



COMMUNITY

PROFILE REPORT 2015



SUSAN G. KOMEN®
WESTERN NEW YORK

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Executive Summary

Introduction to the Community Profile Report

Susan G. Komen® Western New York (WNY) is a 501(c)(3) organization, managed by a Board of Directors, which hires an Executive Director. Komen WNY was originated by a group of committed and passionate community volunteers who put on the first Race for the Cure in Buffalo, NY, in 2001. The all-volunteer organization eventually grew to a size that allowed for the employment of an Executive Director. Under the leadership of the Executive Director, a comprehensive strategic plan was developed to provide focus and future direction for the Affiliate, and the organization has flourished for 15 years. A renewed strategic plan every three to four years, coupled with the Community Profile, enables the Affiliate to respond to the breast health needs of its service area and deliver the greatest impact possible.

Komen Western New York's service area includes eight counties: Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, Orleans and Wyoming. There is a total combined population of about 720,000 women in this region.

Erie and Niagara Counties are more culturally diverse than the rest of the other counties, and have the largest urban centers in the service area. Erie County is home to the City of Buffalo, the largest city in the service area, and to a large population of refugees from over 70 different countries. Large pockets of these urban centers are defined as primarily low-income and medically underserved.

Poverty also exists throughout the Southern Tier counties of Allegany, Cattaraugus and Chautauqua. These areas are defined as rural and medically underserved. Orleans, Genesee, and Wyoming Counties are also defined as rural and medically underserved. Located between Buffalo and Rochester, these counties are often grouped and share services with the Rochester Metropolitan Statistical Area.

Komen WNY is the local source for funding breast cancer detection, support and educational awareness in Western New York with an overall goal of decreasing disparities in care and improving health-care access for underserved populations. Since its inception, Komen WNY has provided over \$4.5 million in research and grant funding for community breast health and breast cancer programs that focus on education, patient navigation and treatment for under-served populations in the eight counties, as well as survivorship support for area residents who have battled the disease.

Organizations interested in applying to funding through Komen WNY must be from a 501(c)(3) entity, provide services within the eight counties of Western New York, and adhere to a rigorous and thorough review process by an independent review panel before being submitted to the Board of Directors for approval. To raise money to support its local grants program, the Affiliate holds several fundraisers, including the Komen signature event, the annual Race for the Cure. Community groups can also initiate and organize their own events and/or promotions to benefit Komen Western New York.

In terms of public policy, Komen participates in several local and regional cancer and chronic disease coalitions, joining forces to battle the many needs of the community. Advocacy around access to care is also part of the Komen WNY mission, with participation in local and national initiatives to ensure quality care for all.

Overall, the Community Profile identifies areas of need in breast healthcare, and aligns the Affiliate's community outreach, grant making and public policy priorities. The results of the Community Profile will drive the Affiliate's funding and programmatic initiatives for 2015-2019. The Affiliate aims to fund programs that address existing barriers due to lack of education and support, financial and transportation constraints,

availability of resources, as well as cultural and language barriers. Komen WNY will fund the most effective and impactful programs to reduce late stage diagnosis, and promote screening and treatment. It also supports efforts that increase community outreach, and establish and strengthen community partnerships.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Quantitative data was gathered and interpreted in order to guide selection of targeted communities. Evidence and statistics were obtained from several credible sources including the US Census Bureau, New York State Cancer Registry, and the State Cancer Profiles on Cancer Control P.L.A.N.E.T. The Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factors Surveillance System (BRFSS) was used to collect information on mammography screening rates across the U.S. In addition, supplemental data were accessed through a direct email request to the New York State Cancer Registry to identify service gaps and areas of need specific to Western New York.

The Affiliate's objective is to reduce breast cancer death rates and late stage diagnoses in the service area. Breast cancer death rate refers to the number of women dying from breast cancer. Late-stage incidence rate shows the number of new cases that were diagnosed at a late stage rather than an early stage, which impacts prognosis. People with breast cancer have a better chance of survival if their disease is found early and treated. The stage of cancer indicates the extent of the disease within the body. Trends will show changes in this over time. The female breast cancer "incidence" means the number of new cases of breast cancer that develop in a specific time period.

To determine priority areas, each county's estimated time to reach Healthy People 2020 (HP2020) targets for late-stage diagnosis and death were compared, and then categorized into seven potential priority levels. Counties' priority status were classified by the following factors; counties that are not likely to achieve either of the HP2020 targets were considered to have the highest needs, counties that have already achieved both HP2020 targets were considered to have the lowest needs, and other counties were classified based on the number of years needed to achieve the HP2020 targets.

Communities with high rates of late stage diagnoses, below average screening rates, high rates of residents living below poverty level, and high rates of residents living without health insurance were selected as target areas.

Of the eight counties in the Affiliate's service area, four target communities were selected:

- Allegany County
- Cattaraugus County
- Erie County
- Wyoming County

Figure 1 shows a map of the intervention priorities for the counties in the Affiliate service area.

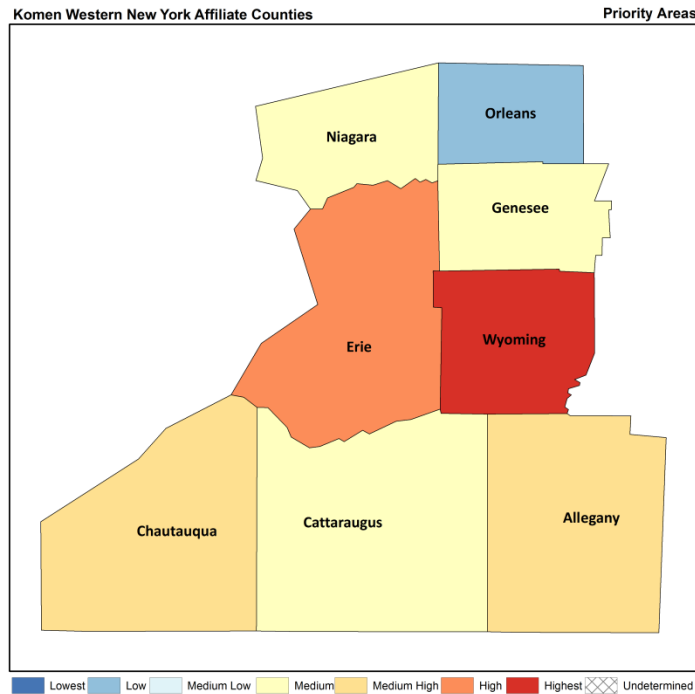


Figure 1. Intervention Priority Areas

Erie County has been identified as a priority county due to the length of intervention time estimated to achieve the HP2020 targets. It is predicated to take 11 years for the county to achieve its target death rate, and 13 years or longer to achieve its target late-stage incidence. Erie County includes the City of Buffalo, and is the largest and most diverse county in the service area. In general, the minority population in Erie County is higher than the rest of the service area, with 14.8 percent Black/African-American residents and 4.6 percent Hispanic/Latina residents. African-American women face higher death rates from breast cancer compared to other races. African American and Hispanic/Latina women are significantly less likely to be diagnosed at an earlier stage than White women.

Cattaraugus County falls into the medium priority guidelines for HP 2020 targets. Cattaraugus County is predicated to take three years to achieve its target death rate, and 11 years or longer to achieve its target late-stage incidence. Cattaraugus County is classified as a rural and medically underserved area in the Southern Tier of Western New York. The annual average female population is 40,877 and 52.3 percent of those women are over the age of 40. 93.9 percent of the total female population is comprised of White women and 38.9 percent of the county residents fall below 250 percent of the poverty line. There are also large Native American and Amish communities in the county.

Allegany County falls into the medium-high priority area for HP 2020 targets. Allegany County is predicated to take 2 years to achieve its target death rate, and 13 years or longer to achieve its target late-stage incidence. Allegany County, located in the Southern Tier, is defined as a rural and medically underserved county. Allegany’s population and geographic demographics are comparable to neighboring Cattaraugus County, with 39 percent of county residents living below 250 percent of the poverty line, and 49.5 percent of the total female population over the age of 40. Due to the similarities and geographic proximity between the two counties, they often collaborate in delivering services.

Wyoming County is unlikely to achieve HP2020 objectives for breast cancer and is the highest priority county. Several factors contribute to this estimation, with economic and access barriers presenting the greatest obstacles. Wyoming County is predicated to take 13 years or longer to achieve its target death rate, and 13 years or longer to achieve its target late-stage incidence. Wyoming County, also located in the Southern Tier,

is the least populated county in the service area, with a total population of just under 42,000 people, and just over 19,000 females. Wyoming County's female population is primarily White and over the age of 40. Over 31 percent of county residents fall below 250 percent of the poverty line.

Overall, the breast cancer late-stage incidence rate in the Affiliate service area was slightly higher than that observed in the US as a whole and the late-stage incidence trend was higher than the US as a whole. The late-stage incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of New York. For the Affiliate service area as a whole, the incidence rate was lower among African Americans than Whites, lower among Asian Pacific Islanders than Whites, and lower among American Indian/Alaska Natives than Whites. The incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas. None of the counties in the Affiliate service area had substantially different incidence rates than the Affiliate service area as a whole.

Overall, the breast cancer death rate in the Affiliate service area was slightly higher 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 significantly higher than that observed for the State of New York. 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. 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.

Health System and Public Policy Analysis

The Health Systems and Public Policy Analysis sought to identify barriers and gaps in the Continuum of Care (CoC), as well as identify opportunities to grow and strengthen breast health resources and awareness. An in-depth analysis of the target counties' health systems and policies was conducted, as well as an examination of both local and statewide public policies.

Of all the target areas, the largest numbers of screening and treatment options are available to women accessing the CoC in Erie County. There are many community based and health based organizations in Erie County that provide a variety of breast health education and support, including cancer care and patient navigation services to residents, particularly to those in underserved communities.

Until recently, few mammography facilities exist inside the City of Buffalo. In early 2015, however, there were at least 2 new Mammography facilities opened in the city.

Patient navigation services are a valuable resource for women transitioning through the CoC. Though some healthcare institutions offer patient navigation at the screening level, the availability of these services are limited. Safety-net practices and health centers see an abundance of patients with multiple complex conditions and often find prioritizing health needs challenging. Limited access to technology makes navigating the complex health system difficult for many women.

In Cattaraugus County, community-based organizations are crucial in providing breast health education and resources to women. Many breast health services offered in the county are provided by the two largest healthcare systems in the Southern Tier region, Southern Tier Community Health Center Network and Olean General Hospital. Most outreach programs in this target area are provided by Cancer Services Program (CSP), funded by the New York State Department of Health. CSP offers education, screening, diagnostics, case management, and treatment assistance for breast, cervical, and colorectal cancers at various locations in the Affiliate's area. Additionally, CSP sponsors low cost or no cost breast and cervical cancer risk reduction services to uninsured or underinsured women, ages 40 and over. Other agencies that provide education and support programs include the Cattaraugus County Health Department and the Breast and Cervical Health Partnership of Cattaraugus County.

Few screening and treatment options exist in Cattaraugus County. Only Olean General Hospital offers chemotherapy treatment services (located in the region's largest city, Olean) and is over an hour drive for many residents. Due to this limitation, many women are referred to hospitals or larger organizations outside of their county to receive breast health services. The distance to screening facilities and treatment services makes accessing breast healthcare difficult for many women. Native American women are eligible to receive services from two healthcare institutions that primarily serve the Native American community, however distance between the reservations require women to travel great distances outside of their communities to access these services. Patient navigation, support groups, and survivorship services are severely lacking in Cattaraugus County. The Affiliate could only identify one location that offered a breast cancer support group, again located in the city of Olean.

Allegany County shares many resources and services with neighboring Cattaraugus County, including the same two large healthcare systems which offer screening mammograms to residents. Community-based organizations play a large role in providing education and support services, several of which aim to reduce financial and transportation barriers. The two counties also share CSP, which provides most of the outreach in this area.

Breast health screening and treatment services are even more limited for women living in Allegany County. The lack of available resources requires women to travel over 60 miles round trip to neighboring counties in order to access services. Although Allegany County offers some services for Native American women, much like Cattaraugus County, resources are limited and require additional travel. Breast cancer support groups and patient navigation programs, at the screening and treatment levels, are limited in Allegany. The Affiliate was unable to identify any breast cancer support groups available in Allegany County, instead residents were required to travel to neighboring Cattaraugus County to access the one support group available to both counties.

Wyoming County has one location that offers screening mammograms to residents; Wyoming County Community Hospital. Oak Orchard Community Health Center provides Clinical Breast Exams. Financial resources for uninsured and underinsured women are available through the Cancer Services Program of Livingston and Wyoming Counties.

Overall, Wyoming County severely lacks breast cancer screening, treatment, and support services, including patient navigation programs. Wyoming County currently has no treatment centers. Due to Wyoming County's rural geography, residents must travel substantial distances to adjacent counties in order to access breast care. Resources for uninsured and underinsured women are available through community-based organizations, such as CSP.

The Health Systems and Public Policy Analysis acknowledged the Affiliate's policy activities and identified opportunities for the Affiliate to grow and strengthen breast health resources and awareness. New York State Medicaid covers mammography and medically necessary radiology services for those eligible. The federal Affordable Care Act (ACA) expanded Medicaid coverage, which insures those under 65 with limited income. Health insurance Marketplace, called the NY State of Health, assesses eligibility and enrolls residents in various insurance products including free or low cost health insurance coverage (like Child Health Plus or Medicaid). If ineligible for Medicaid, private insurance plans are available. NY State of Health does not affect Medicare coverage. The Marketplace is intended to help New Yorkers who are not eligible for Medicaid to receive health insurance coverage.

The New York State Comprehensive Cancer Control Plan 2012-2017 was created by the New York State Cancer Consortium (NYSCC), as a guide to identify and address the cancer burden in New York State. The plan has identified six priority areas including: health promotion and cancer risk reduction, early detection, treatment, survivorship, palliative care, and the health care workforce. Despite progress made in these areas, cancer continues to be the second leading cause of death in New York State. In addition, cancer data show that certain groups in New York continue to suffer disproportionately from cancer and its effects. The risk of developing or dying from cancer varies by race/ethnicity, and disparities are more pronounced with specific cancers.

Overall, the Health Systems and Public Policy Analysis identified three major barriers to access in the identified target areas:

- Lack of availability of screening, diagnosis and treatment facilities, particularly in urban and rural areas.
- Inadequate transportation for both urban and rural women at all stages of the breast care continuum.
- Lack of patient navigation services in all of the target areas; patient navigation services are a valuable resource for women transitioning through the continuum of care.

Qualitative Data: Ensuring Community Input

The Affiliate conducted key informant interviews and focus groups with five different demographic groups from each of the four target areas to gain a more in-depth perspective on the barriers women face in accessing breast health care. These groups included primary care providers, cancer care providers, community-based organizations, women 40 years old and older, and breast cancer survivors. A set of predetermined interview questions were used to guide the conversations. Questions were selected to elicit information about three identified content areas; access to cancer care across the CoC, barriers to screening and early detection, and availability of support services.

The Affiliate conducted key informant interviews with primary care providers, cancer care providers, and community based organizations. All of these groups were identified as important in assisting women through the CoC, specifically recognizing the importance of primary care providers as the gateway to screening mammography. All key informants were asked about the availability of resources in their counties, and barriers women face in seeking screening and/or treatment. Both primary care providers and cancer care providers were asked to consider factors that may contribute to late stage diagnosis, their opinions on current screening guidelines, and barriers they faced in follow up care with patients in treatment.

Women 40 years of age and older, and breast cancer survivors participated in key informant interviews and focus groups. It was important to explore the views of women without breast cancer to understand the barriers they may face in accessing care, particularly in regards to early detection and screening. In addition, the Affiliate wanted to assess the experiences of survivors, specifically the challenges they faced throughout the entire cancer care continuum. Survivors were recruited to share feedback of their experience in navigating the CoC for their treatment resources. Survivors were asked to comment on barriers they faced in getting screened and receiving treatment, the availability of resources and barriers to accessing those resources, and how they thought the continuum of care could be improved.

Overall, similar and recurring barriers existed in each target area among key informants and focus group participants. Financial and transportation barriers were common issues that women faced in accessing quality breast health services. Key informants identified cost and lack of insurance as main concerns inhibiting women from accessing services. The cost of co-pays and potential out of pocket costs for uninsured and underinsured

women deter them from accessing services. Focus groups noted gas prices and frequency of travel for treatments as a concern, particularly for rural communities where inconvenient locations require women to travel great distances for breast health services, and public transportation was not always a reliable alternative. Focus group participants also mentioned a concern for the cost of services and co-pays.

In all target areas, key informants noted fear as a prevalent deterrent for many women from seeking services, and overcoming the fears associated with a potential diagnosis as essential to encouraging women to enter the CoC. Women in the focus groups acknowledged they were fearful of the mammogram procedure itself, having endured painful experiences in the past, and many were afraid of the potential for positive findings.

A lack of appropriate breast health knowledge inhibited many women in the target areas from recognizing the importance of breast screening and early detection. Key informants and focus groups revealed women received breast health knowledge from several sources, including primary care physicians, community based organizations, and media outlets. However, there is still a considerable lack of awareness among residents. Increasing the availability and access to culturally appropriate breast health education can aid in reducing fears and improving screening rates.

Communication deficits and a lack of primary care physicians were largely mentioned among key informants in Allegany and Cattaraugus counties. Many women in the focus groups indicated that having a good rapport with their doctor is an imperative element to their care. Participants across all counties mentioned that if they did not feel comfortable or felt that the physician was not empathetic to their situation, changing doctors was their prerogative. An improvement in communication and coordination of care among the health system is necessary.

Key informants and focus group participants acknowledged family history or knowing someone personally affected by cancer was a strong motivator for seeking screening services. Also, if a woman is more health conscious and visits her doctor regularly, she is more likely to seek screening. Key informants specifically mentioned a lack of time and scheduling challenges as factors preventing women from seeking mammography screening.

Overall, there is a need for increased breast health education, reducing barriers to access to care, and inadequate availability of services, in hopes of making an impact on breast cancer death.

Mission Action Plan

The Affiliate compiled, summarized, and analyzed the data from the Quantitative Data Report, Health Systems and Public Policy Analysis, and Qualitative Data Report. From the analysis, the Affiliate defined one problem statement for each of the four target communities, identifying barriers and gaps in breast health services in each community. Priority areas and measurable objectives aiming to achieve the identified priorities and drive the Affiliate's grant funding initiatives for 2015-2019, are identified below:

Erie County

Data obtained through the Quantitative Report and Qualitative assessment shows that underserved women in Erie County, especially African-American and Latino populations, are significantly less likely to be diagnosed at an early stage of breast cancer. The most common factors that contribute to this problem are barriers to transportation, access to breast health services, and inadequate availability of services. The Affiliate has identified two main priorities with several objectives established to help alleviate the problems:

1. **Decrease disparities in breast care services and increase the number of minority women screened annually in Erie County, by 2019.**
 - a. By Fiscal Year (FY) 2016-2017, make Request for Applications (RFA) aiming to alleviate transportation barriers to breast health services, particularly to breast screenings, a funding priority.
 - b. By 2019, collaborate with other local cancer-focused agencies and the state health department in developing initiatives toward educating underserved populations about breast health.
 - c. By 2019, identify, collaborate with, and support at least three community-based organizations experienced in combating the social and cultural barriers that prevent many underserved women from seeking or successfully accessing breast cancer services.

2. **Promote peer support and patient navigation to increase awareness of the importance of breast health and screening in Erie County, by 2019.**
 - a. In FY 2016-2017, promote grant proposals aiming to support patient navigation programs providing breast health guidance to women.
 - b. By 2019, identify and collaborate with four community-based and/or faith based organizations in the city of Buffalo to disseminate Komen-produced breast health information to the local community.
 - c. By 2019, collaborate with two community-based and/or health organizations and local media and marketing personnel in Erie County to educate the community about Komen Western New York's presence and activities.

Cattaraugus County

Key informant interviews and focus groups conducted in Cattaraugus County revealed that women in Cattaraugus County have limited access to affordable and convenient breast health services, particularly screening and treatment options. The Affiliate has identified two priorities with several objectives created to help address this problem.

1. **By 2019, increase the number of women screened annually by improving access to breast health services in Cattaraugus County.**
 - a. By 2019, increase marketing efforts through media outlets to encourage organizations in Cattaraugus County to submit grant proposals that aim to reduce transportation and financial barriers and improve access to breast health services.
 - b. By 2019, partner with at least two health organizations to understand needs and provide resources for diagnosed breast cancer patients and ensure support.

2. **By 2019, promote peer support and patient navigation in Cattaraugus County to increase the awareness of the importance of breast health and screening.**
 - a. By 2019, promote Community and Small Grant applications in Cattaraugus County, with an emphasis on improving patient navigation, support groups, and/or survivorship.
 - b. By 2019, collaborate with at least two community-based organizations and/or healthcare institutions to provide culturally appropriate outreach efforts to the Seneca Nation of Indians and Amish settlements.
 - c. By 2019, implement a public relations/marketing campaign around Komen-sponsored education and outreach regarding screenings and resources available for breast cancer patients and survivors.

Allegany County

Analysis of the Qualitative Data shows that distance to breast cancer screening and treatment services is a major barrier, impeding access to care for women in Allegany County. Two priorities were identified with objectives developed to aid in tackling the transportation barrier and lack of navigation services in Allegany County.

- 1. Increase the number of women screened annually by improving access to breast health services among women in Allegany County, by 2019.**
 - a. In FY 2016-2017 encourage community-based and/or health organizations in Allegany County to submit grant proposals to increase programs that aim to reduce transportation and financial barriers and improve access to breast health services.
 - b. By 2019, partner with at least two primary care, OB/GYN, and/or health clinics to discuss potential collaboration efforts aiming to alleviate barriers to care in rural areas of Allegany County.

- 2. By 2019, promote peer support and patient navigation in Cattaraugus County to increase the awareness of the importance of breast health and screening.**
 - a. Beginning with 2016-17 RFA, make grant applications targeting programs with an emphasis on patient navigation, support groups, and/or survivorship efforts in Allegany County a funding priority.
 - b. By 2019, partner with Allegany County health organizations and local media and marketing personnel to educate the community about Komen Western New York's presence and activities.

Wyoming County

The Health Systems Analysis and Qualitative Data assessments shows that Wyoming County severely lacks breast cancer screening, treatment, and support services creating major barriers to access for women in this rural, medically underserved region.

- 1. Increase the number of women screened annually by improving access to breast health services among women in Wyoming County by, 2019.**
 - a. Beginning with 2016-17 RFA, make grant applications targeting programs with an emphasis on patient navigation, support groups, and/or survivorship efforts in Wyoming County a funding priority.
 - b. By 2019, partner with at least two Wyoming County organizations for collaboration efforts in education of area residents and providers regarding Komen breast health standards and services.
 - c. Beginning with 2016-17 RFA, identify and target community-based and/or health organizations to submit grant proposals to increase programs reducing transportation and financial barriers and improving access to breast health services in Wyoming County.

- 2. By 2019, promote peer support and patient navigation in Wyoming County to increase the awareness of the importance of breast health and screening.**
 - a. By 2019, offer two grant writing workshops promoting the Community and Small Grants programs targeting providers and community-based organizations Wyoming County in order to provide patient navigation, support groups, and/or survivorship efforts.
 - b. By 2019, develop new partnerships with two primary care and/or OB/GYN providers serving primarily low-income women in Wyoming County to provide patient navigation programs, encourage breast healthcare support and disseminate current Komen supported breast health education and materials.

- c. By 2019, collaborate with one local healthcare institution and local media and marketing personnel in Wyoming County to educate the community about Komen Western New York's presence and activities, and assist in the dissemination of Komen supported breast health education.

Komen Western New York

Quantitative Data shows that many women in the target areas of Komen Western New York are not meeting screening guidelines, and are not set up to meet Healthy People 2020 objectives in the next 10 years. Because so many women in the service area are not set up to meet Health People 2020 objectives, this is a service area wide priority. The Affiliate identified one major priority with objectives generated to address this issue.

1. By 2019, develop new partnerships to advance the Affiliate's mission.

- a. By 2019, develop a partnership with the New York State Cancer Consortium (NYSCC) and formally join the Cancer Consortium to align with statewide initiatives.
- b. By 2019, align the Affiliate's Mission Action Plan with the New York State Comprehensive Control Plan, particularly in regards to measuring the Affiliate's work in helping to improve breast health care.

Disclaimer: Comprehensive data for the Executive Summary can be found in the 2015 Komen Western New York Community Profile Report.

Introduction

Affiliate History

Through the efforts of a number of committed community leaders and health care providers, the Susan G. Komen® Western New York was formed in 2000. For the first four years, the Affiliate was an all-volunteer organization. Under the excellent leadership of the founding board president, the Affiliate grew to a size that allowed for the employment of an Executive Director, followed shortly thereafter by an Education Coordinator. This allowed the Affiliate to manage as a year-round agency active throughout the community with a variety of events.

The founding board members of Komen Western New York prepared a Community Profile to demonstrate the need for an increased awareness of breast cancer and a response to this life threatening disease in the eight counties of Western New York. Under the leadership of the Executive Director, a comprehensive strategic plan was developed to provide immediate focus and future direction for the Affiliate. Committees were organized and duties were delegated to wonderful volunteer resources in the WNY community. The strategic plan coupled with the community profile enabled the Affiliate to respond to the needs of WNY in an efficient and effective manner.

In response to the need identified in the profile, the Affiliate utilized its diverse personal and professional contacts to organize and implement the first Race for the Cure© in Buffalo in May 2001. Although the Affiliate has added other events, the Race continues to be the largest fundraiser.

Komen Western New York has developed an important and significant grant program in response to the community profile. The Affiliate has two approaches to grant making: small grants and community grants. In 2006, the Affiliate instituted a small grants program that allowed it to receive grant requests and begin to forge relationships with grassroots organizations on a year-round basis. In 2010, the Board of Directors raised the level of small grant requests to enable greater support of agencies and programs. Community grants provide larger funding amounts and are awarded once a year. Both large and small grant proposals must provide services within the eight counties of Western New York, and adhere to a rigorous and thorough review process before being submitted to the Board for approval. Since 2000, Komen WNY has awarded over \$3 million dollars of grant support in Western New York for breast cancer outreach and education, support, treatment, and screening. The overall goal of the grant program is to decrease disparities in care and improve healthcare access for under-served populations.

The Affiliate has established strong relationships with community partners, such as the New York State Cancer Services Program (CSP) in Erie and Allegany/Cattaraugus Counties, Roswell Park Cancer Institute, WCA Hospital in Jamestown, and many other community partners. The CSP statewide is often under threat of funding cuts, but the Affiliate has been on the front line in efforts to maintain funding for the CSP. The Affiliate has partnered with other New York State Affiliates to create a strong force with the state government. Komen has supported programs that bring together these partners with direct impact on screening, early diagnosis and treatment.

Affiliate Organizational Structure

The current Board consists of breast cancer survivors, activists, medical and research professionals as well as community leaders who combine their talents, networks and resources to promote the mission of Susan G.

Komen in the Western New York community. The Affiliate identifies specific, unmet breast health needs within the Western New York communities and “fills in the gaps.”

Komen WNY has a strong history of collaboration with other local organizations and includes an active Community Engagement Committee made up of area experts in breast health in the service area. The collaborations also extend to the Grants programs, which fund programs implemented by organizations such as Roswell Park Cancer Institute, Erie County Cancer Services Program, and hospitals both in Buffalo and the rural counties that promote screening, and patient navigation.

Susan G. Komen believes in empowering women by providing reliable breast health information so they can take charge of their health. To help make that happen, Komen WNY volunteers are available to speak to community groups, corporate organizations and schools. This service is provided at no cost as part of the Affiliate’s mission to spread the life-saving message of early detection to the community. The Speakers Bureau is available to present to organizations or groups on a wide range of breast cancer and breast health issues, including the importance of breast self-awareness techniques. Most of the speakers are breast cancer survivors or medical professionals and lend their personal experiences to the presentation.

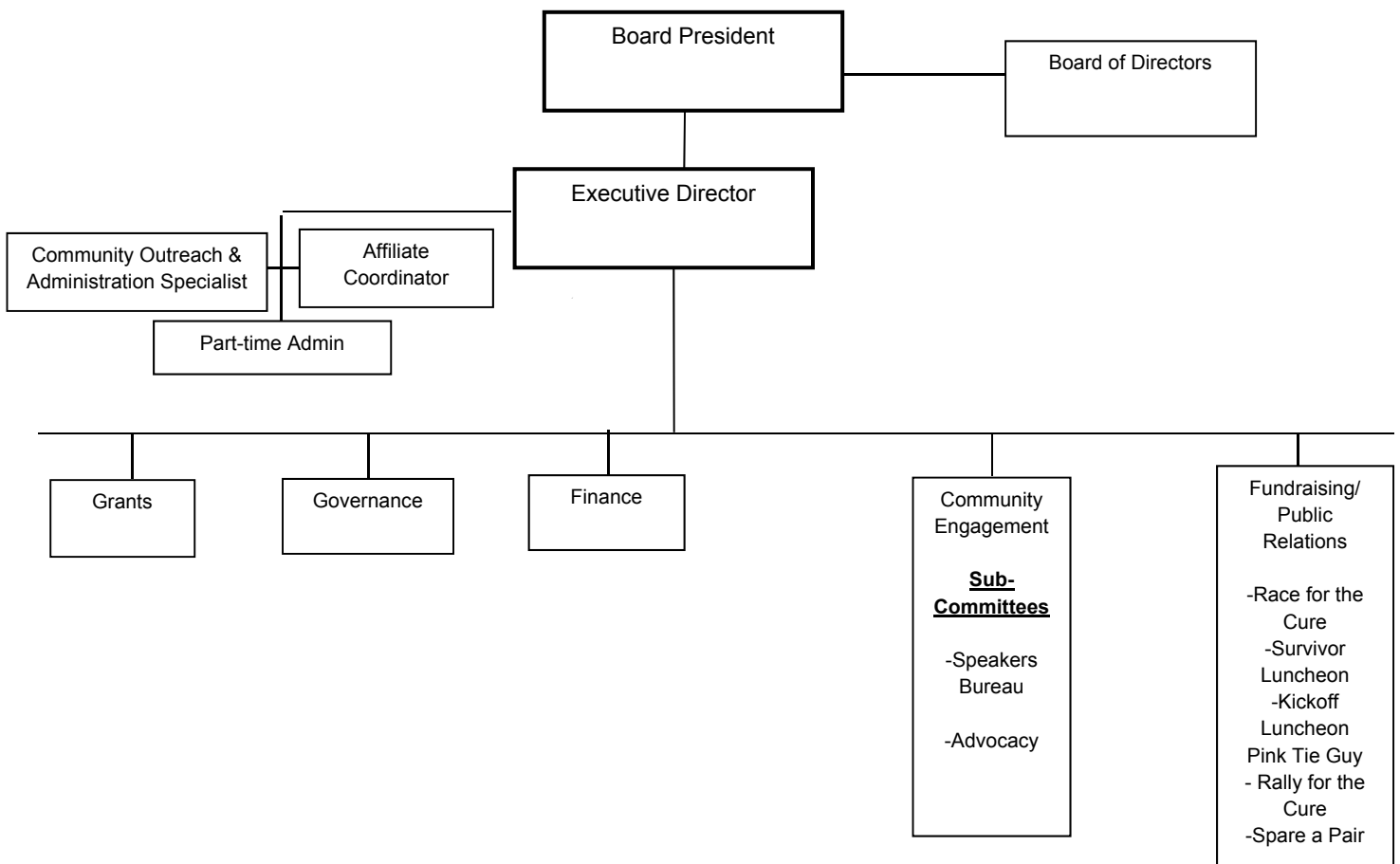


Figure 1.1 Susan G. Komen Western New York Organizational Char

Affiliate Service Area

Komen Western New York serves eight counties: Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, Orleans, and Wyoming with a total of about 720,000 women. The general service area is 86.3 percent white, which is higher than the US average of 78.8 percent. The service area borders Canada to the north, Lake Erie to the west, and Pennsylvania to the south. Western New York is a largely blue collar community with a long history of manufacturing and unions. Special populations exist within the service area. These populations include refugees from over 70 countries, the Seneca Nation of Indians, and Amish settlements.

