



COMMUNITY PROFILE REPORT

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2011

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

The 2013 updated version of the 2011 Community Profile contains modifications due to the changes in Federal and State healthcare funding as of August 2013. Changes are noted in red although this in no way signifies these changes are of greater importance than the remainder of the report.

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Table of Contents

| | |
|--|-----------|
| Executive Summary | 5 |
| Introduction..... | 5 |
| Statistics and Demographic Review | 5 |
| Health Systems Analysis | 6 |
| Qualitative Data Overview | 6 |
| Conclusions | 7 |
| Introduction..... | 8 |
| Affiliate History..... | 8 |
| Organizational Structure | 8 |
| Description of Service Area | 8 |
| Purpose of the Community Profile Report | 10 |
| Breast Cancer Impact in Affiliate Service Area | 12 |
| Methodology | 11 |
| Demographic and Poverty Levels | 11 |
| Breast Cancer Statistics | 13 |
| Breast Cancer Incidence Rates | 13 |
| Breast Cancer Mortality Rates | 13 |
| Breast Cancer Late Stage Diagnosis Rates | 15 |
| Mammography Screening Behavior | 15 |
| Communities of Interest | 15 |
| Conclusions | 15 |
| Health Systems Analysis of Target Communities | 16 |
| Continuum of Care..... | 16 |
| Methodology | 16 |
| Overview of Community Assets | 17 |
| Breast and Cervical Cancer Control Program (BCCCP) | 18 |
| Policy Initiatives | 19 |
| Key Informant Interviews | 19 |
| Conclusions | 19 |
| Breast Cancer Perspectives in the Target Communities..... | 20 |
| Methodology | 20 |
| Review of Qualitative Findings - Survivor Surveys | 20 |
| Review of Qualitative Findings - Focus Groups | 21 |
| Conclusions | 22 |
| Conclusions: What We Learned, What We Will Do | 22 |
| Review of Findings | 22 |
| Conclusions | 23 |
| Action Plan | 23 |

Executive Summary

Introduction

Nancy G. Brinker promised her dying sister – Susan G. Komen – that she would do everything in her power to end breast cancer forever. In 1982 that promise became Susan G. Komen and launched the global breast cancer movement. Today Komen is the world's largest grassroots network of breast cancer survivors and advocates.

The Mid-Michigan Affiliate of Susan G. Komen is working to fulfill the Komen promise to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures. The Affiliate was founded in 2001. Like most Affiliates, Komen Mid-Michigan began as a volunteer-run Race for the Cure®. Since then it has invested a total of over \$4 million in both community grants and national breast cancer research. In 2011, over 6,700 runners and walkers participated in the Race and more than \$536,000 was invested in grants to non-profit organizations to address the breast health needs of Mid-Michigan's diverse communities. Beyond a passionate Board of Directors and dedicated volunteers, Komen Mid-Michigan now has staff in place to bring the promise of Susan G. Komen to our communities.

The Community Profile provides a thorough assessment of breast health services and the state of breast cancer in the Mid-Michigan Affiliate service area which covers Ingham, Eaton, Clinton, Jackson, Shiawassee, Livingston and Washtenaw counties. The profile identifies service gaps, establishes priorities for improving breast health services and evaluates the impact of breast health programs and public policies across the service area. **The current Profile contains limited updates for 2013, primarily dealing with the Affordable Care Act.** An effective Community Profile allows the Affiliate to better align programs, funding and educational activities toward the same goal.

The Affordable Care Act and Modifications to the Community Profile

The implementation of the Affordable Care Act (ACA) has created changes in health care funding at both the State and Federal level. Although the law is in place, there are challenges assessing the paths to the final version of the ACA and how this will affect funding by the Spring of 2014. The Community Profile is based on the best available information as of August, 2013.

The Affordable Care Act (ACA) currently requires commercial insurance companies and state Medicaid plans to provide one baseline screening mammogram to women between the ages of 35-39 free to the patient. It also allows for a yearly screening mammogram for women over 40 to be covered by commercial insurances and state Medicaid plans. We foresee that the total number of screening mammograms that will need to be covered by Komen Mid-Michigan will decrease by the end of this grant cycle. The ACA does not require coverage for diagnostic breast health testing such as diagnostic mammograms, diagnostic biopsies or any other diagnostic test.

Due to Federal and State healthcare changes, the Breast and Cervical Cancer Control Program (BCCCP) will incur funding changes. Caseloads for the program for Fiscal Year 2014 will be reduced by approximately 30%. As required by the CDC, no more than 25% of the caseload may be allocated to women age 40-49. Although there are other means for these patients to receive benefits (insurance, Medicaid), there will be women who 'fall through the cracks'. We foresee a need for supplementing the screening mammograms specifically for this population.

Healthcare institutions and Accountable Care Organizations will increasingly rely on Patient Navigators to assist patients in finding solutions to their healthcare needs. Patient Navigation within cancer care is defined by the National Cancer Institute as "the assistance offered to healthcare consumers (patients, survivors, families and caregivers) to help them access and overcome any barriers to quality care."

Statistics and Demographic Review

Approximately 1.2 million people live in the Affiliate's seven county service area. Eighty two percent of the population is white, with the ethnic minority population concentrated in three cities - Lansing, Jackson and Ypsilanti.

Using data compiled by the Healthcare Business of Thomson Reuters © 2009, the Affiliate examined breast cancer and demographic statistics for our seven-county service area.

Data showed that breast cancer mortality had increased in Michigan since our last Community Profile. In addition, it identified that the population of three cities in our service area, which have a significant ethnic minority population, had a higher rate of late stage diagnosis and breast cancer mortality than the area as a whole. It also seems that knowledge of breast health issues and the need for early detection through screening is lacking in these populations. The Affiliate remains committed to partnering with community-based organizations serving these target populations across our service area.

Another area of concern for the Affiliate is the high number of women age 40 or older who are not receiving regular, annual mammograms. Early detection is the best defense against breast cancer. The Komen Mid-Michigan Affiliate will continue to make increasing mammography screening rates a priority through education and screening programs.

Health Systems Analysis

The Komen Mid-Michigan Affiliate service area is well served by a comprehensive network of hospitals and medical services. Even in the less densely populated counties, services are available, in most cases, within a one-hour drive. That said, access to health care remains a critical issue for uninsured and underinsured individuals.

