volunteer board. This includes the Race committee and Race leadership. As such, the Affiliate expense ratio has remained very low. In 2011, the Affiliate was given an award by Komen Headquarters for having the lowest expense ratio among all Affiliates. The Affiliate has continued to work hard to maintain a low expense ratio and, in turn, grant out the majority of funds received into the service area.

The Affiliate has also been the catalyst in bringing together the two major health systems, Aspirus and Marshfield Clinic, around the central issue of breast cancer. By strategically targeting Board and Race membership and support from both systems, the Affiliate has truly broken down communication barriers and developed partnerships, across both systems that benefit women and men in the communities the Affiliate serves.

The continuum of care provided by the Affiliates granting illustrates this. Breast health and educational programs are provided through grants to local health departments and to one of the two major hospital/clinic systems. Screening, diagnostic, and genetic testing is provided through a grant program run by that same hospital/clinic system. A survivorship program is grant funded through the areas other major clinic system. Finally, a grant-funded Treatment Access Fund is run by a local breast health task force, whose steering committee is comprised of leadership from all area health systems and health departments. Because of the strategic affiliations and partnerships created over the years, the Affiliate is proud to fund the entire continuum of care for men and women in the Affiliates service area.

While the Affiliate still has work to do in the organizational structure in the absence of any paid staff, the Affiliate is proud to say that it has surpassed the \$1 million mark for grants given in 2014 (Table 1). The Affiliate is known as the main local funder for breast cancer programs and services that make an impact in the Central WI service area. The Affiliate holds strong ties with a very resource-rich, community-minded, and locally dedicated group of influencers. The Affiliate is proud of the impact it has made in eight short years and looks forward to strategically taking the Affiliate to the next level.

In 2013, Komen Central Wisconsin funded programs which provided more than 2,000 men and women in the seven county service area with life-saving breast cancer screenings, treatment and education. Wellness Beyond Breast Cancer workshops touched 36 women with their 2013-2104 grant program, representative of all seven service area counties, ranging in age from 26-75 years old. The women who attended the workshops were in various stages of their breast cancer journey - ranging from one week to six years post treatment. Another Grantee qualified more than 280 women for breast cancer detection assistance in 2013. From the mammograms funded by Komen Central Wisconsin last year, breast cancer was detected in 12 women. This compares to a total of four women from the previous six years.

Table 1. Grant data

Number Of Grants	Amount Funded	Fiscal Year
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As mentioned above, the Affiliate is the go-to resource for breast cancer program funding in the Central Wisconsin service area. Komen Central Wisconsin is the central conduit through which information and funds flow that would otherwise not be available in central Wisconsin communities. An illustration of this is the amount of third party events benefitting the Affiliate. Third party donations have increased by approximately \$17,000 since 2009.

The Central Wisconsin local media also views the Affiliate as the lead agency for breast cancer resources. Of the two major local TV stations, one continues to be a substantial media sponsor for the Race year after year. The major radio group and the only outdoor advertising company covering the Central Wisconsin area are also major Race media sponsors year after year. Komen Central Wisconsin is fortunate to have these supportive relationships, which have strategically grown since 2007.

Affiliate Service Area

Komen Central Wisconsin covers seven counties: Marathon, Lincoln, Langlade, Wood, Portage, Taylor and the western half of Shawano (Figure 1). The counties share a common theme; they are predominantly rural with a few small cities. Marathon County is the most populous with 134,735 residents. The counties are predominantly non-Hispanic white, with much smaller populations of Hmong (South East Asian), Hispanic/Latino, American Indian/Alaskan Native and Black/African-American. Marathon County has the largest Hmong population at 5.6 percent, a 1.06 percent increase from the last Community Profile. The true Hispanic/Latino population is unknown as many Hispanic/Latino residents are undocumented workers, many of whom work on dairy farms and mink ranches. Residents in Lincoln County have to travel long distances to receive diagnostic breast care services.

KOMEN CENTRAL WISCONSIN SERVICE AREA

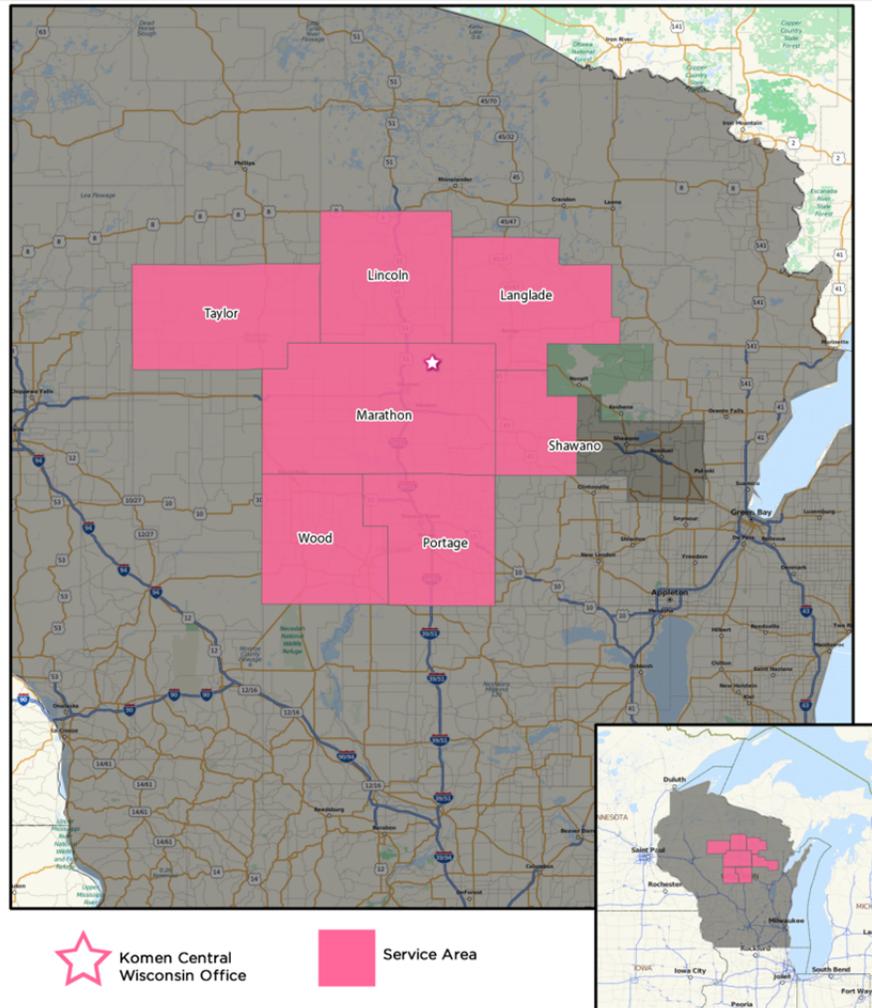


Figure 1. Komen Central Wisconsin service area map

Purpose of the Community Profile Report

The purpose of the 2015 Community Profile is to provide current information on breast cancer and access to the continuum of care so the Affiliate can better understand the present condition of breast cancer in its seven county territories.

The Community Profile is used to clarify the demographics of the seven counties that Komen Central Wisconsin serves, reviews the current breast health programs, institutions and services in those areas and reveals the gaps in breast health services. This profile assists Komen Central Wisconsin with determining its future goals and objectives, as well as, the types of grants awarded by the Affiliate in line with the overall mission of Susan G. Komen. The Community Profile can also help educate and build awareness in the areas of greatest need, and strengthen relationships with sponsors and public policymakers. In addition, as area hospitals and health departments complete their federal/state required community health improvement plans, the data from the Community Profile will provide valuable data, resources and vital information as they complete this process.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

The purpose of the quantitative data report for Susan G. Komen® Central 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 breast cancer late-stage diagnosis and death rate objectives for Healthy People 2020:

<http://www.healthypeople.gov/2020/default.aspx>.

The Quantitative Data report for Susan G. Komen Central Wisconsin was reviewed. Data was also gathered from the Wisconsin Department of Health Services from 2009-2011. This data was used to help determine poverty status and health insurance coverage. The data was compared to the previous Community Profile to track trends and identify areas of increased need. According to the Wisconsin Department of Health Services, the number of uninsured in Marathon County increased by 6,000 and in Lincoln County it decreased by 2,000. People on Medicare in Marathon County increased by 3,000 people while Lincoln County increased by 1,000 people. The number of people on Medicaid in Marathon County was cut in half while Lincoln County saw an increase from less than 1,000 people to 6,000 from 2005-2007 to 2009-2011. Summary from the Quantitative data report showed that the Affiliate's female population is slightly older than that of the US as a whole. There are a substantially larger percentage of people living in rural areas (47.5 percent), a substantially smaller percentage of people without health insurance, and a substantially smaller percentage of people living in medically underserved areas.

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.

Affiliate Service Area Healthy People 2020 Forecasts and Priority Areas

The results presented in Table one 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.

Table 2. Intervention priorities for Komen Central 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
Lincoln County - WI	Highest	13 years or longer	SN	Rural
Shawano County - WI	Highest	13 years or longer	SN	%AIAN, rural, medically underserved
Marathon County - WI	Lowest	Currently meets target	SN	Medically underserved
Portage County - WI	Lowest	Currently meets target	SN	
Wood County - WI	Lowest	Currently meets target	SN	
Langlade County - WI	Undetermined	SN	SN	Rural
Taylor County - WI	Undetermined	SN	SN	Rural, medically underserved

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

Needs Assessment and Priority Areas Summary

Table 2 shows that the counties classified as **highest** priority are:

- Lincoln County
- Shawano County

Summary of key findings

To determine priority areas, each county’s estimated time to reach the HP2020 target for late-stage diagnosis and death were compared and then each county was categorized into seven potential priority levels. Two counties in the Komen Central Wisconsin service area are in the highest priority category: Lincoln County and Shawano County.

Because death rate trend data are not available for the Komen Central Wisconsin service area, it can't be predicted whether the Affiliate service area will meet the HP2020 target of 20.6 female breast cancer deaths per 100,000.

The following counties **currently meet** the HP2020 breast cancer death rate target of 20.6: Marathon County, Portage County, and Wood County.

The following counties are **likely to miss** the HP2020 breast cancer death rate target unless the death rate falls at a faster rate than currently estimated: Lincoln County and Shawano County.

The quantitative data analysis identified Shawano County as a county of need as they are likely to miss the HP 2020 breast cancer death rate target. They have a high percentage of American Indian population in the Eastern half on the county. Since Komen Central Wisconsin only

services the western half of Shawano County the Affiliate is not including it as a targeted community.

Marathon County was chosen as it is the most populous and had the highest minority population and is medically underserved. Lincoln County was chosen as it is likely to miss the HP2020 breast cancer death rate target and due to the population being mostly rural.

Health Systems and Public Policy Analysis

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 2). 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.

The Continuum of Care is the essential framework in analyzing the health systems in Lincoln and Marathon Counties. The cycle of screening, diagnosis, treatment, and follow-up care could happen quite differently in different settings. Gaps in any one of these four components of care can influence the breast cancer statistics in a community.