Erie and Niagara Counties have much more culturally diverse urban centers than the rest of the service area. The residents of these counties are defined as primarily low-income and medically underserved.

Erie County is comprised largely of the city of Buffalo and surrounding suburbs. The County's population of 919,040 is the largest county of the service area. In general, the minority population in Erie County is higher than the rest of the service area. Erie County has a higher population of Hispanic/Latina and African American residents at 4.6 percent. The county is also comprised of 14.8 percent Black/African-American residents. In Erie County both groups are nearly 20 percent less likely than White women to be diagnosed at an early stage, when breast cancer can be most successfully treated.

As such, the potential for social and economic barriers to breast cancer screening and treatment are higher. These factors, combined with the poverty rate of 30.7 percent and 22.9 of residents living in medically underserved areas in Erie County, make access to resources incredibly challenging for many residents.

Niagara County is located in the extreme western part of New York State just north of Erie County. It is adjacent to Lake Ontario on its northern border and the Niagara River and Canada on its western border. Of Niagara County's 214, 249 total population, 7.6 percent of the residents are Black/African-American and 2.5 percent are Hispanic/Latina. Just over half of Niagara County's total population, 51.3 percent are comprised of women. While the median income for residents of Niagara County is \$47,955, 13.7 percent of residents fall below the poverty line.

Cattaraugus County, located in the Southern Tier of Western New York is defined as a rural and medically underserved county. The annual average female population is 40,877 and 52.3 percent of those women are over the age of forty. White women make up 93.9 percent of the population in Cattaraugus County. Cattaraugus County has the highest percentage of American Indians in the service area as well as a large Amish population also lives in Cattaraugus County. From a socioeconomic standpoint, 38.9 percent of Cattaraugus County residents fall below 250 percent of the poverty line and 12.6 percent did not graduate high school.

Allegany County, located in the Southern Tier of Western New York is defined as a rural and medically underserved county. Situated adjacent to Cattaraugus County, the two counties have combined New York State Cancer Services Programs, as well as similar demographics. There is a total population of 48,946, and 49.5 percent of the women living in Allegany are over the age of forty. Similar to Cattaraugus County, 38.7 percent of Cattaraugus County residents fall below 250 percent of the poverty line and 12.1 percent have an education level below high school.

Chautauqua County is the western gateway to New York State, located in its extreme southwest corner between Buffalo, NY and Erie, PA. The total population of Chautauqua is 133,080. The County is geographically and somewhat socially and economically, divided into two regions; the "north county" City of Dunkirk and the "south county" City of Jamestown. The geographic are of Chautauqua County is vast. Half of its residents are sparsely populated, with 58.8 percent of the County's population residing in urban areas and 41.2 percent residing in rural areas. This geographic spread creates transportation and access challenges for residents.

Hispanics are the fastest growing ethnic group in the County, currently making up 6.8 percent of the County's population, followed by 94.1 percent white, and 2.7 percent Black/African-American. Chautauqua County's eastern boundaries are encapsulated by two Seneca Nation reservations resulting in a strong American Indian presence. There is also an extensive Amish community that stretches between Chautauqua and Cattaraugus Counties. 19.1 percent of residents fall below the poverty line.

Genesee County is rurally located between Buffalo and Rochester, New York as well as between two other rural counties, Orleans and Wyoming. With a total population of 59,454 3.1 percent of residents are Black/African-American and 2.9 percent are Hispanic/Latino. 90.3 percent of Genesee County residents have a high school diploma. 73 percent of individuals have health insurance while 13.1 percent do not.

Orleans County has a total population of 42,235 residents. There is a small Amish population in this region. Orleans County is identified as rural according having a density of less than 500 persons per square mile. Despite grouping with the Rochester Metropolitan Statistical Area, Orleans County is a designated member of the WNY region and collaborates with all seven counties in the region. Mostly white with 90.4 residents, Orleans County has 6.4 percent Black/African-American and 4.5 percent Hispanic/Latino residents. Orleans County's median household income is \$48,502. 13.4 percent falls below the poverty line.

Wyoming County is located in the Southern Tier of the Western New York service area. The demographic makeup of this county's female residents is primarily White and over 40 years of age. With a total population of just under 42,000 people, and just over 19,000 females, Wyoming County is the least populated county in the service area.

Socioeconomic characteristics of the region indicate a potential concern about women's access to breast health care. Just over 31 percent of residents fall below 250 percent of the poverty line. The county is defined as rural and medically underserved, indicating that both income and physical distance from screening and treatment locations are barriers to breast health services for the women of Wyoming County.

KOMEN WESTERN NEW YORK SERVICE AREA

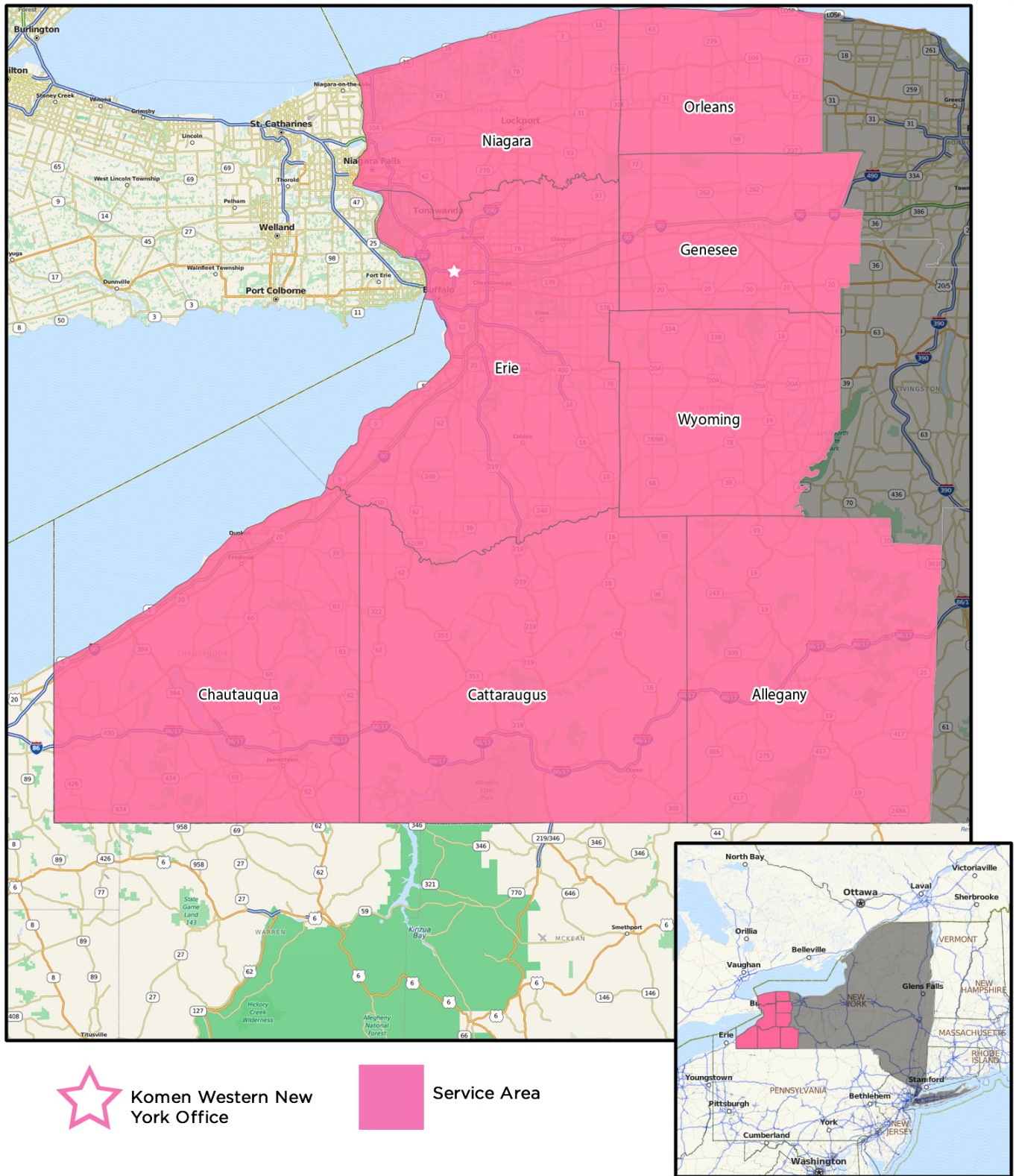


Figure 1.2. Susan G. Komen Western New York Service Area

Purpose of the Community Profile Report

An effective Community Profile will help Komen align its community outreach, grant making, and public policy activities towards the same Mission goal: to save lives and end breast cancer forever by empowering others, ensuring quality care for all and energizing science to find the cures. The Community Profile will allow Affiliates to:

- Include a broad range of people and stakeholders in the Affiliate's work and become more diverse
- Fund, educate and build awareness in the areas of greatest need
- Make data-driven decisions about how to use its resources in the best way – to make the greatest impact
- Strengthen relationships with sponsors by clearly communicating the breast health and breast cancer needs of the community
- Provide information to public policymakers to assist focusing their work
- Strategize direction to marketing and outreach programs toward areas of greatest need
- Create synergy between Mission-related strategic plans and operational activities

Examination of target communities revealed opportunities to grow and influence effective breast health strategies. The results of the Community Profile will aid in driving the Affiliate's funding and programmatic initiatives. The Profile identifies areas of need and improvements in breast healthcare. The Affiliate aims to fund programs that address existing barriers due to lack of education and support, financial and transportation constraints, and availability of resources. The Affiliate will fund the most effective and impactful programs to reduce late stage diagnosis and promote screening and treatment. Supporting efforts that increase community outreach, establish, and strengthen community partnerships are imperative priorities that can have a direct impact on breast health and save lives.

The Community Profile report will be available to the community via several outlets. The Western New York Affiliate website is a valuable resource that provides the community with a link to the Profile as well as with information found in the report. The Affiliate will also utilize social media platforms as a means to get the word out about the local Affiliate's work in the community and build a following. These platforms can also be used to connect interested members of the community with the results of the Profile. The results of the Profile will also be shared with existing networks in the community with which the Affiliate has an existing relationship.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Quantitative Data Report

Introduction

The purpose of the quantitative data report for Susan G. Komen® Western New York 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 (<http://www.healthypeople.gov/2020/default.aspx>).

The following is a summary of Komen® Western New York'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	182,234	122.1	-0.2%	40,736	22.6	-1.9%	64,590	43.8	-1.2%
HP2020	-	-	-	-	-	20.6*	-	-	41.0*	-
New York	9,929,239	14,604	127.7	-0.4%	2,704	22.3	-2.6%	5,026	44.6	-1.6%
Komen Western New York Service Area	794,380	1,363	136.2	0.5%	268	24.8	NA	439	45.1	0.3%
White	689,854	1,253	137.8	0.2%	237	24.0	NA	388	44.1	-0.1%
Black/African American	82,610	93	123.3	7.2%	29	38.8	NA	45	59.1	6.8%
American Indian/Alaska Native (AIAN)	7,578	5	78.9	12.5%	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	14,338	9	98.0	13.0%	SN	SN	SN	3	29.1	6.2%
Non-Hispanic/ Latina	765,989	1,349	137.1	0.5%	266	25.0	NA	433	45.3	0.3%
Hispanic/ Latina	28,392	14	85.0	-2.5%	SN	SN	SN	6	37.5	-5.2%

Population Group	Female Population (Annual Average)	Incidence Rates and Trends			Death Rates and Trends			Late-stage Rates and Trends		
		# 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)
Allegany County - NY	24,336	36	125.5	-0.2%	6	22.3	-4.2%	13	49.8	4.5%
Cattaraugus County - NY	40,877	62	123.6	3.9%	12	22.0	-2.7%	25	48.9	-1.7%
Chautauqua County - NY	68,726	116	132.1	-4.3%	17	17.9	10.9%	36	43.1	-1.7%
Erie County - NY	477,826	840	139.4	2.1%	177	27.0	-2.6%	274	46.8	0.9%
Genesee County - NY	30,275	47	122.2	-5.2%	8	19.3	-3.3%	12	30.1	3.2%
Niagara County - NY	111,309	196	138.0	-2.0%	35	23.6	-1.6%	57	41.4	-2.1%
Orleans County - NY	21,744	32	121.6	-9.4%	6	21.0	-3.1%	10	37.8	-17.2%
Wyoming County - NY	19,287	34	141.8	5.1%	6	24.7	-0.5%	13	55.1	18.6%

*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

Overall, the breast cancer incidence rate and trend in the Komen Western New York service area were higher than that observed in the US as a whole. The incidence rate of the Affiliate service area was **significantly higher** than that observed for the State of New York and the incidence trend was not significantly different than the State of New York.

For the United States, breast cancer incidence in Blacks/African Americans is lower than in Whites overall. The most recent estimated breast cancer incidence rates for APIs and AIANs were lower than for Non-Hispanic/Latina Whites and Blacks/African Americans. The most recent estimated incidence rates for Hispanics/Latinas were lower than for Non-Hispanic/Latina Whites and Blacks/African Americans. For the Affiliate service area as a whole, the incidence rate was lower among Blacks/African Americans than Whites, lower among APIs than Whites, and lower among AIANs than Whites. The incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

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

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 Western New York service area was slightly higher 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 **significantly higher** than that observed for the State of New York.

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 APIs and AIANs were lower than for Non-Hispanic/Latino Whites and Blacks/African Americans. The most recent estimated death rates for Hispanics/Latinas were lower than for Non-Hispanic/Latino Whites and Blacks/African Americans. For the Affiliate service area as a whole, the death rate was higher among Blacks/African Americans than Whites. There were not enough data available within the Affiliate service area to report on APIs and AIANs so comparisons cannot be made for these racial groups. 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.

The death rate was significantly lower in the following county:

- Chautauqua County

The rest of the counties had death rates and trends that were not significantly different than the Affiliate service area as a whole.

Late-stage incidence rates and trends summary

Overall, the breast cancer late-stage incidence rate in the Komen Western New York service area was slightly higher than that observed in the US as a whole and the late-stage incidence trend was higher than the US as a whole. The late-stage incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of New York.

For the United States, late-stage incidence rates in Blacks/African Americans are higher than among Whites. Hispanics/Latinas tend to be diagnosed with late-stage breast cancers more often than Whites. For the Affiliate service area as a whole, the late-stage incidence rate was higher among Blacks/African Americans than Whites and lower among APIs than Whites. There were not enough data available within the Affiliate service area to report on AIANs so comparisons cannot be made for this racial group. The late-stage incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

The late-stage incidence rate was significantly lower in the following county:

- Genesee County

The rest of the counties had late-stage incidence rates and trends that were not significantly different than the Affiliate service area as a whole.

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 Cancer Institute	National Comprehensive Cancer Network	US Preventive Services Task Force
Mammography every year starting at age 40	Mammography every 1-2 years starting at age 40	Mammography every year starting at age 40	<p>Informed decision-making with a health care provider ages 40-49</p> <p>Mammography every 2 years ages 50-74</p>

Because having 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. BRFSS is the best and most widely used source available for information on mammography usage among women in the United States, although it does not collect data matching Komen screening recommendations (i.e. from women age 40 and older). 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 Latina, but only 10.0 percent of the total women in the area are 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%
New York	2,020	1,568	79.7%	77.4%-81.7%
Komen Western New York Service Area	275	211	78.8%	71.9%-84.4%
White	254	195	78.8%	71.8%-84.5%
Black/African American	11	8	74.5%	32.2%-94.7%
AIAN	SN	SN	SN	SN
API	SN	SN	SN	SN
Hispanic/ Latina	SN	SN	SN	SN
Non-Hispanic/ Latina	270	208	80.0%	73.2%-85.4%
Allegany County - NY	13	8	60.4%	27.5%-86.0%
Cattaraugus County - NY	19	15	85.8%	60.7%-95.9%
Chautauqua County - NY	31	24	81.3%	55.3%-93.9%
Erie County - NY	148	116	79.6%	70.1%-86.7%
Genesee County - NY	14	7	39.2%	12.9%-73.8%
Niagara County - NY	34	27	81.0%	61.8%-91.9%
Orleans County - NY	SN	SN	SN	SN
Wyoming County - NY	SN	SN	SN	SN

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 Western New York 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 New York.

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/Latina Whites and Blacks/African Americans. For the Affiliate service area as a whole, the screening proportion was not significantly different among Blacks/African Americans than Whites. There were not enough data available within the Affiliate service area to report on APIs and AIANs so comparisons cannot be made for these racial groups. 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 %
New York	71.7 %	19.0 %	1.1 %	8.3 %	82.4 %	17.6 %	49.5 %	35.4 %	15.5 %
Komen Western New York Service Area	86.3 %	10.7 %	1.0 %	2.1 %	96.0 %	4.0 %	53.1 %	39.4 %	17.9 %
Allegany County - NY	97.1 %	1.4 %	0.3 %	1.2 %	98.6 %	1.4 %	49.5 %	37.2 %	16.6 %
Cattaraugus County - NY	93.9 %	1.7 %	3.6 %	0.8 %	98.3 %	1.7 %	52.3 %	39.1 %	17.0 %
Chautauqua County - NY	95.7 %	2.8 %	0.7 %	0.8 %	94.0 %	6.0 %	53.0 %	40.2 %	18.8 %
Erie County - NY	81.6 %	14.8 %	0.8 %	2.8 %	95.4 %	4.6 %	52.9 %	39.3 %	18.0 %

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
Genesee County - NY	94.9 %	3.0 %	1.2 %	0.9 %	97.6 %	2.4 %	54.1 %	39.5 %	17.9 %
Niagara County - NY	89.9 %	7.6 %	1.2 %	1.2 %	97.7 %	2.3 %	54.5 %	40.3 %	18.1 %
Orleans County - NY	92.4 %	6.2 %	0.7 %	0.7 %	96.0 %	4.0 %	53.4 %	38.1 %	16.0 %
Wyoming County - NY	98.5 %	0.5 %	0.3 %	0.6 %	98.6 %	1.4 %	54.2 %	38.9 %	16.6 %

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	Linguistic-ally Isolated	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age: 40-64)
US	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
New York	15.4 %	14.5 %	32.3 %	8.2 %	21.8 %	8.3 %	12.1 %	20.3 %	12.1 %
Komen Western New York Service Area	11.5 %	14.3 %	32.4 %	8.1 %	4.8 %	1.7 %	24.0 %	19.7 %	9.8 %
Allegany County - NY	12.1 %	16.6 %	38.7 %	8.6 %	1.9 %	0.3 %	78.7 %	18.8 %	10.4 %
Cattaraugus County - NY	12.6 %	16.7 %	38.9 %	8.8 %	1.5 %	0.8 %	61.8 %	28.2 %	13.5 %
Chautauqua County - NY	13.1 %	17.7 %	38.6 %	8.1 %	1.9 %	1.5 %	43.9 %	0.0 %	9.7 %
Erie County - NY	11.1 %	14.2 %	30.7 %	8.0 %	6.2 %	2.3 %	9.4 %	22.9 %	9.1 %
Genesee County - NY	9.5 %	12.5 %	30.6 %	7.5 %	2.9 %	0.8 %	59.9 %	0.0 %	11.2 %
Niagara County - NY	11.1 %	12.8 %	32.6 %	7.9 %	3.7 %	0.8 %	22.4 %	0.0 %	10.5 %
Orleans County - NY	15.0 %	12.1 %	34.6 %	9.9 %	3.6 %	0.4 %	60.9 %	100.0 %	12.2 %
Wyoming County - NY	13.8 %	10.1 %	31.2 %	6.8 %	2.4 %	0.3 %	64.1 %	44.5 %	10.6 %

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 Western New York service area has a substantially larger White female population than the US as a whole, a slightly smaller Black/African American female population, a substantially smaller Asian and Pacific Islander (API) female population, a slightly smaller American Indian and Alaska Native (AIAN) female population, and a substantially smaller Hispanic/Latina female population. The Affiliate's female population is 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 is a slightly smaller percentage of people who are unemployed in the Affiliate service area. The Affiliate service area has a substantially smaller

percentage of people who are foreign born and a slightly smaller percentage of people who are linguistically isolated. There is a slightly larger percentage of people living in rural areas, a substantially smaller percentage of people without health insurance, and a slightly smaller percentage of people living in medically underserved areas.

None of the counties in the Affiliate service area have substantially different population characteristics than the Affiliate service area as a whole.

Priority Areas

Healthy People 2020 forecasts

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

HP2020 has several cancer-related objectives, including:

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

To see how well counties in the Komen Western New York 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.

The data is 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 rates and key breast cancer death determinants such as poverty and linguistic isolation.

Table 2.7. Intervention priorities for Komen Western New York 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
Wyoming County - NY	Highest	13 years or longer	13 years or longer	Rural, medically underserved
Erie County - NY	High	11 years	13 years or longer	
Allegany County - NY	Medium High	2 years	13 years or longer	Rural
Chautauqua County - NY	Medium High	13 years or longer	3 years	Rural
Cattaraugus County - NY	Medium	3 years	11 years	Rural, medically underserved
Genesee County - NY	Medium	Currently meets target	13 years or longer	Rural
Niagara County - NY	Medium	9 years	1 year	
Orleans County - NY	Low	1 year	Currently meets target	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.

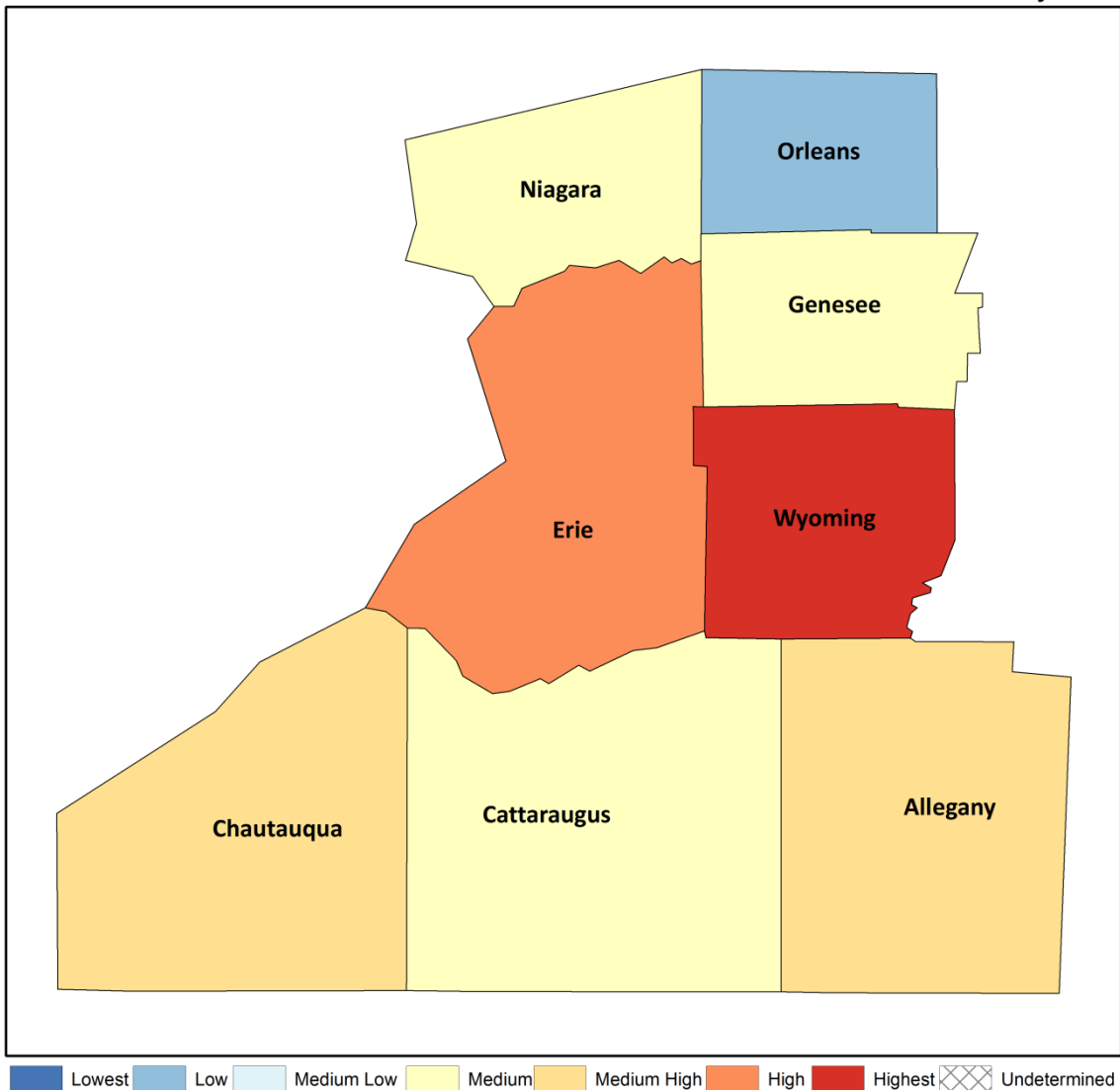


Figure 2.1. Intervention priorities.

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

One county in the Komen Western New York service area is in the highest priority category. Wyoming County is not likely to meet either the death rate or late-stage incidence rate HP2020 targets. Late-stage incidence trends in Wyoming County (18.6 percent per year) indicate that late-stage incidence rates may be increasing, although not significantly

High priority areas

One county in the Komen Western New York service area is in the high priority category. Erie County is not likely to meet the late-stage incidence rate HP2020 target. The death rate in Erie County (27.0 per 100,000) appears to be higher than the Affiliate service area as a whole (24.8 per 100,000) although not significantly.

Additional Quantitative Data Exploration

In addition to the information provided in the preceding Quantitative Data Report, staging data, broken down by race were collected in order to construct a more comprehensive overview of the breast cancer burden in Erie County, which is the most populated county in the Komen Western New York Affiliate service area. The supplemental data were accessed through a direct email request to the New York State Cancer Registry (<http://www.health.ny.gov/statistics/cancer/registry/>), which is nationally certified through the North American Association of Central Cancer Registries, in order to ensure timely, high-quality data collection and reporting.

The Western New York Affiliate service area is comprised of eight counties, six of which are rural: Allegany, Cattaraugus, Chautauqua, Genesee, Orleans, and Wyoming. The residents of these counties are defined as primarily low-income and medically underserved. The general service area is 86.3 percent white, which is higher than the US average of 78.8 percent. In six of the eight counties in the service area, staging data was not reported because there were not enough minority residents to report on.

Unlike the rural counties, Erie and Niagara have more culturally diverse urban centers than the rest of the service area. Erie County has a higher Hispanic/Latina population than the rest of the service area at 4.6 percent. The county is also comprised of 14.8 percent Black/African-American residents, while 7.6 percent of the residents of Niagara County are Black/African-American. Black/African-American women are known to have higher mortality rates from breast cancer and since the stage at diagnosis can be a factor in death rates for breast cancer, additional data was collected to determine if there was a disparity in staging among minority residents in Erie County and the City of Buffalo.

The additional data collected from the New York State Cancer Registry illustrate a clear staging disparity among Black/African-American and Hispanic/Latina women in Erie County. In Erie County both groups are nearly twenty percent less likely than White women to be diagnosed at an early stage, when breast cancer can be most successfully treated. This supplemental information enables the Affiliate to focus specific attention on the Black/African-American and Hispanic/Latina communities of Erie County. Furthermore it will inform further investigations in the Health Systems Analysis, and the Qualitative Data Report.

Table 2.8 Breast Cancer Case Count by County, Race/Ethnicity, and Stage, 2006-2010

County	Race	Stage at Diagnosis								
		Local		Regional		Distant		Unknown		Total
Erie	White	N=2,411	65%	N=946	26%	N=192	8%	N=156	4%	N=3,705
Erie	Black/African-American	N=185	47%	N=158	40%	N=39	10%	N=12	3%	N=391
Erie	Other	N=26	57%	N=16	35%	^		^		N=46
Erie	Hispanic/Latina	N=25	50%	N=19	38%	^		^		N=50

Source NYS Cancer Registry, 2014

Selection of Target Communities

Susan G. Komen® Western New York has selected four target communities within the Affiliate service area. The four target communities are areas with populations that, based on the data, are most vulnerable to gaps in breast cancer services and access to care. Over the next five years, these four communities will be the primary focus of the Affiliate’s resources, outreach, and strategic efforts.

When selecting target communities, the Western New York Affiliate utilized Healthy People 2020 (HP2020), a major federal government initiative that provides specific health objectives for the United States and communities contained within.

HP2020 has several cancer-related objectives, including:

- Reducing women’s death rate from breast cancer (Target 20.6 per 100,000 women).
- Reducing the number of breast cancers that are found at a late-stage (Target: 41.0 cases per 100,000 women).

Komen Western New York’s objective is also to reduce breast cancer death rates and late stage diagnoses in the Affiliate service area. As such, HP2020 trend data for death rates from breast cancer and late stage diagnoses were used by the Affiliate to help determine target communities of need within the Western New York service area. The overall need is based on the time it will take a particular area to meet HP 2020 targets for breast cancer.

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

- Late stage rates and trends
- Below average screening rates
- Residents living below poverty level
- Residents living without health insurance

The selected target communities are:

- Wyoming County
- Erie County
- Cattaraugus County
- Allegany County

Wyoming County

Based on trend data, Wyoming County is unlikely to achieve HP2020 objectives for breast cancer. Table 2.7 indicates that Wyoming will take thirteen years or longer to achieve the goal of 20.6 deaths per 100,000. Table 2.7 indicates it will take thirteen years or longer to achieve an incidence rate of 41 cases per 100,000 late stage diagnoses.

Wyoming County is located in the Southern Tier of the Western New York service area. The demographic makeup of this county's female residents is primarily White and over 40 years of age. With a total population of just under 42,000 people (US Census Bureau – 2010), and just over 19,000 females, Wyoming County is the least populated county in the service area.