The Michigan Breast and Cervical Cancer Control Program (BCCCP) provides an important source of funding for screening services for this group of women. However, beginning in 2011, BCCCP eligibility requirements will restrict access to mammograms for women aged 40-49. Komen is already working within our grantee network to address this need. We will continue to work with Michigan's BCCCP coordinators and our grantee network to support the availability of screening to all women in our seven-county area.

Post-diagnosis support for breast cancer patients is available through a number of health systems and nonprofits in our service area, but the Komen Mid-Michigan Affiliate continues to face the challenge of connecting these services with the medically underserved individuals who lack access to them. The Affiliate intends to continue to work with our grantees to reach out to women in our target populations to connect them with available programs.

Qualitative Data Overview

Our data was obtained primarily through breast cancer survivor surveys, key informant interviews and a focus group discussion. Breast cancer survivors in our service area shared their belief in the need for social support programs; for breast cancer survivors, their partners or spouses, and children, during and following a patient's treatment of breast cancer. Key informant interviews with health providers in the Komen Mid-Michigan Affiliate service area highlighted concerns about the confusion women face with conflicting messages of when to begin regular mammogram screenings. Health care providers also identified a shortage of Michigan's Breast and Cervical Cancer Control Program slots for women ages 40-49 seeking mammograms. Finally, the focus group discussion held in Jackson identified many individual and institutional barriers that may discourage women from seeking a mammogram or follow-up care for breast cancer.

Conclusions

Based on detailed analyses of the demographics and breast cancer data, the Community Profile team identified areas at greater risk of late stage diagnosis and breast cancer mortality. These areas included ethnic minority populations as well as low-income neighborhoods. They also noted the lack of clarity about breast health in the community and gaps in the continuum of care. As a result the Mid-Michigan Affiliate of Susan G. Komen developed the following priorities

Priority 1: Promote breast health **education** and the importance of **early detection and screening** across our service area, particularly in the cities of Lansing, Jackson and Ypsilanti **with an emphasis on African-American women. Efforts must be detailed and measurable.**

Priority 2: Support access to breast screening **and/or diagnostics** for uninsured and underinsured women aged 40-49, and those aged under 40 with a breast health concern. **Efforts must be detailed, measurable and include rationale for number of slots for each procedure based on the ACA breast screening funding requirements and the BCCCP funding decreases.**

Priority 3: Provide breast cancer survivors with programs offering emotional, social and physical support, during and following breast cancer treatment. Efforts must be detailed and measurable.

Priority 4: Increase visibility and knowledge of the Komen Mid-Michigan Affiliate **Mission** throughout its service area. **Efforts must be detailed.**

The Mid-Michigan Affiliate of Susan G. Komen undertakes that, working on these priorities in collaboration with nonprofit organizations and community-based organizations, it will continue to bring the promise of Susan G. Komen to our communities.

Introduction

Affiliate History

The Komen Mid-Michigan Affiliate began with one woman's commitment. In 2001 Christine M. Pearson gathered her friends and family to bring the global breast cancer movement to our community. The Komen Greater Lansing Affiliate initially included three counties in Michigan, but expanded in 2009 to include an additional four counties and become the Komen Mid-Michigan Affiliate. Christine, the Executive Director of the Komen Mid-Michigan Affiliate, has a personal mission to fight breast cancer as it has deeply affected several members of her family.

The first Komen Mid-Michigan Race for the Cure was held in Lansing in 2003. It involved 1700 participants and raised \$125,000. By 2011 the Race involved over 6000 people and raised more than \$380,000. In addition the Affiliate has added a second event, the Ride for the Cure. In three years the Ride has included over 400 participants, raising nearly \$400,000.

Since 2001 the Affiliate has invested more than \$4 million in its promise to end breast cancer forever. Up to 75% of the Affiliate's net profits support local grants to nonprofit organizations for education, screening, treatment and support programs. The remaining dollars, a minimum of 25% of net profits, support national breast cancer research. The Komen Mid-Michigan Affiliate invests more than 83 cents of every dollar to mission work.

