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

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- SHARE – Self-Help for Women with Breast and Ovarian Cancers
- Sisters United in Health
- YWCA of White Plains and Central Westchester
Executive Summary

Introduction to the Community Profile Report

Susan G. Komen® Greater New York City was founded in 1990. The Affiliate has consistently been ranked number one in the Komen network for fundraising and grants awarded for most of the last seven years. It is one of the largest of the 120 Affiliates in the Susan G. Komen network, and to date, the Affiliate has raised over $65 million through donations, corporate support and fundraisers including the Komen Greater New York City Race for the Cure®.

The Affiliate is currently working with a full-time staff of 10. Volunteers are used as needed, usually for support with the Affiliate’s events. Additionally, each department employs undergraduate and graduate level interns from the universities around the service area.

Susan G. Komen Greater NYC is incorporated as a nonprofit organization with its own board of directors and a full-time staff of 10 based in New York City and led by Chief Executive Officer Linda McNeil Tantawi. It has a collaborative and contractual relationship with the national Susan G. Komen organization that enhances the Affiliate’s fundraising, program activities and local influence. The Affiliate’s Board of Directors is a governing board and currently consists of 13 members and oversees multiple important committees including the Grants Policy and Education, Governance, Medical Advisory and Young Professionals Committees. The Grants Policy and Education Committee provides oversight to the Grants and Public Policy program. It includes experts in breast cancer detection, treatment, and research.

The service area includes some of the most populous counties in the country and, at the same time, the more rural county of Suffolk in Long Island. Eight of the nine counties in the Komen Greater NYC region are ranked in the top 10 as the most populous in the state (US Census 2012). Approximately 64.0 percent of New York State’s population resides in the nine counties of the Komen Greater NYC service area. There is tremendous diversity in household income across the Komen Greater NYC service area. While Manhattan, Westchester, Nassau, Suffolk and Rockland counties report higher household incomes, nearly 30.0 percent of households in the service area were making under $25,000 annually (US Census, 2000; 2009 estimates). There are large numbers of individuals who live below the poverty levels in the five boroughs/counties of New York City. The gap between the “haves and have nots” has widened considerably in the region. The numbers of people comprising the middle class have slowly diminished and those who are left continue to struggle financially. (US Census 2000, American Community Survey, 2009-2013). The unemployment rate in this population remains high due to loss of jobs for unskilled workers. There is an estimated 775,000 undocumented individuals in the service area.

The service area is a geographical mix ranging from urban to very rural. The availability and ease of traveling on public transportation varies widely in the service area. In Manhattan (New York County), it is fairly easy to use the subway and buses to travel to most locations in the county. The five counties that comprise New York City are considered urban by city planners; however, parts of Queens and Richmond Counties are quite suburban in nature. Parts of those counties are completely residential where travel to the nearest grocery store requires a car or a
bus ride. Kings County is fairly easy to navigate by bus and subway but interestingly, there are few highways that run into the heart of the county.

Nassau and Suffolk Counties comprise Long Island. Nassau County has both urban and suburban communities. Suffolk County has pockets of suburban neighborhoods, but the county, as a whole, is very rural. The South Fork and North Fork split at Riverhead where the Peconic River empties into the Peconic Bay. It has long been noted that Long Island resembles a fish with the forks forming a tail. Travel from one end of the North Fork to the South Fork without a car is problematic. The bus system requires that you travel to the beginning of each fork and back out again. There is ferry service that crosses the bay between the two forks. Public transportation on Long Island varies widely. Nassau County has a dependable bus system that operates often until quite late at night. Travel around Suffolk County for those without cars is difficult because public transportation is limited both in availability and schedule.

Parts of Queens, Kings and Bronx Counties are easier to navigate than others. Though there are multiple subway lines that travel through these three counties, however, most of them go to the same locations. The bus system does link to the subway system, which means that many residents may have to travel from their homes into a hub and then back out again on another bus.

Westchester and Rockland Counties (Lower Hudson Valley) are considerably smaller counties and are quite residential. Travel into and out of those counties is by train, bus or car. The commuter train, Metro North also serves parts of the Bronx. There is a dependable bus system that serves both counties but service is limited during the evening hours in Rockland County.

The nine counties in the service area are some of the most racially and ethnically diverse in the United States. While Whites and Hispanics/Latinos are the most common racial/ethnic groups across the nine counties, followed by Blacks/African-Americans, the number of Asians continues to grow rapidly. The heterogeneity of the Hispanic/Latino population has increased since 2011. Puerto Ricans, Dominicans, and Mexicans comprise 70.0 percent of Hispanics/Latinos with Ecuadorians, Colombians, and Central Americans considerably contributing to the mosaic of Spanish-speaking populations (CLACLS 2010). Hispanics/Latinos are now the majority population in the Bronx (55.0 percent), with populations of Dominicans and Mexicans in the Bronx continuing to rise (US Census, American Community Survey, 2009-2013). There are also over one million Asian people in the service area, with much heterogeneity within this ethnicity (Cornell University 2013). Among Asians, China is the most common country of origin.

The Affiliate provides funding to between 25-30 organizations each year. There are three granting programs – Community Breast Health, Clinical Research Enrollment and Small Grants. The Community Breast Health grants are awarded annually. The Clinical Research Enrollment grants are two-year grants and are focused on funding activities that increase enrollment of underrepresented individuals in breast cancer clinical research. The Small Grants are available three times a year and fund capacity-building or pilot projects. Approximately 80.0 percent of
grant funding is focused on innovative programs that provide patient navigation/case management for screening and treatment and support programs that provide crucial support services including transportation, financial assistance, meals for patients and their families, legal assistance and programs that eliminate barriers to clinical trials. Twenty percent of the Affiliate’s programs fund education and outreach programs that directly link women to screening.

The Affiliate has co-sponsored and hosted multiple events over the last several years. In August 2013, the Affiliate and the New York headquarters of Pfizer co-sponsored an event that highlighted the work that the Affiliate does to raise awareness and funds and stressed the importance of Pfizer partnering with advocacy organizations like Komen and the potential impact it can have for patients. In October 2014, the Affiliate and Pfizer hosted a breakfast reception for breast cancer survivors. The event included a moderated panel discussion featuring key advocacy leaders from the service area and addressed the importance of elevating the dialogue around breast cancer and metastatic disease. The Affiliate has supported the annual “Breast Cancer in Women of Color” event organized by a breast surgeon who worked at New York Presbyterian and is now at New York University/Langone Medical Center. The Affiliate has provided financial support and has served on the planning committee for the event. Additionally, the Affiliate has hosted educational programs for the general public that range from focus on the importance of screening to clinical trials participation for underrepresented groups.

The Affiliate has participated in a number of community and state-wide initiatives that highlight its breast health leadership role in the service area. The Affiliate has been a member of the state’s comprehensive cancer control coalition, the New York State Cancer Consortium, since 2010.

The Affiliate is a member of the New York State Cancer Education and Detection Advisory Council, a legislatively mandated (through NYS Public Health Law 2904-a) body of health care professionals from across the state. The role of the council is to advise the commissioner regarding provision of information to consumers, patients, and health care providers relating, but not limited to breast, cervical, prostate, testicular and ovarian cancer, including signs and symptoms, risk factors, the benefits of prevention and early detection, guideline concordant cancer screening and disease management, options for diagnostic testing and treatment, new technologies, and survivorship. The council has, as part of its mission, oversight over the Cancer Services Program which is the National Breast and Cervical Cancer Early Detection Program for New York.

In May 2015, the New York State Department of Health hosted a day-long Cancer Prevention Summit. The event addressed general cancer prevention and risk reduction. Affiliate staff served as a member of the planning committee, which comprised health care professionals from around the state, and moderated one of the sessions. In October, 2015, the Affiliate will host a symposium entitled “Truth or Dare: Truths about Breast Cancer Today by Women Daring to Make a Difference.” The program will feature an all-female panel of Komen Scholars, select
individuals from the Affiliate’s Medical Advisory Committee and from key Affiliate medical partners. The audience for the event includes the Affiliate’s constituents, the medical community and key partners.

The purpose of the Community Profile Report is to ensure that the Affiliate’s strategic and operational plans are aligned. The Affiliate’s Grants, Education and Public Policy committee will use the report as a guide to establish grantmaking priorities and drive public policy efforts. The Affiliate will share the report with its public policy partners such as the American Cancer Society and the Leukemia and Lymphoma Society. The report will establish directions for educational needs and help the Affiliate ensure that educational programs are held in the target communities. The Affiliate will use the report as a guide to identify key sponsors of Affiliate events, particularly those prospective organizations located in the target communities, and strengthen relationships with existing sponsors.

