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COMMUNITY PROFILE REPORT 2015

SUSAN G. KOMEN®
NORTHEAST OHIO

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Executive Summary

Introduction to the Community Profile Report

Susan G. Komen® Northeast Ohio was initiated in 1994 by the Junior League of Cleveland as part of its Breast Health Task Force. Since its inception, Komen Northeast Ohio has grown from a grassroots movement to a sophisticated organization that has made a remarkable impact in the community. Komen Northeast Ohio serves 22 counties: Ashland, Ashtabula, Belmont, Carroll, Columbiana, Coshocton, Cuyahoga, Geauga, Harrison, Holmes, Jefferson, Lake, Lorain, Mahoning, Medina, Portage, Richland, Stark, Summit, Trumbull, Tuscarawas, and Wayne. The Northeast Ohio service area is highly diverse and contains several major cities and many small rural towns. Geographic differences in the Affiliate service area reflect differences in race, ethnicity, socio-economics, and education level for the populations that inhabit these areas. Those who live in urban and rural areas tend to have lower incomes, higher levels of unemployment, and lower education levels than those who live in suburban areas. Rural and suburban areas also tend to have less racial and ethnic diversity than urban areas.

Komen Northeast Ohio currently works on two fronts to address local disparities in breast health and breast cancer: targeted internal education and advocacy initiatives and focused external grantmaking efforts. Komen Northeast Ohio's efforts are focused on population-based, systems level interventions. This includes targeting internal programming and grant funded services to the population as a whole, not just individuals who actively seek breast health services, by educating health care providers, leveraging community resources, and creating synergy among stakeholders. Komen Northeast Ohio's staff carefully manages grants to ensure funds are applied effectively and leveraged for maximum impact. In 2014, investment in local evidence-based breast health programs allowed Komen Northeast Ohio to educate over 10,000 individuals and provide more than 4,000 mammograms to those most in need in the Northeast Ohio community. Since 1994, Komen Northeast Ohio has provided nearly $15 million in community grants to Northeast Ohio agencies working to end breast cancer disparities in the Northeast Ohio service area. Komen Northeast Ohio also works actively within community-based committees, associations, and alliances.

A vital first step in fulfilling the promise to end breast cancer forever is to understand the state of breast health and breast cancer in the communities served by the Affiliate. To accomplish this, Komen Northeast Ohio conducts a comprehensive breast health needs assessment at the local level every four years. The needs assessment process helps shed light on why the statistics are the way they are. This information aids in the development of targeted priorities and strategic objectives on how to help bridge the identified gaps in breast health services, known as the Affiliate's Mission Action Plan (MAP). The MAP helps determine the focus of the Affiliate's strategic planning and grantmaking efforts and drives the overall work of the Affiliate. The report strives to make sure local programs supported by Komen Northeast Ohio target the people and areas most in need, ensures they are non-duplicative, and assures they address existing disparities through the application of evidence-based programs appropriate for the target populations. Finally, a quality Community Profile allows the organization to:

- Identify ways to fill gaps through partnerships and additional granting opportunities.
- Establish focused education and outreach efforts to address the community need.

- Drive public policy efforts.
- Establish marketing and communication direction.
- Increase inclusion efforts in the breast cancer community.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Statistical data provided to Komen Northeast Ohio by Komen Headquarters through the Quantitative Data Report (QDR) reveals the Komen Northeast Ohio (NEO) service area experiences a disproportionate burden of breast cancer compared to the other three Ohio Komen Affiliates (Table 1). In an effort to streamline resources, Komen NEO chose five target communities, known as "communities of interest" (COI), within the 22-county service area to do additional investigation. The COI's will help Komen NEO determine why breast cancer statistics are so much poorer in NEO than the rest of the state. The five areas identified as highest priority in the Komen NEO service area are: Ashtabula County, Harrison and Jefferson Counties, Lorain County, Mahoning County, and Cuyahoga County. All of these areas were determined to need 13 years or longer to achieve the Healthy People (HP) 2020 death rate of 20.6 (per 100,000) and late-stage incidence rate of 41.0 (per 100,000), with the exception of Harrison County which had too few numbers to predict death rate trends. In order to stabilize the rates for Harrison County, Komen NEO elected to combine Harrison and Jefferson Counties into one COI, as these counties have very similar demographics and breast cancer statistics, and they are geographically contiguous. Key breast cancer statistics and demographics for each COI can be found in Table 2.

Table 1. Number of new breast cancer cases and deaths by Ohio Komen service areas

Population Group	Female Population	Incidence		Late-Stage Incidence		Deaths	
		# of New Cases	Percent of Total Cases	# of New Cases	Percent of Total Cases	# of Deaths	Percent of Total Deaths
US	154,540,194	198,602		70,218		40,736	
Ohio	5,895,383	8,319	4%	2,972	4%	1,820	4%
Komen NEO	2,309,143	3,470	41.7%	1,213	40.8%	771	42.4%
Komen Columbus	1,442,796	1,895	23%	689	23%	412	23%
Komen Greater Cincinnati	1,581,596	2,179	26%	774	26%	452	25%
Komen NWO	872,335	1,159	14%	432	15%	262	14%

Table 2. Select key indicators for Communities of Interest

Geographic Area	Total Female Population	Females Age 40+	Non-White	Uninsured (40-64)	No Mammography	Incidence Rates	Late-Stage Diagnosis Rates	Death Rates
US	154,540,194	48.3%	21.2%	16.6%	22.5%	122.1	43.7	22.6
Ohio	5,895,383	50.5%	15.8%	14.0%	23.0%	120.8	44.0	24.8
Komen NEO	2,309,143	53.2%	17.0%	14.4%	22.4%	120.6	43.3	24.8
Ashtabula	51,211	53.4%	4.3%	15.8%	20.4%	111.8	43.0	25.7
Cuyahoga	680,385	52.6%	35.2%	15.0%	21.9%	127.8	47.0	25.6
Harrison	8,022	56.1%	3.3%	16.0%	49.4%	97.9	37.8	SN
Jefferson	36,449	56.2%	7.0%	15.2%	36.1%	113.3	43.8	26.1
Lorain	152,434	52.4%	11.2%	13.6%	14.9%	112.8	40.9	27.5
Mahoning	125,084	56.0%	18.4%	15.1%	28.5%	123.1	46.6	28.6

Health System and Public Policy Analysis

An inventory of breast health and breast cancer programs and services in the five COIs was collected from a variety of key organizations and institutions that provide screening, diagnostic, and treatment services, education and outreach programs, and survivor support programs. While every effort was made to ensure these findings were comprehensive, these findings should not be considered exhaustive and/or final.

The Breast Cancer Continuum of Care (CoC) is a model that shows how an individual would typically move through the health care system for breast care (Figure 1). An individual would ideally move through the CoC quickly and seamlessly, receiving timely, quality care in order to achieve the best outcomes. However, individuals often experience delays in moving from one point of the continuum to another, which can contribute to poorer outcomes. There are also many reasons why a person does not enter or continue in the breast cancer CoC. These barriers can include a lack of transportation, system issues including long waits for appointments and inconvenient clinic hours, insurance and affordability barriers, accessibility issues, language barriers, fear, and lack of information - or the wrong information (myths and misconceptions). Resources and assets available to individuals along the CoC were collected for each COI.

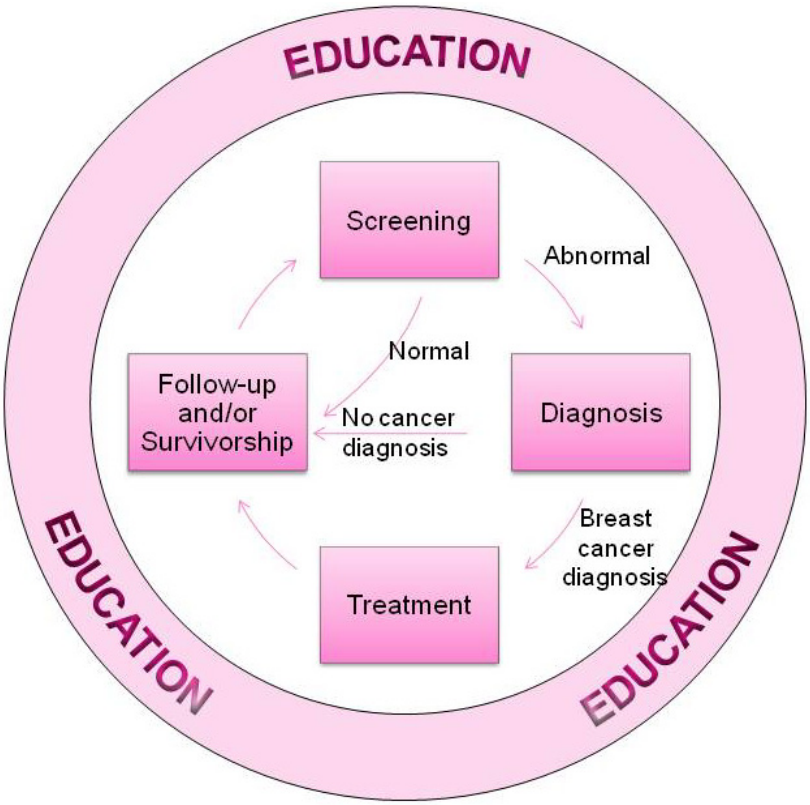

Figure 1. Breast Cancer Continuum of Care (CoC)

There are a total of 28 facilities in **Ashtabula County** that offer 42 services along the breast health CoC. The proportion of individuals to screening facilities is one facility for every 3,414 women. Screening services are available at three major medical centers. There are three Federally Qualified Health Center (FQHC) locations where clinical breast exams (CBEs) and screening mammograms are offered on-site. Ten facilities and providers in Ashtabula County have contracted with Ohio's Breast and Cervical Cancer Program (BCCP). Women can obtain diagnostic services through the major medical centers. The three major medical centers in Ashtabula County are the only places for women to seek treatment for breast cancer, and only one center provides chemotherapy and reconstructive surgery in addition to general surgical services. There are a lack of support services in Ashtabula County focused specifically on survivor needs, including wigs, prostheses, support groups, and complementary therapies. Additionally, there are no medical centers in Ashtabula County that provide radiation oncology services, indicating women in this area who are prescribed radiation may have to travel long-distances to facilities out of their county in order to receive care.

A total of 198 facilities provide 304 breast health services along the CoC to individuals in **Cuyahoga County**. The proportion of individuals to screening facilities is one facility for every 5,916 women. More than 100 facilities provide screening services including 43 FDA approved mammography centers. Only 46 facilities and providers in Cuyahoga County are contracted with the BCCP, which means women – who are otherwise eligible to receive BCCP services – that are screened and diagnosed at a non-contracted facility run the risk of eliminating themselves

from program eligibility. There are 19 community health center locations in Cuyahoga County where women can get CBEs, mammograms, and referrals for diagnostic and treatment services if necessary. There are over 50 locations in Cuyahoga County where diagnostic services are provided on-site. Twenty-four of these locations provide biopsy and 11 provide breast MRI. Patient navigation is provided at 24 locations. There are eight facilities and institutions that offer the full CoC in Cuyahoga County. There are more than 100 support services available to individuals in Cuyahoga County.

Approximately 38 facilities offer 50 services along the breast health CoC in **Harrison and Jefferson Counties**. The proportion of individuals to screening facilities is one facility for every 2,117 women. There are 18 facilities and providers contracted with the BCCP in these counties. CBEs are provided at 17 locations, including family practitioners and three community health centers. Six facilities provide diagnostic mammograms on-site including two FDA approved mammography centers. Patients are referred to one hospital in Harrison County or to the Trinity Health System in Jefferson County for more diagnostic and treatment services. There are no locations to receive breast cancer chemotherapy or radiation treatments in Harrison County. There is also a lack of survivorship services in Harrison and Jefferson Counties, as only two locations offer support groups, alternative therapies, wigs, or mastectomy wear.

Fifty-one facilities provide 88 services along the breast health CoC to individuals in **Lorain County**; however, only eight facilities and providers are contracted with the BCCP. The proportion of screening facilities to individuals in Lorain County is one facility for every 5,256 women. Lorain County has 22 locations where mammograms are provided on-site, including 11 FDA approved mammography centers. There are 21 locations where diagnostic mammograms are provided on-site. There are multiple facilities that provide screening and diagnostic services as well as treatment services, including chemotherapy, radiation, and surgery. There is a lack of survivorship services in Lorain County as there are only two support groups available. There are only two locations that have alternative therapies available, such as exercise and nutrition programs and side effect management.

A total of 75 facilities provide 111 services along the CoC in **Mahoning County**, including one FQHC and 37 BCCP contracted facilities and providers. The proportion of screening facilities available is one facility for every 3,678 women. There are 28 facilities where mammograms are available on site, 16 of which are FDA approved mammography centers. There are 24 locations that provide diagnostic mammography on-site, four of which provide biopsy and four of which provide breast MRIs. Mercy Health's Joanie Abdu Comprehensive Breast Care Center is the only facility to offer the full CoC in Mahoning County. There is a lack of survivorship services, as the only support groups available in Mahoning County are offered through Mercy Health's Joanie Abdu Comprehensive Breast Care Center and the St. Elizabeth Boardman facility. There are only four locations to purchase prostheses and only four locations to purchase mastectomy wear. There are no NCI-designated cancer centers in Mahoning County.

The future implications of the Affordable Care Act (ACA) on the eligibility and utilization of Ohio's BCCP are relatively unknown at this time. One possibility is the income threshold

standards for the program, currently set at 200 percent of the Federal Poverty Level (FPL) in Ohio, may change to mirror that of the newly expanded Medicaid income threshold, set at 138 percent of the FPL. This means any woman who is currently enrolled in BCCP Medicaid that falls between 139 to 200 percent of the FPL may be deemed ineligible for BCCP Medicaid and be expelled from the program. This could cause hundreds of women in active treatment for breast cancer to be without a continuous source of payment for their care and could result in them foregoing needed treatments.

The ACA mandates all individuals obtain health insurance or face a penalty. Individuals who do not obtain health insurance through the individual/small group market or on the Health Insurance Exchanges (HIE) may still be eligible to utilize the BCCP. The ACA also mandates that insurance plans cover preventive services, including screening mammography; however, preventive services as defined by the ACA do not include diagnostic mammography. These services will be the responsibility of the individual to pay at a rate determined by the insurance coverage selected. The impact of high deductible/high co-pay HIE plans may, in fact, create a new “gap” population of underinsured individuals – those who have insurance coverage, but drop out of the CoC due to the high out-of-pocket costs associated with needed services.

While it is still too early to assess the overall impact of the ACA on health care providers, there are some preliminary factors that may be considered. First, with more individuals enrolling into insurance plans and/or Medicaid it can be assumed that more of these individuals will utilize primary care services. This places a larger burden on primary care physicians and internal medicine doctors to care for these formerly uninsured individuals. Research has shown that a large number of areas in the country are classified as “primary care deserts” – areas which have no FQHCs and limited access to timely primary care services. Second, the providers who are working in those areas may be overwhelmed with the new number of patients and may experience substantial wait times for appointments in their practices. Furthermore, many providers and/or health systems do not accept Medicaid as a payment method, leaving many of the new Medicaid recipients without a place to go for care.

While Northeast Ohio is home to multiple, nationally recognized health care systems, individuals in this area still experience adverse health outcomes related to breast cancer. Komen NEO will work with existing facilities, organizations, and programs to ensure needed services along the breast health CoC are available to all individuals in every county served by the Affiliate. Key partnerships include the Ohio Department of Health, regional BCCP enrollment agencies, stakeholders at health systems and clinics, existing and past Komen NEO grantees, and grassroots community-based organizations that reach target populations. The impact of the ACA on the Northeast Ohio region has yet to be seen, but Komen NEO will continue to work with state and federal legislators, health policy coalitions (like the Health Policy Institute of Ohio), and the Komen Ohio Advocacy Coalition to ensure every individual has access to health insurance coverage and sources of ongoing care for breast health/breast cancer needs. Komen NEO will also continue working with the other Komen affiliates in Ohio to determine state-level public policy priorities.

Qualitative Data: Ensuring Community Input

Using the Social Ecological Model (SEM), the Community Profile Team (CPT) identified three target populations in each COI for further investigation. These populations included those who have never been diagnosed with breast cancer (referred to as the "general population"), breast cancer survivors, and health care providers/breast health leaders. The qualitative data collection methods chosen included electronic and paper surveys, key informant interviews, and focus groups.

The CPT developed key assessment questions for each target population based on identified issues. The resulting questions were purposefully crafted to create triangulation among the various data sources. For the general population, survey questions were structured to obtain accurate information on current breast health beliefs, individual breast health and cancer screening practices, knowledge of existing programs and services in the community, and current insurance and health status. The questions targeted to survivors were the same as the general population, with an additional section focused on the individual's experience with the disease, any barriers encountered during treatment, and the quality of care received. Questions targeted to providers/leaders assessed recommendations for breast cancer screenings, patient characteristics and behaviors, services for the uninsured and underinsured, administrative challenges and barriers to care, and the influence of public policies on internal practices.

Key informant interview questions were developed by the CPT based on the preliminary results of the survey data. For the general population, interview questions focused on the individual level barriers to care one may experience, including beliefs, knowledge, and level of understanding related to mammography screening, health care utilization, and breast cancer myths. The questions also probed into community and systems level issues, including availability and accessibility of existing resources, things organizations can do to help facilitate screenings, and possible barriers to care. Questions targeted to survivors were similar to those used for the general population, with additional questions focused on the individual's experience with the disease, any barriers encountered during treatment, and the quality of care received. Questions targeted to providers/leaders assessed recommendations for breast cancer screenings, patient characteristics and behaviors, services for the uninsured and underinsured, administrative challenges and barriers to care, and the influence of the ACA on mammography adherence. Questions for the target populations were tailored for each COI to determine if any regional level differences exist between the different target groups.

Focus group questions were developed by the CPT based on the preliminary results of the survey data to concentrate on issues highlighted by survey respondents. Questions for the general population focused on individual level attitudes, beliefs, and knowledge related to breast health and breast cancer screenings. General population questions also aimed to gain further insights into utilization and knowledge of existing resources for breast health, where individuals go for breast health information and services, and personal opinions about the ACA. Provider focus group questions concentrated on individual and community level variables like patient/client needs, organizational level strengths and weaknesses in addressing identified

needs, administrative and institutional barriers to care, and policy level influences of the ACA on health care behaviors and utilization from the provider perspective.

The qualitative data highlighted many potential barriers in accessing breast cancer screening and treatment services in the COIs, including a lack of awareness of existing resources, the need for more community outreach, and accessibility issues, such as transportation, limited mammography clinic hours, financial limitations, cost issues, and insurance coverage limitations, as well as provider competency and communication issues. The need for more effective education programs that address fear, dispel myths about breast cancer, and address any misunderstandings related to mammography screening initiation and frequency were also identified. Additionally, the qualitative data findings highlighted potential areas for collaborations, effective methods to break down barriers to care, like patient navigation and mobile mammography, and potential new "gap" populations created by the implementation of the ACA.

Mission Action Plan

Using the data and information collected in the three sections of the Community Profile report, the CPT developed a comprehensive plan of action to address the identified issues, known as the Mission Action Plan (MAP). The MAP will act as the roadmap for Komen NEO's future work and provides detailed priorities and objectives the Affiliate will employ to close the gaps along the CoC. The MAP consists of two major components: COI statements of need and Affiliate priorities and objectives.

Ashtabula County Statement of Need: Some women in this county are low-income, rural, and uninsured. This county experiences high rates of deaths and late-stage diagnosis. There is a shortage of primary care providers and women are not aware of and/or are not accessing financial assistance programs offered by health systems. The Affiliate only has an existing relationship with one health facility serving this area. Additionally, there is only one survivor support group in the area. Some women in the community have conflicting priorities when it comes to health and experience transportation issues. Education efforts should be focused on the importance of early detection.

Cuyahoga County Statement of Need: There are a high percentage of low-income, uninsured, and minority women in this county. Women in Cuyahoga County face high incidence, late-stage, and death rates. There are numerous programs and facilities available to women, but they are not aware of and/or are not accessing them. There is a lack of effective education programs, little to no effective stakeholder collaborations, and a need for increased accessibility, more provider champions, and more survivor peer support programs.

Harrison and Jefferson Counties Statement of Need: These counties encompass large medically underserved, low-income, and rural populations. Women in these areas have low screening percentages, and incidence, late-stage, and death rates are all increasing. A limited number of facilities/programs create additional barriers to care and accessibility issues. There

are a limited number of survivor support programs available. Women in this area have conflicting priorities, financial limitations, transportation issues, and a lack of health education.

Lorain County Statement of Need: This area experiences high rates of death and late-stage diagnosis and is made up of a high percentage of low-income, rural women. A low number of facilities/providers in this county are contracted with the BCCP, which limits where low-income patients can be seen for effective, affordable care. There is a need for more community-based education programs, more provider champions, increased financial assistance programs, and more peer support networks for survivors.

Mahoning County Statement of Need: Mahoning County experiences high rates of incidence, late-stage diagnosis, and deaths, and women in this area are not screened on a regular basis. Many women are low-income, unemployed, live in rural areas, and/or belong to a minority group. Many facilities provide the full spectrum of care, have BCCP providers, and offer financial assistance programs, but women here are not aware of and/or are not accessing these services. There is a need for increased education, transportation assistance, and increased insurance coverage.

Affiliate Priority 1: Accessibility - Improve timely access to quality, affordable screening and treatment services for the low-income, underinsured, uninsured, and/or working poor within each Community of Interest.

Objectives for All Communities of Interest

- Objective 1: By the end of FY17, cultivate relationships with at least three health systems and/or community-based organizations in each of the Communities of Interest that result in at least quarterly email updates from partners to aid in the promotion of existing free/low-cost screening programs available for target populations.
- Objective 2: From FY16 through FY19, a comprehensive resource listing that includes all Health Insurance Exchange and Medicaid navigators serving each Community of Interest will be updated annually to assist in the effective navigation of uninsured individuals to ongoing sources of health insurance coverage that best suits their individual needs.
- Objective 3: Beginning with the FY16-17 Community Grant RFA, a key funding priority will be to support the development and expansion of mobile mammography and/or transportation assistance programs for target populations in all five Communities of Interest.
- Objective 4: Beginning with the FY16-17 Community Grant RFA, a funding preference will be given to programs that break down systems-level barriers to care, including assistance with insurance deductibles/co-pays, provision of free/low-cost services, non-traditional clinic hours, and weekend appointment availability, in all Communities of Interest.

Affiliate Priority 2: Quality of Care - Increase the number of effective, evidence-based programs that support the emotional, social, financial, and spiritual well-being of individuals diagnosed with breast cancer and their families within each Community of Interest.

Objectives for All Communities of Interest

- Objective 1: Beginning in the FY16-17 Community Grant RFA, a key funding priority will be to support the development and/or growth of patient navigation programs for individuals in treatment for breast cancer focused on breaking down barriers to treatment, including medical care and service coordination, child care and transportation assistance, social work and community-based referrals, and emotional support in all five Communities of Interest.
- Objective 2: Beginning in the FY16-17 Community Grant RFA, a key funding priority will be to support direct financial assistance programs that assist with cost of living and treatment expenses for individuals in active treatment for breast cancer to facilitate continuation of treatment in all Communities of Interest.
- Objective 3: Beginning in the FY16-17 Community Grant RFA, a key funding priority will be to support the development and implementation of trainings focused on effective, evidence-based communication methods and styles for those working with individuals and families battling breast cancer in all Communities of Interest.

Objectives for Ashtabula County and Harrison and Jefferson Counties

- Objective 4: Beginning in the FY16-17 Community Grant RFA, a key funding priority will be to increase the number of free/low-cost survivor support groups and services that use evidence-based strategies to address the psycho-social, emotional, and physical issues faced by survivors and their family members.

Objectives for Cuyahoga County

- Objective 4: By the end of FY17, host at least one breast cancer survivor education event focused on short- and long-term breast cancer survivor issues and needs.

Affiliate Priority 3: Education - Initiate and support education efforts focused on increasing awareness and utilization of existing resources, the importance of early detection, and motivating women to action with an emphasis on reaching the low-income, underinsured, uninsured, and/or working poor within the Communities of Interest.

Objectives for All Communities of Interest

- Objective 1: By the end of FY19, develop grassroots marketing strategies with at least three non-traditional partners (restaurants, beauty salons, churches, large employers, universities, etc.) and community-based organizations (YWCAs, libraries, food banks, etc.) in each Community of Interest to advertise free/low-cost screening programs and education/awareness events throughout the year.

Objectives for Ashtabula County

- Objective 2: By the end of FY19, partner with at least one community-based organization and/or health care institution to provide a culturally appropriate breast health education event where individuals from target populations can sign up for a free/low-cost mammography appointment.
- Objective 3: Beginning with the FY16-17 Community Grant RFA, a key funding priority will be to support an evidence-based peer-to-peer education program for target populations in Ashtabula County.

Objectives for Cuyahoga County

- Objective 2: By the end of FY19, partner with at least one community-based organization and/or health care institution to provide two culturally appropriate breast health education events where individuals from target populations can sign up for a free/low-cost mammography appointment.
- Objective 3: Beginning in the FY16-17 Community Grant RFA, preference will be given to education programs in Cuyahoga County that focus on motivating women to action and lead to long-term behavior change (e.g., multi-session, cohort education programs).

Objectives for Harrison and Jefferson Counties

- Objective 2: By the end of FY19, partner with at least one community-based organization and/or health care institution to provide a culturally appropriate breast health education event where individuals from target populations can sign up for a free/low-cost mammography appointment.
- Objective 3: Beginning with the FY16-17 Community Grant RFA, a key funding priority will be to support an evidence-based peer-to-peer education program for target populations in Harrison and Jefferson Counties.

Objectives for Lorain County

- Objective 2: By FY18, work with the Affiliate's education committee to develop a plan to recruit and train at least five individuals from Lorain County to join Komen Northeast Ohio's speaker's bureau to increase the Affiliate's on-the-ground presence in this area.
- Objective 3: BY FY19, the newly trained Komen volunteers will provide community-based presentations to target populations on breast health, breast cancer, available community resources, and Komen Northeast Ohio at a minimum of one event each (five events total) in Lorain County.
- Objective 4: By the end of FY19, partner with at least one community-based organization and/or health care institution to provide a culturally appropriate breast health education events where individuals from target populations can sign up for a free/low-cost mammography appointment.
- Objective 5: Beginning in the FY16-17 Community Grant RFA, funding preference will be given to education programs in Lorain County that focus on motivating women to action and lead to long-term behavior change (e.g., multi-session, cohort education programs).

Objectives for Mahoning County

- Objective 2: By the end of FY18, work with the Affiliate's education committee to develop a plan to recruit and train at least five individuals from Mahoning County to join Komen Northeast Ohio's speaker's bureau to increase the Affiliate's on-the-ground presence in this area.
- Objective 3: BY FY19, the newly trained Komen volunteers will provide community-based presentations to target populations on breast health, breast cancer, available community resources, and Komen Northeast Ohio at a minimum of one event each (five events total) in Mahoning County.
- Objective 4: By the end of FY19, partner with at least one community-based organization and/or health care institution to provide a culturally appropriate breast health education events where individuals from target populations can sign up for a free/low-cost mammography appointment.
- Objective 5: Beginning in the FY16-17 Community Grant RFA, a key funding priority will be to support an evidence-based peer-to-peer education program for target populations in Mahoning County.

Affiliate Priority 4: Health care System Performance Improvement - Decrease gaps/breakdowns in the breast health continuum of care and reduce systemic barriers to care through the development of strategic collaborations with stakeholders and non-traditional partners to increase access to and seamless progression through the breast health continuum of care in each of the Communities of Interest.

Objectives for All Communities of Interest

- Objective 1: Beginning with the FY16-17 Community Grant RFA, support the initiation and/or expansion of programs focused on health care system performance improvements in all five Communities of Interest, including: provider education on BCCP; internal training on agency processes for enrollment in financial assistance programs; physician reminder systems; shared medical appointments; development of cross-functional workgroups/teams; creation of internal checklists and protocols; and deployment of data-driven approaches in implementing evidence-based programs.

Objectives for Ashtabula County

- Objective 2: By the end of FY18, join at least one existing community health and/or cancer coalition serving Ashtabula County to explore additional community issues and increase partnership opportunities.
- Objective 3: By the end of FY18, host at least one grant writing workshop in Ashtabula County to increase knowledge of the Affiliate's work, foster inter-agency collaboration, and support the development of grant applications from organizations serving target populations in Ashtabula County.
- Objective 4: By the end of FY19, increase the number of organizational partnerships in Ashtabula County from one to five.

Objectives for Cuyahoga County

- Objective 2: By the end of FY16, host at least two collaborative meetings with hospitals, primary care providers, health clinics, and community-based organizations serving Cuyahoga County to explore additional community issues, discuss possible partnership opportunities, and gauge level of interest in participating in a breast health task force.
- Objective 3: By the end of FY17, establish a breast health task force in Cuyahoga County made up of providers, stakeholders, breast cancer survivors and co-survivors, and community members to reduce duplication through service delivery efficiencies; create stronger and more integrated planning on regional approaches to address public service needs; expand and create opportunities that increase and improve effectiveness of each organization; and enhance program results through leveraged resources, combined resources, and the creation of new resources.
- Objective 4: By the end of FY19, the breast health task force in Cuyahoga County will meet at least quarterly to provide status updates on progress towards achieving the task force's strategic goals and objectives.

Objectives for Harrison and Jefferson Counties

- Objective 2: By the end of FY16, add a medical, public health, or nonprofit professional from one of these rural counties to the Affiliate's Board of Directors to ensure the needs of the many rural communities in the service area are represented on the Board.
- Objective 3: By the end of FY17, join at least one existing community health and/or cancer coalition serving Harrison and Jefferson Counties to explore additional community issues and increase partnership opportunities.
- Objective 4: By the end of FY18, host at least one grant writing workshop in Jefferson County to increase knowledge of the Affiliate's work, foster inter-agency collaboration, and support the development of grant applications from organizations serving target populations in Harrison and Jefferson Counties.
- Objective 5: By the end of FY19, increase the number of organizational partnerships in Harrison and Jefferson Counties from two to seven.

Objectives for Lorain County

- Objective 2: By the end of FY19, join at least one existing community health and/or cancer coalition serving Lorain County to explore additional community issues and increase partnership opportunities.
- Objective 3: By the end of FY19, work in conjunction with the Ohio Department of Health and BCCP Region 12 to schedule at least one provider and health care systems training on the BCCP in an effort to increase provider/systems participation and patient enrollment in the program.
- Objective 4: By the end of FY19, increase the number of organizational partnerships in Lorain County from two to ten.

Objectives for Mahoning County

- Objective 2: By the end of FY17, host at least two collaborative meetings with hospitals, primary care providers, health clinics, and community-based organizations serving Mahoning County to explore additional community issues and discuss possible partnership opportunities.
- Objective 3: By FY17, increase the number of organizational partnerships in Mahoning County from three to ten.

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

Affiliate History

In 1980, Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982 that promise became Susan G. Komen® and launched the global breast cancer movement. Komen is the world's largest grassroots network of survivors and activists and is now the boldest community making the biggest impact in the fight against breast cancer. As the largest nonprofit source of breast cancer research funding outside of the US government, Komen has invested more than $2.5 billion in research and life-saving community programs. Komen's promise is to save lives and end breast cancer forever through empowering people, ensuring quality care for all and energizing science to find the cures.

Susan G. Komen® Northeast Ohio was initiated in 1994 by the Junior League of Cleveland as part of its Breast Health Task Force. The Inaugural Susan G. Komen Northeast Ohio Race for the Cure®, organized by the Junior League, was held in Cleveland, Ohio, that same year. More than 3,000 participants attended the event and $150,000 was raised. All funds were directed to the American Cancer Society for their Breast Education and Screening Together (BEST) program.

In 1999, under new affiliate structure requirements, the Cleveland Chapter and Central Ohio Chapter merged to become Komen Northeast Ohio. Under the new structure, all Race activities became the responsibility of the Affiliate. The office was relocated out of Junior League headquarters and the first employee, the Administrative Director, was hired to manage the Race. In 2003, the Administrative Director was named as the organization's first Executive Director and focus shifted to Board recruitment. The Board added five new members and created working committees to develop the first strategic plan, emphasizing the importance of mission and fundraising.

The organization underwent reorganization in 2006 under the direction of the Board of Directors in an effort to improve communication, better utilize volunteers, and integrate the Race into all aspects of the Affiliate's work. Additional staff was hired and strong board and committee leadership was in place to coordinate all activities to maximize fundraising programs and mission impact. Revenue exceeded $2 million and grant funding exceeded $1 million.

From 2008-09, Komen Northeast Ohio worked with the other Ohio Affiliate's – Komen Cincinnati, Komen Columbus, and Komen Northwest Ohio – to add additional counties to each service area so every county in Ohio would be covered by a Komen Affiliate. Following this expansion, Komen Northeast Ohio's service area increased from 15 counties to 22. In the 2009-10 grant year, $1.5 million was granted to 25 organizations – the most money ever granted out to the most organizations in Affiliate history. In 2010, Komen Northeast Ohio was named Affiliate of the Year out of 115 Affiliate's in the nation by Komen Headquarters.. Also in 2010, the Affiliate started the second Race in its service area, the Akron Race for the Cure. The Affiliate continues to host two annual Race events in the community, The Cleveland Race for the Cure and the Akron Race for the Cure each year.

In 2011, Komen Northeast Ohio began to see a decline in Race participation and revenue generation. A decrease in revenue led to redefined organizational priorities, resulting in a consolidation of staff roles and staff reduction. Grant funds available have also decreased by 45 percent since 2010. In the 2014-15 grant year, Komen Northeast Ohio provided $778,173 to 10 organizations serving the Affiliate's 22 county service area.

Despite the decline in grant funds available, Komen Northeast Ohio continues to make a remarkable impact in the community. Komen Northeast Ohio staff carefully manages grants to ensure funds are applied effectively and leveraged for maximum impact. In 2014, investment in local evidence-based breast health programs allowed Komen Northeast Ohio to educate over 10,000 individuals and provide more than 4, 000 mammograms to those most in need in the Northeast Ohio community. Since 1994, Komen Northeast Ohio has provided nearly $14 million in community grants to Northeast Ohio agencies working to end breast cancer disparities in the Northeast Ohio service area. Komen Northeast Ohio continues to work actively within community-based committees, associations, and alliances, including the Minority Health Alliance of Cleveland, the Ohio Partners for Cancer Control, Philanthropy Ohio's Health Care Committee, and Ohio's Public Health Association to better understand the breast health and breast cancer needs in the communities served by the Affiliate.

Komen Northeast Ohio currently works on two fronts to address local disparities in breast health and breast cancer: targeted internal education/advocacy initiatives and focused external grantmaking efforts. These two areas are governed by the Affiliate's strategic plan, FORWARD 2015 (F15). F15 outlines the strategic focus of the Affiliate: Creating access to the full continuum of care for women most at-risk in the 22 county service area. Komen Northeast Ohio will achieve this goal by investing the critical mass of resources on system level interventions and programs that impact screening percentages and reduce barriers to treatment for at-risk segments of the population in targeted geographic areas.

A key, overarching theme to F15 is that Komen Northeast Ohio's efforts be focused on population-based interventions. This includes targeting internal programs and grant funded services to the population as a whole, not just to those individuals who actively seek breast health services, by educating health care providers, leveraging community resources, and creating synergy among stakeholders. F15 outlines various ways Komen Northeast Ohio can leverage the Affiliate's relationships to other major players, including:

- Act as a catalyst and convener to help lead stakeholder collaborations;
- Become a link for all breast health providers and outreach organizations;
- Establish the Affiliate as a clearinghouse of breast health information for the community; and
- Increase visibility as a community "watch dog" group for breast health services.

Affiliate Organizational Structure

The Affiliate was restructured in 2014 to reflect reduced staff numbers. The Executive Director works with the 12 member governing Board of Director's to oversee the Affiliate's work. The Director of Mission is responsible for all mission-related initiatives and works closely with the Community Outreach Associate to ensure equal access to quality care for all constituents. The Community Outreach Associate provides all community-based educational programs for the Affiliate. The Director of Marketing is responsible for all media communications including social media, collateral and marketing materials, corporate sponsorships, and coordinates two major fundraising events as well as the website and monthly newsletter. The Event Coordinator is responsible for planning and coordinating the Akron and Cleveland Races for the Cure, the Affiliate's largest fundraising event. The Event and Marketing Associate is responsible for third party events, national sponsorships, and supports the efforts of the Director of Marketing and the Event Coordinator. The Finance Coordinator is responsible for managing the financial and operational components of the Affiliate (Figure 1.1*)*. Komen Northeast Ohio also operates with multiple working volunteer committees, including an Associate Council, the Akron and Cleveland Race for the Cure leadership teams and committee members, Strategic Mission Committee, Fund Development Committee, Education Committee, Board Governance, and an independent grant review panel.

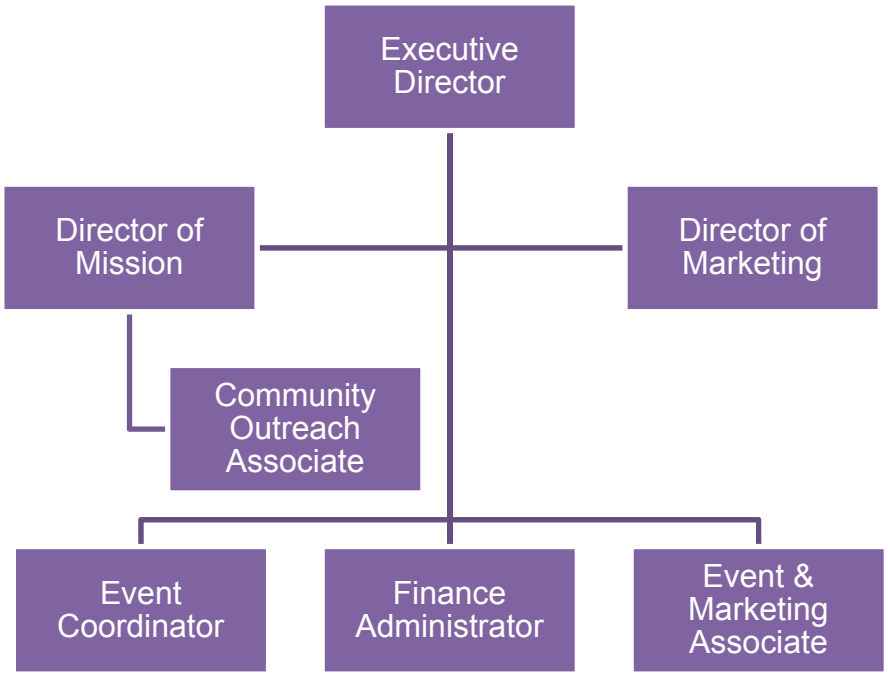

Figure 1.1. Komen Northeast Ohio staff organizational structure

Affiliate Service Area

Komen Northeast Ohio serves 22 counties: Ashland, Ashtabula, Belmont, Carroll, Columbiana, Coshocton, Cuyahoga, Geauga, Harrison, Holmes, Jefferson, Lake, Lorain, Mahoning, Medina, Portage, Richland, Stark, Summit, Trumbull, Tuscarawas, and Wayne (Figure 1.2). The Northeast Ohio service area is highly diverse and contains several major cities and many small rural towns. The largest urban area is the City of Cleveland in Cuyahoga County, followed by the City of Youngstown in Mahoning County, the Cities of Lorain and Elyria in Lorain County, the City of Akron in Summit County, the City of Canton in Stark County, and the City of Mansfield in Richland County. In addition to the large, highly populated cities, the Affiliate serves a large rural population, particularly in the southern most counties. Eleven of these counties (Ashtabula, Belmont, Carroll, Columbiana, Coshocton, Harrison, Holmes, Jefferson, Mahoning, Trumbull and Tuscarawas) are considered Appalachian and many counties house Amish and Mennonite populations. Millersburg, Ohio, located in Holmes County, is home to the world's largest Amish settlement.

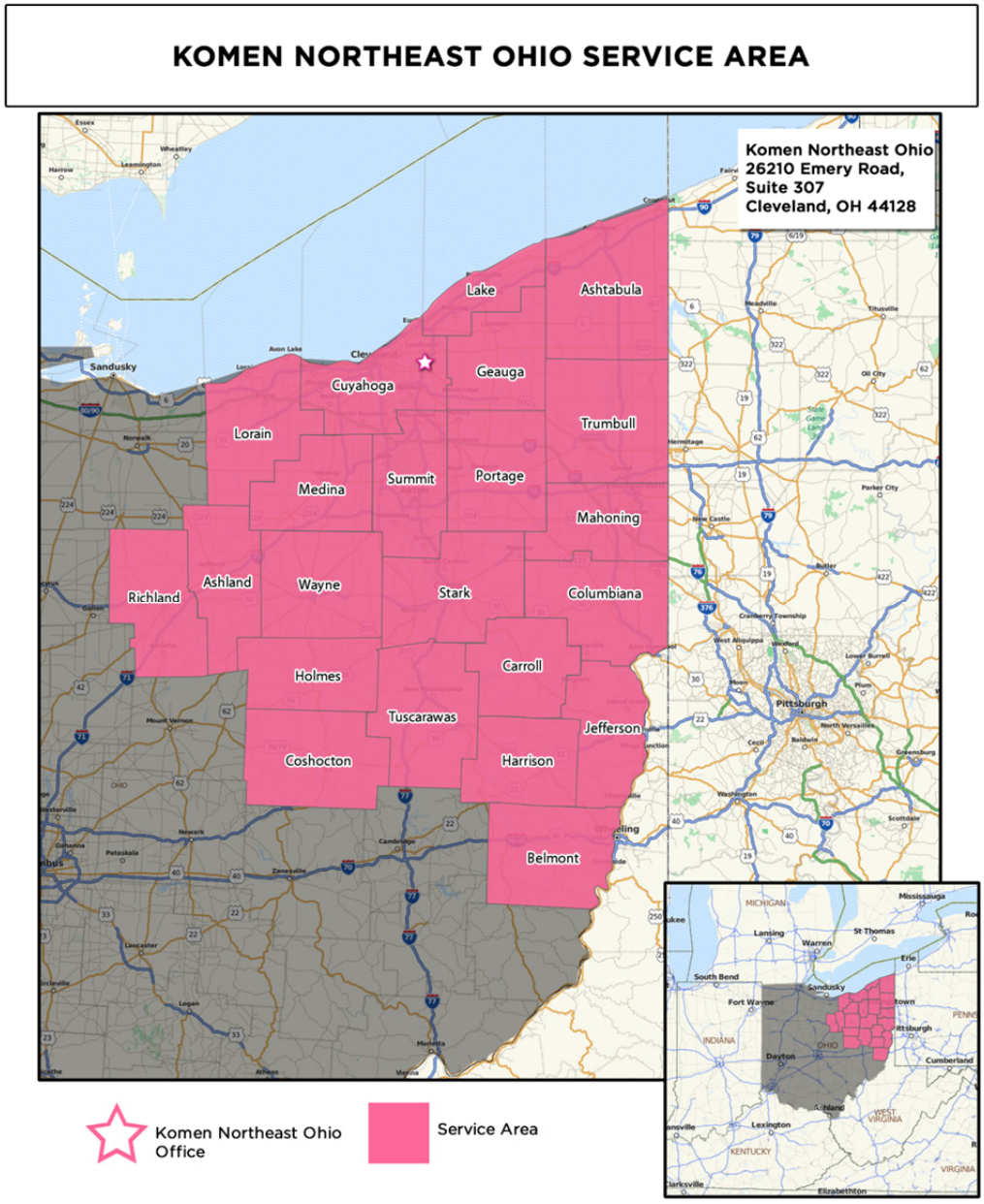

Figure 1.2. Susan G. Komen Northeast Ohio service area

Geographic differences in the Affiliate's service area reflect differences in race/ethnicity, socio-economics, and education levels for the populations that inhabit these areas. Those who live in urban and rural areas tend to have lower incomes, higher levels of unemployment, and lower education levels than those who live in suburban areas. Rural and suburban areas also tend to have less racial and ethnic diversity than urban areas.