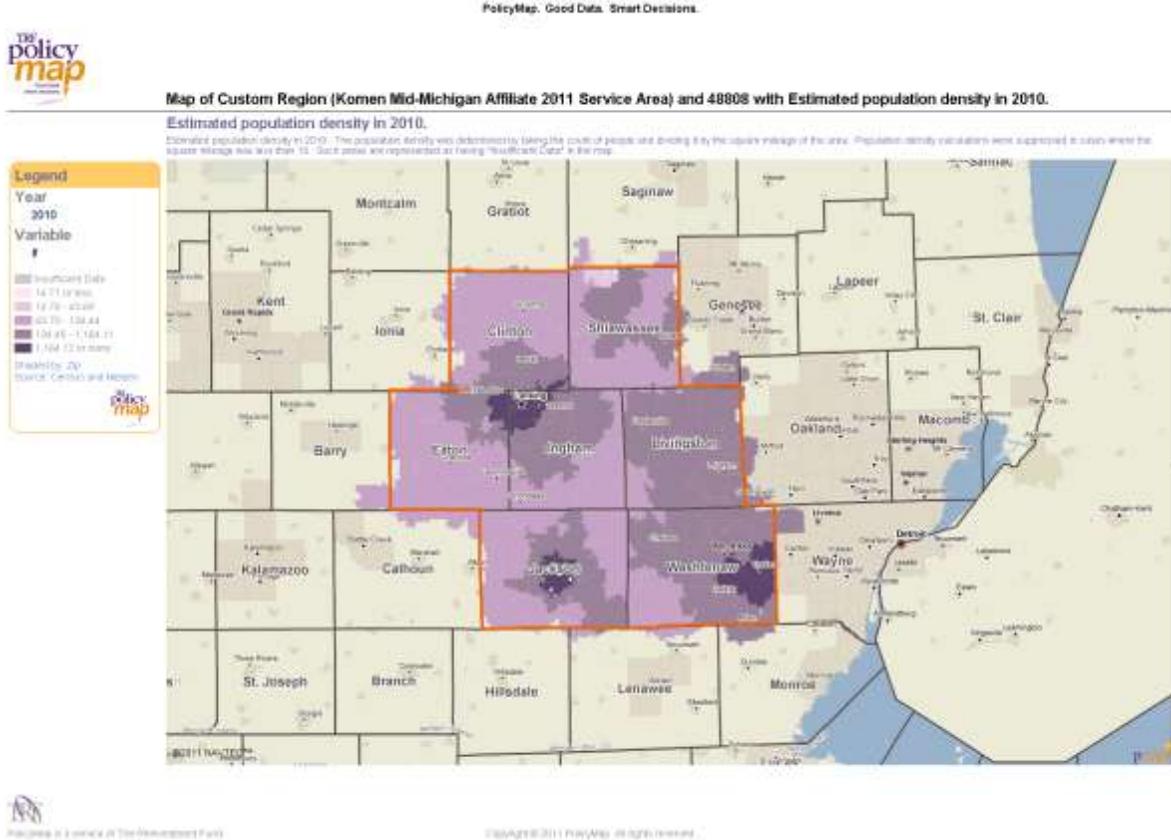
Organizational Structure

The Mid-Michigan Affiliate is led by an eight person Board of Directors. There are five staff members, the Executive Director, Events and Communications Manager, Mission Programs Director, Volunteer and Communications Coordinator, and Finance and Operations Manager. The staff reports to the Executive Director, who reports to the Board. In addition many enthusiastic and dedicated volunteers make the work of the Affiliate possible.

Description of Service Area

The Affiliate service area covers a seven county area (Clinton, Eaton, Ingham, Jackson, Livingston, Shiawassee and Washtenaw) of approximately 1.2 million people. It includes three major cities, Lansing (population 114,000), Ann Arbor (population 113,000), which includes the city of Ypsilanti, and Jackson (33,500). Nearly all the population lives

around these cities in many small towns, villages and rural areas.



Geographically the area is largely flat, with many rivers and lakes and it is mainly agricultural.

The greatest ethnic diversity is found in those counties containing one of the major cities. Both Ingham County, which contains the city of Lansing, and Washtenaw County, which includes Ann Arbor, have a population comprising 12% African Americans. A further 13% of their populations are either Hispanic or Asian. Jackson County, containing the city of Jackson is 8% African American and 4% Hispanic or Asian. Eaton County, which includes some of the suburbs of the City of Lansing, has an ethnic minority population of approximately 13% (of which 6% is African American). Clinton, Livingston and Shiawassee Counties are largely Caucasian.

The Affiliate's area is the site of several major Universities including the University of Michigan, Michigan State University and Eastern Michigan University. This results in a large (over 113,000) student population in the area. All three of these institutions have received funding from Komen for research.

Michigan is suffering from higher unemployment that is higher than the national average. In Ingham, Jackson, Livingston and Shiawassee counties unemployment is higher than the State and National average. There is anecdotal evidence that actual

numbers of the unemployed are higher than statistics show. This is due to the number of people no longer included in the official numbers for a variety of reasons, such as no longer looking for work. The data from the 2010 census show that nearly one in five people in Ingham County are living below the official poverty level. In addition, Shiawassee and Washtenaw Counties have over one in seven of their population below the poverty level. Recent statistics on levels of health insurance are difficult to find, but the most recent data from 2008 shows that over 10% of people are without insurance in Ingham, Jackson, Livingston and Shiawassee counties. It is likely that with the deterioration in the job situation since this time the numbers of the uninsured have increased.

Purpose of the Community Profile Report

To fulfill our mission the Komen Mid-Michigan Affiliate conducts a needs assessment **every four years**, to build a Community Profile. This involves looking at the characteristics of our service area and understanding the availability of breast cancer education, treatment and support programs. Analysis of the community in the profile includes the voices of those living in the target areas and representing target populations as well as quantitative data.

The Community Profile allows the Affiliate to have clear priorities based on sound information and allows the organization to:

- Identify gaps in the continuum of care for women diagnosed with an abnormal mammogram or breast cancer.
- Encourage collaboration within the community by bringing together nonprofits with similar mission programs.
- Drive inclusion efforts in the breast cancer community.
- Determine how and where to provide Breast Self-Awareness Education messaging.
- Drive public policy efforts.

Breast Cancer Impact in Affiliate Service Area

Methodology

Our data analysis covers the Komen Mid-Michigan Affiliate's service area including Clinton, Eaton, Ingham, Jackson, Livingston, Shiawassee and Washtenaw counties. Multiple data sources were used to characterize the impact of breast cancer in the Affiliate service area. Demographic information was taken from the US Census Bureau and information on poverty and unemployment came from the Michigan state government as well as the Bureau of Labor Statistics. The Healthcare Business of Thomson Reuters © was contracted by Susan G. Komen to compile a customized data pack for each Komen Affiliate, providing breast cancer statistics and demographic data for the counties within each Affiliate's service area. The data supplied by Thomson Reuters © are based on 2009 population studies.

There are some limitations to the data. Some data for the counties in the Affiliate service area, such as late-stage breast cancer diagnosis, are approximations derived from national-level data. In addition, small numbers of cases in less populous areas can have a large effect on estimates of rates and percentages in those areas.

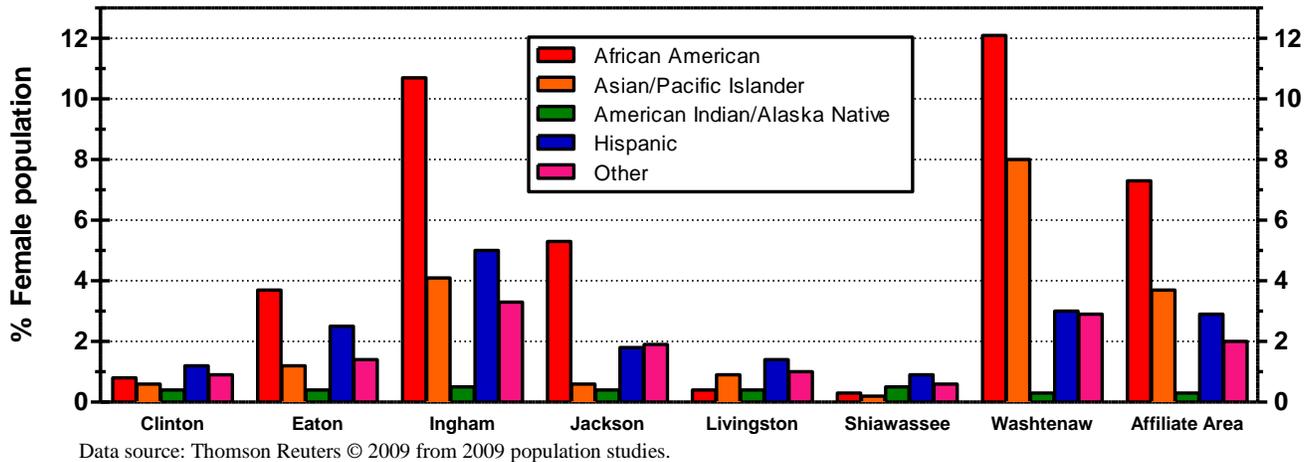
By comparing local data with published national data as well as various breast cancer studies, we identified counties and segments of the population that showed the greatest need for breast cancer-related resources and funding. This formed the basis of our action plan and priorities.