The Director of Communications will create a one page document with key messages from the report that will be included in press kits that will be distributed to local media. The director will distribute a press release and contact local radio and television outlets in an effort to seek opportunities for Affiliate staff and Board members to appear to talk about the key messages from the report. Affiliate staff will seek additional partners with whom they can collaborate to focus on the issues affecting the communities identified in the report.

The report will be posted on the Affiliate’s website in the grantmaking section of the site. A prominent link to the page will be posted on the front page of the website highlighting the report. The Affiliate will share the report with those legislators who have supported the Affiliate over the last several years. Select legislators may be included in media spots along with Affiliate staff that arise once the press release is distributed. The Affiliate will share the community profile download link and the profile’s key points via social media, also videotaping short vignettes featuring Affiliate staff talking about the report and the importance of the information. Those videos will be posted on the Affiliate’s YouTube channel and promoted in social media. The Board chair will include the report as part of the packet of information given to new Board members. The availability of the report will be shared through e-blast messages that are sent to the Affiliate’s constituents. Additionally an announcement about the release of the report will be shared via e-blast messages to current and past grantees. Affiliate staff will also share the one page document at both Affiliate and partner sponsored events.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

The proportion of women who reported having a screening mammography in the past two years was 78.4 percent in New York State and 74.0 percent in the United States overall in 2012. Per the Quantitative Data Report, in the Affiliate’s region the proportion of women who reported having mammographic screening was 80.6 percent.

Given the data on early stage diagnosis and death for Black/African-American and Hispanic/Latina women, the high rates of mammography screening via self-report seem
counterintuitive. This may reflect processes after the screening mammogram takes place that constitute some sort of breakdown in care which promotes a delay in diagnosis.

The Quantitative Data Report (QDR) identified Black/African-American and Hispanic/Latina women as the priority populations for the Affiliate. These two groups were more likely to be diagnosed at a later stage. Additionally, death rates for Black/African-American women were higher than any other racial/ethnic group in the service area. Although the death rates for the other racial and ethnic groups in the Affiliate’s service area were not as high, there was evidence of barriers to early detection or survival. The Affiliate will be able to address these barriers through interventions funded through the granting programs. The QDR highlights the Bronx as a medium-high priority area, followed by Kings County, Richmond County, Rockland County and Suffolk County which were classified as medium priority. The Bronx, Kings, Richmond and Rockland Counties had the highest death rates in the service area. In addition, the QDR also highlighted Suffolk County for its elevated death rates and high proportion of late-stage diagnosis and Westchester County for its elevated breast cancer death. Based on this information, the targeted areas and priority populations are Black/African-American and Hispanic/Latina women living in the Bronx, Brooklyn, Staten Island/ Richmond County, Lower Hudson Valley (Rockland and Westchester Counties), and Suffolk County.

The data elements are noted in Table 1. In addition to the data provided in the QDR, the Affiliate also used data from the sources below:

**New York State Cancer Registry (NYSCR)** Through the New York State Cancer Registry, the NY State Department of Health collects, processes and reports information about all New Yorkers diagnosed with cancer. The New York State Cancer Registry participates in the North American Association of Central Cancer Registries (NAACCR) and uses SEER and NAACCR coding.

**New York City Bureau of Vital Statistics (NYC Vital Statistics)** The Bureau of Vital Records collects all birth and death events that occurred in New York City, basing underlying cause of death on National Center for Health Statistics definitions.

**New York City Community Health Survey (NYC CHS)** The New York City Community Health Survey (CHS) is a telephone survey annually conducted by the Department of Health and Mental Hygiene (DOHMH). Like the Behavioral Risk Factor Surveillance Systems (BRFSS), the CHS collects information from nearly 125 questions providing robust data on the general health of New Yorkers. The survey is used to generate neighborhood, borough, and citywide estimates on a range of chronic diseases and behavioral risk factors including mammography screening.
Table 1. Comparison Between Quantitative Data Report and Additional Quantitative Data Exploration Sources

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<td>NYC Community Health Survey 2012</td>
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Health Systems and Public Policy Analysis

The NYSDOH Cancer Services Program (CSP) oversees the delivery of comprehensive breast, cervical and colorectal cancer screening and diagnostic services to eligible uninsured and underinsured New Yorkers through local screening programs implemented by state-funded CSP contractors. The goal of the CSP is to reduce morbidity and mortality from breast, cervical and colorectal cancers in New York State.

CSP contractors develop relationships with regional providers (e.g., hospitals, clinics, health care providers) and community-based organizations to reach out to priority populations via targeted outreach and population-based strategies in order to provide screening, diagnostic and case management services, public education, data management and quality assurance.

Breast cancer screening services are available at no cost to women who:

- Aged 40 and older
- Do not have health insurance or have health insurance that does not cover the cost of these screenings
- Have household incomes at or below 250 percent of the federal poverty guideline (FPG) or who live above 250 percent of the FPG but attest, on a client consent form, that they are unable to afford the Program’s cancer screening or diagnostic services
- Live in New York State

The priority population for the CSP is people who:

- Are uninsured or underinsured, aged 50 to 64,
• Are medically unserved or underserved, including, but not limited to, individuals who experience barriers to services from race, ethnicity, age, disability, sexual orientation, gender identity, socioeconomic status, cultural isolation and/or geographic location.

CSP contractors and partners also help individuals diagnosed with breast, cervical, colorectal or prostate cancer obtain prompt, comprehensive treatment through the NYS Medicaid Cancer Treatment Program (MCTP), if eligible. Eligible individuals may receive full Medicaid coverage for the duration of their cancer treatment. Although DOH does not support routine population-based screening for prostate cancer, men screened and/or diagnosed with prostate cancer through participating providers are eligible for treatment coverage through the MCTP. To be enrolled, an individual must complete an application with a CSP-trained designee, referred to as a Designated Qualified Entity (DQE). Once an individual is enrolled, full Medicaid coverage is provided for an initial period determined by the type of cancer being treated. Enrollees must receive services from a Medicaid-enrolled provider. MCTP coverage is limited to the individual enrollee and cannot be extended to family members or dependents.

Additional information about the New York State Department of Health Cancer Services Program can be found at the New York State Department of Health website. Visit the Community Programs List to find the local CSP that serves the county/borough in the Komen NYC service region.

Strengths

**Bronx County** - There are six hospitals, 67 community health centers and 26 mammography centers in the Bronx. Two of the six hospitals have multiple locations throughout the Bronx. The Cancer Services Program (NBCCEDP) for the Bronx is based at Lincoln Hospital Medical Center, one of the three Health and Hospitals Corporation (municipal) hospitals in the Bronx. Lincoln provides a host of treatment services – medical and radiation oncology. The Cancer Services Program includes 15 other providers who deliver screening and diagnostic services.

According to the 2010 Census, over 50.0 percent of the population that reside in the Bronx is Hispanic. Many of the Hispanic/Latino residents have limited English and Spanish literacy. All of the medical facilities in the Bronx have bilingual staff to accommodate the language needs of the population.

Though the income level for many residents is below the poverty level, the Bronx is home to three municipal hospitals and a number of Federally Qualified Health Centers that will provide medical care regardless of insurance, income or citizenship status.

**Kings County** - There are 13 hospitals and 49 health centers in Kings County. It provides a full range of treatment services for breast cancer all housed in one location.

**Richmond County** - There are two hospitals located at the northernmost part of Richmond County. According to the National Institute of Health/Health Systems Area data, Richmond University Medical Center is located in an economically depressed region of the county. The hospital is near the Staten Island Ferry terminal. (The Staten Island Ferry is one of only two methods of reaching Staten Island. It is a system of ferries or boats that is operated by the New
York City Department of Transportation.) According to the 2010 Census data, the community surrounding the ferry is over 60.0 percent Black/African-American and Hispanic/Latino and largely under and uninsured. Staten Island University Hospital is located some distance away from the ferry terminal and serves a more affluent population. Both hospitals offer the full range of breast screening, diagnostic and treatment services, including medical oncology and radiation. Richmond University Medical Center’s breast service includes nurse navigators who assist women from screening through diagnosis and treatment.

**Suffolk County** - There are 12 hospitals in Suffolk County. Most of them have comprehensive breast cancer services. Several hospitals opened comprehensive breast cancer centers that include mammography screening and diagnostic services. Treatment for breast cancer varies as some treatment is delivered in doctor’s offices (chemotherapy) rather than in the hospital.

**Lower Hudson Valley (Rockland and Westchester)** - There are 14 hospitals in the two counties of the Lower Hudson Valley. Westchester Medical Center is the safety net hospital for that county. Rockland County’s underserved usually go to Nyack Hospital, Good Samaritan Hospital or the multiple health centers in the county.

**Weaknesses**

**Bronx County** - The Bronx is one of the poorest counties in the region with large numbers of undocumented women.

There are limited patient navigation programs in all of the hospitals. The quality of navigation also differs throughout the Bronx. In some facilities, the case manager is solely devoted to that role and in others; it can be one of many duties. Treatment options in the smaller hospitals can be limited.