Socioeconomic characteristics of the region indicate a potential concern about women's access to breast health care. Just over 31 percent of residents fall below 250 percent of the poverty line. The county is defined as rural and medically underserved, indicating that both income and physical distance from screening and treatment locations are barriers to breast health services for the women of Wyoming County.

The health systems analysis component of this report will take a deeper look at the available breast health services. Due to the region's rural nature and designation as medically underserved, it is vital to gain a clear understanding of how breast health services are currently accessed in the region. Additional research will be necessary to better understand Wyoming County's community partnerships to see how Komen Western New York may be able to build a stronger relationship and build collaborations in that area.

Erie County

Erie County is comprised largely of the city of Buffalo and surrounding suburbs. The county's population of 919,040 is the largest of the service area. Just over 261,000 live in the city of Buffalo. As a whole, Erie County represents the most diverse population in the Affiliate service area. Of these women, 14.8 percent are Black/African-American, which is more than double even the second most populated county in the service area. This is significant due to the high death rates Black/African-American women experience from breast cancer when compared to other races. As illustrated through the additional data collected from the New York State Cancer Registry, Black/African-American women in Erie County are significantly less likely to be diagnosed at an early stage than White women. The same is true for Hispanic/Latina women, who account for 4.6 percent of the population in Erie County.

In general, the minority population in Erie County is higher than the rest of the service area. As such, the potential for social and economic barriers to breast cancer screening and treatment are higher. Those, compounded with the poverty rate of 30.7 percent and 22.9 percent of residents living in medically underserved areas, can make access to resources incredibly challenging for many residents.

While there are many factors that contribute to the breast cancer burden in Erie County, it has been identified as a high priority county due to the amount of intervention time needed to achieve the HP2020 targets. In order

to best understand what interventions might help to improve the trends in death rates and late stage diagnoses, the health systems analysis section of this report will investigate what types of breast cancer services are available and to what communities. Preliminary research has shown that multiple mammography sites have moved from the City of Buffalo to surrounding suburbs. This makes access an issue for women in the city who are not able to access services that are located further from their neighborhoods. It is also imperative to delve into the services that are available to help combat the social and cultural barriers that prevent many minority women from seeking or successfully accessing breast cancer care. A mobile mammography unit is also new to the community. The health systems analysis will research what populations and neighborhoods the unit reaches, as well as future plans to reach additional counties in the service area.

Cattaraugus County:

Cattaraugus County, located in the Southern Tier of Western New York is defined as a rural and medically underserved county. The annual average female population is 40,877 and 52.3 percent of those women are over the age of forty. White women make up 93.9 percent of the population in Cattaraugus County. The second largest percentage of Native Americans in New York State also lives in Cattaraugus County (Cancer Control P.L.A.N.E.T), as well as a significant Amish population. From a socioeconomic standpoint, 38.9 percent of Cattaraugus County residents fall below 250 percent of the poverty line and 12.6 percent did not graduate high school.

Cattaraugus County has been chosen as a target community due to the increasing trend of 3.9 percent for breast cancer incidence and the likelihood that it will take eleven years or more to improve late-stage diagnosis rates. Cattaraugus County falls into the medium priority guidelines for Healthy People 2020 objectives.

Allegany County:

Allegany was selected as a target community because of the proximity to and collaborations with Cattaraugus County. The two counties have combined New York State Cancer Services Programs, as well as similar demographics. Allegany County is situated directly east of Cattaraugus County in the rural Southern Tier of Western New York. There is a total population of 48,946, and 49.5 percent of the women living in Allegany are over the age of forty.

Similar to Cattaraugus County, 38.7 percent of Cattaraugus County residents fall below 250 percent of the poverty line and 12.1 percent have an education level below high school.

Allegany County falls into the medium-high priority area for Healthy People 2020 breast cancer targets. Based on current trends, it is predicted that Allegany will take more than two years to achieve death rate targets of 41 cases per 100,000 people and thirteen years or more to achieve late stage incidence rates of 20.6 cases per 100,000 people.

In the health systems analysis, there will be an investigation into the availability of breast cancer services and programming in Cattaraugus and Allegany Counties. In rural areas such as these, the distance between breast cancer screening and treatment providers is a major barrier, often compounded by financial limitations faced by low-income residents. The health systems analysis will delve into the services available for low-income residents. The availability of the mobile mammography unit will also be investigated as a possible resource for those who face transportation barriers.

Health Systems and Public Policy Analysis

Health Systems Analysis Data Sources

The Community Profile needs assessment seeks to identify local barriers and areas of concern affecting women's transition through the continuum of care, as well as identify opportunities to grow and strengthen breast health resources and awareness. An in-depth analysis of the target counties' health systems and policies was conducted in Allegany, Cattaraugus, Erie, and Wyoming Counties.

The Affiliate utilized online searches and specific website searches to gather data on service providers in identified target areas. The Affiliate reviewed websites and made phone calls to the organizations to collect data that appropriately reflected information necessary for completion of the template and further analysis. Several websites had incorrect or old information. Others were difficult to navigate, which could also pose difficulty for women in the community seeking service information. Wherever possible the Affiliate included an organization's full address and contact person. Many websites did not offer specific contact information but rather used on-line contact fields. The Affiliate included FDA approved mammography centers, hospitals, health departments, health centers (Federally Qualified Health Centers and safety net practices that offered primary care regardless of ability to pay), and free clinics. The Affiliate identified all breast health diagnostic and treatment facilities including those recognized by the American College of Surgeons Commission on Cancer, the American College of Surgeons National Accreditation Program for Breast Centers, and the American College of Radiology Breast Imaging Centers of Excellence. Roswell Park Cancer Institute, located in Erie County but serves all of WNY, is a National Cancer Institute Designated Cancer Center.

Health Systems Overview

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. A woman would ideally move through the CoC quickly and seamlessly, receiving timely, quality care in order to have the best outcomes. Education can play an important role throughout the entire CoC.

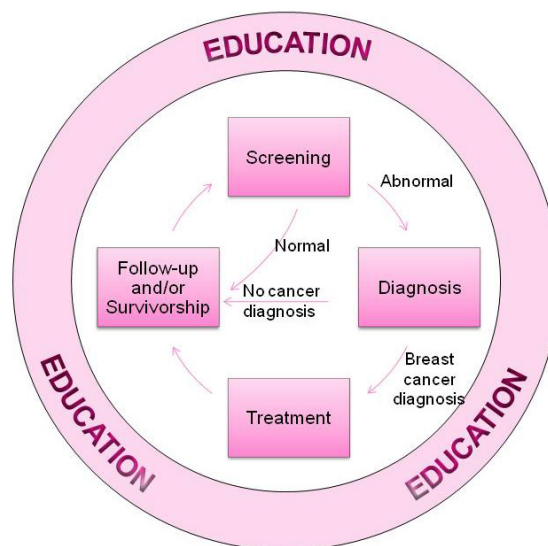


Figure 3.1. Breast Cancer Continuum of Care (CoC)

A woman may enter the continuum at any point. However, the goal is for all women to enter the CoC by getting screened for breast cancer – with a clinical breast exam or a screening mammogram. The primary care infrastructure plays a critical role in this. Family physicians, internists and gynecologists are responsible for conducting clinical breast exams and referring for screening mammography. Rural and underserved urban communities are reliant on Federally Qualified Health Centers (FQHCs) and other safety-net practices (see patients regardless of their ability to pay) and free clinics for these services. Komen’s breast self-awareness messages include screening mammography annually for women 40 years of age and older. Maintenance of screening habits is a challenging but necessary component of follow-up care and regular breast health.

If a screening exam shows abnormal findings, diagnostic follow-up, including diagnostic mammography, breast ultrasound, breast MRI, and/or biopsy, would be needed to confirm breast cancer. If findings are negative (breast cancer was not found), a woman may be followed more closely and may be rescreened anywhere within three to 12 months.

If breast cancer is diagnosed, women are faced with making difficult decisions regarding their treatment. A care team is needed that includes surgeons, oncologists, nurses, technicians, social workers and many others. Treatment needs to include physical and emotional health options for patients and members of their family and for logistical concerns such as navigating insurance, obtaining financial assistance, and symptom management, such as pain, fatigue, sexual issues, bone health, etc. Additional testing and follow-up will be needed regularly.

There are often delays in moving from one point of the continuum to another that contribute to poor outcomes. Many barriers to screening, diagnostic follow-up, and treatment pose issues to breast health care. These include transportation, system issues such as access to cancer care facilities, long appointment wait times, inconvenient hours, language barriers, fear, misinformation (myths and misconceptions), and lack of information.

Education can address barriers to breast care and help a woman progress through the CoC more quickly and can empower a woman to manage anxiety and fear. Education serves as a tool to encourage communication, proactively get test results, and keep follow-up appointments. Education covers topics such as treatment options, how a pathology report is used to determine the best options for treatment, understanding side effects and how to manage them, making healthy lifestyle choices, long term effects of treatment, and formulating questions a woman may have for her providers.

Target Communities

Erie

Erie County is the most populated county (919,866) in the service area, with of the City of Buffalo being more populated (258,959) than any single county in the service area (U.S. Census Bureau, 2009). The most diverse of any county, 38.6 percent of residents are African American, 50.4 percent are White, and 10.5 percent are Hispanic or Latino (U.S. Census Bureau, 2010). The City of Buffalo is the third poorest city in the United States according to the Census Bureau among cities with a population of more than 250,000 (U.S. Census Bureau, 2007).

Strengths

Of all the counties in this service area, Erie County hosts the largest number of options for screening, diagnosis and treatment; there are 35 locations for women to receive screening mammograms, 29 to obtain a breast ultrasound, and 18 to get a breast MRI. One of Erie County’s biggest assets is Roswell Park Cancer Institute (RPCI). It is one of the largest cancer centers in the area, located in the developing Medical Campus

in downtown Buffalo, and is a National Cancer Institute Designated Cancer Center. Windsong Comprehensive Breast Care (WCBW) provides a multidisciplinary approach to care from early detection, diagnosis, consultation, treatment options, and survivorship programs. WCBW links patients to their affiliated radiology and oncology centers. WCBW is Western New York's first and only breast care facility to receive accreditation by the National Accreditation Program for Breast Centers. Several of the mentioned screening and treatment locations are located in the City of Buffalo, many of which are hospital based and are accessible via public transit system.

Aside from screening and treatment services, Erie County is home to many organizations that offer education, support, and survivorship to residents. Cancer care support organizations include, but aren't limited to, transportation to services, complementary therapies (massage, spiritual healing, retreats), side effect management (custom wigs), breast cancer support groups (for individuals, family members, women currently seeking treatment, and women in remission), and counseling and/or nutrition programs. Patient navigation and education programs are available for underserved communities. Specifically, the Buffalo/Niagara Witness Project offers outreach and education to African American Women. Esperanza y Vida offers similar services to Hispanic/Latina women. Cancer Services Program (CSP) of Erie County is instrumental in engaging uninsured and underinsured women in cancer screening, follow-up and treatment.

Weaknesses

While the women in Erie County have greater opportunity to receive breast health services, many locations are situated in the more affluent suburbs and are often out of reach for underserved women in the city. The increase in relocation of screening sites has created a barrier to accessible screening and treatment options as public transit may not always reach these areas and many women lack personal transportation. A new addition is being added to the Roswell Campus that will now offer screening mammography services. Even though many primary care offices offer Clinical Breast Exams (CBEs) and mammography referrals, many women are not being screened according to guidelines. The safety-net practices and health centers see an abundance of patients with multiple complex conditions and often find prioritizing health needs difficult. Information on screening and treatment facilities it is not easily obtained. Many women in underserved communities have limited access to technology and cannot navigate the complex health system. Navigation is available once a diagnosis is made, but resources are limited to engage women in the continuum of care.

Existing Key partnerships

The Affiliate partners with several organizations to provide outreach and encourage breast cancer screening. They have provided funding to Cancer Services Program of Erie County, Esperanza y Vida, the Buffalo/Niagara Witness Project, the University of Buffalo's Department of Family Medicine, International Institute, and others. The Affiliate has partnered with the Cancer Services Program of Erie County to provide free screening to uninsured and underinsured women.

Several projects funded by the Affiliate are in partnership with the mobile mammography coach, operated by WNY Breast Health and the Erie County Medical Center (ECMC) Lifeline Foundation, . With support from Komen, the mobile mammography coach is available at four safety-net practices (UBMD Jefferson Family Medicine, Jericho Road Community Health Center Barton Street, Jericho Road Community Health Center Genesee Street, and ECMC Cleve Hill Family Health Center) once a month through the partnership with the University of Buffalo's Department of Family Medicine. Through this program, patient ambassadors provide peer support and are trained to deliver breast health education to women and assist them through the breast screening process. The presence of the bus at these sites eliminates the need for women to travel to a secondary location for mammography. Women are able to make one trip to their primary care practice and receive their mammogram the same day as other appointments. Women who are not patients at the listed

practices are also able to utilize the services. At the Jericho Road sites, interpreters are available to assist non-English speaking women to receive their mammograms. The patient ambassadors also assist in linking uninsured and underinsured women to Cancer Services Program.

The coach is also utilized by Esperanza y Vida and the Buffalo/Niagara Witness Project at community and faith-based venues. Esperanza y Vida is a program to increase breast and cervical cancer screening in Latinas living in rural and urban areas, and to investigate barriers to cancer care. The Buffalo/Niagara Witness Project educates participants on early cancer detection through stories told by breast and cervical cancer survivors in churches and community settings.

The mobile mammography coach and its partners are some of the strongest partnerships the Affiliate collaborates with in Erie County, especially in underserved communities. The Affiliate hopes to strengthen and maintain existing partnerships as well as build new relationships in the future. Additional partners include WGRZ media, local payers including Independent Health Association and Univera, and hospital systems including Kaleida and Catholic Health Systems.

New and Potential Partnerships

The Affiliate is working to enhance their partnership with primary care and OB/GYN practices in Erie County. Although there are already several existing partnerships, there are other opportunities to expand. Specifically, the Affiliate has engaged the Catholic Health System to assist in getting the word out about Komen and its funded programs to their providers. The Affiliate will also engage new partners in media and marketing to educate the community and assist in the dissemination of efforts supported by Komen.

Cattaraugus County

Cattaraugus County is located in the Southern Tier of Western New York and neighbors Allegany County. With an estimated population of 78,892 (U.S. Census Bureau, 2013), it is defined as rural and medically underserved. Ninety-three percent of residents are white, only one percent are African American, and even fewer are Hispanic/Latina (U.S. Census Bureau, 2009). The Seneca Nation of Indians has reservations in Cattaraugus County. The Allegany Indian Territory is completely within Cattaraugus County, including the City of Salamanca.

Strengths

As Allegany and Cattaraugus Counties share similar demographics, they frequently collaborate in delivering services, one example being a combined New York State Cancer Services Program. The Cancer Services Program provides financial services to uninsured and underinsured women, as well as support for cancer survivors and their loved ones. Most outreach programs in this target area are provided by CSP. Other agencies that provide education and support programs include the Cattaraugus County Health Department and the Breast and Cervical Health Partnership of Cattaraugus County. Funded by the New York State Department of Health, the Breast & Cervical Health Partnership of Cattaraugus County sponsors low cost or no cost breast and cervical cancer risk reduction services to uninsured or underinsured women, ages 40 and over, at various locations in the area.

Weaknesses

In rural areas such as Cattaraugus County, the distance to breast cancer screening facilities and treatment services is a major barrier, impeding access to care. There are few locations in the area that offer screening mammograms, most being located in Olean, the largest city in the county. Olean is located in the southeast section of the county and is over an hour drive on country roads for many area residents. In terms of treatment, there are even fewer options; only one organization in the county, located in Olean, offers chemotherapy

treatment. Due to this limitation, many patients are referred to hospitals or larger organizations outside of the target area to receive screening, diagnostic follow-up, and treatment. Transportation is a major contributor to the lack of screening in Cattaraugus County and continue to pose challenges for women in Cattaraugus County seeking access to cancer care services.

Cattaraugus County's Native American population receives services via the Seneca Nations Health System (SNHS), a recognized non-profit public health organization which maintains a federal contract with the Indian Health Services (IHS) under public health law 93-368 Title 1. Health services are offered to those persons within the Contract Health Services Delivery Area (CHSDA) who are defined as eligible under federal and tribal guidelines. Although the Cattaraugus Indian Health Center and Cattaraugus Community Health Center are located in Chautauqua County (a neighboring county), Native American women in Cattaraugus are eligible to receive services at either location. However, this requires women to travel extensively outside of their communities.

Patient navigation and survivorship services are a valuable resource for women transitioning through the continuum of care. Patient navigation, support groups, and survivorship services are severely lacking in Cattaraugus County. The Affiliate could only identify one location that offered a support group. Again, this was located in the city of Olean at the area's largest hospital.

Existing Key Partnerships

Komen Western New York currently does not have existing key partnerships in Cattaraugus County, but hopes to develop new partnerships in the future.

New and Potential Partnerships

The Affiliate will pursue relationships with health-care entities in the county, including the county's health department programs, primary care practices and the Seneca Nation Health System in Cattaraugus County. The Affiliate will also market their Community and Small Grant Programs to support programming and services that encourage education, awareness, screening and treatment for this underserved target area.

Allegany County

Allegany County is located in the Southern Tier of Western New York. With an estimated population of 48,109 (U.S. Census Bureau, 2013), it is defined as rural and medically underserved.

Strengths

As Allegany and Cattaraugus counties share similar demographics, they frequently collaborate in delivering services. The counties have a combined New York State Cancer Services Program. CSP provides financial services to uninsured and underinsured women, as well as a support group for cancer survivors and their loved ones. Most outreach programs in this target area are provided by CSP. Allegany County offers a few options for preventive and screening services. Two hospitals in Allegany County offer screening mammograms; one hospital, Jones Memorial Hospital, performs biopsies.

Weaknesses

In rural areas such as Allegany County, the distance to breast cancer screening and treatment services is a major barrier, impeding access to care. Due to this limitation, many patients are referred out to a local hospital or larger organization outside of the target area to receive screening, diagnostic follow-up, and treatment. This often requires traveling far distances outside of their communities to the nearest city or surrounding counties to receive services, a major contributor to the lack in screening in these areas. Much like Cattaraugus County, Allegany County's Native American population receives services via the Seneca Nations Health System

(SNHS). Native American women in Allegany County are eligible to receive services from either the Cattaraugus Indian Health Center or Cattaraugus Community Health Center located in a neighboring county.

Health services are offered to those persons within the Contract Health Services Delivery Area (CHSDA) who are defined as eligible under federal and tribal guidelines. The service areas include the counties of Allegany, Cattaraugus, Chautauqua, Erie (excluding the Tonawanda and Tuscarora Territories) and Niagara in New York and Warren County in Pennsylvania. The Lionel R. John Health Center in Allegany County offers a variety of services including preventive services and screening. Although Allegany County offers some services for Native American women, resources are limited and require significant additional travel to access services.

Patient navigation services are a valuable resource for women transitioning through the continuum of care. Patient navigation, support groups, and survivorship services are lacking in rural counties. The Affiliate was unable to identify any support groups available in Allegany County.

Existing Key Partnerships

Komen Western New York currently does not have existing key partnerships in Allegany County, but hopes to develop new partnerships in the future.

New and Potential Partnerships

The Affiliate would like to develop a relationship with primary care practices in Allegany County to encourage the use of the mobile mammography unit to address transportation and financial barriers, as well as the county Department of Health. The Affiliate will also market their Community and Small Grant Programs to support programming and services that encourage education, awareness, screening and treatment for this underserved target area.

Wyoming

Wyoming County is located in the Southern Tier of Western New York and neighbors Erie County. With an estimated population of 41,531 (U.S. Census Bureau, 2013), it is defined as rural and medically underserved.

Strengths

This target area has two locations that offer screening mammograms to residents. Financial resources for uninsured and underinsured women are available through the Cancer Services Program of Livingston and Wyoming Counties.

Weaknesses

Wyoming County severely lacks breast cancer screening, treatment, and support services. Only one location in the county offers mammograms, both screening and diagnostic, therefore many women encounter barriers to accessing screening services. In terms of diagnosis and treatment, there is only one site in the county that offers these services, therefore residents often travel to other areas to access care. Wyoming is a very rural county and is spread out over a large area. For some women, it is closer for them to drive to areas outside the county for treatment and follow up. There are also more options for them to choose from in neighboring counties such as Cattaraugus. To the Affiliate's knowledge, no patient navigation or survivorship services currently exist in Wyoming County.







Existing Key Partnerships

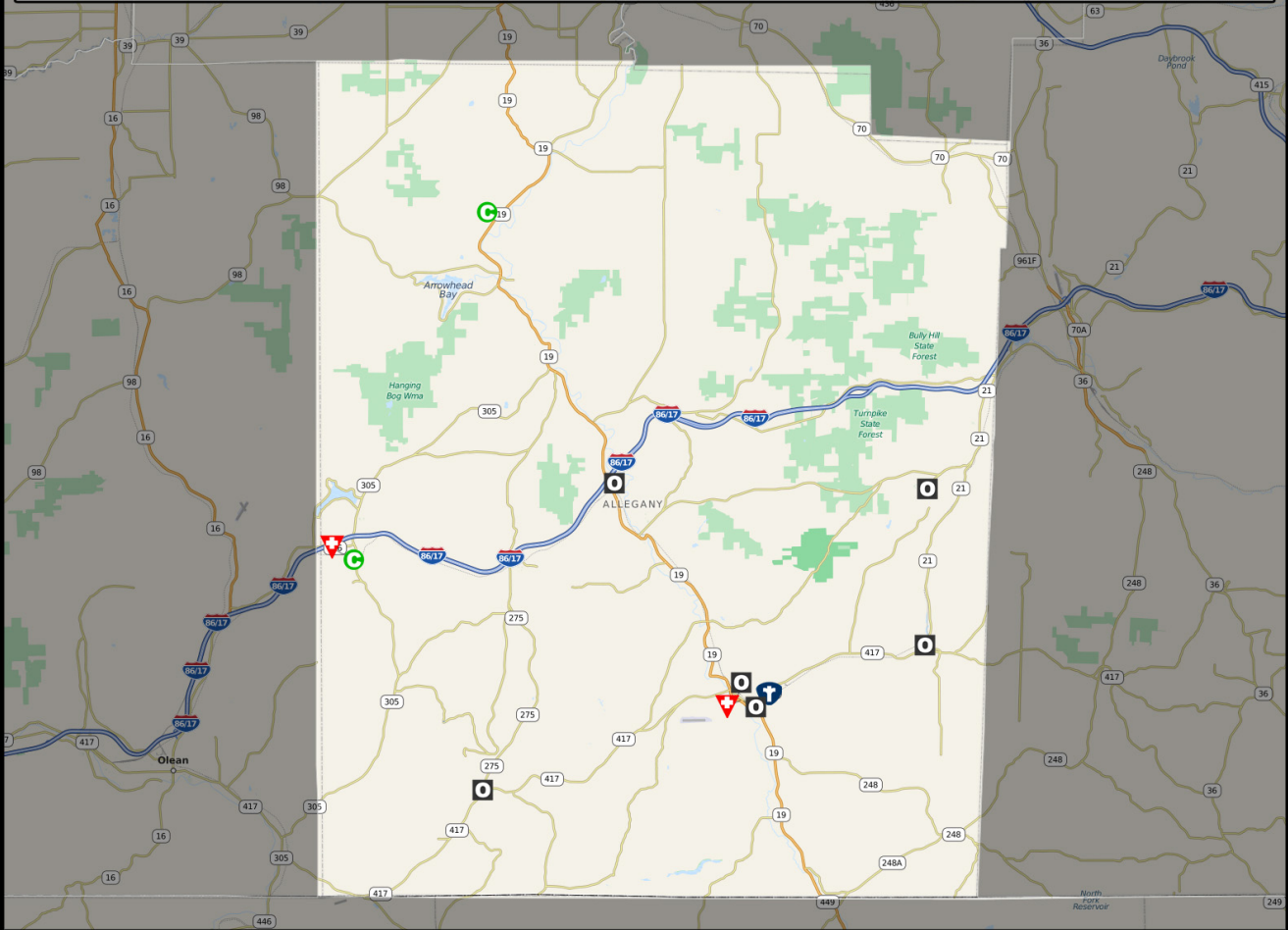
Komen Western New York currently does not have existing key partnerships in Wyoming County, but hopes to develop new partnerships in the future.

New and Potential Partnerships

The Affiliate strives to develop relationships with primary care practices in Wyoming County and the county Department of Health to encourage the use of the mobile mammography coach to address transportation and financial barriers. The Affiliate will also market their Community and Small Grant Programs to support programming and services that encourage education, awareness, screening and treatment for this underserved target area. Wyoming and Livingston County have a shared Cancer Services Program. Since Livingston County is outside of the Affiliate's service area, it has been difficult to establish a working relationship with them. A goal of the Affiliate is to build a partnership with this CSP.

Allegheny County

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



Statistics

Total Locations in Region: 11

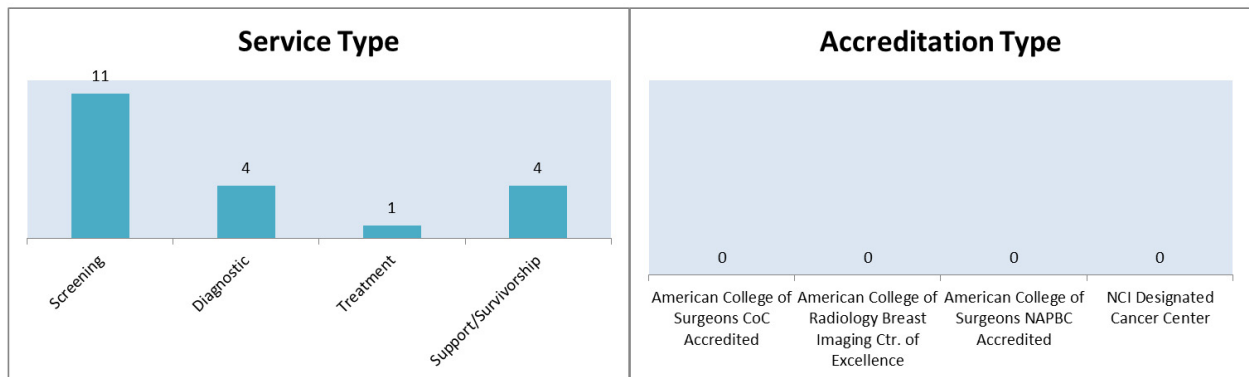





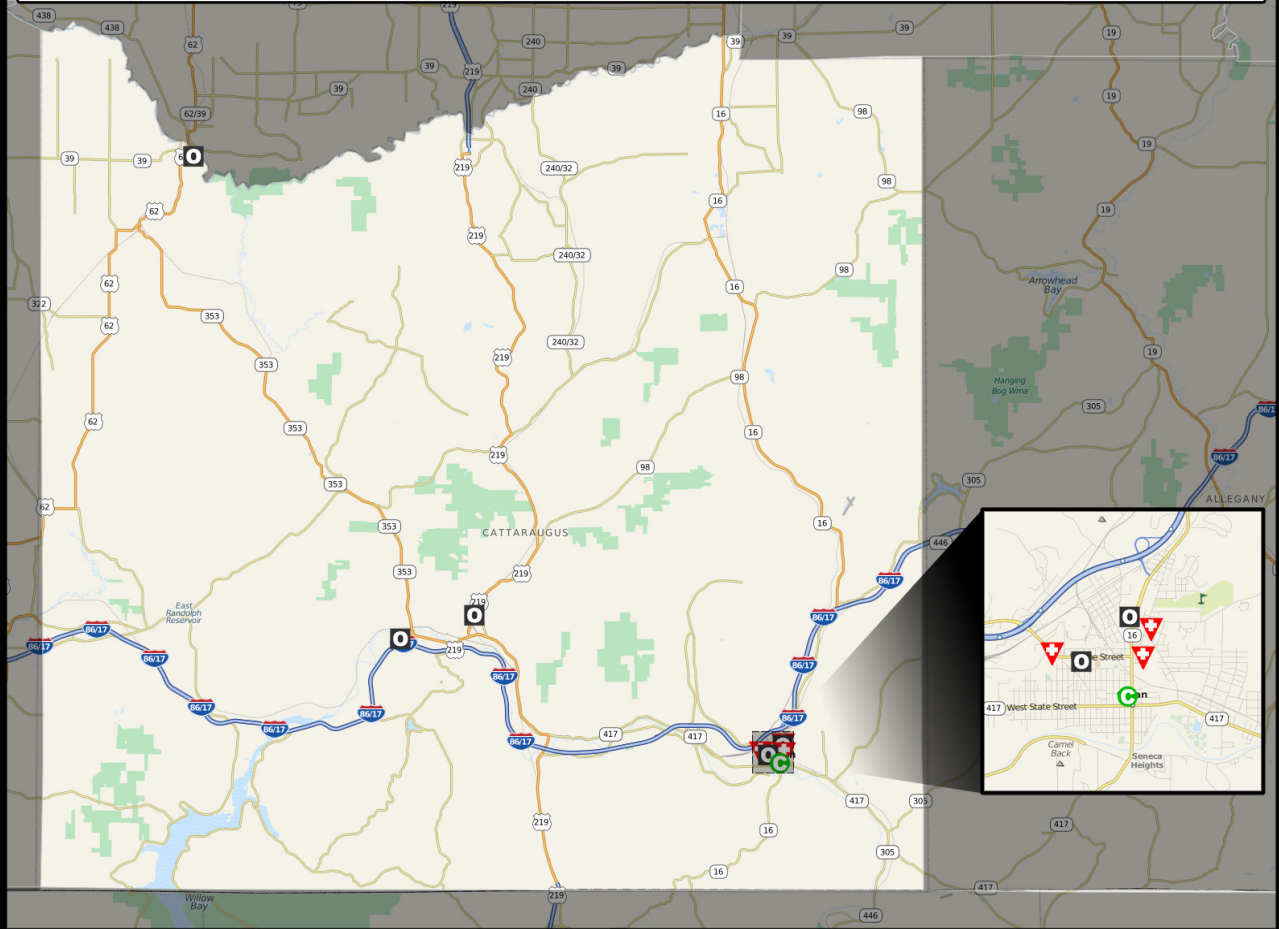


Figure 3.2. Breast Cancer Services Available in Allegheny County

Cattaraugus County

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



Statistics

Total Locations in Region: 10

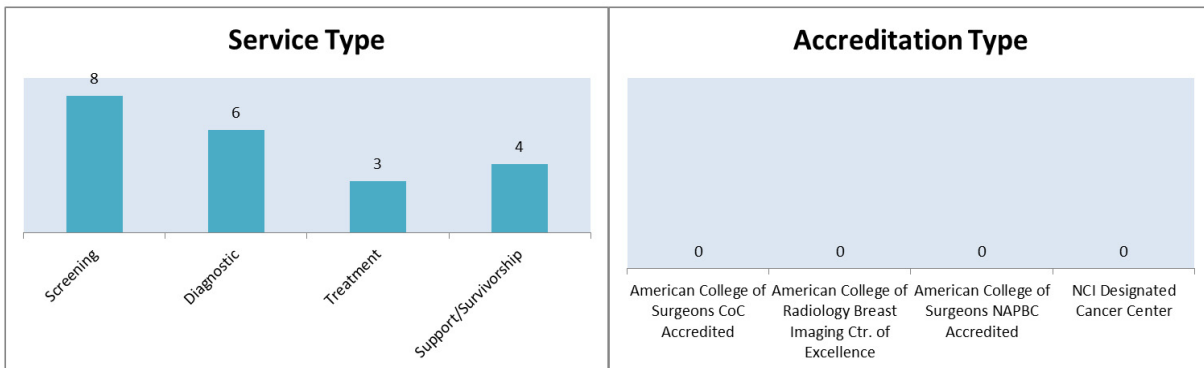
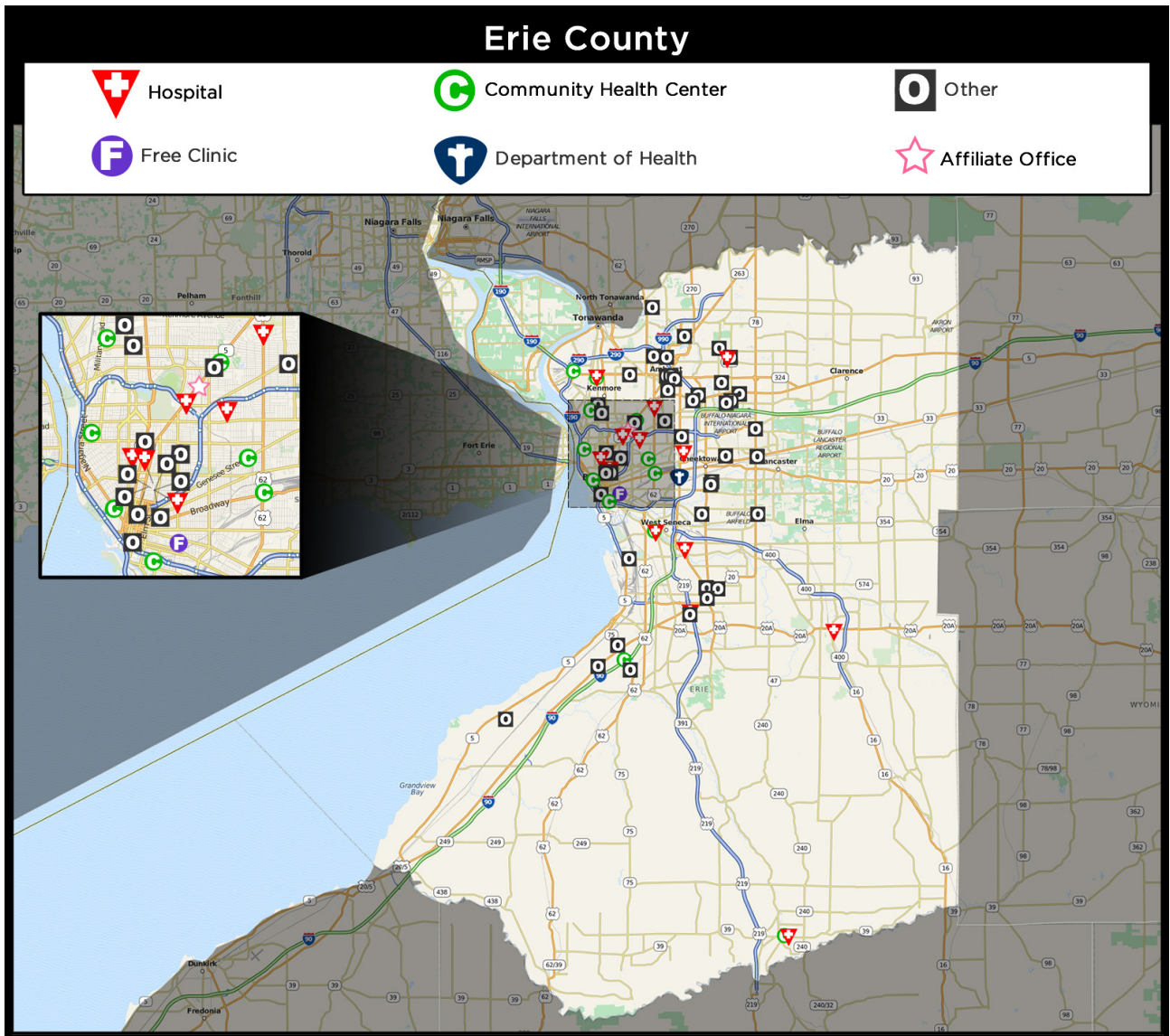