Demographics and Poverty Levels

The Affiliate's service area is well populated, with a total of 1.2 million people living in a seven county area. The population density ranges from 113 people per square mile in Clinton County to 500 people per square mile in Ingham County. This compares with a US average of 85 people per square mile. The population is concentrated in three metropolitan areas, Ann Arbor (population 344,791), Lansing (population 464,036) and Jackson (population 160,248).

The majority, or 82 percent of the population of the Affiliate service area is Caucasian, and approximately 8 percent is black. The black population within the Affiliate area is heavily concentrated in the cities of Ypsilanti (29.17 percent compared to Washtenaw County overall at 12 percent); Lansing (23.7 percent, compared with Ingham County overall at 11 percent); and Jackson (19.7 percent compared with Jackson county overall at 8 percent). In addition 8 percent of Washtenaw County and 4 percent of Ingham County are Asian. 3.6 percent of the Affiliate's population is Hispanic, again concentrated in Washtenaw and Ingham Counties.

Graph 1. Percent Female Population by Minority Ethnicity and County, 2009



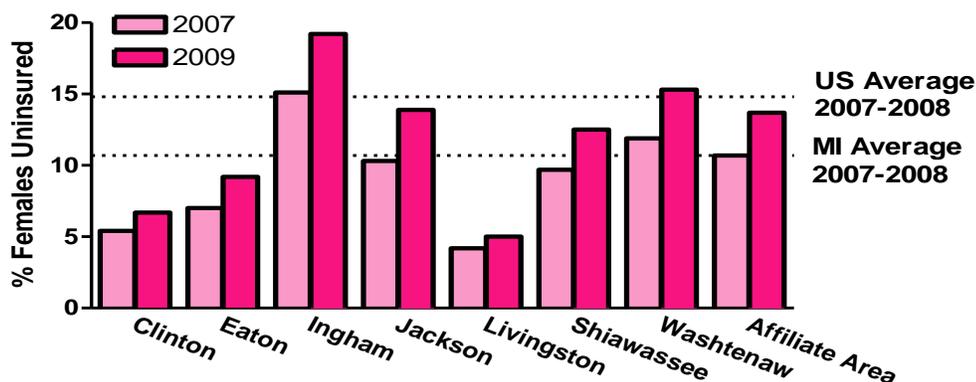
The median income for the Affiliate service area is estimated to be \$54,834 (Thomson Reuters 2009), higher than the US average of \$49,945 (Census Annual Social and Economic Supplement, 2008-2009). However, this covers some notable disparities. Ingham, Jackson and Shiawassee Counties all had median incomes below \$45,500. In addition the median household income was low in the cities of Ypsilanti (\$31,322), Jackson (\$31,654) and Lansing (\$35,774) (www.city-data.com)

Ingham County has 19.1 percent of persons living below the poverty level compared to a US average of 14.3 percent (US Census Quick Facts). In addition Jackson, Shiawassee and Washtenaw Counties have around 14.3 percent of their population living below the poverty level.

It is estimated that over 10 percent of people in Ingham, Jackson, Livingston and Shiawassee Counties do not have health insurance (Michigan Department of Community Health). Although Michigan historically has one of the lowest percentages of uninsured residents among all other states, the situation has deteriorated in recent years as unemployment in the State has risen.

A significant portion of women, ages 18-64 in our service area, lack insurance (see Graph 2 below). Numbers are particularly high in Ingham, Jackson, Washtenaw and Shiawassee Counties. Notably, in all counties associated with the Affiliate service area, there were increases in the number of females that were uninsured from 2007 to 2009.

Graph 2 Uninsured Females Age 18-64 by County



Data source: Thomson Reuters © 2007, 2009 from 2007 and 2009 population

It has been estimated that one in six Michigan residents now relies on Medicaid for health care coverage. Underfunding and additional economic burdens on the public safety net may jeopardize the quality of care delivered to Medicaid recipients and may make it harder to find providers who accept Medicaid.

Breast Cancer Statistics

Incidence Rates

Breast cancer is much more common in women than in men, so rates reflect the incidence in the female population.

Based on the data from Thomson Reuters, the incidence of breast cancer in Michigan is, at 119.9 per 100,000, close to the national average of 118.69 per 100,000. In 2009, the latest year for which figures are available there were 2666 cases of breast cancer diagnosed in our service area. The incidence of breast cancer in the Affiliate area ranged from 98 per 100,000 in Jackson County, to 139 per 100,000 in Livingston County. The incidence for Livingston County is thought to be an overestimate due to an underestimate of population compared to the 2010 census numbers. The incidence of breast cancer is also above the US national average in Clinton (123) and Eaton (123) County. Of most concern is the fact that the incidence of breast cancer has increased since 2007 in every county in the Affiliate's service area. (see Appendix Table 1).