Purpose of the Community Profile Report

A vital first step in fulfilling the promise to end breast cancer forever is to understand the state of breast health and breast cancer in the communities served by the Affiliate. To accomplish this,

Komen Northeast Ohio conducts a comprehensive breast health needs assessment at the local level every four years. The resulting report, the Susan G. Komen Northeast Ohio Community Profile Report, assesses the current conditions of breast health and breast cancer in the Affiliate service area. More specifically, the Community Profile identifies the needs in the service area related to breast health and cancer education, screening, treatment, and survivorship.

The Community Profile includes an overview of demographic and breast cancer statistics for the 22 county service area. This data helps the Affiliate identify regions and communities where populations most in-need live and highlights areas where disparities in breast cancer screening, incidence, late-stage diagnosis, and death rates exist. The report also conducts an analysis of the current programs and services in these areas to identify existing service assets and areas of concern. Once breast health needs and gaps are identified, they are broken down by qualitative data collection and analysis efforts to determine whether the needs in communities can be filled through the Affiliate's efforts in educational programming, grantmaking, partnerships, public policy efforts, or through a combination of several of these tactics.

The data collection process helps shed light on why the statistics are the way they are. This information aids in the development of targeted priorities and strategic objectives on how to help bridge the identified gaps in breast health services, known as the Affiliate's Mission Action Plan (MAP). The MAP helps determine the focus of the Affiliate's strategic planning and grantmaking efforts and drives the overall work of the Affiliate. The report strives to make sure local programs supported by Komen Northeast Ohio target the people and areas most in need, ensures they are non-duplicative, and assures they address existing disparities through the application of evidence-based programs appropriate for the target populations. Finally, a quality Community Profile allows the organization to:

- Identify ways to fill gaps through partnerships and additional granting opportunities.
- Establish focused education and outreach efforts to address the community need.
- Drive public policy efforts.
- Establish marketing and communication direction.
- Increase inclusion efforts in the breast cancer community.

Once an updated Community Profile is published, every effort is made to ensure copies are distributed to members of the general community; local health care systems and providers; community-based health care organizations and coalitions; academic institutions; local, state, and national legislators; and key organizational supporters and partners. A press release along with a full copy of the Executive Summary is sent to all of the major print newspapers and television news stations serving each of the Affiliate's 22 counties to help notify the community of the report and its major findings. The full report will be available for download on Komen Northeast Ohio's website, and paper copies of the report will be printed for distribution to key organizational stakeholders, partners, supporters, and anyone else who does not have access to the electronic report.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Quantitative Data Report

Introduction

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

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

The following is a summary of Komen® Northeast Ohio'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

		Incidence Rates and Trends			Death Rates and Trends			Late-stage Rates and Trends		
Population Group	Female Population (Annual Average)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of Deaths (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)
US	154,540,194	198,602	122.1	-0.2%	40,736	22.6	-1.9%	70,218	43.7	-1.2%
HP2020	.	-	-	-	-	20.6*	-	-	41.0*	-
Ohio	5,895,383	8,319	120.8	-0.1%	1,820	24.8	-1.9%	2,972	44.0	0.6%
Komen Northeast Ohio Service Area	2,309,143	3,470	120.6	0.5%	771	24.8	NA	1,213	43.3	1.3%
White	1,923,627	2,994	119.6	0.7%	657	24.0	NA	1,019	41.9	1.4%
Black/African-American	342,567	418	123.7	0.5%	109	31.6	NA	175	51.7	0.5%
American Indian/Alaska Native (AIAN)	6,508	SN	SN	SN	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	36,441	18	58.6	-4.0%	4	16.2	NA	7	21.0	-3.5%
Non-Hispanic/ Latina	2,243,523	3,443	121.4	0.6%	766	24.9	NA	1,203	43.6	1.4%
Hispanic/ Latina	65,619	27	67.9	-5.3%	5	10.7	NA	10	24.5	-14.2%
Ashland County - OH	27,252	38	116.4	-2.2%	9	25.7	-2.6%	14	44.2	9.5%
Ashtabula County - OH	51,211	72	111.8	1.6%	18	25.7	-1.8%	27	43.0	0.5%
Belmont County - OH	35,007	62	124.3	-6.6%	12	19.9	-2.6%	24	48.4	-8.4%
Carroll County - OH	14,518	19	105.1	-8.8%	4	19.4	-2.0%	6	34.6	7.4%
Columbiana County - OH	54,122	81	112.1	3.9%	16	20.4	-3.3%	28	39.0	4.1%
Coshocton County - OH	18,754	25	102.4	7.3%	6	24.5	-2.0%	11	47.5	0.8%
Cuyahoga County - OH	680,385	1,092	127.8	0.6%	236	25.6	-2.1%	389	47.0	2.6%
Geauga County - OH	47,538	75	126.8	-0.5%	14	23.1	-2.4%	22	37.6	0.0%
Harrison County - OH	8,022	11	97.9	30.0%	SN	SN	SN	4	37.8	16.3%
Holmes County - OH	21,107	17	85.6	-2.1%	5	22.2	-6.1%	5	23.5	-15.4%
Jefferson County - OH	36,449	54	113.3	6.8%	14	26.1	-1.5%	20	43.8	7.9%
Lake County - OH	117,658	187	125.8	-1.0%	45	27.7	-1.2%	61	41.8	-0.4%
Lorain County - OH	152,434	204	112.8	-2.1%	52	27.5	-2.1%	72	40.9	0.9%
Mahoning County - OH	125,084	209	123.1	4.6%	54	28.6	-1.2%	76	46.6	5.2%
Medina County - OH	86,273	127	131.0	1.0%	22	21.8	-2.2%	44	45.0	1.5%
Portage County - OH	81,682	94	107.9	2.5%	21	24.1	-2.1%	35	40.1	1.7%
Richland County - OH	62,269	95	118.5	-3.7%	23	27.7	-0.9%	32	40.2	-9.9%
Stark County - OH	194,429	284	115.5	3.4%	65	23.9	-1.8%	97	40.4	2.2%
Summit County - OH	280,592	400	118.2	-2.9%	89	24.7	-1.8%	143	43.3	-5.7%

		Incidence Rates and Trends			Death Rates and Trends			Late-stage Rates and Trends		
Population Group	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)
Trumbull County - OH	109,408	176	121.1	-0.2%	37	22.1	-1.4%	58	40.4	8.2%
Tuscarawas County - OH	47,136	70	115.5	6.1%	10	14.3	-3.8%	23	40.2	3.0%
Wayne County - OH	57,814	78	117.1	6.7%	16	21.6	-3.4%	23	34.3	9.8%

*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 2005-2009 for incidence and late-stage data and 2006-2010 death data.
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) mortality 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 in the Komen Northeast Ohio service area was slightly lower than that observed in the US as a whole and the incidence trend was higher than the US as a whole. The incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of Ohio.

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 Asians and Pacific Islanders (APIs) and American Indians and Alaska Natives (AIANs) were lower than for Non-Hispanic Whites and Blacks/African-Americans. The most recent estimated incidence rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the incidence rate was slightly 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 incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

The following county had an incidence rate **significantly higher** than the Affiliate service area as a whole:

- Cuyahoga County

The incidence rate was significantly lower in the following counties:

- Holmes County
- Portage County

Significantly less favorable trends in breast cancer incidence rates were observed in the following counties:

- Harrison County

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

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 Northeast Ohio 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 not significantly different than that observed for the State of Ohio.

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 Whites and Blacks/African-Americans. The most recent estimated death rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the death rate was higher among Blacks/African-Americans than Whites 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 death rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

The death rate was significantly lower in the following county:

- Tuscarawas County

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

- Holmes County

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

Late-Stage Incidence Rates and Trends Summary
Overall, the breast cancer late-stage incidence rate in the Komen Northeast Ohio service area was similar to 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 Ohio.

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 following county had a late-stage incidence rate **significantly higher** than the Affiliate service area as a whole:

- Cuyahoga County

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

- Holmes County
- Wayne 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 or did not have enough data available.

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	Informed decision-making with a health care provider ages 40-49 Mammography every 2 years ages 50-74

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 aligning with Komen breast self-awareness messaging (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 Hispanic/Latina, but only 10.0 percent of the total women in the area are Hispanic/Latina, weighting is used to account for this difference.

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

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

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

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

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

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

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

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
US	174,796	133,399	77.5%	77.2%-77.7%
Ohio	5,046	3,891	77.0%	75.5%-78.4%
Komen Northeast Ohio Service Area	1,955	1,519	77.6%	75.2%-79.9%
White	1,733	1,336	76.9%	74.3%-79.2%

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
Black/African-American	173	146	84.2%	75.5%-90.3%
AIAN	10	7	90.8%	48.6%-99.0%
API	SN	SN	SN	SN
Hispanic/ Latina	27	20	77.0%	48.7%-92.2%
Non-Hispanic/ Latina	1,920	1,493	77.7%	75.3%-80.0%
Ashland County - OH	11	9	80.9%	43.3%-95.9%
Ashtabula County - OH	22	18	79.6%	55.6%-92.4%
Belmont County - OH	64	49	77.8%	62.0%-88.2%
Carroll County - OH	24	17	73.8%	47.8%-89.6%
Columbiana County - OH	23	17	66.4%	40.2%-85.3%
Coshocton County - OH	32	25	83.0%	62.6%-93.5%
Cuyahoga County - OH	289	228	78.1%	71.9%-83.3%
Geauga County - OH	24	19	84.1%	60.3%-94.8%
Harrison County - OH	19	12	50.6%	27.2%-73.8%
Holmes County - OH	SN	SN	SN	SN
Jefferson County - OH	72	49	63.9%	50.1%-75.7%
Lake County - OH	56	41	71.5%	56.2%-83.0%
Lorain County - OH	259	212	85.1%	78.4%-90.0%
Mahoning County - OH	259	193	71.5%	64.1%-77.9%
Medina County - OH	31	24	76.9%	57.3%-89.3%
Portage County - OH	41	31	78.3%	60.7%-89.5%
Richland County - OH	61	51	84.6%	70.7%-92.6%
Stark County - OH	262	207	76.9%	70.1%-82.6%
Summit County - OH	248	196	77.7%	70.6%-83.6%
Trumbull County - OH	51	39	84.3%	68.7%-92.9%
Tuscarawas County - OH	72	54	79.9%	66.6%-88.8%
Wayne County - OH	26	21	78.5%	53.8%-92.0%

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 Northeast Ohio 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 Ohio.

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

The following county had a screening proportion **significantly lower** than the Affiliate service area as a whole:

- Harrison County

The remaining counties had screening proportions that were not significantly different than the Affiliate service area as a whole or did not have enough data available.

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

	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 %
Ohio	84.2 %	13.4 %	0.3 %	2.0 %	97.0 %	3.0 %	50.5 %	36.9 %	16.0 %
Komen Northeast Ohio Service Area	83.0 %	15.0 %	0.3 %	1.7 %	96.9 %	3.1 %	53.2 %	39.6 %	17.7 %
Ashland County - OH	97.9 %	1.1 %	0.2 %	0.8 %	99.0 %	1.0 %	51.2 %	38.4 %	17.6 %
Ashtabula County - OH	95.7 %	3.3 %	0.3 %	0.6 %	96.8 %	3.2 %	53.4 %	39.6 %	17.7 %
Belmont County - OH	97.0 %	2.3 %	0.2 %	0.5 %	99.4 %	0.6 %	58.0 %	44.8 %	20.9 %
Carroll County - OH	98.6 %	0.8 %	0.2 %	0.3 %	99.0 %	1.0 %	55.6 %	41.6 %	18.2 %
Columbiana County - OH	97.8 %	1.7 %	0.2 %	0.4 %	99.2 %	0.8 %	55.4 %	42.0 %	19.0 %
Coshocton County - OH	97.7 %	1.6 %	0.3 %	0.4 %	99.2 %	0.8 %	53.1 %	40.0 %	18.4 %
Cuyahoga County - OH	64.8 %	32.0 %	0.3 %	2.9 %	95.2 %	4.8 %	52.6 %	39.1 %	17.8 %
Geauga County - OH	97.5 %	1.6 %	0.1 %	0.8 %	98.9 %	1.1 %	56.7 %	41.5 %	17.6 %
Harrison County - OH	96.7 %	2.9 %	0.1 %	0.2 %	99.5 %	0.5 %	56.1 %	43.1 %	19.4 %
Holmes County - OH	99.2 %	0.5 %	0.1 %	0.2 %	99.2 %	0.8 %	39.6 %	28.5 %	12.6 %
Jefferson County - OH	93.0 %	6.3 %	0.2 %	0.6 %	98.8 %	1.2 %	56.2 %	43.4 %	20.3 %
Lake County - OH	94.4 %	4.0 %	0.2 %	1.5 %	96.8 %	3.2 %	55.6 %	41.3 %	18.4 %
Lorain County - OH	88.8 %	9.4 %	0.5 %	1.3 %	91.7 %	8.3 %	52.4 %	38.2 %	16.4 %
Mahoning County - OH	81.6 %	17.2 %	0.3 %	0.9 %	95.8 %	4.2 %	56.0 %	43.4 %	20.5 %
Medina County - OH	97.0 %	1.6 %	0.2 %	1.2 %	98.4 %	1.6 %	52.6 %	36.5 %	14.6 %
Portage County - OH	92.9 %	5.1 %	0.3 %	1.7 %	98.6 %	1.4 %	48.2 %	34.5 %	14.1 %
Richland County - OH	91.0 %	7.8 %	0.3 %	0.9 %	98.6 %	1.4 %	54.4 %	41.3 %	19.2 %
Stark County - OH	90.1 %	8.6 %	0.3 %	1.0 %	98.4 %	1.6 %	53.8 %	40.5 %	18.5 %
Summit County - OH	81.3 %	16.0 %	0.3 %	2.4 %	98.4 %	1.6 %	52.4 %	38.5 %	16.6 %
Trumbull County - OH	90.0 %	9.1 %	0.2 %	0.7 %	98.6 %	1.4 %	55.9 %	42.6 %	19.5 %
Tuscarawas County - OH	98.0 %	1.1 %	0.4 %	0.6 %	98.5 %	1.5 %	53.8 %	40.8 %	18.8 %
Wayne County - OH	97.0 %	1.9 %	0.2 %	0.9 %	98.6 %	1.4 %	50.1 %	37.0 %	16.4 %

Data are for 2011.
Data are in the percentage of women in the population.
Source: US Census Bureau – Population Estimates

Table 2.5. Population characteristics – socioeconomics

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistic-ally Isolated	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age: 40-64)
US	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
Ohio	12.2 %	14.8 %	33.1 %	9.3 %	3.9 %	1.3 %	22.1 %	14.8 %	14.0 %
Komen Northeast Ohio Service Area	12.3 %	14.6 %	34.0 %	9.7 %	3.9 %	1.5 %	18.2 %	12.1 %	14.4 %
Ashland County - OH	13.6 %	14.6 %	37.0 %	10.0 %	1.9 %	1.1 %	61.9 %	0.0 %	15.5 %
Ashtabula County - OH	15.1 %	17.2 %	40.5 %	10.7 %	1.3 %	0.8 %	46.4 %	0.0 %	15.8 %
Belmont County - OH	13.0 %	14.2 %	39.8 %	7.6 %	0.9 %	0.2 %	54.7 %	22.4 %	15.4 %
Carroll County - OH	15.9 %	13.9 %	38.2 %	7.3 %	0.5 %	0.5 %	71.0 %	20.6 %	15.6 %
Columbiana County - OH	14.3 %	15.9 %	40.8 %	10.8 %	1.1 %	0.2 %	43.9 %	0.0 %	17.2 %
Coshocton County - OH	14.3 %	16.7 %	42.7 %	11.0 %	0.2 %	0.4 %	61.5 %	16.9 %	17.4 %
Cuyahoga County - OH	13.3 %	17.1 %	36.3 %	11.1 %	7.1 %	2.6 %	0.6 %	23.2 %	15.0 %
Geauga County - OH	10.1 %	8.0 %	20.2 %	5.9 %	3.1 %	1.8 %	64.0 %	0.0 %	10.9 %
Harrison County - OH	15.0 %	20.1 %	43.8 %	7.1 %	0.3 %	0.3 %	84.1 %	100.0 %	16.0 %
Holmes County - OH	43.6 %	14.7 %	47.1 %	5.9 %	1.0 %	8.1 %	93.0 %	17.5 %	22.0 %
Jefferson County - OH	12.7 %	16.9 %	40.8 %	8.8 %	1.0 %	0.5 %	39.0 %	11.3 %	15.2 %
Lake County - OH	9.0 %	8.5 %	25.5 %	7.1 %	5.3 %	1.4 %	6.5 %	0.0 %	12.8 %
Lorain County - OH	11.3 %	13.6 %	29.8 %	10.0 %	2.8 %	1.5 %	11.7 %	16.5 %	13.6 %
Mahoning County - OH	12.1 %	17.1 %	38.1 %	11.1 %	3.2 %	1.1 %	15.2 %	17.0 %	15.1 %
Medina County - OH	6.9 %	7.2 %	21.3 %	6.7 %	3.2 %	0.7 %	29.8 %	0.0 %	11.1 %
Portage County - OH	9.6 %	14.3 %	27.8 %	9.9 %	2.7 %	0.8 %	32.8 %	0.0 %	12.5 %
Richland County - OH	15.0 %	13.4 %	35.8 %	9.4 %	1.7 %	0.4 %	32.1 %	0.0 %	14.1 %
Stark County - OH	11.5 %	13.6 %	34.9 %	9.7 %	1.9 %	0.6 %	13.5 %	11.5 %	14.8 %
Summit County - OH	10.0 %	14.5 %	32.1 %	9.4 %	4.2 %	1.1 %	3.9 %	5.2 %	13.6 %
Trumbull County - OH	12.9 %	16.4 %	36.8 %	8.9 %	1.6 %	0.9 %	27.3 %	5.7 %	15.3 %
Tuscarawas County - OH	14.8 %	13.7 %	38.1 %	7.9 %	1.2 %	1.0 %	41.6 %	9.1 %	15.6 %
Wayne County - OH	15.2 %	10.6 %	34.5 %	6.8 %	1.4 %	1.7 %	51.0 %	0.0 %	15.2 %

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 Northeast Ohio service area has a slightly larger White female population than the US as a whole, a slightly larger 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 lower than those of the US as a whole. There are a slightly larger percentage of people who are unemployed in the Affiliate service area. The Affiliate service area has a substantially smaller percentage of people who are foreign born and a substantially smaller percentage of people who are linguistically isolated. There are a slightly smaller percentage of people living in rural areas, a slightly smaller percentage of people without health insurance, and a substantially smaller percentage of people living in medically underserved areas.

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

- Cuyahoga County

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

- Lorain County

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

- Holmes County

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

- Harrison County

The following county has a substantially larger percentage of adults without health insurance than does the Affiliate service area as a whole:

- Holmes County

Priority Areas

Healthy People 2020 Forecasts

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

HP2020 has several cancer-related objectives, including:

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

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

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

These data are used to estimate how many years it will take for each county to meet the HP2020 objectives. Because the target date for meeting the objective is 2020, and 2008 (the middle of the 2006-2010 period) was used as a starting point, a county has 12 years to meet the target.

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

Identification of Priority Areas

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

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

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

Counties are classified as follows (Table 2.6):

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

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

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

If the time to achieve a target cannot be calculated for one of the HP2020 indicators, then the county is classified based on the other indicator. If both indicators are missing, then the county is not classified. This doesn't mean that the county may not have high needs; it only means that sufficient data are not available to classify the county.

Affiliate Service Area Healthy People 2020 Forecasts and Priority Areas

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

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

Trends can change for a number of reasons, including:

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

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

Table 2.7. Intervention priorities for Komen Northeast Ohio 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
Ashtabula County - OH	Highest	13 years or longer	13 years or longer	Rural
Harrison County - OH	Highest	SN	13 years or longer	Poverty, rural, medically underserved
Jefferson County - OH	Highest	13 years or longer	13 years or longer	Rural
Lorain County - OH	Highest	13 years or longer	13 years or longer	%Hispanic
Mahoning County - OH	Highest	13 years or longer	13 years or longer	
Ashland County - OH	High	9 years	13 years or longer	Rural
Coshocton County - OH	High	9 years	13 years or longer	Rural
Cuyahoga County - OH	High	11 years	13 years or longer	%Black/African-American, medically underserved
Portage County - OH	High	8 years	13 years or longer	Rural
Stark County - OH	High	9 years	13 years or longer	
Lake County - OH	Medium High	13 years or longer	5 years	
Medina County - OH	Medium High	3 years	13 years or longer	Rural
Trumbull County - OH	Medium High	5 years	13 years or longer	Rural
Wayne County - OH	Medium High	2 years	13 years or longer	Rural
Carroll County - OH	Medium	Currently meets target	13 years or longer	Rural, medically underserved
Columbiana County - OH	Medium	Currently meets target	13 years or longer	Rural
Richland County - OH	Medium	13 years or longer	Currently meets target	Rural
Summit County - OH	Medium	10 years	1 year	
Tuscarawas County - OH	Medium	Currently meets target	13 years or longer	Rural
Belmont County - OH	Low	Currently meets target	2 years	Rural, medically underserved
Geauga County - OH	Low	5 years	Currently meets target	Rural
Holmes County - OH	Low	2 years	Currently meets target	Education, language, rural, insurance, 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.

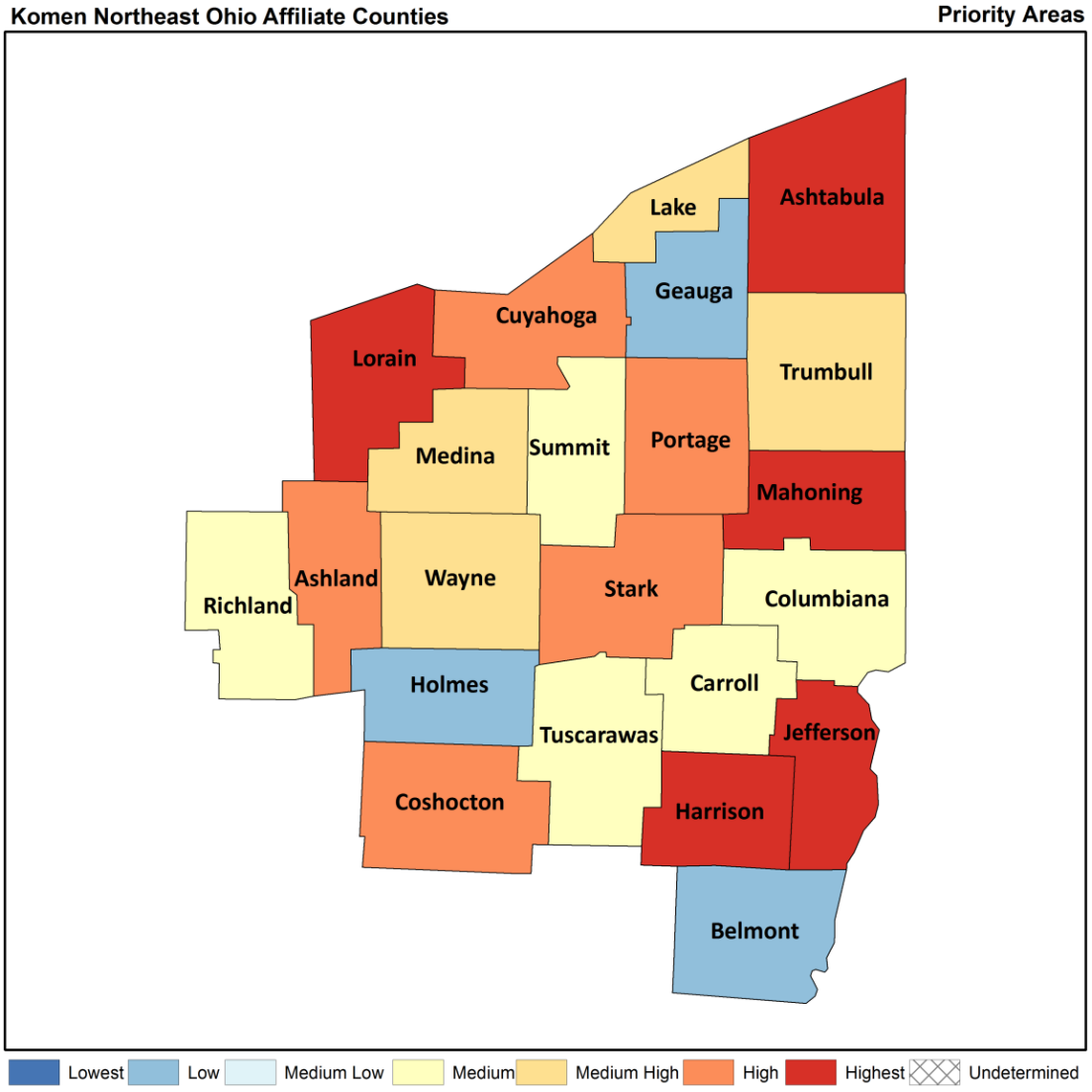

Figure 2.1. Intervention priorities

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

Five counties in the Komen Northeast Ohio service area are in the highest priority category. Four of the five, Ashtabula County, Jefferson County, Lorain County and Mahoning County, are not likely to meet either the death rate or late-stage incidence rate HP2020 targets. One of the five, Harrison County is not likely to meet the late-stage incidence rate HP2020 target.

Incidence trends in Harrison County (30.0 percent per year) are significantly less favorable than the Affiliate service area as a whole (0.5 percent per year). Screening percentages in Harrison County (51.0 percent) are significantly lower than the Affiliate service area as a whole (78.0 percent).

Harrison County has high percentage of poverty. Lorain County has a relatively large Hispanic/Latina population.

High Priority Areas

Five counties in the Komen Northeast Ohio service area are in the high priority category. All of the five, Ashland County, Coshocton County, Cuyahoga County, Portage County and Stark County, are not likely to meet the late-stage incidence rate HP2020 target.

The incidence rates in Cuyahoga County (127.8 per 100,000) are significantly higher than the Affiliate service area as a whole (120.6 per 100,000). The late-stage incidence rates in Cuyahoga County (47.0 per 100,000) are significantly higher than the Affiliate service area as a whole (43.3 per 100,000).

Cuyahoga County has a relatively large Black/African-American population.

Selection of Target Communities

Data reveals that the Komen Northeast Ohio (NEO) service area experiences a disproportionate burden of breast cancer compared to the other three Ohio Komen Affiliates (Table 2.8). The Komen NEO service area accounts for 39.2 percent of the female population in the state of Ohio, which is the greatest concentration of women among the four Ohio Komen Affiliates. Women living within the boundaries of Komen NEO account for 41.7 percent of all new breast cancer cases, 40.8 percent of all new late-stage diagnoses, and 42.4 percent of all breast cancer deaths in the state.

Table 2.8. Number of new breast cancer incidence cases, late-stage cases, and deaths by Ohio Komen service areas

Population Group	Female Population	Incidence		Late-Stage Incidence		Deaths	
		# of New Cases	Percent of Total Cases	# of New Cases	Percent of Total Cases	# of Deaths	Percent of Total Deaths
US	154,540,194	198,602		70,218		40,736	
Ohio	5,895,383	8,319	4.2%	2,972	4.2%	1,820	4.5%
Komen NEO	2,309,143	3,470	41.7%	1,213	40.8%	771	42.4%
Komen Columbus	1,442,796	1,895	22.7%	689	23.1%	412	22.6%
Komen Greater Cincinnati	1,581,596	2,179	26.1%	774	26.0%	452	24.8%
Komen NWO	872,335	1,159	13.9%	432	14.5%	262	14.4%

Data are for years 2006-2010.
Ohio data are compared to US data; Komen Affiliate service area data are compared to Ohio data.
Komen Cincinnati covers areas in the states of Indiana and Kentucky and Komen Northwest Ohio covers areas in the state of Michigan; as a result, the service area data will not add up to match Ohio numbers and the percentages will not total 100%.
Source of population data: US Census Bureau – Population Estimates.
Source of incidence and late-stage data: NAACCR – CINA Deluxe Analytic File.
Source of death rate data: CDC – NCHS mortality data in SEER*Stat.
Percent of total for state calculated over national average.
Percent of total for region calculated over state average.

When compared to the other Ohio Komen Affiliate service areas, Komen NEO accounts for the most demographic diversity, with 83.0 percent White, 15.0 percent Black/African-American, and 3.1 percent Hispanic/Latina (Table 2.9). Although breast cancer incidence is lower among Black/African-American women nationally, they have a 41.0 percent higher breast cancer death rate than White women, making Black/African-American women more susceptible to dying from the disease (Susan G. Komen [Komen], 2014). The five-year relative survival rate for breast cancer among Black/African-American women is only 79 percent compared to 91 percent among White women (Komen, 2014). There are many possible reasons for this difference in survival rates, including biological and genetic differences in tumors, the presence of risk factors, barriers to health care access, health behaviors, and later stage of disease at diagnosis (Komen, 2014).

Table 2.9. Key population characteristics by Komen service area – race and age

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%
Ohio	84.2%	13.4%	0.3%	2.0%	97.0%	3.0%	50.5%	36.9%	16.0%
Komen NEO	83.0%	15.0%	0.3%	1.7%	96.9%	3.1%	53.2%	39.6%	17.7%
Komen Cincinnati	83.9%	13.6%	0.3%	2.2%	97.7%	2.3%	49.2%	35.4%	15.0%
Komen Columbus	85.3%	11.8%	0.4%	2.6%	97.3%	2.7%	47.3%	33.6%	13.9%
Komen NWO	90.5%	8.0%	0.4%	1.1%	95.6%	4.4%	50.6%	37.4%	16.3%

Data are for 2011.
Ohio data are compared to US data; Komen Affiliate service area data are compared to Ohio data.
Data are in the percentage of women in the population.
AIAN – American Indian Alaska Native
API – Asian Pacific Islander
Komen Cincinnati covers areas in the states of Indiana and Kentucky and Komen Northwest Ohio covers areas in Michigan; as a result, the numbers will not add up to 100% for service area level data.
Source: US Census Bureau – Population Estimates.

The Komen NEO service area also encompasses a large population of Amish women; Holmes County is home to the largest Amish settlement in the world, representing 227 Amish church districts and 30,000 Amish individuals (Katz, Ferketich, Broder-Oldach, Harley, Reiter, Paskett, & Bloomfield, 2012; "Ohio Amish" n.d.). Research has shown that Amish women have lower breast cancer incidence rates than their non-Amish counterparts, but are diagnosed at more advanced stages than non-Amish women (Katz, Ferketich, Paskett, Harley, Reiter, Lemeshow, & Bloomfield, 2011). Amish women typically lack insurance and do not seek mainstream medical care due to their beliefs, possibly contributing to their later stage at diagnosis.

Additionally, more than half (53.2 percent) of the female population living in the Komen NEO service area are over the age of 40 (Table 9). Given that an individual's chance of being diagnosed with breast cancer increases with age, women in Komen NEO's service area are more at-risk of developing, and dying from, the disease (Susan G. Komen [Komen], 2013).

Because the NEO region encompasses the majority of female residents in Ohio, NEO contains a higher number of females with no insurance when compared to the other Ohio Komen Affiliates (Table 2.10). Lack of insurance is a barrier to screening, diagnosis, and treatment for breast cancer, leading to potentially worse survival outcomes for this group of women (Sabatino, Thompson, Coughlin & Schappert, 2009; Urban, Anderson & Peacock, 1994). While a lack of insurance is said to play a primary role in influencing a woman's decision to actively seek out breast cancer screening services, research has shown that up to 50 percent of insured women do not receive annual mammography (Laino, 2011). This indicates that insured women may face barriers other than financial limitations that contribute to higher than average Affiliate service area statistics. These issues will be explored further in the Health Systems Analysis and Qualitative Data sections of this report.

Table 2.10. Health insurance estimates for females ages 40-64 in Ohio Komen service areas

	US	Ohio	Komen NEO	Komen Columbus	Komen Greater Cincinnati	Komen NWO
Female Population	154,540,194	5,895,383	2,309,143	1,442,796	1,581,596	872,335
No Health Insurance (percentage)	16.6%	13.4%	14.4%	14.2%	13.2%	13.4%
No Health Insurance (number of individuals)	25,653,672	789,981	332,516	204,877	208,770	116,892

Ohio data are compared to US data; Komen Affiliate service area data are compared to Ohio data.
Source of population data: US Census Bureau – Population Estimates.
Source of health insurance data: US Census Bureau – Small Area Health Insurance Estimates (SAHIE) for 2011.
Komen Cincinnati covers areas in the states of Indiana and Kentucky and Komen Northwest Ohio covers areas in the state of Michigan; as a result, the service area data will not add up to match Ohio numbers and the percentages will not total 100%.

Statistics provided in this report further illuminate the great challenges that Komen NEO faces in addressing the many demographic and socio-economic differences within the 22-county Affiliate service area. The NEO service area encompasses large urban population centers, like the city of Cleveland in Cuyahoga County and the city of Akron in Summit County; sprawling suburban areas of high affluence, like Geauga, Lake, and Medina Counties; and many poverty-stricken communities in rural Appalachia, like Holmes, Jefferson, Harrison, and Columbiana Counties.

For instance, only 20.2 percent of Geauga County residents have incomes below 250 percent of the Federal Poverty Level (FPL), while nearly half (48.1 percent) of Holmes County residents have incomes below 250 percent of the FPL. Less than 7.0 percent of Medina County residents have less than a high school education, while 43.6 percent of Holmes County residents never graduated high school. Only 5.3 percent of Summit County residents live in medically underserved areas, while 100 percent of Harrison County residents live in a medically underserved area (Table 2.5). These statistical disparities show that the breast health needs and barriers to breast health services will look different for each county in the Komen NEO service area.

In an effort to streamline resources and be most effective in research efforts, Komen NEO has chosen five target communities, known as “communities of interest” (COI), within the 22-county service area to do additional investigation. These COI’s will help Komen NEO determine why breast cancer statistics are so much poorer in NEO than the rest of the state. When selecting COI’s, Komen NEO reviewed Healthy People (HP) 2020 goals and objectives related to breast cancer.

Additional key indicators reviewed in the COI selection process include:

- Total female population
- Percent of female population over the age of 40
- Percent of non-White female population
- Percent of health insurance among women ages 40-64
- Mammography screening percentages
- Residents living below the Federal Poverty Level

- Residents living in rural areas
- Residents living in medically underserved areas
- Breast cancer incidence rates and trends
- Breast cancer death rates and trends
- Late-stage breast cancer diagnosis rates and trends

The five areas identified as highest priority in the Komen NEO service area are: Ashtabula County, Harrison County and Jefferson County, Lorain County, Mahoning County, and Cuyahoga County (Table 2.11). All of these areas were determined to need 13 years or longer to achieve the Healthy People 2020 death rate of 20.6 (per 100,000) and late-stage incidence rate of 41.0 (per 100,000), with the exception of Harrison County which had too few numbers to predict death rate trends (Table 2.7). In order to stabilize the rates for Harrison County, Komen NEO elected to combine Harrison and Jefferson Counties into one COI, as these counties have very similar demographics and breast cancer statistics, and they are geographically contiguous.

Table 2.11. Select key indicators for communities of interest

Geographic Area	Total Female Population	Females Age 40+	Non-White	Uninsured (40-64)	No Mammography	Incidence Rates	Late-Stage Diagnosis Rates	Death Rates
US	154,540,194	48.3%	21.2%	16.6%	22.5%	122.1	43.7	22.6
Ohio	5,895,383	50.5%	15.8%	14.0%	23.0%	120.8	44.0	24.8
Komen NEO	2,309,143	53.2%	17.0%	14.4%	22.4%	120.6	43.3	24.8
Ashtabula	51,211	53.4%	4.3%	15.8%	20.4%	111.8	43.0	25.7
Cuyahoga	680,385	52.6%	35.2%	15.0%	21.9%	127.8	47.0	25.6
Harrison	8,022	56.1%	3.3%	16.0%	49.4%	97.9	37.8	SN
Jefferson	36,449	56.2%	7.0%	15.2%	36.1%	113.3	43.8	26.1
Lorain	152,434	52.4%	11.2%	13.6%	14.9%	112.8	40.9	27.5
Mahoning	125,084	56.0%	18.4%	15.1%	28.5%	123.1	46.6	28.6

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 population data: US Census Bureau – Population Estimates.
Source of health insurance data: US Census Bureau – Small Area Health Insurance Estimates (SAHIE) for 2011.
Source of screening data: CDC – Behavioral Risk Factor Surveillance System (BRFSS).
Source of incidence and late-stage data: NAACCR – CINA Deluxe Analytic File.
Source of death rate data: CDC – NCHS mortality data in SEER*Stat.

Ashtabula County

Ashtabula County has a large female population (n=51,211) that represents 2.2 percent of the Komen NEO service area. Although the incidence rate (111.8) is lower than the US (122.1), Ohio (120.8), and Komen NEO service area (120.6), Ashtabula County's death rate (25.7) is higher than those same areas (22.6, 24.8, and 24.8 respectively). The late-stage diagnosis rate (43.0) is above the HP2020 goal and is increasing at a rate of 0.5 percent annually.

Ashtabula County has a large rural population (46.4 percent), a slightly older population of females aged 40 and older (53.4 percent), and a considerable amount of the population (17.2 percent) have incomes below 100 percent of the FPL. There is also a significant portion of 40-

64 year olds (40.5 percent) who have incomes below 250 percent of the FPL. There are, however, a high percentage of women in Ashtabula County who receive a mammogram at least every two years (79.6 percent). Knowing that women in Ashtabula County are being screened at such a high percentage, there must be other factors contributing to the area's high death rate. This issue will be explored further in the Heath Systems Analysis and Qualitative Data sections of this report.

Harrison County and Jefferson County

Because Harrison County has small numbers of cases and similar population characteristics to Jefferson County, combining these two counties together helps stabilize incidence and death rates. The combination of these two areas also helps address the shared community characteristics of an older female and rural population. Both Harrison and Jefferson Counties have unfavorable incidence rate trends when compared to the Komen NEO service area.

Harrison County has a small population of females (n=8,022), accounting for 0.3 percent of the total population in the Komen NEO service area. The incidence rate in this county is low (97.9), but the area has a significantly increasing incidence trend of 30.0 percent. The death rate for Harrison County is unable to be determined due to small numbers. The late-stage diagnosis rate of 37.8 is below the Komen NEO rate of 43.3, but there is a substantial increasing trend of 16.3 percent. The number of new breast cancer cases and cancer deaths suggest that the rates and trends should be interpreted with caution, as low numbers of cases can produce unstable rates.

Harrison County is a completely (100 percent) medically underserved area with a large rural population (84.1 percent) experiencing high levels of residents with incomes below poverty level (20.1 percent under 100 percent FPL, 43.8 percent under 250 percent FPL). Additionally, this population exhibits significantly low numbers of mammography screening every two years (50.6 percent). These socioeconomic characteristics coupled with the breast cancer statistics indicate that women in Harrison County potentially experience barriers when trying to access breast health services. The Health Systems Analysis component of this report will investigate this issue, as it is vitally important to understand how accessible breast health services are to women in this region.

Jefferson County has a population of 36,449 females (1.6 percent of the service area population). The incidence rate is 113.3 with an increasing trend of 6.8 percent. The death rate is 26.1 with a slight decreasing trend of 1.5 percent. The late-stage diagnosis rate (43.8) is average compared to the US, Ohio, and Komen NEO service area, but the county has a large increasing trend of 7.9 percent. Important attributes of Jefferson County include a larger Black/African-American female population (6.3 percent), a large rural population (39.0 percent), low mammography screening percentage (63.9 percent), and one of the highest percentages of females 65 years of age and older (20.3 percent) in the Komen NEO service area. Given the similarities of Harrison and Jefferson Counties, Komen NEO will investigate whether or not women in these counties experience similar barriers to education, screening, and treatment services in the next sections of this report.

Lorain County

Lorain County has a large female population (n=152,434) that represents 6.6 percent of the Komen NEO service area. The incidence rate in Lorain County is 112.8, which is lower than the US, Ohio, and Komen NEO service area rates; however, Lorain County has a substantially high death rate (27.5) compared to national, state, and service area level data. Although Lorain County has decreasing incidence and death rate trends, it has an increasing late-stage trend (0.9 percent). The population in Lorain County is diverse, with large Hispanic/Latino (8.3 percent, n=12,652) and Black/African-American populations (9.4 percent, n=14,329). Screening percentages among women in Lorain County are higher than average (85.1 percent), indicating that variables other than access to screening facilities and early detection are contributing to the high death rates facing this COI. The issue of high screening percentages coupled with high death rates will be further explored in the Heath Systems Analysis section of this report.

Mahoning County

Mahoning County was also identified as an area of highest need. This county has a larger female population of 125,084, representing 5.4 percent of the Komen NEO service area. The incidence rate of 123.1 has a significantly high trend (4.6 percent) and is higher than the US, Ohio, and Komen NEO service area rates. The death rate has a significant decreasing trend (1.2 percent), but the actual death rate of 28.6 is substantially higher than the US, Ohio, and the Komen NEO service area rates. Lastly, the late-stage incidence rate (46.6) is higher than the US, Ohio, and the Komen NEO service area with a significant increasing trend (5.2 percent).

Mahoning County has a larger Black/African-American female population (17.2 percent, n=21,514) than the majority of the Komen NEO service area; a high percentage of the population is unemployed (11.1 percent); a large portion of 40-64 year olds (38.1 percent) have incomes below 250 percent of the FPL; a high percentage of females over the age of 40 (56.0 percent) live in this area; and 1.1 percent of the population is linguistically isolated. The mammography screening percentage for Mahoning County is lower than the Komen NEO service area (71.5 percent and 77.6 percent respectively). Mahoning County is different from every other COI discussed thus far, as it has high rates of incidence, late-stage diagnosis, and deaths. Reasons for these high levels will be explored in the subsequent sections of this report.

Cuyahoga County

Cuyahoga County is an urban county that houses the city of Cleveland, the most populous city in the Komen NEO service area. Cuyahoga County accounts for 29.5 percent of the Komen NEO service area's female population, or 680,385 females. Both the incidence rate (127.8) and late-stage diagnosis rate (47.0) are significantly higher than the Komen NEO service area rate. The death rate is 25.6, which is higher than the US, Ohio, and the Komen NEO service area rates. Interestingly, Cuyahoga County is home to more than half of all of the screening and treatment facilities in the Komen NEO service area; thus, a lack of available resources is probably not a contributing factor to these statistics. There is a high probability, however, that even though these facilities are available to women in Cuyahoga County, they may not be easily or equally accessible for all populations.

Cuyahoga County represents a diverse population, including Black/African-American females (32.0 percent, n=217,723); Hispanic/Latina females (4.8 percent, n=32,659); Asian Pacific Islander females (2.9 percent, n=19,731); 11.1 percent unemployed; 7.1 percent foreign born; 2.6 percent linguistically isolated; and 23.2 percent of women who live in medically underserved areas. Women in Cuyahoga County are screened at levels that mirror national, state, and regional level averages (78.1 percent), but a large population of females in Cuyahoga County lack health insurance (57,058 women). Because Cuyahoga County represents high levels of minority women, high percentage of individuals with no insurance, and demonstrates high rates of incidence and late-stage diagnosis, it was chosen as the final COI.