Support services are limited as well. Montefiore has a well-regarded peer support program but is located in the northern part of the Bronx and is not easily accessible by subway. There are limited support groups for Hispanics/Latinos and young women.

**Kings County** - Kings County (Brooklyn) is one of the most populous counties in the state. Many of the hospitals are overcrowded and understaffed. Unfortunately one of hospitals, Long Island College Hospital (LICH), recently closed. That places an additional burden on Brooklyn Hospital, the only facility near LICH. There are three municipal hospitals in Brooklyn – Kings County/Downstate Medical Center, Woodhull and Coney Island Hospital. Kings County is unique in that there are few highways into the county and a few of the area’s hospitals are accessible only by bus. It takes a fair amount of time to travel from one side of the county to the other. There are few support services. Patients are often referred to Manhattan or to Queens since part of Kings County borders Queens. Patient navigation services are limited and differ in quality. Women of color who reside in Kings County have an extraordinarily high death rate which may be due to the difficulties in accessing treatment.

**Richmond County** - Medical care for the medically underserved residents in Richmond County is limited. There are no municipal hospitals in the county. There are few community health centers. Richmond County is committed to serving the uninsured and underinsured but the two
hospitals that serve that population have limited services because of budget shortfalls.

There are few breast surgeons or oncologists in the county. The Black/African-American and Hispanic/Latino populations are small but most residents live at or below the Federal poverty line, are under and uninsured and suffer from other chronic conditions like diabetes and hypertension. Employment opportunities are few and there are limited support services.

**Suffolk County** - Most of the underserved population on the East End of Long Island of Suffolk County is geographically and culturally isolated. The public transportation system in Suffolk County is not extensive. Those without access to cars must travel one hour or more by bus to the larger towns. There is fragmented bus service and the buses that do run, do so sporadically.

The hospitals are spread from one end of the county to the other but Eastern Suffolk is particularly underserved. The medical professionals call that area “the land of no.” There are few support services, no case management, few medical professionals and no transportation to get to the physicians who are there. Several physicians in Suffolk County no longer accept Medicaid so women are forced to go to Nassau County, which can be quite the hardship.

The major medical center in Suffolk County is at Stonybrook Medical Center which is a state-run facility, and serves as the safety net hospital for the county. It is located in Western Suffolk County and is approximately two to two and a half hours from people who live in Eastern Suffolk.

**Lower Hudson Valley (Rockland and Westchester Counties)** - Transportation in Rockland County is limited. There are buses but they run sporadically. There aren’t many oncologists in the area forcing many to travel to Westchester or Manhattan.

The Affiliate’s Health Systems and Public Policy Analysis findings highlight New York’s commitment to ensuring that medically underserved populations gain access to quality care. The Cancer Services Program (CSP), the state’s NBCCEDP program, is deeply entrenched in the communities of color and provides much needed navigation and case management services. The Medicaid Cancer Treatment Program accepts women who have seen a Cancer Services Program provider but may not have been enrolled in the CSP. There is no plan to eliminate the Cancer Services Program and it continues to be supported by New York’s legislators.

The New York State of Health, New York’s insurance Marketplace, has enrolled over one million people since it opened in 2013. The bulk of those individuals enrolled in Medicaid. Over 90.0 percent of those who enrolled stated that they were uninsured in the year prior to enrollment, thus highlighting the benefit of the Affordable Care Act. With the implementation of the Affordable Care Act, New York expanded Medicaid eligibility levels to 138.0 percent FPL for all eligible New Yorkers. Since New York’s eligibility levels already largely met this new federal standard, this expansion affected single and childless adults whose eligibility had been set at 100.1 percent FPL. As projected, a relatively small percentage (13.0 percent) of the persons who enrolled in Medicaid through the Marketplace was newly eligible as a result of the Medicaid expansion. In an effort to help undocumented women undergoing cancer treatment, there was
an option to enroll patients into Emergency Medicaid.

Uninsured and undocumented residents in the region benefit from being able to obtain care from the 11 municipal or safety-net hospitals operated by the Health and Hospitals Corporation (HHC) in the region. The HHC hospitals will see any patient regardless of ability to pay or citizenship status. However, because of the inability for many to pay for care and reduced Medicaid reimbursement, the HHC hospitals have faced severe financial shortfalls in the last several years leading to reductions in services. There are also gaps within the HHC system. In an effort to eliminate duplication of services within the hospitals, patients may have to obtain care at two or more facilities.

The bulk of the needs in the Komen Greater NYC region are focused on patient navigation, support, survivorship and access to quality care. Transportation is also a much needed service for those living in Richmond, Suffolk, Rockland and Westchester Counties. The continuum of care highlights the need for education to patients and medical providers regarding the importance of treatment completion. That may involve encouraging health care providers to ensure that once patients leave their care, there is some level of follow up. New York State has struggled with creating survivorship plans. The barriers seem to be related to limited options in electronic medical records. A crucial need includes eliminating those systems barriers that prevent patients from moving from point A (surgery) to point B (chemotherapy and/or radiation). Kings County continues to suffer from a lack of access to medical care. The hospitals are strong and provide comprehensive services but are overcrowded. Hospital officials and medical personnel observe that patients can spend hours in waiting rooms waiting for medical appointments.

**Qualitative Data: Ensuring Community Input**

The questions the Affiliate had to consider in the Qualitative section included: why are the death and late-stage diagnosis rates so high if screening percentages are more than adequate? What are the specific barriers that prevent a patient from moving from screening to diagnosis, from diagnosis to treatment, and from starting to completion of treatment and these barriers unique to women of certain ethnicities? Whose responsibility is it to ensure that a patient completes the diagnostic or treatment plan – primary care provider, radiologist, oncologist, or surgeon? What barriers, if any, do patients in those communities face in accessing those services in a timely and culturally appropriate fashion?

The data methods utilized included key informant interviews and literature reviews. The key informant questions were focused on patient level factors that included family support and a patient’s competing priorities (family, work, etc.). Provider level factors included levels of availability of patient navigation, cultural competency, accessibility (appointment hours), knowledge of community resources and resources for survivorship. System level questions focused on insurance, health facility shortages and poorly equipped facilities.

**Findings**

In the Qualitative section, the Affiliate identified specific barriers that prevent a patient from moving from screening to diagnosis, from diagnosis to treatment, and from initiating to
completing treatment. Factors that enable care at the patient level are education and family support while the competing priorities of work and family demands served as barriers to accessing care along the continuum. At the health care provider level, factors that enabled care were provider cultural competence, provision of patient navigation services and extended hours of operation and increased appointment availability. Barriers to care were lack of provider knowledge of health care resources. At the health system level, comprehensive health insurance, funds for low cost and free breast care and community outreach enabled care along the continuum. Barriers to care were health facility shortage areas as well lack of equipped multi-modality facilities. For example, Kings County has several large hospitals that provide comprehensive medical services however, the hospitals are constantly overcrowded. For those living in Richmond and Suffolk Counties and the Hudson Valley, transportation is a major barrier to care. Patients without cars have to travel long distances on inadequate public transportation systems. Providing comprehensive patient navigation and support and eliminating systems barriers that prevent patients from moving from point A (surgery) to point B (chemotherapy and/or radiation) is crucial. New York has also struggled with development of survivorship plans making treatment completion a continuum of care priority. Health care professionals from around the region state that survivorship care plans can be generated through the electronic medical records (EMR), but EMR vendors state that it will be very costly to update the various EMR systems.

Mission Action Plan

The problem statements and priorities developed after triangulation of data from the target communities include:

1. Black/African-American and Hispanic/Latina women continue to be diagnosed with breast cancer at late-stages. Black/African-American women have higher death rates than other demographic groups. Problem Statements: Black/African-American women in the Bronx, Kings, Richmond, Westchester and Rockland Counties have the highest death rates in the Komen Greater New York City area. Suffolk County has the highest proportion of late-stage breast cancer diagnosis for Black/African-American women.

Priority - After reviewing the QDR, reduce the number of late-stage diagnoses and high death rates among Black/African-American, Hispanic/Latina and other vulnerable women in Bronx, Kings, Richmond, Westchester, Rockland, and Suffolk Counties.

Objectives

- By December 2015, update the 2016 Komen Greater NYC RFA to reflect the funding priority of Black/African-American, Hispanic/Latina and other vulnerable women in these counties.
- In 2016, identify and meet with at least two new community-based organizations that target Black/African-American, Hispanic/Latina or other vulnerable women in these counties.
- By January 2016, develop partnerships with ten community-based organizations in Bronx, Kings, Richmond, Rockland and Suffolk Counties that serve Black/African-American and Hispanic/Latina women in an effort to increase the number of grant
applications for Screening Coordination and Support & Treatment.