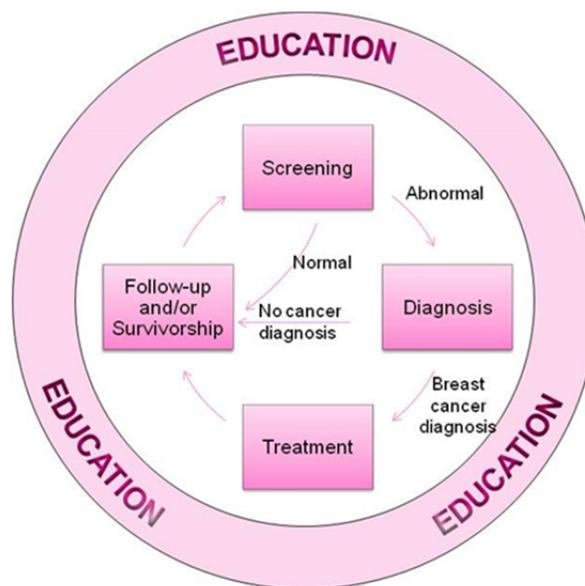


Figure 2. Breast Cancer Continuum of Care (CoC)

The Affiliates assessment determined that many primary care centers are available for entry into the continuum of care, but mammography services are scant in Lincoln County. In Tomahawk to the north, only screening mammography is available and those needing diagnostic services must travel to Oneida County to the north, Merrill in southern Lincoln County or to Marathon County. All facilities accept Medicaid, Medicare and WWWP.

In Marathon County a woman is more likely to move through the Continuum of Care more quickly and seamlessly, receiving timely, quality care as the Health Systems that provide the complete Continuum of care are located in Marathon County.

Both major health systems in Marathon County also provide Mobile screening mammography services throughout Marathon County and at a few sites in Lincoln County which allow access into their systems for continuation of care. Unfortunately if a patient in Lincoln County does need treatment she will have to travel which may limit compliance and influence breast cancer statistics.

Public Policy Overview

The Affiliate enjoys a strong relationship with the legislature and have recently engaged a relationship with the Wisconsin Breast Cancer Coalition, (an advocacy group) and look forward to making advancements in Breast care throughout Wisconsin together. The Affiliate and the

WBCC have the support of Local legislatures in issues and laws regarding the breast health of Wisconsin women. They were instrumental in having legislature delay changes to the Wisconsin Well Woman Program (WWWP) that would have limited access for women to free screening services.

When Wisconsin elected not to accept the federal funding to expand the Medicaid program as provided for and envisioned by the Affordable Care Act, many county boards began seeking ways to access those funds on their own. Last year, twenty County Boards passed resolutions calling on the state to take the money. This year, they are passing resolutions to hold advisory referendums during the November election calling on the legislature to accept the federal funding. As of July 18, Dunn, Lincoln, Outagamie, Milwaukee, Eau Claire, Clark, LaCrosse and Dane Counties have all passed resolutions to hold referendums. WBCC has issued a letter to county boards across the state encouraging them to pass these resolutions and is one of many health advocacy organizations collaborating with Citizen Action Wisconsin to impress upon this administration the importance of ensuring access to quality, affordable health care for everyone in Wisconsin.

The Affiliate also has a working relationship with the two southern Wisconsin Komen Affiliates to address public policy together for all of Wisconsin to address future breast health public policy activities.

The Affiliate concludes that access to the CoC is limited in Lincoln County but a woman has access to the complete CoC in Marathon County however financial and cultural barriers limit their seeking breast screening. The Affiliate will continue to work with the legislature in an effort to continue to improve access to quality affordable health care.

Qualitative Data: Ensuring Community Input

Susan G. Komen Central Wisconsin sought to identify gaps in service, cultural barriers, and identify needs of newly diagnosed breast cancer patients. Komen Central Wisconsin chose two methods for collecting data, focus groups and an online survey tool, Survey Monkey. The Wisconsin Well Woman Coordinator for the Marathon County Health Department conducted the focus groups. The focus groups were used to identify gaps in services and/or specific needs associated with the participants personal lives during treatment such as ability to pay for bills, transportation, etc. The data was collected in written and verbal formats. The SurveyMonkey questionnaire for race participants and medical providers was developed by some of Komen Central Wisconsin's board members. Sample questions were utilized from the Community Profile tool kit to assist with identification of potential gaps and barriers. All participants who received the survey had an option to opt out of the survey.

Focus Group

There were 30 individual names provided by the three health care systems in Marathon County to invite for this cohort. There were nine women who agreed to participate from the list.

SurveyMonkey

Random samplings of 731 race participants were chosen to complete the survey of over 1000 names available. The names were removed who did not have email addresses, had responded to previous surveys or opted out of the survey. The Affiliate had 80 respondents to the survey,

87 percent of the participants were from the Affiliates seven county service area. Of those 75 percent were from the two target counties of Marathon and Lincoln.

The medical professionals who were sent surveys were obtained from the list of committee members participating on the Marathon County Breast Health Coalition and/or who provide services to breast cancer patients. There were 22 surveys sent to this cohort and only four responded.

Qualitative Data Overview

Komen Central Wisconsin chose to use focus groups and the database of race participants as a representative sample of individuals of all ages, ethnicity and demographic areas. These representative samples are individuals affected by breast cancer personally, family member/support or provider of services and/or believe in the cause associated with the Komen foundation. The formats provided the Affiliate the opportunity to reach the most individuals based on the geographic area of the Affiliate and the unique needs of each area, urban versus rural. The questions asked were on a variety of topics associated with screening, barriers, identified needs or gaps in services, and resources available. Some of these questions were taken from the Community Profile toolkit provided by Komen.

Qualitative Data Findings

The key questions were to identify gaps in service, cultural barriers and identify needs of newly diagnosed breast cancer patients. It is noted the cohort were similar in their responses to identified barriers and increasing access to screening services with responses of; afraid of results, discomfort/pain due to mammogram, no insurance/high deductible and lack of money. The suggestions to increase access or outreach included free or reduced costs mammograms, the use of mobile mammography, increase in education/advertisement and providers stressing the importance of screening for breast cancer.

The identified factors for the limitation of the data were the response rates for the surveys and the focus groups. Only 10.9 percent of the surveys were completed by the race participants and 18 percent of the providers, of these 75 percent were from the target counties. In addition to the response rate, not all of the questions were answered which limited the findings. The focus groups were only done in Marathon County as a pilot to see the needs of those recently diagnosed with breast cancer with the plan to provide a treatment access fund to them. If the program is successful the Affiliate would like to duplicate the fund in Lincoln County and other counties in the service area.

The successes of the surveys and focus groups were that they identified that patients are receiving care in a timely manner. The gaps are that there are cultural and financial barriers as well as fear of results and pain during the exam that keep women from getting the recommended screenings.

This information will assist hospitals and local health departments in the Affiliate service area who are statutorily required to complete community health assessments/community health improvement plans in Wisconsin. This information will assist these organizations to address the identified goals and objectives for public health/population health in the Healthiest Wisconsin 2020 (Chronic Disease and Prevention) and Healthy People 2020 (Cancer) to reduce the incidence of breast cancer.

Mission Action Plan

Through review of the quantitative data, qualitative data and Health Systems and Public Policy Analysis (HSPPA), the Profile Committee acknowledges the Affiliate service area needs to continue addressing the challenge of access to mammography and early detection in both Lincoln and Marathon counties. The counties share a common theme; they are predominately rural with a few small cities. Marathon County is the most populous, with 134,735 residents. The counties are predominantly non-Hispanic White, with much smaller populations of Hmong (South East Asian), Hispanic/Latino, American Indian/Alaskan Native and Black/African-American. Marathon County has the largest Hmong population at 5.6 percent, a 1.06 percent increase from the last Community Profile. The true Hispanic/Latino population is unknown as many of the Hispanic/Latino are undocumented workers, many of whom work on dairy farms. The Quantitative Data report documented a two percent Hispanic/Latino population in the Affiliate as a whole.

In 2013 and 2014, major changes to the Wisconsin Well Woman Program (WWWP) have negatively impacted access and financial resources to uninsured and under-insured women in the target counties. Due to funding cuts and program restructuring, annual enrollment access into WWWP has been restricted from 300+ women to less than 100. In addition, county health department coordinators for breast health resources and coordination of care funding have been cut. The current model to be implemented in Wisconsin effective July 1, 2015, will have one coordinator for the Affiliate service area as the state moves to a regionalized model. This will be a burdensome task for one coordinator to know the breast health resources for all seven counties in the area.

Based on both focus-group and key informant survey data, health care providers, community members, and survivors, there remains evidence that a large number of women are afraid of or uninformed about the importance of breast cancer screening. The data for race participant respondents identified 76 percent had mammograms and 30 percent have had breast cancer. A total of 64-69 percent of respondents reported finding a lump or experiencing pain and family/friends made them seek breast cancer screening services. Anecdotally, many women simply overwhelmed with everyday needs and financial concerns to make it a priority. The Affiliate's focus will be to facilitate resource navigation to community grant-funded programs and particularly expand these in Lincoln County.

Thus, the data gathered from questionnaire respondents, focus groups, HSPPA, and quantitative data supports the following direction for the 2015 Community Profile Action Plan:

- Increased breast health education in the target counties
- Increased rural access to screening and diagnostic mammography, particularly in Lincoln County
- Increased access to coverage for diagnostic mammography, particularly in Lincoln County
- Financial assistance for newly diagnosed breast cancer patients in Marathon and Lincoln Counties

Problem Statement:

The quantitative and qualitative data and HSPPA identified a need to increase the opportunities for rural and minority women to receive breast health education, screening, and diagnostic testing, particularly in Marathon and Lincoln counties as they have limited access.

Priority: Increase access to breast health services, breast health education and public awareness for women in Lincoln and Marathon County.

Objective 1

Conduct at least one grant writing workshop in the cities of Merrill and Tomahawk in Lincoln County prior to the 2016-2017 and 2017-2018 funding cycles. This will be to inform the community of the findings of the Komen Central Wisconsin's Community Profile and enable them an opportunity to apply for funding that would directly impact the community.

Objective 2

Increase solicitation for Komen Central Wisconsin's community grant RFPs from mammography programs that utilize multi-site, mobile mammography, and/or non-traditional service locations in Lincoln and Marathon Counties. This will be accomplished by inviting Aspirus, Marshfield Clinic, and Ministry Health Center to grant writing workshops in Spring of 2016.

Objective 3

Increase public awareness of Komen Central Wisconsin small and community grants in Lincoln County prior to 2016-2017 funding cycle. This will be done using print and television media as well as community partners.

Problem Statement: According to Quantitative and Qualitative Data collected, women in the target communities of Lincoln County have an increasing death rate.

Priority: Increase screening compliance and access to financial aid during treatment in Lincoln and Marathon Counties. The Affiliate will continue to build community partnerships with providers and local businesses. The Affiliate will reach out to providers to increase screening compliance as well as to local companies to increase access to financial aid.

Objective 1

Recruit and retain one board member from Lincoln County by the 2016-2017 Komen Central Wisconsin funding year. A Lincoln County board member will be able to speak on behalf of the women of Lincoln County and serve as a liaison to and advocate for their community. As an advocate, this person will be able to inform community residents of available services. They will also help recruit providers and local businesses.