Health Systems Analysis Data Sources

An inventory of breast health and breast cancer programs and services in the five Communities of Interest (COI) was collected from a variety of key organizations and institutions that provide screening, diagnostic, and treatment services, education and outreach programs, and survivor support programs. Comprehensive internet searches were conducted and data was utilized from numerous organizations, including the Ohio Department of Health, Food and Drug Administration (FDA) approved mammography centers, the Affiliate's grantee network, and the Center for Health Affairs Ohio Hospital Association (see Appendix A for a complete list of online resources). In addition, hospitals, health departments, health centers, and free clinics in all COIs were contacted by telephone to verify and further explore the information available online, such as hours of operation, phone number, and clinical services offered.

Information collected through these means was inputted into a Health Systems Analysis spreadsheet by service type: screening, diagnostics, treatment, and support. The screening service category encompasses clinical breast exams (CBEs), screening mammograms, mobile mammography units, ultrasounds, and patient navigation. The category of diagnostics includes diagnostic mammograms, ultrasounds, biopsy, MRI, and patient navigation. Treatment modalities counted were chemotherapy, radiation, surgery consultations, surgery, reconstruction, and patient navigation. Support encompasses a broad range of services including support groups, wigs, mastectomy wear, individual counseling/psychotherapy, exercise/nutrition programs, complementary therapies, transportation assistance, financial assistance for cost of living expenses, as well as end of life care, legal services, and education.

In order to understand the effect available health systems have on the statistics for the Affiliate's COIs and the individuals the Affiliate serves, the identified resources were plotted on asset maps by Susan G. Komen Headquarters' Information Technology (IT) staff to visually illustrate the services (or lack thereof) available in each county. Appendix B shows the geographic location of facilities available to women within the borders of the Affiliate's COIs. While every effort was made to ensure these findings were comprehensive, it may be possible that a facility or organization was missed or has since closed; as a result, these findings should not be considered exhaustive and/or final.

Quality of Care Indicators

For all health care facilities and hospitals, an additional layer of analysis was applied using quality of care indicators. Quality of care indicators are quantifiable measures related to the process of care, outcomes of care, and patient satisfaction levels from a particular program and/or organization. Multiple national organizations have developed key quality of care indicators for breast health services, and if an organization meets all of the key indicators they are designated an "accredited" health care institution. These accreditations outline key quality of care indicators health care institutions must meet in order to obtain and/or retain accreditation status. The following six accreditations were considered high quality of care indicators in Komen NEO's health system analysis.

FDA Approved Mammography Facilities

The Food and Drug Administration (FDA) passed the Mammography Quality Standards Act (MQSA) in 1992 to ensure facilities meet standards for performing high quality mammography. Accreditation bodies administer the MQSA to evaluate and accredit mammography facilities based upon quality standards. These quality standards are extensive and outline how a facility can operate. For instance, physicians interpreting mammograms must be licensed to practice medicine, be certified to interpret radiological procedures including mammography, and must complete continuing experience or education to maintain their qualifications (US Food and Drug Administration [US FDA], 2014). Radiologic technologists must also be trained and licensed to perform general radiographic procedures and complete continuing experience or education to maintain their qualifications. Facilities are required to maintain personnel records to document the qualifications of all personnel who work at the facility such as physicians, radiologic technologists, or medical physicists.

All radiographic equipment used in FDA approved mammography centers must be specifically designed for mammography and must not be equipment designed for general purpose or equipment that has been modified with special attachments for mammography. Equipment regulations also apply to compression paddles, image receptor size, light fields and magnification, focal spot selection, x-ray film, film processing solutions, lighting, and film masking devices. Facilities must also prepare a written report of the results of each mammography examination performed under its certificate. The report must include the name of the patient and an additional patient identifier, date of examination, the name of the interpreting physician, and the overall final assessment of findings. Findings from mammograms are classified into four different categories, including negative, benign, probably benign, and highly suggestive of malignancy. An assessment can also be assigned as incomplete indicating additional imaging evaluation is needed.

FDA approved mammography facilities are obligated to communicate the results of mammograms to the patient and the patient's primary care provider in a written report within 30 days. Each facility must also maintain mammography films and reports in a permanent medical record for a period of no less than five years or longer if mandated by State or local law. Patients can request to permanently or temporarily transfer the original mammograms and patient report to a medical institution, physician, health care provider, or to the patient directly. Any fees for providing transfer services shall not exceed the documented costs associated with this service.

A quality assurance program must be established at each facility to ensure safety, reliability, clarity, and accuracy of mammography services. At least once a year, each facility undergoes a survey by a medical physicist that includes the performance of tests to ensure the facility meets quality assurance requirements. The FDA evaluates the performance of each certificated agency annually through the use of performance indicators that address the adequacy of program performance in certification, inspection, and enforcement activities. Only facilities that

are accredited by FDA accrediting bodies or are undergoing accreditation by accrediting bodies may obtain a certificate from the FDA to legally perform mammography (US FDA, 2014).

Federally Qualified Health Centers (FQHCs)
Federally Qualified Health Centers (FQHCs) are community-based organizations that receive grants under Section 330 of the Public Health Service Act to provide health services to persons of all ages regardless of their ability to pay. FQHCs must serve an underserviced area or population, provide comprehensive services including preventive care, offer a sliding fee scale, have ongoing quality assurance programs, and have a governing board of directors. FQHCs qualify for enhanced reimbursement from Medicare, Medicaid, and other public benefits (US Department of Health and Human Services [US DHHS], n.d.).

American College of Surgeons Commission on Cancer Certification (CoCC)
Applying and sustaining an American College of Surgeons Commission on Cancer Certification (CoCC) is a voluntary effort a cancer program can undertake to ensure a range of services necessary to diagnose and treat cancer, as well as rehabilitate and support patients and their families, are available (American College of Surgeons [ACoS], 2013). There are various categories of cancer programs, and each facility is assigned a category based on the type of facility or organization, services provided, and cases accessioned or recorded. Program categories include: Integrated Network Cancer Program (INCP); NCI-Designated Comprehensive Cancer Center Program (NCIP); Academic Comprehensive Cancer Program (ACAD); Veterans Affairs Cancer Program (VACP); Comprehensive Community Cancer Program (CCCP); Hospital Associate Cancer Program (HACP); Pediatric Cancer Program (PCP); and Freestanding Cancer Center Program (FCCP) (ACoS, 2013).

CoCC cancer programs are surveyed every three years. In preparation for survey, the cancer committee for that facility must assess program compliance with the requirements for all standards outlined in *Cancer Program Standards 2012: Ensuring Patient-Centered Care*. An individual must then review and complete an online Survey Application Record (SAR). In addition, the individual responsible for completing the SAR will perform a self-assessment and rate compliance with each standard using the Cancer Program Ratings Scale.

The surveyor's role is to assist in accurately defining the standards and verifying the facility's cancer program is in compliance. To accomplish this task, the surveyor will meet with the cancer committee, cancer registry staff and cancer liaison physicians, review pathology reports, and attend a cancer conference to observe the multidisciplinary patient management discussions and confirm treatment is planned using nationally recognized, evidence-based treatment guidelines. CoCC-accredited programs must also submit documentation of cancer program activities with the SAR using multiple sources such as policies, procedures, manuals, and grids.

Each cancer program standard is rated on a compliance scale that consists of the score of (1+) commendation, (1) compliance, (5) noncompliance, and (8) not applicable. A deficiency is defined as any standard with a rating of five. A deficiency in one or more standards will affect

the accreditation award. Commendation ratings (+1) are valid for eight standards, can only be earned at the time of survey, and are used to determine the accreditation award and award level (bronze, silver, or gold). Accreditation awards are based on consensus ratings by the cancer program surveyor, CoCC staff, and when necessary, the Program Review Subcommittee. A program can earn one of the following Accreditation Awards; three-year with commendation accreditation, three-year accreditation, three-year accreditation with contingency, provisional accreditation, or no accreditation. Programs are surveyed at three-year intervals from the date of survey.

Award notification takes place within 45 days following the completed survey and will include The Accredited Cancer Program Performance Report. This report includes a comprehensive summary of the survey outcome and accreditation award, the facility's compliance rating for each standard, an overall rating compared with other accredited facilities nation- and state-wide, and the category of accreditation. In addition, a narrative description of deficiencies that require correction, suggestions to improve or enhance the program, and commendations awarded are also included.

American College of Surgeons National Accreditation Program for Breast Centers (NAPBC)
The American College of Surgeons' National Accreditation Program for Breast Centers (NAPBC) is a consortium of national professional organizations focused on breast health and dedicated to improving quality of care and outcomes for patients with diseases of the breast (ACoS, 2014). The NAPBC utilizes evidence-based standards as well as patient and provider education, and encourages leaders from major disciplines to work together to diagnose and treat breast disease. The NAPBC has defined 28 program standards and 17 program components of care that provide the most efficient and contemporary care for patients diagnosed with diseases of the breast. Quality standards cover a range of topics and levels of operation including leadership, clinical management, research, community outreach, professional education, and quality improvement (ACoS, 2014).

To be considered for initial survey, breast center leadership must ensure clinical services, interdisciplinary/multidisciplinary conference(s), and quality management programs are in place and ensure a facility can meet the requirements outlined for all standards. Critical standards include having breast program leadership that is responsible and accountable for services and also establishes, monitors, and evaluates the interdisciplinary breast cancer conference frequency, multidisciplinary and individual attendance, prospective case presentation, and total case presentation annually. In addition, the interdisciplinary patient management standard requires patient management to be conducted by an interdisciplinary team after a patient is diagnosed with breast cancer.

Breast center leadership then completes a pre-application to participate and pay for the survey fee within 30 days of the receipt from the NAPBC. To prepare for a survey, the breast center must complete a Survey Application Record (SAR) prior to the on-site visit. The SAR is intended to capture information about the breast center activity and includes portions of individuals to perform a self-assessment and rate compliance with each standard using a provided rating

system. The NAPBC will then complete a survey of the facility within six months. A survey of a facility typically includes a tour of the center, a meeting between the surveyor and breast center leadership and staff, chart and medical record review, and the attendance of a breast conference.

Accreditation awards are based on consensus ratings by the surveyor, the NAPBC staff, and, if required, the Standards and Accreditation Committee. Accreditation award is based on compliance with 28 standards. A three year, full accreditation is granted to centers that comply with 90 percent or more of the standards with resolution of all deficient standards documented within 12 months of survey. Centers that do not resolve all deficiencies within the 12 month period risk losing NAPBC accreditation status and are required to reapply. Once a performance report and certificate of accreditation are issued, these centers are surveyed every three years.

A three-year contingency accreditation is granted to centers that meet less than 90 percent but more than 75 percent of the standards at the time of survey. The contingency status is resolved by the submission of documentation of compliance within 12 months from the date of survey. A performance report and certificate of accreditation are issued, and these facilities are surveyed every three years. An accreditation can be deferred if a center meets less than 75 percent of the standards at the time of the survey. The deferred status is resolved by the submission of documentation of compliance within 12 months from the date of survey. Based on the resolution of deficiencies and survey results, a performance report and certificate of accreditation are issued, and these facilities are surveyed every three years. For the complete list of NAPBC quality standards, visit: http://www.napbc-breast.org/standards/standards.html.

American College of Radiology Breast Imaging Centers of Excellence (BICOE)
The American College of Radiology (ACR) Breast Imaging Centers of Excellence (BICOE) designation is awarded to breast imaging centers that seek and earn accreditation in the ACR's entire voluntary breast imaging accreditation programs and modules, in addition to the Mandatory Mammography Accreditation Program (MMAP) (American College of Radiology [ACR], n.d.). The ACR MMAP is designed to provide facilities with peer review and constructive feedback on staff qualifications, equipment, quality control, quality assurance, image quality, and radiation dose. This ensures facilities comply with the 1992 Mammography Quality Standards Act (MQSA), which requires all mammography facilities be accredited. In order to receive the ACR's BICOE designation, a facility must be accredited by the ACR in mammography, stereotactic breast biopsy, breast ultrasound, and, effective January 1, 2016, breast MRI.

The ACR will send a BICOE certificate to each facility that fulfills the necessary requirements. The designation remains in effect as long as all breast imaging facilities (an organizations home location or a different location) remain accredited in all required breast imaging services provided. If the center or facility neglects to renew any of its accreditations or fails during renewal, the facility will be notified that it no longer has the BICOE designation and the BICOE certificate must be removed from public display. Some centers will need to specifically request a BICOE designation, while in most cases the ACR will consult its database and automatically

provide an eligible center a BICOE certificate if the center is at a single physical location and meets all breast imaging requirements (ACR, n.d.).

National Cancer Institute Designated Cancer Centers
A National Cancer Institute (NCI) designated Cancer Center is an institution dedicated to researching the development of more effective approaches to the prevention, diagnosis, and treatment of cancer (National Cancer Institute [NCI], 2012). A NCI-designated Cancer Center conducts cancer research that is multidisciplinary and incorporates collaboration between institutions and university medical centers. This collaboration also provides training for scientists, physicians, and other professionals interested in specialized training or board certification in cancer-related disciplines. NCI-designated Cancer Centers also provide clinical programs that offer the most current forms of treatment for various types of cancers and typically incorporate access to clinical trials of experimental treatments. In addition, public education and community outreach regarding cancer prevention and screening are important activities of a NCI-designated Cancer Center (NCI, 2012).

Health Systems Overview

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

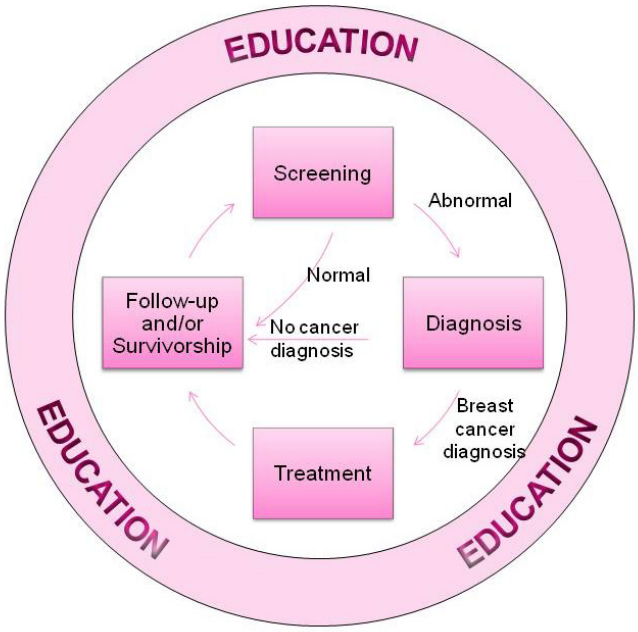

Figure 3.1. Breast Cancer Continuum of Care (CoC)

While an individual may enter the continuum at any point, ideally someone would enter the CoC by getting screened for breast cancer with either a clinical breast exam or a screening mammogram. If the screening test results are normal, they would loop back into follow-up care, where they would get another screening exam at the recommended interval (e.g., every year). Education plays a role in both providing education to encourage people to get screened and reinforcing the need to continue to get screened routinely thereafter.

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

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

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

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

Additionally, individuals may not have access to quality, affordable care in accessible locations, which can prevent them from either entering in or advancing through the CoC. In a recent study of geographic access and the use of screening mammography, an inadequate capacity of

screening services was defined as less than 1.2 mammography machines per 10,000 women aged 40 or older (Elkin et al., 2010). The study also found that residence in a county with inadequate mammography capacity was associated with lower odds of a recent mammogram, controlling for demographic and health care characteristics. The authors also noted that efforts to increase the number of mammography machines in low-capacity areas may improve breast cancer screening percentage and help reduce geographic disparities in breast cancer screening (Elkin et al., 2010).

Insurance status and coverage type can also act as barriers to entering and moving through the CoC. For example, among women younger than 65 years of age, lacking health insurance or having a fee-for-service insurance was strongly associated with failure to report a recent cancer screening (Hsia et al, 2000). In addition, an analysis of the National Cancer Database revealed that individuals without health insurance or with Medicaid coverage were more likely to present with advanced-stage breast cancer (Halpem, Bian, Ward, Schrag & Chen, 2007).

Patient navigators have been shown to increase the likelihood that an individual will stay in the breast health CoC (Phillips, Rothstein, Beaver, Sherman, Freund & Battaglia, 2011). In regards to patient navigation services offered in Northeast Ohio, though, there is much variation between organizations in how navigation services are organized and delivered. Depending on where a woman receives care, the level and type of patient navigation may vary. For example, the Cleveland Clinic has four different types of navigators to help an individual through the CoC. These include clinical navigators to assist with outpatient clinical areas such as the diagnosis, treatment and follow-up portions of care; service navigators to help individuals connect with social service agencies; financial navigators to assist with financial concerns or applications for insurance; and community navigators that collaborate with neighborhood agencies. Other organizations, such as MetroHealth and University Hospitals, have different types of patient navigators that work with physicians to coordinate care and communicate with members of an individual's care team to create smooth transitions throughout a patient's treatment and reduce barriers to receiving care.

Resources and assets available to individuals along the CoC were collected for each COI (Table 3.1). The following sections outline the specific breast health and breast cancer services available to all individuals within the geographic boundaries of each COI.

Table 3.1. Breast health services in Communities of Interest

Characteristic	Ashtabula	Cuyahoga	Harrison and Jefferson	Lorain	Mahoning
Total Female Population	51,211	680,385	44,471	152,434	125,084
Total Number of Facilities	29	190	42	53	61
Total Number of BCCP Providers	10	46	18	8	35
Screening Services	15	119	22	29	35
Diagnostic Services	4	58	5	22	21
Treatment Services	2	16	3	7	4
Support Services	19	106	22	30	16
Total Number of Services	**40**	**299**	**52**	**88**	**76**

Total number of services calculated by adding number of screening, diagnostic, treatment, and support services.

Ashtabula County

There are a total of 29 facilities in Ashtabula County that offer 40 services along the breast health CoC. The proportion of individuals to screening facilities is one facility for every 3,414 women. Individuals can obtain a clinical breast exam (CBE) from a general practitioner, but are generally referred to one of the larger hospitals or medical centers in Ashtabula County for a screening and/or diagnostic mammogram, ultrasound, or biopsy. Screening services are available at three major medical centers: Ashtabula County Medical Center (ACMC), University Hospitals Conneaut Medical Center, and University Hospitals Geneva Medical Center. There are three FQHC locations in Ashtabula County – Andover Primary Care (two locations) and Ashtabula Community Health Center - where CBEs and screening mammograms are offered on-site.

Ten facilities and providers in Ashtabula County have contracted with Ohio's Breast and Cervical Cancer Program (BCCP). ACMC and UH Geneva Medical Center are contracted to deliver screening and diagnostic services for women enrolled in the BCCP. ACMC, University Hospitals Conneaut Medical Center, and the Conneaut Family Health Center are FDA approved mammography facilities. Additionally, Project Hoffnung, a free screening program run by the Center for Appalachia Research in Cancer Education, serves Ashtabula County residents by delivering culturally competent breast health information and free women's health screenings to Amish and Mennonite communities via mobile mammography.

Women can obtain diagnostic services through ACMC, University Hospitals Conneaut Medical Center, and University Hospitals Geneva Medical Center. All three facilities offer diagnostic mammography services, and all but University Hospitals Conneaut offer breast ultrasounds. All locations except ACMC offer biopsies; however, ACMC provides breast MRI services. The three major medical centers in Ashtabula County are the only places for women to seek treatment for breast cancer. ACMC is the only provider for chemotherapy and reconstructive surgery in addition to general surgical services.

There are a lack of support services in Ashtabula County focused specifically on survivor needs, including wigs, prostheses, support groups, and complementary therapies. The only services available to breast cancer patients and survivors are 'A Woman's Place' at Discount Drug Mart, Bula Beauty Supply where wigs can be purchased, and Martha's Essential Fittings, a clothing boutique that sells wigs and mastectomy wear. Additionally, the American Cancer Society (ACS) established the 'Look Good…Feel Better Program' at ACMC, which provides free cosmetic kits and workshops for women receiving treatment for breast cancer. There are no survivor support groups or complimentary therapy services available in Ashtabula County, leaving many patients with no emotional support or coping mechanisms.

Gaps in the Continuum of Care

In addition to the lack of support services available, there are no locations in Ashtabula County that have been awarded the American College of Surgeons Commission on Cancer Certification, the National Cancer Institute Designated Cancer Centers, the American College of Radiology Breast Imaging Centers of Excellence, or any facilities that have been recognized by the American College of Surgeons National Accreditation Program for Breast Centers. Additionally, there are no medical centers in Ashtabula County that provide radiation oncology services, indicating that women in this area who are prescribed radiation may have to travel long-distances to facilities out of their county in order to receive care.

Partnerships and Opportunities

Komen NEO provided 10 years of grant funds to University Hospitals Geneva Medical Center for education, CBEs, mammograms, and patient navigation. While the organization was approved for funding in the 2014-2015 grant year, the Affiliate's grant funds were depleted before money could be provided to them. This means Komen NEO does not currently have a grantee geographically located in this COI. Despite not being funded, UH Geneva is still a key partner for the Affiliate and continues to work with Komen NEO to find sources of care for uninsured women in Ashtabula County.

It would be in the best interest of the Affiliate to begin forging partnerships with the two FQHCs in Ashtabula County, as they share a similar mission and target populations. Additionally, provisions outlined in the Affordable Care Act (ACA) expand the capacity of FQHCs and provide funding for navigators to enroll uninsured individuals into ongoing sources of health insurance coverage (National Association of Community Health Centers [NACHC], n.d.). Additionally, Komen NEO will work on locating transportation assistance services for individuals in need of radiation oncology treatment.

Cuyahoga County

A total of 190 facilities provide 299 breast health services along the CoC to individuals in Cuyahoga County. The proportion of individuals to screening facilities is one facility for every 5,717 women, lower than the Ashtabula County proportion. More than 100 facilities provide screening services including 43 FDA approved mammography centers. This is the largest number of screening services for all of the COI's under review; however, Cuyahoga County contains the largest percentage of the female population in Northeast Ohio, indicating that there

is a need for more screening services in this county. Only 46 facilities and providers in Cuyahoga County are contracted with the BCCP.

Women's Diagnostic Center provides a mobile mammography unit, which includes a portable digital mammography machine, to organizations that request it. The Case Comprehensive Cancer Center (CCCC) – a partnership between University Hospitals Seidman Cancer Center, Cleveland Clinic Taussig Cancer Center, and Case Western Reserve University's Medical School – provides community breast screenings through the mobile unit and education to the community regardless of the individual's ability to pay. The CCCC is an NCI-designated Cancer Center. MetroHealth Cancer Center, the County hospital, provides on-site mammography in addition to community health fairs that utilize the mobile mammography unit to provide breast cancer education and screenings to communities' in-need. In addition, MetroHealth employs bilingual breast staff and provides publications and medical care in Spanish for individuals whose native language is not English.

There are 19 community health center locations in Cuyahoga County where women can get CBEs, mammograms, and referrals for diagnostic and treatment services if necessary. These facilities include North Coast Health Ministry (an FQHC "look alike" that does not receive federal funds) and four FQHCs with multiple locations. These FQHCs include Northeast Ohio Neighborhood Health Services (NEON), Care Alliance, Neighborhood Family Practice, and The Free Clinic. NEON has eight locations and partners primarily major health systems, like the Cleveland Clinic, to provide screening and diagnostic breast health care. NEON has mammography screening services available at some of their campuses. Care Alliance has four locations, Neighborhood Family Practice has five locations, and The Free Clinic has one location; each of these FQHCs provides CBEs, mammograms, and referrals to hospitals for further diagnostic and treatment services.

There are over 50 locations in Cuyahoga County where diagnostic services are provided on-site. Twenty-three of these locations provide biopsy and 11 provide breast MRI. Patient navigation is provided at 25 locations including multiple facilities owned by The Cleveland Clinic, University Hospitals, and MetroHealth. Additionally, there are eight locations that have received the American College of Radiology Breast Imaging Center of Excellence designation.

There are seven facilities and institutions that offer the full CoC in Cuyahoga County. These facilities include: University Hospitals Case Comprehensive Cancer Center, University Hospitals Southwest General, The Cleveland Clinic Taussig Cancer Center, Fairview Hospital, Hillcrest Hospital, The Veteran's Affairs Medical Center, and MetroHealth's Main Campus. MetroHealth's West 150th Health and Surgery Center also provides the full CoC with the exception of radiation treatment. The Cleveland Clinic, University Hospitals, and MetroHealth all provide comprehensive patient navigation programs. Most individuals at these health systems are connected to a navigator at the point of screening and are followed throughout the CoC.

There are 13 locations that are American College of Surgeons CoCC accredited in addition to the National Cancer Institute (NCI) designated Case Comprehensive Cancer Center. There are

also five locations which maintain programs that received the American College of Surgeons National Accreditation Program for Breast Centers.

There are more than 100 support services available to individuals in Cuyahoga County. Over 20 locations exist where individuals can purchase wigs, seven locations to buy mastectomy wear, and 11 locations to buy prostheses. There are 25 education programs in Cuyahoga County and 18 support groups available through organizations such as The Cleveland Clinic, MetroHealth, University Hospitals, and The Gathering Place. MetroHealth, University Hospitals Case Comprehensive Cancer Center, and The Cleveland Clinic offer patient support in the form of complementary therapies, side effect management, and exercise and nutrition programs.

Gaps in the Continuum of Care

Cuyahoga County has the highest concentration of breast health services of all COIs, including an NCI-designated Cancer Center. While Cuyahoga County has the largest number of services available in all of the COIs under investigation, the incidence rate (127.8) and late-stage rate (47.0) of breast cancer are significantly higher than the Komen service area (Table 2.1). Cuyahoga County also has a high percentage of uninsured individuals (15.0 percent) aged 40-64 years old, which may influence the availability of access and use of various facilities and treatment modalities (Table 2.5). The relationship between availability of services and access will be explored further in the Qualitative Data section of this report.

Additionally, of the 106 locations that provide screening, diagnostic, and treatment services along the CoC, only 44.0 percent of those facilities are contracted with the BCCP. This means women – who are otherwise eligible to receive BCCP services – that are screened and diagnosed at a non-contracted facility run the risk of eliminating themselves from program eligibility.

Partnerships and Opportunities

Komen NEO partners with many of the health systems, FQHCs, and community-based organizations within Cuyahoga County, as the Komen NEO offices are based in Cleveland and the majority of stakeholder outreach is conducted in this area. Nearly 50 percent of Komen NEO's grantees during the 2014-2015 grant year were located in Cuyahoga County, one of which is the BCCP office for Region 12. To date, the Affiliate has only partnered with two of the four FQHCs in Cuyahoga County; more work will be done to forge collaborations with the two FQHCs that have yet to partner with the Affiliate. Komen NEO will also work with the Region 12 office of the BCCP and the Ohio Department of Health to educate providers and facility administrators on the importance of contracting with the BCCP in an effort to increase the number of BCCP providers in Cuyahoga County.

Harrison and Jefferson Counties

Approximately 42 facilities offer 52 services along the breast health CoC in Harrison and Jefferson Counties. The proportion of individuals to screening facilities is one facility for every 2,021 women. There are 18 facilities and providers that are contracted with the BCCP in these counties. CBEs are provided at 17 locations, including family practitioners and three community

health centers. The three community health centers include Freeport Family Health Center, Family Medical Care, and the Jefferson County 4th Street Health Center. Women can obtain a screening mammogram at the Jefferson County 4th Street Health Center, Harrison Community Hospital, Trinity Medical Center East & West, Images Mammography Center, and at Steuben Radiology Associates, Inc. In addition, two mobile mammography units, from Tiffany Breast Care Center in Youngstown and Diagnostic Medical X-Ray and Imaging in Boardman, serve Harrison and Jefferson Counties.

There are five facilities that provide diagnostic mammograms on-site including two FDA approved mammography centers (Images Mammography Center and Harrison Community Hospital). Images Mammography Center in Jefferson County is part of Trinity Health System and provides diagnostic services, such as diagnostic mammograms and breast biopsies. The BCCP provides diagnostic care through Harrison Community Hospital, Trinity Medical Center East, Images Mammography Center, and the Jefferson County 4th Street Health Center.

Patients are referred to Harrison Community Hospital, the only hospital in Harrison County, or to the Trinity Health System, which includes Trinity Medical Center East, Trinity Medical Center West, and the Tony Teramana Cancer Center, in Jefferson County for more diagnostic and treatment services. Harrison Community Hospital provides screening, diagnostic, and general surgical services to patients.

In regards to treatment options, The Tony Teramana Cancer Center, located in Jefferson County and part of the Trinity Health System, provides the most comprehensive care of any facility located within the two counties. At the Tony Teramana Cancer Center, chemotherapy and radiation are available as well as patient navigation. General surgery is available at Trinity Medical Center West, but there are no reconstructive surgical services available to individuals in these counties.

Tony Teramana Cancer Center and Trinity Medical Center East offer a support group, side effect management, exercise and nutrition programs, and education. Trinity Medical Center West and the Steubenville and Jefferson County health departments provide education materials regarding breast health. There are no locations that offer complimentary therapies. There are two locations to buy wigs in Jefferson County, Hair Unlimited and Maebelle's Wigs & Beauty Supply, but no locations in Harrison County. There are no locations in either county to purchase mastectomy wear. Prostheses can be purchased at two locations in Jefferson County, Hanger Prosthetics & Orthotics and Orthotic-Prosthetic Clinic.

Gaps in the Continuum of Care

Breast health care resources are limited in Harrison County, as Harrison County Hospital is the only location to obtain a mammogram and/or diagnostic services. As evidenced by past studies, availability of mammography screening centers may influence mammography screening percentages (Haplam et al., 2007). Given that nearly 50 percent of women in Harrison County have not received a mammogram in the last two years, it could be said that there is an

inadequate number of screening facilities available to women in this county. This issue will be explored further in the Qualitative Data Analysis section of this report.

There are also no locations to receive breast cancer treatment in Harrison County, meaning an individual would need to travel between 20-30 miles to receive treatment in neighboring Jefferson County. This distance may pose a barrier to receiving treatment for individuals in Harrison County. This issue will also be explored further in the Qualitative Data Analysis section of this report.

There is also a lack of survivorship services in Harrison and Jefferson Counties, as only two locations offer support groups or alternative therapies. In addition, there are only two locations to purchase prostheses and nowhere in either county to purchase mastectomy wear. There are no locations in either Harrison or Jefferson County that have been awarded the American College of Surgeons Commission on Cancer Certification; the National Cancer Institute Designated Cancer Centers; the American College of Radiology Breast Imaging Centers of Excellence; or any facilities that have been recognized by the American College of Surgeons National Accreditation Program for Breast Centers.

Partnerships and Opportunities
Komen NEO currently partners with Trinity Health System, which operates BCCP Region 9, to provide breast health screening and diagnostic services to women of all ages that meet program eligibility requirements in these counties. Little to no relationship exists, however, with the three community health centers serving these counties. Komen NEO will begin conducting outreach to organizational leaders at these health centers to establish an ongoing relationship. The Affiliate will also attempt to locate and/or establish transportation assistance programs in Harrison County for screening services, given that many women may have to travel out of county to receive a mammogram due to the lack of available facilities.

Lorain County
Fifty-three facilities provide 88 services along the breast health CoC to individuals in Lorain County; however, only eight facilities and providers are contracted with the BCCP. The proportion of screening facilities to individuals in Lorain County is one facility for every 5,256 women. CBEs are provided through two family practitioners that collaborate with the BCCP and one community health center, the Lorain County Free Clinic.

Lorain County has 24 locations where mammograms are provided on-site, including 11 locations that are FDA approved mammography centers: University Hospitals Avon Health Center, University Hospitals Elyria Medical Center, Cleveland Clinic Richard E Jacobs Health Center, Premium Diagnostics Center, The Cleveland Clinic Foundation at Chestnut Commons, Mercy Diagnostic Center North, Mercy Health Regional Medical Center, Cleveland Clinic Lorain Family Health Center, Superior Medical Care (Lorain & Sheffield Village), and Mercy Allen Hospital. Mercy Regional Medical Center is recognized as an American College of Radiology Breast Imaging Centers of Excellence.

There are 22 locations where diagnostic mammograms are provided on-site. The BCCP provides services such as diagnostic mammograms and biopsies through Mercy Regional Medical Center, Mercy Allen Hospital, Mercy Diagnostic Center (Elyria South), The Cleveland Clinic at Chestnut Commons, and Premium Diagnostic Center. In regards to treatment options, The Cleveland Clinic's Lorain Family Health & Surgery Center offers the most comprehensive care by providing screening and diagnostic services as well as treatment services, including chemotherapy, radiation and surgery. Mercy Cancer Center also provides chemotherapy and radiation treatment services.

The Cleveland Clinic's Lorain Family Health & Surgery Center provides patient support with programs such as patient navigation, exercise and nutrition programs, individual therapy, support groups, complementary therapies, financial assistance and side effect management. University Hospital's Elyria Medical Center and Avon Health Center, as well as the Cleveland Clinic's Richard E. Jacobs Elyria Family Health Center and Mercy Medical Center, offer only surgical treatment services. In addition, University Hospital's Elyria Medical Center is a facility that is recognized by the American College of Surgeons Commission on Cancer Certification as a Community Cancer Program.

Gaps in the Continuum of Care

Given the proportion of screening services available to women in Lorain County, some women may choose to travel to surrounding counties, like Cuyahoga, where more locations are available to obtain screening services. There is a lack of survivorship services in Lorain County as there are only two support groups, one available through Mercy Cancer Center and one available through the Cleveland Clinic. There are only two locations that have alternative therapies available, such as exercise and nutrition programs and side effect management. These are Cleveland Clinic's Lorain Family Health & Surgery Center and Mercy Cancer Center. There are no locations in Lorain County that have the American College of Surgeons NAPBC accreditation or there are no designated cancer centers.

Additionally, out of the 53 locations that provide screening, diagnostic, and treatment services along the continuum of care, only 15 percent of those facilities are contracted with the BCCP. This means women – who are otherwise eligible to receive BCCP services – that are screened and diagnosed at a non-contracted facility run the risk of eliminating themselves from the program.

Partnerships and Opportunities

Komen NEO has provided grant funds to Mercy Regional Medical Center and BCCP Region 12, which covers Lorain County, for education, screening, and diagnosis of uninsured women in Lorain County. The Affiliate has provided education materials to the one FQHC serving Lorain County, but more work will be done to forge a stronger partnership with this organization. Komen NEO will also work with the Region 12 office of the BCCP and the Ohio Department of Health to educate providers and facility administrators on the importance of contracting with the BCCP in an effort to increase the number of BCCP providers in Lorain County.

Mahoning County

A total of 61 facilities provide 76 services along the CoC in Mahoning County, including one FQHC and 37 BCCP contracted facilities and providers. The proportion of screening facilities available is one facility for every 3,573 women. There are 23 facilities where mammograms are available on site, 16 of which are FDA approved mammography centers. One of these centers is the Mahoning Valley Imaging/Tiffany Breast Care Center, which operates a mobile unit that provides mammograms in Mahoning and surrounding counties. Diagnostic and Medical X-Ray Imaging in Boardman also operates a mobile unit. The Youngstown Community Health Center and the Midlothian Free Clinic are community health clinics that provide CBEs, but they do not provide mammography services.

Another screening facility, Medical Imaging Diagnostics, located in Mahoning County provided mobile mammography services up until the winter of 2013. During this time, an extreme drop in temperature known as the "polar vortex" caused a pipe to burst in the offices of Mahoning Valley Imaging. The pipe burst caused massive damages and the office has been closed ever since. While their mobile unit is still operational, this facility is left without a physical location to process, read, and interpret the films taken on the mobile unit. As a result, the mobile unit has been parked and out of commission, affecting the ability of many community-based screening programs who contracted Medical Imaging's services to continue their work.

There are 18 locations that provide diagnostic mammography on-site, four of which provide biopsy and four of which provide breast MRIs. Mercy Health'sJoanie Abdu Comprehensive Breast Care Center and its affiliated location, St. Elizabeth Health Center, provide patient navigation. Mercy Health's Joanie Abdu Comprehensive Breast Care Center is the only facility to offer the full CoC in Mahoning County. The Joanie Abdu Comprehensive Breast Care Center is recognized as an American College of Radiology Breast Imaging Centers of Excellence, the American College of Surgeons National Accreditation Program for Breast Centers, and the American College of Surgeons Commission on Cancer Certification as an Integrated Network Cancer Program.

An additional campus of Mercy Health – St. Elizabeth Health Center – is also recognized by the American College of Surgeons Commission on Cancer Certification as an Integrated Network Cancer Program. Radiation treatment is also available from Mercy Health's St. Elizabeth Boardman Cancer Center; however, there are no other treatment services at this location for breast cancer, such as reconstructive surgery. Reconstructive surgery is available at the Joanie Adbu Comprehensive Breast Care Center and through Valley Surgical Arts Inc, both of which are contracted with Ohio's BCCP, as well as through Northside Medical Center.

The St. Elizabeth Boardman Cancer Center and the Joanie Abdu Comprehensive Breast Care Center offers support groups, and the Joanie Adbu Comprehensive Breast Care Center also offers individual counseling. There are no locations to receive complimentary therapies in Mahoning County. There are 11 locations to purchase wigs and four locations to purchase prostheses. There are two locations to purchase mastectomy wear including Western Reserve Prosthetics and Pink Promises Boutique.

Gaps in the Continuum of Care
There is a lack of survivorship services, as the only support groups available in Mahoning County are offered through the Mercy Health's Joanie Abdu Comprehensive Breast Care Center and the St. Elizabeth Boardman facility. There are only four locations to purchase prostheses and only four locations to purchase mastectomy wear. There are no NCI-designated Cancer Centers in Mahoning County.

The loss of the mobile unit at Medical Imaging Diagnostics has put an additional strain on the other three mobile units – Women's Diagnostic Center out of Cuyahoga County, Diagnostic and Medical X-Ray Imaging in Mahoning County, and Tiffany Breast Center in Mahoning County – to cover the events traditionally covered by Medical Imaging Diagnostics. As a result, many community-based screening clinics have been postponed or eliminated due to a lack of availability for the mobile units.

Partnerships and Opportunities
Komen NEO provides funding for BCCP Region 9, which covers Mahoning County, for education, screening, and diagnostic procedures for the uninsured. The Affiliate is also in the initial planning stages for a multi-tiered education and screening program for the uninsured in collaboration with multiple organizations serving Mahoning County. Komen NEO hopes to reach more at-risk individuals in the communities they live in to educate them on the importance of early detection and the resources available to them throughout Mahoning County.

Komen NEO currently has limited partnerships with health systems in Mahoning County. Komen NEO will continue working with the Region 9 office of the BCCP and the Ohio Department of Health to educate providers and health system administrators on the importance of contracting with the BCCP in an effort to increase the number of BCCP providers in Mahoning County. In addition, the Affiliate will work on building partnerships with the existing mobile units, free clinics, and screening facilities in the county that provide services to the uninsured and underinsured.

Services Available to All COIs
Susan G. Komen operates a comprehensive website and a breast care telephone helpline that provides free, professional support services to anyone with breast cancer questions or concerns, including breast cancer survivors and their families (Susan G. Komen [SGK], 2014). The helpline is offered in English and Spanish and questions can also be emailed to helpline@komen.org. Komen NEO offers free education and training sessions on breast health, breast self-awareness, breast cancer, the BCCP, and other breast cancer issues for the public and health care providers throughout the year. Komen NEO also provides an annual luncheon/symposium for breast cancer survivors focused on addressing common concerns following a breast cancer diagnosis.

The Karen P. Nakon Breast Cancer Foundation and the JD Breast Cancer Foundation, based in Lorain and Cuyahoga Counties respectively, provide financial assistance to qualifying applicants who are struggling with the loss of income due to a breast cancer diagnosis and/or breast

cancer treatment. The American Cancer Society also operates an extensive website that offers information and resources regarding breast cancer treatment and support services. Information on the webpage is available in English and Spanish and links are provided for cancer information in Asian or Pacific Islander languages.

Public Policy Overview

National Breast and Cervical Cancer Early Detection Program

Congress amended the Public Health Service Act to establish the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) in 1990. The NBCCEDP, funded by the Centers for Disease Control and Prevention (CDC), provides grants to states that fund timely access to breast and cervical cancer screening, diagnostic testing, case management, and other support services and activities to uninsured women between the ages of 40-64 with incomes below 250 percent of the federal poverty level (FPL) (Centers for Disease Control & Prevention [CDC], n.d.; Benard et al., 2011; Bhaskara et al., 2008; Chien et al., 2011; Rosenbaum, 2012; CDC, 2013). The NBCCEDP operates as a cooperative partnership with state and local agencies, hospital systems, and breast health providers (Benard et al., 2011; Bhaskara et al., 2008).

While the NBCCEDP proved an effective program at providing access to breast and cervical cancer screenings, it created a gap among the uninsured due to an inherent shortcoming: a lack of any provision to finance the actual diagnosis, treatment, and follow-up care for women diagnosed with breast cancer through the program (Chien et al., 2011; Rosenbaum, 2012). As a result, Congress enacted the Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA) in 2000 (Chien et al., 2011; Rosenbaum, 2012). The BCCPTA relies on public financing to provide full Medicaid benefits to uninsured women between the ages of 40-64 that are screened and/or diagnosed through the NBCCEDP and are found in need of treatment for breast cancer (Bhaskara et al., 2008; Chien et al., 2011; Rosenbaum, 2012). The BCCPTA is a disease-specific expansion of Medicaid and was the US government's first effort to use a population-wide public health screening program as a portal for bringing uninsured women into Medicaid (Chien et al., 2011).

Since its implementation in 1991, the NBCCEDP has provided nearly 10 million breast and cervical cancer screening exams to almost four million uninsured women, with diagnoses of more than 52,000 breast cancers (Rosenbaum, 2012). Between 2007 and 2011, more than 1.6 million mammograms were provided to uninsured women and nearly 17,000 cancers that would have otherwise gone undetected were diagnosed (CDC, 2013).

Ohio's Breast and Cervical Cancer Project

The Breast and Cervical Cancer Project (BCCP) in Ohio began in 1994 and is operated by 11 Regional Enrollment Agencies (REAs). The BCCP provides free breast and cervical cancer services to eligible Ohio women who do not qualify for Medicaid. Services include mammograms, pap tests, office visits, clinical breast exams, colposcopy, breast ultrasound, biopsies and other diagnostic procedures, and case management. Women are considered eligible if they do not have health insurance, are low income (live in households with incomes between 100 and 200 percent of FPL), and are at least 40 years of age. This is a critical and

lifesaving safety-net program for the working poor in Ohio. These are the same women who earn too much income to qualify for expanded Medicaid, but not enough to qualify for tax credits in the state insurance marketplace. Without BCCP, they would not have affordable access to these services.

Women can self-refer to BCCP by contacting the appropriate REA to determine program eligibility and to facilitate enrollment into the program. If eligible, BCCP case managers will assist in scheduling appointments for services with local providers. To qualify for a mammogram, women must be at least 50 years old. Women between the ages of 40-49 may receive a mammogram if indicated by an abnormal clinical breast exam, strong family history, or other factors. If a woman is not eligible to enroll in BCCP, a referral is made to local resources in her area. Further information regarding the Ohio BCCP and enrollment eligibility is available from the Ohio Department of Health website.

Federal law allows states the option of providing access to treatment through what is known as BCCP Medicaid to certain women diagnosed with breast or cervical cancer, including pre-cancerous conditions, through the BCCP. The Ohio Department of Medicaid operates BCCP Medicaid in coordination with ODH and benefits are issued through the Ohio Medicaid program (Ohio Department of Medicaid, n.d.). BCCP Medicaid is only offered to certain women who were diagnosed through the BCCP, are ages 40 to 64 years, are Ohio residents and U.S citizens or qualified aliens, are uninsured, and are in need of treatment for breast and/or cervical cancer including pre-cancerous conditions. Further information can be found through the Ohio Department of Medicaid website.