Mortality Rates

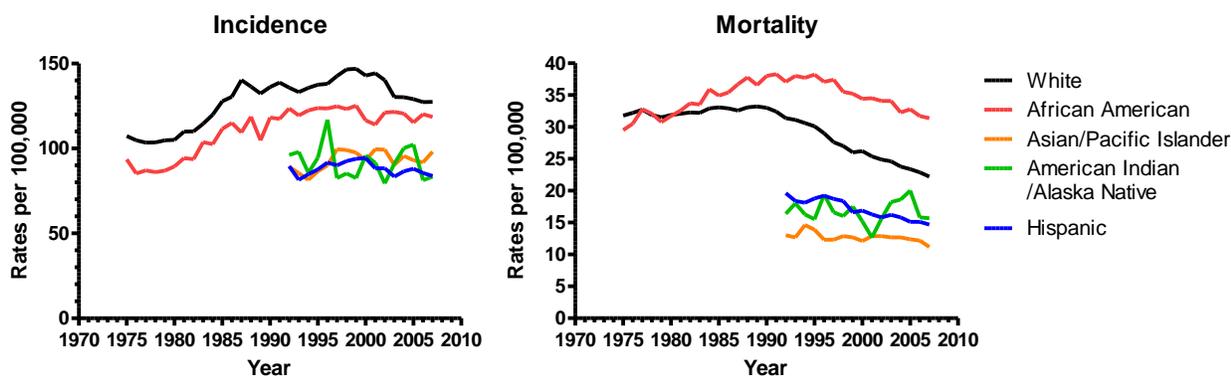
Breast cancer remains the second leading cause of cancer death in Michigan. (Healthy Michigan 2010). Overall mortality from breast cancer in the Affiliate's service area is

22.47 per 100,000, which is below the US rate of 24.5 per 100,000 (CDC Wonder, 2010). However, this overall rate does obscure some variation between counties, notably Jackson County which has a high mortality rate of 28.8 per 100,000. Indeed the breast cancer mortality rate is high in every zip code area across Jackson County and this warrants further investigation. The mortality rate is also high in Shiawassee County at 25.0 per 100,000 and Eaton County at 24.94 per 100,000. These rates should be interpreted with caution though as the numbers used to calculate the rates are low.

Since 1990, the US mortality rate from breast cancer has steadily decreased which is likely due to the advances in imaging technology, the adoption of mammographic screening in conjunction with public education campaigns and provider recommendations (Ikei et al. 2007; Marshall, Ziogas & Anton-Culver. 2009b). However, it should be noted that mortality rates have increased in Mid-Michigan (by 2.0 per 100,000) between 2007 and 2009 while they decreased in the US as a whole (decrease of 0.7 per 100,000). The increase in mortality rates was noted in all seven counties. It may be hypothesized that this is due to the increasing population in Michigan which is without health insurance, or to increasing poverty rates in the state. It is known that breast cancer patients from lower-income areas have lower 5-year survival rates than those from higher-income areas at every stage of diagnosis*. The rise does indicate a continuing need for education and outreach regarding breast health.

Despite a decrease in overall mortality rates, considerable disparities remain in the US for women from certain ethnic groups and who are low-income.

Graph 3. Trends in Female Breast Cancer Incidence and Mortality Rates by Race and Ethnicity in the US (1975-2007)



Rates are age-adjusted to the 2000 US Std Population (19 age groups - Census P25-1103).
 Source: Incidence data for whites and blacks are from the SEER 9 areas (San Francisco, Connecticut, Detroit, Hawaii, Iowa, New Mexico, Seattle, Utah, Atlanta). Incidence data for Asian/Pacific Islanders, American Indians/Alaska Natives and Hispanics are from the SEER 13 Areas (SEER 9 Areas, San Jose-Monterey, Los Angeles, Alaska Native Registry and Rural Georgia)
 Created by www.seer.cancer.gov/csr/1975_2007/download_csr_datafile.php/sect_04_zfig.04.csv on 02/08/2011

However this is not reflected in the Mid-Michigan service area. Statistics show that African American women have the highest all- age mortality rate (24.09 per 100,000), compared with that for Caucasian women (19.88 per 100,000). The high mortality rate

in Jackson County occurs across every zip code regardless of its minority population. However these figures again should be treated with caution due to the statistically low numbers involved.

Late-Stage Diagnosis Rates

It is notable that there was higher percentage of stage IV diagnoses in the cities of Lansing, Jackson and Ypsilanti (4.5 %+) compared to the area as a whole (4.4%). This was also the case for stage III diagnoses. These cities are areas with a high ethnic minority population. It is known that both African American and Hispanic women are more likely to be diagnosed at a later stage of cancer and are less likely to survive five years after diagnosis than white women (Surveillance Research Program, National Cancer Institute). See graph 3 above. Late-stage diagnosis of breast cancer is commonly associated with more invasive and larger tumors, lack of routine screening that allows for early detection, greater pain and medical complications arising from metastasis, and higher mortality rates. Minority women in general are less likely to repeat mammography (Blancard, K. et al, 2004) the number one defense against breast cancer.

Mammography Screening Behavior

Susan G. Komen recommends that women of average risk aged 40 or older should be screened annually. The Michigan Department of Community Health released figures in February 2011 citing that only 56% of women in Michigan age 40 or older are receiving appropriately timed breast cancer screening. Given the critical role mammography plays in the fight against breast cancer, we find it alarming that a significant portion of women age 40 or older did not receive a mammogram in the last 12 months. The underlying reasons for not having a mammogram are unclear, but this appears to represent a need for education throughout the Affiliate area on the value of early detection.

Communities of Interest

Based on the national evidence on the higher breast cancer mortality rate among ethnic minorities and the notably higher rates of late stage diagnosis in parts of the service area with high ethnic minority populations it was decided to focus efforts on the cities of Jackson, Lansing and Ypsilanti. Further, the high rate of breast cancer mortality across Jackson County warrants further investigation.

Conclusions

An examination of the data shows a worrying increase in breast cancer incidence and mortality in the Komen Mid-Michigan Affiliate service area. There is also concern about the high mortality rate in Jackson county and high rates of late-stage diagnosis in the cities of Jackson, Lansing and Ypsilanti. These communities should be a focus for the Affiliate's efforts. The Affiliate also needs to pay attention to the low rates of women receiving mammography across the service area and understand what role lack of health insurance plays in this.

Health Systems Analysis of Target Communities

Continuum of Care

The Breast Cancer Continuum of Care (Figure 2) represents how a woman typically moves through the health care system to be screened for breast cancer, and if necessary, receives follow-up diagnostic tests and treatment for breast cancer. This model can be used as a guide when assessing why some women do not receive regular screening and why others who are screened may not receive timely diagnostic tests, treatment or follow-up care.