Objective 2

From FY15-FY19 in order to better identify the needs of women in Lincoln County, the Affiliate will continue to retain at all times at least one grant reviewer who will act on behalf of, and obtain grants for, the citizens of Lincoln County.

Objective 3

Beginning September of 2015, the Affiliate will meet quarterly with the Lincoln and Marathon County community partners such as Health Department, area mammography providers, and regional WWWP representatives. The objective will be to identify initiatives to improve the continuum of care cycle and resource navigation for rural women.

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

Introduction

Affiliate History

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Affiliate Organizational Structure

Komen Central Wisconsin is currently an all-volunteer organization, composed of a Board of Directors and a number of Committees chaired by Board members.

Board of Directors:

President	Sandy Draeger
Vice President	Kristine Alston
Secretary & Survivorship Chair	Kim LePine
Treasurer	Tricia Nielsen
Board Development Chair	Jennifer Smith
Grants Committee Chair	Patty Krug
Fundraising Chair	Deb Clements
Events Committee Chair	Sandy Draeger

Advocacy Committee Chair	Kathy Frierson
Technology Chair	John Willems Van Dijk
Public Relations Chair	Vacant
Education Chair	Vacant
Race Chair	Vacant
Volunteer Chair	Vacant

Affiliate Service Area

Komen Central Wisconsin covers seven counties: Marathon, Lincoln, Langlade, Wood, Portage, Taylor and the western half of Shawano (Figure 1.1). The counties share a common theme; they are predominantly rural with a few small cities. Marathon County is the most populous with 134,735 residents. The counties are predominantly non-Hispanic white, with much smaller populations of Hmong (South East Asian), Hispanic/Latino, American Indian/Alaskan Native and Black/African-American. Marathon County has the largest Hmong population at 5.6 percent, a 1.06 percent increase from the last Community Profile. The true Hispanic/Latino population is unknown as many Hispanic/Latino residents are undocumented workers, many of whom work on dairy farms and mink ranches. Residents in Lincoln County have to travel long distances to receive diagnostic breast care services.

KOMEN CENTRAL WISCONSIN SERVICE AREA

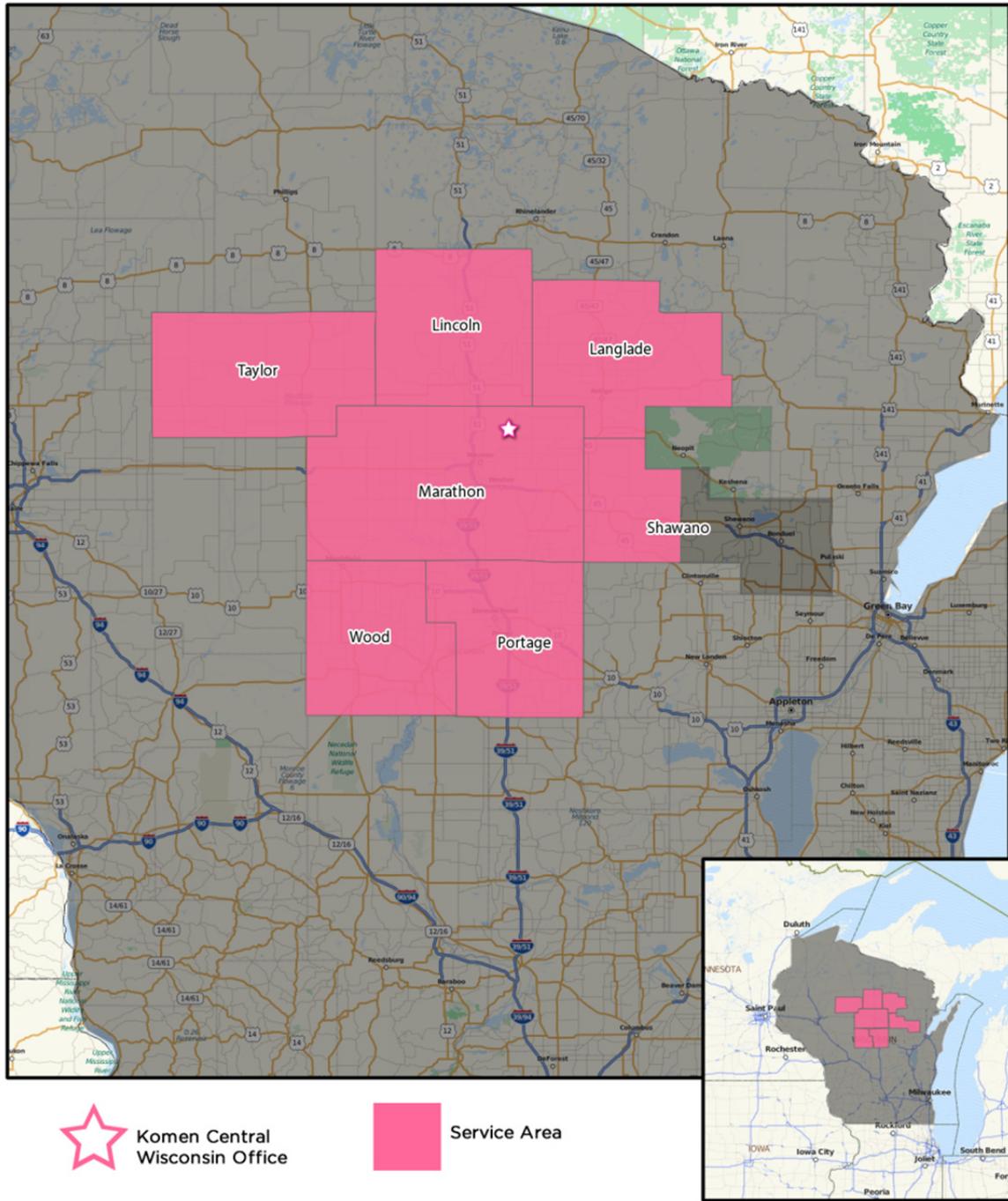


Figure 1.1. Susan G. Komen Central Wisconsin service area

Purpose of the Community Profile Report

The purpose of the 2015 Community Profile is to provide current information on breast cancer and access to the continuum of care so the Affiliate can better understand the present condition of breast cancer in its seven county territories.

The Community Profile is used to clarify the demographics of the seven counties that Komen Central Wisconsin serves, reviews the current breast health programs, institutions and services in those areas and reveals the gaps in breast health services. This profile assists Komen Central Wisconsin with determining its future goals and objectives, as well as, the types of grants awarded by the Affiliate in line with the overall mission of Susan G. Komen. The Community Profile can also help educate and build awareness in the areas of greatest need, and strengthen relationships with sponsors and public policymakers. In addition, as area hospitals and health departments complete their federal/state required community health improvement plans, the data from the Community Profile will provide valuable data, resources and vital information as they complete this process.

The Community Profile Report will be shared with the following community partners to increase partnerships through the following mediums:

Major Race Sponsors and Donors	Hard copy mailed & .pdf emailed
Minor Race Sponsors and Donors	.pdf emailed
Area Health Care Systems	Hard copy mailed & .pdf emailed
County Health Officers	Hard copy mailed
Grantees (past and present)	Hard copy mailed & .pdf emailed
Race Participants	.pdf emailed
Community at Large	Link on Affiliate website
Media Outlets	.pdf emailed with press release

A letter of introduction and “asks” will be included with each hard copy mailed. In addition, the Affiliate will work to schedule meetings with key partners to discuss the Community Profile findings and elicit support for important next steps.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Quantitative Data Report

Introduction

The purpose of the quantitative data report for Susan G. Komen® Central 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 Central 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 Central Wisconsin Service Area	194,392	NA	NA	NA	49	18.9	NA	NA	NA	NA
White	184,953	NA	NA	NA	48	19.0	NA	NA	NA	NA
Black/African-American	1,141	NA	NA	NA	SN	SN	SN	NA	NA	NA
American Indian/Alaska Native (AIAN)	2,794	NA	NA	NA	SN	SN	SN	NA	NA	NA
Asian Pacific Islander (API)	5,504	NA	NA	NA	SN	SN	SN	NA	NA	NA
Non-Hispanic/ Latina	190,874	NA	NA	NA	49	18.9	NA	NA	NA	NA
Hispanic/ Latina	3,518	NA	NA	NA	SN	SN	SN	NA	NA	NA
Langlade County - WI	10,102	13	92.7	NA	SN	SN	SN	NA	NA	NA
Lincoln County - WI	14,513	25	124.1	NA	6	27.7	9.0%	NA	NA	NA
Marathon County - WI	66,135	112	144.4	NA	16	19.1	-2.4%	NA	NA	NA
Portage County - WI	34,706	45	119.2	NA	7	17.8	-2.0%	NA	NA	NA
Shawano County - WI	20,944	29	107.6	NA	7	24.9	0.6%	NA	NA	NA
Taylor County - WI	10,070	12	96.3	NA	SN	SN	SN	NA	NA	NA
Wood County - WI	37,923	54	109.9	NA	8	14.4	-4.5%	NA	NA	NA

*Target as of the writing of this report.

NA – data not available.

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

Data are for years 2006-2010.

Rates are in cases or deaths per 100,000.

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

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

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

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

Incidence rates and trends summary

Breast cancer incidence data was not available for the Komen Central Wisconsin service area.

The following counties had incidence rates higher than the State of Wisconsin:

- Lincoln County
- Marathon County
- Portage County

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 Central Wisconsin service area was lower than that observed in the US as a whole and the death rate trend was not available for comparison with the US as a whole. The death rate of the Affiliate service area was not significantly different than that observed for the State of 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. There were not enough data available within the Affiliate service area to report on Blacks/African-Americans, APIs and AIANs so comparisons cannot be made for these racial groups. Also, there were not enough data available within the Affiliate service area to report on Hispanics/Latinas so comparisons cannot be made for this group.

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

- Lincoln 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 was not available for the Komen Central 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 Central Wisconsin Service Area	155	127	83.4%	75.5%-89.1%
White	149	125	86.0%	78.2%-91.2%
Black/African-American	SN	SN	SN	SN
AIAN	SN	SN	SN	SN
API	SN	SN	SN	SN
Hispanic/ Latina	SN	SN	SN	SN
Non-Hispanic/ Latina	155	127	83.4%	75.5%-89.1%
Langlade County - WI	19	15	80.4%	56.7%-92.8%
Lincoln County - WI	22	16	84.2%	60.0%-95.0%
Marathon County - WI	34	32	89.4%	72.3%-96.4%
Portage County - WI	15	14	85.5%	57.3%-96.3%
Shawano County - WI	32	26	84.1%	64.1%-94.0%
Taylor County - WI	14	9	70.0%	41.3%-88.5%
Wood County - WI	19	15	75.7%	49.9%-90.7%

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

Data are for 2012.

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

Breast cancer screening proportions summary

The breast cancer screening proportion in the Komen Central Wisconsin service area was not significantly different than that observed in the US as a whole. The screening proportion of the Affiliate service area was not significantly different than the State of 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. There were not enough data available within the Affiliate service area to report on Blacks/African-Americans, APIs and AIANs so comparisons cannot be made for these racial groups. Also, there were not enough data available within the Affiliate service area to report on Hispanics/Latinas so comparisons cannot be made for this group.