- By February 2017, reach out to current and potential partners to discuss the need to fund more patient navigation programs that ensure early screening, detection and treatment for Black/African-American and Hispanic/Latina women in Bronx, Kings, Richmond Rockland, Westchester and Suffolk Counties.

2. Programs need to be culturally competent and sensitive in providing bilingual and bicultural personnel and materials for Hispanic/Latina women.

**Priority** - Increase access to culturally competent breast health programs among undocumented immigrants, immigrants of African descent, and Hispanics/Latinas in Bronx, Kings, Richmond, Rockland, Westchester and Suffolk Counties.

**Objectives**
- By December 2015, update the 2016 Komen Greater NYC RFA to reflect the funding priority of culturally competent programs that provide bilingual/ bicultural personnel and materials for Bronx, Kings, Richmond, Rockland, Westchester and Suffolk Counties.
- By July 2016, convene a meeting or webinar of current and past Komen-funded patient navigation programs and other interested stakeholders to discuss best practices in outreach to diverse communities and cultural competency.
- By February 2016, make staff of current and past Komen Greater NYC-funded programs aware that Komen materials are available in: Spanish, Arabic, Korean and Russian.

3. Health care providers need to be educated on the availability of free and/or low-cost breast care resources in their area to promote facility and provider collaboration.

**Priority** - Increase provider education regarding the availability of free and low-cost breast services, and encourage and facilitate provider and facility collaboration to providers that serve Black/African-American and Hispanic/Latina patients.

**Objectives**
- By December 2015, update the 2016 Komen Greater NYC RFA to reflect the increased need for provider education about local breast care services such as CSP, Emergency Medicaid, the New York State of Health and the Medicaid Cancer Treatment Program for providers that serve Black/African-American and Hispanic/Latina women the Bronx, Kings, Richmond, Westchester, Rockland and Suffolk Counties.
- By July 2016, convene a meeting or webinar of current and past Komen Greater NYC-funded patient navigation programs and other interested stakeholders to discuss provider outreach, education, and collaboration best practices.

4. Vulnerable populations such as undocumented immigrants, immigrants of African descent, and Hispanics/Latinas have limited access to support and patient navigation programs.
Priority—Support advocacy around comprehensive insurance and reducing out of pocket costs for women in the Affiliate’s service area. Support advocacy and initiatives to explore how better use the Medicaid Redesign Team-designated Delivery System Reform Incentive Payment (DSRIP). Support advocacy for funding to support multi-modality care in Health Facility Shortage Areas particularly in Suffolk, Rockland and Westchester Counties to address limitations in care in those areas.

Objectives

- By 2016 and beyond, continue to advocate for continued funding of the Cancer Services Program by educating local legislators through grassroots lobbying.
- By July 2016, convene a meeting of Komen partners to discuss development of mass media campaigns targeted to consumers providing education and concrete educational tools on how to choose insurance products in the NY State of Health exchange.
- By January 2016, lobby the members of the New York State Cancer Consortium to adopt this issue as an area of focus as the new Comprehensive Cancer Control Plan is developed.
- By July 2016, convene a workgroup that will work on ensuring administrative action by New York State on recommendations of the Medicaid Redesign Committee regarding streamlining of Emergency Medicaid.
- By January 2016, convene a workgroup of the NY State Cancer Consortium or Cancer Education and Advisory Council to study health facility shortage areas in the five regions and map community assets with high degrees of clinical quality (those facilities with accreditations from the American College of Surgeons Commission on Cancer, American College of Radiology Breast Imaging Center of Excellence and National Cancer Institute designated Cancer Center).
- By January 2016, identify and support programs that enhance provider collaboration in these shortage areas and help connect women to available and high quality resources.
- By April 2016, identify demonstration programs and initiatives that facilitate referral between primary care physicians, radiologists, surgeons and oncologists in these health facility shortage areas by collaborating with Komen GNYC partners and stakeholders.
- By April 2016, support advocacy for funding to support multi-modality care in these shortage areas by collaborating with the Cancer Education and Early Detection Advisory Council.

Disclaimer: Comprehensive data for the Executive Summary can be found in the 2015 Susan G. Komen® Greater New York City Community Profile Report.
Affiliate History

Susan G. Komen® Greater New York City was founded in 1990. The Affiliate has consistently been ranked number one in the Komen network for fundraising and grants awarded for most of the last seven years. It is one of the largest of the 120 Affiliates in the Susan G. Komen network and to date the Affiliate has raised over $65 million through donations, corporate support and fundraisers including the Komen Greater New York City Race for the Cure®.

The Affiliate has co-sponsored and hosted multiple events over the last several years. In August, 2013, the Affiliate and the New York headquarters of Pfizer co-sponsored an event that highlighted the work that the Affiliate does to raise awareness and funds and stressed the importance of Pfizer partnering with advocacy organizations like Komen and the potential impact it can have for patients. In October 2014, the Affiliate and Pfizer hosted a breakfast reception for breast cancer survivors. The event included a moderated panel discussion featuring key advocacy leaders from the service area and addressed the importance of elevating the dialogue around breast cancer and metastatic disease. The Affiliate has supported the annual “Breast Cancer in Women of Color” event organized by a breast surgeon who worked at New York Presbyterian and is now at New York University/Langone Medical Center. The Affiliate has provided financial support and has served on the planning committee for the event. Each year the Affiliate participates in multiple events around the service area during Breast Cancer Awareness Month. The events include baseball games, bowling matches, ping pong tournaments, spinning classes and fashion shows. The Affiliate’s involvement in these events ranges from speaking opportunities for Affiliate staff to providing educational materials. Additionally, the Affiliate has hosted educational programs for the general public that range from focus on the importance of screening to clinical trials participation for underrepresented groups.

The Affiliate provides funding to between 25-30 organizations each year. There are three granting programs – Community Breast Health, Clinical Research Enrollment and Small Grants. The Community Breast Health grants are awarded annually. The Clinical Research Enrollment grants are two-year grants and are focused on funding activities that increase enrollment of underrepresented individuals in breast cancer clinical research. The Small Grants are available three times a year and fund capacity-building or pilot projects. Approximately 80.0 percent of grant funding is focused on innovative programs that provide patient navigation/case management for screening and treatment and support programs that provide crucial support services including transportation, financial assistance, meals for patients and their families, legal assistance and programs that eliminate barriers to clinical trials. Twenty percent of the Affiliate’s programs fund education and outreach programs that directly link women to screening.

In FY 2014-2015, the Affiliate funded nearly $2.1 million in grants to 26 local breast health screening, treatment, education, and support programs in the five boroughs of New York City, all of Long Island, and Westchester and Rockland Counties. As a result of the Affiliate’s funding, the success of patient navigation programs has led to increased institutional funding for patient navigation staff at several local hospitals. For example, the Komen-funded program at a hospital in Queens decreased the number of no-shows for the mammography screening.
department so dramatically that the hospital’s leadership provided additional funding to the program when the Affiliate had to lower the cap for the Community Breast Health grants. As a result of the Affiliate’s technical assistance, one of the Westchester-based grantees that was having trouble meeting their deliverables, experienced a complete turnaround and is now exceeding their projected numbers.

The Affiliate has participated in a number of community and state-wide initiatives that highlight its breast health leadership role in the service area. The Affiliate has been a member of the state’s comprehensive cancer control coalition, the New York State Cancer Consortium, since 2010. The Affiliate’s mission staff person is one of the co-chairs of the Steering Committee (SC) for the Consortium. The role of the co-chairs is to provide guidance and direction to the SC and the associated committees. In addition to serving on the Steering Committee, the Komen Greater NYC mission staff person is on the Communication, Membership, Nominations and Clinical Trials committees.

The Affiliate is a member of the New York State Cancer Education and Detection Advisory Council, a legislatively mandated (through NYS Public Health Law 2904-a) body of health care professionals from across the state. The role of the council is to advise the commissioner regarding provision of information to consumers, patients, and health care providers relating, but not limited to, breast, cervical, prostate, testicular and ovarian cancer, including signs and symptoms, risk factors, the benefits of prevention and early detection, guideline concordant cancer screening and disease management, options for diagnostic testing and treatment, new technologies, and survivorship. The council has, as part of its mission, oversight over the Cancer Services Program which is the National Breast and Cervical Cancer Early Detection Program for New York.

The Affiliate is also a member of the Breast Cancer Disparities Roundtable, a group headed by the New York City Department of Health and Mental Hygiene. The Roundtable is a coalition of health professionals from within the five counties of New York City and is charged with addressing issues that impact breast health and the Cancer Services Programs.