States agencies that administer the BCCP are given three options regarding patient eligibility and how and where eligible women are diagnosed. Option 1 states that any woman who meets age, income, and insurance requirements is eligible to enroll into the BCCP regardless of where services are administered and/or who administers them. The state government is also required to contribute funding to the federal funds allotted to that particular state. Option 2 states that program eligible women must be diagnosed by a provider who has signed a contract with the BCCP administrative office in that state. Option 2 also requires the state government to contribute funding to the federal funds allotted to that particular state. Option 3 is the same as option 2, but with no state funds being contributed to the program budget. Ohio is an Option 2 state, which means individuals with incomes at or below 200 percent of the FPL will be eligible to enroll in BCCP Medicaid as long as they meet age, income, and insurance requirements and are diagnosed by a provider contracted with the BCCP system. If a woman who is otherwise eligible to receive BCCP services in Ohio is diagnosed by a provider outside of the BCCP network, she is automatically deemed ineligible for enrollment into BCCP Medicaid.

Komen NEO maintains a relationship with the NBCCEDP through Komen Headquarters' advocacy department. Komen NEO has a strong working relationship with the Ohio BCCP program, both at the state and local level. The state relationship is maintained through Komen Columbus, and Komen NEO provides or has awarded grant funding to all four BCCP regional enrollment agencies located within the service area. Komen Ohio Affiliates have been a strong ally for the BCCP, advocating on their behalf with local legislators to support a bill to increase funding for the BCCP through a tax check-off box and maintain BCCP Medicaid funding in the state budget for 2016-2017.

State Comprehensive Cancer Control Plan

The CDC created the National Comprehensive Cancer Control Program (NCCCP) to help states, tribes, and territories form coalitions to conduct comprehensive cancer assessments. Ohio received funding from the CDC in 2002 to establish Ohio's Comprehensive Cancer Control Program. The Ohio Partners for Cancer Control (OPCC) is a statewide coalition dedicated to reducing the burden of cancer for all Ohioans. The coalition includes representatives from various organizations that have cancer prevention and control as a priority of their mission. The Ohio Comprehensive Cancer Control (CCC) Plan 2011-2014 was released by the OPCC and includes numerous objectives and goals to reduce the cancer burden in the state of Ohio.

Breast cancer objectives outlined in Ohio's CCC Plan include increasing the proportion of women aged 40 years and older who have utilized screening, early detection, and follow-up services for breast cancer (Ohio Partners for Cancer Control [OPCC], 2012). The OPCC has created multiple strategies under each objective that outlines how the objectives will be achieved. These include advocating for increased funding for programs that support free and low cost mammography for uninsured and underinsured women, as well as creating strategic partnerships with state and local systems to reach age-appropriate women who have never been screened for breast cancer (OPCC, 2012). In addition, the OPCC seeks to improve age-appropriate screening among members of large health plans and employers and to encourage all health care providers to create office policies that ensure the recommendation of early detection screening for women with no or limited health care insurance (OPCC, 2012).

The OPCC also seeks to advance public knowledge about the impact of family history and genetics on cancer risk and management and improve access to cancer risk assessment services and genetic testing (OPCC, 2012). The OPCC promotes adult cancer patient enrollment in clinical trials through CoC accredited cancer programs. In addition, the OPCC seeks to optimize the quality of life for cancer survivors and co-survivors through community-based wellness programs and clinical linkages. In order to do this, the OPCC will gather information on cancer specific services offered in Ohio to assess what locations are lacking essential services in regards to psychosocial support services (OPCC, 2012).

Komen NEO works with the OPCC through Komen Columbus, as OPCC meetings take place in Columbus, OH. Additionally, many Komen NEO current and former grantees sit on the OPCC and advocate on behalf of the Affiliate. At this time, there is need for improvement in regards to partnership and coordination between the Komen NEO and the OPCC; however, Komen NEO will work towards identifying key leadership and stakeholders within OPCC and work towards initiating a dialogue and expanding the working relationship with them in coordination with Komen Columbus.

The Affordable Care Act

The Patient Protection and Affordable Care Act was passed by Congress and then signed into law by the President on March 23, 2010. On June 28, 2012 the Supreme Court rendered a final decision to uphold the health care law. The major goals of the Affordable Care Act (ACA) include increasing access to new health insurance plans, improving the quality and coverage of

existing health care and insurance plans, and to make health care more affordable (US Government Printing Office, 2010). The US Department of Health also created a new website, Healthcare.gov, to help individuals identify and compare health insurance programs in their geographic area. This website also contains reference material and the latest updates regarding the health care law.

Health Insurance Exchanges, Essential Health Benefits, and Medicaid Expansion
Health insurance plans are available through the regular insurance market as an individual or small group, through an employer, or through a Health Insurance Exchange (HIE). A HIE is a place where consumers can purchase subsidized health insurance coverage created by the ACA. Each state has a HIE operated by either the federal government or by the state (National Association of Community Health Centers [NACHC], n.d.). In Ohio, the HIE is federally facilitated and accepts enrollment during specific open enrollment periods. In 2014, the open enrollment period was November 14th, 2014 through January 15th, 2015. In subsequent years, the open enrollment period will be October 15th through December 7th (ODM, n.d.).

Beginning in 2014, all new insurance plans sold in the individual and small group market or through the HIE must contain the full set of Essential Health Benefits (EHB). These plans must also include reforms that prohibit cost sharing for preventive services, annual or lifetime dollar limits for EHBs, and practices such as excessive waiting periods, rescissions, and charging more or denying coverage for individuals with pre-existing conditions (NACHC, n.d.). Insurance market and rating rules have also been changed to allow rating variations to be based only on age, premium rating area, family composition, and tobacco use in the individual and the small group market and on the HIEs.

In addition, all enrollees under the age of 19 cannot be discriminated against for pre-existing health conditions, and young adults can be covered under their guardians insurance until age 26 unless they are eligible for coverage elsewhere (NACHC, n.d.). Ohio has its own set of dependent care regulations which allow for certain young adults to be covered by their parents insurance until the age of 28 (ODM, n.d.). All insurance plans that existed continuously without meaningful changes before March 23, 2010 were grandfathered in and considered minimum essential coverage; these plans are not required to contain the EHB package and other ACA requirements (NACHC, n.d.).

The EHB package includes a number of categories of services such as prevention and wellness services, chronic disease management, pediatric care including oral and vision care, maternity and newborn care, emergency services, ambulatory patient services, hospitalization, laboratory services, prescription drugs, rehabilitative services and devices, and mental health and behavioral health services. Preventive services encompass a number of services including screening mammography, but not necessarily diagnostic mammography or breast cancer treatment modalities (NACHC, n.d.).

Health insurance plans offered on the HIEs must be certified as a Qualified Health Plan (QHP), contain the EHB package, be licensed by the state, and have a sufficient network (NACHC,

n.d.). Each HIE offers four levels of insurance coverage and a catastrophic plan for individuals under 30 years old or those that meet certain income levels. In general, benefits are similar among the plans offered, while the percentage of total average costs for covered benefits a plan will cover and pay for vary between plan tiers, meaning co-pays and deductibles can vary immensely (Table 3.2).

Table 3.2. Health Insurance Exchange (HIE) plan tiers

Plan Tier:	Expected Costs Covered	Consumer Responsible
Platinum	90%	10%
Gold	80%	20%
Silver	70%	30%
Bronze	60%	40%

The ACA also includes a mandate stating all individuals, with a few exceptions (financial hardship, religious objections, and undocumented immigrants) must obtain a health insurance plan; this is referred to as the individual mandate (NACHC, n.d.). The penalty for individuals who decline to purchase health insurance is the greater of two amounts – a specified percentage of income or a specified dollar amount. The percentages of income and dollar amount are phased in over time and will increase annually by the cost of living adjustment. In 2014 the fee is one percent of income or $95, increasing to two percent of income or $325 in 2015 and two and a half percent of income or $695 in 2016. Individuals and families with incomes that fall between 100 percent and 400 percent of the FPL are eligible to receive cost-sharing subsidies and insurance premium credits through refundable and advanceable tax credits to purchase insurance through the HIEs. Insurance plan premium credits are tied to the second lowest cost Silver plan in the area and will vary with income so that the premium an individual or family must pay will not exceed a specific percentage of income (NACHC, n.d.).

In 2014, Ohio chose to expand Medicaid coverage to all non-Medicare eligible individuals under the age of 65 with incomes up to 138 percent of the FPL based on modified adjusted gross income. Eligible low-income adults are offered plans through the HIE which must include the EHBs. By choosing to expand the Medicaid program, Ohio will receive more than $23.8 billion in federal funding over the next six years, money that could enhance state and local health programs (ODM, n.d.).

According to the US Census Bureau, data collected from 2010-2012 revealed approximately 11.7 percent of individuals in Ohio (approximately 1.5 million people) aged 40-64 had no health insurance, a figure only slightly lower than the national average of 15.1 percent (Small Area Health Insurance Estimates [SAHIE], n.d.). Data recently released by the US Department of Health and Human Services for the state of Ohio show that after the introduction of the ACA 154,668 individuals have signed up for health insurance coverage and another 156,899 individuals became eligible for Medicaid or the Children's Health Insurance Plan (CHIP), which provides government health care plans for low income families (US DHHS, 2014). This means a possible reduction in the number of uninsured individuals in the state of Ohio by approximately 21 percent.

Implications of ACA on State NBCCEDP Eligibility and Utilization

The future implications of the ACA on the eligibility and utilization of the Ohio BCCP are relatively unknown at this time. One possibility is the income threshold standards for the program, currently set at 200 percent of the FPL in Ohio, may change to mirror that of the newly created Medicaid income threshold, set at 138 percent of the FPL. This means that any woman who is currently enrolled in BCCP Medicaid that falls between 139 to 200 percent of the FPL may be deemed ineligible for BCCP Medicaid and will essentially be kicked out of the program. This could cause hundreds of women in active treatment for breast cancer to be without a continuous source of payment for their care and could result in them foregoing needed treatments. It has been shared with Komen representatives that if this does happen in Ohio, case managers in the program would work directly with those women to get them enrolled in expanded Medicaid coverage and/or HIE plans so they would have a seamless transition from one insurance source to the other and not miss any scheduled treatments.

As stated previously, the ACA mandates that all individuals obtain health insurance or face a penalty. Individuals that do not obtain health insurance through the individual/small group market or on the HIEs may still be eligible to utilize the Ohio BCCP. The ACA also mandated that insurance plans cover preventive services, including screening mammography services; however, preventive services as defined by the ACA do not include diagnostic mammography services or breast cancer treatment services. These services will be the responsibility of the individual to pay at a rate determined by the amount of insurance coverage selected.

It could be said that previously uninsured individuals who have enrolled in insurance coverage through the HIEs or Medicaid expansion who would have otherwise qualified for BCCP services may have been better off had they remained uninsured at their point of diagnosis. The reasons for this are two-fold. First, many of the high deductible/high co-pay plans, including Bronze and Silver level plans, do not cover the costs of diagnostic procedures and/or certain treatment modalities. While a woman covered under these plans may have access to free mammography screenings under the EHB, the costs of moving forward with a diagnostic or treatment procedure may be too burdensome to bear, causing the woman to decide not to move forward in the CoC. Second, had this woman remained uninsured, she may have been able to enroll into the BCCP, where all needed and necessary services were available to her free of charge through BCCP Medicaid. The impact of these high deductible/high co-pay plans may, in fact, be creating a new “gap” population of underinsured individuals – those who have insurance coverage, but drop out of the CoC due to the high costs associated with needed services.

Implications of ACA for Health Care Providers

Information released in 2014 from the Colorado Hospital Association (CHA) and the Center for Health Information and Data Analytics (CHIDA) reported that the Medicaid proportion of patient volume increased substantially at hospitals in states that chose to expand Medicaid, such as Ohio (Colorado Hospital Associate [CHA], 2014). In addition, it was reported that the proportion of self-pay and charity care declined in states that expanded Medicaid (CHA, 2014). This data shows that previously uninsured patients are now enrolled in Medicaid due to expansion and they are utilizing health care services.

While it is still too early to assess the overall impact of the ACA on health care providers, there are some preliminary factors that may be considered. First, with more individuals enrolling into insurance plans and/or Medicaid it can be assumed that more of these individuals will be utilizing primary care services, as evidenced by the findings of the CHA and CHIDA. This places a larger burden on primary care physicians and internal medicine doctors to care for these formerly uninsured individuals. Research has shown that a large number of areas in the country are classified as "primary care deserts" – areas which have no federally qualified health centers (FQHCs) and limited access to timely primary care services. Harrison County, a COI for Komen NEO, could be considered a primary care desert, as it is 100 percent medically isolated. Newly insured individuals in these areas may face a shortage of providers and/or facilities to access in order to receive services. Second, the providers working in those areas may be overwhelmed with the new number of patients and may experience substantial wait times for appointments in their practices. Furthermore, many providers and/or health systems do not accept Medicaid as a payment method, leaving many of the new Medicaid recipients without a place to go for care.

Implications of ACA for Komen Northeast Ohio

According to figures reported by the American Community Survey for the sample years 2010-2012 by the US Census Bureau, the Northeast Ohio region has health insurance coverage rates similar to the state average, with approximately 11.7 percent of individuals uninsured (Center for Community Solutions [CCS], n.d.). While large cities in Ohio, such as Cleveland and Youngstown, may provide more opportunities to access health care, there are often more uninsured individuals in these urban areas that need assistance with the cost of care. For example, Cleveland has an uninsured rate of approximately 17.6 percent and Youngstown approximately 15.5 percent (CCS, n.d.).

While the long-term effects of the ACA will take time to emerge, some initial impacts of the law and Medicaid expansion are evident. For example, the ACA and Medicaid expansion has increased the number of individuals covered by health insurance plans in the state of Ohio, and 52.0 percent of the 154,668 individuals that selected a marketplace plan were aged 45-64. In Ohio, 208,280 individuals enrolled in Medicaid or the Children's Health Insurance Program (CHIP) during the open enrollment period (CCS, n.d.). While health insurance coverage has increased, there will still be uninsured individuals, including documented and undocumented immigrants, individuals suffering from financial hardship, and individuals over the age of 65 without considerable work history. These individuals will still need health care and breast health services that are provided through programs such as the Ohio BCCP and Komen NEO grantees.

Additionally, Komen NEO may need to rethink internal grantmaking strategies to reach populations most in-need of assistance in the breast health CoC. Now that screening services are covered under the EHB packages for insured individuals, Komen NEO may not need to fund as many free mammograms as the Affiliate has in the past. The Affiliate may also need to redefine "underinsured" to include those individuals enrolled into high deductible/high co-pay plans under the HIEs. Because diagnostic procedures may be too expensive for these

individuals, the Affiliate may need to allocate more grant funds to diagnostic services. Due to the fact that diagnostic procedures are more expensive than typical screening mechanisms, this will cause the number of individuals served annually by the Affiliate to decrease.

Komen Northeast Ohio Public Policy Activities

Komen NEO is very active in state advocacy initiatives. The Affiliate conducts an annual State Lobby Day in conjunction with the other three Komen Ohio Affiliates where staff, volunteers, and grant recipients meet with legislators in Columbus to review Komen's state legislative priorities. Komen NEO staff also meets periodically with federal legislators when they are in-district to discuss Komen Headquarters' legislative priorities. Additionally, the Affiliate has hosted three Race for the Cure Kick-Off Cookouts, including two in 2013, where legislators can meet with key Race volunteers, breast cancer survivors, and corporate sponsors to better understand the impact Komen has on the community. Komen NEO staff has also provided newsletter articles to state legislators during the month of October to promote breast cancer awareness month.

Beginning in 2008, Komen NEO staff and board members formed a strong relationship with Representative Kirk Schuring (R – Canton), which led to the passage of House Bill 112 (HB 112) in October of 2013. HB 112 created a check-off box for Ohio's BCCP on the state income tax return form. All tax payers in Ohio are now able to donate a portion or all of their state income tax return directly to Ohio's BCCP. The BCCP tax check-off will enable the program to serve up to 1,700 additional women (approximately an 11 percent increase over current levels) with life saving and cost saving access to early detection and diagnostic services. Funds donated through the tax check-off go directly to the state's BCCP office and the funds will be monitored through ODH. At the bill signing for HB 112, Ohio's Governor, John Kasich, announced that the state of Ohio will match all donations made during the 2014 tax year two-to-one, meaning a donation of $50 will amount to $100 donated to the program.

Komen Northeast Ohio was also a strong proponent for Senate Bill 99 (SB 99), which was signed into law by Governor John Kasich in June of 2014. SB 99 prohibits insurance companies from charging more for oral cancer drugs than for traditional intravenous treatments. This piece of legislation will help reduce the financial burden for cancer patients by creating more affordable access to newer drugs that can be more effective.

Since Medicaid was expanded in Ohio to 138 percent FPL, women who are eligible for BCCP between 139 to 200 percent FPL are not Medicaid eligible and may qualify to purchase private insurance with tax credits in the state Health Insurance Exchange (HIE). Currently, women who fall in this income group are still being enrolled in BCCP Medicaid; however, in March 2015, the governor's proposed biennial state budget would disenroll women who are dually eligible for private insurance tax credits and BCCP Medicaid. These program cuts would result in uninsured women who are screened and diagnosed through BCCP with no affordable treatment options, as purchasing insurance on the HIE may not be affordable, even with the tax credits. This could result in significant gaps and delays in follow-up care and treatment for women diagnosed with breast cancer through BCCP with incomes between 139 and 200 percent FPL.

In the Spring of 2015, the four Ohio Komen Affiliates banded together with other Ohio cancer advocacy groups to reinstate funding for the BCCP Medicaid. As a result of these efforts, an

amendment to the budget was submitted in the Senate to restore funding at previous funding levels. Komen's advocacy efforts also secured support from the primary opponents to BCCP Medicaid in the House. The budget issue is still ongoing at the time of publication, but the four Ohio Komen Affiliate's are confident that funding for BCCP Medicaid will be restored. Affiliate's will post updates on their websites once more information is available. The four Ohio Komen Affiliate's will continue to work collaboratively with ODH, the regional BCCP offices, and all Ohio legislators over the next four years to ensure needed funds for both the screening and treatment programs are secured in the state's biennial budget. Additionally, the Ohio Komen Affiliate's will continue to advocate for the provision of any necessary training to health systems and/or private practitioners to increase the number of providers contracted with the BCCP in Ohio.

Continuous state-level advocacy priorities are determined by Komen Ohio's Advocacy Coalition, which consists of staff representatives from each of the four Ohio Komen Affiliates. This coalition conducts monthly conference calls to discuss any new or pending legislation related to breast health, changes and/or modifications to Ohio's BCCP, and any other issues related to breast health advocacy. Potential areas of focus for state-level advocacy initiatives include maintaining state level contributions to the BCCP, transitioning Ohio from an Option 2 to an Option 1 state, requiring providers to inform women with dense breasts of available treatment options, and expanding BCCP coverage to the underinsured and men.

Health Systems and Public Policy Analysis Findings

While Northeast Ohio is home to multiple, nationally recognized health care systems, including the Cleveland Clinic and University Hospitals, individuals in this area still experience adverse health outcomes related to breast cancer. Komen NEO will work with existing facilities, organizations, and programs to ensure needed services along the breast health CoC are available to all individuals in every county served by the Affiliate. Key partnerships include ODH, regional BCCP enrollment agencies, stakeholders at health systems and clinics, existing and past Komen NEO grantees, and grassroots community-based organizations that reach target populations.

The impact of the ACA on the Northeast Ohio region has yet to be seen, but Komen NEO will continue to work with state and federal legislators, health policy coalitions (like the Health Policy Institute of Ohio), and the Komen Ohio Advocacy Coalition to ensure every individual has access to health insurance coverage and sources of ongoing care for breast health/breast cancer needs. Komen NEO will also continue working with the other Komen affiliates in Ohio to determine state-level public policy priorities.

Qualitative Data Sources and Methodology Overview

To complement the statistics and information gathered in the previous sections of this report, qualitative data was collected from key populations in each Community of Interest (COI). Qualitative data methods involve the collection of information and stories from individuals living and working in specific areas. These stories speak to the real matters reflected by the numbers and provide insights and a more comprehensive understanding of issues facing those communities. According to the Community Toolbox, qualitative data assessment methods can be used to illuminate "the subtleties behind the numbers – the feelings, small actions, or pieces of community history" that could potentially contribute to the existing breast cancer disparities in Northeast Ohio (KU Work Group for Community Health and Development, 2014).

To assist in the creation of key assessment questions to be used in the qualitative research efforts, the socio-ecological model (SEM) of health was utilized as a guide. The SEM considers health issues from both the micro- and macro-level perspectives and examines how individual and environmental determinants influence health outcomes (McLeroy, Bibeau, Steckler, and Glanz, 1988). There are five major components in the SEM (Figure 4.1). The first is the intrapersonal level, which focuses on individual level characteristics including personal knowledge, attitudes, and behaviors. This is followed by the interpersonal level, which includes social networks and support systems like families, work groups, and friends. The third component, the institutional level, encompasses the social institutions an individual belongs to; these institutions contain specific organizational characteristics and the formal and informal rules and regulations for order. The community level is next, which focuses on the relationships among the various institutions and organizations an individual belongs to. Finally, the SEM considers the public policy level, which includes the various local, state, and national laws and policies. Approaching the data collection process using the SEM as a framework allows for an examination of the ways each level influences the other and could identify potential solutions to the multi-faceted issues contributing to breast cancer disparities.

Using the SEM, the Community Profile Team (CPT) identified three target populations in each COI for further investigation. These populations included those who have never been diagnosed with breast cancer, breast cancer survivors, and health care providers/breast health leaders. Those who have never been diagnosed with breast cancer, referred to as the "general population," were chosen as a target group to assess breast health knowledge, attitudes, beliefs, and health care utilization. Men were not excluded in the research efforts, but because more women are affected by the disease, data collection focused on women more than men. Breast cancer survivors, defined as any person who has received a positive breast cancer diagnosis from a licensed health care practitioner, were chosen as a key group to examine any potential barriers encountered in accessing breast cancer treatments and to identify issues related to survivor support. Breast health providers, defined as those involved in the delivery of direct health services, and breast health leaders, defined as those who work in the breast health and/or health care field but do not practice medicine, were chosen as a target group to assess administrative barriers to care, potential areas of collaboration, and identify points along the

continuum of care (CoC) where individuals could fall out. These populations were also chosen to identify any promising best practices used by local health care systems to address existing disparities at the systems level.

Figure 4.1. Socio-Ecological Model of health

An ambitious qualitative data collection plan and timeline spanning six months was drafted and implemented by various members of the CPT (Appendix C). The CPT elected to utilize at least two qualitative data collection methods per target population in each COI to meet best practice standards (Table 4.1). The qualitative data collection methods chosen included electronic and paper surveys, key informant interviews, and focus groups.

Table 4.1. Northeast Ohio qualitative data collection plan by Community of Interest (COI)

	Qualitative-Based Survey	Key Informant Interviews	Focus Groups
Ashtabula County	All target populations	General population and survivors	Providers/Leaders
Cuyahoga County	All target populations	Survivors	General population and providers/leaders
Harrison and Jefferson Counties	All target populations	Providers/Leaders and survivors	General population
Lorain County	All target populations	General population and survivors	Providers/Leaders
Mahoning County	All target populations	Providers/Leaders and survivors	General population

Surveys are a common tool used to gather information from community members to support, expand, and/or better understand previously collected data. Surveys also help collect information on individual behaviors, beliefs, and attitudes and can help determine the level of knowledge that currently exists on breast health issues. People often feel more comfortable filling out surveys due to their anonymous nature. Surveys can be done quickly, reach more people in the community, and yield larger sample sizes than other qualitative methods. There are some drawbacks to surveys, including low response rates, no opportunity to clarify questions or responses, and difficulties in obtaining representative samples from target populations; because of these issues, it is often hard to generalize the findings of surveys to larger populations. Surveys were chosen as a primary method of collection by the CPT due to the convenience of collecting information from a potentially large number of people in an inexpensive and quick way. For these reasons, all key populations in each COI were targeted for survey participation.

The second qualitative method chosen was key informant interviewing (Table 4.1). Key informant interviews are structured conversations between a researcher and a representative from a target population that allow for in-depth and probing questions on specific issues. These types of interviews help gain a better understanding of the attitudes and beliefs of target population members. They also allow the respondent to openly discuss a topic at length to clarify issues and responses as needed so definitive connections can be made between breast cancer statistics and community issues. Some limitations to key informant interview data include participant selection (including the “right” informants), potential interviewer bias, and the generalization of results to the larger population. Key informant interviews were chosen as a primary data collection method by the CPT because they are inexpensive, are fairly simple to conduct, and the CPT felt existing business and personal connections with organizations, stakeholders, and Komen grantees could provide a robust audience to recruit individuals.

Finally, the CPT chose to conduct focus groups within certain populations in key areas (Table 4.1). Focus groups are structured discussions used to obtain in-depth information from a group of five to ten people about a specific topic. The purpose of a focus group is to collect information about people’s opinions, beliefs, attitudes, behaviors, motivations and perceptions – not to come to a consensus or conclusion. These discussions are an efficient way to assess the range and depth of an issue and uncover factors that influence opinions, behaviors, or motivations in a short amount of time. Like any qualitative method, focus groups pose distinct challenges. It can be difficult to recruit enough representative participants, they can be expensive, they are often hard to schedule, and the results may be difficult to generalize to the larger population. Focus groups were chosen as a primary data collection method by the CPT because of business and personal connections with already existing groups and Komen grantees that could provide a rich and diverse audience to recruit participants. Additionally, members of the CPT have experience in coordinating and facilitating focus groups and lent their expertise with no monetary charge.

After reviewing the Quantitative Data Report and the Health Systems and Public Policy section analysis findings and utilizing the SEM, the CPT developed key assessment questions for each target group based on identified issues. The resulting questions were purposefully crafted to

create triangulation among the various data sources. Triangulation is defined as “the combination of methodologies in the study of the same phenomenon” (Jick, 1979). Examining the same issue using multiple methodologies, if they lead to the same conclusions, provides a more definitive and accurate representation of the variable under investigation (Jick, 1979). For these reasons, questions used in the three data collection methodologies were crafted to address similar issues and themes.

Survey Development and Recruitment Methodology

In an effort to have the surveys available to participants as soon as possible, survey questions were the first to be developed (Appendix D). For the general population, the questions were structured in order to obtain accurate information on current breast health beliefs, individual breast health and cancer screening practices, knowledge of existing programs and services in the community, and current insurance and health status. The questions targeted to survivors were the same as the general population, with an additional section added that focused on the individual’s experience with the disease, any barriers encountered during treatment, and the quality of care received. Questions targeted to providers and leaders assessed recommendations for breast cancer screenings, patient characteristics and behaviors, services for the uninsured and underinsured, administrative challenges and barriers to care, and the influence of public policies on internal practices. Initial survey questions for all target populations were vetted by two external qualitative data experts for structure, wording, and literacy level and were revised as necessary.

Final survey questions and informed consent forms were sent to Cleveland State University’s (CSU) Institutional Review Board (IRB) for approval in July of 2014. Approval for dissemination was granted in August of 2014. Once IRB approval was obtained, survey questions were entered into SurveyMonkey, an online based survey collection and analysis tool, by a Master of Public Health (MPH) student. An accompanying, identical paper survey for those with limited/no computer access was also designed and professionally printed. Paper surveys included a postage-paid envelope addressed to the Affiliate to facilitate the data collection process. Sample sizes needed to obtain a 95 percent confidence interval in the survey data were calculated for the general population based on the total number of females living in each COI using an online sample size calculator (Table 4.2). Sample sizes for survivors and providers/leaders in each COI were unable to be calculated because the Affiliate was not able to obtain accurate data related to the current number of breast cancer survivors and breast health providers/leaders that live/work in each COI. Affiliate staff, however, set an internal goal of collecting at least 100 surveys from each of these populations in all COIs.

Table 4.2. Sample sizes needed in general population surveys to obtain 95 percent confidence interval

County	Total Female Population	Sample Size Needed
Ashtabula	51,211	381
Cuyahoga	680,385	384
Harrison/Jefferson	44,471	381
Lorain	152,434	383
Mahoning	125,084	383

Each individual who completed a survey submitted an IRB approved informed consent form, granting the Affiliate permission to use their responses in the final analysis. Electronic surveys were enabled with Secure Sockets Layer (SSL) encryption to protect private information entered through these means; additionally, IP address tracking was disabled to ensure there was no way to link survey data back to a specific participant. Electronic results from the surveys and the subsequent analysis will be stored on the Affiliate's firewall-secure, password-protected internal server for at least five years. Completed paper surveys and informed consent forms will be stored in a locked file cabinet at the Affiliate office for a minimum of five years to ensure limited access to the data and participant anonymity for information submitted through these means. At the conclusion of the five year period, the paper surveys and consent forms will be destroyed. Additionally, survey responses will be reported aggregately with anonymous representative quotes used as needed to protect respondent confidentiality and anonymity.

All COIs – General Population and Survivor Surveys
Links to the general population and survivor electronic surveys went live and paper surveys were distributed in the COIs beginning in September of 2014. Two targeted email-blasts were sent to a convenience sample of women who had not been diagnosed and survivors from the Affiliate's internal database for all COIs, including over 18,500 non-survivors and 1,100 survivors with mailing addresses in the COIs. Links to the electronic surveys were also featured prominently on the Affiliate's website and in the Affiliate's monthly newsletters during the months of September through December of 2014. The surveys were continuously promoted on the Affiliate's social media pages (Facebook and Twitter) from September 2014 through December 2014 to further encourage a broad range of individuals to participate. Additionally, Affiliate staff personally reached out to multiple providers, health systems, community organizations, support groups, and Komen grantees in the COIs to assist in the survey dissemination process.

Nearly 500 paper surveys were distributed to various community-based organizations in the COIs, including public libraries, YWCAs/YMCAs, food banks, hair salons, grocery stores, and churches to collect information from a simple random sample of individuals in the COIs. Paper surveys were distributed by Affiliate staff and a MPH student. These organizations were chosen as distribution points for surveys based on input from a Komen Headquarters workgroup that determined these community-based organizations to be the best places to obtain a simple random sample of participants from the target populations (Susan G. Komen Affiliate Leadership and Development Session, 2013). Promotional flyers with the survey links were also created and distributed to numerous organizations in the COIs to hand out to individuals at community events and/or participants in community programs. On-site survey distribution and data collection was done by a MPH student. On-site collection efforts, conducted at a food bank in Mahoning County and grocery stores in Harrison and Jefferson Counties, helped facilitate increased involvement from community members and increased survey response rates in these COIs. Paper surveys received by the Affiliate were hand entered into SurveyMonkey by Affiliate staff to consolidate the data and ease the analysis process.

A preliminary analysis of the survey data collected from these populations was conducted at the end of September 2014. This preliminary analysis helped identify certain questions that were

consistently left blank and/or skipped by the majority of respondents. Following this analysis, some survey questions were modified and some were eliminated entirely to account for participant confusion and/or non-response. The edited surveys were open for participants until the end of December 2014.

All COIs – Breast Health Provider/Leader Surveys
Links to the electronic surveys were distributed to breast health providers/leaders in the COIs in September of 2014 using a convenience sample from the Affiliate's internal database. The CPT elected not to provide this population with paper surveys due to limited monetary resources for printing. Two targeted email-blasts were sent to more than 60 providers/leaders representing 40 different community organizations, hospitals, health departments, free clinics, women's clinics, and federally qualified health centers identified in the health systems analysis as serving the COIs. Additionally, personalized emails were sent to the same convenience sample of breast health providers/leaders from the COIs by Affiliate staff encouraging them to promote the surveys among their colleagues and peers. Personalized emails were also sent directly to 2014-15 Affiliate grant recipients and key partners serving the COIs for dissemination among their staff. Phone calls were made to 2014-15 Komen NEO grant Project Directors and key health care facilities in the COIs to stress the importance of participation and dissemination within their organization.

A preliminary analysis of the survey data collected from these populations was conducted at the end of September 2014. This preliminary analysis helped identify certain questions that were consistently left blank and/or skipped by the majority of respondents. Following this analysis, some survey questions were modified and some were eliminated entirely to account for respondent confusion and/or non-response. The edited surveys were open for participants until the end of December 2014.

Key Informant Interview Development and Recruitment Methodology
Key informant interview questions were developed by the CPT in late September 2014 based on the preliminary results of the survey data. The goal of the key informant interview questions was to shed light not only on the issues identified in the Quantitative Data Report and Health Systems and Public Policy section analyses, but also those identified by the survey respondents. Initial key informant questions were developed by Affiliate staff; the CPT then added additional questions, rephrased questions for clarity, and assessed questions for health literacy levels. Key informant interviews questions were developed for all three target populations in each of the COIs (Table 4.1). Due to time limitations, the Affiliate was unable to secure an external review of the final interview questionnaire.

For the general population, interview questions mainly focused on the individual level barriers to care one may experience, including beliefs, knowledge, and level of understanding related to mammography screening, health care utilization, and breast cancer myths. The questions also probed into community and systems level issues, including availability and accessibility of existing resources, things organizations can do to help facilitate screenings, and possible barriers to care. The questions targeted to survivors were similar to the ones used for the

general population, with additional questions added that focused on the individual's experience with the disease, any barriers encountered during treatment, and the quality of care received. Much like the surveys, questions targeted to providers and leaders assessed recommendations for breast cancer screenings, patient characteristics and behaviors, services for the uninsured and underinsured, administrative challenges and barriers to care, and the influence of the Affordable Care Act (ACA) on mammography adherence. Questions for the target populations were tailored for each COI (Appendix E) to determine if any regional level differences exist between the different target groups.

To aid in the data collection process, a key informant interview facilitator script was developed by Affiliate staff (Appendix F). A script was developed to help streamline and coordinate the data collection process and ensure all interview participants were provided with the same information. The script supplied the facilitator with a basic introduction to the CP, the purpose of the interview, an explanation of how and why COIs were chosen, and the opportunity for respondents to ask questions about the data collection process. Additionally, the facilitator script guided the interviewer to go over the informed consent process and included ground rules for the discussion.

Key informant questions, the facilitator guide, and informed consent forms were approved by CSU's IRB in October of 2014. Each individual who participated in a key informant interview completed an IRB approved informed consent form, granting the Affiliate permission to use their responses in the final analysis. If the interview was conducted over the phone for convenience, the interviewer read the informed consent form to the respondent and obtained verbal consent to participate. All electronic interview responses and participant informed consent forms will be stored on the Affiliate's fire-wall secured, password-protected internal server for a minimum of five years. All original paper interview notes will be stored at the Affiliate office in a locked file cabinet for a minimum of five years; at the conclusion of the five years, paper notes and informed consent forms will be destroyed to protect respondent confidentiality. Additionally, interview responses will be reported aggregately with anonymous representative quotes used as needed to protect respondent confidentiality and anonymity.

A minimum goal of 12 key informant interviews per population in each COI was set according to Komen Headquarters' best practice standards. Key informant interviews were conducted during the months of November and December of 2014. All respondents were recruited using a combination of simple random, convenience, and snowball sampling methods. These methods were chosen to help recruit individuals from a diverse group of organizations, backgrounds, and experiences in a short amount of time. All key informant interviews were conducted by Affiliate staff either in-person or over the phone based on the availability and preference of the respondent. Responses were recorded by hand or electronically, with some responses read back to the participant to ensure accuracy. Hand recorded interview notes were electronically transcribed by Affiliate staff immediately following the interview.

Ashtabula County – General Population and Survivors
Emails were sent by Affiliate staff to six key stakeholders and health care organizations in Ashtabula County promoting the need to recruit interview participants. A conference call was held with the program staff at an Ashtabula County hospital to identify key community organizations, civic groups, businesses, and survivor support groups to contact for participant recruitment. These referrals were followed-up via phone by a MPH student. The regional Breast and Cervical Cancer Project (BCCP) office serving Ashtabula County was also contacted by Affiliate staff to help identify survivors living in this area. Due to time limitations, the Affiliate was unable to secure on the ground recruitment of interview participants in Ashtabula County.

Cuyahoga County – Survivors
Emails were sent by Affiliate staff to more than 20 key stakeholders and organizations in Cuyahoga County in an effort to recruit survivors to participate in key informant interviews. Phone calls were placed by Affiliate staff to all 2014-15 Komen grant Project Directors serving Cuyahoga County for participant referrals. The regional BCCP office serving Cuyahoga County was also contacted to help identify BCCP recipients who would be willing to participate in an interview. Due to time limitations, the Affiliate was unable to secure on the ground recruitment of interview participants in Cuyahoga County.

Harrison and Jefferson Counties – Providers and Survivors
Emails were sent by Affiliate staff to ten organizations and stakeholders serving Harrison and Jefferson Counties to recruit both provider and survivor key informants. Affiliate staff also contacted the health departments, federally qualified health centers, and breast health departments in the hospital systems identified in the health systems analysis as serving Harrison and Jefferson Counties by phone to explain the purpose of the interviews, stress the importance of participation, and obtain referrals. The regional BCCP office serving Harrison and Jefferson Counties was also contacted by Affiliate staff to recruit survivors enrolled in the BCCP program. A MPH student spent two days at groceries stores in these counties handing out flyers to recruit survivors from the general public to participate.

Lorain County – General Population and Survivors
Emails were sent by Affiliate staff to four key organizational stakeholders in Lorain County to recruit participants from their patient/client populations. The regional BCCP office serving Lorain County was also contacted by Affiliate staff to recruit both survivors and BCCP beneficiaries to participate. One hospital system utilized their parish nurse community outreach program to distribute flyers promoting the interview efforts to over 90 churches in Lorain County. Affiliate staff also attended a survivor support group offered through one of the hospital systems in Lorain County to speak about the purpose of the interviews, the findings to date, and the importance of participating in data collection efforts.

Mahoning County – Providers and Survivors
Emails were sent by Affiliate staff to more than ten organizations and stakeholders to help recruit interview participants. The regional BCCP office serving Mahoning County was contacted to help identify survivors living in the area that had been served by this program. Phone calls were made by Affiliate staff to major health systems, health departments, and federally qualified

health centers to recruit providers to participate in key informant interviews. A MPH student spent many days on the ground in Mahoning County going to provider facilities, community organizations, churches, and other public settings handing out flyers promoting the key informant interviews to recruit participants.

Focus Group Development and Recruitment Methodology

Much like the key informant interview questions, focus group questions were developed by the CPT in late September 2014 based on the preliminary results of the survey data to concentrate on issues highlighted by survey respondents. Because focus groups allow for an in-depth discussion of key issues from multiple points of view at one time, the goal in the development of the focus group questions was to obtain the most perspectives on key issues through a small number of targeted, concise questions (Appendix G). Initial focus group questions were developed by Affiliate staff. The CPT then added additional questions, rephrased questions for clarity, and assessed questions for health literacy levels. Focus group questions were targeted to providers, members of the general population, or both of these populations in each COI (Table 4.1). Due to time constraints, the Affiliate was unable to secure an external review of the final focus group questionnaire.

Questions for the general population focused on individual level attitudes, beliefs, and knowledge related to breast health and breast cancer screenings. General population questions also aimed to gain further insights into utilization and knowledge of existing resources for breast health, where individuals go for breast health information and services, and personal opinions about the ACA. Provider focus group questions concentrated on individual and community level variables like patient/client needs, organizational level strengths and weaknesses in addressing identified needs, administrative and institutional barriers to care, and policy level influences of the ACA on health care behaviors and utilization from the provider perspective.

As with key informant interviews, a focus group moderator script was developed to help streamline and coordinate the data collection process and ensure all focus groups were provided with the same information (Appendix H). The script supplied the moderator with a basic introduction to the CP, the purpose of the report, an explanation of why COIs were chosen, and the opportunity for respondents to ask questions about the data collection process. Additionally, the facilitator script guided the interviewer to go over the informed consent process, included ground rules for the discussion, and contained “leading” questions the moderator could use to probe deeper into issues and generate a more substantial discussion.

Focus group questions, moderator script, and informed consent forms were approved by CSU’s IRB in October of 2014. Each individual who participated in a focus group completed an IRB approved informed consent form, granting the Affiliate permission to use their responses in the final analysis. Focus group participants also completed an IRB approved demographic form to quickly assess the background and key variables for participants (Appendix I). The general population form collected information related to participant age, race, primary care and mammography utilization, family history of breast cancer, insurance status, and where they receive information on health. The provider demographic form collected information related to

the number of years in the breast health field, areas of expertise, patient demographics, screening recommendations, services available to the uninsured, institutional relationships with the BCCP, and methods of distribution for information related to breast health and services provided.

All electronic focus group responses, informed consent forms, and demographic forms will be housed on the Affiliate's fire-wall secured, password-protected internal server for a minimum of five years. All original paper focus group notes will be stored at the Affiliate office in a locked file cabinet for a minimum of five years. At the conclusion of the five years, paper notes and informed consent forms will be destroyed to protect respondent confidentiality. Focus group responses will be reported aggregately with anonymous representative quotes used as needed to protect respondent's identity from being disclosed. Additionally, if focus group participants were recruited from already existing groups or organizations, no specific names of participating facilities will be shared.

A minimum goal of three focus groups per population in each COI (Table 4.1) was set according to Komen Headquarters' best practice standards. Each focus group consisted of five-ten participants per group. Focus groups were conducted during the months of October through December of 2014. All participants were recruited using a combination of simple random and convenience sampling methods. Simple random sampling was chosen in an effort to recruit enough representative participants from key populations. Convenience sampling methods were also chosen due to time and capacity constraints related to organizing and recruiting independent focus group participants. Convenience methods focused on utilizing existing groups and institutional networks, such as church members and organizational staff/teams

The majority of focus groups were conducted by Affiliate staff; however, two general population focus groups in Cuyahoga County were conducted by a member of the CPT and one general population focus group in Mahoning County was conducted by a MPH student. Focus group participants from the general population were provided with $10 each and a bag of Komen branded items as an incentive for participation. Participants from the provider/leader populations were only provided with a bag of Komen branded items as incentive to participate due to limited financial resources. All focus groups, with the exception of the general population focus groups, were tape recorded and electronically transcribed by Affiliate staff. Hand recorded focus group notes made by the facilitators of the general population groups were electronically transcribed following the focus groups. Transcribed notes created by the CPT member and MPH student were then sent to Affiliate staff for analysis.

Ashtabula County – Breast Health Provider/Leader Focus Groups
Affiliate staff reached out to two major health systems and one federally qualified health center serving Ashtabula County via email to schedule a focus group with members of those facilities staff/team members. The Affiliate had an established relationship with one health system, but had not previously worked with the other health system or the federally qualified health center. Emails to these organizations were followed up by Affiliate staff via phone call to explain the purpose of the research efforts and stress the importance of participation.

Cuyahoga County – General Population and Breast Health Provider/Leader Focus Groups
Affiliate staff reached out to three health systems and one federally qualified health center serving Cuyahoga County via email and phone call to schedule focus groups with organization staff/team members. Affiliate staff also reached out to two churches the Affiliate has established relationships and/or personal connections with to schedule a focus group to be conducted at the church with members from the respective congregations. One CPT member who works closely with a large church in the Cleveland area volunteered to recruit enough congregation members from the general population to conduct two focus groups.

Harrison and Jefferson Counties – General Population Focus Groups
Due to limited existing relationships with organizations serving Harrison and Jefferson Counties, a MPH student conducted on the ground outreach in these areas to identify potential groups and organizations to target for focus group efforts. Potential groups/organizations approached included churches, food banks, and staffs at hair salons. Affiliate staff also reached out to the BCCP office serving these counties via email to identify groups they utilize in community outreach and education efforts for potential focus group participants.

Lorain County – Breast Health Provider/Leader Focus Groups
Affiliate staff reached out to two health systems the Affiliate has established relationships with and one federally qualified health center that has limited to no past partnership with the Affiliate via email to schedule focus groups with members of their organizational staff. Emails were followed up with personal phone calls by Affiliate staff to further explain the purpose of the research efforts and the importance of participating.