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

Population Characteristics

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

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

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

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

Table 2.4. Population characteristics – demographics

Population Group	White	Black /African-American	AIAN	API	Non-Hispanic /Latina	Hispanic /Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
US	78.8 %	14.1 %	1.4 %	5.8 %	83.8 %	16.2 %	48.3 %	34.5 %	14.8 %
Wisconsin	89.1 %	7.1 %	1.2 %	2.6 %	94.2 %	5.8 %	49.8 %	36.0 %	15.5 %
Komen Central Wisconsin Service Area	94.8 %	0.7 %	1.5 %	3.0 %	97.9 %	2.1 %	52.7 %	38.8 %	17.6 %
Langlade County - WI	97.5 %	0.6 %	1.4 %	0.5 %	98.3 %	1.7 %	59.2 %	45.6 %	22.2 %
Lincoln County - WI	98.5 %	0.4 %	0.4 %	0.6 %	98.9 %	1.1 %	58.4 %	43.9 %	20.7 %
Marathon County - WI	93.0 %	0.9 %	0.6 %	5.6 %	97.8 %	2.2 %	51.1 %	36.8 %	16.1 %
Portage County - WI	95.8 %	0.8 %	0.5 %	3.0 %	97.4 %	2.6 %	47.0 %	34.2 %	14.5 %
Shawano County - WI	90.2 %	0.6 %	8.7 %	0.5 %	97.9 %	2.1 %	55.7 %	41.5 %	20.4 %
Taylor County - WI	98.7 %	0.5 %	0.3 %	0.5 %	98.4 %	1.6 %	53.6 %	39.6 %	18.1 %
Wood County - WI	96.3 %	0.8 %	1.0 %	1.9 %	97.8 %	2.2 %	55.2 %	41.2 %	19.2 %

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 – socioeconomic

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistically Isolated	In Rural Areas	In Medically Underserved 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 Central Wisconsin Service Area	11.1 %	10.7 %	28.7 %	6.9 %	2.8 %	0.9 %	47.5 %	14.5 %	9.2 %
Langlade County - WI	12.5 %	11.7 %	38.3 %	7.6 %	1.7 %	0.5 %	59.2 %	14.0 %	11.6 %
Lincoln County - WI	11.9 %	10.6 %	29.9 %	6.1 %	1.1 %	0.1 %	54.0 %	0.0 %	9.3 %
Marathon County - WI	11.2 %	9.4 %	26.2 %	6.7 %	4.0 %	1.2 %	43.0 %	20.6 %	9.1 %
Portage County - WI	9.4 %	12.7 %	24.9 %	6.7 %	3.3 %	1.3 %	36.0 %	3.3 %	7.8 %
Shawano County - WI	11.9 %	11.3 %	33.3 %	8.0 %	1.2 %	0.7 %	74.4 %	23.9 %	12.5 %
Taylor County - WI	14.6 %	12.5 %	34.9 %	7.9 %	1.3 %	0.6 %	80.4 %	37.9 %	10.7 %
Wood County - WI	10.2 %	10.0 %	28.9 %	6.9 %	2.4 %	0.5 %	36.7 %	8.0 %	7.8 %

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

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

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

To see how well counties in the Komen Central 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 Central 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
Lincoln County - WI	Highest	13 years or longer	NA	Rural
Shawano County - WI	Highest	13 years or longer	NA	%AIAN, rural, medically underserved
Marathon County - WI	Lowest	Currently meets target	NA	Medically underserved
Portage County - WI	Lowest	Currently meets target	NA	
Wood County - WI	Lowest	Currently meets target	NA	
Langlade County - WI	Undetermined	SN	NA	Rural
Taylor County - WI	Undetermined	SN	NA	Rural, medically underserved

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.

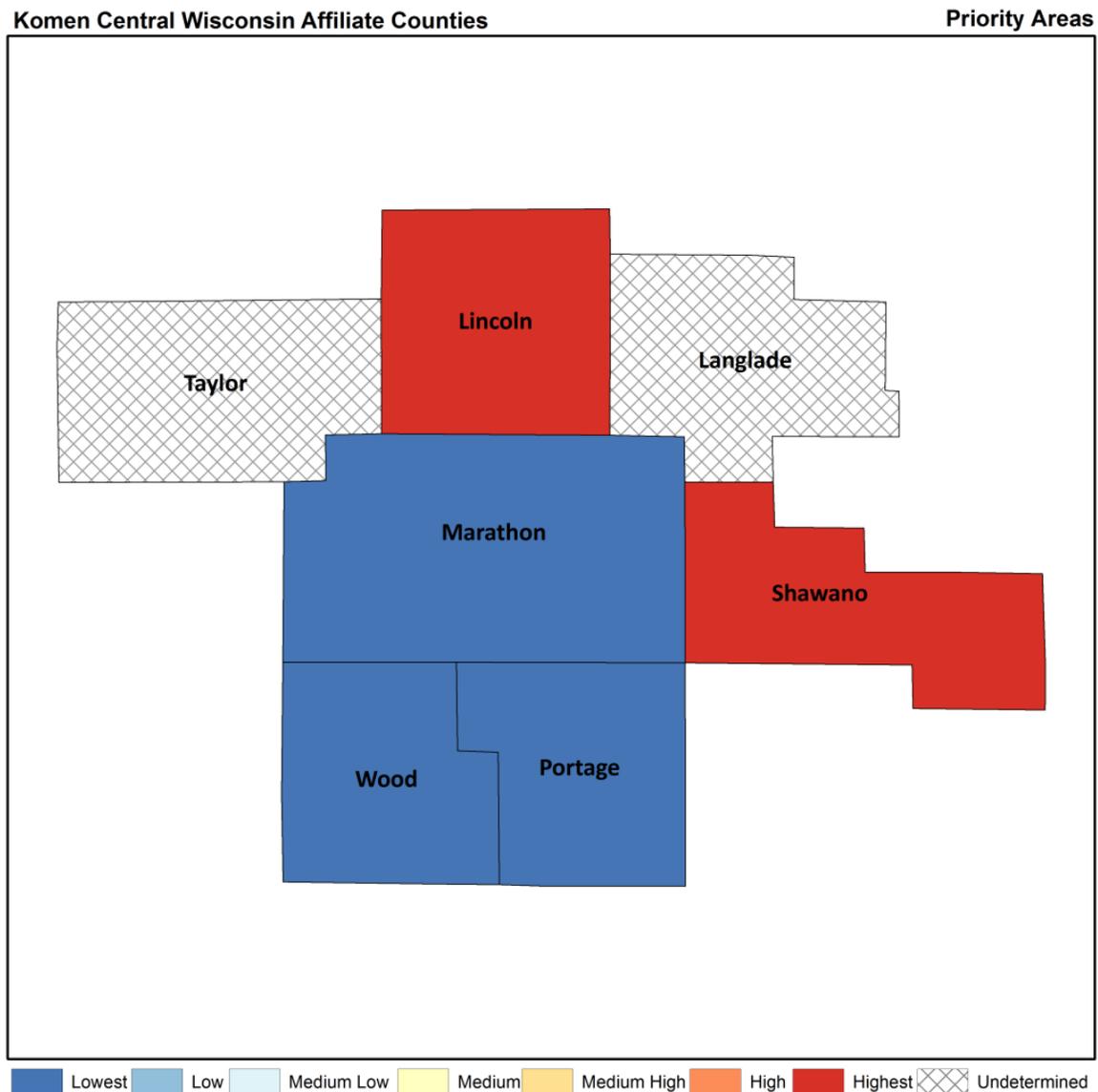


Figure 2.1. Intervention priorities

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

Two counties in the Komen Central Wisconsin service area are in the highest priority category. Both of the two, Lincoln County and Shawano County, are not likely to meet the death rate HP2020 target.

Shawano County has a relatively large AIAN population.

Selection of Target Communities

In order to be the most efficient stewards of resources, Susan G. Komen Central Wisconsin has chosen two target communities within the service area. The Affiliate will focus strategic efforts on these target communities over the course of the next four years. Target communities are those communities which have cumulative key indicators showing an increased chance of vulnerable populations likely at risk for experiencing gaps in breast health services and/or barriers in access to care.

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

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

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

The selected target communities are: Lincoln and Marathon Counties.

The quantitative data analysis identified Shawano County as a county of need as they are likely to miss the HP 2020 breast cancer death rate target. They have a high percentage of American Indian population in the Eastern half on the county. Since Komen Central Wisconsin only services the western half of Shawano County the Affiliate is not including it as a targeted community.

Marathon County was chosen as it is the most populous, has the highest minority population and is medically underserved. Lincoln County was chosen as it is likely to miss the HP2020 breast cancer death rate target, its increasing death rate since the last Community Profile (2011), and due to the largely rural population.

Health Systems and Public Policy Analysis

Health Systems Analysis Data Sources

In order to obtain accurate data of mammography services in the target communities of Marathon and Lincoln counties the following resources were used:

- FDA approved mammography centers,
- American College of Surgeons National Accreditation Program for Breast Centers program,
- American College of Surgeons Commission on Cancer certification,
- American College of Radiology Breast Imaging Centers of Excellence
- NCI designated Cancer Centers.

The health system inventory tool was used to gather information of the services provided by each health system in the target communities. From these resources the Health System Analysis template was completed and the data analyzed to determine where the gaps in care exist.

Health Systems Overview

Overview of Continuum of Care

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 process.

While a woman may enter the continuum at any point, ideally, a woman would enter the CoC when 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 to encourage women to get screened and reinforcing the need to continue to get screened routinely thereafter outlining the current recommendation.

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)

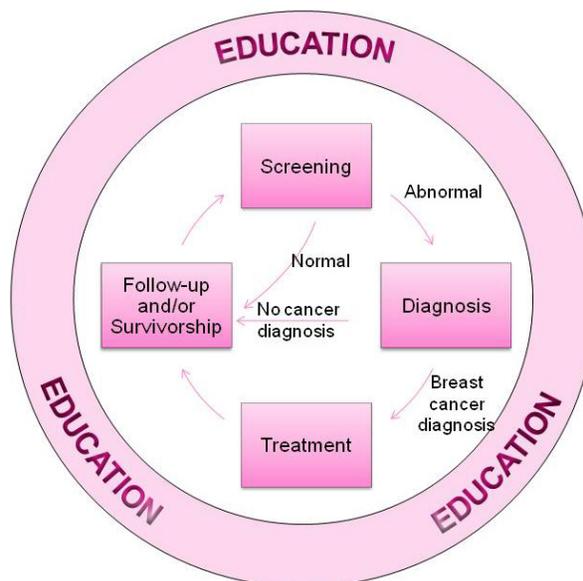


Figure 3.1. Breast Cancer Continuum of Care (CoC)

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 and up to 12 months for most women. Education plays a role in communicating the importance of proactively obtaining test results, keeping follow-up appointments and acknowledging the importance of these measures. Education can empower a woman and help manage the emotions of anxiety and fear.