In May 2013, an Affiliate staff person appeared at a conference hosted by the Memorial Sloan-Kettering Cancer Center entitled “Expanding your research portfolio and building new research partnerships to advance translational science, community engagement, and health equity.” The staff person participated on a panel discussion of the importance of clinical research and health equity.

In May 2015, the New York State Department of Health is hosting a day-long Cancer Prevention Summit. The event will address general cancer prevention and risk reduction. The Affiliate serves as a member of the planning committee, which comprises health care professionals from around the state.
**Affiliate Organizational Structure**

The Affiliate is currently working with a full-time staff of ten. Volunteers are used as needed, usually for support with the Affiliate’s events. Additionally, each department employs undergraduate and graduate level interns from the universities around the service area.

Susan G. Komen Greater NYC is incorporated as a nonprofit organization with its own board of directors and a full-time staff of 10 based in New York City and led by Chief Executive Officer Linda McNeil Tantawi (Figure 1.1). It has a collaborative and contractual relationship with the national Susan G. Komen organization that enhances the Affiliate’s fundraising, program activities and local influence. The Affiliate’s Board of Directors is a governing board and currently consists of 13 members and oversees multiple important committees including the Grants Policy and Education, Governance, Medical Advisory and Young Professionals Committees. The Grants Policy and Education Committee, provides oversight to the Grants and Public Policy program. It includes experts in breast cancer detection, treatment, and research.

![Komen Greater NYC Organizational Chart](image)

**Figure 1.1. Susan G. Komen Greater New York City Organizational Structure**

**Affiliate Service Area**

The service area includes some of the most populous counties in the country and, at the same time, the more rural county of Suffolk in Long Island (Figure 1.2). Eight of the nine counties in the Komen Greater NYC region are ranked in the top ten as the most populous in the state (US Census 2012). Approximately 64.0 percent of New York State’s population resides in the nine counties of the Komen Greater NYC service area. There is tremendous diversity in household income across the Komen Greater NYC service area. While Manhattan, Westchester, Nassau,
Suffolk and Rockland counties report higher household incomes, nearly 30.0 percent of households in the service area were making under $25,000 annually (US Census, 2000; 2009 estimates). There are large numbers of individuals who live below the poverty levels in the five boroughs/counties of New York City. The gap between the “haves and have nots” has widened considerably in the region (Table 1.1) The numbers of people comprising the middle class have slowly diminished and those who are left continue to struggle financially (US Census 2000, American Community Survey, 2009-2013). The economic recession in the US has particularly affected the medically underserved in the Komen Greater NYC region leaving many who were already one paycheck away from disaster in grave circumstances. The unemployment rate in this population remains high due to loss of jobs for unskilled workers. There is an estimated 775,000 undocumented individuals in the service area.

<table>
<thead>
<tr>
<th>Table 1.1. Affiliate Service Area Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than HS Education</td>
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<tr>
<td>------------------------</td>
</tr>
<tr>
<td>US</td>
</tr>
<tr>
<td>New York</td>
</tr>
<tr>
<td>Komen Greater New York City Service Area</td>
</tr>
<tr>
<td>Bronx County - NY</td>
</tr>
<tr>
<td>Kings County - NY</td>
</tr>
<tr>
<td>Nassau County - NY</td>
</tr>
<tr>
<td>New York County - NY</td>
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<tr>
<td>Queens County - NY</td>
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<tr>
<td>Richmond County - NY</td>
</tr>
<tr>
<td>Rockland County - NY</td>
</tr>
<tr>
<td>Suffolk County - NY</td>
</tr>
<tr>
<td>Westchester County - NY</td>
</tr>
</tbody>
</table>

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 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.

The service area is a geographical mix ranging from urban to very rural. The availability and ease of traveling on public transportation varies widely in the service area. In Manhattan (New York County), it is fairly easy to use the subway and buses to travel to most locations in the county. The five counties that comprise New York City are considered urban by city planners; however parts of Queens and Richmond Counties are quite suburban in nature. Parts of those
counties are completely residential where travel to the nearest grocery store requires a car or a bus ride. Kings County is fairly easy to navigate by bus and subway but interestingly, there are few highways that run into the heart of the county. There are eight-lane streets that traverse the county that can become clogged with traffic during rush hour.

Travel to Richmond County requires a ride on the Staten Island Ferry or a car or bus over a bridge. Many communities in Richmond County feature steep hills that can make travel within the county in the winter months difficult. The county depends on a bus system that operates on a limited schedule and runs poorly in bad weather.

Nassau and Suffolk Counties comprise Long Island. Nassau County has both urban and suburban communities. Suffolk County has pockets of suburban neighborhoods, but the county, as a whole, is very rural. There are still working farms in the county. There are also vineyards on what is known as the North and South Forks of Suffolk County. The South Fork and North Fork split at Riverhead where the Peconic River empties into the Peconic Bay. It has long been noted that Long Island resembles a fish with the forks forming a tail. Travel from one end of the North Fork to the South Fork without a car is problematic. The bus system requires that you travel to the beginning of each fork and back out again. There is ferry service that crosses the bay between the two forks. Public transportation on Long Island varies widely.

Nassau County has a dependable bus system that operates often until quite late at night. Travel around Suffolk County for those without cars is difficult because the bus system is limited both in availability and schedule. The Long Island Railroad is the commuter train that serves Nassau and Suffolk Counties and portions of Queens. It operates until late at night but service is more readily available in Queens and Nassau Counties vs. in Suffolk County.

Parts of Queens, Kings and Bronx Counties are easier to navigate than others. Though there are multiple subway lines that travel through these three counties, however, most of them go to the same locations. The bus system does link to the subway system but it means that for many residents, they have travel from their homes into a hub and then back out again on another bus.

Westchester and Rockland Counties (Lower Hudson Valley) are considerably smaller counties and are quite residential. Travel into and out of those counties is by train, bus or car. The commuter train, Metro North also serves parts of the Bronx. There is a dependable bus system that serves both counties but service is limited during the evening hours in Rockland County.

The nine counties in the service area are some of the most racially and ethnically diverse in the United States. While Whites and Hispanics/Latinos are the most common racial/ethnic groups across the nine counties, followed by Blacks/African-Americans, the numbers of Asians continues to grow rapidly. The heterogeneity of the Hispanic/Latino population has increased since 2011. Puerto Ricans, Dominicans, and Mexicans comprise 70.0 percent of Hispanics/Latinos with Ecuadorians, Colombians, and Central Americans considerably contributing to the mosaic of Spanish-speaking populations (CLACLS 2010). Hispanics/Latinos are now the majority population in the Bronx (55.0 percent), with populations of Dominicans and Mexicans in the Bronx continuing to rise (US Census, American Community Survey, 2009-
2013). There are also over one million Asian people in the service area, with much heterogeneity within this ethnicity (Cornell University 2013). Among Asians, China is the most common country of origin (Table 1.2).

<table>
<thead>
<tr>
<th>Table 1.2. Affiliate Service Area Demographics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Population</strong></td>
</tr>
<tr>
<td>----------------------</td>
</tr>
<tr>
<td>1,386,364</td>
</tr>
<tr>
<td><strong>White</strong></td>
</tr>
<tr>
<td><strong>Black or African-American</strong></td>
</tr>
<tr>
<td><strong>American Indian/Alaska Native</strong></td>
</tr>
<tr>
<td><strong>Asian</strong></td>
</tr>
<tr>
<td><strong>Asian Indian</strong></td>
</tr>
<tr>
<td><strong>Chinese</strong></td>
</tr>
<tr>
<td><strong>Filipino</strong></td>
</tr>
<tr>
<td><strong>Japanese</strong></td>
</tr>
<tr>
<td><strong>Korean</strong></td>
</tr>
<tr>
<td><strong>Vietnamese</strong></td>
</tr>
<tr>
<td><strong>Other Asian</strong></td>
</tr>
<tr>
<td><strong>Native Hawaiian/Other Pacific Islander</strong></td>
</tr>
<tr>
<td><strong>Some Other Race</strong></td>
</tr>
</tbody>
</table>

Table 2 US Census Bureau *Other Asians include individuals from Pakistan, Bangladesh and Nepal
Figure 1.2. Susan G. Komen Greater New York City Service Area
**Purpose of the Community Profile Report**

The purpose of the Community Profile Report is to ensure that the Affiliate’s strategic and operational plans are aligned. The Affiliate’s Grants, Education and Public Policy committee will use the report as a guide to establish grantmaking priorities and drive public policy efforts. The Affiliate will share the report with its public policy partners such as the American Cancer Society and the Leukemia and Lymphoma Society. The report will establish directions for educational needs and help the Affiliate ensure that educational programs are held in the target communities. The Affiliate will use the report as a guide to identify key sponsors of Affiliate events, particularly those prospective organizations located in the target communities, and strengthen relationships with existing sponsors.