Figure 3.3. Breast Cancer Services Available in Cattaraugus County



Statistics

Total Locations in Region: 82

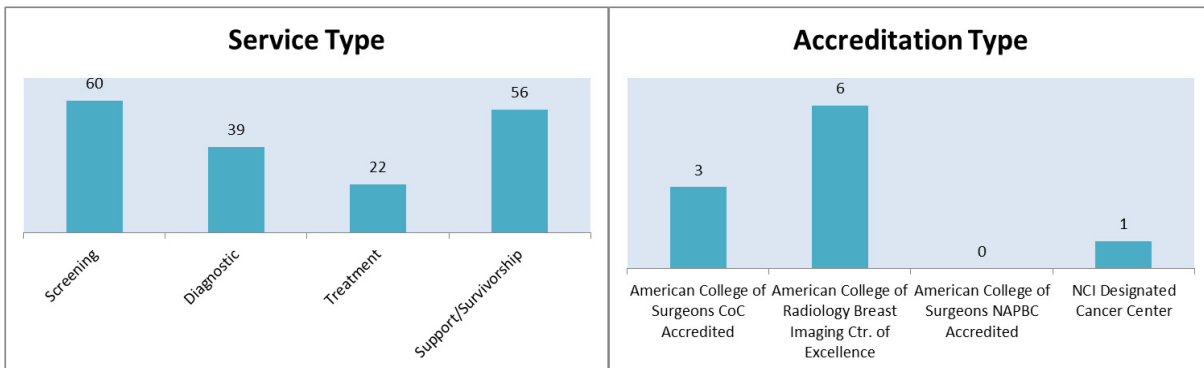






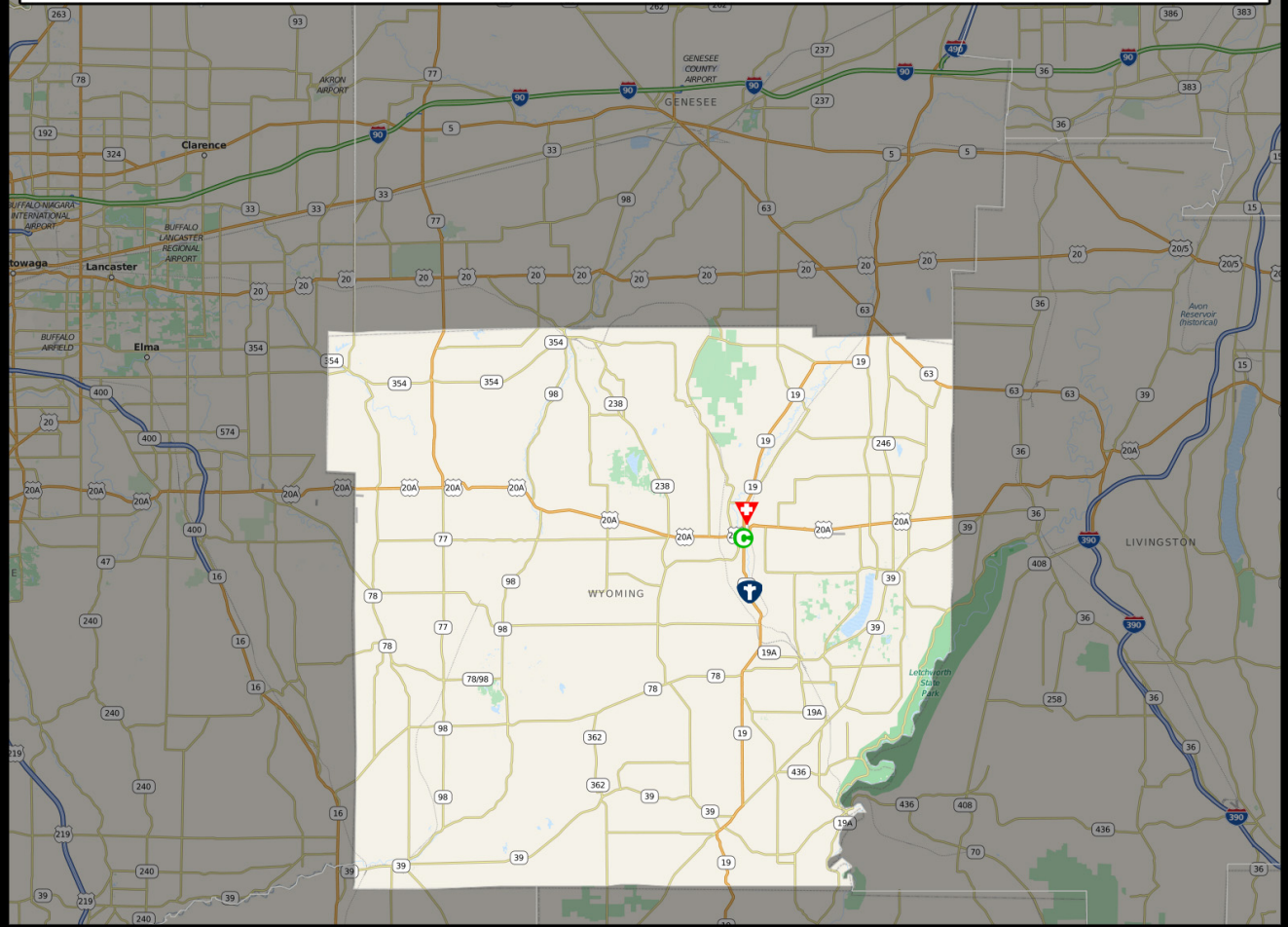


Figure 3.4. Breast Cancer Services Available in Erie County

Wyoming County

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



Statistics

Total Locations in Region: 3

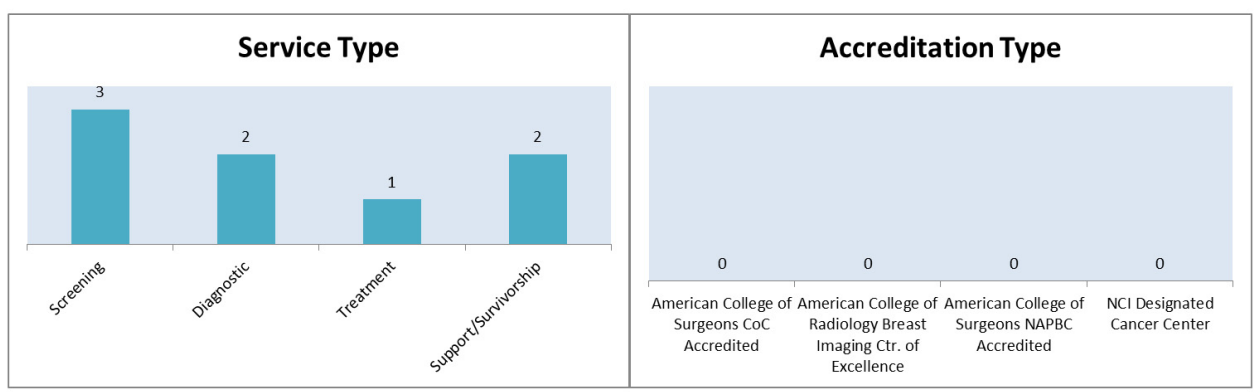


Figure 3.5. Breast Cancer Services Available in Wyoming County

Public Policy Overview

National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

NYS NBCCEP Policy

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) supports the New York State Cancer Services Program. CSP offers education, screening, diagnostics, case management and treatment assistance to residents for breast, cervical and colorectal cancers. The program is funded through the Centers for Disease Control (CDC) and further supplemented by the New York State Department of Health, and has a presence in every county. Under this program, underinsured and uninsured women age 40 years or older (and women under 40 who are at high risk of breast cancer) are eligible to receive mammograms and clinical breast exams (CBE). Diagnostic and treatment services are available for women with positive findings. The WNY Affiliate of Susan G. Komen has an established working relationship with Cancer Services Program of Erie County. Women of Cattaraugus, Allegany, and Wyoming Counties are served by their local Cancer Services Program.

Points of contact

NYS Number: 1-800-442-CANCER (2262)

Cancer Services Program of Allegany and Cattaraugus Counties

Jennifer Baker
3453- B Route 417 East
Wellsville, NY 14895

(585) 593-4839

http://allegany.ny.networkofcare.org/ph/services/agency.aspx?pid=CancerServicesofAlleganyandCattaraugusCounty_1058_11_0

Cancer Services Program of Erie County

Program Director, Michelle Wysocki (716) 858-7376

Address: 95 Franklin St. Room 950
Buffalo, NY 14202

Phone: (716) 858-7376

Fax: (716) 858-7964

<http://cspwny.org>

Cancer Services Program of Livingston and Wyoming Counties

Wyoming County Health Department
5362 Mungers Mill Rd.
Building A
Silver Springs, NY 14550

Men's and Women's Reproductive Health Services

Phone: (585) 786-8881 or 800-466-1191

<http://www.wyomingco.net/health/cancerservices.html>

Accessing Medicaid Treatment in NYS

New York State is an Option 3 state, following full state compliance with the Medicaid eligibility requirements of 133 percent of the Federal Poverty Line (\$16,105 a year for one person or \$32,913 for a family of four). Option 3 signifies that Medicaid services are available regardless of where the patient was originally screened.

NYS Medicaid covers screening, digital and film mammography. NYS Medicaid Managed Care/Family Health Plus benefits include coverage of medically necessary radiology services provided by qualified practitioners in the provision of diagnostic radiology, diagnostic ultrasound, nuclear medicine, radiation oncology, and magnetic resonance imaging (MRI). These services may only be performed upon the order of a qualified practitioner. Providers should contact the member's Medicaid Managed Care/Family Health Plus Plan for specific coverage and prior authorization requirements.

Relationship between Cancer Services Programs and Medicaid

Unlike most Medicaid programs, where enrollment occurs at the local department of social services, the point of entry for Medicaid Cancer Treatment Program (MCTP) is the Cancer Services Program, where designated qualified entities are located to assist individuals in completing the enrollment process.

To be enrolled in the MCTP, an individual must complete an application with a New York State Department of Health Cancer Services Program trained designee, referred to as a Designated Qualified Entity (DQE). A DQE is a person designated and trained by the New York State Department of Health as a "Qualified" entity to assist individuals to complete the MCTP application. To be eligible, an individual must be a resident of New York State (NYS), a United States (US) citizen or an alien with satisfactory immigration status, and not covered under any creditable insurance at the time of MCTP application. Once an individual is enrolled in the MCTP, if breast cancer is found, eligible men and women may be able to enroll through MCTP to receive full Medicaid coverage for the entire time of treatment (and in some cases pre-cancerous conditions of these cancers). Recertification is required yearly, if the individual is still in need of treatment, at which time eligibility is reassessed. Enrollees must receive services from a Medicaid enrolled provider in order to have their services covered. MCTP coverage is limited to the individual enrollee and cannot be extended to family members or dependents. If an individual who meets the requirements appears to be eligible for Medicaid in any of the mandatory categories, the individual will be given Medicaid coverage under the MCTP for as long as they need cancer treatment.

Contact

<http://www.health.ny.gov/diseases/cancer/>

Cancer Services Program: 1-866-442-2262

Medicaid Help Line: 1-800-541-2831

E-mail: canserv@health.state.ny.us

Silver Springs, NY 14550

Affiliate's Relationship with CSP

Currently, the Affiliate has an established working relationship with Cancer Services Program in Erie County. The Affiliate plans to establish and strengthen its relationships with the "rural and medically underserved" target counties (which often have barriers in accessing breast cancer screening options). The Affiliate will also market their Community and Small Grant Programs to support programming and services that encourage education, awareness, screening and treatment for all its target areas.

Comprehensive Cancer Control Coalition (NYSCC)

Breast Cancer Objectives

The New York State Comprehensive Cancer Control Plan 2012-2017 was created over an 18-month period by the NYS Cancer Consortium (NYSCC), a statewide network of individuals and organizations dedicated to addressing the cancer burden in NYS, as a guide to identify and address cancer burden in NYS. The Plan

serves as a framework for the NYSCC, professionals and interested parties in the coming years as they engage in actions and initiatives to ease the burden of cancer in local communities and across the state. The Plan has identified six priority areas, which represent the cancer care continuum, including: health promotion and cancer risk reduction, early detection, treatment, survivorship, palliative care, and health care workforce. Each priority area section includes measurable objectives; suggested strategies; and evidence-based, evidence-informed, best practices and promising practices. Outlined below are the defined priorities including the measurable objectives for each priority as it pertains to breast health:

1. **Health Promotion & Cancer Risk Reduction** - All New Yorkers will have current, evidence-based information, resources and opportunities to adopt and maintain health-promoting behaviors and to reduce the risk of cancer.

Measurable Objectives:

- By 2017, assess available measures related to the utilization of genetic services such as those that track:
 - Data on genetic counseling visits sought by, and genetic tests ordered for, New Yorkers at risk for BRCA 1 or 2 mutations, and
 - The proportion of New York residents with a family history of breast and/or ovarian cancer who receive genetic counseling.

2. **Early Detection** - All New Yorkers will receive age-appropriate, evidence-based, guideline-driven screening services for the early detection of cancer.

Measurable Objectives:

- By 2017, increase the proportion of women who receive breast cancer screening based on the most recent guidelines by at least five percent.
- Reduce the rate of female breast cancer identified at late stages to 41.7 cases per 100,000 females by 2017.

3. **Treatment** - All New Yorkers will have access to high quality, comprehensive cancer care at an affordable cost.

Measurable Objectives:

- By 2017, increase the number of eligible men and women enrolled annually in the NYS MCTP by at least five percent.
- By 2017, monitor trends in the number of American College of Surgeons Commission on Cancer-accredited facilities in the state as well as the number of such programs that receive special commendations (e.g. "outstanding achievement" awards).
- By 2017, establish a means by which to assess the number of cancer patients enrolled in cancer treatment clinical trials.

4. **Survivorship** - All New Yorkers will have equal access to evidence-based, evidence-informed and guideline-driven services and appropriate, high-quality follow-up care that supports cancer survivors, families and caregivers.

Measureable Objectives:

- By 2017, establish a means by which to assess cancer survivor health outcomes
 - The proportion of cancer survivors across all populations receiving a written care plan.
 - The mental and physical health-related quality of life of cancer survivors.
 - The proportion of cancer survivors engaging in regular physical activity.
 - The number of health care facilities adhering to National Quality Forum consensus standards for symptom management and end-of-life care.

5. **Palliative Care** - All New Yorkers will have access to evidence-based, evidence-informed and guideline-driven patient and family-centered palliative care services.

Measurable Objectives:

- By 2017, increase the number of health care professionals either board-certified or certified in hospice and palliative care, including:
 - Increase the number of New York board-certified physicians with a sub-certification in hospice and palliative medicine to 149.
 - Increase the number of nurses in New York who have a certification in Hospice and Palliative Care to:
 - 75 Advance Practice Nurses
 - 650 Registered Nurses
 - 75 Licensed Practical and Vocational Nurses
 - 200 Nurses Assistants, and
 - 20 Administrators
- Increase the number of Hospice and Palliative Care Certified Social Workers, certified through the National Association of Social Workers (NASW) and the National Hospice and Palliative Care Organization (NHPCO) to:
 - 50 Advanced Certified Hospice and Palliative Care Social Workers
 - 10 Certified Hospice and Palliative Care Social Workers
- By 2017, increase to 15 the number of providers approved to provide pediatric palliative care services available under the Care at Home Medicaid Waiver Program I/II for children with special needs.

6. **Health Care Workforce** - All New Yorkers will have access to an adequate supply of health care providers with demonstrated competencies in cancer risk reduction, detection, treatment, supportive services and palliative care.

Measureable Objectives:

- By 2017, establish ongoing assessments of the specialties and geographic locations of the cancer care workforce in NYS.

Despite progress made in these areas, cancer continues to be the second leading cause of death in NYS. Although decreases were seen in the number of new cases of lung, female breast, colorectal and prostate cancer, these cancer types remain the most common cancers diagnosed in NYS men and women and still

account for approximately half of all cancer cases and deaths in NYS. In addition, cancer data show that certain groups in New York continue to suffer disproportionately from cancer and its effects. The risk of developing or dying from cancer varies across populations and disparities are more pronounced with specific cancers.

The NYSCC serves as a baseline for statewide cancer rates and offers metrics used to assess changes in rates. By aligning with the NYSCC Cancer Action Plan, the Affiliate can support statewide efforts and be able to better show how their work is helping to move the needle to improve breast health care.

Affiliate's Current Relationship

The Affiliate does not have a formal relationship with the NYSCC. Several partners have been involved in the development of the NYSCC and serve on NYSCC committees. There is a WNYCC that Komen has worked very closely with to align priorities and host events.

Establish and Strengthen Relationships between the Affiliate and the NYSCC

The Affiliate will formally join the Cancer Consortium and will participate in various committees. The Affiliate will assess where the New York State Comprehensive Control Plan aligns with the Community Profile, particularly in regards to measuring improvement in breast health. This partnership can also strengthen public policy efforts to improve breast health outcomes.

Affordable Care Act (ACA)

State Action on Insurance Exchange Program

Under the federal Affordable Care Act, New York State set up a Marketplace, called NY State of Health (previously called the New York Health Benefit Exchange). NY State of Health has established five Regional Advisory Committees, comprised of representatives of consumers, small business, health care providers, insurance agents and brokers, labor organizations and other stakeholders, pursuant to Governor Cuomo's Executive Order No. 42 to provide advice and make recommendations on the establishment and operation of the Marketplace, including recommendations about relevant regional factors. The Marketplace can be used to assess eligibility and enroll in various insurance products including free or low cost health insurance coverage (like Child Health Plus or Medicaid). If ineligible for Medicaid, private insurance plans are available in the Health Insurance Marketplace. Applicants may be eligible for tax credits that lower the cost of their monthly premiums and for lower out-of-pocket costs. This will depend on family size and income. **NY State of Health does not affect Medicare coverage.** The Marketplace is intended to help New Yorkers who are not eligible for Medicare get health insurance coverage.

State Action on Medicaid Expansion

NYS is moving forward with Medicaid expansion which will allow Medicaid coverage for adults under age 65 with incomes up to 133 percent federal poverty level. Since NYS has committed to the expansion in 2014, they will receive a 100 percent federal match through 2020 and 90 percent beyond that.

Estimated number of uninsured before and after insurance mandates

Prior to the Affordable Care Act, the data, which represent the first-year open enrollment period, show that more than 80 percent of enrollees reported being uninsured at the time of application. Enrollment occurred in every county in the state and across all health plans, and across a mix of age groups. From October 1, 2013 through April 15, 2014, 960,762 New Yorkers enrolled into a health plan through NY State of Health; 370,604 enrolled in a Qualified Health Plan; 64,875 enrolled in Child Health Plus; and 525,283 enrolled in Medicaid. The total completed applications were 1,319,239.

Implications of ACA on State NBCCEDP

Even though ACA reform includes facets that encourage breast health and early detection and treatment, it is estimated that 1.7 million women will remain uninsured and will be eligible for services within the Cancer Services Program. The CSP will bridge services for the most difficult populations to get screened including non-English speaking and poorly educated women.

Implications of ACA on State Health Care Providers

The ACA impacts the healthcare system and healthcare provider's roles within the system by improving insurance coverage, expanding access, allowing health care to be more affordable, and improving the quality of healthcare. In order to provide enhanced quality of care, healthcare providers can assure the successful implementation ACA to reduce economic barriers to cancer screening. There are several strategies that can be implemented to improve cancer screening rates such as:

- Educating patients about the benefits of cancer screening and ways to overcome barriers to screening. There is a lack of education and understanding on the issues of breast health/screening and awareness of breast cancer. Many women may not understand the importance of screening, and are uninformed or unclear about risk factors.
- Remove structural barriers (e.g. provide transportation, adjust appointment hours, offer screening in varied settings, eliminate/simplify administrative processes) to cancer screening.
- Integrate cancer screening into routine clinical preventive services wherever possible (e.g. provide opportunities for cancer screening along with immunization, blood pressure screening, etc.).
- Develop systems to assess and monitor disparities and barriers related to cancer screening and diagnostic services.

Implications of ACA for the Affiliate

All Komen priorities were included in health care reform. These priorities include mammography as a required benefit, breast cancer education for young women, access to clinical trials, access to navigation, elimination of pre-condition exclusions, and out of pocket spending limits.

Affiliate Public Policy Activities

The Affiliate's policy goals are to influence and engage WNY media, public officials and the community-at-large to drive the legislative agenda on breast cancer policy issues and community needs. This is carried out by relationships with State and National public officials to reinforce the targeted issues. The Policy committee participates in Lobby Day annually to reinforce existing relationships and support Komen Advocacy Alliance (KAA) efforts, and to set action plans for participation with the Congress member in their home district, including local Race participation, site visits and press conferences. The Komen Advocacy Alliance hosts Lobby Day activities in Washington DC for the Affiliate Network to participate and lobby for the most important Federal breast cancer issues. The program begins with an intense training on "talking points" and messaging to engage the elected officials from the Affiliate's respective service area and ascertain their pledge to support legislation critical to Komen's mission to save lives and end breast cancer.

The NYS Affiliates meet monthly by phone and annually in person to coordinate statewide issues, and collaborate as a unified entity with other organizations with similar goals. Such partners include the American Cancer Society, Leukemia and Lymphoma Society, Coalition to Save Cancer Screening, Western New York Cancer Coalition, AreYouDense, Inc., and others.

In September 2013, the Affiliate hosted a webinar in partnership with the Western New York Cancer Coalition in an effort to offer insight about the changes and policies brought forth by the Affordable Care Act. The webinar provided updates on the latest information regarding implementation of the Health Insurance

Marketplace (Exchanges), part of the Affordable Care Act, and to start discussing strategies to educate the uninsured, under-insured, and small businesses about expanded insurance coverage options.

A new NYS law designed to help improve breast cancer detection and risk reduction took effect in January 2013. NYS Public Health Law § 2404-c requires providers of mammography services to notify and inform their patients if a patient's mammogram demonstrates dense breast tissue. The new law requires mammography providers to include a notification in the summary of the mammography report provided to patients who are found to have dense tissue. Although the WNY Affiliate was not involved in the legislation, the Affiliate has helped to disseminate the information to local providers.

At the federal level, up until January 2013, Louise Slaughter of the 28th District was on the powerful Rules Committee, which sets the schedule for voting on particular pieces of legislation, and is a member of the Congressional Caucus for Women's Issues. With background in microbiology and public health, she also is a member of several health related caucuses, including the House Cancer Awareness Working Group, which was created to educate Congress and the public about the dangers of cancer. It has been working to get funding to help find a cure for the disease, while also promoting early detection methods to improve the rate of survival of cancer patients. Rep. Slaughter is an advocate of additional funding for cancer research. Unfortunately the 28th congressional district was eliminated and Rep. Slaughter is now in the 25th district outside of the Affiliate service area. However, the 25th district borders the Affiliate service area.

Brian Higgins (recently redistricted to 26th District) has a particular interest in cancer and healthcare, and has been a good advocate for Komen issues. He is a member of the House Bipartisan Cancer Caucus, and on the Foreign Affairs and Homeland Security Committees. He has introduced legislation for cancer research funding, the oral chemo bill, and has been a co-sponsor of other bills in this arena. Rep. Higgins has participated in the Race for the Cure® race day program for the past two years, and has run the Affiliate Race with his staff members. Rep. Higgins was also in attendance for the last two years at a Komen small grant funded breast cancer awareness walk hosted in the east side of Buffalo, an underserved community in the city.

Public Policy Committee members have had several meetings with Reps. Slaughter and Higgins, and have good contacts within their staff. They have been receptive to advocacy and outreach efforts. Representative Thomas Reed in the 29th District is new to Congress, and is on the Judiciary and Transportation and Infrastructure Committees. Komen WNY plans to visit him during future Lobby Days and potentially establish a relationship with him in the future.

The Public Policy Committee of Komen WNY has established a relationship with newly appointed 27th District Representative Chris Collins. Staff members from the office of Chris Collins have participated in the Race for the Cure for the last two years.

At the local level, Byron Brown, Mayor of Buffalo, has also participated in the Race for the Cure race day program and a small grant funded breast cancer awareness walk in the east side of Buffalo. Additionally, various NYS Assembly members have participated at other affiliate functions.

Potential Future Public Policy Activities

A current list of elected officials in the target areas will be maintained. The Affiliate will reach out to legislative representatives serving the Affiliate service area to discuss the needs in these communities and how the Affiliate can work with them to address the gaps in care. The Affiliate will take on a more active role in disseminating breast health legislation throughout the service area, and engaging community members in this important process.

Health Systems and Public Policy Analysis Findings

Although there are many resources for breast health in Western New York (WNY), they are mostly located in Erie County. However, many living in Erie County cannot access these services. The rural target communities are even more limited when trying to access these services. Three major issues have been identified as driving the barriers to access:

- Availability of screening, diagnosis and treatment facilities, particularly in rural areas.
- Transportation for women at all stages of the breast care continuum; rural and urban women alike are challenged in getting to places of service. Many resources in Erie County are located in the suburbs and are not easily accessible by public transportation for women living in the city. For the rural counties, there are no public transportation options for women.
- Lack of patient navigation in target areas. Patient navigation services are a valuable resource for women transitioning through the continuum of care. There are few traditional patient navigation services in the area. Erie County has some patient navigation services through Catholic Health Systems, WNY Breast Health, and Roswell Park Cancer Institute, once a diagnosis has occurred. Wyoming, Allegany, and Cattaraugus Counties are severely lacking in these services; little to no patient navigation services or support and survivorship services exist. Another barrier is that the resources that are available are unknown by patients and providers, and can be difficult to access.

The Affiliate has established relationships with the ECMC Lifeline Foundation mobile mammography coach, the Cancer Services Program (CSP) in Erie County, and many community partners. Currently the Affiliate collaborates with several partners to provide mobile mammography services, although most are located in the city. Moving forward, the Affiliate will work to create linkages with the mobile mammography coach and local partners in Allegany, Cattaraugus, and Wyoming Counties. The Affiliate plans to establish a relationship with the Livingston/Wyoming Cancer Services Program.

In addition, representatives from several CSPs sit on the Komen WNY Community Engagement Committee. Many of the programs have received small and community grant funds from the Affiliate in recent years. The CSP statewide is often under threat of funding cuts, but the Affiliate has been on the front line in efforts to maintain funding for the CSP. The Affiliate has partnered with other New York state Affiliates to create a strong force with the state government. The Affiliate will strengthen their relationship with the New York State Cancer Consortium and develop its policy in alignment with the National Komen Office, and will also support and disseminate information on legislative issues at the local, state, and national levels. Komen has supported programs that bring together these partners with direct impact on screening, early diagnosis and treatment.