Mahoning County – General Population Focus Groups
A MPH student from Mahoning County attempted to recruit general population members from this COI to participate in focus groups. On the ground outreach was conducted with academic institutions, YWCAs, and other community-based organizations to recruit potential participants. Personal connections the MPH student had with existing groups in Mahoning County were also utilized to recruit focus group participants.

Qualitative Data Overview

Survey Overview

Respondents and Data Analysis
Survey responses and data from the three target populations were exported from SurveyMonkey into three separate Microsoft Excel workbooks. The responses for each target population were then sorted by COI, and data from each COI was given its own worksheet within the target population workbook. Affiliate staff then calculated the total number of responses and percentages for each question response using Excel's built in formula and calculator features. Responses from individuals who did not indicate which COI they lived/worked in were excluded from the final analysis.

Despite the best efforts of the Affiliate to promote the electronic surveys and distribute the paper surveys among the target populations in the COIs, survey responses yielded very small

response rates (Table 4.3) with little diversity among the general population and survivor respondents (Table 4.4). Demographics were not collected for provider/leader survey respondents, but information was collected regarding agency type (Table 4.5). The responses across all groups in each COI taken collectively, however, did produce enough data that data saturation occurred. Data saturation occurs when the collection of new or additional data becomes redundant and does not shed any more light on the issue(s) under investigation (Mason, 2010).

Table 4.3. Survey response rates by Community of Interest (COI)

County of Interest	Target Population	Sample Size Target	Number of Surveys Completed	Response Rate
Ashtabula County	General population	381	6	1.6%
	Breast cancer survivors	100	5	3.0%
	Breast health providers/leaders	100	4	4.0%
Cuyahoga County	General population	384	57	14.8%
	Breast cancer survivors	100	87	87.0%
	Breast health providers/leaders	100	27	27.0%
Harrison and Jefferson Counties	General population	381	10	2.6%
	Breast cancer survivors	100	0	0.0%
	Breast health providers/leaders	100	5	5.0%
Lorain County	General population	383	12	31.3%
	Breast cancer survivors	100	27	27.0%
	Breast health providers/leaders	100	5	5.0%
Mahoning County	General population	383	109	28.5%
	Breast cancer survivors	100	8	8.0%
	Breast health providers/leaders	100	5	5.0%

Response rate percentage calculated by dividing actual number of surveys completed by the sample size target.

Table 4.4. Survey respondent demographics for general population and survivors

Demographic Variable		Ashtabula County		Cuyahoga County		Harrison/Jefferson Counties		Lorain County		Mahoning County	
		General (n=6)	Survivor (n=3)	General (n=57)	Survivor (n= 87)	General (n=10)	Survivor (n=0)	General (n=12)	Survivor (n=27)	General (n=109)	Survivor (n=8)
Race	AIAN	0 (0.0%)	0 (0.0%)	1 (1.8%)	2 (2.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	6 (5.5%)	0 (0.0%)
	API	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (8.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Biracial	0 (0.0%)	1 (33.3%)	0 (0.0%)	2 (2.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (1.0%)	0 (0.0%)
	Black/ African American	0 (0.0%)	0 (0.0%)	8 (14.0%)	9 (10.3%)	1 (10.0%)	0 (0.0%)	0 (0.0%)	1 (3.7%)	17 (15.6%)	4 (50.0%)
	White	6 (100.0%)	2 (66.7%)	47 (82.5%)	75 (86.2%)	9 (90.0%)	0 (0.0%)	12 (100.0%)	26 (96.3%)	75 (67.9%)	4 (50.0%)
	Prefer not to answer	0 (0.0%)	0 (0.0%)	3 (5.3%)	1 (1.1%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	7 (6.4%)	0 (0.0%)
		(n=6)	(n=1)	(n=57)	(n=77)	(n=8)	(n=0)	(n=9)	(n=25)	(n=109)	(n=6)
Ethnicity	Hispanic/ Latina	0 (0.0%)	0 (0.0%)	1 (1.7%)	1 (1.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (8.0%)	9 (8.3%)	6 (100.0%)
	Non-Hispanic/ Latina	4 (66.7%)	1 (33.3%)	44 (77.4%)	69 (89.6%)	6 (100%)	0 (0.0%)	9 (100.0%)	22 (88.0%)	56 (51.4%)	0 (0.0%)
	Prefer not to answer	1 (16.7%)	0 (0.0%)	5 (8.8%)	3 (3.9%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	16 (14.7%)	0 (0.0%)
		(n=6)	(n=3)	(n=54)	(n=79)	(n=9)	(n=0)	(n=10)	(n=24)	(n=86)	(n=8)
Age	0-29	1 (16.7%)	0 (0.0%)	5 (9.3%)	1 (1.3%)	2 (22.2%)	0 (0.0%)	2 (20.0%)	0 (0.0%)	16 (18.6%)	0 (0.0%)
	30-39	2 (33.3%)	0 (0.0%)	11 (20.4%)	4 (5.1%)	2 (22.2%)	0 (0.0%)	1 (10.0%)	1 (4.2%)	21 (24.4%)	0 (0.0%)
	40-49	2 (33.3%)	2 (66.7%)	9 (16.7%)	15 (19.0%)	1 (11.2%)	0 (0.0%)	4 (40.0%)	8 (33.3%)	16 (18.6%)	3 (42.9%)
	50-64	1 (16.7%)	1 (33.3%)	23 (42.5%)	43 (54.4%)	2 (22.2%)	0 (0.0%)	2 (20.0%)	9 (37.5%)	25 (29.1%)	4 (57.1%)
	65+	0 (0.0%)	0 (0.0%)	6 (11.1%)	16 (20.2%)	2 (22.2%)	0 (0.0%)	1 (10.0%)	6 (25.0%)	8 (9.3%)	0 (0.0%)
		(n=6)	(n=3)	(n=56)	(n=86)	(n=10)	(n=0)	(n=11)	(n=27)	(n=108)	(n=8)
Insurance Status	Insured	6 (100.0%)	3 (100.0%)	56 (100.0%)	86 (100.0%)	9 (90.0%)	0 (0.0%)	11 (100.0%)	27 (100.0%)	90 (93.3%)	8 (100.0%)
	Not insured	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (10.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	18 (16.7%)	0 (0.0%)
	I do not know	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

AIAN stands for American Indian Alaska Native.
API stands for Asian Pacific Islander.
Percentages for each variable were calculated using the total number of respondents for that specific item rather than the total number of survey respondents.

Table 4.5. Provider survey respondents – agency type

Agency Type	Ashtabula County	Cuyahoga County	Harrison/Jefferson Counties	Lorain County	Mahoning County
	(n=4)	(n=25)	(n=5)	(n=5)	(n=5)
Academic Institution	0 (0.0%)	1 (4.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Community Clinic	0 (0.0%)	1 (4.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Community Organization	1 (25.0%)	1 (4.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Faith-based Organization	0 (0.0%)	0 (0.0%)	1 (20.0%)	1 (20.0%)	0 (0.0%)
Federally Qualified Health Center	0 (0.0%)	3 (12.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Government Organization	0 (0.0%)	0 (0.0%)	1 (20.0%)	0 (0.0%)	0 (0.0%)
Health Department	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (20.0%)	0 (0.0%)
Hospital	2 (50.0%)	19 (76.0%)	3 (60.0%)	3 (60.0%)	5 (100.0%)
Nonprofit	1 (25.0%)	4 (16.0%)	2 (40.0%)	2 (40.0%)	0 (0.0%)
Women's Center	1 (25.0%)	3 (12.0%)	0 (0.0%)	1 (20.0%)	0 (0.0%)

For agency type, respondents could choose more than one selection; therefore, percentages may not add up to 100%.

Open-ended responses for each question were uploaded into an online word cloud generator so quick assessments could be made on common words and terms used by survey respondents (Figures 4.2, 4.3, and 4.4). Common terms became key categories, and the responses were then hand coded in Excel by Affiliate staff into appropriate categories. This method of analysis was chosen due to staff experience with Excel and hand coding qualitative data. The chosen categories grouped answers together that were analytically similar and addressed the key questions of the CPT. A survey codebook for each target population was utilized to ensure consistent and accurate coding of open-ended responses across all populations and COIs.

Initial coding of open-ended responses resulted in the identification of more than 30 codes. Upon further review, redundant codes were reduced to 15. These codes were then consolidated into four separate meaningful categories: accessibility, awareness/education, quality of care, and health care system performance improvement. Some key quotes and individual responses were flagged in the Excel spreadsheets to be referred to as representative of the four meaningful categories.

Key Survey Results across Populations and COIs

When asked "At what age do you think individuals should begin having regular clinical breast exams (CBE)," the majority of all three target populations indicated CBE initiation should begin when an individual is in their 20s (Table 4.6). When asked "At what age should individuals begin receiving mammograms," the majority of general population and survivor respondents indicated mammography should begin in an individual's 30s, whereas providers/leaders noted mammography should begin in an individual's 40s (Table 4.6). One member of the general population in Lorain County stated, "People don't realize that it is common for women in their 30's to get breast cancer." It would appear that as more and more people hear of individuals in

their 30s receiving breast cancer diagnoses, they go against doctor's recommendations and believe mammography screenings should begin almost 10 years earlier.

Figures 4.2, 4.3, and 4.4: Responses for survey question, "Why do you think people do not know when to start getting checked for breast cancer?"

Figure 4.2. Providers/Leaders, Lorain County

Figure 4.3. General Population, Mahoning County

Figure 4.4. Survivors, Cuyahoga County

When asked "Do you think people understand when to begin mammography screenings," the overwhelming majority of general population and survivor respondents said no. As one general population respondent from Cuyahoga County noted, "I don't know when I was supposed to start so I assume other people don't know either." The majority of providers, though, said yes (Table 4.6). These results indicate a separation in beliefs between these populations regarding individual level understanding of mammography initiation. The question "Why don't people understand when to begin mammography screenings," however, produced similar results from all three populations (Table 4.6). Common responses among the populations in all COIs included denial/ignorance, misleading/conflicting information, health is not a priority, lack of awareness of existing resources, and lack of education on importance of early detection and when to begin screenings.

Barriers to breast cancer screenings listed among survey respondents across all populations and COIs were similar to the responses listed for reasons why mammography initiation is not well understood. Primary barriers to screening services listed were accessibility issues (no weekend hours, no walk-in clinics, etc.), lack of transportation services, health is not considered a priority, lack of education, cost limitations, and insurance coverage issues (Table 4.6). One survivor from Ashtabula County noted most people think breast cancer "will never happen to them because no family" member has ever been diagnosed. A provider serving

Harrison/Jefferson Counties stated that “fear, lack of knowledge that there are programs to assist financially, transportation, [and] no physician to order the mammogram” all present unique barriers to individuals obtaining the screenings they need.

In regards to the recently enacted Health Insurance Exchanges (HIE) and Medicaid expansion under the ACA, the majority of general population and survivor survey respondents are aware of the new law (Table 4.7). Most respondents, however, did not believe the law would help them (Table 4.7). This could be possible due to the fact that the majority of survey respondents were already covered by some type of insurance program(s) (Table 4.6). Those covered under the HIE programs, though, were not very satisfied with the coverage their plan(s) provided. One survivor from Mahoning County stated, “I have had breast cancer, am a survivor, and am seriously thinking about skipping this year's mammogram. The reason? Due to the ACA, my insurance deductible per person for my family is now $5,000.00. I have been unemployed for three months and won't be able to pay the bill even though I HAVE [*sic*] ‘insurance.’”

Along those lines, provider survey respondents in each COI noted that patients they see who are newly enrolled in HIE programs encounter issues, including high deductibles, co-pays, and out of pocket costs, that keep cancer screenings out of reach for the newly insured population. Most of the costs are not related to screening mammography, however; the majority of the high costs are now incurred by individuals who need additional diagnostic services following an abnormal mammogram. Many facilities are providing financial assistance in the form of sliding scale fees, free services, and other additional financial support to break down these barriers. For example, a provider serving Cuyahoga County stated, “Patient's can be rated to help with co-pays, some providers will waive co-pays if unaffordable and an apt [*sic*] is very needed in extreme cases.” A provider serving Lorain County also said they will offer “financial support for non covered services.”

Table 4.6. Common survey results across all populations

Survey Response	Ashtabula County			Cuyahoga County			Harrison/Jefferson Counties			Lorain County			Mahoning County		
At what age should people begin receiving clinical breast exams?															
	General (n=6)	Survivor (n=3)	Provider (n=2)	General (n=57)	Survivor (n= 87)	Provider (n=20)	General (n=10)	Survivor (n=0)	Provider (n=3)	General (n=12)	Survivor (n=27)	Provider (n=5)	General (n=108)	Survivor (n=8)	Provider (n=2)
20s	5 (83.3%)	3 (100.0%)	2 (100.0%)	42 (73.7%)	58 (66.7%)	20 (100.0%)	8 (80.0%)	0 (0.0%)	3 (100.0%)	12 (100.0%)	18 (66.7%)	5 (100.0%)	64 (59.3%)	6 (75.0%)	2 (100.0%)
30s	0 (0.0%)	0 (0.0%)	0 (0.0%)	11 (19.3%)	26 (29.9%)	0 (0.0%)	1 (10.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	8 (29.6%)	0 (0.0%)	32 (29.5%)	2 (25.0%)	0 (0.0%)
40s	1 (16.7%)	0 (0.0%)	0 (0.0%)	4 (7.0%)	3 (3.4%)	0 (0.0%)	1 (10.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (3.7%)	0 (0.0%)	11 (10.2%)	0 (0.0%)	0 (0.0%)
50s	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (1.0%)	0 (0.0%)	0 (0.0%)
At what age should people begin receiving mammograms?															
	General (n=6)	Survivor (n=3)	Provider (n=2)	General (n=56)	Survivor (n=86)	Provider (n=20)	General (n=10)	Survivor (n=0)	Provider (n=3)	General (n=12)	Survivor (n=27)	Provider (n=8)	General (n=109)	Survivor (n=8)	Provider (n=2)
20s	1 (16.7%)	0 (0.0%)	0 (0.0%)	7 (12.5%)	18 (20.9%)	0 (0.0%)	3 (30.0%)	0 (0.0%)	0 (0.0%)	3 (25.0%)	4 (14.8%)	0 (0.0%)	35 (32.1%)	2 (25.0%)	0 (0.0%)
30s	4 (66.7%)	2 (66.7%)	0 (0.0%)	23 (41.1%)	35 (40.7%)	0 (0.0%)	3 (30.0%)	0 (0.0%)	0 (0.0%)	6 (50.0%)	16 (59.2%)	0 (0.0%)	45 (41.2%)	4 (50.0%)	0 (0.0%)
40s	1 (16.7%)	1 (33.3%)	2 (100.0%)	25 (44.6%)	33 (38.4%)	19 (95.0%)	4 (40.0%)	0 (0.0%)	3 (100.0%)	3 (25.0%)	7 (26.0%)	8 (100.0%)	27 (24.7%)	2 (25.0%)	2 (100.0%)
50s	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (1.8%)	0 (0.0%)	1 (5.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (2.0%)	0 (0.0%)	0 (0.0%)
Do you think people understand when to start getting checked for breast cancer?															
	General (n=6)	Survivor (n=3)	Provider (n=2)	General (n=56)	Survivor (n=87)	Provider (n=16)	General (n=10)	Survivor (n=0)	Provider (n=3)	General (n=12)	Survivor (n=27)	Provider (n=5)	General (n=109)	Survivor (n=8)	Provider (n=4)
Yes	1 (16.7%)	1 (33.3%)	2 (100.0%)	17 (30.4%)	27 (31.0%)	11 (68.8%)	4 (40.0%)	0 (0.0%)	3 (100.0%)	3 (25.0%)	10 (37.0%)	4 (80.0%)	30 (27.5%)	2 (25.0%)	2 (50.0%)
No	5 (83.3%)	2 (66.7%)	0 (0.0%)	28 (50.0%)	49 (56.3%)	3 (27.3%)	4 (40.0%)	0 (0.0%)	0 (0.0%)	7 (58.3%)	13 (48.2%)	0 (0.0%)	58 (53.2%)	6 (75.0%)	0 (0.0%)
I do not know	0 (0.0%)	0 (0.0%)	0 (0.0%)	11 (19.6%)	11 (12.7%)	2 (50.0%)	2 (20.0%)	0 (0.0%)	0 (0.0%)	2 (16.7%)	4 (14.8%)	1 (20.0%)	21 (19.3%)	0 (0.0%)	2 (50.0%)

Survey Response	Ashtabula County			Cuyahoga County			Harrison/Jefferson Counties			Lorain County			Mahoning County		
Why don't people understand when to begin mammography screenings?															
	General (n=4)	Survivor (n=1)	Provider (n=1)	General (n=27)	Survivor (n=40)	Provider (n=5)	General (n=3)	Survivor (n=0)	Provider (n=0)	General (n=5)	Survivor (n=11)	Provider (n=0)	General (n=36)	Survivor (n=5)	Provider (n=2)
Denial/ Ignorance	0 (0.0%)	0 (0.0%)	0 (0.0%)	3 (11.1%)	10 (25.0%)	0 (0.0%)	2 (66.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (5.6%)	2 (40.0%)	0 (0.0%)
Fear	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (5.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (40.0%)	1 (50.0%)
Lack of awareness	1 (25.0%)	0 (0.0%)	0 (0.0%)	3 (11.1%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (20.0%)	0 (0.0%)	0 (0.0%)	10 (27.8%)	0 (0.0%)	0 (0.0%)
Lack of education	0 (0.0%)	0 (0.0%)	1 (100.0%)	6 (22.2%)	12 (30.0%)	1 (20.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	4 (80.0%)	1 (9.1%)	0 (0.0%)	24 (66.7%)	1 (20.0%)	2 (100.0%)
Misleading or conflicting information	1 (25.0%)	0 (0.0%)	0 (0.0%)	9 (33.3%)	13 (32.5%)	4 (80.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (20.0%)	4 (36.4%)	0 (0.0%)	1 (2.8%)	1 (20.0%)	0 (0.0%)
No doctor	3 (75.0%)	0 (0.0%)	0 (0.0%)	1 (3.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (20.0%)	0 (0.0%)	0 (0.0%)	1 (2.8%)	0 (0.0%)	0 (0.0%)
No insurance/ Limited coverage	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (3.7%)	1 (2.5%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (9.1%)	0 (0.0%)	1 (2.8%)	0 (0.0%)	1 (50.0%)
No referral from doctor	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (3.7%)	0 (0.0%)	1 (20.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	3 (8.3%)	0 (0.0%)	0 (0.0%)
Not a priority	0 (0.0%)	0 (0.0%)	0 (0.0%)	5 (18.5%)	4 (10.0%)	0 (0.0%)	3 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (18.2%)	0 (0.0%)	3 (8.3%)	1 (20.0%)	0 (0.0%)
Youth	0 (0.0%)	1 (100.0%)	0 (0.0%)	2 (7.4%)	10 (25.0%)	0 (0.0%)	1 (33.3%)	0 (0.0%)	0 (0.0%)	2 (40.0%)	4 (36.4%)	0 (0.0%)	3 (8.3%)	1 (20.0%)	0 (0.0%)

Survey Response	Ashtabula County			Cuyahoga County			Harrison/Jefferson Counties			Lorain County			Mahoning County		
What do you think would encourage people to get checked for breast cancer?															
	General (n=6)	Survivor (n=3)	Provider (n=2)	General (n=43)	Survivor (n=39)	Provider (n=19)	General (n=5)	Survivor (n=0)	Provider (n=4)	General (n=6)	Survivor (n=16)	Provider (n=5)	General (n=76)	Survivor (n=7)	Provider (n=5)
Awareness campaigns	2 (33.3%)	0 (0.0%)	0 (0.0%)	14 (60.9%)	20 (51.3%)	0 (0.0%)	4 (80.0%)	0 (0.0%)	0 (0.0%)	2 (33.3%)	0 (0.0%)	0 (0.0%)	19 (25.0%)	0 (0.0%)	0 (0.0%)
Community events	2 (33.3%)	1 (33.3%)	1 (50.0%)	9 (20.9%)	12 (30.8%)	5 (26.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (33.3%)	1 (6.3%)	0 (0.0%)	8 (10.5%)	3 (42.9%)	0 (0.0%)
Encouragement from family and friends	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (2.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	4 (5.3%)	0 (0.0%)	0 (0.0%)
Feel something on own/BSE	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (20.0%)	0 (0.0%)	0 (0.0%)	1 (16.7%)	0 (0.0%)	0 (0.0%)	7 (9.2%)	0 (0.0%)	0 (0.0%)
Free screenings	0 (0.0%)	1 (33.3%)	0 (0.0%)	3 (7.0%)	4 (10.3%)	11 (68.8%)	0 (0.0%)	0 (0.0%)	4 (100.0%)	0 (0.0%)	0 (0.0%)	3 (60.0%)	8 (10.5%)	0 (0.0%)	4 (80.0%)
Hospital/ Organizational Outreach	2 (33.3%)	1 (33.3%)	2 (100.0%)	3 (7.0%)	7 (17.9%)	4 (21.1%)	0 (0.0%)	0 (0.0%)	2 (50.0%)	1 (16.7%)	1 (6.3%)	4 (80.0%)	7 (9.2%)	1 (14.3%)	0 (0.0%)
Increased accessibility	0 (0.0%)	0 (0.0%)	1 (50.0%)	4 (9.3%)	0 (0.0%)	19 (100.0%)	1 (20.0%)	0 (0.0%)	4 (100.0%)	0 (0.0%)	0 (0.0%)	5 (100.0%)	2 (2.6%)	0 (0.0%)	3 (60.0%)
Increased education	0 (0.0%)	3 (100.0%)	2 (100.0%)	7 (16.3%)	8 (20.5%)	3 (15.8%)	1 (20.0%)	0 (0.0%)	0 (0.0%)	1 (16.7%)	12 (75.0%)	2 (40.0%)	9 (11.8%)	0 (0.0%)	1 (20.0%)
Information from doctors	1 (16.7%)	0 (0.0%)	1 (100.0%)	10 (23.3%)	4 (10.3%)	7 (36.8%)	0 (0.0%)	0 (0.0%)	2 (50.0%)	0 (0.0%)	2 (12.5%)	4 (80.0%)	9 (11.8%)	0 (0.0%)	2 (40.0%)
Information from employers	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (2.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Insurance status	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (2.3%)	1 (2.6%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Know someone diagnosed/ family history	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (2.3%)	0 (0.0%)	0 (0.0%)	1 (20.0%)	0 (0.0%)	0 (0.0%)	2 (33.3%)	0 (0.0%)	0 (0.0%)	14 (18/4%)	1 (14.3%)	0 (0.0%)
I do not know/ I am unsure	0 (0.0%)	0 (0.0%)	0 (0.0%)	9 (20.9%)	0 (0.0%)	0 (0.0%)	1 (20.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	5 (31.3%)	0 (0.0%)	14 (18.4%)	2 (28.6%)	0 (0.0%)

Survey Response	Ashtabula County			Cuyahoga County			Harrison/Jefferson Counties			Lorain County			Mahoning County		
What do you think makes it difficult for people to get checked for breast cancer?															
	General (n=6)	Survivor (n=3)	Provider (n=2)	General (n=51)	Survivor (n=70)	Provider (n=16)	General (n=7)	Survivor (n=0)	Provider (n=4)	General (n=10)	Survivor (n=21)	Provider (n=5)	General (n=78)	Survivor (n=8)	Provider (n=4)
Accessibility issues	0 (0.0%)	1 (33.3%)	1 (50.0%)	12 (23.5%)	0 (0.0%)	5 (31.3%)	1 (14.3%)	0 (0.0%)	0 (0.0%)	2 (20.0%)	2 (9.5%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Denial	0 (0.0%)	1 (33.3%)	0 (0.0%)	0 (0.0%)	10 (14.3%)	1 (6.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	5 (23.8%)	1 (20.0%)	0 (0.0%)	2 (25.0%)	0 (0.0%)
Fear	0 (0.0%)	2 (66.7%)	1 (50.0%)	18 (35.3%)	35 (50.0%)	6 (37.5%)	0 (0.0%)	0 (0.0%)	1 (25.0%)	3 (30.0%)	7 (33.3%)	2 (40.0%)	4 (5.1%)	3 (37.5%)	1 (25.0%)
Financial limitations	3 (50.0%)	1 (33.3%)	1 (50.0%)	14 (27.5%)	21 (30.0%)	2 (12.5%)	3 (42.9%)	0 (0.0%)	1 (25.0%)	5 (50.0%)	3 (14.3%)	1 (20.0%)	0 (0.0%)	4 (50.0%)	2 (50.0%)
Insurance issues	3 (50.0%)	0 (0.0%)	1 (50.0%)	17 (33.3%)	19 (27.1%)	4 (25.0%)	4 (57.1%)	0 (0.0%)	1 (25.0%)	2 (20.0%)	7 (33.3%)	1 (20.0%)	14 (17.9%)	3 (37.5%)	2 (50.0%)
Lack of awareness	0 (0.0%)	0 (0.0%)	0 (0.0%)	4 (7.8%)	0 (0.0%)	1 (6.3%)	1 (14.3%)	0 (0.0%)	0 (0.0%)	1 (10.0%)	0 (0.0%)	1 (20.0%)	6 (7.7%)	0 (0.0%)	0 (0.0%)
Lack of education	2 (33.3%)	2 (66.7%)	0 (0.0%)	5 (9.8%)	12 (17.1%)	3 (18.8%)	0 (0.0%)	0 (0.0%)	3 (75.0%)	0 (0.0%)	2 (9.5%)	3 (60.0%)	22 (28.2%)	2 (25.0%)	1 (25.0%)
Misinformation/ Conflicting information	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (1.4%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (4.8%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
No doctor	1 (16.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (25.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	6 (7.7%)	0 (0.0%)	0 (0.0%)
Not a priority	1 (16.7%)	0 (0.0%)	1 (50.0%)	13 (25.5%)	9 (12.9%)	0 (0.0%)	1 (14.3%)	0 (0.0%)	1 (25.0%)	3 (30.0%)	4 (19.0%)	1 (20.0%)	4 (5.1%)	0 (0.0%)	2 (50.0%)
Transportation issues	2 (33.3%)	0 (0.0%)	1 (50.0%)	3 (5.9%)	8 (11.4%)	3 (18.8%)	1 (14.3%)	0 (0.0%)	1 (25.0%)	2 (20.0%)	3 (14.3%)	2 (40.0%)	43 (55.1%)	1 (12.5%)	2 (50.0%)
Youth	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (1.4%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
I do not know/ I am unsure	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (12.5%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (4.8%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

Table 4.7. Perceptions of the Affordable Care Act among general population and survivor survey respondents

	Ashtabula County		Cuyahoga County		Harrison/Jefferson Counties		Lorain County		Mahoning County	
Do you know we now have a national health insurance program (Examples: Affordable Care Act, health care exchanges, Obamacare, etc.)?										
	General (n=6)	Survivor (n=3)	General (n=57)	Survivor (n=86)	General (n=10)	Survivor (n=0)	General (n=12)	Survivor (n=26)	General (n=106)	Survivor (n=7)
Yes	6 (100.0%)	3 (100.0%)	52 (91.2%)	81 (94.2%)	7 (70.0%)	0 (0.0%)	10 (83.3%)	21 (80.8%)	76 (71.7%)	7 (100.0%)
No	0 (0.0%)	0 (0.0%)	5 (8.8%)	5 (5.8%)	3 (30.0%)	0 (0.0%)	2 (16.7%)	5 (19.2%)	30 (28.3%)	0 (0.0%)
Do you think the national health insurance program will help you?										
	General (n=6)	Survivor (n=3)	General (n=52)	Survivor (n=82)	General (n=7)	Survivor (n=0)	General (n=10)	Survivor (n=22)	General (n=76)	Survivor (n=8)
Yes	4 (66.7%)	0 (0.0%)	11 (21.2%)	12 (14.6%)	2 (28.6%)	0 (0.0%)	1 (10.0%)	4 (18.2%)	30 (39.5%)	2 (25.0%)
No	2 (33.3%)	2 (66.7%)	26 (50.0%)	40 (48.8%)	2 (28.6%)	0 (0.0%)	7 (70.0%)	15 (68.2%)	27 (35.5%)	3 (37.5%)
I do not know	0 (0.0%)	1 (33.3%)	15 (28.8%)	30 (36.6%)	3 (42.8%)	0 (0.0%)	2 (20.0%)	3 (13.6%)	19 (25.0%)	3 (37.5%)

Key Informant Interviews

Respondents and Data Analysis

Affiliate staff had more success in recruiting individuals to participate in key informant interviews in some COIs than in others (Table 4.8). While response rates did not meet the best practice goals, the information provided by the respondents did produce response saturation across the target populations. Key informant interview data was only collected from a total of 11 breast cancer survivors in Lorain (n=9; 81.8 percent) and Cuyahoga Counties (n=3; 27.3 percent). Most key informants were identified using referrals from Affiliate partners. Those who were interviewed were primarily White women (n=9; 81.8 percent), followed by three Black/African-American women (27.3 percent). There was a broad range for age at diagnosis among the participants, with 45 being the youngest and 71 being the oldest.

Table 4.8. Key informant interview response rates by Community of Interest (COI)

County of Interest	Target Population	Sample Size Target	Number of Interviews Completed
Ashtabula County	General population	11	0
	Breast cancer survivors	11	0
Cuyahoga County	Breast cancer survivors	11	3
Harrison and Jefferson Counties	Breast cancer survivors	11	0
	Breast health providers/leaders	11	0
Lorain County	General population	11	0
	Breast cancer survivors	11	9
Mahoning County	Breast cancer survivors	11	0
	Breast health providers/leaders	11	0

Data collected from key informant interviews were recorded in separate Microsoft Word documents for each participant. Much like the survey data analysis process, responses to all open-ended questions were collected from each participant for each question and uploaded into an online word cloud generator to expedite the process of identifying consistent messages and responses. Key terms were then used to create categories, which were then coded by hand by Affiliate staff. A codebook was utilized to ensure consistent and accurate coding of open-ended

responses across all respondents. Hand coding of data was chosen due to staff experience with this method, and the limited amount of data collected facilitated the hand coding process. Initial coding of key informant data resulted in 18 categories, which were then consolidated into the same four meaningful categories as the survey responses: accessibility, awareness/education, quality of care, and health care system improvement.

Key Interview Results across Populations and COIs

The results from the key informant interviews can only be compared to the survivor survey responses because interviews were only conducted with survivor populations in Lorain and Cuyahoga Counties. Similar to survey results, most survivors (n=9; 81.8 percent) in all COIs believed mammography initiation should begin in a woman's 30s due to the increased number of cases of breast cancer being diagnosed in women under 40. There were mixed feelings on whether or not people in the community understand when to begin breast cancer screenings. The general feeling from most, though, was that recent conflicting information on this subject has caused mass confusion and led to apathy among the general population. Most survivors felt breast self-examinations were beneficial as long as they are accompanied by mammography, as mammograms can catch things you cannot feel. The overall message from survivors on this issue was to have individuals do anything they can in order to catch breast cancer in its earliest stages.

Among those interviewed, multiple barriers to obtaining needed preventive health services were identified that were similar to the barriers listed by survivor survey respondents. The main themes that emerged dealt with issues related to costs of services, insurance status, and financial limitations. In regards to cost issues, one survivor from Lorain County stated, "If you are a person on a very tight budget, [a mammogram] is not going to be as high a priority as rent or food for children. There are so many single moms now with too much to take care of."

All but one of the survivors who were interviewed had insurance and a primary care doctor at the time of diagnosis (n=10; 90.9 percent). The one survivor who did not have health insurance was eventually enrolled in Ohio's BCCP Medicaid program. Insurance status, however, does not necessarily translate to a smooth ride through the CoC. A survivor from Lorain County said the out of pocket costs she endured created additional "emotional stress" for her while she was going through treatment and that "the bills started coming as soon as [her] surgery was over." A survivor from Cuyahoga County, however, said that her health insurance allowed her to "focus on her health and heal" due to the excellent coverage she was provided. These findings indicate that type of insurance and coverage plan have an influence on the emotional well-being of an individual going through breast cancer treatments.

Individual fear and denial/ignorance were also mentioned as barriers to preventive cancer screenings. "A lot of people think breast cancer is a death sentence," said one survivor from Lorain County, while another survivor from the same county noted, "There is fear of the procedure and fear of the answer." Another survivor from Lorain County stated, "I think women are just afraid. If you don't have the screening, you won't get diagnosed." These findings are very much in line with the results generated from survey respondents.

Related to this is the issue that many women do not think they will get breast cancer because they are too young and/or it is not in their family's medical history. This is very much in line with

the survey results from all three target populations. These misconceptions may be contributing to the breast cancer disparities in these COIs. Many of those interviewed also identified some additional myths/misconceptions they had heard about breast cancer, including that the disease could be caused by using deodorant, wearing underwire bras, using cell phones/storing cell phones in bras, and/or being exposed to radiation from the mammogram itself. Three survivors (n=8; 37.5 percent) in Lorain County mentioned environmental causes of the disease in their communities, including polluted water supplies, power lines, and plastic bottles.

Another issue that consistently appeared among the survivors interviewed, much like survivors who completed surveys, was the need for increased education. One area of focus included the need to educate employers. Patients in treatment for breast cancer will need time off of work, and employers need to understand that this time is necessary to promoting a stress free environment for the patient. Similar to the survey respondents, those who were interviewed noted there needs to be more education and increased awareness of the existing free programs to help break down the previously identified barriers to care. As one survivor from Cuyahoga County noted, “You know it’s time to get one, but you have to know who to call and where to go.”

It was also noted among survivor interviewees that educational messages should have a positive spin. One survivor in Lorain County stated, “You have to give communications a positive attitude. Don’t be afraid, you have to deal with what you get. The key is talking about it, sharing success stories, sharing the importance of it. There needs to be more acceptance.” One survivor from Cuyahoga County, though, stated that education and awareness efforts can be fruitless if women are not personally motivated to seek screening services. She said, “There’s all this education, public service announcements. Some women just don’t get it. I think they hear the information, but they don’t really understand the importance of it. ‘I’m just too busy, I’m afraid, it’s a bother’… they don’t really understand the importance of it.”

Knowledge and attitudes of providers came up frequently among those interviewed as a factor that influenced their journey through the continuum of care. Some survivors noted their providers were very good, but others felt some providers needed to be educated on compassionate communication. Communication from health care providers was found to be very important to providing quality care and keeping women motivated to come back for necessary screenings and/or treatments. As one survivor from Lorain County noted, her doctor “was very caring. Some women got very upset, but he’s the type of doctor who put his arms around you and just held you. He was very caring and compassionate.” Another survivor from Lorain County, however, said, “I had a very bad experience during one of my surgeries. The technicians were very mean and rude.”

In addition to provider attitudes, peer and community support came up as a common way to help patients during treatments. According to those who were interviewed, support can come in many forms from family, friends, churches, and community organizations. Some women received rides to treatments or prepared meals from friends and families, some received financial assistance for cost of living expenses from community organizations, and some received emotional support from peers, support groups at hospitals and community organizations, and churches they belonged to. Many survivor interviews revealed distinct benefits to being paired with a survivor who had undergone similar treatments and/or patient

navigator during treatments. It was noted among many interviewees, as well as survey respondents, that other survivors and navigators provided emotional support, helped answer medical questions, offered advice on treatment options, and assisted some women in gaining access to needed community resources like assistance with cost of living expenses. For these reasons, peer survivors and patient navigators seem to be an excellent way to mitigate barriers to treatment.

For most survivors who were interviewed, transportation to and from appointments for treatments was not an issue. One survivor in Cuyahoga County did have transportation barriers, but the hospital worked with her to arrange assistance for daily radiation appointments. This help was secured through the facility's social worker. There were, however, indications from those interviewed that transportation issues could pose problems for others in their community. "There's a lot of rural in Lorain County. Rural meaning there are no sidewalks and the mailboxes are on the street. And there is no public transportation in Lorain County," noted one interviewee.

When asked how much time passed from initial discovery of a breast problem to diagnosis and treatment, the timeline was typically less than or equal to one to two months. These findings are in line with those produced by survivor survey respondents. According to the National Quality Measures for Breast Centers (NQMBC), excellent level facilities will have a timeline of around 120 days from initial discovery to surgery and/or treatment (NQMBC, n.d.). It would appear, then, that the facilities where survivor interviewees were treated are complying with national standards in this regard.

Focus Groups

Participants and Data Analysis

Affiliate staff and CPT members had minor success in recruiting participants from two target populations for focus groups in the five COIs (Table 4.9). Four provider focus groups were conducted in total (n=23). Two took place at different hospital systems in Lorain County (n=11; 47.8 percent), one was held with a hospital system in Cuyahoga County (n=5; 27.8 percent), and one was conducted with a hospital system in Ashtabula County (n=7; 30.4 percent). Some basic information was collected from the Lorain County and Ashtabula County focus group participants via the IRB approved demographic form (Table 4.10). Demographic information was not collected from the Cuyahoga County providers, as this focus group was conducted over the phone and demographic forms could not be distributed. All facilities that participated in focus groups were BCCP contracted facilities, recommended CBEs begin at age 20 and mammography begin at age 40, and that mammograms occur at least annually.

Table 4.9. Focus group response rates by Community of Interest (COI)

County of Interest	Target Population	Sample Size Target	Number of Focus Groups Completed
Ashtabula County	Breast health providers/leaders	3	1
Cuyahoga County	General population	3	2
	Breast health providers/leaders	3	1
Harrison and Jefferson Counties	General population	3	0
Lorain County	Breast health providers/leaders	3	2
Mahoning County	General population	3	1

Three general population focus groups were conducted in total (n=19). Two were held at a church in Cuyahoga County with Black/African-American women of various ages (n=12; 63.2 percent) and one was conducted on a college campus with young students of various races in Mahoning County (n=7; 36.8 percent). Among those in the Cuyahoga County focus group who were over the age of 40 (n=6; 50.0 percent), all had received a mammogram in the last year. While the number of focus groups held in each COI for each population did not meet best practice standards, the information provided by the participants did produce response saturation across the target populations in each COI where focus groups were held.

Table 4.10. Provider focus group participant demographic information

Demographic Variable		Ashtabula County (n=7)	Lorain County (n=11)
Number of years in field	Less than 1 year	1 (14.3%)	1 (9.1%)
	1-5 years	1 (14.3%)	3 (27.3%)
	5-10 years	4 (57.1%)	1 (9.1%)
	10-15 years	0 (0.0%)	1 (9.1%)
	15-20 years	1 (14.3%)	0 (0.0%)
	More than 20 years	0 (0.0%)	3 (27.3%)
Areas of expertise*	Community outreach/education	4 (57.1%)	7 (63.6%)
	Patient navigation	1 (14.3%)	6 (54.5%)
	Cultural competency	0 (0.0%)	2 (18.2%)
	Disparities	0 (0.0%)	4 (36.4%)
	Research	1 (14.3%)	0 (0.0%)
	Primary care	1 (14.3%)	2 (18.2%)
	Mammography	1 (14.3%)	3 (27.3%)
	Radiology	0 (0.0%)	1 (9.1%)
	Oncology	1 (14.3%)	1 (9.1%)
	Surgery	1 (14.3%)	2 (18.2%)
	Survivor Issues	1 (14.3%)	2 (18.2%)
Best methods to distribute information in communities served*	Churches	4 (57.1%)	9 (81.8%)
	Shopping centers/malls	1 (14.3%)	5 (45.5%)
	Radio	1 (14.3%)	5 (45.5%)
	Internet	4 (57.1%)	5 (45.5%)
	Primary care doctor	6 (85.7%)	8 (72.7%)
	Word of mouth	4 (57.1%)	8 (72.7%)
	Mail	5 (71.4%)	6 (54.5%)
	Television	1 (14.3%)	3 (27.3%)
	Newspaper	3 (42.9%)	8 (72.7%)
	Social media	4 (57.1%)	3 (27.3%)

*Participants could choose more than one option for certain questions; therefore, percentages may not add up to 100%.

Responses from provider focus groups conducted by Affiliate staff were recorded and transcribed into separate Microsoft Word documents for each group. The three general population focus groups were summarized by the respective facilitators and sent to Affiliate staff for inclusion in the final analysis. Similar to the survey and key informant data analysis process, responses to all open-ended questions were collected from each focus group for each question and uploaded into an online word cloud generator to expedite the process of identifying consistent messages and responses. Key terms were then used to create categories, which were then hand coded by Affiliate staff. A codebook for each target population was utilized to ensure consistent and accurate coding of open-ended responses across all populations and COIs. Hand coding of data was chosen due to staff experience and the limited amount of data collected facilitated an easy hand coding process. Initial coding of focus group data was done in a way so that each code represented one of the four meaningful categories developed during the survey and key informant interview analysis: accessibility, awareness/education, quality of care, and health care system improvement.

Focus Group Results across Populations and COIs

Because focus groups were only conducted with providers and members of the general population, the results from the focus groups can only be compared to the provider and general population survey responses. Results from all focus groups conducted are in line with the results produced from the surveys. Among the general population focus groups, most participants indicated that mammography should begin between the ages of 30-45. Providers, however, all recommend that mammography begin at age 40 for women at average risk and 10 years before the first age of diagnosis if there is a strong family history. It seems there is a lack of understanding on when to begin mammography initiation, which could be the result of conflicting guidelines among organizations and hospital facilities. As one Lorain County provider noted, “There is still a lot of confusion on screening mammograms and when or what age to begin them. People still think it’s contradictory on what they should do. Even with a family history, they don’t know when to begin screenings.”

Another finding that further reinforced the previously identified barriers to care related to preventive health not being a priority for women. As one provider in Cuyahoga County noted, “Part of it is women not making their health a priority. When you are working two jobs, raising three kids by yourself, a mammogram is not important at all. Even getting to the doctor or going to the gym once a week is a problem.” A Lorain County provider also stated that breast health is “…not a priority. They are only worried about health in [a] general sense and believe if they can still function, then they are not sick.” Women not taking time out for themselves also appeared as a key issue in the two general population focus groups conducted in Cuyahoga County.

Issues of fear and denial as barriers to screenings were also prominent among all focus group participants. “There is an intense fear of what is unknown. We give talks on breast cancer and breast health awareness, but a lot of the women say ‘It’s just better if I don’t know.’ There’s a level of anxiety that we can’t address adequately and that’s something we’ve been working on,” noted one provider from Cuyahoga County. Additionally, a provider in Ashtabula County noted, “Women are afraid to tell you something is wrong out of fear of being turned away,” and even when assistance is provided to cover the cost of a mammogram “…women are afraid to be screened because they are afraid there is no help for them if they are diagnosed.” The mentality of not wanting to know about problems not only relates to the fear of being diagnosed with the

disease, but also fear of treatments, fear of surgery, fear of how they will pay for treatments, fear of losing hair, and fear of what will happen to their families if they die.

In agreement with the survey and key informant data previously collected, both providers and general population focus group participants identified barriers related to costs of care and finances. An Ashtabula County provider stated, “A lot of economic despair exists here. Mammography is not important when you can’t feed your kids. There are so many other dynamics that take precedent. How do you incentivize it in a way that’s important to them?” This sentiment was echoed by a Cuyahoga County provider who noted that the people who need the most help are low-income individuals who may not be able to take time off of work for a mammogram because they cannot afford to miss a day of work. Lorain County providers also noted that finances are a huge concern in their area and a lot of the women who fall out of the CoC either have no insurance or have insurance plans with high deductibles. One Lorain County provider stated, “Money is number one. Paying for treatment, cost of living expenses. Even those with insurance have these concerns. With insurance, there are issues with getting treatments paid for.”