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

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

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

The Continuum of Care is the essential framework in analyzing the health systems in Lincoln and Marathon Counties. The cycle of screening, diagnosis, treatment, and follow-up care could happen quite differently in different settings. Gaps in any one of these four components of care can influence the breast cancer statistics in a community.

The Affiliate's findings determined that many primary care centers are available for entry into the continuum of care, but mammography services are scant in Lincoln County (Figure 3.2). In the town of Tomahawk, only screening mammography is available and those needing diagnostic services must travel to Oneida County to the north (50 miles roundtrip), Merrill in southern Lincoln County (44 miles roundtrip) or to Marathon County (88 miles roundtrip). All facilities accept Medicaid, Medicare and the Wisconsin Well Woman Program (WWWP).

A major barrier for women in Lincoln County is lack of adequate transportation. There is no public transportation available to access these sites for diagnostic services. Women who

experience this as a hardship must rely on family and friends who have the time and money to offer transportation to them when appointments are available.

In Marathon County, a woman is more likely to move through the continuum of care more quickly and seamlessly, receiving timely, quality care as the health systems that provide the complete Continuum of Care are located in Marathon County (Figure 3.3).

Both major health systems in Marathon County also provide mobile screening mammography services throughout Marathon County and at a few sites in Lincoln County which allow access into their systems for continuation of care. Unfortunately, if a patient in Lincoln County does need treatment she will have to travel which may limit compliance and influence her prognosis.

One of the Central Wisconsin Komen Affiliates 2014 grant recipients provided free screening mammograms as well as free diagnostic mammograms, breast ultrasound, breast biopsies, breast MRI, MRI biopsies and genetic counseling and testing to qualifying patients living in the Komen Central Wisconsin service area. During the last grant cycle the grantee diagnosed 12 breast cancers. In the previous four grant cycles the grantee diagnosed a total of four cancers. The provision of free diagnostic services may have encouraged more women to seek care that may not have otherwise due to financial constraints.

Another grant recipient will be provided financial assistance to newly diagnosed breast cancer patients in the current grant cycle. By providing financial assistance the hope is to improve survivorship outcomes. This will be a good partnership going forward and may afford the opportunity to fill current gaps in compliance with treatment in all counties.

Another 2014 grant recipient offered “Wellness Beyond Breast Cancer” classes to women in Lincoln, Wood and Marathon Counties. These classes are available to all women in the Affiliate area regardless where they receive their diagnosis or treatment. The program provides another dimension of the Continuum of Care addressing follow-up and/or survivorship. This holistic wellness program is designed to help women regain physical, emotional, intellectual, psychological and spiritual strength after undergoing breast cancer treatment. Survivors and their guests are welcomed to share their stories and participate in conversations regarding healthy living and survivorship.