Qualitative Data: Ensuring Community Input

Qualitative Data Sources and Methodology Overview

The quantitative and health services analyses revealed major barriers in engaging women throughout the Breast Cancer Continuum of Care (CoC). The most striking concerns were the high rates of late stage diagnoses in our target communities, the limited community resources available for education, screening, and treatment, and the barriers to accessing cancer care. Barriers identified included transportation, costs of screening and treatment, and care coordination for those diagnosed with breast cancer. Based on these findings, the Affiliate conducted an in-depth qualitative assessment that focused on three objective areas: 1) access to cancer care across the CoC, 2) barriers to screening and early detection, and 3) availability of support services.

The Affiliate was thoughtful and strategic about the groups of respondents they would approach for the qualitative assessment. To best assess the objective areas, the Affiliate included primary care providers, cancer care providers, community based organizations, women 40 and older, and breast cancer survivors. It was important to receive input from those who had perspective on the various stages of the cancer care continuum. The Affiliate was also conscientious of the unique demographic communities that reside in the target communities. The City of Buffalo, located in Erie County, has a large population of low-income African American and Latina women, as well as a growing community of refugees from over 70 different countries. Cattaraugus and Allegany counties are home to several territories belonging to the Seneca Nation of Indians (SNI), and some of the largest Amish settlements in New York.

To allow for a comparison of differing perspectives and experiences regarding the breast cancer CoC for women in each county, the Affiliate utilized key informant interviews and focus groups as the primary data collection methods. A set of predetermined questions were used to guide the conversations. Questions were selected to elicit information across the three identified content areas and were appropriate for the experience of each informant group. The same questions were used across all target areas for each informant group in order to make comparisons.

All sessions were led by a research team member from the Department of Family Medicine at the University at Buffalo. Each participant was provided with consent documentation which was reviewed prior to the start of each focus group and interview. A guide of questions were followed to facilitate focus groups and interviews. Women 40+ and survivors completed demographic surveys at each session. Komen giveaways were provided for all focus groups members. All interviews and focus groups were audiotaped and transcribed for analysis. Two reviewers independently coded each transcript. Codes were grouped into themes and cogent quotes were identified. The codes were reviewed for agreement; discordant responses were discussed and those codes were agreed upon.

Sampling

Primary Care Providers

The Affiliate selected primary care providers (PCPs) with whom they had a personal rapport to enhance participation. Providers were contacted by e-mail and phone, and asked if they were willing to participate in an interview. A research team member would schedule a convenient time to conduct the interview, although most times providers were interviewed on the spot. If a selected provider was not interested in participating, the Affiliate reached out to a different provider at the practice. Primary care providers included family physicians, internists, and OB/GYNs. The Affiliate recognizes the importance of primary care providers as the gateway to screening

Box 4.1 Questions: Primary Care Providers

1. *What breast health educational resources are available to the women you care for?*
2. *From your perspective, what barriers prevent women 40 and older that you care for from getting mammograms?*
3. *What role do you plan in your patient's care once a breast cancer diagnosis is made?*
4. *What role do you play in the follow-up care of your patients that are breast cancer survivors?*
5. *____ County is shown as having a high rate of late-stage diagnosis. What factors do you think might contribute to this high rate of late stage diagnosis?*
6. *Do you have any concerns regarding*

mammography. Primary care providers conduct clinical breast exams and refer patients for screening mammography, and are often the first line of defense for patients who present with symptoms. They also help navigate and follow up with patients who have been diagnosed.

Providers were purposefully sampled to represent various practices who serve the target communities; the interview questions selected are shown in Box 4.1. Practices within the target areas were identified, and providers within those practices were recruited to participate.

Key informant interviews were selected as the data collection method for primary care providers recognizing their busy schedules and limited availability. Interviews were conducted in person or by telephone based on the convenience of the provider.

Cancer Care Providers

Striving to gain diverse input, providers were purposefully sampled based on type of service they provide and the location of their practice. Cancer care providers (CCPs) included anyone who provides direct care to women throughout the cancer care continuum including but not limited to oncologists, mammography technicians, radiologists, and surgeons. There is a diverse range of providers that women interact with between screening and treatment, and the Affiliate recognized the importance of getting input from these various providers.

The questions selected are shown in Box 4.2. Practices within the target areas were identified, and providers within those practices were recruited to participate. The Affiliate selected providers with whom they had a personal rapport with to enhance participation. Komen volunteers were willing to suggest providers that might participate. Practices were contacted by e-mail and phone, and asked if a provider within their practice was willing to participate in an interview. A research team member scheduled a convenient time to conduct the interview, although most times providers were interviewed on the spot. If a selected provider was not interested in participating, the Affiliate reached out to a different provider at that practice.

Key informant interviews were selected as the data collection method for cancer care providers, recognizing their busy schedules and limited availability. Interviews were conducted in person or by telephone based on the convenience of the provider.

Community Based Organizations

Community based organizations (CBOs) were solicited based on their first-hand knowledge about the community and its residents, as well as the impact that breast cancer has had on the individuals the organization serves. Community based organizations were diverse and included but were not limited to Health Departments, Cancer Services Programs, breast cancer networks and coalitions, and support groups. These organizations provided a critical role in facilitating navigation through the cancer care continuum, providing education about cancer risk reduction, screening and treatment, and offering support for those with a diagnosis.

Box 4.2. Questions: Cancer Care Providers

1. *What resources are available for women with breast cancer in _____ County?*
2. *What barriers do you face in providing quality care to women diagnosed with breast cancer?*
3. *Do you have any concerns regarding breast cancer screening guidelines?*
4. *What barriers do you face in maintaining follow-up care for breast cancer survivors?*
5. *_____ County is shown as having a high rate of late-stage diagnosis. What factors do you think might contribute to this high rate of late stage diagnosis?*

Box 4.3. Questions: Community Based Organizations

1. *Where do women in your community get information on breast health and breast cancer screening?*
2. *In your opinion, what are some factors as to why women don't get mammograms? b. What are some factors as to why they do get mammograms?*
3. *What challenges do you face in helping women through the continuum of cancer care process from education and screening through to follow-up?*
4. *What are some strategies that you've used to engage women in their breast*

CBOs were purposefully sampled based on type of organization and the role it plays in the cancer care continuum. Contacts were chosen from the organizations listed in the health services analysis template. Again, the Affiliate wanted to obtain diverse experiences; the questions selected for CBOs are shown in Box 4.3.

Key informant interviews were selected as the data collection method for community based organizations due to busy schedules and diverse locations. Interviews were conducted in person or by telephone based on the convenience of the participant.

Women 40 years of age and older

Women 40 years of age and older were recruited from all the Affiliate's target areas for the qualitative assessment, specifically from the City of Buffalo in Erie County and the three rural counties of Cattaraugus, Allegany and Wyoming. The Affiliate wanted to assess the views of women without breast cancer to assess barriers they may face in accessing care, particularly in regards to early detection. A combination of snowball and purposive sampling were used to recruit participants for the focus groups. The Affiliate targeted existing groups and posted flyers in doctors' offices and community based organizations. As a means of recruitment, flyers were passed out at community events and venues, safety-net clinics, government assistance programs, support groups, hospitals, churches, and public establishments.

Focus groups were selected as the data collection method because they are often a valuable platform for individuals to share their experiences while hearing from others who may have similar experiences. The groups were held downtown at the offices of the Profile Team or in community venues that were easily accessible for community partners. A short demographic survey was completed by each participant, and Komen giveaways were provided for all focus groups. The focus group interview questions can be found in Box 4.4.

Breast Cancer Survivors

Breast cancer survivors were recruited from all the Affiliate's target areas for the qualitative assessment, specifically from the City of Buffalo in Erie County and the three rural counties of Cattaraugus, Allegany and Wyoming. The Affiliate wanted to assess the experiences of survivors, specifically the challenges they faced throughout the cancer care continuum. A combination of snowball and purposive sampling were used to recruit participants. The Affiliate targeted existing groups and posted flyers in doctors' offices and community based organizations. Flyers were passed out at community events and venues, safety-net clinics, government assistance programs, support groups, hospitals, churches, and public establishments as a means of recruitment.

Focus groups were selected as the data collection method because they are often a valuable platform for individuals to share their experiences while hearing from others who may have similar experiences. The groups were held downtown at the offices of the Profile Team or in community venues that were easily accessible for community partners. A short demographic survey was completed by each participant, and Komen giveaways were provided for all focus groups. The focus group interview questions can be found in Box 4.5.

Box 4.4. Questions: Women 40 years & older

1. How has breast cancer affected your life?
2. Where do women in your community get information on breast health and breast cancer screening?
3. Mammograms are a screening test that can identify cancer. Why don't women get mammograms?
4. What goes through your mind when you learn that someone has been diagnosed with breast cancer?
5. What community supports are available to women who have been diagnosed with breast cancer in ____ County? i.e. Support Groups, Patient Navigation, etc.

Box 4.5. Questions: Survivors

1. What barriers did you face in getting screened for breast cancer?
2. What barriers did you face getting treatment for breast cancer?
3. What was the worst experience you had during your treatment?
4. What was the best experience you had during your treatment?
5. Where do women in your community get information on breast health and breast cancer screening?
6. What would make it easier for women to access breast health and screening resources?
7. What resources were available for you to help you through your treatment?
8. What would have made your diagnosis and treatment experience better? What would be on your wish list for other women being diagnosed with breast cancer?

Special Considerations

The Affiliate gave special considerations to the special populations existing in the target communities; these populations include refugees from over 70 countries, the Seneca Nation of Indians, and the Amish. Challenges presented such as language and cultural barriers prevented involving these groups in the assessment. In order to include perspective of these communities, the Affiliate asked providers and community based organizations who serve these special populations to provide general responses and then to give perspective on these specific groups.

Cattaraugus and Allegany Counties often share resources and women may travel between counties to access services. Some providers and community based organizations were asked to provide insight into both counties and were therefore counted as an informant for both counties.

Wyoming County shares many resources and services with adjacent Livingston County which is not in the Affiliate's service area. Identifying primary care providers within the boundaries of Wyoming County proved challenging. No cancer care providers exist in Wyoming County.

Table 4.1 Overall Participation

Participant Type		Primary Care Providers	Cancer Care Providers	CBOs	Women 40 years +		Cancer Survivors	
Data Collection Method		Key Informant Interviews			Focus Group			
		# Participants			# Part.	# Group(s)	# Part.	# Group(s)
County	Allegany	1	3	6	N/A		9	1
	Cattaraugus	4	3	7	4	1	9	1
	Erie	12	8	12	13*	3	6	3
	Wyoming	1	2	N/A	N/A		N/A	

*It is important to mention that three men participated in a focus group in Erie County for women 40+. This focus group was conducted during a regularly scheduled community group meeting. The men were invited to participate in the discussion, although they were not included in the numbers for the focus group in the chart. They contributed considerably to the discussion, providing valuable insight and personal experiences of loved ones affected by breast cancer.

Ethics

Each participant was provided with consent documentation which was reviewed prior to the start of each focus group and interview. Members of the focus groups were asked to maintain the confidentiality of the group. All information obtained from the interviews/focus groups was kept confidential. All materials were kept locked in a cabinet and electronic data was saved in a password protected folder on the research associates computer.

Qualitative Data Overview

The Community Profile Team transcribed, independently read, and coded all key informant interviews and focus groups. From that data, themes/categories were generated. Several common themes reoccurred often from the key informant interviews and focus groups conducted in each target community. The results were compiled for each group in each target area; comparisons were made across groups to identify similarities and differences. Comparisons were also made across counties for each group.

Erie County

In Erie County, the focus groups were held downtown at the offices at the University at Buffalo with one facilitator and each session was audio recorded. A total of six focus groups, three for survivors and three for women over 40, were conducted. Thirty-two key informant interviews were conducted with PCPs, CBOs, and CCPs. A majority of the key informants serve a largely urban and minority population in the City of Buffalo.

Access to cancer care across the CoC

The health care system can be challenging to navigate, particularly for those with financial, insurance, or transportation barriers. The cost of services, including co-pays, can deter women from seeking breast health services.

Primary care providers noted that a lack of adequate insurance or a lack of any insurance at all can prevent women from seeking services. Some women do not have a primary care doctor and therefore are missing opportunities for education on the importance of breast health screening and encouragement to get screened. People who are underinsured or uninsured may not seek screening.

A lack of availability of services reduces access to cancer care resources. Radiology services are sparse in the city and there is an overall limited availability of mammography facilities. Many of the residents of Erie County face transportation issues and may not have reliable personal transportation. The majority of mammography facilities in the area are located outside of the city of Buffalo and in the suburbs and are not accessible via bus route or metro line. Some comments from providers:

“Transportation, they are unable to get to places that do breast screening”

“Transportation is always an issue that goes on with mammography”

A Mobile Mammography Coach introduced into the Western New York community in 2012 has been successful in alleviating transportation and financial barriers for some in the City of Buffalo and other places in Erie County. The coach reaches medically underserved women living in the city of Buffalo. The Mammography Coach has also recently been servicing areas of Cattaraugus County, another target community of the Profile. Patient Ambassadors assist women in navigating the mammography process.

“We work very closely with the mammogram bus and the women and the peers actually come to our site at least once a month”

“Well we have absolutely loved the bus parking right outside our door. [women] may or may not know how to get to the mammography unit... and our office is really pretty easy to do”

Barriers to screening and early detection

Barriers to screenings and early detection identified include fear, lack of communication within health systems and a lack of prioritizing of mammograms.

In all target areas, fear has been identified as a substantial issue, inhibiting many women from seeking breast health services. Providers mentioned patients' fear of the potential of pain or discomfort associated with the mammogram, fear of positive findings, and a general fear of the mammogram itself to be major deterrents. Informants noted that some women have had painful experiences in the past and do not want to endure that again. Overcoming the fears associated with a potential diagnosis is essential to encouraging women to enter the continuum of care.

“Fear of pain, having experienced pain before and not wanting to experience it again”

Increased efforts towards improving communication between a woman's care team as she navigates the breast cancer CoC was cited as a health systems barrier that needed to be addressed, particularly if a woman does not follow up after receiving a referral for mammography. Office processes may not necessarily appropriately track the people who are due for their mammograms. There is sometimes a lack of communication between the primary care provider and an OB/GYN who may make a referral for

mammography, but that information does not get passed along to the primary doctor. Providers stated that there can also be challenges when providers don't share test results or patient notes.

Need for a referral also poses an issue for women seeking breast health services. A woman might have an appointment set up, but when she arrives with no referral she cannot be seen. If she is denied at the door and has to reschedule, it's unlikely that she'll return for an appointment.

"There should be a little bit better coordination between the outside agencies"

Lack of primary care providers can prevent women from receiving breast screening services. A lack of primary care can cause interruptions in healthcare. These gaps in services create greater opportunities for mammograms due dates to go unnoticed.

Providers noted that women were more likely to get a mammogram if a family member or someone they knew had been diagnosed with breast cancer. Knowing someone personally or being aware of one's own family history greatly encouraged women to seek breast health screening. Also, women who are proactive in their health care and see a doctor regularly were more likely to have a mammogram done. Other factors include procrastination, a general unwillingness to follow up with mammogram referrals, and not seeking care until they find a lump or experience some form of abnormality.

Some women have had mammograms done for many years without issue and do not understand the importance of continuing breast health services. One provider mentioned that some women believe that prayer and spirituality will take care of them. Also, scheduling appointments can be an issue. Finding a time that is convenient for the patient can be difficult. Some women work during the day and are unable to get to mammography facilities in the evening, particularly those that are located a considerable distance away.

Availability of support services

Women often receive their breast health information primarily from their primary care providers and community based organizations. Providers indicated that many women in the City of Buffalo do not understand the importance of screening, and are uninformed or unclear about risk factors. Those who do seek screening are confused about how often to be screened, as well as about treatment options and follow-up care.

Providers had concerns about the variety of screenings available. Conflicting mammography guidelines could lead to confusion for women and healthcare providers. Women receive breast health information from a variety of sources including the media, particularly during October (Breast Cancer Awareness Month). Having access to such varying information can lead to myths, misconceptions, and confusion.

Informants acknowledge some confusion themselves regarding breast cancer screening guidelines. The most common guidelines mentioned were the American College of Radiology, United States Preventive Services Task Force, American College of Physicians, and American College of Obstetrics and Gynecology.

One provider mentioned a misconception that some women believe that seeking care causes cancer. They believe that if they go to the doctor they will receive a breast cancer diagnosis. One provider acknowledged a lack of cultural sensitivity that could potentially create barriers and mistrust within the system. Another provider, whose office serves primarily refugee patients, helps with reducing cultural barriers to care by ensuring refugee women are able to get to appointments and securing translation services when necessary.

Cancer care providers

Access to cancer care across the CoC

Healthcare coverage issues are substantial and problematic for the community hindering the ability to obtain services. Financial barriers for women seeking care as well as for cancer treatment facilities can inhibit access

to adequate cancer care resources. Many facilities cannot afford the new state of the art equipment. More facilities would be willing to invest if services were reimbursed better.

Insurance is an important factor in whether a woman receives necessary services. The ability to afford co-payments or out of pocket costs can get expensive, discouraging people from receiving necessary services such as therapy for lymphedema (swelling of the limbs after surgery) or prescription drug coverage. One provider identified an organization that provides underinsured or uninsured women with resources to obtain compression garments to aid in treating their condition. One cancer care provider mentioned recent insurance policy changes negatively affecting women receiving breast cancer treatment from their institution. These recent changes no longer allow women to receive follow up mammograms performed at their cancer treatment center because it is not a free standing center. Patients that have been receiving longtime services must disrupt care and begin receiving services elsewhere.

Another cancer care treatment center hosts a “free mammo day”, with provided transportation. They also work closely with New York State’s Cancer Services Program, a program federally funded by the Center for Disease Control (CDC) and further supplemented by the New York State Department of Health that offers education, screening, diagnostics, case management and treatment assistance to residents for breast, cervical and colorectal cancers.

“Insurance is a big thing because they aren’t able to get the services and the products that they need.”

Transportation was cited as a factor deterring women from appropriate access to services. Women who do not have reliable transportation cannot make it to their appointments or therapy sessions. Some patients are coming in from rural communities several hours away. While patients may be seeking resources from a particular cancer treatment center, many women are reluctant to come in to the city. The ability for them to come to an area several hours away for all aspects of their care can be limited.

One cancer care provider’s concern with guidelines was that there are many papers that come out every few years with varying perspectives on breast screening. It can be difficult for people to know which guidelines to follow. In general, many CCPs were comfortable with the guidelines that they chose to follow. One provider sits on a panel where they have an active input into some of the guidelines that are used around the country for breast cancer care. Although which guidelines were not specifically mentioned, it was alluded to be some of the more commonly used guidelines.

Barriers to screening and early detection

Cancer care providers mentioned many barriers to screenings, thus reducing the opportunities for early detection. Fear of being tested and anxiety associated with the exam was mentioned as factors by only two providers.

There is a lack of communication between healthcare providers. Partnerships between oncologists and primary care doctors are not streamlined. They do not have shared medical records or a formalized process for follow up care. Communicating to care providers from outside institutions or for patients that see providers at multiple different locations is challenging, particularly in getting up to date imaging reports and ensure all steps in a treatment plan are completed. Making the process after diagnosis as easy as possible and helping patients navigate their course is essential to providing quality care across the cancer care continuum.

A variety of factors influence whether a woman seeks breast health services. Availability of appointments after standard working hours may encourage more women to get screened. CCPs mentioned that patients delay seeking medical evaluation or do not follow cancer screening recommendations. However, one radiology clinic representative indicated that the population of women seen at the facility are diligent about following up with their care and understand the ramifications of detecting the cancer earlier.

Availability of support services

CCPs agree that improving education and public awareness of breast health is a necessary endeavor. Many patients are not aware of recommendations or why preventative healthcare is important. Many CCPs were aware of resources available to women in Erie County, such as medical services, nutritional services, genetic counseling, lodging, hospice, navigation, and community groups and non-profit organizations that offer support and recommend their patients to them. One cancer treatment center offers the Look Good Feel Better program, a program offered free of charge that holds group workshops that teach beauty techniques to female cancer patients to help them combat the appearance related side effects of cancer treatment. In regards to cancer screening guidelines, cancer care providers acknowledged some confusion for patients with which guidelines to follow. The availability of a variety of sources of information can lead to some confusion and inaccurate information. However, overall cancer care providers felt comfortable with the guidelines they chose to follow and did not note any concerns other than the confusion having so many guidelines available can place on women.

“It is hard for the people to understand, the public to understand how important the screening is because they are getting all these mixed messages”

Community Based Organizations

Access to cancer care across the CoC

Community based organization informants mentioned that many mammography centers in the city of Buffalo have either closed or relocated farther out into the suburbs. One CBO emphasized a need for increased incentives and promotion of screening services to women in the County. Women who would like to utilize the mobile mammography unit but are uninsured are referred to Cancer Services. Lack of reliable transportation and insurance were also identified as barriers to accessing breast health services.

“Financial burden so many times can be overwhelming.”

Barriers to screening and early detection

Informants cited that fear remains a pervasive deterrent to screening. Fear of the exam itself or a fear of pain were mentioned often. Some women have heard horror stories or have had unfortunate experiences themselves and decide to never be screened again. Some have received positive results and are afraid to go back for follow up because they are afraid to hear something else. Some women just do not want to think about the status of their breast health.

“We hear people complain that they think it is going to be painful.”

Two informants indicated that gaps with care coordination and navigation pose an issue. Currently, there is a disconnect between the medical jargon that providers use with patients. Providers often may not notice how the medical terminology is received by the patients when talking with them about their healthcare. Patients may not speak up for fear of appearing as if they do not understand the doctor. It was suggested that increasing communication and collaborations among organizations that provide similar services and educational outreach may maximize opportunities to reach women at risk.

Scheduling and timing have been identified by key informants as barriers to mammography for women. Many women are too busy either with work, taking care of family, or just meeting daily life needs to take the time to schedule and keep an appointment. Finding a time that is convenient for both women during available hours at the mammography facility can be difficult. One informant noted that difficulty in scheduling and that needing to reschedule an appointment reduces the likelihood that a woman will maintain follow-up appointments.

Some women face denial that further care or cancer treatment may be necessary and choose not to follow-up. There may also be a belief that it won't happen to them. Some women are just aren't interested in their breast health.

Informants stated that women may be already overwhelmed with daily life and the last thing they are worried about is preventive health. People who grew up with preventive health as a regular aspect of their life are more prone to make health-related appointments and well visits. The strongest factors that influence women to seek screening are if a family member or someone they knew personally had been affected by breast cancer or if they had been advised by their doctor.

"The last thing someone is going to worry about is a mammogram if they can't put food on the table for their kid"

"A lot of these young women today are double income families and so both parents are working and have a lot of responsibilities"

Availability of support services

Key informants stated that there is a lack of education and understanding on the importance of breast health and screening among women in Erie County. Although many community based organizations, primary care providers, and hospitals offer educational resources regarding breast health, there is still a need for increased education among women.

It appears women in the city of Buffalo are unaware of the variety of resources available to them throughout the county. Since death rates for African-American women are considerably higher, targeted programs are needed to reach these women and ensure they seek regular screening and understand resources that are available to them. Many community based organizations make their presence known at health fairs and participate in community events, bringing education directly into the community. These were cited as desirable and effective strategies for engaging women in the breast cancer CoC. It was mentioned that one of the first points of contact with the healthcare system is not with the physician but with the front desk. Investing the front line staff in breast cancer awareness could be an integral step in spreading awareness and sharing information. With physician and staff turnover, it can be difficult for offices and clinics to maintain consistency with distribution of breast health information. Therefore role of community based organizations is vital in ensuring in public awareness of breast health.

"I think that bringing services in to the community is a good approach, I think it is effective... I think that you have to bring the services out to the community"

"I just think that van has really hit on a great outreach"

Hispanic/Latina women living in the city of Buffalo face challenges accessing facilities that speak their language or provide culturally appropriate educational materials and resources. Most facilities are primarily English speaking and not many facilities provide interpretative services or translated materials. One informant utilizes the mobile mammography unit because staff from the organization can go with women to the bus and interpret for them. A lack of childcare was also mentioned as a barrier to care.

"We have a lot of problems finding a clinic that they are able to go and that they speak Spanish."

Survivors that may feel that their treatment or surgery is over and want to forget it ever happened can be a stumbling block for follow up care. It is important to remind survivors that follow up care is a continuation throughout their lifetime, even after treatment is completed.

Access to cancer care across the CoC

A lack of transportation and child care present barriers to access in cancer care. Informants were not aware of any resources specific to refugees that are not available to other populations. As a means of overcoming literacy and language barriers, one informant would turn educational sessions into a game and make it fun for women participating.

Barriers to screening and early detection

Although neither of the two informants experiences any cases of actual diagnosis with the refugee population, they encountered some with history or who were at risk. Factors that encourage screening include increased education, knowing somebody close who might have been diagnosed or passed away because of cancer, or if their doctor suggested screening.

Fear prevents many refugee women from going for screening. They are afraid of finding something. The fear is so pervasive women do not even want to utter the word “cancer” for fear that if they say it they might get it. In some instances shame can be a barrier. Women may think if they find out that anything is not normal that it’s going to be embarrassing

“They actually refer to it as ‘that disease’”

Availability of support services

Breast cancer education has a very positive impact on refugee women. Much of the education comes from their primary care doctor or community based organizations. One CBO reaches out to resettlement agencies, English as a Second Language (ESL) classes, other CBOs, health fairs, and some faith based organizations. An informant finds that there is not enough information for many of them about what screening entails and why it’s important to get done. One informant said refugee women sometimes believe in myths and misconceptions about screening and about causes of cancer such as not eating certain types of food reduces their risk of cancer. Oftentimes, refugee women are lacking local support systems. They lack child care during screenings and/or treatment.

In addition, facilities encounter language and culture differences. Providing interpreters or as much information in their own language as possible could assist in eliminating that barrier.

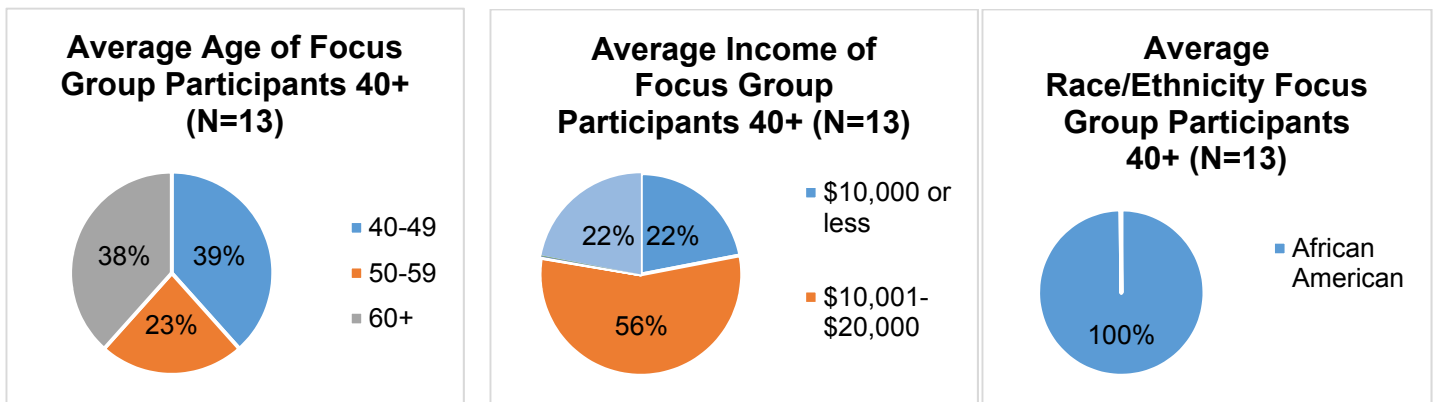


Figure 4.1 Erie County Women 40+ Focus Group Demographics

Access to cancer care across the CoC

All three focus groups have identified insurance status and cost of services as a factor preventing women from seeking services. Some women felt that their level of insurance and what they could afford to pay affects the

type of healthcare they receive. As a result, people with a lack of insurance may not seek non-emergent health care.

Barriers to screening and early detection

Fear was cited as a leading reason why women are not getting screened. The fear of “finding something” or receiving a breast cancer diagnosis leads women to avoid screening. Women continue to fear the possibility of a painful or uncomfortable mammogram. Some women have had uncomfortable experiences in the past inhibiting them from seeking services in the future. Also, the fear of “not knowing” what the results could be or if they were diagnosed what that could mean for them cause women to become worried and have anxiety associated with screening resulting in not wanting to have a mammogram done.

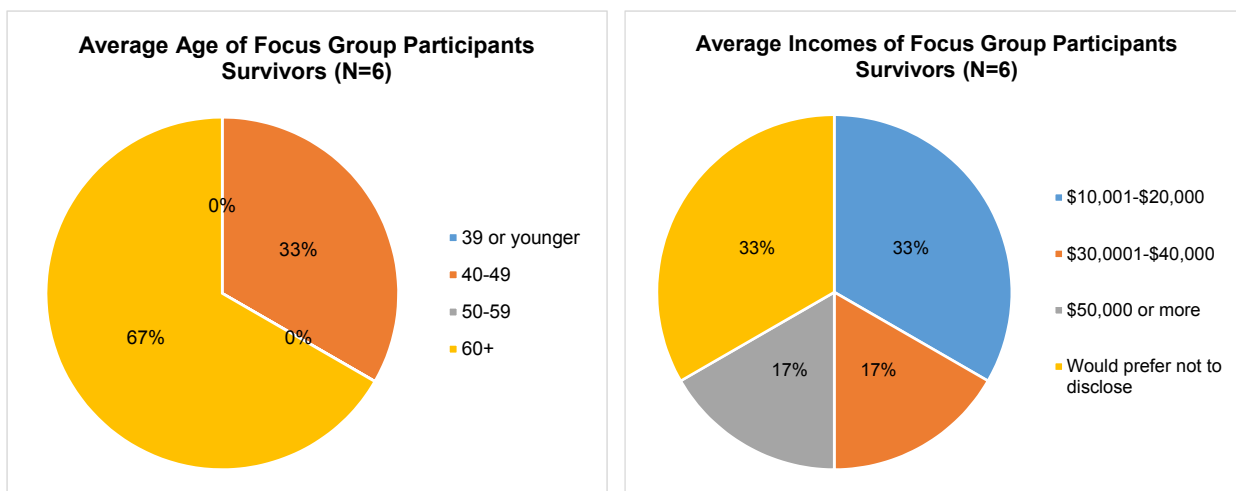
Women from all focus groups felt that a patient’s relationship with the doctor was critical to seeking screening and treatment services. Focus group participants felt that trust was of high importance and if a woman did not like or agree with their doctor it was their choice to get a different doctor. Many women cited experiences of dealing with health care providers that lacked compassion and understanding either during screening or cancer treatment.

“Doctor’s don’t have, a lot of them don’t have compassion for their patient, they’re just another customer.”