The Director of Communications will create a one page document with key messages from the report that will be included in press kits that will be distributed to local media. The director will distribute a press release and contact local radio and television outlets in an effort to seek opportunities for Affiliate staff and Board members to appear to talk about the key messages from the report. Affiliate staff will seek additional partners with whom they can collaborate to focus on the issues affecting the communities identified in the report.

The report will be posted on the Affiliate’s website in the grantmaking section of the site. A prominent link to the page will be posted on the front page of the website highlighting the report. The Affiliate will share the report with those legislators who have supported the Affiliate over the last several years. Select legislators may be included in media spots along with Affiliate staff that arise once the press release is distributed. The Affiliate will share the community profile download link and the profile’s key points via social media, also videotaping short vignettes featuring Affiliate staff talking about the report and the importance of the information. Those videos will be posted on the Affiliate’s YouTube channel and promoted in social media. The Board chair will include the report as part of the packet of information given to new Board members. The availability of the report will be shared through e-blast messages that are sent to the Affiliate’s constituents. Additionally an announcement about the release of the report will be shared via e-blast messages to current and past grantees. Affiliate staff will also share the one page document at both Affiliate and partner sponsored events.
Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Quantitative Data Report

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

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

The following is a summary of Komen Greater New York City’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

<table>
<thead>
<tr>
<th>Population Group</th>
<th>Incidence Rates and Trends</th>
<th>Death Rates and Trends</th>
<th>Late-stage Rates and Trends</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female Population (Annual Average)</td>
<td># of New Cases (Annual Average)</td>
<td>Age-adjusted Rate/100,000</td>
</tr>
<tr>
<td>US</td>
<td>154,540,194</td>
<td>182,234</td>
<td>122.1</td>
</tr>
<tr>
<td>HP2020</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>New York</td>
<td>9,929,239</td>
<td>14,604</td>
<td>127.7</td>
</tr>
<tr>
<td>Komen Greater New York City Service Area</td>
<td>6,328,769</td>
<td>8,943</td>
<td>126.1</td>
</tr>
<tr>
<td>White</td>
<td>3,996,282</td>
<td>6,480</td>
<td>136.4</td>
</tr>
<tr>
<td>Black/African-American</td>
<td>1,575,347</td>
<td>1,749</td>
<td>108.0</td>
</tr>
<tr>
<td>American Indian/Alaska Native (AIAN)</td>
<td>75,001</td>
<td>4</td>
<td>6.8</td>
</tr>
<tr>
<td>Asian Pacific Islander (API)</td>
<td>682,139</td>
<td>571</td>
<td>83.1</td>
</tr>
<tr>
<td>Non-Hispanic/Latina</td>
<td>4,831,521</td>
<td>7,664</td>
<td>132.4</td>
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<tr>
<td>Hispanic/Latina</td>
<td>1,497,248</td>
<td>1,279</td>
<td>99.1</td>
</tr>
<tr>
<td>Bronx County - NY</td>
<td>725,871</td>
<td>777</td>
<td>107.4</td>
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<tr>
<td>Kings County - NY</td>
<td>1,305,362</td>
<td>1,501</td>
<td>110.0</td>
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<tr>
<td>Nassau County - NY</td>
<td>686,503</td>
<td>1,253</td>
<td>146.2</td>
</tr>
<tr>
<td>New York County - NY</td>
<td>839,136</td>
<td>1,261</td>
<td>137.0</td>
</tr>
<tr>
<td>Queens County - NY</td>
<td>1,135,835</td>
<td>1,478</td>
<td>114.1</td>
</tr>
<tr>
<td>Richmond County - NY</td>
<td>238,781</td>
<td>362</td>
<td>131.1</td>
</tr>
<tr>
<td>Rockland County - NY</td>
<td>155,930</td>
<td>239</td>
<td>134.1</td>
</tr>
<tr>
<td>Suffolk County - NY</td>
<td>753,581</td>
<td>1,235</td>
<td>139.8</td>
</tr>
<tr>
<td>Westchester County - NY</td>
<td>487,770</td>
<td>836</td>
<td>141.5</td>
</tr>
</tbody>
</table>

*Target as of the writing of this report.

NA – data not available.

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

Data are for years 2006-2010.

Rates are in cases or deaths per 100,000.

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


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

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


**Incidence rates and trends summary**

Overall, the breast cancer incidence rate in the Komen Greater New York City service area was slightly higher 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 New York.

For the United States, breast cancer incidence in Blacks/African-Americans is lower than in Whites overall. The most recent estimated breast cancer incidence rates for 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 lower among Blacks/African-Americans than Whites, lower among APIs than Whites, and lower among AIANs than Whites. The incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

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

- Nassau County
- New York County
- Suffolk County
- Westchester County

The incidence rate was significantly lower in the following counties:

- Bronx County
- Kings County
- Queens 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 Greater New York City service area was similar to that observed in the US as a whole and the death rate trend was not available for comparison with the US as a whole. The death rate of the Affiliate service area was not significantly different than that observed for the State of New York.

For the United States, breast cancer death rates in Blacks/African-Americans are substantially higher than in Whites overall. The most recent estimated breast cancer death rates for APIs and AIANs were lower than for Non-Hispanic 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
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 death rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

The death rate was significantly lower in the following county:

- Queens County

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

- Rockland 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 Greater New York City service area was slightly higher than that observed in the US as a whole and the late-stage incidence trend was lower than the US as a whole. The late-stage incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of New York.

For the United States, late-stage incidence rates in Blacks/African-Americans are higher than among Whites. Hispanics/Latinas tend to be diagnosed with late-stage breast cancers more often than Whites. For the Affiliate service area as a whole, the late-stage incidence rate was about the same among Blacks/African-Americans and 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:

- Suffolk County

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

- Queens 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.*

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

*As of October 2015

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

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

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

- The number of women living in an area that 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 that 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 35.1 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

<table>
<thead>
<tr>
<th>Population Group</th>
<th># of Women Interviewed (Sample Size)</th>
<th># w/ Self-Reported Mammogram</th>
<th>Proportion Screened (Weighted Average)</th>
<th>Confidence Interval of Proportion Screened</th>
</tr>
</thead>
<tbody>
<tr>
<td>US</td>
<td>174,796</td>
<td>133,399</td>
<td>77.5%</td>
<td>77.2%-77.7%</td>
</tr>
<tr>
<td>New York</td>
<td>2,020</td>
<td>1,568</td>
<td>79.7%</td>
<td>77.4%-81.7%</td>
</tr>
<tr>
<td>Komen Greater New York City Service Area White</td>
<td>769</td>
<td>605</td>
<td>80.6%</td>
<td>77.2%-83.6%</td>
</tr>
<tr>
<td>Black/African-American SN</td>
<td>118</td>
<td>94</td>
<td>77.4%</td>
<td>67.8%-84.7%</td>
</tr>
<tr>
<td>AIAN</td>
<td>SN SN SN</td>
<td>SN SN SN</td>
<td>79.1%</td>
<td>75.1%-82.6%</td>
</tr>
<tr>
<td>API</td>
<td>17 14 14</td>
<td>93.8%</td>
<td>77.9%-98.5%</td>
<td></td>
</tr>
<tr>
<td>Hispanic/ Latina</td>
<td>82 72</td>
<td>89.9%</td>
<td>79.6%-95.3%</td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic/ Latina</td>
<td>683</td>
<td>529</td>
<td>79.0%</td>
<td>75.3%-82.3%</td>
</tr>
<tr>
<td>Bronx County - NY</td>
<td>56 46</td>
<td>72.7%</td>
<td>57.9%-83.8%</td>
<td></td>
</tr>
<tr>
<td>Kings County - NY</td>
<td>85 68</td>
<td>79.2%</td>
<td>68.1%-87.1%</td>
<td></td>
</tr>
<tr>
<td>Nassau County - NY</td>
<td>149 125</td>
<td>87.7%</td>
<td>80.3%-92.5%</td>
<td></td>
</tr>
<tr>
<td>New York County - NY</td>
<td>83 66</td>
<td>84.4%</td>
<td>74.1%-91.2%</td>
<td></td>
</tr>
<tr>
<td>Queens County - NY</td>
<td>94 69</td>
<td>80.3%</td>
<td>70.8%-87.3%</td>
<td></td>
</tr>
<tr>
<td>Richmond County - NY</td>
<td>25 22</td>
<td>92.3%</td>
<td>74.4%-98.0%</td>
<td></td>
</tr>
<tr>
<td>Rockland County - NY</td>
<td>25 18</td>
<td>67.3%</td>
<td>43.9%-84.5%</td>
<td></td>
</tr>
<tr>
<td>Suffolk County - NY</td>
<td>152 110</td>
<td>75.6%</td>
<td>65.7%-83.3%</td>
<td></td>
</tr>
<tr>
<td>Westchester County - NY</td>
<td>100 81</td>
<td>79.4%</td>
<td>67.0%-88.0%</td>
<td></td>
</tr>
</tbody>
</table>

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 Greater New York City service area was not significantly different than that observed in the US as a whole. The screening proportion of the Affiliate service area was not significantly different than the State of New York.