Lincoln County



Hospital



Community Health Center



Other



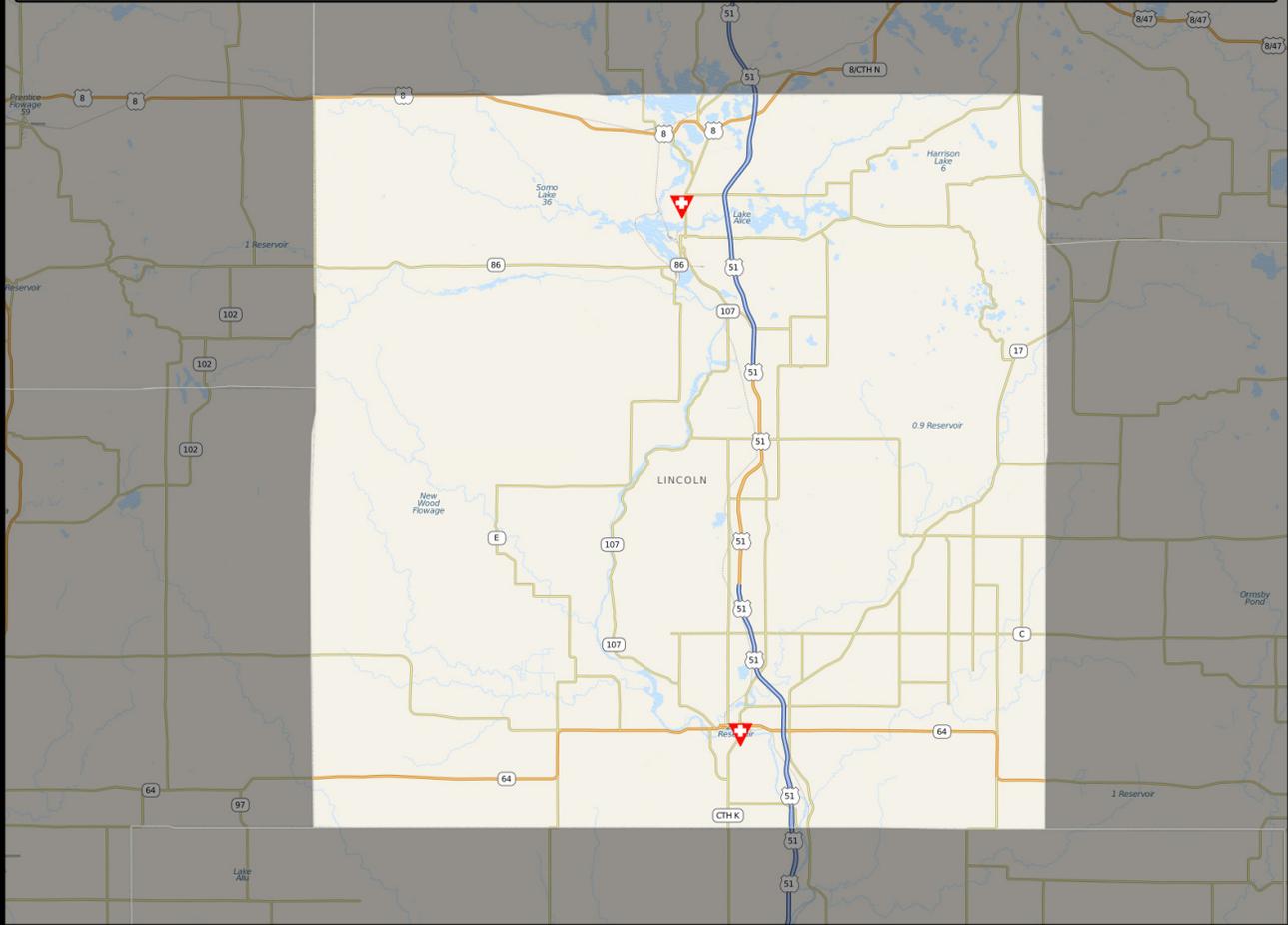
Free Clinic



Department of Health



Affiliate Office



Statistics

Total Locations in Region: 2

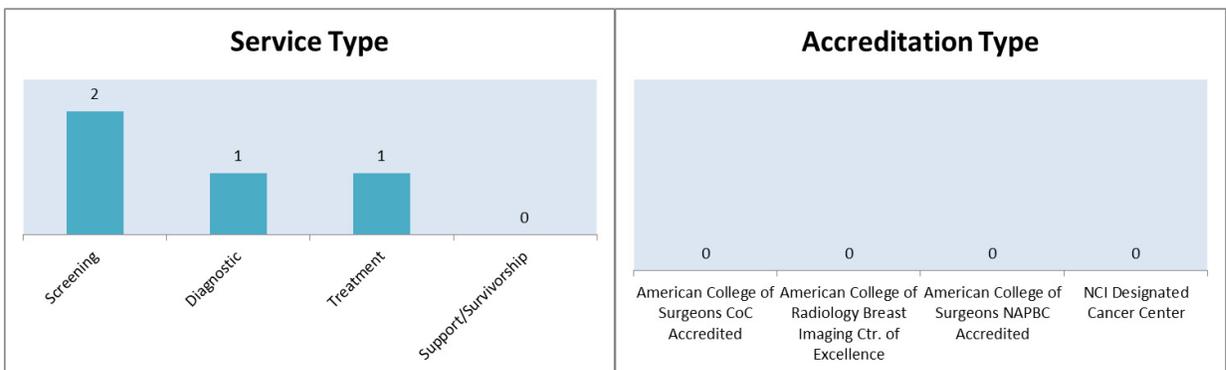


Figure 3.2. Breast cancer services available in Lincoln County

Marathon County



Hospital



Community Health Center



Other



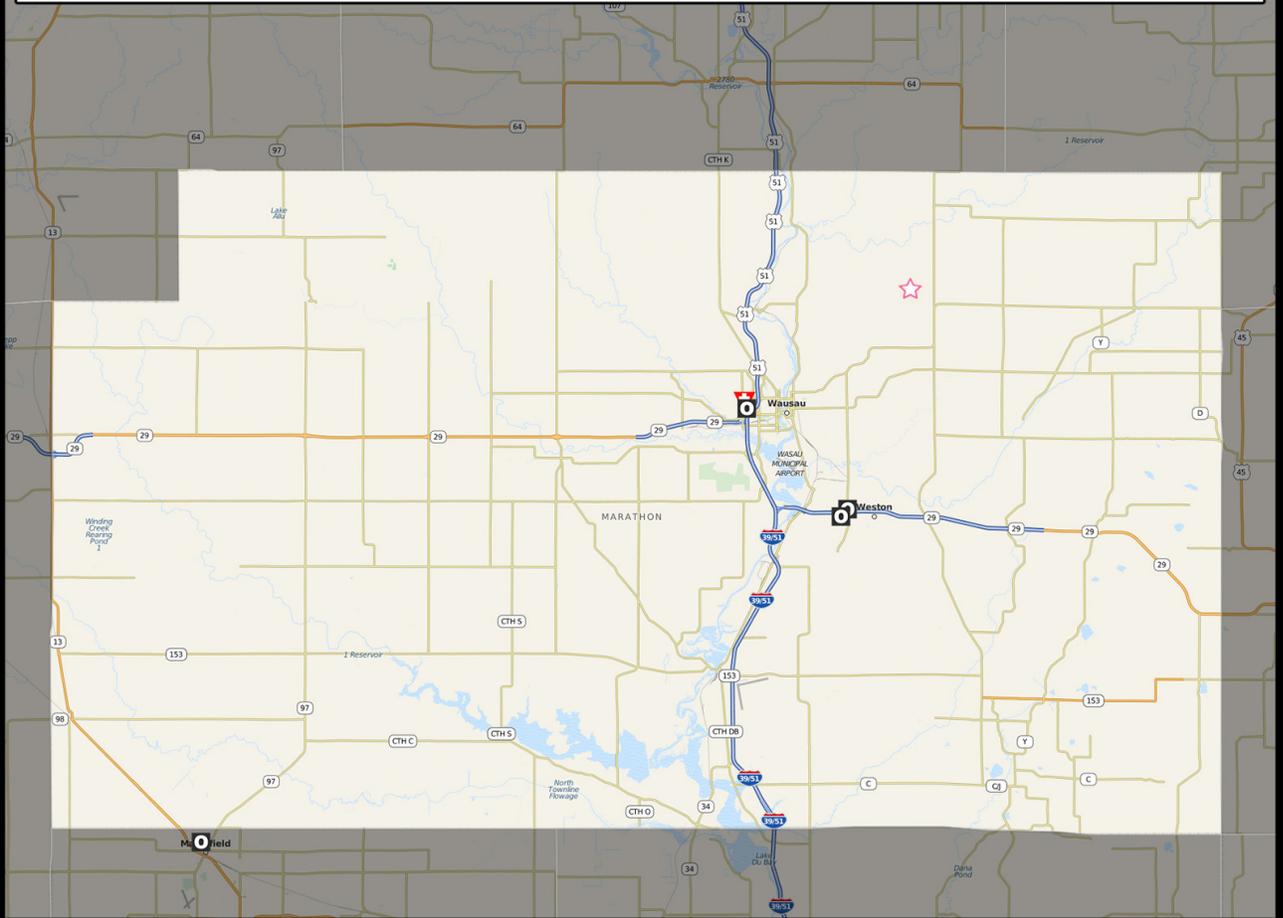
Free Clinic



Department of Health



Affiliate Office



Statistics

Total Locations in Region: 5

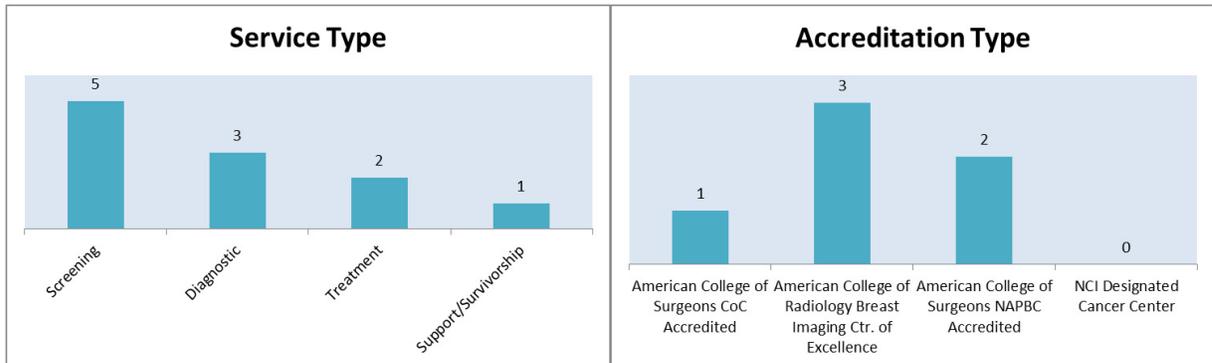


Figure 3.3. Breast cancer services available in Lincoln County

Public Policy Overview

The Affiliate enjoys a strong relationship with the legislature and has recently engaged in a relationship with the Wisconsin Breast Cancer Coalition (WBCC), (an advocacy group) and look forward to making advancements in breast care throughout Wisconsin together. The Affiliate and the WBCC have the support of local legislatures in issues and laws regarding the breast health of Wisconsin women.

The Affiliate and the WBCC were instrumental in having the Wisconsin legislature delay changes to the Wisconsin Well Woman Program (WWWP) that would have limited access for eligible women to free screening services. Due to this advocacy, delayed changes to the program will become effective, July 2015 versus the expectation of July 2014.

When Wisconsin elected not to accept the federal funding to expand the Medicaid program as provided for and envisioned by the Affordable Care Act, many county boards began seeking ways to access those funds on their own. Last year, twenty county boards passed resolutions calling on the state to take the money. This year, the State legislature is passing resolutions to hold advisory referendums during the November election calling on the legislature to accept the federal funding. As of July 18, 2014 Dunn, Lincoln, Outagamie, Milwaukee, Eau Claire, Clark, LaCrosse and Dane Counties have all passed resolutions to hold referendums.

WBCC has issued a letter to county boards across the state encouraging them to pass these resolutions and is one of many health advocacy organizations collaborating with [Citizen Action Wisconsin](#) to impress upon this administration the importance of ensuring access to quality, affordable health care for everyone in Wisconsin.

The Affiliate also has a working relationship with the two southern Wisconsin Komen Affiliates to address public policy together for all of Wisconsin to address future breast health public policy activities.

National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

The Wisconsin Well Woman Program (WWWP) provides preventive health screening services to women with little or no health insurance coverage. Well Woman pays for mammograms, Pap tests, certain other health screenings, and multiple sclerosis testing for women with high risk signs of multiple sclerosis. The program is administered by the Wisconsin Department of Health Services, Division of Public Health, and is available in all 72 Wisconsin counties and 11 tribes. Wisconsin's NBCCEDP program is the Wisconsin Well Woman Program (WWWP). Currently women can enroll for this program through program coordinators in every county.

In December 2013 the Wisconsin Department of Health Services proposed a restructure of the WWWP to ensure that it remains viable and available for women who need it, even as many women currently served by the screening program find they can access comprehensive coverage through BadgerCare (Medicaid) or the federal health insurance Marketplace. The Department's original proposal was to replace the current network of 1,000 provider sites and 83 local coordinating agencies with a model in which health systems would provide both screening and coordination of services. This was to go into effect July 1, 2014. It was believed that most women would be enrolled in either BadgerCare or a health exchange and that the WWWP would not be needed.

Stakeholders in the provider and coordinator communities reached out to WWWP with questions, concerns and suggestions about the proposed model. Due to the impact of advocacy on this proposed public policy by multiple organizations, they modified the original proposal and extended the time line to 2015. The Department believes that additional enrollment data and information on BadgerCare Plus and Marketplace should be evaluated and incorporated into the updated proposal. Under the current eligibility levels of the WWWP, many participants who are currently in the program will have access to full health coverage through either BadgerCare or the Marketplace.

For those women who are between 0 percent and 100 percent of the Federal Poverty Level (FPL), Wisconsin BadgerCare program will provide the full standard benefit, greatly expanding the level of services available to women in this income group. For women between 100 percent and 250 percent FPL, private health insurance is available through the Federal Marketplace. Many of these women based on the information provided, would not have accessed this option because the premiums were still considered cost prohibitive for them. Effective April 1st, 2014, there will be no coverage gap for women in Wisconsin.

The Affiliate has been kept abreast of the ongoing changes in the WWWP and will work with them to inform the women in the service area of the changes and how to access services as well as partner with them to identify any gaps that may arise. In addition, based on the Department of Health Services proposal for the change in the WWWP program of having a coordinator in each county to the proposed one or two in a region (i.e. Northern Region, encompassing 15 counties), the Affiliate will work diligently with the new format to inform the coordinator of services offered through grantees, Affiliate and national office.

Wisconsin Comprehensive Cancer Control Plan

The Wisconsin Comprehensive Cancer Control Plan 2010-2015 (WI CCC Plan) was developed in collaboration with partners across Wisconsin. Strategies and action steps across the cancer continuum are presented throughout the WI CCC Plan for organizations to implement over the next five years to reduce the burden of cancer in the state.

The WI CCC Plan 2010-2015 goals are:

- Reduce the risk of developing cancer.
- Increase early detection through appropriate screening for cancer.
- Reduce death and disability from cancer.
- Improve the quality of life for cancer survivors.
- Reduce suffering from cancer.
- Improve the quality of cancer-related data.

Wisconsin cancer death rates and incidence 2010 rates and 2015 goals for breast cancer are:

- 2010 death rate 23.4 and 2015 goal 19.7;
- 2010 incidence rate 122.7 and 2015 goal 113.0

The goal is to increase early detection through appropriate screening for cancer. The priorities are focused on breast, cervical and colorectal cancer screenings. Screening for these three cancers has been proven to reduce death. In Wisconsin, the percent of women age forty and

older who had a mammogram in the past two years decreased from 80.2 percent in 2002 to 76.3 percent in 2008.

In addition to traditional cancer screenings, genetic counseling with appropriate genetic testing can aid in the identification of high risk individuals and families who need increased screening for earlier cancer detection. According to the National Cancer Institute, approximately 5.0 to 10.0 percent of all cases of cancer are hereditary.

The WI CCC priorities for cancer screenings are:

- Priority I: Increase public awareness of recommended cancer screenings
- Priority II: Implement health care system based strategies to increase cancer screening percentages
- Priority III: Increase access to cancer screenings
- Priority IV: Increase the number of high risk individuals who receive a cancer risk assessment

Targets for change are:

Increase percent of women 40 years and older who had a mammogram in the past two years:

Baseline: 76 percent *2015 Goal:* 90 percent

Treatment, survivorship, palliative care and data collection were also addressed and have priorities and targets for change.

Strategies and action steps from the WI CCC Plan 2010-2015 will be prioritized annually for implementation by the steering committee through a systematic process using specific, measurable criteria. The resulting priorities will set the direction for the implementation efforts of the statewide coalition for the following year. Implementation of the plan will also take place through organizations dedicated to cancer control all across Wisconsin.

Each organization can use the plan as a guide for specific strategies and action steps they choose to implement over the next four years. To ensure the continued implementation of this plan, the current coalition of public and private partners must be maintained and expanded to develop, implement, and promote the WI CCC Plan.

This plan aligns with the goals and objectives outlined for Healthy People 2020 and Healthiest Wisconsin 2020. In addition, numerous partners including the three Susan G. Komen Wisconsin Affiliates are listed as providing resources and in partnership to accomplish the goals and objectives of the plan.

Affordable Care Act Overview

On March 23, 2010, President Obama signed comprehensive health reform, the Patient Protection and Affordable Care Act, into law. The law focuses on provisions to expand coverage, control health care costs, and improve health care delivery system.

Major themes/goals include:

- Expand access to care through insurance coverage
- Enhance the quality of health care
- Improve coverage for those with health insurance

- Make health care more affordable

The intent is to improve coverage for those with health insurance and enhance quality by:

- Prohibiting insurers from denying coverage based on pre-existing conditions
- Prohibiting annual/lifetime caps on coverage
- Prohibiting insurers from rescinding coverage
- Establishing minimum benefit standards
- Providing coverage of preventative services with no cost-sharing

Moreover, the ACA also provides two subsidies to make insurance more affordable: one that provides assistance to make premiums more affordable and a second that assists in lowering out-of-pocket costs. While the ACA allows for premium subsidies for individuals with income between 100 percent and 400 percent FPL, the out-of-pocket subsidies are only available to those with incomes between 100 percent and 250 percent. It is WWWP's hope that through the outreach efforts of the past months as well as ongoing enrollment activities, they will help eligible Wisconsin women gain lifesaving health insurance through BadgerCare and the Federal Marketplace.

All of the following Komen priorities were included in health reform:

- Mammography as a required benefit
- Breast cancer education for young women
- Access to clinical trials and patient navigation
- Elimination of pre-existing condition exclusions, lifetime and annual caps
- Out-of-pocket spending limits

Essential health benefits must include preventive and wellness services and chronic disease management.

The Affordable Care Act will impact screening mammography as it is a required benefit under the act. Currently the Affiliate is not sure how much it will increase screening volumes as the estimated number of people to sign up for the exchange has not yet been realized.