Women cited that being aware of their own family history with breast cancer or knowing someone personally who was diagnosed with breast cancer motivated them to seek breast health screening. Women in the focus groups admitted to not receiving a mammogram due to other health concerns that took precedence in their life. One woman stated that she did not think breast health crossed a woman’s mind that often. Of the women in the 40+ focus group, a majority of them did not have a family history of breast cancer. Although they recognized the importance of breast health screening it appeared that they were overall not too worried about their breast health due to having no known family history of breast cancer.

Availability of support services

Some women in the focus group were not aware of resources in their own community. Most women were familiar with Roswell Park Cancer Institute (RPCI) and assumed that RPCI had support and resources but did not know for certain. Women were not familiar with the variety of community based organizations in Erie County that provided support and education resources. Generally women were unaware of Cancer Services Program, when discussed during focus groups. The CSP has a presence in every county allowing uninsured women 40 or older (or younger, if family history/or palpable finding) eligibility for breast cancer screenings. Women who utilize the CSP have the freedom to attend any regional mammography center for screening; however, many uninsured women do not access the Cancer Services Program due to a lack of awareness of its existence and services offered.



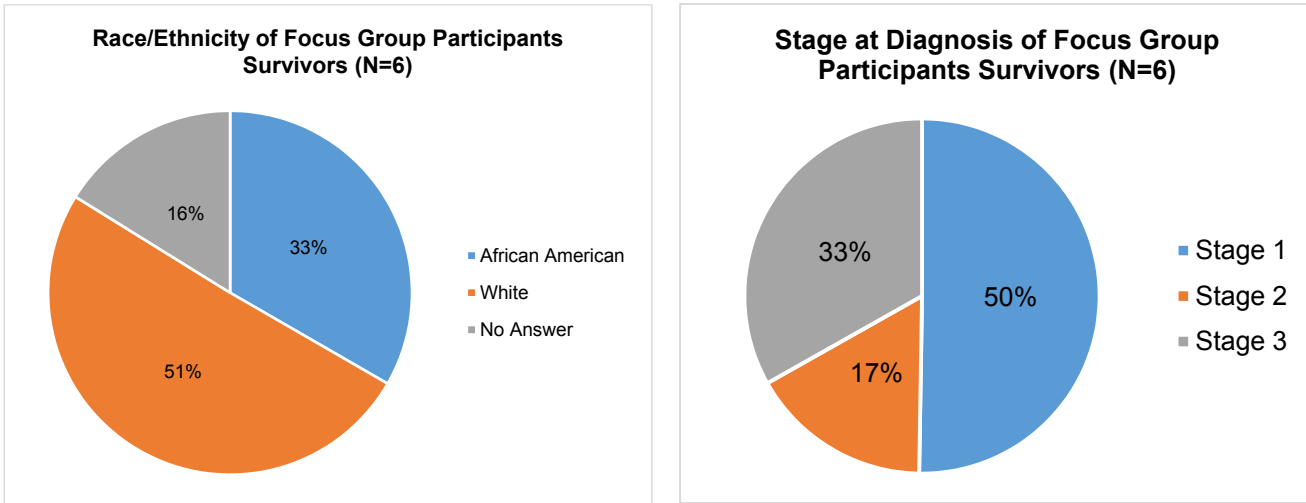


Figure 4.2 Erie County Survivors Focus Group Demographics

Access to cancer care across the CoC

Women in the survivors’ focus groups identified that insurance status and cost of services can prevent women from seeking services. One uninsured breast cancer survivor had a particularly difficult time navigating her diagnosis and treatment process and was unaware of the resources offered by CSP and the Medicaid Cancer Treatment Program (MCTP).

Barriers to screening and early detection

Women from all focus groups felt that a patient’s relationship with the doctor was critical to seeking screening and treatment services. Focus group participants felt that trust was of high importance and if a woman did not like or agree with their doctor it was their choice to change to a different doctor.

Some women experienced periods of depression post diagnosis. Some women felt alone during treatment, particularly due to the side effects, which made many patients tired and lethargic. At times family members and friends would be unavailable. Others experienced medical complications such as lymphedema and hematoma. Facing yet another obstacle to their treatment further exacerbated the feelings of loneliness and sadness.

“Sometimes I’d be so down, because it seemed like I’d be there all by myself”

Availability of support services

Survivors indicated seeking support among other survivors is a valuable resource. Learning from one another’s experiences and sharing strategies was helpful during treatment and after. Most participants were aware of support resources in the area, although they acknowledge not utilizing many resources at the beginning of the diagnosis or during treatment. Side effects of the treatment left many women unable to participate in support groups or access support resources. Participants noted the shock of the diagnosis and figuring out what next steps to take was overwhelming. Several women noted insufficient communication after their initial diagnosis is relayed to them by their doctor. One woman was shown a video, where others receive so much information from their physician it was difficult to process and retain when they were in such disbelief. Another woman’s doctor told her mother who then told her that she had cancer rather than tell her directly. Participants stated that a patient navigator would have been helpful. None of the women in the focus groups used a patient navigator to guide them through the breast cancer CoC. This was due to either the time they were diagnosed patient navigators did not exist, or they were unaware of the services and were not offered navigation. The support of family and friends, as well as the support of other survivors, was crucial to women diagnosed with

breast cancer. One woman went through treatment with a neighbor who was diagnosed as well and they acted as a support system for one another.

“Meeting new people, new patients, newly diagnosed women and just being supportive of their situation. Just doing it together and just kind of like crying on each other’s shoulders”

“They sat me down in front of a video to watch it but I can’t remember one second of it because I was so upset”

Table 4.2. Comparison of themes across Erie County

POPULATION OF INTEREST	THEMES						
	Fear	Knowledge	Health System Issues	Priority of Mammogram	Access to Services	Medical Complications	Culture
PCPs	x	x	x	x	x		x
CCPs	x	x	x	x	x	x	
CBOs	x	x	x	x	x		x
40+	x	x	x	x	x		
Survivors	x	x	x	x	x	x	

Cattaraugus County

Primary Care Providers

Access to cancer care across the Continuum of Care

Primary care providers (PCPs) identified several barriers in terms of access to cancer care across the continuum of care. Providers mentioned that locations for screening and treatment are limited in Cattaraugus County, and often inconvenient for women to get to; it is common for women to drive outside the target area. Issues with insurance are also a barrier to accessing services, especially for those women who are uninsured or underinsured. For those that have insurance, they face challenges such as high copays and high deductibles, and often find themselves stuck in a gap of care.

“What we see basically is women don’t have insurance, even though that’s changing, and without insurance they don’t think they’re eligible for any services, so they neglect their health”

Reliable transportation was another common barrier women face in accessing breast health services as public transportation does not exist in Cattaraugus County, and all the screening and treatment sites are located in a central location in Olean NY.

Barriers to screening & early detection

Several themes were identified when it came to barriers to screening and early detection. Providers mentioned that fear can keep women from being screened, especially the fear of having a positive finding.

Another barrier that was identified when it came to screening were physician and health system issues, primarily the lack of primary care physicians among women in Cattaraugus County. There is also a high turnover rate among physicians.

“A lot of people in this county don’t have primary care physicians; they really don’t have that gateway to care sometimes. And then sometimes their primary care providers leave. I think we have a pretty high turnover rate of primary care physicians. So when they leave women kind of drop having a primary care provider, and really don’t seek further care or preventive care.”

When it came to priority of mammograms, PCPs identified several reasons as to why women don't get screened. Overall, they felt that most women simply procrastinate and put off getting their mammograms; they don't have time, and they don't make the time. While PCPs encourage screening, many women are concerned with other aspects of their health, and those take priority over screening.

Availability of support services

When it comes to availability of support services, PCPs confirmed that they are a primary source of breast health education for women in Cattaraugus County. One barrier that was identified to accessing educational services was that many women do not know where to go to get information or support outside of their doctor's office, especially for free services and financial assistance.

As previously mentioned, Cattaraugus County is home to special populations including the Seneca Nation of Indians and a fairly large Amish population. These groups are known for statistically low participation in preventative care, affecting screening rates.

Cancer Care Providers

Access to cancer care across the CoC

Cancer care providers (CCPs) in Cattaraugus County identified several barriers in terms of access to cancer care across the CoC. Themes were similar to those mentioned by primary care providers, such as costs, unreliable transportation and the lack of availability of services.

Regarding insurance, CCPs often see that the costs associated with treatment prevent women from receiving proper care. Again, insurance is a huge barrier for women who are uninsured. For those with insurance, obstacles include masses of co-pays and high deductibles.

In terms of available services, there are limited treatment locations in Cattaraugus County, and women sometimes have to drive far distances to received care.

"We have relatively rural and impoverished population in part of the county, and trying to get them resources and see them in a timely fashion is difficult. And if they don't have transportation, they don't have ways to access what they need."

Transportation was cited as a barrier to why women don't receive appropriate treatment; CCPs mentioned that women often miss treatment due to lack of transportation. The costs of travel to and from appointments add up quickly, thus putting a financial burden on women. Unfortunately, CCPs find that some patients take cost into consideration when making decisions on their treatment.

Barriers to screening & early detection

For CCPs, a major barrier to screening and treatment is communication with patients. Cattaraugus County is very rural and some patients live in areas without high-speed internet or cell service. Some women are also transient, and change addresses and phone numbers frequently which proves difficult for CCPs to provide follow-up care.

"You know, if you have a population that is kind of transient you might not be able to get a hold of them for follow up."

Availability of support services

When it comes to availability of support services, CCPs noted that community-based organizations serve as a primary source of breast health education for women in Cattaraugus County. Specifically, CCPs mentioned the

Cancer Services Program of Allegany & Cattaraugus Counties for financial assistance and educational information.

Community-Based Organizations

Access to cancer care across the CoC

Community-based organizations (CBOs) in Cattaraugus County identified several barriers in terms of access to cancer care across the CoC. Many of the concerns mirrored those of the PCPs and CCPs. Screening and treatment locations are often inconvenient and require driving long distances. Costs associated with screening and treatment are barriers to women receiving proper care; Cattaraugus County has a low median income and many women work minimum wage jobs. Other issues included women being uninsured or underinsured, and the fact that many women do not have reliable transportation to get to appointments.

“I would say our transportation issues are huge...we are geographically large. And a lot of people either only have one vehicle or they don’t have a vehicle at all, and we don’t have mass transportation.”

In terms of availability of services, there are a limited locations for women to choose from, especially when it comes to follow-up appointments or additional testing.

Barriers to screening & early detection

Several themes were identified when it came to barriers to screening and early detection. CBOs mentioned that fear can keep women from being screened, specifically the fear of radiation from the mammogram procedure and that the mammogram is painful/uncomfortable. Also, the fear of being diagnosed with breast cancer was mentioned as a reason why women don’t get screened, as well as a reason why they do get screened.

“We have had some people say there weren’t going to get a mammogram because it hurt, they had one and it hurt. We have had people say they aren’t getting a mammogram because of the radiation, so there are all those myths still down here.”

Another theme was physician and health system issues. Much like the providers, the CBO’s note that many women do not have primary care providers, and that there is a high turnover rate of primary care physicians. Women also tend to mistrust the health care system, and recent changes in health care policy have furthered that mistrust.

When it comes to priority of mammograms, CBOs identified several reasons as to why women don’t get screened; many were the same that PCPs acknowledged. Generally they feel that women procrastinate and just put off getting screened. They noted that women are often distracted with other aspects of their lives such family, other health issues, or simply addressing basic needs. They feel that those that do get screened probably do so because there was a family history, or they know someone who was diagnosed. They also feel that encouragement from PCPs, friends and family play a role in women getting screened.

Availability of support services

When it comes to availability of support services, CBOs noted that they serve as a primary source of breast health education for women in this target area, specifically the Cancer Services Program and the health department. They also mentioned that churches, PCPs and hospitals also play a role in educating women about screening. Although there are different places women can go, there are still some myths and misconceptions when it comes to screening.

In terms of availability of support services, they felt that many women weren’t sure where to go to get information, specifically for the free and low cost services, which can create a barrier to them getting screened.

There are some existing avenues that are used for awareness and education e.g. health fairs, a local support group, and community events, but those are far and few between.

CBOs noted that in terms of educating these groups, materials not always culturally sensitive to their cultures. The also mentioned that cultural norms, such as not routinely following preventive care, can create a barrier in getting these women screened.

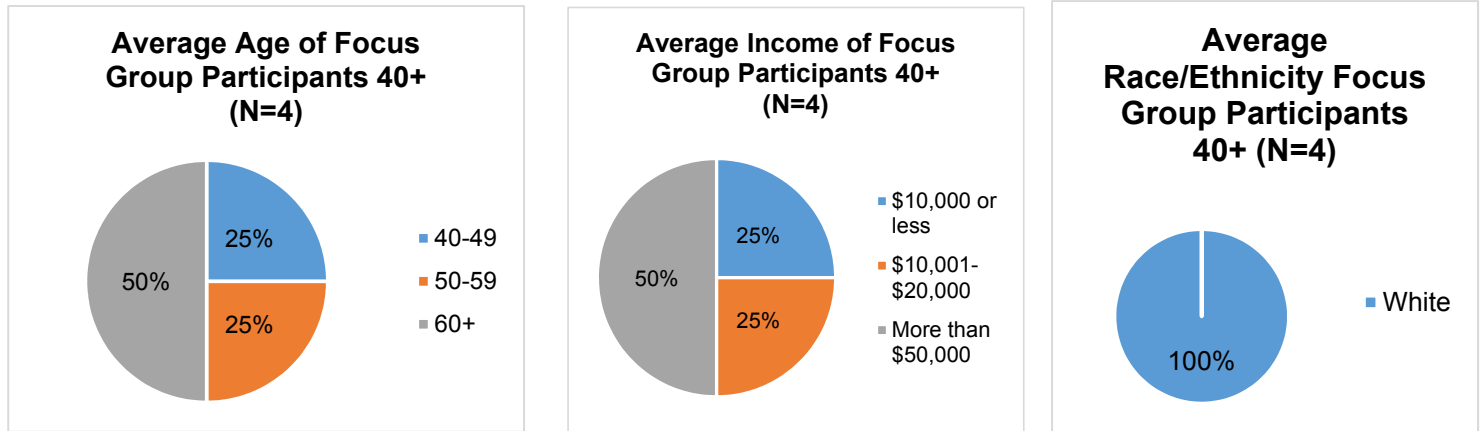


Figure 4.3. Cattaraugus County Women 40+ Focus Group Demographics

Access to cancer care across the CoC

Women 40 and older in Cattaraugus County identified several barriers they face when it comes to accessing cancer care across the CoC. Overall, responses of women were comparable with those of the other target groups. Women find that screening and treatment options are located in areas that are inconvenient and difficult to get too. For many women, the cost of screening or treatment can be a barrier for women in this area, especially when it comes to those who are underinsured/uninsured. The quantitative section of the report identified 38.9 percent of residents of Cattaraugus County as falling below 250 percent of the poverty line. Women also mentioned that transportation is a contributing factor as to why women aren't screened; there isn't a public transportation system, and options for shuttles and cab services are very limited. Overall, there is a lack of availability of services.

“But then again, you’re trying to connect this route with that route because you have to be here at that time and it might be several towns from where you’re going and it’s hard geographic, economic, and I want to say educational.”

Barriers to screening & early detection

Women 40 and older were very vocal when it came to pinpointing barriers to screening and early detection. Fear was a prominent theme; fear that the procedure is painful and uncomfortable, and of being diagnosed with breast cancer. They noted that many women are generally anxious when it comes to mammograms.

“I think that’s the bad part about getting women to screen regularly, is the fear factor.”

When it comes to priority of mammograms, women had similar feedback to the CBOs. Women were more concerned with other aspects of life such as taking care their family and work. For the most part, women procrastinated in getting screened or just did not have the time. It can be challenging for women to coordinate their care when they are concerned with other aspects of life.

“I mean definitely, especially the people I work with, a lot of times, their kids have been removed. Their big thing is ‘how do I get my kids back?’ They’re not worrying about their own physical well-being.”

Women also mentioned that the factors such as family history played a role in why women do get screened. They also noted that knowing someone who had been diagnosed was a motivating factor, especially when living in a close-knit small town where everyone knows each other.

Availability of support services

When it comes to availability of support services, women 40 and older all said that they received education on breast health primarily from their doctors. They also mentioned specifically the Cancer Services Program and the Health Department as two CBOs that generally had available information as well.

Overall, women 40 and older felt that there was a lack of awareness in the target area, and that many women weren’t sure where to go for educational information, particularly for the free services. They also felt that despite available services, there were still many myths and misconceptions that prevented women from being screened.

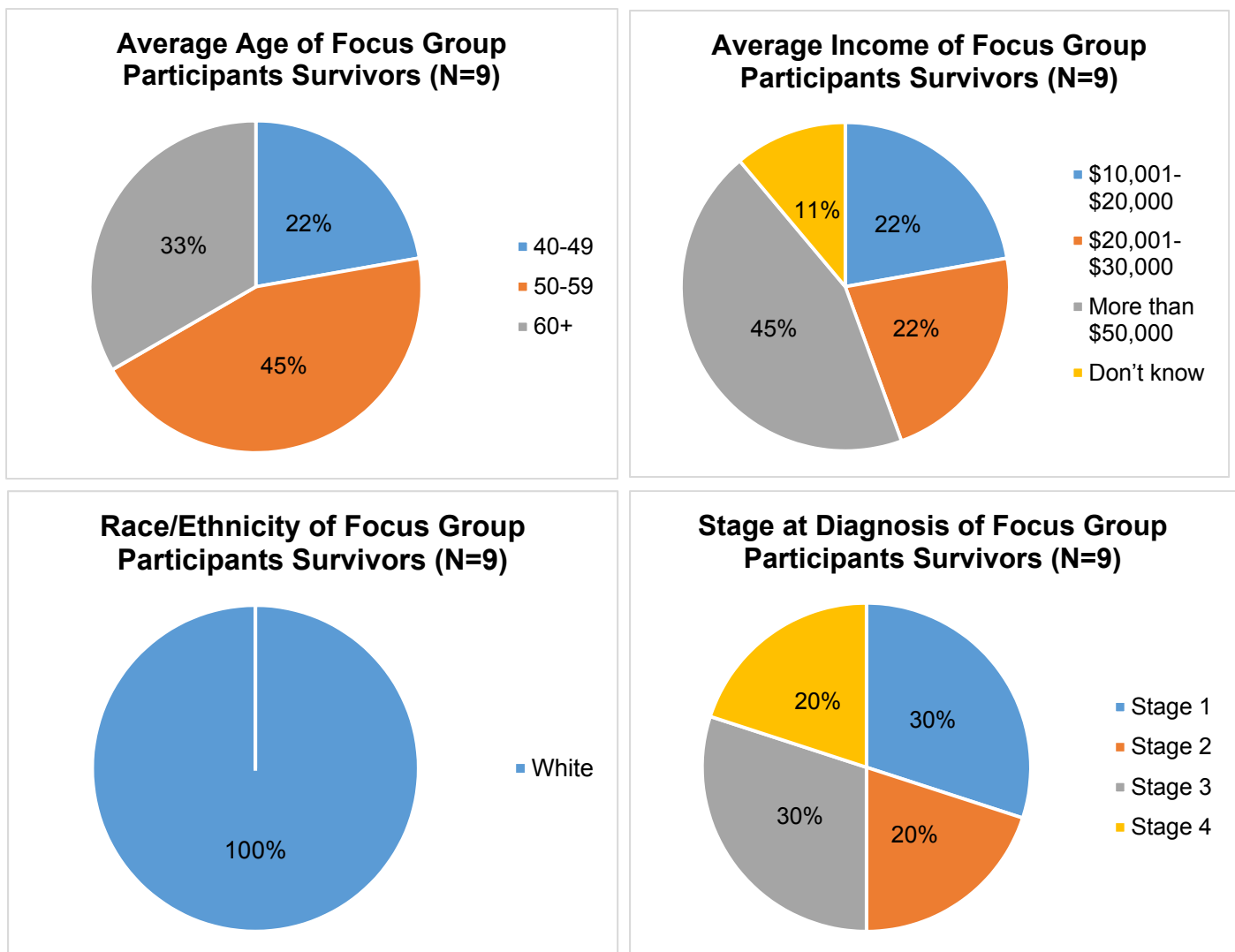


Figure 4.4 Cattaraugus County Survivors Focus Group Demographics

Access to cancer care across the CoC

Survivors in Cattaraugus County identified several barriers they face when it came to accessing cancer care across the CoC. Overall, responses of survivors were comparable with those of the other target groups. Survivors found treatment options were located in areas that were inconvenient to access, having to travel between Buffalo or Rochester for care. For many survivors the cost of screening or treatment was a barrier, especially when it came to those who are underinsured/uninsured. For those with insurance, copays and high deductibles were a source of stress, and unfortunately it played a role in the care they received.

“Yeah if you are under long term care, and you are going right along, I mean the copays add up and if you don’t have a lot of money, we really need help in this area.”

Survivors also mentioned that transportation was a contributing factor as to why women were not being properly screened and treated. There isn’t a public transportation system in the county, and options for shuttles and cab services are very limited. Overall, there was a lack of availability of services. Survivors were very vocal when it came to discussing support and survivorship. Most of them cited that they only knew of one support group in the target area, and that there were essentially no navigation services for women when diagnosed.

“When a woman is diagnosed with breast cancer, immediately she needs to know a lot of things, she has a lot of questions, she is very frightened.”

“When they first called and told me I had cancer, you go into brain freeze and you really don’t know where to go and where to start and I really think that there should be something, like you have to find the agency first, and if you don’t know where to start...then there should be a pamphlet or something out there that says this is what you need to do first, second, third, to help you get started to know where to go.”

Barriers to screening & early detection

Survivors had great insight when it came to barriers to screening and early detection. Fear was a prominent theme; fear that the procedure is painful and uncomfortable, and of being diagnosed with breast cancer. Another theme was physician and health system issues. For some survivors, coordination of care was lacking, especially once they were diagnosed. They felt that communication between doctors’ offices and specialists was sometimes absent. In terms of priority of mammograms, survivors felt that it was hard for women to get screened because they were concerned with other aspects of life such as work and their family.

Medical complications was another theme with survivors, primarily with the impact that breast cancer has on mental health and emotional well-being, especially during and after treatment.

Availability of support services

When it came to availability of support services, survivors said that they received education on breast health primarily from their doctors. They also mentioned CBOs as a source, specifically the Cancer Services Program as being integral to women in Cattaraugus County when it came to financial assistance and education. Survivors felt very strongly about the education from other survivors, and have found that support to be very important in their breast cancer care. Overall, survivors felt strongly that education should start earlier, and that more young women need to be educated on knowing their bodies and what is normal. Overall, survivors felt there was a lack of awareness and education for women in this target area, especially when it comes to treatment and its side effects, and where women can go for emotional support.

“Somehow we have to get out the message that there is help and there is a starting point, and I think that is where we need to help, is to let women know what to do and what’s your starting point.”

Table 4.3 Comparison of themes across Cattaraugus County

POPULATION OF INTEREST	THEMES						
	Fear	Education/ Knowledge	Health System Issues	Priority of Mammogram	Access to Services	Medical Complications	Culture
PCPs	X	X	X	X	X		X
CCPs		X	X	X	X		X
CBOs	X	X	X	X	X		X
40+	X	X	X	X	X		
Survivors	X	X	X	X	X	X	

Allegany County

In Allegany County, many of the key informant interviews, and one focus group, were interchangeable with Cattaraugus County due to the fact that both counties share many services between one another. In many instances key informants’ feedback was applicable to both counties and the experiences of women in focus groups represented the experiences of average rural women when seeking breast health resources. A single focus group was held with breast cancer survivors. The coordinator of the Cancer Services Program of Allegany and Cattaraugus County assisted with the scheduling with a breast cancer support group held at the Radiation Oncology Clinic associated with Olean General Hospital in Olean, NY. A total of six Key Informant Interviews were conducted.

Primary Care Providers

Access to cancer care across the CoC

One provider was interviewed in Allegany County. Many people in this county do not have a primary care doctor. This limits their access to services. This informant noted transportation and financial constraints as barriers to access cancer care services. The cost of services is an issue for many. The lack of reliable transportation and the cost associated with the transportation such as gas or the affordability of public transportation was of concern to the informant.

"A lot of people in the area that just don't have any money... five dollars in gas is a big deal to get to their appointments."

Barriers to screening and early detection

This informant noted some barriers to screening for women in Allegany such as patients not making their appointments or waiting too long and not coming into the office until something is really wrong.

Availability of support services

Lack of knowledge was discussed as a barrier as was lack of community resources within the county. It was stated that women receive educational information from their primary care providers and hospitals. However, there is a general lack of understanding of screening guidelines and a general lack of education. The primary care provider also noted their own inexperience with referring to specialists for cancer.

"There is a little confusion now what the latest recommendation is... There's bodies of organizations that recommend screening only based on risk factors. And other organizations yearly mammograms is what's recommended. So there's a lot of confusion there, what the best treatment." Cancer Care Providers

Access to cancer care across the CoC

Key informants noted issues with insurance, particularly for those who are uninsured or underinsured. Cancer care providers have heard from women that they did not seek care because of their insurance status. They work closely with Cancer Services Program and a local community based organization to access resources such as gas cards and financial assistance with co-pays. Cost of co-pays is a major concern for women living in Allegany County. They do not want to start treatments until they know exactly how much it is going to cost. Unfortunately, some patients take that into consideration when making their decision on whether or not to receive treatment.

Allegany County is a relatively rural and impoverished population. Transportation is a major barrier to access. If women do not have a reliable means of transportation they do not have ways to access what they need. For many women in this area the locations for screening and treatment are often inconvenient and too far to drive. One local hospital offered free mammograms just for the month of October during Breast Cancer Awareness month.

Barriers to screening and early detection

Informants noted challenges in communicating with patients as a potential barrier to screening. Such a rural and transient population with many individuals navigating in and out of the healthcare system makes it difficult to keep in touch with women to emphasize the importance of breast health.

Availability of support services

Although there is not a lot of educational resources in Allegany County, informants work closely with a local community based organization to provide educational materials to the women they care for.

A large Native American population resides in Allegany County. Informants work pretty well the Native American Community. The reservation secures transportation and covers co-pays for Native women seen at their office.

Community Based Organizations

Access to cancer care across the CoC

Cost was a major issue discussed for women accessing care in Allegany County. However the cost of transportation and its impact on a woman's ability to access breast health care was emphasized. One solution suggested by one key informant was to work with providers to offer all the services in one day, like a screening day event. Traveling also ties in with these issues, as many people lack reliable transportation, and the area is spread out.

“if they have insurance and they know their insurance will pay for the mammogram, without them having a huge copay or having to meet a huge deductible before the mammogram... just simply having that knowledge make them feel comfortable in having the procedure done.”

One informant acknowledged the lack of treatment options available to women in Allegany County. They may have screening or some diagnostic procedures completed, and then choose not to have treatments when they find they have to travel long distances for treatment. There are not any treatment facilities offered in Allegany County. The utilization and availability of the mobile mammography coach was also discussed as an asset to the Native Americans on the reservation, but this does not resolve the issues of the lack of treatment services.

Barriers to screening and early detection

The health system was noted as an issue in Allegany County. One informant discussed how changes in healthcare policy could be both an asset and a barrier to screening. Lack of prioritization of mammography

was another potential barrier noted by informants. This group gave quite a bit of insight into why women do get screened as opposed to why they do not. Having a family history, or knowing someone who was diagnosed with breast cancer was thought to be a prompt for women to get screened. An abnormal finding was considered further motivation for women to maintain annual mammography.

Encouragement from a primary care provider was an important asset to maintaining annual breast health screening. It was also mentioned that some women were just health conscious and active in their healthcare, therefore were cognizant of being screened every year. On the other hand, factors such as procrastinating or just putting it off, and not having time were notable barriers. Some women wait until something is really wrong prior to seeking care. Due to these barriers, many women may find it hard to find time to get screened.

"I think a lot of people in this area do not seek primary care."

"They wait until it's too late. Or they don't come to the office until something is really wrong."

Availability of support services

Education and knowledge was primarily discussed as a necessity to getting women screened and in proper treatment. Key informants stated that women received breast health and breast cancer information from their primary care provider, community based organizations including the health department's family planning clinic and cancer services program, as well as from other women or survivors. However, a couple of barriers were noted, such as a general lack of education on the part of the patient and the provider. One key informant noted his inexperience with referring for breast cancer. It was also noted that women may be lacking information, despite the numerous places from which to get information.

The mobile mammography coach was considered an asset for the Native Americans in the area. However, a cultural norm of fearing to leave the reservation was also identified as a barrier. Because of this fear, the mammography bus would become even more of an asset for this population.

"There is a little confusion now what the latest recommendation is... There's bodies of organizations that recommend screening only based on risk factors. And other organizations yearly mammograms is what's recommended. So there's a lot of confusion there, what the best treatment." Survivors

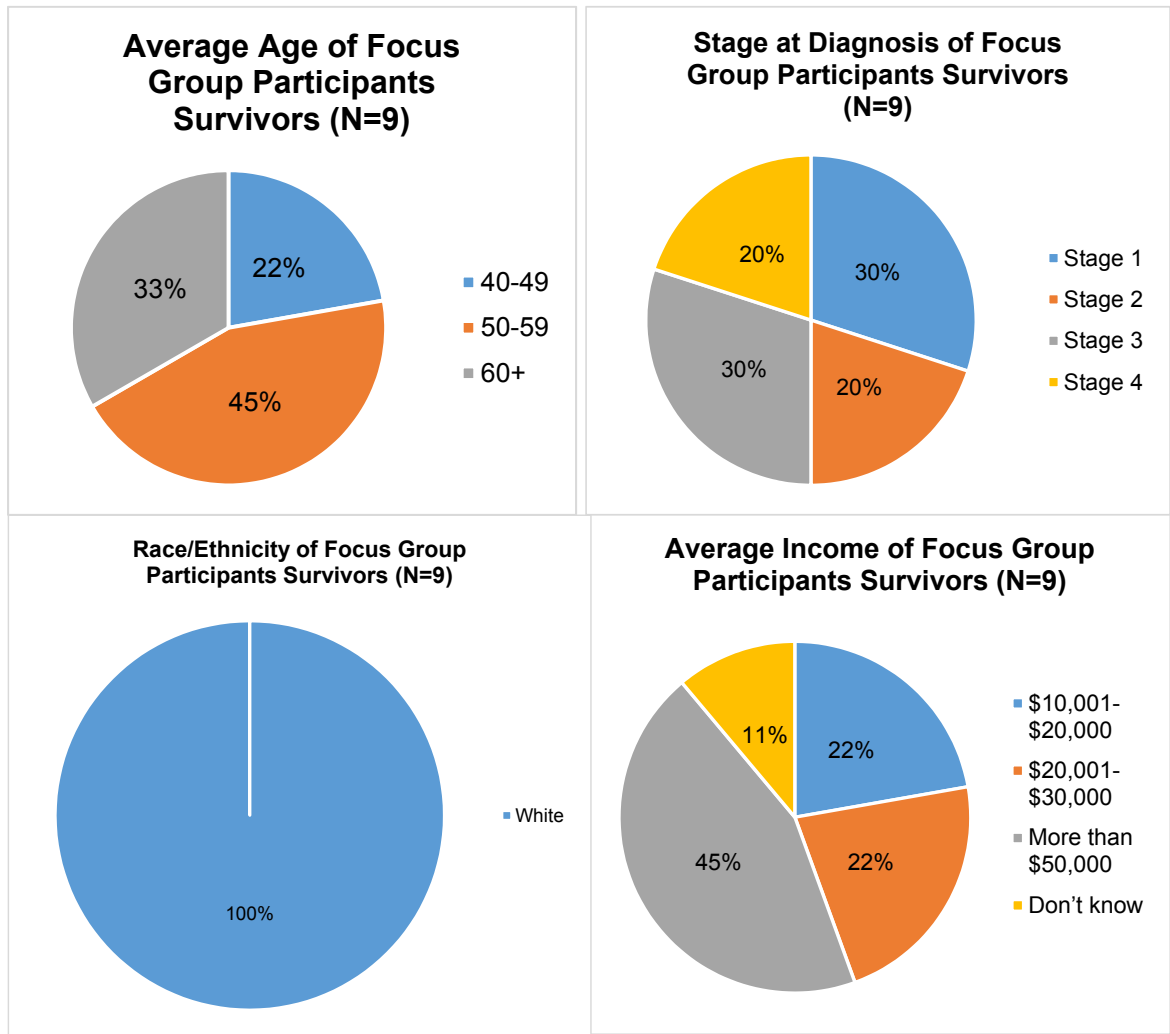


Figure 4.5 Allegheny Survivors Focus Group Demographics

Access to cancer care across the CoC

Survivors in Allegheny County identified several barriers they face when it came to accessing cancer care across the CoC. Overall, responses of survivors were comparable with those of the other target groups. Survivors found treatment options were located in areas that were inconvenient to access, having to travel between Buffalo or Rochester by car. For many survivors the cost of screening or treatment was a barrier, especially when it came to those who are underinsured/uninsured. For those with insurance, copays and high deductibles were a source of stress, and unfortunately played a role in the care they received.