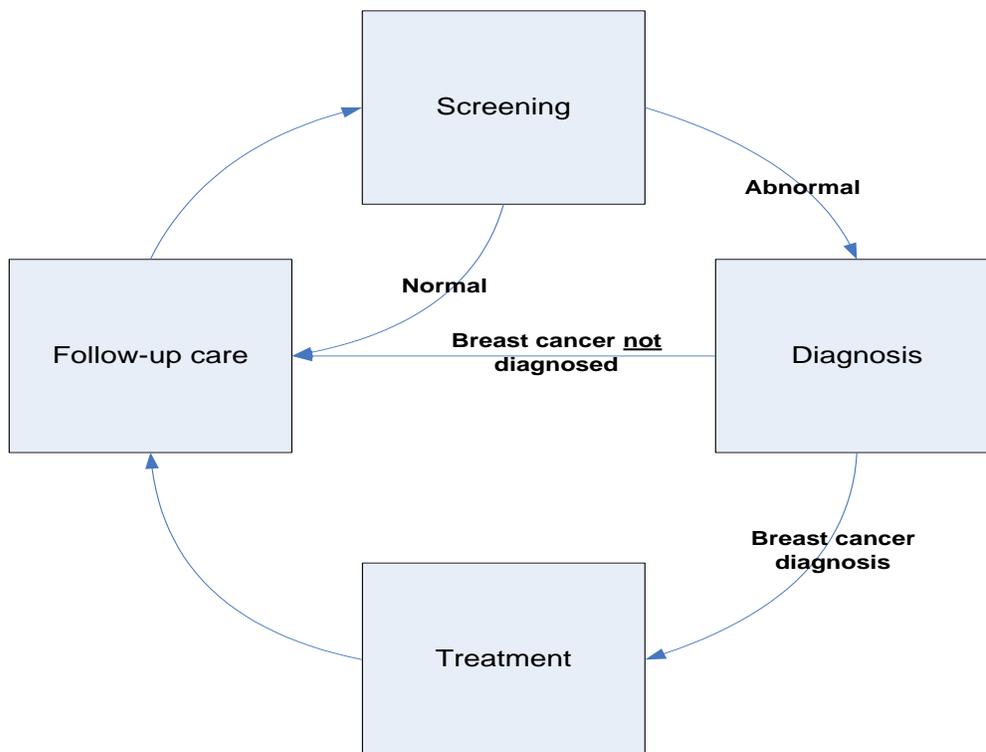


Figure 2: Continuum of care.

Methodology

Quantitative and qualitative analyses of the health systems in the Mid-Michigan Affiliate service area were used.

Initially an inventory was compiled of all the major health care resources in the area. An analysis was carried out of providers, programs, services and Komen Mid-Michigan Affiliate relationships across the service area. To build upon our research, key informant interviews were conducted in person and over the phone. Interviews were done with the representatives from the Center for Family Health and Allegiance Women's Health Center, both in Jackson County, and the Ingham County Health Department – a coordinating agency of the Michigan Breast and Cervical Cancer Control Program. Data, from the following sources were also used: www.PolicyMap.com, Michigan Department of Community Health and the Michigan Breast and Cervical Cancer Early Detection Program.

Overview of Community Assets

Each of the main cities in the region has at least one major healthcare provider.

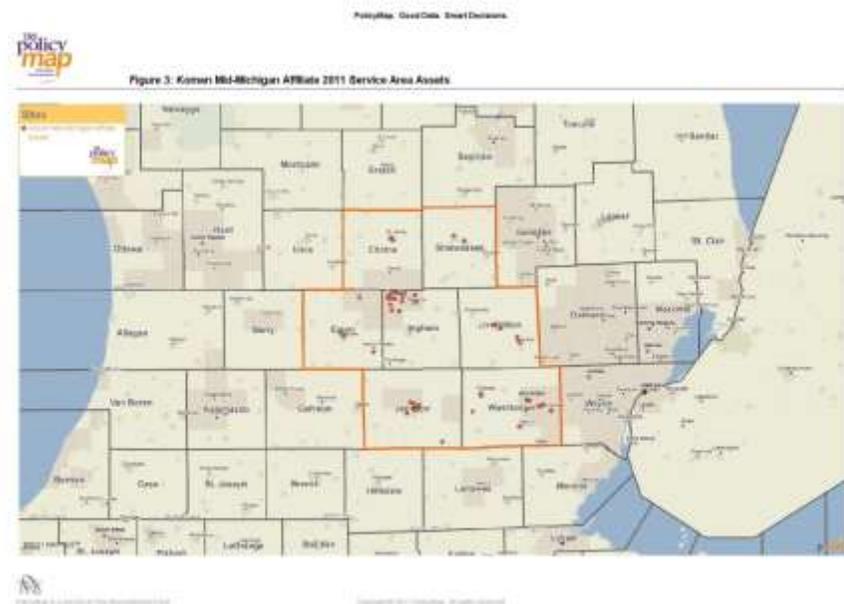
Jackson is served by the Allegiance Health System which has a hospital and over a dozen satellite clinics and services in the area. Jackson residents also are served by the Center for Family Health, a Federally Qualified Health Center which serves Medicaid, uninsured and underinsured patients. There are five mammography sites in Jackson County, three are part of the Allegiance Health System, based in the city of Jackson, and accept Medicaid patients. The other two, one in Jackson and one in Brooklyn do not accept Medicaid.

The Greater Lansing area, including Ingham, Eaton and Clinton counties, is served by two large hospitals – Sparrow Health System and McLaren-Greater Lansing Hospital and the hospitals satellite clinic locations. The Greater Lansing community also is served by the Michigan State University's medical school and associated health services. In addition, Eaton and Clinton counties each have small community hospitals: Hayes Green Beach Memorial Hospital in Charlotte (Eaton County) and Sparrow Clinton Hospital (Clinton County).

In the Ann Arbor metropolitan area, which includes Ypsilanti, the University of Michigan hospital and medical school serve Washtenaw and Livingston Counties. The University of Michigan is a public hospital and as such accepts cases from across the area. In addition, the Saint Joseph Mercy Health System serves patients with two hospital locations in Ypsilanti and Howell.

Shiawassee County is home to Memorial Healthcare, a community hospital and smaller satellite clinics.

Each major health system offers varying services specific to breast cancer, including comprehensive breast clinics, mammography facilities, surgeons, follow-up cancer care and support services. Access for those in rural communities still results in less than an hour drive to an accredited health care provider.