For the United States, breast cancer screening proportions among Blacks/African-Americans are similar to those among Whites overall. APIs have somewhat lower screening proportions than Whites and Blacks/African-Americans. Although data are limited, screening proportions among AIANs are similar to those among Whites. Screening proportions among Hispanics/Latinas are similar to those among Non-Hispanic 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 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 screening proportion among Hispanics/Latinas was not significantly different than among Non-Hispanics/Latinas.

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

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

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

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

- The race, ethnicity, and age data are based on the total female population in the area (e.g. The percent of females over the age of 40).
- The socioeconomic data are based on all the people in the area, not just women.
- Income, education and unemployment data don’t include children. They’re based on people age 15 and older for income and unemployment and age 25 and older for education.
- The data on the use of English, called “linguistic isolation”, are based on the total number of households in the area. The Census Bureau defines a linguistically isolated household as one in which all the adults have difficulty with English.
### Table 2.4. Population characteristics – demographics

<table>
<thead>
<tr>
<th>Population Group</th>
<th>White</th>
<th>Black /African-American</th>
<th>ALAN</th>
<th>API</th>
<th>Non-Hispanic /Latina</th>
<th>Hispanic /Latina</th>
<th>Female Age 40 Plus</th>
<th>Female Age 50 Plus</th>
<th>Female Age 65 Plus</th>
</tr>
</thead>
<tbody>
<tr>
<td>US</td>
<td>78.8%</td>
<td>14.1%</td>
<td>1.4%</td>
<td>5.8%</td>
<td>83.8%</td>
<td>16.2%</td>
<td>48.3%</td>
<td>34.5%</td>
<td>14.8%</td>
</tr>
<tr>
<td>New York</td>
<td>71.7%</td>
<td>19.0%</td>
<td>1.1%</td>
<td>8.3%</td>
<td>82.4%</td>
<td>17.6%</td>
<td>49.5%</td>
<td>35.4%</td>
<td>15.5%</td>
</tr>
<tr>
<td>Komen Greater New York City Service Area</td>
<td>62.5%</td>
<td>24.8%</td>
<td>1.3%</td>
<td>11.4%</td>
<td>75.5%</td>
<td>24.5%</td>
<td>48.2%</td>
<td>34.0%</td>
<td>14.9%</td>
</tr>
<tr>
<td>Bronx County - NY</td>
<td>45.9%</td>
<td>46.2%</td>
<td>3.3%</td>
<td>4.6%</td>
<td>46.3%</td>
<td>53.7%</td>
<td>43.5%</td>
<td>29.5%</td>
<td>12.6%</td>
</tr>
<tr>
<td>Kings County - NY</td>
<td>48.5%</td>
<td>39.2%</td>
<td>1.2%</td>
<td>11.1%</td>
<td>80.7%</td>
<td>19.3%</td>
<td>44.2%</td>
<td>31.1%</td>
<td>13.2%</td>
</tr>
<tr>
<td>Nassau County - NY</td>
<td>77.9%</td>
<td>13.0%</td>
<td>0.5%</td>
<td>8.5%</td>
<td>85.6%</td>
<td>14.4%</td>
<td>54.2%</td>
<td>38.9%</td>
<td>17.4%</td>
</tr>
<tr>
<td>New York County - NY</td>
<td>65.7%</td>
<td>20.0%</td>
<td>1.4%</td>
<td>12.9%</td>
<td>74.5%</td>
<td>25.5%</td>
<td>45.8%</td>
<td>33.2%</td>
<td>15.4%</td>
</tr>
<tr>
<td>Queens County - NY</td>
<td>50.4%</td>
<td>23.0%</td>
<td>1.5%</td>
<td>25.2%</td>
<td>73.2%</td>
<td>26.8%</td>
<td>48.6%</td>
<td>34.3%</td>
<td>14.9%</td>
</tr>
<tr>
<td>Richmond County - NY</td>
<td>78.5%</td>
<td>12.6%</td>
<td>0.7%</td>
<td>8.2%</td>
<td>82.8%</td>
<td>17.2%</td>
<td>50.4%</td>
<td>35.6%</td>
<td>14.7%</td>
</tr>
<tr>
<td>Rockland County - NY</td>
<td>78.5%</td>
<td>13.8%</td>
<td>0.6%</td>
<td>7.1%</td>
<td>84.7%</td>
<td>15.3%</td>
<td>48.7%</td>
<td>34.9%</td>
<td>15.5%</td>
</tr>
<tr>
<td>Suffolk County - NY</td>
<td>86.6%</td>
<td>8.8%</td>
<td>0.6%</td>
<td>4.0%</td>
<td>83.7%</td>
<td>16.3%</td>
<td>52.3%</td>
<td>36.2%</td>
<td>15.6%</td>
</tr>
<tr>
<td>Westchester County - NY</td>
<td>75.5%</td>
<td>17.2%</td>
<td>0.9%</td>
<td>6.4%</td>
<td>78.7%</td>
<td>21.3%</td>
<td>52.6%</td>
<td>37.3%</td>
<td>16.8%</td>
</tr>
</tbody>
</table>

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.

<table>
<thead>
<tr>
<th>Population Group</th>
<th>Less than HS Education</th>
<th>Income Below 100% Poverty</th>
<th>Income Below 250% Poverty (Age: 40-64)</th>
<th>Unemployed</th>
<th>Foreign Born</th>
<th>Linguistically Isolated</th>
<th>In Rural Areas</th>
<th>In Medically Underserved Areas</th>
<th>No Health Insurance (Age: 40-64)</th>
</tr>
</thead>
<tbody>
<tr>
<td>US</td>
<td>14.6%</td>
<td>14.3%</td>
<td>33.3%</td>
<td>8.7%</td>
<td>12.8%</td>
<td>4.7%</td>
<td>19.3%</td>
<td>23.3%</td>
<td>16.6%</td>
</tr>
<tr>
<td>New York</td>
<td>15.4%</td>
<td>14.5%</td>
<td>32.3%</td>
<td>8.2%</td>
<td>21.8%</td>
<td>8.3%</td>
<td>12.1%</td>
<td>20.3%</td>
<td>12.1%</td>
</tr>
<tr>
<td>Komen Greater New York City Service Area</td>
<td>17.5%</td>
<td>15.1%</td>
<td>33.7%</td>
<td>8.6%</td>
<td>31.0%</td>
<td>12.3%</td>
<td>0.6%</td>
<td>25.6%</td>
<td>13.3%</td>
</tr>
<tr>
<td>Bronx County - NY</td>
<td>30.8%</td>
<td>28.5%</td>
<td>56.1%</td>
<td>13.0%</td>
<td>33.0%</td>
<td>18.1%</td>
<td>0.0%</td>
<td>61.0%</td>
<td>15.6%</td>
</tr>
<tr>
<td>Kings County - NY</td>
<td>22.0%</td>
<td>22.1%</td>
<td>47.2%</td>
<td>9.5%</td>
<td>37.3%</td>
<td>17.4%</td>
<td>0.0%</td>
<td>46.0%</td>
<td>15.4%</td>
</tr>
<tr>
<td>Nassau County - NY</td>
<td>10.1%</td>
<td>5.2%</td>
<td>15.9%</td>
<td>6.4%</td>
<td>20.9%</td>
<td>5.2%</td>
<td>0.2%</td>
<td>0.0%</td>
<td>9.0%</td>
</tr>
<tr>
<td>New York County - NY</td>
<td>15.0%</td>
<td>17.6%</td>
<td>35.1%</td>
<td>8.4%</td>
<td>28.6%</td>
<td>10.2%</td>
<td>0.0%</td>
<td>45.5%</td>
<td>10.9%</td>
</tr>
<tr>
<td>Queens County - NY</td>
<td>19.9%</td>
<td>13.7%</td>
<td>39.0%</td>
<td>9.0%</td>
<td>47.8%</td>
<td>18.4%</td>
<td>0.0%</td>
<td>9.9%</td>
<td>19.4%</td>
</tr>
<tr>
<td>Richmond County - NY</td>
<td>12.6%</td>
<td>11.0%</td>
<td>25.5%</td>
<td>6.8%</td>
<td>20.9%</td>
<td>6.2%</td>
<td>0.0%</td>
<td>4.0%</td>
<td>8.8%</td>
</tr>
<tr>
<td>Rockland County - NY</td>
<td>12.1%</td>
<td>11.6%</td>
<td>21.5%</td>
<td>6.5%</td>
<td>22.0%</td>
<td>7.8%</td>
<td>0.7%</td>
<td>2.4%</td>
<td>10.3%</td>
</tr>
<tr>
<td>Suffolk County - NY</td>
<td>10.5%</td>
<td>5.7%</td>
<td>18.8%</td>
<td>6.4%</td>
<td>14.2%</td>
<td>4.2%</td>
<td>2.6%</td>
<td>0.4%</td>
<td>10.1%</td>
</tr>
<tr>
<td>Westchester County - NY</td>
<td>12.7%</td>
<td>8.9%</td>
<td>18.9%</td>
<td>7.2%</td>
<td>24.6%</td>
<td>7.3%</td>
<td>3.3%</td>
<td>18.2%</td>
<td>10.2%</td>
</tr>
</tbody>
</table>