“Yeah if you are under long term care, and you are going right along, I mean the copays add up and if you don’t have a lot of money, we really need help in this area.”

Survivors also mentioned that transportation was a contributing factor as to why women were not being properly screened and treated. There isn’t a public transportation system in the county, and options for shuttles and cab services are very limited. Overall, there was a lack of availability of services. Survivors were very vocal when it came to discussing support and survivorship. Most of them cited that they only knew of one support group in the target area, and that there were essentially no navigation services for women when diagnosed.

“When a woman is diagnosed with breast cancer, immediately she needs to know a lot of things, she has a lot of questions, she is very frightened.”

“When they first called and told me I had cancer, you go into brain freeze and you really don’t know where to go and were to start and I really think that there should be something, like you have to find the agency first, and if you don’t know where to start...then there should be a pamphlet or something out there that says this is what you need to do first, second, third, to help you get started to know where to go.”

Barriers to screening & early detection

Survivors had great insight when it came to barriers to screening and early detection. Fear was a prominent theme; fear that the procedure is painful and uncomfortable, and of being diagnosed with breast cancer. Another theme was physician and health system issues. For some survivors, coordination of care was lacking, especially once they were diagnosed. They felt that communication between doctors’ offices and specialists was sometimes absent. In terms of priority of mammograms, survivors felt that it was hard for women to get screened because they were concerned with other aspects of life such as work and their family.

Medical complications was another theme with survivors, primarily with the impact that breast cancer has on mental health and emotional well-being, especially during and after treatment.

Availability of support services

When it came to availability of support services, survivors said that they received education on breast health primarily from their doctors. They also mentioned CBOs as a source, specifically the Cancer Services Program as being integral to women in Allegany County when it came to financial assistance and education. Survivors felt very strongly about the education from other survivors, and have found that support to be very important in their breast cancer care. Overall, survivors felt strongly that education should start earlier, and that more young women need to be educated on knowing their bodies and what is normal. Overall, survivors felt there was a lack of awareness and education for women in this target area, especially when it comes to treatment and its side effects, and where women can go for emotional support.

“Somehow we have to get out the message that there is help and there is a starting point, and I think that is where we need to help, is to let women know what to do and what’s your starting point.”

Table 4.4 Comparison of themes across Allegany County

POPULATION OF INTEREST	THEMES						
	Fear	Knowledge	Health System Issues	Priority of Mammogram	Access to Services	Medical Complications	Culture
PCPs		x	x	x	x		
CCPs		x	x	x			x
CBOs	x	x	x	x	x		
Survivors	x	x	x	x	x	x	

Wyoming County

In Wyoming County, three key informant interviews were conducted. No focus groups were held in this county.

Primary Care Providers

Access to cancer care across the CoC

The primary care provider interviewed in Wyoming County had little to say concerning access to the CoC. Insurance was brought up and it was mentioned that those who are uninsured are referred to the health department for a free mammogram.

Barriers to screening and early detection

Several fears were discussed as barriers to being screened. Along with anxiety, the fear that the mammogram is painful or uncomfortable, and the fear of being diagnosed with breast cancer were also mentioned as barriers.

There were several physician and health system issues discussed as well, although mostly in terms of the primary care provider's role after diagnosis and in breast cancer survivor's follow-up care. The primary care provider was satisfied with their role, and with the coordination of care and communication between themselves and the specialists the patients go to.

Priority of mammograms seemed to be a major barrier according to this key informant. Lack of motivation and lack of time on the part of patients are important barriers to screening. However it was mentioned that many women do get screened because of encouragement from their primary care provider.

"The one I can think of, she says she had a terrible experience, and that she's decided that she's never going to go back again... there are some women that have had those experiences that don't want to go back."

"We just get back to the routine health maintenance...we encourage them to continue follow up with whatever their recommendations are with their specialist, whether it be the oncologist, the surgeon or both... we encourage regular follow up with them."

"A couple of patients who just refuse to do any further mammograms...They've made up their mind that they don't want to have them anymore...There's the women who just get busy with their schedules... they just, you know, don't schedule [mammograms]."

Availability of support services

The provider noted that many people received most of their educational information from their primary care physician. There is a general lack of education on the part of providers as to a cutoff date to stop mammograms. It was also mentioned that there is a lot of confusion surrounding screening guidelines.

"They're confused by the recent newer recommendations, and they weren't sure if they should go or not, between the 40-50 year old and then the older women if they should go every year or not, and so we usually clarify this at their office visits, and we recommend the annual mammogram screening."

Community Based Organizations

Access to cancer care across the CoC

There were many access issues noted by the two community based organizations informants in Wyoming County. Insurance, both under and uninsured, was of concern, and identified as a barrier to accessing screening or care in general. Transportation was another barrier to accessing cancer care due to the frequent visits and necessary travel. Tying in with the transportation issue is the lack of available services and the

inconvenient location of available services. These two were related, as more services available in the county would also improve the convenience. There is no support for survivors in Wyoming County.

“One of the largest requests is transportation assistance because gas is so expensive and they have to go so frequent”

“We have no cancer services in our vicinity. We have a surgeon that does excisional biopsies, but once they have been diagnosed they need to refer and they would have to go out of town.”

“The other thing there is a great need for is our cancer support groups for family members or survivors or clients positive with the disease, there is nothing for them.”

Barriers to screening and early detection

Fear was a major barrier noted by the informants from community based organizations. They mentioned fear of radiation from the mammogram procedure, fear that the mammogram is painful or uncomfortable, fear of being diagnosed with breast cancer, and general fear as well.

A woman’s priority of a mammogram was also noted. Time was a major factor noted by both of the community based organization informants. However the importance of being on an every year schedule and encouragement from the primary care provider was also mentioned as important to encouraging screening.

Availability of support services

The informants for the community based organizations felt that there was a lot of information available to women in Wyoming County. They noted that women could get educational information from their primary care physicians, hospitals, and other community based organizations, including the health department, the media and internet, programs during breast cancer awareness month and from other women or survivors. However the importance of improving provider education was also discussed.

“The wealth of coverage of promotion of breast cancer awareness month, around the month of October, might move someone to action who has not been screened timely.”

“We do try to make [providers] cognizant of reminding their female clients of the importance of being screened and helping them connect with screening resources if they need it.”

Table 4.5 Comparison of themes across Wyoming County

POPULATION OF INTEREST	THEMES						
	Fear	Knowledge	Health System Issues	Priority of Mammogram	Access to Services	Medical Complications	Culture
PCPs	x	x	x	x	x		
CBOs	x	x	x	x	x		

Comparisons across Target Communities Key Informants

In order to reflect the overall percentages of themes, key informants (CBOs, PCPs, CCPs) and focus group participants (40+ and survivors), were combined across each county for calculation. Percentages were calculated by dividing the number of key informants across an individual county by the total number of informants in that same county.

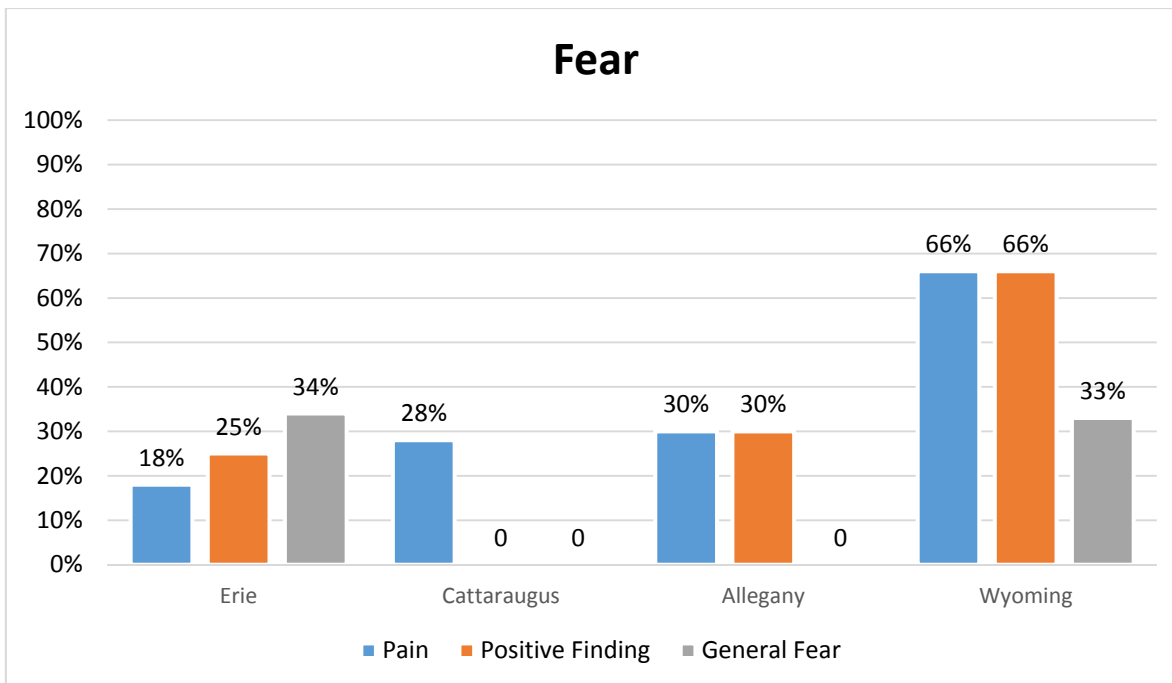


Figure 4.6 Key Informant Responses - Fear

In all target areas, fear has been identified as an issue, inhibiting many women from seeking breast health services. Overcoming the fears associated with a potential diagnosis is essential to encouraging women to enter the CoC.

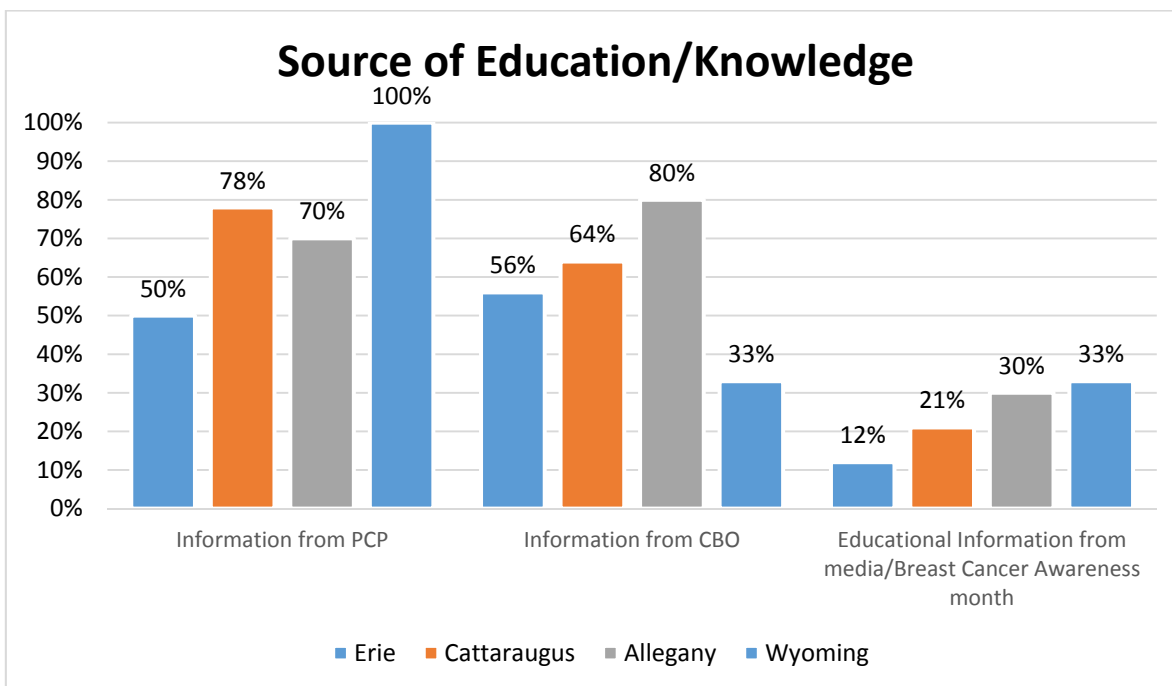


Figure 4.7 Key Informant Responses – Education/Knowledge

Many women in the rural communities of Cattaraugus, Allegany, and Wyoming Counties, as well as within the City of Buffalo receive breast health information primarily from their primary care physician. Other sources of information include a variety of community based organizations, and media sources.

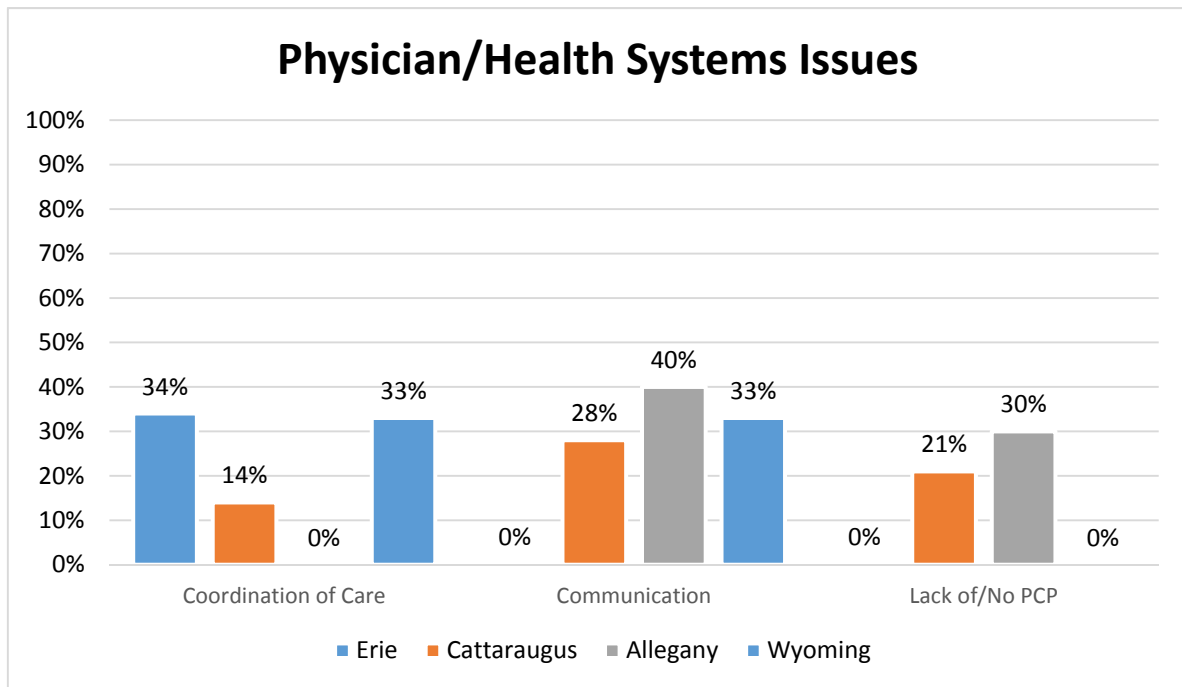


Figure 4.8 Key Informant Responses – Physician/Health Systems Issues

Coordination of care was a substantial barrier to the breast health CoC in all counties, although the percentage for Allegany was so small it is not shown. Communication deficits and a lack of PCP were largely mentioned among informants in Allegany and Cattaraugus counties.

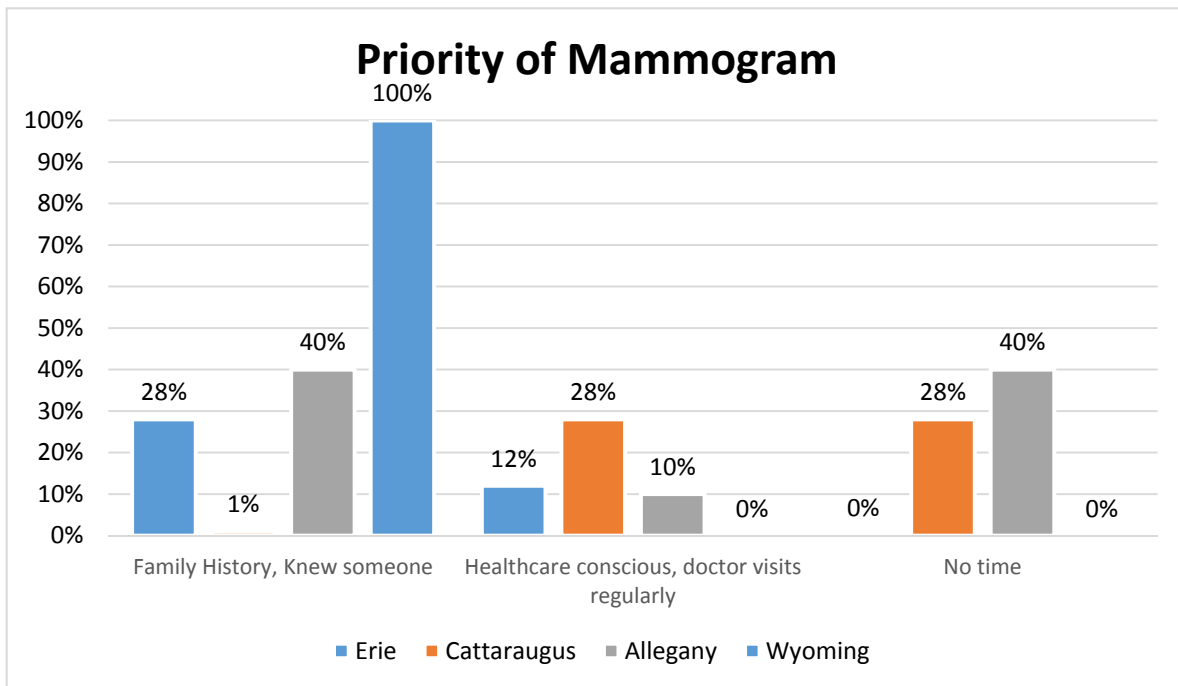


Figure 4.9 Key Informant Responses – Priority of Mammogram

Family history or knowing someone was a strong motivator for women to seek breast screening services in Erie, Allegany, and Wyoming Counties. Also, if a woman is more health conscious and visits her doctor regularly, she is more likely to seek screening in those counties as well. A lack of time was indicated in Cattaraugus and Wyoming as a factor as to why women may not seek screening. Busy schedules either with work or family and other life priorities make scheduling mammograms challenging.

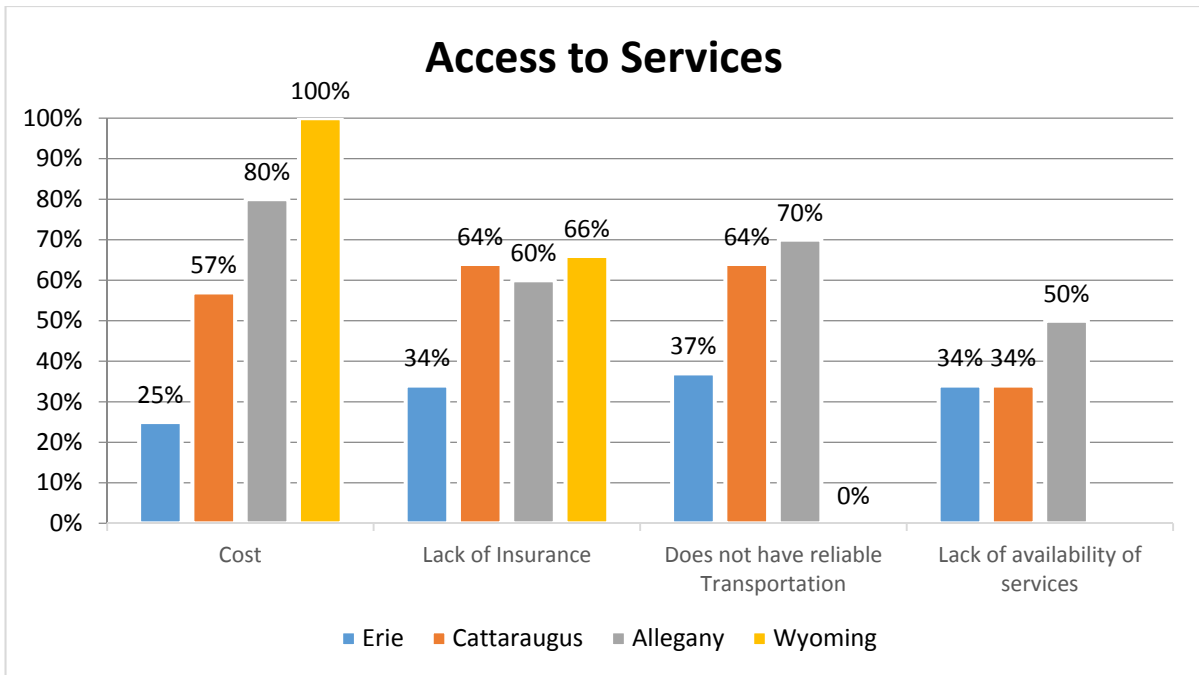


Figure 4.10 Key Informant Responses – Access to Services

In all target areas cost and insurance status were acknowledged as main concerns inhibiting women from accessing services. The cost of co-pays or potential out of pocket costs for the uninsured and underinsured can deter women from accessing services. Transportation and availability of services were also mentioned as major factors preventing women from accessing services.

Comparisons across Target Communities Focus Groups

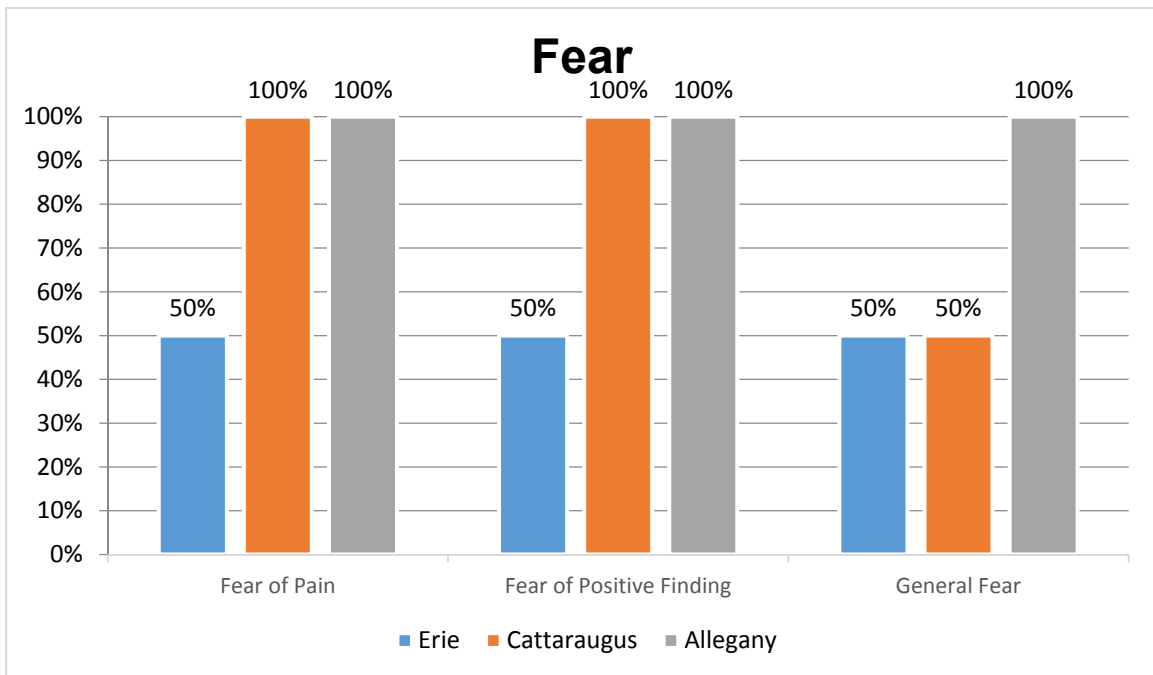


Figure 4.12 Key Informant Responses - Fear

In all target areas women that participated in focus groups mentioned fear as a leading factor preventing women from seek breast health services. Women may have experiences painful mammograms in the past and are hesitant to go again or have hurt that mammograms are painful. Women are fearful of “finding something” or be diagnosed with breast cancer. A general fear surrounding breast health or of the exam itself was a prevalent sentiment among the focus groups.

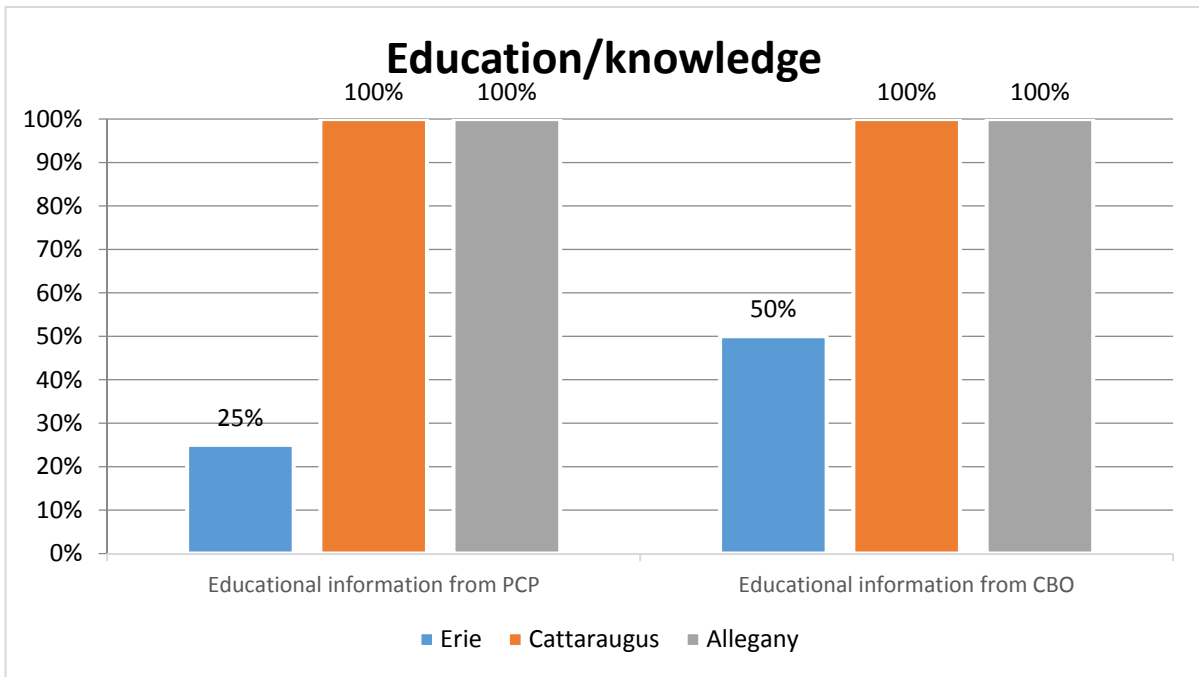


Figure 4.13 Key Informant Responses – Education/Knowledge

In all target areas women received their breast health educational information either from their primary care doctor or a community based organization in their area, with CBOs identified more often.

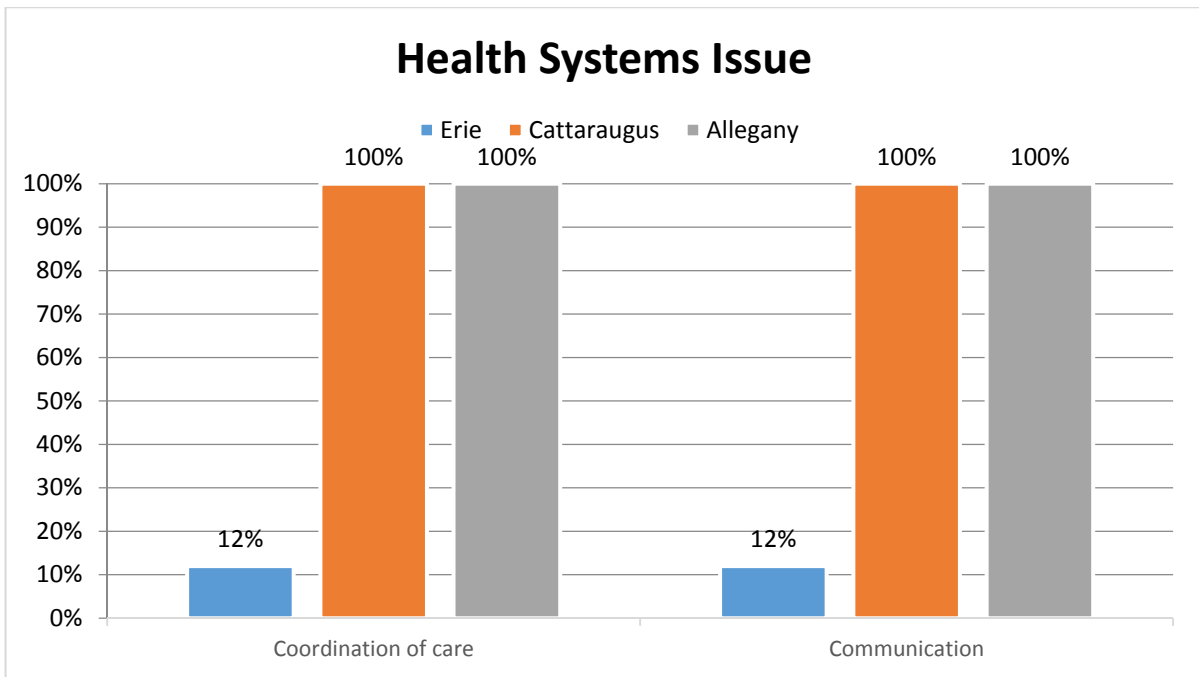


Figure 4.14 Key Informant Responses – Health Systems Issue

An improvement in communication and coordination of care among the health system is necessary. Many women indicated that having a good rapport with the doctor is imperative to their care. Participants across all counties mentioned that if she did not feel comfortable or felt that the physician was not empathic to her situation, changing doctors was her prerogative.