Breast and Cervical Cancer Control Program (BCCCP)

Since 1991, the Michigan Department of Community Health (MDCH) has implemented a comprehensive Breast and Cervical Cancer Control Program (BCCCP) through a multi-year grant from the U.S. Centers for Disease Control and Prevention. With these funds, low-income women have access to cancer screening services and follow-up care, including cancer treatment if that should be needed. Michigan's BCCCP screened 31,130 women for breast cancer in 2010 (Michigan Public Health Institute). To be eligible for the Michigan BCCCP, a woman must be between 40-64 years old, be uninsured, or underinsured, and have a household income at or below 250% of the federal poverty level. The decrease in funding for BCCCP in recent years has caused the State of Michigan to restrict eligibility for screening mammograms. In 2010, up to 40% of women receiving mammography screening for breast cancer through the BCCCP were ages 40-49. In 2013, the number of women receiving mammography screening for breast cancer through the BCCCP ages 40-49 will be capped at 25%. **Along with this, funding for BCCCP will decrease overall 30% in FY2014.** This cap on mammography screening for women ages 40-49 will bring Michigan in line with the Center for Disease Control recommendations. Nevertheless these restrictions in coverage will create a gap in service for women ages 40-49 in Michigan

Policy Initiatives

The Komen Mid-Michigan Affiliate along with four additional Affiliates - the West Michigan Affiliate, Southwest Michigan Affiliate, Northwest Ohio Affiliate and the Komen Detroit Race for the Cure® advocate for continued State support of the Michigan Breast and Cervical Cancer Control Program and the four federal issues that are in the Komen Tool Kit. These issues include support of the Cancer Drug Parity Act, Actively Living with Cancer Care Plan Act, continued research funding, continued BCCCP funding. We are meeting with legislators at both the state and federal levels to accomplish these goals. We are involved in coalitions at the state level to further these efforts and to continue as a voice for breast health advances in Michigan.

Changes to Medicaid under the Patient Protection and Affordable Care Act go into effect on January 1, 2014. The federal law is expected to extend health insurance coverage to 32 million Americans nationwide, covering nearly all individuals under age 65 up to 133 % of poverty. (The Henry J. Kaiser Foundation). Changes to the uninsured and underinsured populations in Michigan cause the Komen Mid-Michigan Affiliate to address priorities on an ongoing basis and reevaluate our role in supporting the continuum of care.

Key Informant Interviews

The strongest message taken from the six key informant interviews was the need to have clear and unified mammogram screening recommendations. In September 2009, the U.S. Preventative Task Force issued a recommendation for women ages 40-49 to make individualize decisions to begin breast health screening according to the patient's context and values. This recommendation runs contrary to the American Cancer Society, National Cancer Advisory Board, and Susan G. Komen mammogram recommendations that women of average risk should begin regular mammography screening at age 40. The U.S. Preventative Task Force recommendations have created confusion about when women should begin mammogram screening.

Conclusions

Women in the Komen Mid-Michigan Affiliate service area have good access to high-level health care systems, usually within an hour drive. The State of Michigan has in place a program to help low income and underinsured women obtain a mammogram, although in this economic climate the program is restricted by limited funding. The Affiliate will need to continue to advocate for this program. Also new guidelines on mammograms for women ages 40-49 have created both confusion and limitations in

availability, both of which are areas of concern for the Affiliate. The Affiliate will need to play a role through providing grants to nonprofit organizations who can address the education and screening needs of women in our service area **especially the African American population whose mortality rates are higher than other ethnicities**. The Affiliate also must engage our constituents in spreading the breast health awareness message.

Breast Cancer Perspectives in the Target Communities

Methodology

In order to qualitatively assess levels of breast health awareness, barriers to care and perceptions and knowledge of Susan G. Komen, the Affiliate conducted both a survey and a focus group interview.

A survey was developed for breast cancer survivors, designed to capture the needs of survivors in all areas of the Komen Mid-Michigan Affiliate service area. The surveys were implemented using the online survey tool SurveyMonkey. The survey link was emailed to the addresses in the Komen Mid-Michigan survivor database. Survivors completed 21 surveys, with at least one breast cancer survivor completing the survey from each county in the Affiliate service area. The survey included a mixture of 32 closed and open ended questions to gain perspective on survivor experiences in seeking screening, treatment and support.

The Affiliate chose to conduct a focus group in Jackson County. The focus group was held in Jackson in February 2011, and comprised of women ages 40-64 who were not breast cancer survivors. Rosalyn Beene-Harris, MPH, was contracted to facilitate the focus group discussion and develop a report on key findings. At the beginning of the session, an explanation of the purpose, discussion etiquette, confidentiality and the use of recording/note-taking methods were provided. Verbal consent was obtained and the session was audio taped and transcribed by the moderator omitting identifying information. Allegiance Women's Health Center was selected as the host site for the focus group. Although a total of eight women from Jackson County were recruited, only five were able to participate in the discussion. Lunch was provided prior to the session and an honorarium (a \$25 Visa gift card) was distributed at the end of the session.

Review of Qualitative Findings

Survivor Surveys

While most of the survivors who completed the Breast Cancer Survivor Survey indicated they did not experience financial burdens during treatment for cancer, uninsured and underinsured women struggled financially. One survivor commented that due to lack of insurance she had waited months before seeking county resources.

Survivors were clear on the importance of the support that they had received. This had come from many different sources including a spouse, partner or significant other, parents, children, friends, and church or houses of worship. Survivors did feel that there was a need for post-therapeutic support that was not always available. One survivor shared “When you are all done and you feel like you've been put out to pasture since you've completed all your treatments. That is when I felt the most lonely”.

Focus Group

Results from the focus group, identified by Rosalyn Beene-Harris, centered around two main areas – individual barriers and institutional barriers.

Individual Barriers

It was clear from the focus groups that barriers existed on an individual level. One major barrier was a lack of knowledge. This knowledge deficit included –

- Lack of perceived chance of breast cancer diagnosis. Women were not aware of the effect of their family medical history on their risk of breast cancer.
- Lack of knowledge and awareness of breast health care. Seeking health care beyond the recommended physical was identified as a potential barrier for some women.
- Increased fear of the mammography screening process. Participants identified fear of the unknown and known examination process, feelings of embarrassment, or lack of comfort as barriers. One woman commented “Once you've had it done, especially if you've had at that time of the month when you are tender anyway and you remember that pain. I really don't want to go through that again”.