Wisconsin did not choose the Medicaid expansion plan at this time and as pointed out earlier there are multiple county boards wanting to seek their own funds. Due to not choosing the expansion the presumption is that there would have been women eligible to enroll in Medicaid and receive services who will no longer qualify for this benefit. Medicaid access matters: A recent study, found an increase in the number of mammograms received by women with Medicaid coverage compared to their peers who applied, but were not able to enroll in Medicaid.

Wisconsin has opted for Option 3 of the health insurance exchange program. This option states a woman can receive Medicaid services regardless of where she was originally screened as long as she would otherwise meet the other eligibility requirements.

As stated earlier, the Wisconsin Department of Health Services, based on their assessment determined WWWP would not be needed with ACA as women would be covered under BadgerCare or health exchanges. As of August 2014, people have not enrolled in BadgerCare or the health exchanges as predicted.

The following identified gaps will remain: Even with ACA, the Congressional Budget Office (CBO) estimates that nearly 30 million non-elderly individuals will be uninsured in 2016. These include undocumented immigrants, individuals eligible for Medicaid but not enrolled, individual exempt from mandate (i.e. no income tax, religious exemptions, or other hardships. Those that will choose to remain uninsured and pay the penalty

Komen Central Wisconsin continues to analyze the options for care, identifying needs and gaps in the service area per the mission of the Affiliate and National. The diverse membership of the Komen Central Wisconsin board and committees noting the representation of public and private partnerships from health systems, health departments and consumers provides the Affiliate with the opportunity to stay abreast of the impact of public policy on health systems.

These opportunities allow the Affiliate to continue the role as advocates and as a change agent in the Affiliate region and in the State of Wisconsin. The Affiliate will continue with the established partners and outreach to new partners to reevaluate and assess identified gaps in the health system analysis tool. The goal of the Affiliate is to meet the Healthy People 2020, Healthiest Wisconsin 2020 and the Wisconsin Cancer Control Plan identified goals and strategies for identification, education and survivorship for breast cancer.

Affiliate's Public Policy Activities

1. The Affiliate participates in annual state and federal lobby days as needed
2. The Affiliate works closely with the South Central Affiliate on state legislative issues
3. The Affiliate's Advocacy Chair utilizes National policy and advocacy tools and messaging
4. The Affiliate works with community partners to keep abreast of needed public policy work and utilizes these community partners to the extent possible in needed advocacy

Health Systems and Public Policy Analysis Findings

In summary, women in Lincoln County have barriers to entering the CoC at screening, as there are limited screening facilities. They are more likely to enter at diagnosis but then may not follow through with treatment as lack of public transportation limits their ability to get to appointments.

Continued partnerships with the two major health systems will continue to reach the underserved and bridge the gaps in Lincoln and Marathon Counties. The partnership with the grant recipient who is providing funding to newly diagnosed women will hopefully allow more women to overcome the financial barriers of continuing treatment. The Affiliate will continue to reach out to health care providers to make them aware of the services that are available to their patients so more women can be served

Komen Central Wisconsin's public policy work will continue to strive to influence public officials in decreasing the gaps in access to screening, diagnosis and treatment and educating the women of Wisconsin of the need for early detection.

Qualitative Data: Ensuring Community Input

Qualitative Data Sources and Methodology Overview

Methodology

Susan G. Komen® Central Wisconsin sought to identify gaps in service, cultural barriers, and identify needs of newly diagnosed breast cancer patients. Komen Central Wisconsin chose two methods for collecting data, focus groups and an online survey tool, SurveyMonkey.

The two methods chosen are due to the geographic area of the Affiliate noting drive time from Marathon County of one or more hours encompassing seven counties. The focus groups were held in Marathon County. The Affiliate completed a Business Associate Agreement with the Marathon County Health Department, who provided in-kind support to survey area key informants on behalf of the Affiliate. The survey tool was used to reach out to individuals with identified email addresses from the list of race participants. The survey tool was also used to gauge the medical professionals throughout the three medical systems providing care in the Affiliate area.

The Wisconsin Well Woman Coordinator for the Marathon County Health Department conducted the focus groups. The lists of participants were names of survivors submitted by the three major health systems providing services in the Affiliate area. The focus groups were used to identify gaps in services and/or specific needs associated with the participants personal lives during treatment such as ability to pay for bills, transportation, etc. The data was collected in written and verbal formats.

The SurveyMonkey questionnaire for race participants and medical providers was developed by some of Komen Central Wisconsin's board members. Sample questions were utilized from the Community Profile tool kit to assist with identification of potential gaps and barriers. Marathon County Health Department has an account with SurveyMonkey to send unlimited number of questionnaires. The Marathon County Health Department personnel have training to develop and format questions to reflect statistically significant responses for data reports. All participants who received the survey had an option to opt out of the survey.

Focus Group

There were 30 individual names provided by the three health care systems in Marathon County to invite for this cohort. There were nine women who agreed to participate from the list. Figure 4.1 provides the demographics for this group.

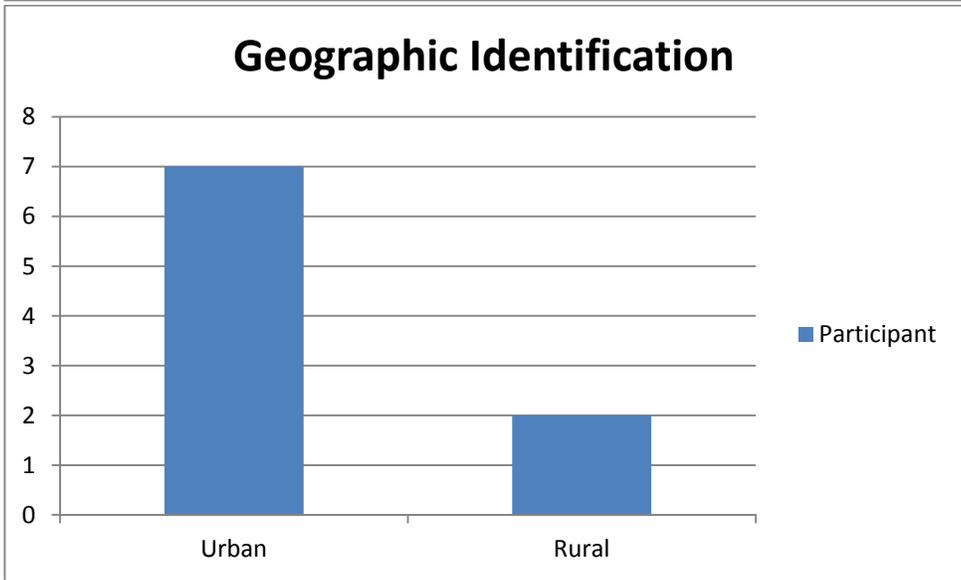
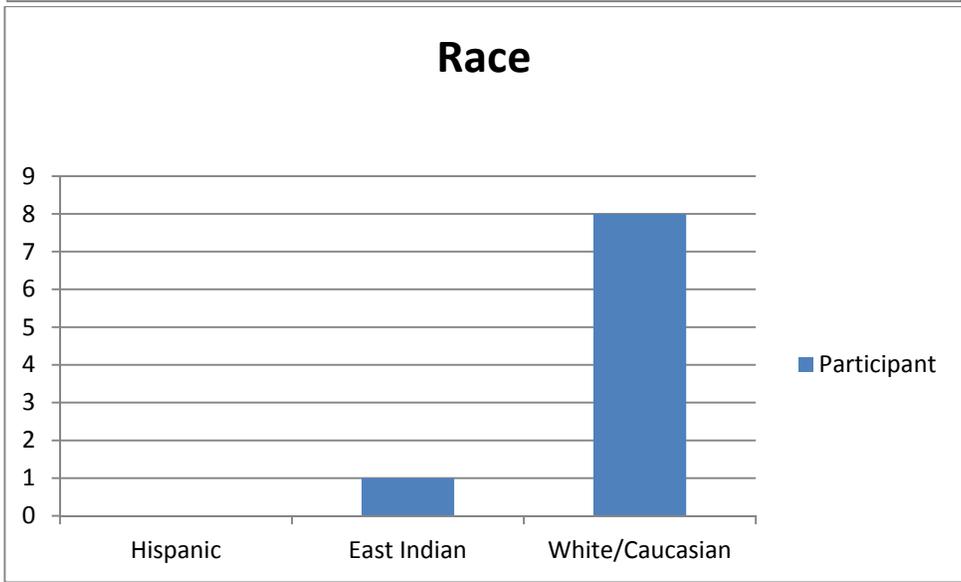
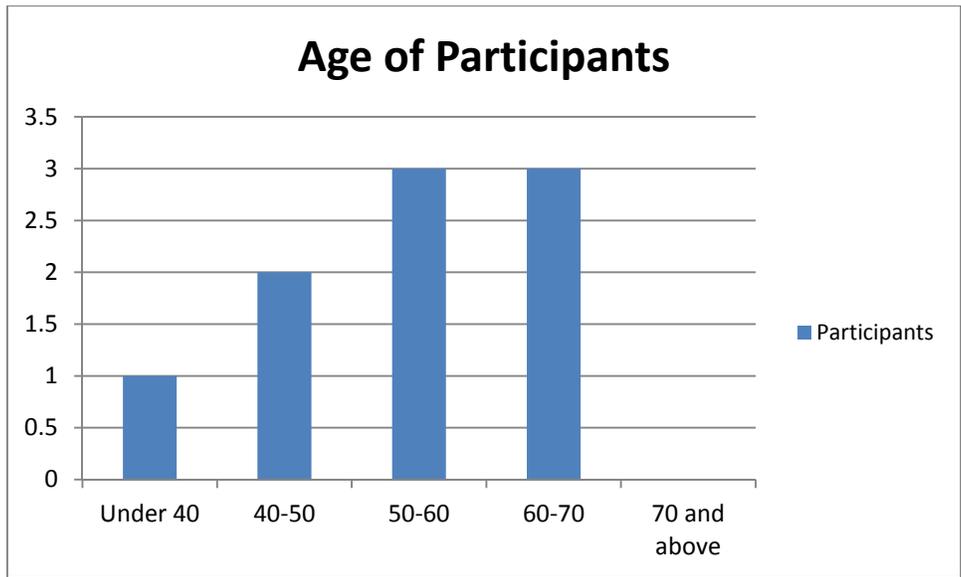


Figure 4.1 Focus group data

SurveyMonkey

Random samplings of 731 race participants were chosen to complete the survey of over 1000 names available. The names were removed who did not have email addresses, had responded to previous surveys or opted out of the survey. The Affiliate had 80 respondents to the survey, 87 percent of the participants were from the Affiliates seven county service area. Of those 75 percent were from the two target counties of Marathon and Lincoln.

The medical professionals who were sent surveys were obtained from the list of committee members participating on the Marathon County Breast Health Coalition and/or who provide services to breast cancer patients. There were 22 surveys sent to this cohort and only four responded.

Ethics

The focus group, race participants and medical providers who participated in the data collection were done so by Marathon County Health Department staff. The Health Department staff followed the governmental regulations for consent to participate, maintenance of confidentiality and protection of any identifying information. All participants were afforded the opportunity to not participate in the surveys, as noted by not consenting, opting out of the survey or did not answer the surveys. For the purposes of this report, the Affiliate was provided the aggregate data collected by the Marathon County Health Department staff.