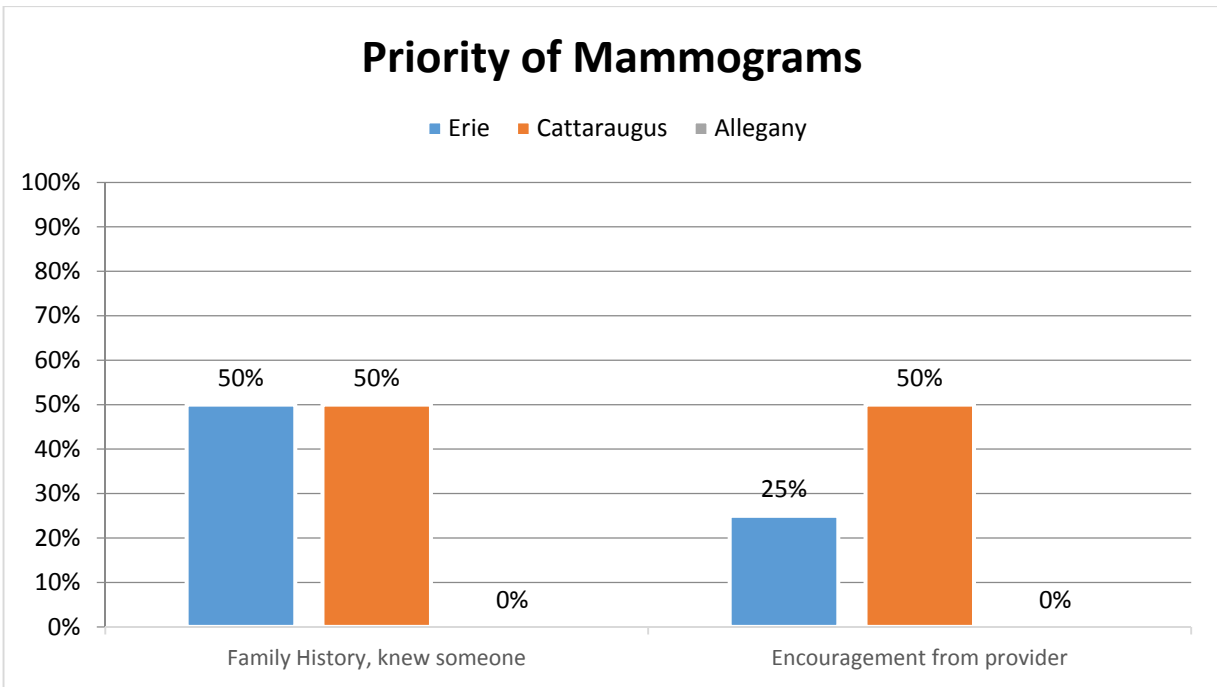


Figure 4.15 Key Informant Responses – Priority to Mammograms

Knowing someone personally or having a family history of breast cancer encouraged women to seek breast health services. Encouragement from their provider was also a strong motivator.

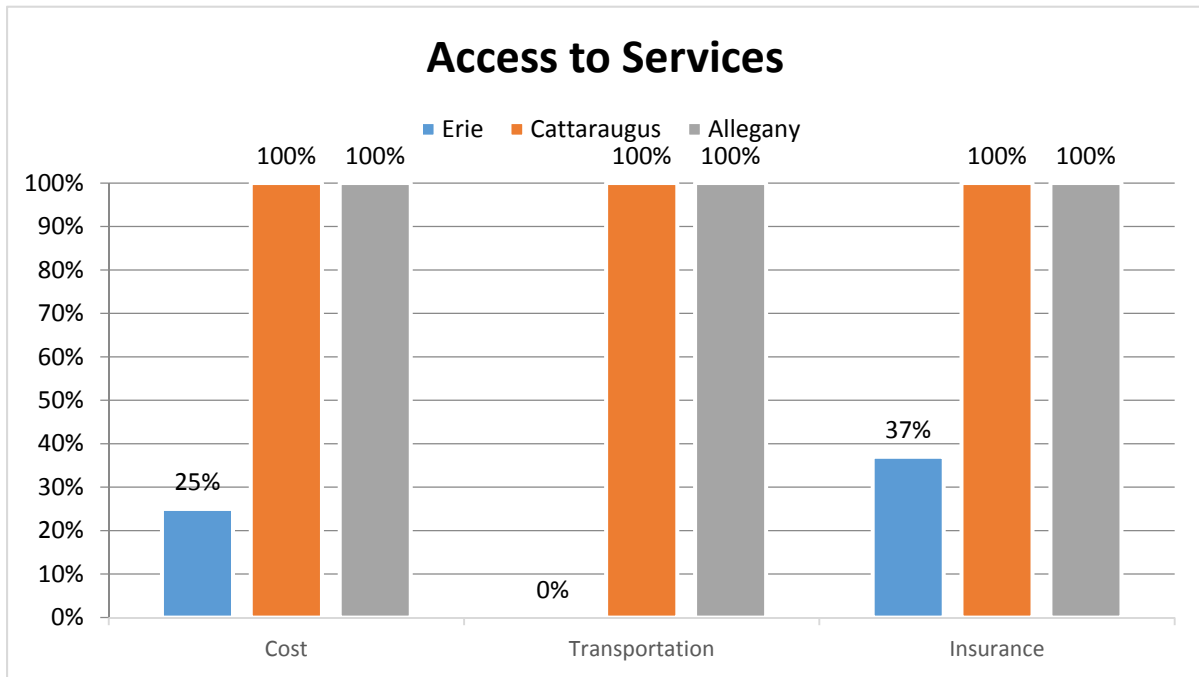


Figure 4.16 Key Informant Responses – Access to Services

In all target areas cost and insurance status influenced access to services. Women were concerned with cost of services and co-pays. Transportation costs and the reliability of transportation were factors as well. For the rural communities, the price of gas and frequency of travel for treatments was a concern. Public transportation was not always a reliable alternative for many women.

Qualitative Data Findings

Limitations of the Qualitative Data

Strengths

Despite the small sample sizes in interviews and focus groups completed, participants were knowledgeable people who were familiar with the health landscape in the area, and provided great insight. To allow for a comparison of differing perspectives and experiences regarding the breast cancer CoC for women in each county, the Affiliate utilized key informant interviews and focus groups as the primary data collection methods.

The Affiliate was cognizant of the unique demographic makeup of the target communities and made every effort to reach out to all populations. The City of Buffalo, located in Erie County, has a large population of low-income African American and Latinas, as well as a growing community of refugees from over 70 different countries. Cattaraugus and Allegany counties are home to members of the Seneca Nation of Indians (SNI), and some of the largest Amish settlements in New York State. The Affiliate was able to elicit some perspective from key informants on refugees, Latinas, the Amish, and Native American populations.

In an attempt to gain diverse input, informants were purposefully sampled based on type of service they provide and the location of their practice. Cattaraugus and Allegany Counties often share resources and women may travel between counties to access services. Some providers and community based organizations were able to provide insight into both counties. The Affiliate recognized the importance of primary care providers in screening mammography. Primary care providers are often the initial points of contact for patients who exhibit symptoms related to breast cancer. Their role in helping women navigate the health care system and follow up with patients who have been diagnosed is integral in ensuring successful navigation of the breast cancer CoC. Informants from community based organizations provided first-hand knowledge about the community and its residents, as well as the impact that breast cancer has had on the individuals the organization serves. These organizations were essential in providing up-to date and relevant breast health education and support services, as well as facilitating navigation through the cancer care continuum.

The Affiliate wanted to assess the views of women without breast cancer to evaluate barriers they may face in accessing care, particularly in regards to early detection. Additionally, the Affiliate wanted to assess the experiences of survivors, specifically the challenges they faced throughout the cancer care continuum. In doing so the Affiliate was able to recruit women 40 years of age and older and breast cancer survivors from three counties, one urban and two rural. Focus group participant's demographics varied across counties allowing for effective comparisons.

The qualitative analysis confirmed findings of the quantitative and health systems analysis and offered contextual content for these findings. Major gaps in access to breast health services exist across all counties and are documented across target groups.

Weaknesses

The Community Profile Team faced some challenges with recruitment for focus groups in Erie County. A combination of complications such as poor response rates and lack of community support resulted in smaller sample sizes. Many attempts were made to schedule women and survivors for focus groups. However, despite agreement for participation and reminder phone calls, many women did not show up for the groups. Approximately 83 women 40+ and 20 survivors were recruited for participation in Erie County. In addition recommendations and recruitment from PCPs and CBOs were utilized. Additionally, the Profile Team was unable to interview 12 cancer care informants. Many cancer treatments specialists were very busy taking care of patients in need and declined to participate in an interview due to time constraints. Others did not respond to outreach attempts from the Team.

The Team encountered some difficulties with recruitment for focus groups for women 40 and over and survivors in Cattaraugus and Allegany Counties. These areas are particularly rural and it can be difficult for women to travel great distances. The Team reached out to Cancer Services Program and the Health

Department in these counties as well as recommendations from CBOs and PCPs to assist with recruitment. The small amount of focus groups can be attributed to several obstacles in recruitment such as poor response rates, a small county population, and few community supports in the area. In addition, there is only one cancer treatment center in the area. There are few community based organizations as well. Though few primary care practices exist in the region, the Affiliate attempted to reach out to the majority of practices. However, there were very little responses to outreach attempts.

The Team was unable to complete any focus groups in Wyoming County due to poor response rates, a small county population, and few community supports in the area. Wyoming County shares many resources and services with adjacent Livingston County that is currently out of the Komen WNY's target area. Identifying primary care providers within the boundaries of Wyoming County proved challenging. Few screening options exist in Wyoming County with no cancer treatment options at all. The county has limited community based organizations or support resources. Though few primary care practices exist in the region, the Affiliate attempted to reach out to the majority of practices. However, there were very little responses to outreach attempts.

Erie

Erie County is comprised largely of the city of Buffalo and surrounding suburbs. Erie County represents the most diverse population in the Affiliate service area. The quantitative report indicated that African American women face higher death rates from breast cancer when compared to other races. Social and economic barriers to breast cancer screening and treatment are higher for residents of Erie, making access to resources incredibly challenging for many residents.

In order to best understand what interventions might help to improve the trends in death rates and late stage diagnoses, the health systems analysis section of this report identified the types of breast cancer services available and to what communities. Of all the counties in this service area, Erie County hosts the largest number of options for screening and treatment. Although many resources and support services are available to women in Erie County, fewer mammography facilities exist in the city of Buffalo. Multiple mammography sites have moved from the City of Buffalo to surrounding suburbs.

The increase in relocation of screening sites has created a barrier to accessible screening and treatment options as public transit may not always reach these areas and many women lack personal transportation. This section of the report aimed to investigate this trend in addition to the many other factors that contribute to the breast cancer burden in Erie County. From the quantitative report, the Affiliate examined diverse and varied services that are available to help combat the social and cultural barriers that prevent many minority women from seeking or successfully accessing breast cancer services. The health systems analysis identified many agencies and organizations serving minority and underserved women in the city of Buffalo. Community based organizations were identified based on their awareness about the community, as well as the impact that breast cancer has had on the individuals the organizations serves. These organizations provided a critical role in facilitating navigation through the cancer care continuum, providing education about cancer risk reduction, screening and treatment, and offering support for those with a diagnosis. Striving to gain diverse input, providers were purposefully sampled based on type of service they provide and the location of their practice. Primary care providers and cancer care providers were included as well to reflect the findings from the health systems analysis that provided any type of direct clinical care to women in Erie County.

A mobile mammography unit has been present in the community for two years. The health systems analysis researched what populations and neighborhoods the unit reaches, driving the direction of the qualitative section. The unit reaches African American and Latina women in Erie County. Many informants indicated the success and value of utilizing such a resource in the community. Additionally, organizations using the unit provide peer support and education materials available for underserved communities. Cancer Services Program of Erie County is instrumental in engaging uninsured and underinsured women in cancer screening, follow-up and treatment. The presence of CSP and its services are still relatively unknown to women in Erie County. The qualitative section suggested that promotion efforts emphasizing the benefits of using the program

may need to be increased, particularly in doctor's offices. Patients and providers alike were aware of the breakdown in the continuum of cancer care.

The Affiliate concludes that increasing access to navigation at the screening level is imperative to engage women in the CoC. Many women in underserved communities have limited access to technology and cannot navigate the complex health system. The mobile mammography unit and its partners are some of the strongest partnerships the Affiliate collaborates with in the area, especially in underserved communities. It is important for the Affiliate to continue to fund programs to address barriers due to knowledge, access and availability. Furthermore, maintaining existing partnerships as well as building new relationships in the future.

Cattaraugus and Allegany

Cattaraugus and Allegany counties are located in the Southern Tier of Western New York and are defined as rural and medically underserved. The two counties share similar demographics, frequently collaborating in delivering services such as a combined New York State Cancer Services Programs. The health systems analysis investigated the availability of breast cancer services and programming in Cattaraugus and Allegany Counties. Two large healthcare systems were identified as available to women in both counties. In terms of treatment, there are few options; only one organization in Cattaraugus County, located in Olean, offers chemotherapy treatment. Two hospitals in Allegany County offer screening mammograms. Other community based organizations are present, and great resources to the communities. Organizations that provide education and support programs include the Health Department and the Breast and Cervical Health Partnership. The Affiliate successfully reached out to several community based organizations in the region. The informants were knowledgeable about the community and its residents, as well as the impact that breast cancer has had on the individuals the organization serves. The quantitative report recognized Cattaraugus County as having the second largest percentage of Native Americans in New York State as well as a significant Amish population. Two informants shared valuable insight on both populations and their access to the breast cancer CoC. Although few primary care and cancer care treatment centers are present in either county, the Affiliate successfully reached out to a number of institutions identified in the health systems analysis.

In rural areas such as these, the distance between breast cancer screening and treatment providers is a major barrier, often compounded by financial limitations faced by low-income residents. Transportation gaps continue to pose an issue for women in these counties seeking access to services, a major contributor to the lack of screening in these areas. Women seeking services must travel great distances to surrounding cities to access care. No standard mass transit exists in these counties. This is a concern across the CoC from screening through to treatment and supportive care. Due to the limitation of availability, many patients are referred to hospitals or larger organizations outside of the target area to receive screening and/or diagnostic follow-up. Recently, Cattaraugus County began utilizing a mobile mammography unit. The presence of the unit should address transportation, financial, and availability barriers that currently prevent many women from accessing breast health services in both Allegany and Cattaraugus County. Moreover, patient navigation and survivorship services are a valuable resource for women transitioning through the CoC. Patient navigation services are severely lacking in Cattaraugus County, along with support and survivorship services.

The Affiliate concludes that building a relationship with the Seneca Nation and Amish communities in Cattaraugus County is essential to encourage breast healthcare. Continuing to provide funding and support to programs such a mobile mammography unit alleviates some of the barriers women face in Allegany and Cattaraugus counties. Promoting patient navigation, support groups, and survivorship efforts in the counties is vital.

Wyoming

The quantitative data section indicated the socioeconomic characteristics of the region were potential concerns regarding women's access to breast health care. Just over 31 percent of residents fall below 250 percent of the

poverty line. The county was defined as rural and medically underserved, indicating that both income and physical distance from screening and treatment locations were barriers to breast health services for the women of Wyoming County.

The health systems analysis component took a deeper look at the available breast health services in Wyoming. There were two primary health care systems in the region, one of which provided screening mammography. The Affiliate conducted a key informant interview with a provider from the institution that provided breast screening services. Cancer Services Program has a large presence in Wyoming County, assisting women with financial and transportation barriers to care. The Affiliate was able to reach out to the program coordinator of CSP as well as the public health administrator of the Health Department. Due to the region's rural nature and designation as medically underserved, it was vital to gain a clear understanding of how breast health services are currently accessed in the region.

Wyoming County has very few screening options and no cancer treatment options at all. Increased cancer services such as treatment centers, navigation, survivorship resources, and support groups are vital to ensuring women successfully enter the breast cancer CoC. Cost and transportation continue to be a barrier for women in Wyoming County. Services are either inaccessible due to location or do not exist in the county.

Based on the analysis of what is currently available for women to access screening for early detection, and for treatment, the Affiliate concludes that continuing to interface with the county to develop relationships among primary care practices and key partners. Marketing Community and Small Grant Programs to support programming and services that encourage education, awareness, screening and treatment for this target area is essential to address the barriers of access to the breast cancer CoC.

Mission Action Plan

Breast Health and Breast Cancer Findings of the Target Communities

Quantitative data from the national office of Susan G. Komen, and data obtained through a direct request from the New York State Cancer Registry, were reviewed to identify service gaps and areas of need in Western New York. Komen Western New York's service area is comprised of eight counties: Allegany, Cattaraugus, Chautauqua, Erie, Niagara, Genesee, Orleans, and Wyoming. Data on death rates from breast cancer and late stage diagnoses were used to help determine target communities with the most need within the Western New York service area. The overall need is based on the time it will take a particular area to meet Healthy People (HP) 2020 targets for breast cancer.

Communities with high rates of late stage diagnoses, below average screening rates, high rates of residents living below poverty level, and high rates of residents living without health insurance were selected as target areas.

Of the eight counties in the Affiliate's service area, four target communities were selected:

- Erie County
- Cattaraugus County
- Allegany County
- Wyoming County

The Affiliate's objective is to reduce breast cancer death rates and late stage diagnoses in the service area.

Erie County has been identified as a high priority county due to the amount of intervention time needed to achieve the HP2020 targets. Erie County includes the city of Buffalo and is the largest and most diverse county in the service area. In general, the minority population in Erie County is higher than the rest of the service area, with 14.8 percent Black/African-American residents and 4.6 percent Hispanic/Latina residents. The quantitative report indicated that African-American women face higher death rates from breast cancer compared to other races. African American and Hispanic/Latina women are significantly less likely to be diagnosed at an earlier stage than White women.

Cattaraugus County is classified as a rural and medically underserved area, with 93.9 percent of the total female population comprised of White women and 38.9 percent of the county residents falling below 250 percent of the poverty line. There are also large Native American and Amish populations located in the county. Cattaraugus County falls into the medium priority guidelines for HP 2020 objectives.

Allegany County's population and geographic demographics are comparable to neighboring Cattaraugus County, with 39 percent of county residents falling below 250 percent of the poverty line, and 49.5 percent of the total female population over the age of 40. Due to the similarities and geographic proximity between the two counties, they often collaborate in delivering services. Allegany County falls into the medium-high priority area for HP 2020.

Wyoming County is the least populated county in the service area, with a majority of the county's female population being White and over the age of 40. Over 31 percent of county residents fall below 250 percent of the poverty line. Wyoming County is unlikely to achieve HP2020 objectives for breast cancer. Several factors contribute to this estimation, with economic and barriers to accessing breast health services among the greatest obstacles.

Health Systems Analysis

The Health Systems and Public Policy Analysis conducted in these four communities indicated a lack of access to cancer care providers and breast health services across the continuum of cancer care in rural communities in Cattaraugus, Allegany and Wyoming, and the urban communities in Erie County.

Support for individuals and navigation through the complex healthcare system is also lacking, particularly for screening and pre-diagnosis. The lack of awareness of community resources (where they exist) is a challenge for women, and also for primary care and cancer care providers.

The largest number of screening and treatment options available to women accessing the continuum of care was in Erie County. Many organizations in Erie County provide a variety of educational and support services to residents, particularly serving underserved communities. Erie County also has the most options for cancer care services of the target areas.

Despite the many resources available, fewer mammography facilities exist inside the city of Buffalo, but instead are located in surrounding suburbs, making access to them difficult for women living in the city.

In Cattaraugus County, there are limited breast health resources. Community-based organizations play a vital role in offering breast health support to women, with most of the education being provided by the two large healthcare systems. However, few cancer care treatment options are available to women in Cattaraugus County. Only one organization, located in Olean, offers chemotherapy treatment.

Allegany County shares many resources and services with neighboring Cattaraugus County. The same two healthcare systems serving Cattaraugus County residents also serve Allegany County residents. Treatment options are even more limited to women living in Allegany County, and they often travel great distances to neighboring counties in order to access treatment services.

Wyoming County severely lacks breast cancer screening, treatment, and support services. Only one location in the county offers mammograms. Currently, no treatment centers exist in Wyoming County. Due to Wyoming County's rural geography, residents must travel substantial distances outside of Wyoming to adjacent counties in order to access screening and treatment care.

This analysis also looked at the public policies that affect progress through the Continuum of Care. The New York State Cancer Services Program (CSP) offers education, screening, diagnostics, case management and treatment assistance for breast, cervical and colorectal cancers. It currently has a presence in every county in the Affiliate's area, and is an asset to under and uninsured women age 40 and over, and those under 40 who are at high risk for breast cancer, as well as those who receive a diagnosis.

NYS Medicaid covers mammography and medically necessary radiology services for those eligible. The New York State Comprehensive Cancer Control Plan 2012-2017 was also created by the NYS Cancer Consortium (NYSCC), as a guide to identify and address the cancer burden in NYS. The plan has identified several priority areas including: health promotion and cancer risk reduction, early detection, treatment, survivorship, palliative care, and the health care workforce. The health systems analysis component took a deeper look at the available breast health services in the service area, and the relative NYS public policies. Leading to multiple questions:

- How do these system and policy barriers contribute to late stage diagnosis?
- Do the system and policy barriers present the same way in each target community?
- What is the interplay of culture, knowledge and social determinants of health that compound access issues?

Qualitative Data

The qualitative analysis highlighted the challenges within the cancer care continuum for underserved women and stressed a need for education in a cultural context that addresses access to care, barriers to screening, and availability of services in hopes of making an impact on breast cancer deaths. The Affiliate gauged perspectives of primary care providers, cancer care providers, and community based organizations, using key informant interviews and focus groups. Furthermore, breast cancer survivors and women 40 years and older that are eligible for mammograms contributed to the findings through focus groups.

Major barriers to breast screening existed in each target area, which could decrease opportunities for early detection. Similar and recurring barriers were noted across the counties. Financial and transportation barriers were consistent issues that women face in accessing quality breast health services. Cost and insurance status were identified as main concerns inhibiting women from accessing services. The cost of co-pays or potential out of pocket costs for uninsured and underinsured women can deter them from accessing services. A lack of available breast health services further prevented women from accessing services. Inconvenient locations required women to travel great distances to screening and treatment sites, leaving women often unable to afford the cost of travel. Public transportation was not always a reliable alternative for many women in the rural areas.

In all target areas, fear was a prevalent deterrent for many women from seeking services. Women were fearful of the mammogram procedure itself, having endured painful experiences in the past, and were afraid of the potential for positive findings.

A lack of appropriate breast health knowledge inhibits many women in the target communities from recognizing the importance of breast screening and early detection. Several sources, including primary care physicians, community based organizations, and media outlets, provided a variety of breast health education to residents. Increasing availability and access to breast health education can aid in reducing fears and improve breast screening rates.

The data generated from the qualitative section led to several questions that the Affiliate aims to address in the Mission Action Plan:

- How can the Affiliate assist in the education of women and their providers?
- How can the Affiliate aid in reducing the transportation and financial barriers rampant in the target communities that prevent many women from seeking and accessing quality breast health care?
- How can the Affiliate increase screening and early detection rates in the target communities?
- In what ways can the Affiliate assist in generating greater resources and support services to women in the target communities?

Data obtained through the Quantitative Report and Qualitative assessment shows that underserved women in Erie County, especially African-American and Latino populations, are significantly less likely to be diagnosed at an early stage of breast cancer.

Priority 1: Decrease disparities in breast care services and increase the number of minority women screened annually, aiming for early detection and increasing availability of support services within Erie County by 2019.

Objective 1: In Fiscal Year (FY) 2016-17, make Request for Application (RFA) aiming to alleviate transportation barriers to breast health services, particularly to breast screenings, a funding priority.

Objective 2: By 2019, collaborate with other local cancer-focused agencies and the state health department in developing initiatives toward educating underserved populations in Erie County about breast health.

Objective 3: By 2019, identify, collaborate with, and support at least three community-based organizations experienced in combating the social and cultural barriers that prevent many underserved (i.e. African American, Hispanic/Latina, refugee) women in Erie County from seeking or successfully accessing breast cancer services.

Erie County, continued

Priority 2: *Promote peer support and patient navigation to increase awareness of the importance of breast health and screening through increased education, community outreach, and social support in Erie County by 2019.*

Objective 1: Beginning in FY 2016-17, promote grant proposals in Erie County through Komen Western New York's website, emails, social media, other community outreach and fundraising events, aiming to support patient navigation programs providing breast health guidance to women at the screening level, treatment options, and offering support for those with a diagnosis.

Objective 2: By 2019, identify and collaborate with four community-based and/or faith based organizations in the underserved areas of the city of Buffalo in Erie County to disseminate Komen-produced breast health information to the local community. The goal will be to reduce fear associated with the mammogram procedure, encourage women to seek regular screening, and understand resources that are available.

Objective 3: By 2019, collaborate with two community-based and/or health organizations and local media and marketing personnel in Erie County to educate the community about Komen Western New York's presence and activities, and assist in the dissemination of Komen supported breast health education.

Cattaraugus County

Key informant interviews and focus groups conducted in Cattaraugus County revealed that women in Cattaraugus County have limited access to affordable and convenient breast health services, particularly screening and treatment options.

Priority 1: *By 2019, increase the number of women screened annually by improving access to breast health services in medically underserved areas of Cattaraugus County.*

Objective 1: By 2019 increase marketing in Cattaraugus County through Komen WNY's website, emails, social media, other community outreach and fundraising events, aiming to encourage organizations in Cattaraugus County to submit grant proposals that aim to reduce transportation and financial barriers and improve access to breast health services.

Objective 2: By 2019, partner with at least two health organizations to understand needs and provide resources for diagnosed breast cancer patients in Cattaraugus County and work with caregivers in rural areas to ensure support.

Cattaraugus County, continued

Priority 2: *Promote peer support and patient navigation in Cattaraugus County to increase the awareness of the importance of breast health and screening through increased education, community outreach, and social support by 2019.*

Objective 1: By 2019, promote Community and Small Grant applications in Cattaraugus County, targeting primary care practices, community-based organizations, and health organizations with an emphasis on improving patient navigation, support groups, and/or survivorship efforts.

Objective 2: By 2019, collaborate with at least two community-based organizations and/or healthcare institutions (one that works with Seneca Nation of Indians and one that works with Amish settlements) to provide culturally appropriate breast health care and outreach efforts in Cattaraugus County.

Objective 3: By 2019, implement a public relations/marketing campaign in Cattaraugus County around Komen-sponsored education and outreach regarding screenings and resources available for breast cancer patients and survivors.

Allegany County

Analysis of the Qualitative Data shows that distance to breast cancer screening and treatment services is a major barrier, impeding access to care for women in Allegany County

Priority 1: Increase the number of women screened annually by improving access to breast health services among women in medically underserved areas of Allegany County, by 2019.

Objective 1: Beginning in FY 2016-17, encourage community-based and/or health organizations in Allegany County to submit grant proposals to increase programs that aim to reduce transportation and financial barriers and improve access to breast health services (i.e. gas cards, taxi fee coverage, etc.)

Objective 2: By 2019, partner with at least two primary care, OB/GYN, and/or health clinics to discuss potential collaboration efforts aiming to alleviate barriers to care in rural areas of Allegany County.

Allegheny County, continued

Priority 2: By 2019, promote peer support and patient navigation to increase the awareness of the importance of breast health and screening through increased education, community outreach, and social support in Allegheny County.

Objective 1: Beginning with 2016-17 RFA, make grant applications targeting programs with an emphasis on patient navigation, support groups, and/or survivorship efforts in Allegheny County a funding priority.

Objective 2: By 2019, partner with Allegheny County health organizations and local media and marketing personnel to educate the community about Komen Western New York's presence and activities, and assist in the dissemination of Komen-supported breast health education.

Wyoming County

The Health Systems Analysis and Qualitative Data assessments shows that Wyoming County severely lacks breast cancer screening, treatment, and support services creating major barriers to access for women in this rural, medically underserved region.

Priority 1: Increase the number of women screened annually by improving access to breast health services among women in rural, medically underserved areas of Wyoming County by decreasing barriers to screening and early detection and increasing availability of support services, by 2019.

Objective 1: Beginning with 2016-17 RFA, make grant applications targeting programs with an emphasis on patient navigation, support groups, and/or survivorship efforts in Wyoming County a funding priority.

Objective 2: By 2019, partner with at least two Wyoming County organizations for collaboration efforts in education of area residents and providers regarding Komen breast health standards and services.

Objective 3: Beginning in FY 2016-17 RFA, identify and target community-based and/or health organizations to submit grant proposals to increase programs reducing transportation and financial barriers and improving access to breast health services in Wyoming County.

Wyoming County, continued

Priority 2: *Promote peer support and patient navigation in Wyoming County to increase the awareness of the importance of breast health and screening through increased education, community outreach, and social support.*

Objective 1: By 2019, offer two grant writing workshops promoting the Community and Small Grants programs targeting providers and community-based organizations in Wyoming County in order to provide patient navigation, support groups, and/or survivorship efforts.

Objective 2: By 2019, develop new partnerships with two primary care and/or OB/GYN providers serving primarily low-income women in Wyoming County to provide patient navigation programs to their patients, encourage breast healthcare support and disseminate current Komen supported breast health education and materials.

Objective 3: By 2019, collaborate with one local healthcare institution and local media and marketing personnel in Wyoming County to educate the community about Komen Western New York's presence and activities, and assist in the dissemination of Komen supported breast health education.

Komen Western New York

Quantitative Data shows that many women in the target areas of Komen Western New York are not meeting screening guidelines, and are not set up to meet Healthy People 2020 objectives in the next 10 years.

Priority 1: By 2019, develop new partnerships to advance the Affiliate's mission.

Objective 1: By 2019, develop a partnership with the New York State Cancer Consortium (NYSCC) and formally join the Cancer Consortium to align with statewide initiatives.

Objective 2: By 2019, align the Affiliate's Mission Action Plan with the New York State Comprehensive Control Plan, particularly in regards to measuring the Affiliate's work in helping to improve breast health care.

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