Another consistent theme that supports previous findings was accessibility. Transportation was cited as a large barrier in Ashtabula County and a Lorain County provider said, “Transportation is everything. We have no reliable public transportation and there is limited bus service. We can help schedule times for pick-ups and drop-offs […], but we need a van for patients.” All provider groups noted they are missing the hard-working, employed individuals who work in the evenings or cannot take time off of work during the day because of limited hours of operation for mammography services. Even when mammograms are offered on the weekends, however, it is difficult to get women to come in on their day off as noted by a Cuyahoga County provider.

Issues related to education were also persistent across the focus group participants. The young women in the Mahoning County focus group shared that they wish their providers would educate them on how to perform breast self-exams and the signs and symptoms to look for. The Cuyahoga County general population participants and all providers from the various COIs recognized a need to educate women on appropriate screening guidelines, as conflicting ideologies have caused mass confusion in the general public on when to initiate mammograms and the frequency of screenings. Another educational issue was getting the word out about free programs. One provider in Ashtabula County said that …”there is help for women who need financial assistance, but they need to get to us in order to receive the help. If they don’t know we’re here, how can we help them?” This issue came up in all provider focus groups. Mahoning County general population participants further supported this finding, stating they would not know where to go for a screening if they did not have insurance.

Additionally, more education needs to occur related to myths and misconceptions surrounding an individual’s susceptibility of developing the disease. As one Ashtabula County provider put it, “Women think that because their mammogram has always been fine, they do not need to have them anymore.” This mentality was identified to be stronger among younger women who have no family history of breast cancer. Mahoning County general population participants did note, however, that if breast cancer runs in the family, they would be much more likely to get screened on a regular basis. For example, one participant’s grandmother had breast cancer, so

her mother made her get checked regularly. The participant now continues to get checked regularly because it has become a standard part of her health routine.

When participants were asked what methods should be employed by organizations to address cost, accessibility, and education issues, multiple strategies were identified that were in line with survey findings. All provider focus groups stressed a need to have physician champions on board with programs targeted to the uninsured. A provider in Cuyahoga County stated, “We have physicians go out into the field [to educate], which helps establish a bit of trust. That certainly helps.” Providers also noted that primary care doctors should be educating women on the importance of regular screenings, which was further supported by the general population participants.

It was recommended that community outreach be conducted in schools and churches to help address these gaps in education. A Lorain County provider recommended more education for young adults so they can become familiar with the signs and symptoms, become empowered, and know that a lump does not always mean cancer. The young adults in the Mahoning County group also felt that education should begin in high school so everyone is learning when and how often to be screened, to break down confusion, and get people talking about the disease. The Mahoning County participants noted that talking about screening with their peers made them more comfortable because they learned their peers were screened and they want to fit in with their social groups.

Education sessions should also focus on changing personal motivations, because educational messages currently being used are “not sinking in.” One provider in Cuyahoga County said, “Perhaps the importance of repeated engagement with the folks, so that, I don’t even know how this would be possible, so that there’s not one interaction, but it’s repeated over time.” Additionally, educational messages should focus on all the signs and symptoms of breast cancer, like inverted nipples, nipple discharge, and rippling of the skin, and not just lumps. “Everyone knows to check for a lump,” said one Lorain County provider, “but there are other warning signs.”

Mobile mammography was frequently mentioned by all participants across populations and COIs as a way to break down accessibility issues. “We need more mobile units, more convenience. Location, location, location. If they have to do it on their own time, they are not going to do it,” stated one Ashtabula County provider. A provider from Cuyahoga County recognized that education sessions are more impactful if the attendees could receive a mammogram on a mobile unit immediately following the education. Mobile units were also identified as effective ways to address issues related to transportation and taking time off of work.

Patient navigation was frequently mentioned in the provider focus groups as a way to break down barriers to care. All facilities that participated in focus groups have patient navigators on staff. It was recognized that having a navigator there to assist individuals helps maintain coordinated care, helps prevent breakdowns in communication, and keeps women coming back for necessary appointments. As one Lorain County provider noted, “There are no barriers to treatment here because of the navigators.” A Lorain County provider from a different facility also stated that navigators are the key to getting women in the door.

Additionally, provider focus group participants noted that increased collaboration would help address the persistent disparities in Northeast Ohio. One Cuyahoga County provider stated, "One of the concerns I've had for a while is the disconnect [*sic*] between some of the services that are available and [Cuyahoga County's] continuing high-rank in terms of deaths. There is a need to present different stakeholders with information, have them then collectively identify solutions, but there would need to be an incentive to do this. I think it would be terrific to think about a different approach to bring stakeholders together – community members, community agencies that support the different education initiatives, both public and private stakeholders including the wonderful medical centers we have." It was documented across all providers that getting stakeholders together and keeping them engaged are challenges. Barriers to these types of collaborations included competing service markets, limited administrative and/or financial support, and recruiting members from diverse communities to participate. These findings are consistent with the responses of provider survey respondents.

Provider focus group participants also identified issues related to the ACA and the BCCP. All financial assistance programs for the uninsured offered at each provider facility have seen a decline in the number of uninsured women requesting free mammograms; however, these programs are seeing an increase in the number of individuals with HIE coverage that need more assistance with co-payments because their deductibles are very high. "Some of these deductibles are between $3,000-$5,000. If you have difficulty paying $500, $5,000 is insurmountable," noted one provider from Cuyahoga County. Additionally, the newly insured population does not know how to navigate health systems, so some are still dependent on the charitable programs that offer additional navigation assistance. It was also noted that while mammograms are covered, there is still a need to pay for interpretation of results and any subsequent diagnostic procedures that may be determined necessary.

Qualitative Data Findings

The findings from the qualitative data efforts assisted in answering most of the key questions of the CPT following the analysis of the Quantitative Data Report and the Health Systems and Public Policy Analysis data. The findings helped illuminate the individual, interpersonal, community, systems, and public policy related assets, barriers to care, and points along the CoC where individuals may fall out. The qualitative data assessed breast health knowledge, attitudes, beliefs, and health care behaviors among those who live in the COIs and emphasized the need for more education addressing fear, screening guidelines, and individual level barriers to care (i.e., health is not a priority, not aware of where to go for assistance, etc.).

Ashtabula County

Women in Ashtabula County have conflicting priorities given the large number of single mothers and economic despair in the area. Women in this area do not understand the importance of early detection and are not aware of the financial assistance programs for screening and treatment. Education programs need to be effective for low-income, working poor, rural women and should come from providers/hospital systems to establish trust. Education programs should address issues of fear and denial, be targeted to younger women, and dispel conflicting information regarding screening guidelines. Community outreach is needed to advertise free programs in the area. There is a need for increased transportation assistance and financial

assistance programs are needed for newly insured populations with high deductibles/co-pays. Free, mobile mammography programs were recommended as a solution to multiple issues facing women in this community.

Cuyahoga County

Women in Cuyahoga County experience multiple breakdowns in the CoC. There is a lack of educational programs that motivate women to action. Education programs should address issues related to fear, dispel common breast cancer myths, counsel on appropriate screening guidelines, and increase awareness of existing financial assistance programs. Education should take place in schools and churches. Provider champions should take part in community education efforts to establish trust and educate peers/colleagues on available programs. More stakeholder collaborations are needed to address high death rates in Cuyahoga County. Mobile mammography, patient navigators, non-traditional clinic hours, and free/low-cost screening programs are needed to break down personal and financial barriers to care. Survivors, both uninsured and insured, need assistance with treatment and cost of living expenses. Financial assistance programs are needed for newly insured populations with high deductibles/co-pays. There is also a need for peer-to-peer support networks for survivors.

Harrison and Jefferson Counties

Most survey respondents from these counties believe mammography should begin in a woman's forties and most people understand when to begin receiving mammograms, but these findings do not support the quantitative data. Factors preventing women from obtaining needed screenings include health not being a priority and the belief that mammography is an older woman's disease. Women in this area experience insurance/financial barriers to obtaining needed services, and there is a lack of education related to breast health in the area. Free/low-cost services, increased accessibility, more awareness/education campaigns, and information received from doctors were recommended as ways to increase mammography initiation and adherence. The limited amount of qualitative data collected in these areas indicates the need for the Affiliate to establish stronger relationships with traditional and non-traditional partners serving these areas.

Lorain County

There is a lack of educational programs in Lorain County that show positive messages and motivate women to action. Education programs should address issues related to fear, dispel common breast cancer myths, counsel on appropriate screening guidelines, and increase awareness of existing financial assistance programs. Education should take place in schools and churches. Provider champions should take part in community education efforts to establish trust and educate peers/colleagues on available programs. Mobile mammography, patient navigators, non-traditional clinic hours, and free/low-cost screening programs are needed to break down personal and financial barriers to care. Financial assistance programs are needed for newly insured populations with high deductibles/co-pays. There is also a need for peer-to-peer support networks for survivors and programs that help with treatment and cost of living expenses.

Mahoning County

More education is needed in Mahoning County to dispel confusion surrounding screening guidelines and to get women talking about breast health. Education should be targeted to women under the age of 40, particularly high school students. Providers need to be educated on

appropriate screening guidelines; providers also need to pass this messaging onto their patients, recommend mammography, and teach women how to perform BSEs. Transportation is a major barrier for women in this area, as well as issues with insurance coverage/cost limitations for services.

Conclusions

The qualitative data highlighted potential barriers in accessing breast cancer screening and treatment services in the COIs, including a lack of awareness of existing resources, the need for more community outreach, and accessibility issues, such as transportation; limited mammography clinic hours; financial limitations, cost issues, and insurance coverage limitations; and provider competency and communication issues. Additionally, the qualitative data findings identified potential areas for collaborations, effective methods to break down barriers to care, like patient navigation and mobile mammography, and potential new "gap" populations created by the implementation of the ACA.

The data collected, however, did present some limitations. Despite the efforts to recruit enough participants across all qualitative data methods, low response rates for the surveys and not meeting best practice goals regarding the number of interviews and focus groups conducted indicate the results from these methods cannot necessarily be generalized to the larger populations in the COIs. The data collected through these means also did not come from diverse populations, which indicates the results are not representative of the entire population under investigation. Low response rates from non-diverse audiences in certain COIs indicates that development of partnerships with health systems and organizations serving these areas should be emphasized by the Affiliate. Partnerships will allow for more in-depth connections being made to these populations. Additionally, because the focus groups were conducted by three different facilitators, facilitator bias could be a potential issue for these methods. The use of a facilitator script was an attempt to minimize this, and it is unlikely that bias was a serious issue.

Breast Health and Breast Cancer Findings of the Target Communities

Quantitative Data Analysis: Key Findings

The data provided by Komen Headquarters in the Quantitative Data Report revealed the Northeast Ohio (NEO) service area bears a meaningful burden of breast cancer in the State of Ohio. The NEO service area accounts for 39.2 percent of the female population, 41.7 percent of all new breast cancer cases, 40.8 percent of all new late-stage diagnoses, and 42.4 percent of all breast cancer deaths in the state. The Komen NEO service area represents the most demographic diversity in the state, with 83.0 percent White, 15.0 percent Black/African-American, and 3.1 percent Hispanic/Latina. Additionally, 14.4 percent of the female population living in the NEO service area are without health insurance and more than half (53.2 percent) are over the age of 40.

To increase Komen NEO's effectiveness in the quantitative research efforts, Komen NEO chose five target communities, known as "communities of interest" (COI), within the 22-county service area to do additional investigation. Healthy People 2020 objectives for breast cancer late-stage diagnosis and death rates were used as benchmarks in determining the communities of highest need. Additional key indicators reviewed in the selection process included the total female population; percent of female population over the age of 40; rates of health insurance; mammography screening percentages; poverty percentages; medically underserved areas; rural areas; breast cancer incidence rates; and other vital statistics. Based on the data provided, the Community Profile Team (CPT) chose five COIs for additional investigation: Ashtabula County, Cuyahoga County, Harrison and Jefferson Counties (combined to form one COI), Lorain County, and Mahoning County.

Health Systems and Public Policy Analysis: Key Findings

The Health Systems Analysis (HSA) revealed multiple disparities and breakdowns in the breast health continuum of care (CoC) in the COIs. The more urban COIs – Cuyahoga, Lorain, and Mahoning Counties – have an appropriate number of health care systems and facilities that offer a wide range of services along the continuum of care; however, individuals in these areas still experience adverse health outcomes related to breast cancer. This indicates that factors beyond availability of necessary resources prevent women from accessing, entering, and staying in the CoC. The more rural COIs – Ashtabula County and Harrison and Jefferson Counties – on the other hand, lack an appropriate number of facilities and services to adequately address the breast health needs of the community, which indicates accessibility and availability may be major forces preventing women from accessing, entering, and staying in the CoC.

The impact of the Affordable Care Act (ACA) and Medicaid expansion on the Northeast Ohio region has yet to be seen. Preliminary outcomes indicate a decreased need for safety-net screening programs targeted to the uninsured, like Ohio's Breast and Cervical Cancer Project (BCCP), and an increased need for programs that assist with paying down high deductibles on Health Insurance Exchange (HIE) coverage that leave many women without the ability to afford costly diagnostic procedures and treatments, if needed. Komen NEO will continue to work with

state and federal legislators, health policy coalitions, and the Komen Ohio Advocacy Coalition to determine state-level public policy priorities, including expanding BCCP coverage to the underinsured and men.

Qualitative Data Analysis: Key Findings

Based on the findings from the Quantitative Data Analysis and Health Systems and Public Policy Analysis sections, the CPT developed a set of key questions to answer during the qualitative data collection process. The questions focused on the individual, interpersonal, community, systems, and public policy related assets, barriers to care, and points along the CoC where individuals may fall out. Key questions were framed so they could adequately assess the breast health knowledge, attitudes, beliefs, and health care behaviors among those who live and work in the COIs. Qualitative data was collected from three target populations – the general population (those never diagnosed with breast cancer), breast cancer survivors, and breast health providers/stakeholders – in all COIs using surveys, key informant interviews, and focus groups.

The data collected from the mixed qualitative data collection methods highlighted potential barriers in accessing breast cancer screening and treatment services in the COIs, including a lack of awareness of existing resources, the need for more community outreach, and accessibility issues related to cost of services and insurance coverage. Barriers to care beyond those related to cost were also identified, including limited transportation, limited mammography clinic hours, and provider competency and communication issues. The need for more effective education programs that address fear, dispel myths about breast cancer, and address any misunderstandings related to mammography screening initiation and frequency was also identified. Additionally, the qualitative data findings identified potential areas of collaborations, effective methods to break down barriers to care, such as patient navigation and mobile mammography, and potential new "gap" populations created by the implementation of the ACA and Medicaid expansion in Ohio.

Mission Action Plan

Using the data and information collected in the three sections of the Community Profile Report, the CPT developed a comprehensive plan of action to address the identified issues, known as the Mission Action Plan (MAP). The MAP will act as the roadmap for Komen NEO's future work and provides detailed priorities and objectives the Affiliate will employ to close the gaps along the CoC. The MAP consists of two major components: COI statements of need and Affiliate priorities and objectives.

Statements of need were created by Komen NEO staff, which were then edited and approved by the CPT. The CPT held a two hour brainstorming meeting to craft initial priorities based on the statements of need. It was decided by all that, because the major themes and needs in each COI were very similar, overarching priorities would be created, followed by individualized objectives for each COI as appropriate to address the unique needs of those communities and the populations they encompass. Final priorities and objectives were created by Komen NEO staff based on internal resources and staff capacity. Objectives were also drafted to further support existing programs and services already offered by Komen NEO. The final MAP was

approved by the CPT via email and presented to the Komen NEO Strategic Mission Committee and Board of Directors for approval in March of 2015.

The following statements of need, priorities, and objectives outline the specific goals and activities Komen NEO will implement to address existing community needs in each COI. This MAP will be effective for the next four years, with a biennial update on the status of each objective provided in the summer of 2017. All implementation and evaluation efforts towards accomplishing the identified priorities and objectives will be monitored by Komen NEO staff and reported on four times a year to the Affiliate's Strategic Mission Committee and the Board of Directors.

COI Statements of Need

Ashtabula County
There are many women in this county who are uninsured, live below the Federal Poverty Level (low-income), and/or live in rural areas. This county experiences high rates of breast cancer deaths and late-stage diagnosis. There is a shortage of primary care providers and women are not aware of and/or are not accessing financial assistance programs offered by health systems. The Affiliate only has an existing relationship with one health facility serving this area. Additionally, there is only one survivor support group in the area. Some women in the community have conflicting priorities when it comes to health and many encounter transportation issues. Education efforts should be focused on the importance of early detection and increase awareness of existing resources.

Cuyahoga County
There are high percentages of low-income, uninsured, and/or minority women in this county. Women in Cuyahoga County face high incidence, late-stage diagnosis, and death rates. There are numerous programs and facilities available to women, but women are not aware of and/or are not accessing them. There is a lack of effective community-based education programs, little to no effective stakeholder collaborations, and a need for increased accessibility, more provider champions, and more peer-to-peer survivor support programs.

Harrison and Jefferson Counties
These counties encompass large medically underserved, low-income, and rural populations. Women in these areas have low screening percentages, and incidence, late-stage, and death rates are all increasing. A limited number of facilities/programs create additional barriers to care and accessibility issues. There are a limited number of survivor support programs available. Women in this area have conflicting priorities when it comes to health, financial limitations, transportation issues, and a lack of health education.

Lorain County
This area experiences high rates of breast cancer deaths and late-stage diagnosis and is made up of a high percentage of low-income, rural women. A low number of facilities/providers in this county are contracted with the BCCP, which limits where low-income patients can be seen for effective, affordable care. There is a need for more community-based education programs, more provider champions, increased financial assistance programs, and more peer-to-peer support networks for survivors.

Mahoning County
Mahoning County experiences high rates of breast cancer incidence, late-stage diagnosis, and deaths, and women in this area are not screened on a regular basis. Many women are low-income, unemployed, live in rural areas, and/or belong to a minority group. Many facilities provide the full spectrum of care, have BCCP providers, and offer financial assistance programs, but women here are not aware of and/or are not accessing these services. There is a need for increased education, transportation assistance, and increased insurance coverage.

Affiliate Priority 1: Accessibility
Improve timely access to quality, affordable screening and treatment services for the low-income, underinsured, uninsured, and/or working poor within each Community of Interest.

Objectives for All Communities of Interest

- Objective 1: By the end of FY17, cultivate relationships with at least three health systems and/or community-based organizations in each of the Communities of Interest that result in at least quarterly email updates from partners to aid in the promotion of existing free/low-cost screening programs available for target populations.
- Objective 2: From FY16 through FY19, a comprehensive resource listing that includes all Health Insurance Exchange and Medicaid navigators serving each Community of Interest will be updated annually to assist in the effective navigation of uninsured individuals to ongoing sources of health insurance coverage that best suits their individual needs.
- Objective 3: Beginning with the FY16-17 Community Grant RFA, a key funding priority will be to support the development and expansion of mobile mammography and/or transportation assistance programs for target populations in all five Communities of Interest.
- Objective 4: Beginning with the FY16-17 Community Grant RFA, a funding preference will be given to programs that break down systems-level barriers to care, including assistance with insurance deductibles/co-pays, provision of free/low-cost services, non-traditional clinic hours, and weekend appointment availability, in all Communities of Interest.

Affiliate Priority 2: Quality of Care
Increase the number of effective, evidence-based programs that support the emotional, social, financial, and spiritual well-being of individuals diagnosed with breast cancer and their families within each Community of Interest.

Objectives for All Communities of Interest

- Objective 1: Beginning in the FY16-17 Community Grant RFA, a key funding priority will be to support the development and/or growth of patient navigation programs for individuals in treatment for breast cancer focused on breaking down barriers to treatment, including medical care and service coordination, child care and transportation assistance, social work and community-based referrals, and emotional support in all five Communities of Interest.

- Objective 2: Beginning in the FY16-17 Community Grant RFA, a key funding priority will be to support direct financial assistance programs that assist with cost of living and treatment expenses for individuals in active treatment for breast cancer to facilitate continuation of treatment in all Communities of Interest.
- Objective 3: Beginning in the FY16-17 Community Grant RFA, a key funding priority will be to support the development and implementation of trainings focused on effective, evidence-based communication methods and styles for those working with individuals and families battling breast cancer in all Communities of Interest.

Objectives for Ashtabula County and Harrison and Jefferson Counties

- Objective 4: Beginning in the FY16-17 Community Grant RFA, a key funding priority will be to increase the number of free/low-cost survivor support groups and services that use evidence-based strategies to address the psycho-social, emotional, and physical issues faced by survivors and their family members.

Objectives for Cuyahoga County

- Objective 4: By the end of FY17, host at least one breast cancer survivor education event focused on short- and long-term breast cancer survivor issues and needs.

Affiliate Priority 3: Education

Initiate and support education efforts focused on increasing awareness and utilization of existing resources, the importance of early detection, and motivating women to action with an emphasis on reaching the low-income, underinsured, uninsured, and/or working poor within the Communities of Interest.

Objectives for All Communities of Interest

- Objective 1: By the end of FY19, develop grassroots marketing strategies with at least three non-traditional partners (restaurants, beauty salons, churches, large employers, universities, etc.) and community-based organizations (YWCAs, libraries, food banks, etc.) in each Community of Interest to advertise free/low-cost screening programs and education/awareness events throughout the year.

Objectives for Ashtabula County

- Objective 2: By the end of FY19, partner with at least one community-based organization and/or health care institution to provide a culturally appropriate breast health education event where individuals from target populations can sign up for a free/low-cost mammography appointment.
- Objective 3: Beginning with the FY16-17 Community Grant RFA, a key funding priority will be to support an evidence-based peer-to-peer education program for target populations in Ashtabula County.

Objectives for Cuyahoga County

- Objective 2: By the end of FY19, partner with at least one community-based organization and/or health care institution to provide two culturally appropriate breast health education events where individuals from target populations can sign up for a free/low-cost mammography appointment.

- Objective 3: Beginning in the FY16-17 Community Grant RFA, preference will be given to education programs in Cuyahoga County that focus on motivating women to action and lead to long-term behavior change (e.g., multi-session, cohort education programs).

Objectives for Harrison and Jefferson Counties

- Objective 2: By the end of FY19, partner with at least one community-based organization and/or health care institution to provide a culturally appropriate breast health education event where individuals from target populations can sign up for a free/low-cost mammography appointment.
- Objective 3: Beginning with the FY16-17 Community Grant RFA, a key funding priority will be to support an evidence-based peer-to-peer education program for target populations in Harrison and Jefferson Counties.

Objectives for Lorain County

- Objective 2: By FY18, work with the Affiliate's education committee to develop a plan to recruit and train at least five individuals from Lorain County to join Komen Northeast Ohio's speaker's bureau to increase the Affiliate's on-the-ground presence in this area.
- Objective 3: By FY19, the newly trained Komen volunteers will provide community-based presentations to target populations on breast health, breast cancer, available community resources, and Komen Northeast Ohio at a minimum of one event each (five events total) in Lorain County.
- Objective 4: By the end of FY19, partner with at least one community-based organization and/or health care institution to provide a culturally appropriate breast health education event where individuals from target populations can sign up for a free/low-cost mammography appointment.
- Objective 5: Beginning in the FY16-17 Community Grant RFA, funding preference will be given to education programs in Lorain County that focus on motivating women to action and lead to long-term behavior change (e.g., multi-session, cohort education programs).

Objectives for Mahoning County

- Objective 2: By the end of FY18, work with the Affiliate's education committee to develop a plan to recruit and train at least five individuals from Mahoning County to join Komen Northeast Ohio's speaker's bureau to increase the Affiliate's on-the-ground presence in this area.
- Objective 3: By FY19, the newly trained Komen volunteers will provide community-based presentations to target populations on breast health, breast cancer, available community resources, and Komen Northeast Ohio at a minimum of one event each (five events total) in Mahoning County.
- Objective 4: By the end of FY19, partner with at least one community-based organization and/or health care institution to provide a culturally appropriate breast health education event where individuals from target populations can sign up for a free/low-cost mammography appointment.
- Objective 5: Beginning in the FY16-17 Community Grant RFA, a key funding priority will be to support an evidence-based peer-to-peer education program for target populations in Mahoning County.

Affiliate Priority 4: Health care System Performance Improvement

Decrease gaps/breakdowns in the breast health continuum of care and reduce systemic barriers to care through the development of strategic collaborations with stakeholders and non-traditional partners to increase access to and seamless progression through the breast health continuum of care in each of the Communities of Interest.

Objectives for All Communities of Interest

- Objective 1: Beginning with the FY16-17 Community Grant RFA, support the initiation and/or expansion of programs focused on health care system performance improvements in all five Communities of Interest, including: provider education on BCCP; internal training on agency processes for enrollment in financial assistance programs; physician reminder systems; shared medical appointments; development of cross-functional workgroups/teams; creation of internal checklists and protocols; and deployment of data-driven approaches in implementing evidence-based programs.

Objectives for Ashtabula County

- Objective 2: By the end of FY18, join at least one existing community health and/or cancer coalition serving Ashtabula County to explore additional community issues and increase partnership opportunities.
- Objective 3: By the end of FY18, host at least one grant writing workshop in Ashtabula County to increase knowledge of the Affiliate's work, foster inter-agency collaboration, and support the development of grant applications from organizations serving target populations in Ashtabula County.
- Objective 4: By the end of FY19, increase the number of organizational partnerships in Ashtabula County from one to five.

Objectives for Cuyahoga County

- Objective 2: By the end of FY16, host at least two collaborative meetings with hospitals, primary care providers, health clinics, and community-based organizations serving Cuyahoga County to explore additional community issues, discuss possible partnership opportunities, and gauge level of interest in participating in a breast health task force.
- Objective 3: By the end of FY17, establish a breast health task force in Cuyahoga County made up of providers, stakeholders, breast cancer survivors and co-survivors, and community members to reduce duplication through service delivery efficiencies; create stronger and more integrated planning on regional approaches to address public service needs; expand and create opportunities that increase and improve effectiveness of each organization; and enhance program results through leveraged resources, combined resources, and the creation of new resources.
- Objective 4: By the end of FY19, the breast health task force in Cuyahoga County will meet at least quarterly to provide status updates on progress towards achieving the task force's strategic goals and objectives.

Objectives for Harrison and Jefferson Counties

- Objective 2: By the end of FY16, add a medical, public health, or nonprofit professional from one of these rural counties to the Affiliate's Board of Directors to ensure the needs of the many rural communities in the service area are represented on the Board.
- Objective 3: By the end of FY17, join at least one existing community health and/or cancer coalition serving Harrison and Jefferson Counties to explore additional community issues and increase partnership opportunities.
- Objective 4: By the end of FY18, host at least one grant writing workshop in Jefferson County to increase knowledge of the Affiliate's work, foster inter-agency collaboration, and support the development of grant applications from organizations serving target populations in Harrison and Jefferson Counties.
- Objective 5: By the end of FY19, increase the number of organizational partnerships in Harrison and Jefferson Counties from two to seven.

Objectives for Lorain County

- Objective 2: By the end of FY19, join at least one existing community health and/or cancer coalition serving Lorain County to explore additional community issues and increase partnership opportunities.
- Objective 3: By the end of FY19, work in conjunction with the Ohio Department of Health and BCCP Region 12 to schedule at least one provider and health care systems training on the BCCP in an effort to increase provider/systems participation and patient enrollment in the program.
- Objective 4: By the end of FY19, increase the number of organizational partnerships in Lorain County from two to ten.

Objectives for Mahoning County

- Objective 2: By the end of FY17, host at least two collaborative meetings with hospitals, primary care providers, health clinics, and community-based organizations serving Mahoning County to explore additional community issues and discuss possible partnership opportunities.
- Objective 3: By FY17, increase the number of organizational partnerships in Mahoning County from three to ten.

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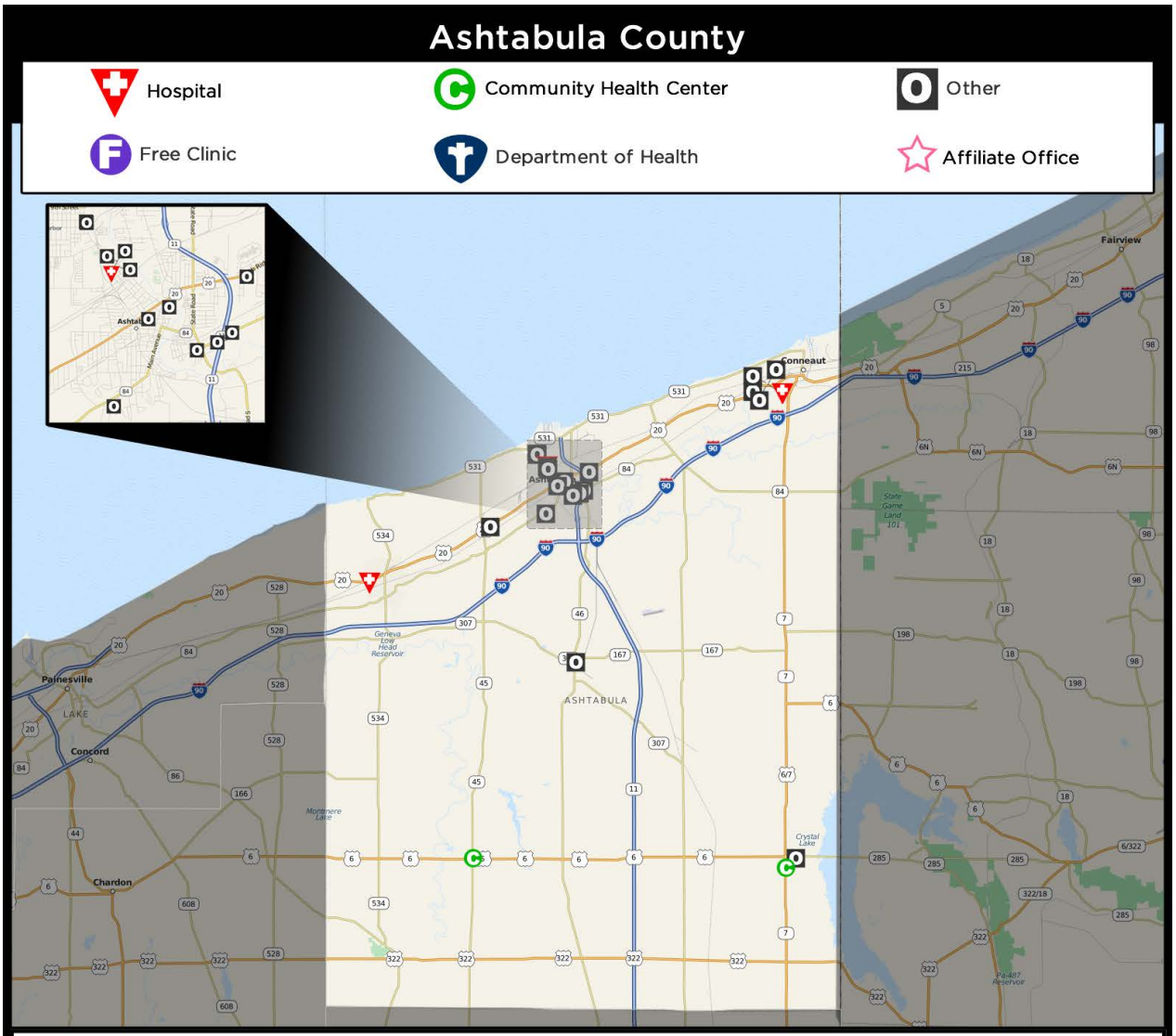
Appendices

Appendix A: Web Resources Used in Health Systems Analysis

- The Center for Health Affairs, Northeast Ohio's Hospital Association, Member Directory (Cleveland, Ohio) www.chanet.org
- The Henry J. Kaiser Family Foundation, State Health Facts: www.kff.org
- Ohio Department of Jobs and Family Services: http://jfs.ohio.gov/
- US Department of Health and Human Services, Federally Qualified Health Centers (FQHCs): http://www.hrsa.gov/healthit/toolbox/RuralHealthITtoolbox/Introduction/qualified.html
- Ohio Association of Community Health Centers: http://www.ohiochc.org/
- Akron Regional Hospital Member Directory www.arha.org
- Komen NEO grant applicant and grant recipient database
- http://www.radiologyimagingcenters.com/
- American College of Surgeons Commission on Cancer Certification: http://datalinks.facs.org/cpm/CPMApprovedHospitals_Search.htm
- American College of Surgeons national Accreditation Program for Breast Center: http://datalinks.facs.org/napbc/napbc_results.cfm?STATECODE=OH
- American College of Radiology Breast Imaging Centers of Excellence: http://www.acr.org/Quality-Safety/Accreditation/Accredited-Facility-Search
- National Cancer Institute Designated Cancer Centers: http://cancercenters.cancer.gov/cancer_centers/cancer-centers-list2.html
- FDA approved Mammography Centers: http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMQSA/mqsa.cfm
- National Hospice and Palliative Care Organization: http://www.nhpco.org/quality-partners-who-are-they
- Healthcare.gov: https://www.Healthcare.gov
- Medicaid.gov: http://www.medicaid.gov/affordablecareact/affordable-care-act.html
- American Cancer Society: www.cancer.org
- The Karen P. Nakon Foundation: www.nakonfoundation.org
- The JD Breast Cancer Foundation: www.jdbcfoundation.org

Appendix B: Asset Maps for Northeast Ohio COIs



Statistics

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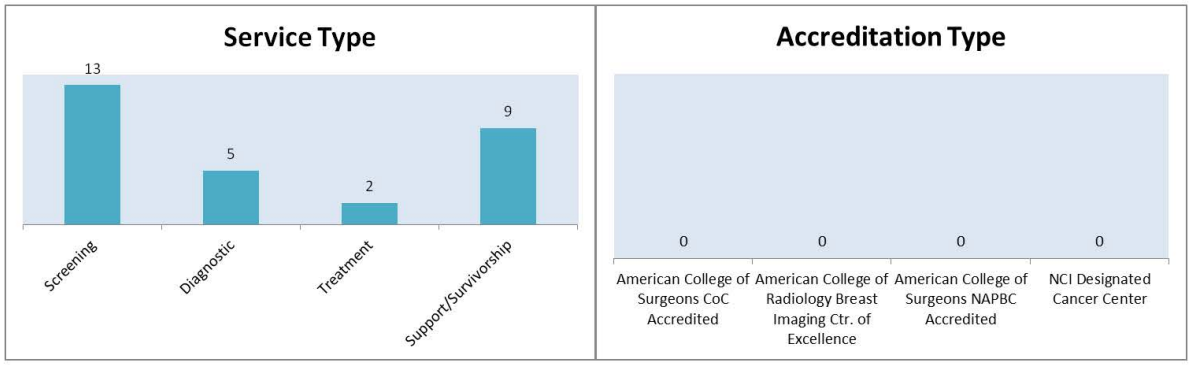
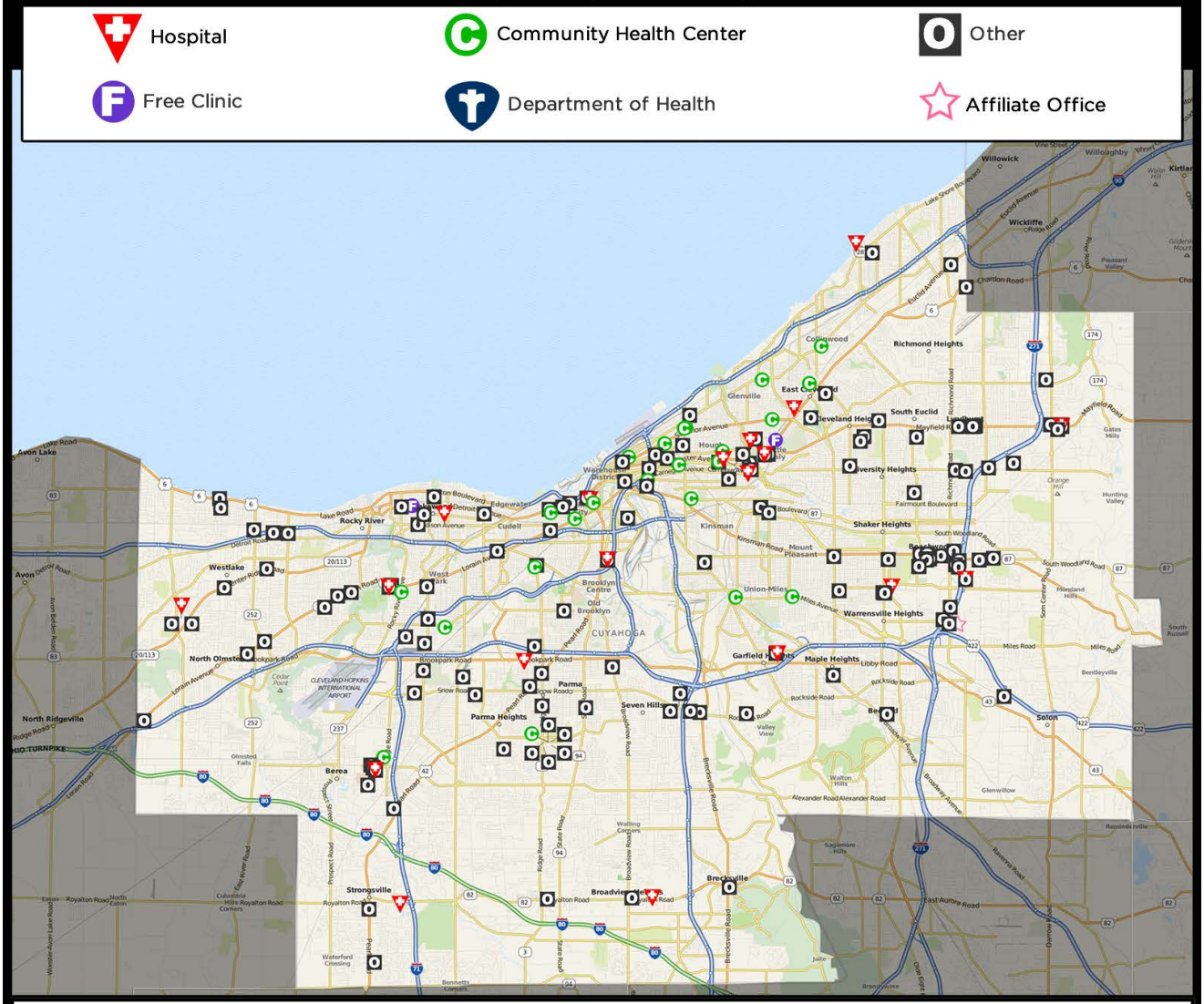


Cuyahoga County



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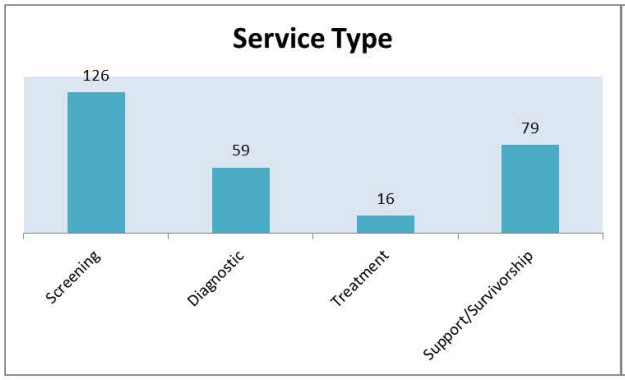
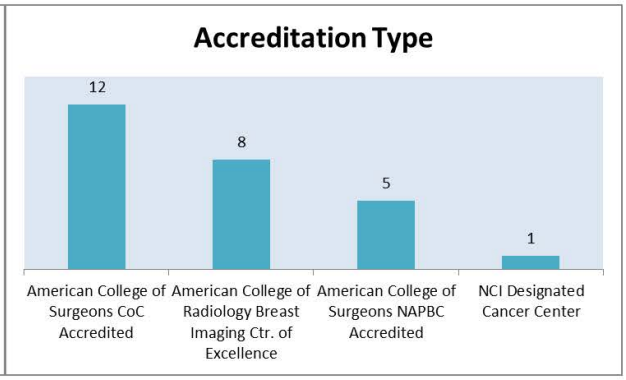
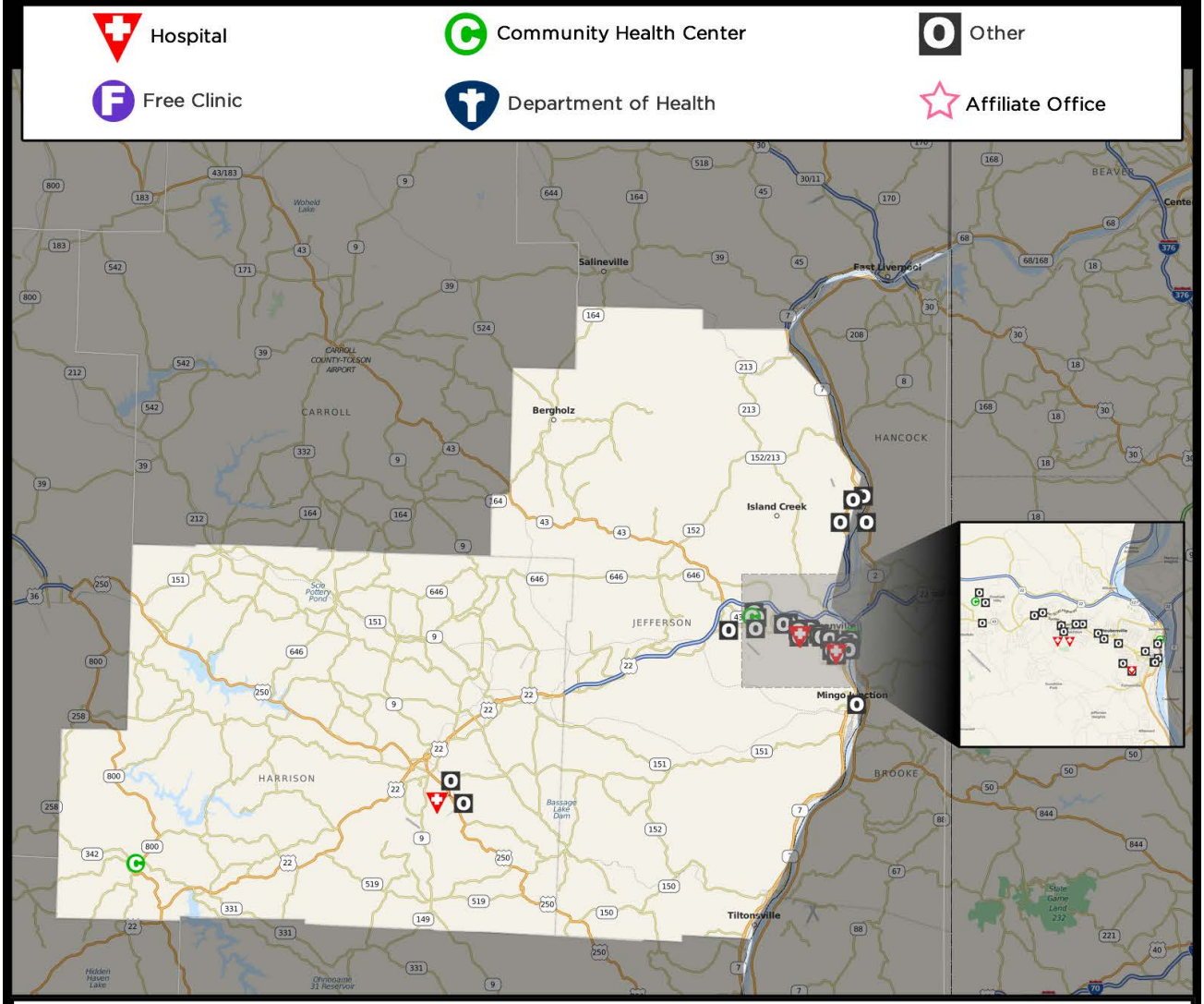