Qualitative Data Overview

Komen Central Wisconsin chose to use focus groups and the database of race participants as a representative sample of individuals of all ages, ethnicity and demographic areas. These representative samples are individuals affected by breast cancer personally, family member/support or provider of services and/or believe in the cause associated with the Komen foundation. The formats provided the Affiliate the opportunity to reach the most individuals based on the geographic area of the Affiliate and the unique needs of each area, urban versus rural. The questions asked were on a variety of topics associated with screening, barriers, identified needs or gaps in services, and resources available. Some of these questions were taken from the Community Profile toolkit provided by Komen.

The identified successes of the focus group participants are *“appreciative for the quick response by the health care system identifying their breast cancer status and the collaboration between the health care systems to meet their needs.”* The identified hardships for the focus group participants included assistance associated with their personal lives including *“paying bills, obtaining the means for proper nutrition, preparation of meals, and other household chores.”* The focus group participants felt Komen could help with *“gas cards, groceries, “money for bills without all the hoops”* and *“one local place listing all the resources available”*. The focus group participants used the following identified phrases: *“make it personal for what they need”* and *“Open the help to middle class”* as important factors for consideration for breast health services.

The data for race participant respondents identified 76 percent had mammograms and 30 percent have had breast cancer. The race respondents (64-69 percent) reported finding a lump or experiencing pain and family/friends made them seek breast cancer screening services.

In reference to barriers for screening, 85 percent responded no insurance or high deductibles, 63 percent lacked the funding, 57 percent were afraid of results and 54 percent associated discomfort with a mammogram.

The race respondents identified lack of knowledge of the importance of mammograms (68 percent) and language (48 percent) as cultural barriers for breast health screenings.

The race respondents provided suggestions to increase access to services for screening to offer free screenings or cost associated with screenings, increase mobile access and advertise/educate the importance of screening. The race respondent's answers reflected local medical providers should stress the importance of screening at visits and outreach.

The race respondents provided the following answers related to the question of what breast cancer meant to you included *"fear, scary, death, catch early, screen", "Fear, but hope." "I've had several friends go through it, the health care they received was incredible and they are survivors for many years", and "It's encouraging to know that a diagnosis is not a death sentence."*

The data for medical provider's respondents identified 50 percent were actual providers of services. The providers utilized several methods to provide breast health education and outreach services. The providers reported provision of pamphlets and brochures (75 percent), referral for patient navigator (50 percent) services and referral to the American Cancer Society Reach for Recovery (25 percent) program. The providers identified the Hmong population as the group who does not seek breast health services as recommended by screening guidelines.

The providers have informational materials provided are written in English (100 percent), Spanish (75 percent) and Hmong (25 percent). The support programs identified in the Affiliate area include: Aspirus free mammogram, Angel Fund and the Look Good, Feel Good program from the American Cancer Society. The providers identified factors contributing to late-stage diagnosis are being afraid of results (100 percent), pain/discomfort of mammogram (75 percent), no insurance/high deductible (75 percent), lack of transportation (75 percent) and lack of money (50 percent).

The medical providers identified the following information for making it easier for patients to access screening mammograms: *"In our area our patients have easy access to facilities that have screening mammography.", " We have evening hours for people that work and even add some appointments onto our day to accommodate patient's schedules", " Making patients aware of the programs out there to help them with the financial needs.", " Practitioners and their staff should discuss with patients if there is a reason why their patients are not having a screening mammogram and help them address whatever the issues are" and " Some patients just don't know how to go about getting the help they qualify for and need."*

The common themes between the respondents were the identified barriers and the reasons associated with late-stage diagnosis (afraid of results, discomfort/pain due to mammogram, no insurance/high deductible and lack of money). The suggestions to increase access or outreach included free or reduced costs mammograms, the use of mobile mammography, increase in education/advertisement and providers stressing the importance of screening for breast cancer.

Qualitative Data Findings

The key questions were to identify gaps in service, cultural barriers and identify needs of newly diagnosed breast cancer patients. It is noted the cohort were similar in their responses to identified barriers and increasing access to screening services with responses of; afraid of results, discomfort/pain due to mammogram, no insurance/high deductible and lack of money. This lends to the significance of the response results and the issues the Affiliate should address in the future for granting of funds, identified gaps for services/resources and education/advertisement resources.

The identified factors for the limitation of the data were the response rates for the surveys and the focus groups. Only 10.9 percent of the surveys were completed by the race participants and 18 percent of the providers, of these 75 percent were from the target counties. In addition to the response rate, not all of the questions were answered which limited the findings. The focus groups were only done in Marathon County as a pilot to see the needs of those recently diagnosed with breast cancer with the plan to provide a treatment access fund to them. If the program is successful the Affiliate would like to duplicate the fund in Lincoln and other counties in the service area.

The successes of the surveys and focus groups were that they identified that patients are receiving care in a timely manner. The gaps are that there are cultural and financial barriers as well as fear of results and pain during the exam that keep women from getting the recommended screenings.

This information will assist hospitals and local health departments in the Affiliate service area who are statutorily required to complete community health assessments/community health improvement plans in Wisconsin. This information will assist these organizations to address the identified goals and objectives for public health/population health in the Healthiest Wisconsin 2020 (Chronic Disease and Prevention) and Healthy People 2020 (Cancer) to reduce the incidence of breast cancer.

Mission Action Plan

Breast Health and Breast Cancer Findings of the Target Communities

Through review of the quantitative data, qualitative data and Health Systems and Public Policy Analysis (HSPPA), the Profile Committee acknowledges the Affiliate service area needs to continue addressing the challenge of access to mammography and early detection in both Lincoln and Marathon Counties. The counties share a common theme; they are predominately rural with a few small cities. Marathon County is the most populous, with 134,735 residents. The counties are predominantly non-Hispanic White, with much smaller populations of Hmong (South East Asian), Hispanic/Latino, American Indian/Alaskan Native and Black/African-American. Marathon County has the largest Hmong population at 5.6 percent, a 1.06 percent increase from the last Community Profile. The true Hispanic/Latino population is unknown as many of the Hispanic/Latino are undocumented workers, many of whom work on dairy farms. The Quantitative Data report documented a two percent Hispanic/Latino population in the Affiliate as a whole.

The focus groups and surveys showed that people still feel access to screening mammography is underutilized and the fear of breast cancer also limits those that are screened. While Affiliate grant-funded programs provided increased access in 2012-2014, there remains a difficulty in assisting rural and minority populations overcome barriers to screening mammography such as travel, language/culture barriers, and finances. The two major health systems that serve Marathon and Lincoln Counties do have mobile units that provide screening mammograms but access to diagnostic services are limited to Marathon County. The HSPPA identified that Lincoln County will not meet Healthy People 2020 goals due to the continued higher than average death rates in Lincoln County. This specifically illustrates earlier diagnosis is vitally important.

In 2013 and 2014, major changes to the Wisconsin Well Woman Program (WWWP) have negatively impacted access and financial resources to uninsured and under-insured women in the target counties. Due to funding cuts and program restructuring, annual enrollment access into WWWP has been restricted from 300+ women to less than 100. In addition, county health department coordinators for breast health resources and coordination of care funding have been cut. The current model to be implemented in Wisconsin effective July 1, 2015, will have one coordinator for the Affiliate service area as the state moves to a regionalized model. This will be a burdensome task for one coordinator to know the breast health resources for all seven counties in the area.

Based on both focus-group and key informant survey data, health care providers, community members, and survivors, there remains evidence that a large number of women are afraid of or uninformed about the importance of breast cancer screening. The data for race participant respondents identified 76 percent had mammograms and 30 percent have had breast cancer. A total of 64-69 percent of respondents reported finding a lump or experiencing pain and family/friends made them seek breast cancer screening services.

In reference to barriers for screening, 85 percent responded no insurance or high deductibles, 63 percent lacked the funding, 57 percent were afraid of results and 54 percent associated discomfort with a mammogram. The cultural barriers were 68 percent lack knowledge of the importance of mammograms and 48 percent noted language barriers.

Anecdotally, many women simply overwhelmed with everyday needs and financial concerns to make it a priority. The Affiliate's focus will be to facilitate resource navigation to community grant-funded programs and particularly expand these in Lincoln County.

Thus, the data gathered from questionnaire respondents, focus groups, HSPPA, and quantitative data supports the following direction for the 2015 Community Profile Action Plan:

- Increased breast health education in target counties
- Increased rural access to screening and diagnostic mammography, particularly in Lincoln County
- Increased access to coverage for diagnostic mammography, particularly in Lincoln County
- Financial assistance for newly diagnosed breast cancer patients in Marathon and Lincoln Counties

Mission Action Plan

Problem Statement:

The quantitative and qualitative data and HSPPA identified a need to increase the opportunities for rural and minority women to receive breast health education, screening, and diagnostic testing, particularly in Marathon and Lincoln counties as they have limited access.

Priority: Increase access to breast health services, breast health education and public awareness for women in Lincoln and Marathon County.

Objective 1

Conduct at least one grant writing workshop in the cities of Merrill and Tomahawk in Lincoln County prior to the 2016-2017 and 2017-2018 funding cycles. This will be to inform the community of the findings of the Komen Central Wisconsin's Community Profile and enable them an opportunity to apply for funding that would directly impact the community.

Objective 2

Increase solicitation for Komen Central Wisconsin's community grant RFPs from mammography programs that utilize multi-site, mobile mammography, and/or non-traditional service locations in Lincoln and Marathon Counties. This will be accomplished by inviting Aspirus, Marshfield Clinic, and Ministry Health Center to grant writing workshops in Spring of 2016.

Objective 3

Increase public awareness of Komen Central Wisconsin small and community grants in Lincoln County prior to 2016-2017 funding cycle. This will be done using print and television media as well as community partners.

Problem Statement: According to Quantitative and Qualitative Data collected, women in the target communities of Lincoln County have an increasing death rate.

Priority: Increase screening compliance and access to financial aid during treatment in Lincoln and Marathon Counties. The Affiliate will continue to build community

partnerships with providers and local businesses. The Affiliate will reach out to providers to increase screening compliance as well as to local companies to increase access to financial aid.

Objective 1

Recruit and retain one board member from Lincoln County by the 2016-2017 Komen Central Wisconsin funding year. A Lincoln County board member will be able to speak on behalf of the women of Lincoln County and serve as a liaison to and advocate for their community. As an advocate, this person will be able to inform community residents of available services. They will also help recruit providers and local businesses.

Objective 2

From FY15-FY19 in order to better identify the needs of women in Lincoln County, the Affiliate will continue to retain at all times at least one grant reviewer who will act on behalf of, and obtain grants for, the citizens of Lincoln County.

Objective 3

Beginning September of 2015, the Affiliate will meet quarterly with the Lincoln and Marathon County community partners such as Health Department, area mammography providers, and regional WWWP representatives. The objective will be to identify initiatives to improve the continuum of care cycle and resource navigation for rural women.

References

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

SEER Summary Stage. Young, 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).