Institutional Barriers

Members of the focus group also highlighted institutional barriers. These included

- Provider lack of communication and awareness. The participants identified missed educational opportunities from a number of physicians in explaining where the breast health care resources were located, what occurred during a mammography screening, and the value of clinical guidelines
- Cost and insurance. One woman commented “I just recently lost my job, so I no longer have insurance. And I got the baseline mammogram but I don't know, you know, if I'll get a mammogram this year or not. It all depends on what my financial situation will be at that time. I am due for one in the fall. So, I'll have to make a decision at that time whether I can afford it. Hopefully, I'll a job and will have insurance”.

- Distance to services. The focus group participants also believed that a barrier to seeking services is the inability to afford and obtain reliable transportation. “Reserve-a-ride is more expensive than the regular public transportation. And they are on a schedule. So, if you have like an early morning [appointment], they may not be in operation yet”.

Focus Group Discussion Results

Overall, the participants were able to share their experiences in seeking breast health care in and around the city of Jackson. It was apparent that the women were disadvantaged by their lack of knowledge about Breast Health and of the system that seeks to treat them. Key themes that were identified included a lack of awareness of breast health education and resources; a perceived level of risk and fear; the cost and lack of insurance; and a lack of reliable transportation. In the future it would be helpful to conduct further focus groups in Lansing and Ypsilanti to discover if perceptions are similar in those communities.

Conclusions

Hearing the voices of the women in Komen Mid-Michigan Affiliate area reinforces our need to better understand the availability of breast health services and barriers to those services. The opinions shared in the survivor survey address the difficulties of uninsured and underinsured women when undergoing treatment as well as the need for continued services for all survivors after treatment. The focus group discussion highlighted barriers to breast health as seen in one high need community.

Conclusions: What We Learned, What We Will Do

Review of Findings

The data collected and analyzed in this assessment identified key areas that are of concern to the Affiliate.

Levels of mammography in Michigan are worryingly low and may reflect widespread confusion over screening guidelines. In addition women interviewed by the Affiliate demonstrated a lack of knowledge of breast health guidelines. This demonstrates an opportunity for increased education, to both providers and patients, about breast health and the importance of regular screenings as well as how to navigate the system.

Data analysis shows that, although lower than the national average, breast cancer mortality is increasing in Michigan. Late stage diagnosis and mortality rates are higher in the cities of Jackson, Lansing and Ypsilanti, which have high ethnic minority populations, than in the general Affiliate area, (see Graph 3). This represents a clear need to work to ensure that these populations have knowledge of and access to the continuum of care.

Quantitative analysis as well as anecdotal evidence points to a gap in services in the area for women with breast health concerns who are under 40 years old as well as to limited services for those aged 40-49.

Although transportation was seen to be a barrier by interviewees, the Affiliate has found that this not to be a significant factor.

The Affiliate also has learned from breast cancer survivors in our service area, that support during treatments is important. We know psychosocial support may offer better outcomes for breast cancer survivors following their treatment, thus the Affiliate will continue to work with community-based organizations to ensure survivorship programs exist to cover a wide range of support for women and their families.

Our health systems analysis shows the Komen Mid-Michigan Affiliate service area has a strong network of health care providers and Breast and Cervical Cancer Control Program Coordinators. Our partners in the fight against breast cancer also can be found in the Affiliate's grantee network. Overall, the Affiliate needs to do more to strengthen our current relationships with health care providers and grantees and form new contacts with nonprofit organizations and community-based organizations that will help us reach women in all seven of our service area counties.

Conclusions

After analyzing all of the findings the Community Profile team determined the following priorities for the Affiliate over the next two years.

1. Promote breast health awareness and the importance of screening across our service area, particularly in the cities of Lansing, Jackson and Ypsilanti.
2. Support access to breast **screening and diagnostics for** uninsured and underinsured women aged 40-49, and those aged under 40 with a breast health concern.
3. Provide breast cancer survivors with programs offering emotional, social and physical support during and following breast cancer treatment.
4. Increase the Komen Mid-Michigan Affiliate visibility throughout its service area.

Action Plan

The mission of the Affiliate, which encompasses outreach and education initiatives, grants and public policy will include the following action plan. The priorities and recommendations listed below will help the Affiliate target our education and grant funding efforts to bring positive changes to the breast health of women in our seven-county service area.

1. **Priority 1:** Promote breast health education and the importance of early detection and screening across our service area, particularly in the cities of Lansing, Jackson and Ypsilanti with an emphasis on African American women.

Objective 1: Ensure that all grantees are delivering Breast Self-Awareness messaging in line with Komen recommendations.

Objective 2: Determine the most appropriate health fair expo occasions to deliver the BSA message in each city. Arrange attendance.

Objective 3: Develop partnerships in each priority area to develop outreach to ethnic minority populations.

Objective 4: To include more information on the Affiliate's website about local provision of services and BSA.

Objective 5: Investigate reasons for low levels of screening across the area.

2. **Priority 2:** Support access to breast screening and diagnostics for uninsured and underinsured women aged 40-49 and those aged under 40 with a breast health concern.

Objective 1: Work with existing grantees and cultivate new grantee relationships to ensure qualified nonprofit organizations know funding opportunities are available through the Komen Mid-Michigan Affiliate.

Objective 2: Stress the importance of early detection and the successes of Michigan's Breast and Cervical Cancer Control Program to legislators making important decisions about the program's state funding through and sharing timely legislative updates with Komen Mid-Michigan's advocates.

Objective 3: Work with BCCCP, **grantees and other healthcare institutions** to identify areas of insufficient provision.

3. **Priority 3:** Provide breast cancer survivors with programs offering emotional, social and physical support during and following breast cancer treatment.

Objective 1: Ensure that reports from current grantees include evaluations from survivor participants assessing the value of the program.

Objective 2: Compile a list of support services available for breast cancer survivors in our service area and feature the list on the Komen Mid-Michigan Affiliate web site.

4. **Priority 4:** Increase the Komen Mid-Michigan Affiliate visibility throughout its service area.

Objective 1: Provide networking opportunities for grantees at grantee orientation **and at least two other times per year.**

Objective 2: The Affiliate should develop a visible presence by regular attendance at existing community health coalitions.

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