Harrison & Jefferson Counties



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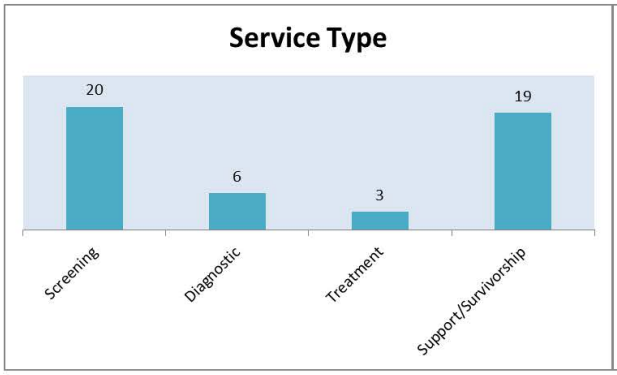
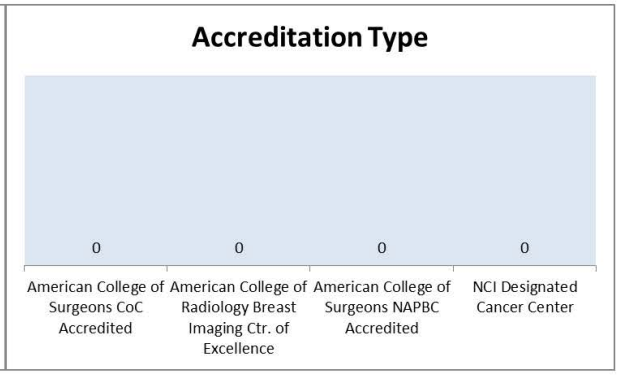
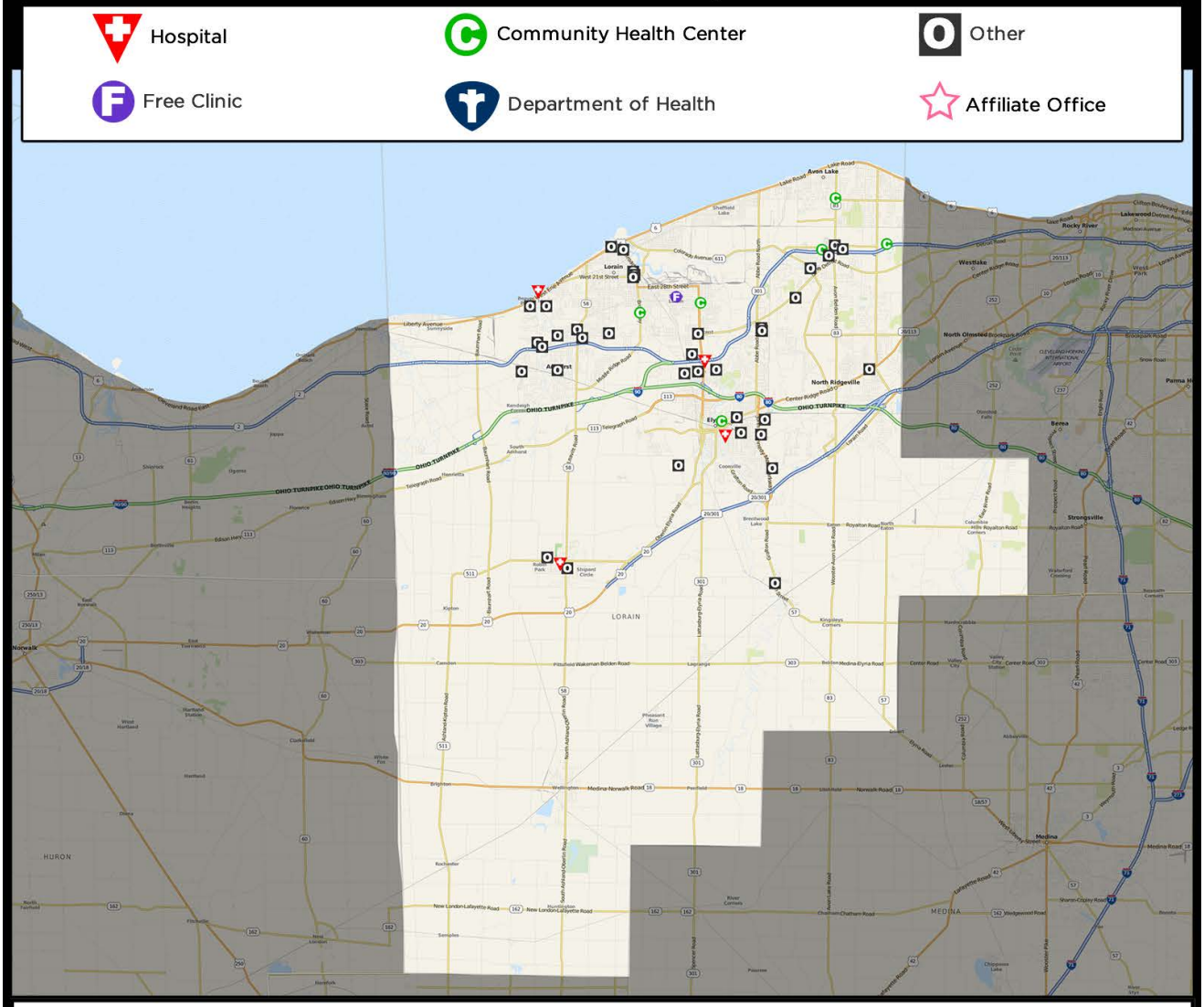


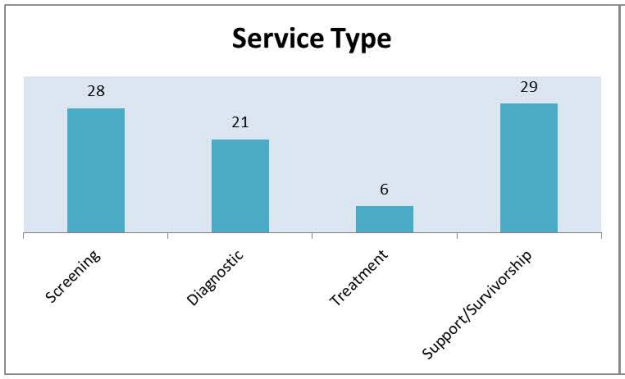


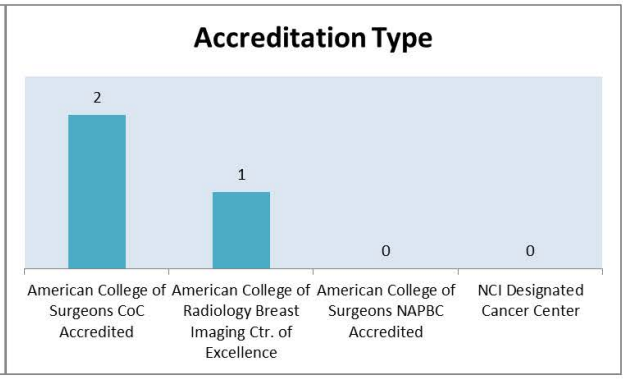
Lorain County



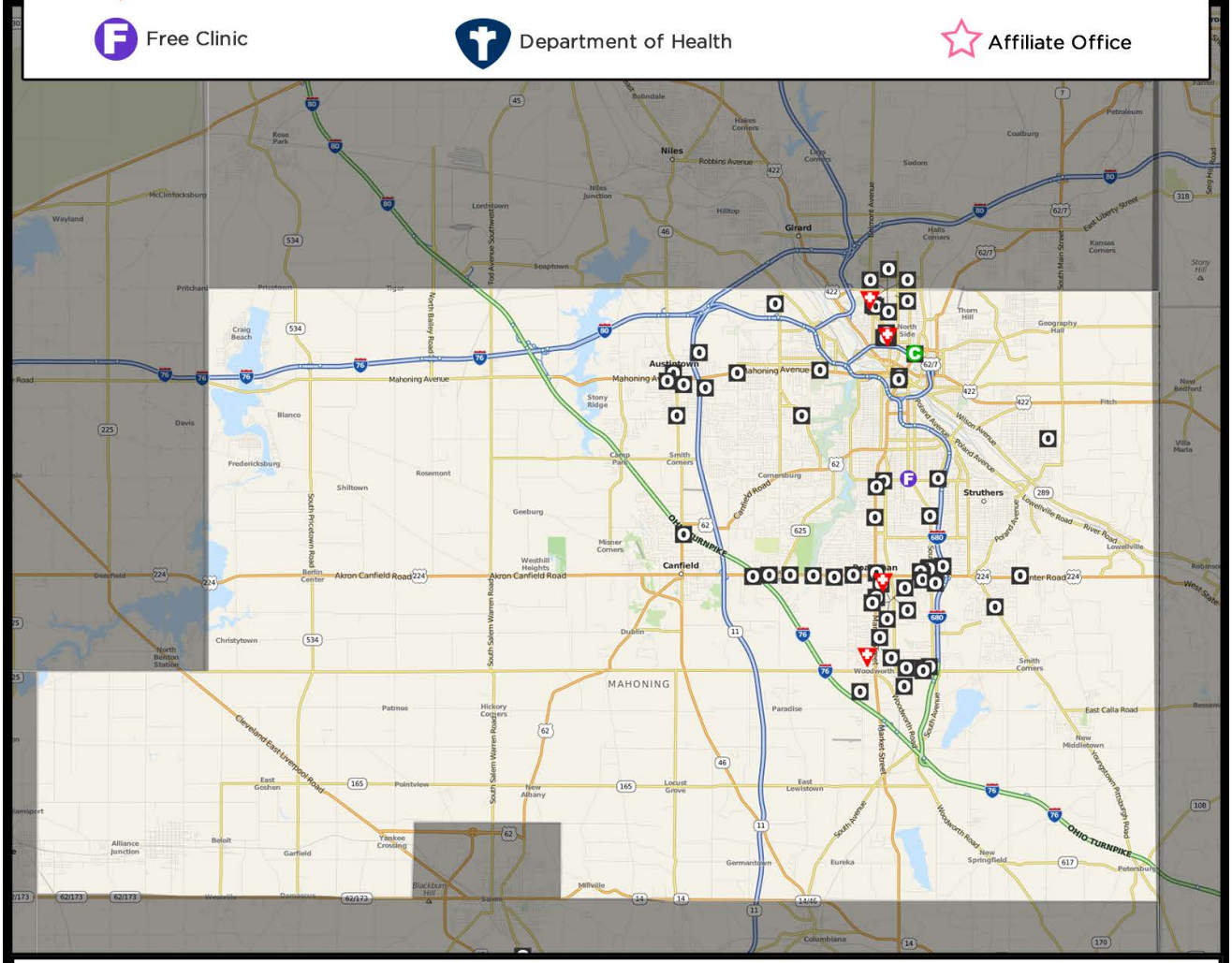
Statistics

Total Locations in Region: 51



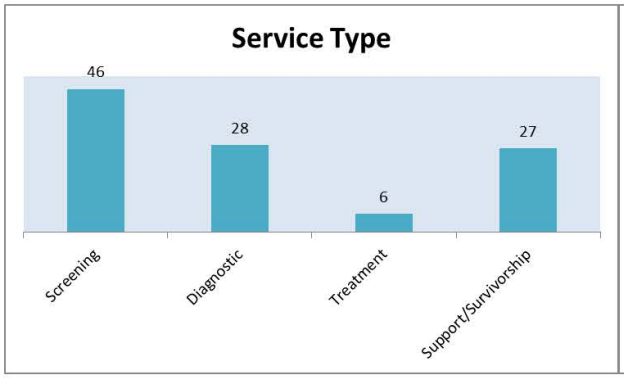


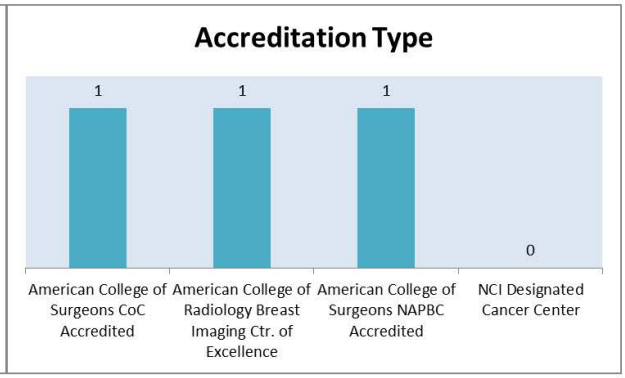
Mahoning County



Statistics

Total Locations in Region: 75





Appendix C: Qualitative Date Collection Timeline

July – August 2014

- Survey questions finalized
- Survey format and design finalized
- IRB application submitted to Cleveland State
- Brainstorm survey distribution sites
    - Reach out to contacts at sites to ensure participation
    - Begin designing electronic survey
- Draft communications plan and timeline for emailed invitations to participate created
- Secure focus group sites and dates/times

September 2014

- Survey distribution and collection (surveys open throughout month)
- Draft key informant interview and focus group questions
- Advertise and recruit focus group participants
- Begin recruiting key informant interviews

October 2014

- Analyze survey results
- Conduct focus groups and key informant interviews

November 2014

- Conduct focus groups and key informant interviews
- Begin initial analysis of focus group and key informant results

December 2014

- Close electronic surveys for all populations on December 31
- Conduct focus groups and key informant interviews
- Analyze all data collected to date; begin making initial interpretations

January 2015

- Conduct final analysis of all data
- Make final interpretations and identify major themes across populations, COIs, and data collection methodologies

Appendix D: Survey Questions

General Population Survey Questions

Section 1 – Breast Health Perspectives

1. Have you ever been diagnosed with breast cancer?
    a. Yes
    b. No

    **If an individual answers yes to this question on the electronic survey, they will be redirected to a webpage with the link to the survivor survey*
2. In your opinion, what is the appropriate age for individuals to begin receiving clinical breast exams (a clinical breast exam is an exam of the breast performed by a health care provider to check for lumps or other changes)?
    a. 20's
    b. 30's
    c. 40's
    d. 50's
    e. 60's and over
3. In your opinion, what is the appropriate age for individuals to begin having mammograms (a mammogram is a health screening tool that uses X-rays to create images of the breasts to detect early signs of breast cancer)?
    a. 20's
    b. 30's
    c. 40's
    d. 50's
    e. 60's and over
4. Generally speaking, do you feel individuals understand when to begin breast cancer screenings?
    a. Yes
    b. No
    c. I do not know

    *If no, why do you feel individuals do not understand when to begin breast cancer screenings?
5. Generally speaking, do you think individuals understand how often they should receive breast cancer screenings (e.g., once a year)?
    a. Yes
    b. No
    c. I do not know

    *If no, why do you feel individuals do not understand how often they should receive breast cancer screenings?
6. Have you ever had a clinical breast exam?
    a. Yes
    b. No
    c. I do not know

    *If yes, when was your last clinical breast exam?
        a. In the past month
        b.1-6 months
        c. 6-12 months
        d. More than 1 year ago
        e. I do not know

    *If yes, how often do you receive clinical breast exams?
        a. More than once a year
        b. Once a year

c. Once every two years
d. Once every three years
e. More than three years apart
f. I do not know

7. Have you ever had a mammogram?
    a. Yes
    b. No
    c. I do not know

    *If yes, when was your last mammogram?
    a. In the past month
    b.1-6 months ago
    c. 6-12 months ago
    d. More than 1 year ago
    e. I do not know

    *If yes, how often do you receive mammograms?
    a. More than once a year
    b. Once a year
    c. Once every two years
    d. Once every three years
    e. More than three years apart
    f. I do not know
8. What, if anything, would motivate/motivates you to get screened for breast cancer? [Please select all that apply]
    a. A doctor/nurse recommended I receive a breast cancer screening
    b. A close friend/family member was diagnosed
    c. Educational programs or information were passed out in my community
    d. Family history
    e. Found a lump with self-exam
    f. Friend encouraged me to get screened
    g. Genetic testing
    h. Heard about the importance of screening on the news/internet
    i. Heard about an organization offering free breast cancer screenings
    j. Other [Please specify]
9. Are you aware of any community programs and/or organizations that provide education on breast health?
    a. Yes
    b. No
    c. I do not know

    *If yes, what are those programs?

    *If yes, do you think those programs are effective? Why or why not?
10. Are you aware of any community programs and/or organizations that provide breast cancer screening services?
    a. Yes
    b. No
    c. I do not know

    *If yes, what are those programs?

    *If yes, do you think those programs are effective? Why or why not?
11. In your opinion, what benefits, if any, are present in your community that encourage individuals to get screened for breast cancer?
12. In your opinion, what makes it difficult for individuals to get screened for breast cancer?

13. What are some suggestions you have that would make it easier for individuals to access breast cancer screening services?
14. Do you know how to access breast health services?
    a. Yes
    b. No
    * If yes, how do you access these services?
    * If no, who would you ask to find out?
15. Would you know how to access services for a male partner/ friend/ family member?
    a. Yes
    b. No

Section 2 – Insurance Status

1. Do you currently have health insurance?
    a. Yes
    b. No
    c. I do not know

    *If yes, what type(s) of insurance do you have? [Please mark all that apply]
        a. Medicare
        b. Medicaid
        c. Private insurance (self-pay, provided at work, covered by spouse, etc.)
        d. Other [Please specify]

    *If you have private insurance, how do you pay for it?
        a. Self-pay
        b. Spouse
        c. Receive health insurance through my employer/work
        d. Other [Please specify]
2. Do you currently have a primary care doctor (a primary care doctor is a physician who provides both the first contact for a person with an undiagnosed health concern as well as continuing care of varied medical conditions)?
    a. Yes
    b. No
    c. I do not know
3. Do you know if your insurance covers breast health screenings?
    a. Yes
    b. No
    c. I do not know
4. Do you know if your insurance covers breast cancer treatment?
    a. Yes
    b. No
    c. I do not know
5. Do you know of any financial assistance programs that are available to women for breast cancer screenings?
    a. Yes
    b. No
    c. I do not know

    *If yes, what programs do you know about and do you think they are effective?
6. Do you know about the state of Ohio's Breast and Cervical Cancer Project (BCCP)?
    a. Yes
    b. No
    c. I do not know
7. Do you know we now have a national health insurance program (e.g., Affordable Care Act, health care exchanges, Obamacare, etc.)?
    a. Yes

b. No

*If yes, do you think you personally will be positively impacted by the national health insurance program? Why or why not?

Section 3- Komen

1. What is your understanding of how Komen Northeast Ohio (NEO) uses the money raised locally?

2. Outside of Race for the Cure, please rate your perception of Komen NEO as Strongly Agree, Agree, Disagree, Strongly Disagree, or Unsure:
    a. Komen NEO is a resource to local survivors
    b. Komen NEO is an educational expert in our community
    c. Komen NEO is the leader in breast health awareness in our community
    d. Komen NEO has an influence on public policy/government spending
    e. Komen NEO is a strong partner with other breast health organizations
    f. Komen NEO is an organization that embraces all
    g. Komen NEO is an organization that empowers women
    h. Komen NEO uses donor's funds wisely
    i. Komen NEO communicates its message well to the community
    j. Komen NEO impacts lives in our community

3. What other perception, if any, do you have of Komen NEO?

Section 4 – Demographic Information

1. What county do you currently live in?
2. What city do you currently live in?
3. What is your race? [Please select all that apply]
    a. American Indian or Alaska Native
    b. Asian Pacific Islander
    c. Black
    d. White
    e. Biracial/Multiracial
    f. Not sure
    g. Prefer not to answer
4. What is your ethnicity? [Please select all that apply]
    a. Amish/Mennonite
    b. Hispanic/Latina
    c. Non-Hispanic/Latina
    d. Not sure
    e. Prefer not to answer
5. In what year were you born?
6. What is the highest level of education you have <u>completed</u>?
    a. Less than 8th grade
    b. 9th- 12th grade, no diploma
    c. High school graduate
    d. GED
    e. Trade/technical/vocational training
    f. Some college, no degree
    g. Associates degree
    h. Bachelor's degree
    i. Some post graduate work
    j. Post graduate degree
    k. Master's degree
    l. Professional degree/certificate
    m. Doctoral degree

7. How many people currently live in your household?
    a. 1
    b. 2
    c. 3
    d. 4
    e. 5
    f. 6 or more
8. What is your total annual (yearly) household income?
    a. Less than $15,000
    b. $15,000 - $29,999
    c. $30,000 - $44,999
    d. $45,000 - $59,999
    e. $60,000 - $74,999
    f. $75,000 - $99,999
    g. $100,000 or more

Survivor Survey Questions

Section 1 – Breast Cancer/Health Perspectives

1. In your opinion, what is the appropriate age for individuals to begin receiving clinical breast exams (a clinical breast exam is an exam of the breast performed by a health care provider to check for lumps or other changes)?
    c. 20's
    d. 30's
    e. 40's
    f. 50's
    g. 60's and over
2. In your opinion, what is the appropriate age for individuals to begin having mammograms (a mammogram is a health screening tool that uses X-rays to create images of the breasts to detect early signs of breast cancer)?
    h. 20's
    i. 30's
    j. 40's
    k. 50's
    l. 60's and over
3. Generally speaking, do you feel individuals understand when to begin breast cancer screenings?
    a. Yes
    b. No
    c. I do not know
        *If no, why do you feel individuals do not understand when to begin breast cancer screenings?
4. Generally speaking, do you feel individuals understand how often they should receive breast cancer screenings (e.g., once a year)?
    a. Yes
    b. No
    c. I do not know
        *If no, why do you feel individuals do not understand how often they should receive breast cancer screenings?
5. Prior to your breast cancer diagnosis, what, if anything, motivated you to get screened? [Please select all that apply]
    a. A doctor/nurse recommended I go after performing a clinical breast exam
    b. A doctor/nurse recommended I go while I was being seen for something unrelated

c. A close friend/family member was diagnosed
d. Annual screening
e. Educational programs or information were passed out in my community
f. Family history
g. Friend encouraged me to go
h. Found a lump with self-exam
i. Genetic testing
j. Heard about the importance of screening on the news/internet
k. Other [Please specify]

6. Are you aware of any community programs and/or organizations that provide education on breast health?
    a. Yes
    b. No
    *If yes, what are those programs?

*If yes, do you think those programs are effective? Why or why not?

7. Are you aware of any community programs and/or organizations that provide breast cancer screening services?
    a. Yes
    b. No
    *If yes, what are those programs?

*If yes, do you think those programs are effective? Why or why not?

8. In your opinion, what benefits are available in your community that encourage individuals to get screened for breast cancer?
9. In your opinion, what makes it difficult for individuals in your community to get screened for breast cancer?
10. What are some suggestions you have that would make it easier for individuals to access breast cancer screening services?

Section 2 – Your Breast Cancer Experience

1. How old were you when your breast cancer was diagnosed?
    a. 18-34
    b. 35-39
    c. 40-44
    d. 45-49
    e. 50-54
    f. 55-59
    g. 60-64
    h. 65-69
    i. 70 or older
2. How was your breast cancer initially discovered?
    a. Doctor or nurse discovered it during a clinical breast exam
    b. Mammogram
    c. Self-exam
    d. MRI
    e. Partner noticed it
    f. Ultrasound
    g. I do not know
    h. Other [Please specify]
3. What stage was your breast cancer when it was diagnosed?
    a. 0
    b. I
    c. II
    d. III
    e. IV

f. I do not know

4. What method was used to first diagnose your breast cancer?
    a. Biopsy
    b. Breast ultrasound
    c. Diagnostic mammogram
    d. MRI
    e. Surgery
    f. I do not know
    g. Other [Please specify]
5. How much time passed from your initial discovery of a breast problem to the time you were diagnosed with breast cancer?
    a. Less than 1 week
    b. 1-2 weeks
    c. 3-4 weeks
    d. More than 1 month
6. How much time passed from your initial breast cancer diagnosis to the time you began treatment?
    a. Less than 1 month
    b. 1-2 months
    c. 2-3 months
    d. 3-4 months
    e. More than 4 months
7. What type(s) of treatment did you receive? [Please mark all that apply]
    a. Adjuvant therapy (treatment that is given in addition to the primary, main or initial treatment, e.g., Herceptin, Tamoxifan)
    b. Chemotherapy
    c. Radiation
    d. Surgery – lumpectomy
    e. Surgery – mastectomy
    f. I do not know
    g. Other [Please specify]
8. Are you currently in treatment for breast cancer?
    a. Yes
    b. No
    c. I do not know
9. Did you receive any complementary and/or alternative treatments? (Complementary and alternative treatments include a range of medical therapies that fall beyond the scope of scientific medicine, but may be used alongside it in the treatment of disease and ill health. Examples include acupuncture, osteopathy, guided imagery, reiki, etc.)
    a. Yes
    b. No
    c. I do not know
        *If yes, what therapies did you receive?
10. How far did you have to travel to receive your breast cancer treatments?
    a. 0-10 miles
    b. 10-50 miles
    c. 50-100 miles
    d. More than 100 miles
    e. I do not know
11. Were you connected to a patient navigator (assistance provided by health care staff to guide patients through the health care system) during your treatment(s)?
    a. Yes
    b. No

*If yes, what kind of assistance did the patient navigator offer to you? Was the assistance provided by the patient navigator helpful? What can patient navigators do to improve the patient experience during treatment?

12. What are the barriers you faced when going through breast cancer treatment?
13. What are the benefits you received when going through breast cancer treatment?
14. Did you neglect other areas of your health (e.g., high blood pressure, diabetes, etc.) while going through breast cancer treatments?
    a. Yes
    b. No
    c. Why or why not?
15. What are you doing currently to maintain your health?
16. What services and/or programs should Komen Northeast Ohio offer to better support breast cancer survivors?

Section 3 – Health Insurance Status

1. Did you have health insurance at the time of your diagnosis?
    a. Yes
    b. No
    c. I do not know
2. If yes, what type of health insurance did you have? [Please check all that apply]
    a. BCCP Medicaid
    b. Hospital Care Assurance Program (H-CAP)
    c. Medicare
    d. Medicaid
    e. Private insurance (self-pay, provided at work, covered by spouse, etc.)
    f. I do not know
    g. Other [Please specify]
3. If yes, what percentage of your treatment was covered by your insurance?
    a. 100%
    b. Almost 100%, minimal co-pays
    c. 75%
    d. 50%
    e. 25%
    f. 0%
    g. I do not know
4. In what ways did your health insurance coverage (or lack of coverage) affect you? [Check all that apply]
    a. Created emotional stress
    b. Created a financial hardship
    c. Encouraged me to look for help in my community
    d. Influenced my decision to be screened
    e. Influenced my decision to receive treatment/follow-up care
    f. None
    g. Other [Please specify]
5. Did your health insurance status change during the course of your treatment?
    a. Yes
    b. No
    c. I do not know
    *If yes, what changed and how did that affect your treatment plan?
6. Do you currently have health insurance coverage?
    a. Yes
    b. No
    c. I do not know

7. If yes, what type of health insurance coverage do you currently have?
    a. BCCP Medicaid
    b. Hospital Care Assurance Program (H-CAP)
    c. Medicare
    d. Medicaid
    e. Private insurance
    f. I do not know
    g. Other [Please specify]
8. Do you know we now have a national health insurance program (Affordable Care Act, health care exchanges, Obamacare, etc.)?
    a. Yes
    b. No
        *If yes, do you think you personally will be positively impacted by the national health insurance program? Why or why not?

Section 4 – Demographic Information

1. What county do you currently live in?
2. What city do you currently live in?
3. What is your race? [Please select all that apply]
    a. American Indian or Alaska Native
    b. Asian Pacific Islander
    c. Black
    d. White
    e. Biracial/Multiracial
    f. Not sure
    g. Prefer not to answer
4. What is your ethnicity? [Please select all that apply]
    a. Amish/Mennonite
    b. Hispanic/Latina
    c. Non-Hispanic/Latina
    d. Not sure
    e. Prefer not to answer
5. In what year were you born?
6. What is the highest level of education you have completed?
    a. Less than 8th grade
    b. 9th- 12th grade, no diploma
    c. High school graduate
    d. GED
    e. Trade/technical/vocational training
    f. Some college, no degree
    g. Associate degree
    h. Bachelor's degree
    i. Some post graduate work
    j. Post graduate degree
    k. Master's degree
    l. Professional degree/certificate
    m. Doctoral degree
7. How many people currently live in your household?
    a. 1
    b. 2
    c. 3
    d. 4
    e. 5
    f. 6+

8. What is your total annual (yearly) household income?
    a. Less than $15,000
    b. $15,000 - $29,999
    c. $30,000 - $44,999
    d. $45,000 - $59,999
    e. $60,000 - $74,999
    f. $75,000 - $99,999
    g. $100,000 or more
9. Please share any other comments:

Breast Health Provider/Leader Survey Questions

Section 1 – Contact Information

1. Contact Information
    a. Name
    b. Company
    c. Role/position
    d. Address
    e. Address 2
    f. City/Town
    g. State
    h. ZIP/postal code
    i. Country
    j. Email address
    k. Phone Number
2. At what type of organization are you currently employed? [Please mark all that apply]
    a. Academic institution
    b. Community Clinic
    c. Community organization
    d. Faith-based organization
    e. Federally Qualified Health Center
    f. Government organization
    g. Health Department
    h. Hospital
    i. Hospice
    j. Nonprofit organization
    k. Private practice
    l. Women's Health Center
    m. Other health care provider [Please specify]

Section 2 – Populations Served

1. What neighborhoods or towns does your practice serve?
2. Please estimate the racial backgrounds of the women you serve. [Please make sure the percentages total 100%]
    a. American Indian or Alaska Native
    b. Asian Pacific Islander
    c. Black
    d. White
    e. Biracial/Multiracial
    f. Not Sure
3. Please estimate the ethnic backgrounds of the women you serve. [Please make sure the percentages total 100%]
    a. Amish/Mennonite
    b. Hispanic/Latina

c. Non-Hispanic/Latina
d. Not sure

Section 3 – Mammography Screenings

For the purposes of this survey, a mammography screening is a health screening tool that uses X-rays to create images of the breasts to detect early signs of breast cancer.

1. What is your practice's recommendation for mammography screening for women at average risk for developing breast cancer (e.g., no inherited gene mutations, no family history)?
2. What is your practice's recommendation for mammography screening for women at high risk for developing breast cancer (e.g., inherited gene mutations, family history)?
3. Do you personally agree with the mammography screening guidelines promoted by your practice?
    a. Yes
    b. No
    c. Why or why not?
4. From your perspective, do the women you serve understand the mammography screening guidelines promoted by your practice?
    a. Yes
    b. No
    c. Why or why not?
5. From your perspective, do the women you serve adhere to the mammography screening guidelines promoted by your practice?
    a. Yes
    b. No
    c. Why or why not?
6. Where does your practice refer women that are in need of a screening mammogram that **have** health insurance coverage?
7. Where does your practice refer women that are in need of a screening mammogram that **do not have** health insurance coverage?
8. From your perspective, what are the most effective methods, if any, that motivate and/or facilitate women to seek mammography screening services? [Please choose the 3 most effective]
    a. Appointment reminder calls
    b. Bi-lingual services
    c. Conduct or attend health fairs
    d. Distribution of educational literature
    e. Free screenings
    f. Mobile mammography
    g. On-site child care
    h. One-on-one education
    i. Patient navigation (assistance provided by health care staff to guide patients through the health care system)
    j. Provide incentives
    k. Provides other services during breast screening event (e.g. blood pressure screenings)
    l. Shared medical appointments
    m. Small group educational sessions
    n. Transportation assistance
    o. Walk-in screenings
    p. None
    q. Other [Please specify]
9. Does your practice offer any of the services listed above? Why or why not?

10. From your perspective, what factors prevent the women you serve from seeking breast health care?
11. From your perspective, what factors prevent women from following through on a referral for a mammogram?
12. From your perspective, what services could be added to breast health and breast cancer programs to help improve mammography screening percentages?
13. From your perspective, are there any cultural barriers (e.g. language barriers, cultural beliefs) to breast health in the communities you serve?
14. Are you aware of any financial assistance programs in your community that help women access mammography screening services?
    a. Yes
    b. No

    *If yes, what are the names of the financial assistance programs and what types of assistance do they offer your patients?

Section 4 – Partnerships and Collaborations

1. What organizations are currently working with the same populations as your practice?
2. Do you presently partner with any other local organizations providing breast health services to your patients?
    a. Yes
    b. No
    c. Why or why not?
3. If yes, what are the names of those organizations and what is the nature of your partnership?
4. If no, have you made efforts to partner with any organizations?
    a. Yes
    b. No
    c. I do not know
5. Do you have collaborations in place for working with community residents?
    a. Yes
    b. No
    c. I do not know
6. What breast cancer groups/organizations/coalitions do you or members of your practice belong to and what is your role (e.g. member, leadership)?
7. What are some barriers to collaboration? [Please choose the 3 greatest barriers]
    a. Competing social service needs
    b. Competition for funds
    c. Failed past effort
    d. Lack of internal capacity/resources (funding, size, staff)
    e. Lack of support from organizational leadership
    f. Market competition
    g. Other organizations are not accountable
    h. Other organizations are unreliable
    i. Unaware of local coalitions
    j. Other [Please specify]
8. What are the most effective ways for organizations working in the field of breast cancer to collaborate more? [Please choose the 3 most effective]
    a. Improve communication across organizations
    b. Participate in area coalitions
    c. Partner with organizations already working with medically underserved women
    d. Referrals to collaborative organizations
    e. Referrals to financial support services
    f. Referrals to screening services
    g. Other [Please specify]

Section 5 – Systemic Issues

1. What laws or public policies make it difficult for women to get breast health services?
2. What laws or public policies make it easy for women to get breast health services?
3. What internal organizational policies make it difficult for women to obtain breast health services at your practice (e.g., practice does not accept Medicare, require a primary care physician on record, etc.)?
4. Are you a Breast and Cervical Cancer Project (BCCP) provider?
    a. Yes
    b. No
    c. I do not know
5. Is your practice a contracted facility with the BCCP?
    a. Yes
    b. No
    c. I do not know
6. Are you familiar with women seen at your practice who have fallen through the gaps, meaning women have been diagnosed outside of the BCCP system, but would have otherwise qualified for BCCP?
    a. Yes
    b. No
    c. I do not know
7. Is there a target audience for training on the BCCP program in your organization?
    a. Yes
    b. No
    c. I do not know
8. Have providers in your area been trained on new law and policy issues?
    a. Yes
    b. No
    c. I do not know
    *If yes, what issues have they been trained on?
9. What trainings, if any, are needed for health care providers to better serve women in need of mammography screenings?
10. Does your practice have any system(s) in place to help enroll women in the health care exchanges created under the Affordable Care Act (ACA)?
    a. Yes
    b. No
    * If yes, what has your organization done to facilitate enrollment into the new health care exchanges and/or Medicaid expansion for uninsured women?
11. What steps, if any, is your practice taking to address new “gap” populations created by the health care exchanges (e.g., high co-pay, high deductible plans)?
12. What organizational or procedural problems, if any, do you women have trouble with when trying to receive assistance for mammography screening?
    a. Do not take the woman’s insurance
    b. Language barriers
    c. Paperwork/process is too complicated
    d. Process takes too long
    e. Requires stable address/phone numbers
    f. Women do not have the necessary documents to fill out the forms
    g. None
    h. I do not know
    i. Other [Please specify]

Section 6 – Survey Referral

1. Contact 1
    a. Name
    b. Company
    c. Address
    d. Address 2
    e. City/town
    f. State
    g. ZIP/postal code
    h. Country
    i. Email address
    j. Phone number
2. What survey should contact #1 be sent?
    a. Provider
    b. Community Leader
    c. Breast Cancer Survivor
    d. General Population
3. Contact 2
    a. Name
    b. Company
    c. Address
    d. Address 2
    e. City/town
    f. State
    g. ZIP/postal code
    h. Country
    i. Email address
    j. Phone number
4. What survey should contact #2 be sent?
    a. Provider
    b. Community Leader
    c. Breast Cancer Survivor
    d. General Population

Appendix E: Key Informant Interview Questions

Ashtabula County – General Population

Consent:

I have some very basic demographic questions for you first.

Current age:
City of residence:
Insurance status:
Race/ethnicity:

The next set of questions deal with screening beliefs and behaviors.

1. When do you think is an appropriate age for women to begin receiving mammograms?

2. How often do you think women should receive mammograms (e.g., once a year)? Why do you feel this way?

3. Do you think people understand when to begin receiving mammograms or how often women should receive mammograms? Why or why not?

4. Do you have a primary care doctor?
    a. If yes, does your doctor talk to you about breast health?
    b. Does your doctor perform CBEs (a CBE is when a health care provider checks the breast for lumps or other changes)? If yes, how often do you receive them?
    c. Encourage you to get mammograms?
    d. When does/How often does your doctor suggest you get a mammogram?
    e. Have you ever performed a self-breast exam on yourself? Why or why not?
    f. Do you think breast self-exams are helpful? Why or why not?

5. What are some things you know or have heard about the causes of breast cancer and the treatment of breast cancer? [For instance, have you heard breast cancer is caused by using deodorant? Do you believe that? Why or why not? Do you think people will only get breast cancer if it runs in their family? Do you think mammograms help or not? Etc.]

These next questions relate to breast health and breast cancer in your county.

6. In your opinion, what are the top three things organizations/people in Ashtabula County can do to help encourage women to get screened for breast cancer?

7. In your opinion, what are the top three barriers in Ashtabula County that may prevent women getting the screenings they need in?

8. Where in your community would you go to receive information on health and cancer prevention? Why would you choose those facilities/resources?

9. Where in your community would you go to receive a CBE and/or a mammogram if you needed one? Why would you choose those facilities/locations?

10. On average, how far do you have to travel to receive health care services?
    a. Is the travel distance to a health facility a burden for you? Why or why not?
    b. What is your primary mode of transportation for health related issues?

This next question focuses on breast cancer in Ashtabula County. Before I ask you the question, though, I should give you a bit of background information. Ashtabula County has a very high death rate from breast cancer, meaning more people in Ashtabula die from the disease every year than in other parts of Northeast Ohio. This tells us that perhaps women in Ashtabula County may not be getting screened for breast cancer, so that it can be caught in its earliest, most treatable stages. BUT, more than 80 percent of women over the age of 40 in Ashtabula County say they have received a mammogram in the last two years. This leads us to believe something is happening here that prevents women from gaining access to the treatment they need.

11. What do you think are some of the factors beyond screening that may be contributing to a high death rate in Ashtabula County?

Ashtabula County – Survivors

Consent:

I have some very basic demographic questions for you first.

Current age:
Age at diagnosis:
Insurance status at diagnosis:
Stage at diagnosis:
Where were you treated:
Race/ethnicity:

The next set of questions deal with screening beliefs and behaviors.

1. When do you think is an appropriate age for women to begin receiving mammograms?

2. How often do you think women should receive mammograms (e.g., once a year)? Why do you feel this way?

3. Do you think people understand when to begin receiving mammograms or how often women should receive mammograms? Why or why not?

4. In your opinion, what are the top three things organizations can do to help encourage women to get screened for breast cancer?

5. In your opinion, what are the top three barriers to women getting the screenings they need?

6. Prior to your breast cancer diagnosis, did you have a primary care doctor?
    a. If yes, did your doctor talk to you about breast health?
    b. Perform CBEs?
    c. Encourage you to get mammograms?
    d. When did your doctor suggest you get a mammogram?

In the next couple of questions, I'll ask you about your experience with breast cancer and the care you received.

7. Are you currently in treatment for breast cancer?
    a. If yes, what treatments are you currently undergoing and where do you receive these services?
    b. If no, what treatments did you receive and where did you go to receive these services?

c. How often do you get screened now?

8. Tell me a bit about your breast cancer journey.
    a. How was breast cancer initially discovered?
    b. How much time passed from your mammogram to the time you were diagnosed?
    c. How much time passed from the time you were diagnosed to your treatments?
    d. What barriers did you face in getting the treatments you needed, if any?
    e. What role did your insurance status play in your care plan?
    f. What are some of the things that helped you in your journey, i.e., family support, patient navigator, helpful provider, etc.?

9. What are some things that encouraged you to go get screened before your breast cancer diagnosis (i.e., doctor told you, family member was diagnosed, found a lump, etc.)?
    a. Have you ever performed a self-breast exam on yourself? Why or why not?
    b. Do you think breast self-exams are helpful? Why or why not?

10. On average, how far do you/did you have to travel to receive breast cancer treatments? Is/Was the travel distance to the health facility a burden for you? Why or why not?

This next question focuses on breast cancer in Ashtabula County. Before I ask you the question, though, I should give you a bit of background information. Ashtabula County has a very high death rate from breast cancer, meaning more people in Ashtabula die from the disease every year than in other parts of Northeast Ohio. This tells us that perhaps women in Ashtabula County may not be getting screened for breast cancer, so that it can be caught in its earliest, most treatable stages. But, more than 80 percent of women over the age of 40 in Ashtabula County say they have received a mammogram in the last two years. This leads us to believe something is happening here that prevents women from gaining access to the treatment they need.

11. What do you think are some of the factors beyond screening that may be contributing to a high death rate?

12. The statistics for this area indicate women who live here experience barriers when they attempt to access treatment services. What do you think are the top three barriers women face when trying to obtain breast cancer treatment services (i.e., cannot take time off of work, cost limitations, child care issues, no transportation, etc.)?

These are the last two questions I have for you, and they relate to resources in your community.

13. Where in your community would you tell people to go to receive information on health and cancer prevention? Why would you choose those facilities/resources?

14. Where in your community would you tell people to go to receive a CBE and/or a mammogram if they needed one? Why would you choose those facilities/locations?

Cuyahoga County – Survivors

Consent:

I have some very basic demographic questions for you first.

Current age:
Age at diagnosis:

Insurance status at diagnosis:
Stage at diagnosis:
Where were you treated:
Race/ethnicity:

The next set of questions deal with screening beliefs and behaviors.

1. When do you think is an appropriate age for women to begin receiving mammograms?

2. How often do you think women should receive mammograms (e.g., once a year)? Why do you feel this way?

3. Do you think people understand when to begin receiving mammograms or how often women should receive mammograms? Why or why not?

4. In your opinion, what are the top three things organizations can do to help encourage women to get screened for breast cancer?

5. In your opinion, what are the top three barriers to women getting the screenings they need?

6. Prior to your breast cancer diagnosis, did you have a primary care doctor?
    a. If yes, did your doctor talk to you about breast health?
    b. Perform CBEs?
    c. Encourage you to get mammograms?
    d. When did your doctor suggest you get a mammogram?

In the next couple of questions, I'll ask you about your experience with breast cancer and the care you received.

7. Are you currently in treatment for breast cancer?
    a. If yes, what treatments are you currently undergoing and where do you receive these services?
    b. If no, what treatments did you receive and where did you go to receive these services?
    c. How often do you get screened now?

8. Tell me a bit about your breast cancer journey.
    a. How was breast cancer initially discovered?
    b. How much time passed from your mammogram to the time you were diagnosed?
    c. How much time passed from the time you were diagnosed to your treatments?
    d. What barriers did you face in getting the treatments you needed, if any?
    e. What role did your insurance status play in your care plan?
    f. What are some of the things that helped you in your journey, i.e., family support, patient navigator, helpful provider, etc.?

9. What are some things that encouraged you to go get screened before your breast cancer diagnosis (i.e., doctor told you, family member was diagnosed, found a lump, etc.)?
    a. Have you ever performed a self-breast exam on yourself? Why or why not?
    b. Do you think breast self-exams are helpful? Why or why not?

10. On average, how far do you/did you have to travel to receive breast cancer treatments? Is/Was the travel distance to the health facility a burden for you? Why or why not?

This next question focuses on breast cancer in Cuyahoga County. Before I ask you the question, though, I should give you a bit of background information. As a whole, Cuyahoga County has more women who are diagnosed with the disease compared to other counties in Ohio, but with most of the female population living here, it sort of makes sense. Women diagnosed in Cuyahoga County tend to be diagnosed with a later stage of the disease (stages 2-4), though, which tells us women here may not be getting screened on a regular enough basis to catch cancers early. Screening percentages tell us a different story. We know 80 percent of women in Cuyahoga County over the age of 40 receive a mammogram at least every two years.

Cuyahoga County also has a very high number of women who pass away from the disease. This high death rate could be caused by the late stage of diagnosis, but there could be other factors at play. We could also say perhaps there are a limited number of resources available to women once they are diagnosed, but we know this is not true with Cleveland (numerous facilities available).

This leads us to believe something is happening here that prevents women from gaining access to the treatment they need.

11. The statistics for this area indicate women who live here experience barriers when they attempt to access treatment services. What do you think are the top three barriers women face when trying to obtain breast cancer treatment services (i.e., cannot take time off of work, cost limitations, child care issues, no transportation, etc.)?

These are the last two questions I have for you, and they relate to resources in your community.

12. Where in your community would you tell people to go to receive information on health and cancer prevention? Why would you choose those facilities/resources?

13. Where in your community would you tell people to go to receive a CBE and/or a mammogram if they needed one? Why would you choose those facilities/locations?

Harrison/Jefferson Counties – Providers

Consent:

My first questions relate to some basic demographic and practice information about you personally.

Number of years in breast health field:
Specialty areas/areas of expertise:
Current place of employment:
Number of years with current employer:

This next set of questions relates to the breast health and breast cancer care at your facility and your personal beliefs about breast cancer screenings.

1. What are your practice's/facility's recommendations for the age to begin CBEs and mammograms? Do you agree with these recommendations? Why or why not?
    a. Do you personally speak with your clients/patients about breast health? If yes, what information do you share with them?

2. Do you think people understand when to begin receiving mammograms or how often women should receive mammograms? Why or why not?

a. What can be done to better educate the women you serve on appropriate screening guidelines?

3. What are some of the most common services your patients' request (i.e., complementary and alternative medicine, survivor support groups, radiation oncology, 3D mammograms/tomography, etc.)? Where can women go to obtain these services?
    a. Are there any services your clients need that you do not offer to the populations you serve? If so, what are those services?
    b. Is there a need for someone to provide those services and why?

4. What are your organization's strengths in addressing breast health issues that other organizations can learn from? Can you provide an example of a best practice approach?

5. What are some of the major challenges you face as a health care provider in ensuring no one falls through the cracks and all patients receive the care they need regardless of insurance status?
    a. Does your facility care for uninsured patients?
    b. If yes, on average, what would you estimate the percentage of uninsured patients to insured patients that request services from you would be?
    c. If no, where do you refer uninsured individuals to so they can receive care? Why do you refer women to those facilities/organizations?

6. What do you think organizations can do to close the gap in order to effectively address breast health disparities in your community?

7. List two or three of your most important administrative challenges at your practice/facility that prevent you from helping all of the patients/clients you serve.
    a. With these challenges, what are some of your lessons learned?
    b. How can these lessons be incorporated into future programs aimed at reducing breast health disparities?

The next two questions relate specifically to breast cancer in Harrision/Jefferson County.

8. Statistics show that only 50% of women who live in Harrison and/or Jefferson County have received a mammogram in the last two years. In your opinion, what are the top three barriers women in your community face when attempting to get a mammogram?

9. What do you think is the average distance your clients travel to obtain services at your facility? Do you think this affects breast cancer screening percentages?

My final question relates to the Affordable Care Act.

10. With the recent implementation of the ACA and the provision that mammograms be covered, have you seen an increase in the number of patients requesting this service?
    a. If you have, how are you preparing to serve this increase in patients?
    b. If you have not, do you anticipate more women will ask for these services?
    c. Are there any new "gap areas" you feel have been created due to the passage of the ACA (i.e., diagnostics not covered, mammograms only covered for women over 40, mammograms only covered every two years, etc.)?
    d. What are you doing to encourage and/or facilitate enrollment into the health exchanges and/or Medicaid expansion?

Harrison/Jefferson Counties – Survivors

Consent:

I have some very basic demographic questions for you first.

Current age:
Age at diagnosis:
Insurance status at diagnosis:
Stage at diagnosis:
Where were you treated:
Race/ethnicity:

The next set of questions deal with screening beliefs and behaviors.

1. When do you think is an appropriate age for women to begin receiving mammograms?

2. How often do you think women should receive mammograms (e.g., once a year)? Why do you feel this way?

3. Do you think people understand when to begin receiving mammograms or how often women should receive mammograms? Why or why not?

4. In your opinion, what are the top three things organizations can do to help encourage women to get screened for breast cancer?

5. In your opinion, what are the top three barriers to women getting the screenings they need?

6. Prior to your breast cancer diagnosis, did you have a primary care doctor?
    a. If yes, did your doctor talk to you about breast health?
    b. Perform CBEs?
    c. Encourage you to get mammograms?
    d. When did your doctor suggest you get a mammogram?

In the next couple of questions, I'll ask you about your experience with breast cancer and the care you received.

7. Are you currently in treatment for breast cancer?
    a. If yes, what treatments are you currently undergoing and where do you receive these services?
    b. If no, what treatments did you receive and where did you go to receive these services?
    c. How often do you get screened now?

8. Tell me a bit about your breast cancer journey.
    a. How was breast cancer initially discovered?
    b. How much time passed from your mammogram to the time you were diagnosed?
    c. How much time passed from the time you were diagnosed to your treatments?
    d. What barriers did you face in getting the treatments you needed, if any?
    e. What role did your insurance status play in your care plan?
    f. What are some of the things that helped you in your journey, i.e., family support, patient navigator, helpful provider, etc.?

9. What are some things that encouraged you to go get screened before your breast cancer diagnosis (i.e., doctor told you, family member was diagnosed, found a lump, etc.)?
    a. Have you ever performed a self-breast exam on yourself? Why or why not?

b. Do you think breast self-exams are helpful? Why or why not?

10. On average, how far do you/did you have to travel to receive breast cancer treatments? Is/Was the travel distance to the health facility a burden for you? Why or why not?

My next questions relate to breast health and breast cancer specifically in Harrision/Jefferson County.

11. Statistics show that only 50% of women who live in Harrison and/or Jefferson County have received a mammogram in the last two years. In your opinion, what are the top three barriers women in your community face when attempting to get a mammogram?

12. Where in your community would you tell people to go to receive information on health and cancer prevention? Why would you choose those facilities/resources?

13. Where in your community would you tell people to go to receive a CBE and/or a mammogram if they needed one? Why would you choose those facilities/locations?

Lorain County – General Population

Consent:

I have some very basic demographic questions for you first.

Current age:
City of residence:
Insurance status:
Race/ethnicity:

The next set of questions deal with screening beliefs and behaviors.

1. When do you think is an appropriate age for women to begin receiving mammograms?

2. How often do you think women should receive mammograms (e.g., once a year)? Why do you feel this way?

3. Do you think people understand when to begin receiving mammograms or how often women should receive mammograms? Why or why not?

4. Do you have a primary care doctor?
    a. If yes, does your doctor talk to you about breast health?
    b. Does your doctor perform CBEs (a CBE is when a health care provider checks the breast for lumps or other changes)? If yes, how often do you receive them?
    c. Encourage you to get mammograms?
    d. When does/How often does your doctor suggest you get a mammogram?
    e. Have you ever performed a self-breast exam on yourself? Why or why not?
    f. Do you think breast self-exams are helpful? Why or why not?

5. What are some things you know or have heard about the causes of breast cancer and the treatment of breast cancer? [For instance, have you heard breast cancer is caused by using deodorant? Do you believe that? Why or why not? Do you think people will only get breast cancer if it runs in their family? Do you think mammograms help or not? Etc.]

These next questions relate to breast health and breast cancer in your county.

6. In your opinion, what are the top three things organizations/people in Ashtabula County can do to help encourage women to get screened for breast cancer?

7. In your opinion, what are the top three barriers in Ashtabula County that may prevent women getting the screenings they need in?

8. Where in your community would you go to receive information on health and cancer prevention? Why would you choose those facilities/resources?

9. Where in your community would you go to receive a CBE and/or a mammogram if you needed one? Why would you choose those facilities/locations?

10. On average, how far do you have to travel to receive health care services?
    a. Is the travel distance to a health facility a burden for you? Why or why not?
    b. What is your primary mode of transportation for health related issues?

This next question focuses on breast cancer in Lorain County. Before I ask you the question, though, I should give you a bit of background information. As a whole, Lorain County has a very low incidence rate from breast cancer, meaning women in Lorain County aren't diagnosed with breast cancer any more than women who live in a different county in Northeast Ohio. Additionally, most of the women in Lorain County over the age of 40 have reported they have received a mammogram at least in the last two years. This tells us women here are screened at above average rates and diagnosed at average rates.

However, women in Lorain County are more likely to die from the disease given the very high death rate associated with the county. Basically, while women here aren't diagnosed any more than another county, they die from the disease more often.

This leads us to believe something is happening here that prevents women from gaining access to the treatment they need.

11. What do you think are some of the factors beyond access to screening services that may be contributing to a high death rate?

12. Given the high rates of breast cancer screening in Lorain County, coupled with multiple locations providing screening services and the high death rate, what do you think are the top three barriers women face when trying to obtain breast cancer treatment services (i.e., cannot take time off of work, cost limitations, child care issues, no transportation, etc.)?

Lorain County – Survivors

Consent:

I have some very basic demographic questions for you first.

Current age:
Age at diagnosis:
Insurance status at diagnosis:
Stage at diagnosis:
Where were you treated:
Race/ethnicity:

The next set of questions deal with screening beliefs and behaviors.

1. When do you think is an appropriate age for women to begin receiving mammograms?

2. How often do you think women should receive mammograms (e.g., once a year)? Why do you feel this way?

3. Do you think people understand when to begin receiving mammograms or how often women should receive mammograms? Why or why not?

4. In your opinion, what are the top three things organizations can do to help encourage women to get screened for breast cancer?

5. In your opinion, what are the top three barriers to women getting the screenings they need?

6. Prior to your breast cancer diagnosis, did you have a primary care doctor?
    a. If yes, did your doctor talk to you about breast health?
    b. Perform CBEs?
    c. Encourage you to get mammograms?
    d. When did your doctor suggest you get a mammogram?

In the next couple of questions, I'll ask you about your experience with breast cancer and the care you received.

7. Are you currently in treatment for breast cancer?
    a. If yes, what treatments are you currently undergoing and where do you receive these services?
    b. If no, what treatments did you receive and where did you go to receive these services?
    c. How often do you get screened now?

8. Tell me a bit about your breast cancer journey.
    a. How was breast cancer initially discovered?
    b. How much time passed from your mammogram to the time you were diagnosed?
    c. How much time passed from the time you were diagnosed to your treatments?
    d. What barriers did you face in getting the treatments you needed, if any?
    e. What role did your insurance status play in your care plan?
    f. What are some of the things that helped you in your journey, i.e., family support, patient navigator, helpful provider, etc.?

9. What are some things that encouraged you to go get screened before your breast cancer diagnosis (i.e., doctor told you, family member was diagnosed, found a lump, etc.)?
    a. Have you ever performed a self-breast exam on yourself? Why or why not?
    b. Do you think breast self-exams are helpful? Why or why not?

10. On average, how far do you/did you have to travel to receive breast cancer treatments? Is/Was the travel distance to the health facility a burden for you? Why or why not?

This next question focuses on breast cancer in Lorain County. Before I ask you the question, though, I should give you a bit of background information. As a whole, Lorain County has a very low incidence rate from breast cancer, meaning women in Lorain County aren't diagnosed with breast cancer any more than women who live in a different county in Northeast Ohio. Additionally, most of the women in Lorain County over the age of 40 have reported they have received a mammogram at least in the last two years. This tells us women here are screened at above average rates and diagnosed at average rates.

However, women in Lorain County are more likely to die from the disease given the very high death rate associated with the county. Basically, while women here aren't diagnosed any more than another county, they die from the disease more often.

This leads us to believe something is happening here that prevents women from gaining access to the treatment they need.

11. What do you think are some of the factors beyond access to screening services that may be contributing to a high death rate?

12. Given the high rates of breast cancer screening in Lorain County, coupled with multiple locations providing screening services and the high death rate, what do you think are the top three barriers women face when trying to obtain breast cancer treatment services (i.e., cannot take time off of work, cost limitations, child care issues, no transportation, etc.)?

13. Where in your community would you tell people to go to receive information on health and cancer prevention? Why would you choose those facilities/resources?

14. Where in your community would you tell people to go to receive a CBE and/or a mammogram if they needed one? Why would you choose those facilities/locations?

Mahoning County – Providers

Consent:

My first questions relate to some basic demographic and practice information about you personally.

Number of years in breast health field:
Specialty areas/areas of expertise:
Current place of employment:
Number of years with current employer:

This next set of questions relates to the breast health and breast cancer care at your facility and your personal beliefs about breast cancer screenings.

1. What are your practice's/facility's recommendations for the age to begin CBEs and mammograms? Do you agree with these recommendations? Why or why not?
    a. Do you personally speak with your clients/patients about breast health? If yes, what information do you share with them?

2. Do you think people understand when to begin receiving mammograms or how often women should receive mammograms? Why or why not?
    a. What can be done to better educate the women you serve on appropriate screening guidelines?

3. What are some of the most common services your patients' request (i.e., complementary and alternative medicine, survivor support groups, radiation oncology, 3D mammograms/tomography, etc.)? Where can women go to obtain these services?
    a. Are there any services your clients need that you do not offer to the populations you serve? If so, what are those services?
    b. Is there a need for someone to provide those services and why?

4. What are your organization's strengths in addressing breast health issues that other organizations can learn from? Can you provide an example of a best practice approach?

5. What are some of the major challenges you face as a health care provider in ensuring no one falls through the cracks and all patients receive the care they need regardless of insurance status?
    a. Does your facility care for uninsured patients?
    b. If yes, on average, what would you estimate the percentage of uninsured patients to insured patients that request services from you would be?
    c. If no, where do you refer uninsured individuals to so they can receive care? Why do you refer women to those facilities/organizations?

6. What do you think organizations can do to close the gap in order to effectively address breast health disparities in your community?

7. List two or three of your most important administrative challenges at your practice/facility that prevent you from helping all of the patients/clients you serve.
    a. With these challenges, what are some of your lessons learned?
    b. How can these lessons be incorporated into future programs aimed at reducing breast health disparities?

The next two questions relate specifically to breast cancer in Mahoning County.

8. Mahoning County is home to multiple screening facilities, but the statistics for this area show women who live here are not being screened. What do you think are the top three barriers women here face when trying to obtain breast cancer screening services (i.e., cannot take time off of work, cost limitations, child care issues, no transportation, don't think they need one, etc.)?

9. Mahoning County is also home to multiple breast cancer treatment centers, but the death rate from breast cancer in this area is higher than both the state and national averages. What do you think are the top three barriers women here face when trying to obtain breast cancer treatment services?

10. What do you think is the average distance your clients travel to obtain services at your facility? Do you think this affects breast cancer screening and treatment rates?

My final question relates to the Affordable Care Act.

11. With the recent implementation of the ACA and the provision that mammograms be covered, have you seen an increase in the number of patients requesting this service?
    a. If you have, how are you preparing to serve this increase in patients?
    b. If you have not, do you anticipate more women will ask for these services?
    c. Are there any new "gap areas" you feel have been created due to the passage of the ACA (i.e., diagnostics not covered, mammograms only covered for women over 40, mammograms only covered every two years, etc.)?
    d. What are you doing to encourage and/or facilitate enrollment into the health exchanges and/or Medicaid expansion?

Mahoning County – Survivors

Consent:

I have some very basic demographic questions for you first.

Current age:
Age at diagnosis:
Insurance status at diagnosis:
Stage at diagnosis:
Where were you treated:
Race/ethnicity:

The next set of questions deal with screening beliefs and behaviors.

1. When do you think is an appropriate age for women to begin receiving mammograms?

2. How often do you think women should receive mammograms (e.g., once a year)? Why do you feel this way?

3. Do you think people understand when to begin receiving mammograms or how often women should receive mammograms? Why or why not?

4. In your opinion, what are the top three things organizations can do to help encourage women to get screened for breast cancer?

5. In your opinion, what are the top three barriers to women getting the screenings they need?

6. Prior to your breast cancer diagnosis, did you have a primary care doctor?
    a. If yes, did your doctor talk to you about breast health?
    b. Perform CBEs?
    c. Encourage you to get mammograms?
    d. When did your doctor suggest you get a mammogram?

In the next couple of questions, I'll ask you about your experience with breast cancer and the care you received.

7. Are you currently in treatment for breast cancer?
    a. If yes, what treatments are you currently undergoing and where do you receive these services?
    b. If no, what treatments did you receive and where did you go to receive these services?
    c. How often do you get screened now?

8. Tell me a bit about your breast cancer journey.
    a. How was breast cancer initially discovered?
    b. How much time passed from your mammogram to the time you were diagnosed?
    c. How much time passed from the time you were diagnosed to your treatments?
    d. What barriers did you face in getting the treatments you needed, if any?
    e. What role did your insurance status play in your care plan?
    f. What are some of the things that helped you in your journey, i.e., family support, patient navigator, helpful provider, etc.?

9. What are some things that encouraged you to go get screened before your breast cancer diagnosis (i.e., doctor told you, family member was diagnosed, found a lump, etc.)?
    a. Have you ever performed a self-breast exam on yourself? Why or why not?
    b. Do you think breast self-exams are helpful? Why or why not?

10. On average, how far do you/did you have to travel to receive breast cancer treatments? Is/Was the travel distance to the health facility a burden for you? Why or why not?

My next questions relate specifically to Mahoning County.

11. Mahoning County is home to multiple screening facilities, but the statistics for this area show women who live here are not being screened. What do you think are the top three barriers women here face when trying to obtain breast cancer screening services (i.e., cannot take time off of work, cost limitations, child care issues, no transportation, don't think they need one, etc.)?

12. Mahoning County is also home to multiple breast cancer treatment centers, but the death rate from breast cancer in this area is higher than both the state and national averages. What do you think are the top three barriers women here face when trying to obtain breast cancer treatment services?

13. Where in your community would you tell people to go to receive information on health and cancer prevention? Why would you choose those facilities/resources?

14. Where in your community would you tell people to go to receive a CBE and/or a mammogram if they needed one? Why would you choose those facilities/locations?

Appendix F: Key Informant Interview Script

Introduction

My name is [INSERT NAME HERE] and I am working with Komen Northeast Ohio to collect information for the 2015 Community Profile. The Community Profile is a report we publish where we assess where barriers to or gaps in breast health services may exist in [XX] County.

Part of our research involves collecting stories and information from people who live in this area. That's why we are conducting this interview. We hope to complete at least 12, and the themes that emerge from these interviews will help us decide where to direct our grant dollars and what kind of education programs we should be doing. The information will also help us learn about programs taking place in the community and address any outreach or policy needs. Your knowledge is incredibly valuable and we appreciate you taking the time to participate in the interview.

Do you have any questions for me about why we are conducting the interviews?

Now I'll go over the interview process with you. The interview consists of 10 questions and will last approximately 20 to 30 minutes**.** I will be writing down your answers as we go, so there may be long pauses and I may repeat some of your words back to you to make sure I am writing them down correctly.

All of your answers will be recorded anonymously, meaning there is no way anyone could trace the answers I write down back to you specifically. If we quote anything you say in our final report, it will be reported without your name.

Do you have any questions at this point about the interview process?

Because this is considered research with a human subject, we must get your informed consent before we start with the questions. This means you have been made aware of certain things and understand your rights as a research participant. At this time, I will take a few minutes and go over the consent form with you. Some of the information in the consent form is a repeat of what I've already told you, but these items are very important. At the end of the consent form, if you agree to participate, please [say yes or no][sign and date].

Informed Consent

The purpose of this interview is to gain insight into your perceptions of breast health and breast cancer in Northeast Ohio. It is our hope that the information from this interview will contribute to a better understanding of the gaps, needs, and barriers in breast health and breast cancer in Northeast Ohio.

Your participation in this discussion is strictly voluntary and all responses will be anonymous when the information is presented. You may choose to withdraw from the discussion at any time without penalty. However, your participation is very important to the success of the final report.

There are no risks associated with participating in this interview beyond those or ordinary daily living.

If you have any concerns about your rights as a research participant, you may contact the Cleveland State University Institutional Review Board at (216) 687-3630.

Do you have any questions about the interview process at this time?

- **Ask for verbal consent**: Do you agree to participate in this study knowing that you can withdraw at any point with no consequences? (Document date and time)
- **Ask for written consent**: At this time, I kindly ask you to read and sign the provided consent form.

Ground Rules
The ground rules for this focus group are:

- There are no right or wrong answers, everyone's experiences and opinions are equally important; we genuinely want to know what you think about these issues
- Your responses will remain anonymous and your confidentiality is assured
- If you have questions during the interview, please feel free to ask them at any time

Questions
Go over the appropriate question guides with the interviewee.

Closing
Thank you very much for your time. Your knowledge and insights will be very helpful in assisting Komen Northeast Ohio. The information you provided will help us identify gaps and unmet needs in the breast health community.

The 2015 Community Profile report will be completed in the fall of 2015; the report will be posted online, but if you would like to provide me with your email address we can make sure you receive an electronic copy. The 2011 Community Profile Report can currently be found on Komen Northeast Ohio's website at www.komneneohio.org.

Thank you again for your assistance.

Appendix G: Community Profile Focus Group Questions

Ashtabula County – Providers

The first set of questions has to do with the services provided at your facility.

1. What are some of the most common services your patients' request (i.e., complementary and alternative medicine, survivor support groups, radiation oncology, 3D mammograms/tomography, etc.)? Where can women go to obtain these services?
    a. Are there any services your clients need that you do not offer to the populations you serve? If so, what are those services?
    b. Is there a need for someone to provide those services and why?

2. What are your organization's strengths in addressing breast health issues that other organizations can learn from? Can you provide an example of a best practice approach?

3. What do you think organizations can do to close the gap in order to effectively address breast health disparities in your community?

The next questions relate to the challenges you face personally as health care providers.

4. What are some of the major challenges you face as health care providers in ensuring no one falls through the cracks and all patients receive the care they need?

5. List two or three of your most important administrative challenges at your practice/facility that prevent you from helping all of the patients/clients you serve.
    a. With these challenges, what are some of your lessons learned?
    b. How can these lessons be incorporated into future programs aimed at reducing breast health disparities?

This next question focuses on the challenges facing your patients and the clients you serve.

6. What are some of the major challenges your patients/clients face when attempting to access breast health screening and treatment services (i.e., cannot take time off of work, cost limitations, child care issues, no transportation, etc.) in your community?
    a. Are there any language barriers to accessing care (e.g., signage only printed in English) present at your facility?
    b. Are there cultural beliefs/stigmas about health care or breast cancer that influence or hinder people from seeking care?

7. What are some common myths and/or misconceptions, if any, you have heard about breast health, mammography, or breast cancer from the patients you serve?
    a. How do you attempt to educate your patients to help breakdown and combat these beliefs?
    b. What has been successful for you in changing people's minds?

The next question focuses specifically on breast cancer in Ashtabula County.

8. Ashtabula County has a high death rate from breast cancer, but 80 percent of women over the age of 40 are screened at least every two years. What do you think are some of the factors beyond screening that may be contributing to a high death rate?

My final question asks about the Affordable Care Act and its impact on your patients, your facility, and your ability to provide quality care.

9. With the recent implementation of the ACA and the provision that mammograms be covered, have you seen an increase in the number of patients requesting this service?
    a. If you have, how are you preparing to serve this increase in patients?
    b. If you have not, do you anticipate more women will ask for these services?
    c. Are there any new "gap areas" you feel have been created due to the passage of the ACA (i.e., diagnostics not covered, mammograms only covered for women over 40, mammograms only covered every two years, etc.)?
    d. What are you doing to encourage and/or facilitate enrollment into the health exchanges and/or Medicaid expansion?

Cuyahoga County – Providers

The first set of questions has to do with the services provided at your facility.

1. What are some of the most common services your patients' request (i.e., complementary and alternative medicine, survivor support groups, radiation oncology, 3D mammograms/tomography, etc.)? Where can women go to obtain these services?
    a. Are there any services your clients need that you do not offer to the populations you serve? If so, what are those services?
    b. Is there a need for someone to provide those services and why?

2. What are your organization's strengths in addressing breast health issues that other organizations can learn from? Can you provide an example of a best practice approach?

3. What do you think organizations can do to close the gap in order to effectively address breast health disparities in your community?

The next questions relate to the challenges you face personally as health care providers.

4. What are some of the major challenges you face as health care providers in ensuring no one falls through the cracks and all patients receive the care they need?

5. List two or three of your most important administrative challenges at your practice/facility that prevent you from helping all of the patients/clients you serve.
    a. With these challenges, what are some of your lessons learned?
    b. How can these lessons be incorporated into future programs aimed at reducing breast health disparities?

This next question focuses on the challenges facing your patients and the clients you serve.

6. What are some of the major challenges your patients/clients face when attempting to access breast health screening and treatment services (i.e., cannot take time off of work, cost limitations, child care issues, no transportation, etc.) in your community?
    a. Are there any language barriers to accessing care (e.g., signage only printed in English) present at your facility?
    b. Are there cultural beliefs/stigmas that influence or hinder people from seeking care?

7. What are some common myths and/or misconceptions, if any, you have heard about breast health, mammography, or breast cancer from the patients you serve?
    a. How do you attempt to educate your patients to help breakdown and combat these beliefs?
    b. What has been successful for you in changing people's minds?

The next set of questions focus specifically on breast cancer in Cuyahoga County.

8. Cuyahoga County has high incidence, death and late-stage diagnosis rates, but nearly 80 percent of women here are screened every two years. What do you think are some of the factors beyond access to screening services that may be contributing to a high death rate?

9. Cuyahoga County is also home to more than 125 screening facilities, but the statistics for this area indicate women who live here experience barriers when they attempt to access screening services. What do you think are the top three barriers women face when trying to obtain breast cancer screening services (i.e., cannot take time off of work, cost limitations, child care issues, no transportation, etc.)?

10. Only 37% of all screening facilities and providers in Cuyahoga County are contracted with the BCCP. Does your organization participate in this program? What do you think are some of the barriers to becoming a BCCP provider?

My final question asks about the Affordable Care Act and its impact on your patients, your facility, and your ability to provide quality care.

11. With the recent implementation of the ACA and the provision that mammograms be covered, have you seen an increase in the number of patients requesting this service?
    a. If you have, how are you preparing to serve this increase in patients?
    b. If you have not, do you anticipate more women will ask for these services?
    c. Are there any new "gap areas" you feel have been created due to the passage of the ACA (i.e., diagnostics not covered, mammograms only covered for women over 40, mammograms only covered every two years, etc.)?
    d. What are you doing to encourage and/or facilitate enrollment into the health exchanges and/or Medicaid expansion?

Cuyahoga County – General Population

The first set of questions relates to your understanding of breast health, breast cancer, and breast cancer screenings.

1. When do you think is an appropriate age for women to begin receiving mammograms? How often do you think women should receive mammograms (e.g., once a year)? Why do you feel this way?

2. Do you think people understand when to begin receiving mammograms or how often women should receive mammograms? Why or why not?

3. What are some things that would encourage you to go get screened for breast cancer (i.e., doctor told you, family member was diagnosed, found a lump, etc.)?
    a. Have you ever performed a self-breast exam on yourself? Why or why not?
    b. Do you think breast self-exams are helpful? Why or why not?

4. What are some things you know or have heard about the causes of breast cancer and the treatment of breast cancer? [For instance, have you heard breast cancer is caused by using deodorant? Do you believe that? Why or why not? Do you think people will only get breast cancer if it runs in their family? Do you think mammograms help or not? Etc.]
    a. Where would you go to receive accurate information on breast health and cancer prevention? Why would you choose those facilities/resources?

b. If you would choose an internet site, how do you know the information provided on that site is true/accurate?
c. Where would you go if you needed a CBE and/or a mammogram? Why would you choose those facilities/locations?

My next set of questions focuses specifically on breast cancer in Cuyahoga County.

5. Cuyahoga County has high incidence, death and late-stage diagnosis rates, but nearly 80 percent of women here are screened every two years. What do you think are some barriers outside of screening that may be contributing to these high rates?

6. Cuyahoga County is also home to more than 125 screening facilities, but the statistics for this area show women who live here may face barriers when they attempt to get a CBE or mammogram. What do you think are the top three barriers women face when trying to obtain breast cancer screening services (i.e., cannot take time off of work, cost limitations, child care issues, no transportation, etc.)?

My last question asks about the Affordable Care Act.

7. Do you think the ACA will make it easier for women to get the screenings they need? Why or why not?

Harrison/Jefferson Counties – General Population

The first set of questions relates to your understanding of breast health, breast cancer, and breast cancer screenings.

1. When do you think is an appropriate age for women to begin receiving mammograms? How often do you think women should receive mammograms (e.g., once a year)? Why do you feel this way?

2. Do you think people understand when to begin receiving mammograms or how often women should receive mammograms? Why or why not?

3. What are some things that would encourage you to go get screened for breast cancer (i.e., doctor told you, family member was diagnosed, found a lump, etc.)?
    a. Have you ever performed a self-breast exam on yourself? Why or why not?
    b. Do you think breast self-exams are helpful? Why or why not?

4. What are some things you know or have heard about the causes of breast cancer and the treatment of breast cancer? [For instance, have you heard breast cancer is caused by using deodorant? Do you believe that? Why or why not? Do you think people will only get breast cancer if it runs in their family? Do you think mammograms help or not? Etc.]
    a. Where would you go to receive accurate information on breast health and cancer prevention? Why would you choose those facilities/resources?
    b. If you would choose an internet site, how do you know the information provided on that site is true/accurate?
    c. Where would you go if you needed a CBE and/or a mammogram? Why would you choose those facilities/locations?

My next set of questions focuses specifically on breast cancer in Harrison/Jefferson County.

5. On average, how far do you have to travel to receive health care services? Is the travel distance to a health facility a burden for you? Why or why not?

6. Statistics show that only 50% of women who live in Harrison and/or Jefferson County have received a mammogram in the last two years. In your opinion, what are the top three barriers women in your community face when attempting to get a mammogram?

7. What are some things you know or have heard about the causes of breast cancer and the treatment of breast cancer? [For instance, have you heard breast cancer is caused by using deodorant? Do you believe that? Why or why not? Do you think people will only get breast cancer if it runs in their family? Do you think mammograms help or not? Etc.]

My last question asks about the Affordable Care Act.

8. Do you think the ACA will make it easier for women to get the screenings they need? Why or why not?

Lorain County – Providers

The first set of questions has to do with the services provided at your facility.

1. What are some of the most common services your patients' request (i.e., complementary and alternative medicine, survivor support groups, radiation oncology, 3D mammograms/tomography, etc.)? Where can women go to obtain these services?
    a. Are there any services your clients need that you do not offer to the populations you serve? If so, what are those services?
    b. Is there a need for someone to provide those services and why?

2. What are your organization's strengths in addressing breast health issues that other organizations can learn from? Can you provide an example of a best practice approach?

3. What do you think organizations can do to close the gap in order to effectively address breast health disparities in your community?

The next questions relate to the challenges you face personally as health care providers.

4. What are some of the major challenges you face as health care providers in ensuring no one falls through the cracks and all patients receive the care they need?

5. List two or three of your most important administrative challenges at your practice/facility that prevent you from helping all of the patients/clients you serve.
    a. With these challenges, what are some of your lessons learned?
    b. How can these lessons be incorporated into future programs aimed at reducing breast health disparities?

This next question focuses on the challenges facing your patients and the clients you serve.

6. What are some of the major challenges your patients/clients face when attempting to access breast health screening and treatment services (i.e., cannot take time off of work, cost limitations, child care issues, no transportation, etc.) in your community?
    a. Are there any language barriers to accessing care (e.g., signage only printed in English) present at your facility?
    b. Are there cultural beliefs/stigmas about health care or breast cancer that influence or hinder people from seeking care?

7. What are some common myths and/or misconceptions, if any, you have heard about breast health, mammography, or breast cancer from the patients you serve?
    a. How do you attempt to educate your patients to help breakdown and combat these beliefs?
    b. What has been successful for you in changing people's minds?

The next question focuses specifically on breast cancer in Lorain County.

8. Lorain County has a low breast cancer incidence rate and high rates of breast cancer screenings every two years, but the death rate is higher than the state and national averages. What do you think are some of the factors beyond access to screening services that may be contributing to a high death rate?

9. Given the high rates of breast cancer screening in Lorain County, coupled with multiple locations providing screening services and the high death rate, what do you think are the top three barriers women face when trying to obtain breast cancer treatment services (i.e., cannot take time off of work, cost limitations, child care issues, no transportation, etc.)?

10. Only 28% of all screening facilities and providers in Lorain County are contracted with the BCCP. Does your organization participate in this program? What do you think are some of the barriers to becoming a BCCP provider?

My final question asks about the Affordable Care Act and its impact on your patients, your facility, and your ability to provide quality care.

11. With the recent implementation of the ACA and the provision that mammograms be covered, have you seen an increase in the number of patients requesting this service?
    a. If you have, how are you preparing to serve this increase in patients?
    b. If you have not, do you anticipate more women will ask for these services?
    c. Are there any new "gap areas" you feel have been created due to the passage of the ACA (i.e., diagnostics not covered, mammograms only covered for women over 40, mammograms only covered every two years, etc.)?
    d. What are you doing to encourage and/or facilitate enrollment into the health exchanges and/or Medicaid expansion?

Mahoning County – General Population

The first set of questions relates to your understanding of breast health, breast cancer, and breast cancer screenings.

1. When do you think is an appropriate age for women to begin receiving mammograms? How often do you think women should receive mammograms (e.g., once a year)? Why do you feel this way?

2. Do you think people understand when to begin receiving mammograms or how often women should receive mammograms? Why or why not?

3. What are some things that would encourage you to go get screened for breast cancer (i.e., doctor told you, family member was diagnosed, found a lump, etc.)?
    a. Have you ever performed a self-breast exam on yourself? Why or why not?
    b. Do you think breast self-exams are helpful? Why or why not?

4. What are some things you know or have heard about the causes of breast cancer and the treatment of breast cancer? [For instance, have you heard breast cancer is caused by using deodorant? Do you believe that? Why or why not? Do you think people will only get breast cancer if it runs in their family? Do you think mammograms help or not? Etc.]
    a. Where would you go to receive accurate information on breast health and cancer prevention? Why would you choose those facilities/resources?
    b. If you would choose an internet site, how do you know the information provided on that site is true/accurate?
    c. Where would you go if you needed a CBE and/or a mammogram? Why would you choose those facilities/locations?

My next set of questions focuses specifically on breast cancer in Mahoning County.

5. Mahoning County is home to multiple screening facilities, but the statistics for this area show women who live here are not being screened. What do you think are the top three barriers women here face when trying to obtain breast cancer screening services (i.e., cannot take time off of work, cost limitations, child care issues, no transportation, don't think they need one, etc.)?

6. Mahoning County is also home to a comprehensive breast cancer treatment center, but the death rate from breast cancer in this area is higher than both the state and national averages. What do you think are the top three barriers women here face when trying to obtain breast cancer treatment services?

My last question asks about the Affordable Care Act.

7. Do you think the ACA will make it easier for women to get the screenings they need? Why or why not?

Appendix H: Focus Group Moderator Script

Welcome
At this time, I would like to welcome all of you to this focus group conducted by Susan G. Komen Northeast Ohio. First, I would like to thank all of you for taking the time out of your schedules to take part in this discussion. We appreciate your willingness to participate.

I have some demographic forms that I will pass around now. If you could please take a moment to fill out this information so we can have an idea of who is participating in these focus groups, it would be greatly appreciated. Please do NOT put your name on these demographic forms so that your information can remain anonymous.

Introduction
My name is [INSERT NAME] and I am working with Susan G. Komen Northeast Ohio to collect data related to breast health resources and breast cancer in [INSERT COUNTY]. [EXPLAIN ROLE WITHIN KOMEN NORTHEAST OHIO, I.E., INTERN, STAFF MEMBER, VOLUNTEER, ETC.]

Purpose of the Community Conversation
The purpose of this focus group is to better understand what resources are available to individuals in [INSERT COUNTY NAME] county related to breast health and breast cancer. This information will be included as part of the research in Komen Northeast Ohio's 2015 Community Profile Report. The information you provide to us today will help identify any barriers and/or assets present in your community related to breast health.

Komen Northeast Ohio will then direct grant dollars to organizations and health systems that break down the identified barriers and help women in-need gain access to quality, affordable breast health education, screening, and diagnostic services. Your responses tell us where grant funds should go so Komen can make the biggest impact in your community. The final report will also provide local organizations and health systems with vital information they can use to better serve their patients and clients.

Informed Consent
At this time, I will take three minutes and read the consent form to you. At the end of the consent form, if you agree to participate, please sign and date.

Your participation in this discussion is strictly voluntary and all responses will be anonymous when the information is presented. You may choose to withdraw from the discussion at any time. However, your collaboration is very important for the success of the final report. In addition, all information will be kept confidential and anonymous in the final report.

Ground Rules
The ground rules for this focus group are:

- We ask that only one person talk at a time so all comments can be acknowledged and noted appropriately
- We want you to do the talking and would like it if everyone participates; however, we understand if you choose not to speak on certain topics/questions and we respect your boundaries
- There are no right or wrong answers, everyone's experiences and opinions are equally important; we genuinely want to know what you think about these issues
- We will be tape recording the focus groups to ensure we capture everyone's opinions as accurately as possible
- Your responses will remain anonymous and your confidentiality is assured

- What happens in this room stays in this room
- As the moderator, I do reserve the right to end a discussion or move the discussion along in the interest of time

Getting to Know You
At this time, I would like all of you to introduce yourselves in a few sentences in order to break the ice and make everyone feel comfortable such as name, why you are here today, and one word that describe you.

Before getting started
Are there any questions before we get started? At this time, I will turn on the tape recorder and we can get begin the discussion.

Get Started
Ask questions and respond:
- Can you tell me more about what you just said?
- Can you give me a specific example?
- Could you explain what you mean by that?
- Can you tell me something else about…?

End
At this time, the focus group has now concluded and we thank you so much for participating!

Appendix I: Community Profile Focus Group Participant Demographic Form

General Population

Date of focus group: _____

Location of focus group: _____

1. Please select **one of the choices** below that best represents your current age:
   ____ 39 years of age and younger
   ____ 40-49 years of age
   ____ 50-59 years of age
   ____ 60 years of age and older

2. What county do you live in? _____

3. What is your zip code? _____

4. Have you ever had a mammogram? (A mammogram is an X-ray picture of the breast doctors use to check for breast cancer.) ☐Yes ☐ No

   a. If yes, at what age did you have your first mammogram?_____years

   b. How long has it been since you had your last mammogram? **Please check one.**

      ☐ Within the past year (anytime less than 12 months ago)
      ☐ Within the past 2 years (1year but less than 2 years ago)
      ☐ Within the past 3 years (2 years but less than 3 years ago)
      ☐ Within the past 5 years (3 years but less than 5 years ago)
      ☐ 5 or more years ago
      ☐ Don't know or not sure

5. Have you ever been diagnosed with breast cancer? ☐Yes ☐ No

   a. If yes, at what age were you diagnosed?_____years

   b. What stage of breast cancer were you diagnosed with? **Please check one.**

      Stage 1 ☐ Stage 2 ☐ Stage 3☐ Stage 4 ☐

6. Has anyone related to you been diagnosed with breast cancer? **Please check all that apply.**

   Grandmother☐ Mother☐ Sister☐ Daughter☐ Aunt ☐ Other☐

   If Other, please specify: _____

7. What is your Race? **Please check all that apply.**
    ____ White
    ____Black or African-American
    ____ American Indian or Alaska Native
    ____ Asian (e.g. Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese)
    ____ Native Hawaiian or Other Pacific Islander (e.g. Native Hawaiian, Guamanian/Chamorro, Samoan)
    ____ Other (please write your race):
    _____

8. Are you of Hispanic, Latino/a or Spanish origin? **Please check all that apply.**
    ____ No, not of Hispanic, Latino/a, or Spanish origin
    ____ Yes, Mexican, Mexican-American, Chicano/a
    ____ Yes, Puerto Rican
    ____ Yes, Cuban
    ____ Yes, another Hispanic, Latino/a, or Spanish origin
    ____ Yes, other (please write your origin):
    _____

9. Do you have one person you think of as your personal doctor or health care provider?
    ____ Yes, only one
    ____ Yes, but I have more than one
    ____ No, I do not have a personal doctor/provider

10. Do you currently have health insurance?
    ____ Yes, I have health insurance
    ____ No, I do not have health insurance
    ____ I do not know if I have health insurance

11. Where do you receive information related to your health? **Please check all that apply.**
    ____ Church
    ____ Shopping
    ____ Radio
    ____ Internet
    ____ My doctor
    ____ Word of mouth (From whom or where: _____)
    ____ Mail delivered to your home
    ____ Television
    ____ Newspapers
    ____ Social Media (e.g. Facebook, twitter)

Breast Health Providers/Leaders

Date of focus group: _____

Location of focus group: _____

1. How many years have you worked in the breast health/breast cancer field
    ____ Less than one (1) year
    ____ Between 1-5 years

____ Between 5-10 years
____ Between 10-15 years
____ Between 15-20 years
____ More than 20 years

2. What is/are your specialty areas and areas of expertise? **Please select all that apply.**
____ Community outreach and education
____ Patient navigation
____ Cultural competency
____ Breast health disparities
____ Breast health/breast cancer research
____ Primary care
____ Mammography
____ Other (Please specify):
_____
____ Radiology
____ Oncology
____ Breast surgery
____ Complementary therapies
____ Adjuvant therapy
____ Breast cancer survivor issues

3. What county/counties do the women you serve live in?

_____

_____

4. What are your practice's/facility's recommendations regarding the appropriate age for women at average risk of developing breast cancer to begin receiving clinical breast exams? **Please check one.**
____ 20s
____ 30s
____ 40s
____ 50s
____ 60s and older

5. What are your practice's/facility's recommendations regarding the appropriate age for women at average risk of developing breast cancer to begin receiving mammograms? **Please check one.**
____ 20s
____ 30s
____ 40s
____ 50s
____ 60s and older

6. What are your practice's/facility's recommendations regarding the frequency at which women should receive mammograms? **Please check one**.
____ More than once a year
____ Once a year
____ Once every other year
____ Once every three years

____ More than three years apart

7. Please estimate the percentage of women you serve in each of the following racial/ethnic groups. **Please make sure percentages add up to 100%.**
   - ____ White
   - ____ Black or African-American
   - ____ American Indian or Alaska Native
   - ____ Asian (e.g. Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese)
   - ____ Native Hawaiian or Other Pacific Islander (e.g. Native Hawaiian, Guamanian/Chamorro, Samoan)
   - ____ Hispanic/Latina
   - ____ Other (please specify): _____

8. Does your practice/facility provide resources and services to uninsured individuals?
   - ____ Yes, uninsured individuals have access to all of the services we offer
   - ____ Yes, but the services offered to the uninsured are limited
   - ____ No, we do not provide services to individuals without health insurance

9. Do you know if your facility is contracted with Ohio's Breast and Cervical Cancer Project (BCCP)?
   - ____ Yes, our facility is contracted with the BCCP
   - ____ Yes, but only some of our providers are contracted with the BCCP
   - ____ No, our facility is not a BCCP contracted provider
   - ____ I do not know if our facility contracts with the BCCP

10. Where in the community do you distribute information related to breast health and the services you provide? **Please check all that apply.**
    - ____ Church
    - ____ Shopping
    - ____ Radio
    - ____ Internet
    - ____ My doctor
    - ____ Word of mouth (From whom or where: _____)
    - ____ Mail delivered to your home
    - ____ Television
    - ____ Newspapers
    - ____ Social Media (e.g. Facebook, twitter)