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

The following counties have substantially larger Black/African-American female population percentages than that of the Affiliate service area as a whole:
- Bronx County
- Kings County

The following county has substantially larger API female population percentages than that of the Affiliate service area as a whole:
- Queens County

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

The following county has substantially lower education levels than that of the Affiliate service area as a whole:
- Bronx County

The following counties have substantially lower income levels than that of the Affiliate service area as a whole:
- Bronx County
- Kings County

The following county has substantially lower employment levels than that of the Affiliate service area as a whole:
- Bronx County

The counties with substantial foreign born and linguistically isolated populations are:
- Kings County
- Queens County
The following county has substantially larger percentage of adults without health insurance than does the Affiliate service area as a whole:

- Queens County

**Priority Areas**

**Healthy People 2020 forecasts**

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

HP2020 has several cancer-related objectives, including:

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

To see how well counties in the Komen Greater New York City 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**

<table>
<thead>
<tr>
<th>Time to Achieve Late-stage Incidence Reduction Target</th>
<th>Time to Achieve Death Rate Reduction Target</th>
</tr>
</thead>
<tbody>
<tr>
<td>13 years or longer</td>
<td>13 years or longer</td>
</tr>
<tr>
<td>Highest</td>
<td>Highest</td>
</tr>
<tr>
<td>High</td>
<td>Medium High</td>
</tr>
<tr>
<td>Medium High</td>
<td>Medium Low</td>
</tr>
<tr>
<td>Medium Low</td>
<td>Low</td>
</tr>
<tr>
<td>Low</td>
<td>Lowest</td>
</tr>
<tr>
<td>Highest</td>
<td>Unknown</td>
</tr>
</tbody>
</table>

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 Greater New York City service area with predicted time to achieve the HP2020 breast cancer targets and key population characteristics

<table>
<thead>
<tr>
<th>County</th>
<th>Priority</th>
<th>Predicted Time to Achieve Death Rate Target</th>
<th>Predicted Time to Achieve Late-stage Incidence Target</th>
<th>Key Population Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bronx County - NY</td>
<td>Medium High</td>
<td>5 years</td>
<td>13 years or longer</td>
<td>%Black/African-American, %Hispanic/Latina, education, poverty, employment, language, medically underserved</td>
</tr>
<tr>
<td>Kings County - NY</td>
<td>Medium</td>
<td>5 years</td>
<td>10 years</td>
<td>%Black/African-American, poverty, foreign, language, medically underserved</td>
</tr>
<tr>
<td>Richmond County - NY</td>
<td>Medium</td>
<td>7 years</td>
<td>4 years</td>
<td></td>
</tr>
<tr>
<td>Rockland County - NY</td>
<td>Medium</td>
<td>Currently meets target</td>
<td>13 years or longer</td>
<td></td>
</tr>
<tr>
<td>Suffolk County - NY</td>
<td>Medium</td>
<td>5 years</td>
<td>12 years</td>
<td></td>
</tr>
<tr>
<td>Nassau County - NY</td>
<td>Medium Low</td>
<td>2 years</td>
<td>6 years</td>
<td>Medically underserved</td>
</tr>
<tr>
<td>New York County - NY</td>
<td>Medium Low</td>
<td>3 years</td>
<td>3 years</td>
<td></td>
</tr>
<tr>
<td>Westchester County - NY</td>
<td>Medium Low</td>
<td>2 years</td>
<td>3 years</td>
<td></td>
</tr>
<tr>
<td>Queens County - NY</td>
<td>Low</td>
<td>Currently meets target</td>
<td>3 years</td>
<td>%API, foreign, language, insurance</td>
</tr>
</tbody>
</table>

NA – data not available.
SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period).
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.

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

Medium high priority areas
One county in the Komen Greater New York City service area is in the medium high priority category. Bronx County is not likely to meet the late-stage incidence rate HP2020 target.

Bronx County has a relatively large Black/African-American population, a relatively large Hispanic/Latina population, low education levels, high poverty rates, high unemployment and a relatively large number of households with little English.

Medium priority areas
Four counties in the Komen Greater New York City service area are in the medium priority category. One of the four, Rockland County is not likely to meet the late-stage incidence rate HP2020 target. One of the four, Richmond County is expected to take seven years to reach the death rate HP2020 target. Two of the four, Kings County and Suffolk County, are expected to take from 10 to 12 years to reach the late-stage incidence rate HP2020 target.

The incidence rates in Suffolk County (139.8 per 100,000) are significantly higher than the Affiliate service area as a whole (126.1 per 100,000). The late-stage incidence rates in Suffolk County (50.3 per 100,000) are significantly higher than the Affiliate service area as a whole (45.2 per 100,000).

Kings County has a relatively large Black/African-American population, high poverty rates, a relatively large foreign-born population and a relatively large number of households with little English.

Additional Quantitative Data Exploration

The purpose of the quantitative data report is to combine data from credible sources and to use said data to identify the highest priority areas for evidence-based breast cancer programs.
Susan G Komen Greater New York City consists of nine counties. Of these three counties are contiguous to the US mainland—these are two counties of the lower Hudson Valley: Rockland county and Westchester county. The Bronx is the only mainland county of New York City. The four other New York City counties/boroughs are New York/Manhattan, Brooklyn/Kings, Queens, and Staten Island/Richmond. Finally, Suffolk county and Nassau county are two counties of the Greater Service area that are located on the most eastern portion of Long Island. Because the Susan G Komen Greater New York City includes some of the most populous, diverse, and well-studied counties in the country, the Affiliate requested and received additional in depth and up to date data from relevant sources on the nine Greater NYC counties served.

**Methods:** Where possible the Affiliate used the same data sources as contained in the QDR. Table 2.8 compares the sources for this data exploration to the QDR. The Affiliate obtained additional quantitative data from other agencies as described below.

*New York State Cancer Registry (NYSCR)* - Through the New York State Cancer Registry, the NY State Department of Health collects, processes, and reports information about all New Yorkers diagnosed with cancer. The New York State Cancer Registry participates in the North American Association of Central Cancer Registries (NAACCR) and uses SEER and NAACCR coding.

*New York City Bureau of Vital Statistics (NYC Vital Statistics)* - The Bureau of Vital Records collects all birth and death events that occurred in New York City, basing underlying cause of death on National Center for Health Statistics definitions.

*New York City Community Health Survey (NYC CHS)* - The New York City Community Health Survey (CHS) is a telephone survey annually conducted by the Department of Health and Mental Hygiene (DOHMH). Like the Behavioral Risk Factor Surveillance Systems (BRFSS), the CHS collects information from nearly 125 questions providing robust data on the general health of New Yorkers. The survey is used to generate neighborhood, borough, and citywide estimates on a range of chronic diseases and behavioral risk factors including mammography screening.
Table 2.8. Comparison Between Quantitative Data Report and Additional Quantitative Data Exploration Sources

<table>
<thead>
<tr>
<th>Table Entry</th>
<th>QDR Data Sources</th>
<th>Additional Data Exploration Data Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incidence</td>
<td>NAACCR 2006-2010</td>
<td>NYS Cancer Registry 2007-2011</td>
</tr>
<tr>
<td></td>
<td></td>
<td>NYC Vital Statistics 2008-2012</td>
</tr>
<tr>
<td>Late-stage Diagnosis</td>
<td>NAACCR 2006-2010</td>
<td>NYS Cancer Registry 2007-2011</td>
</tr>
<tr>
<td>Screening Mammography</td>
<td>BRFSS 2012</td>
<td>NYC Community Health Survey 2012</td>
</tr>
<tr>
<td>Socioeconomic Measures</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Results:

Incidence

This section will review breast cancer incidence rates for the service area by geographic area, race/ethnicity and age group.

The breast cancer incidence rate for 2007-2011, the last period for which data were available, in the Komen Greater New York City service area overall was 127.5 per 100,000, higher than the national rate of 124.6 per 100,000 but lower than the state rate of 128.6 per 100,000.

Incidence rates varied by geographic area or county (see Fig 2.2 Breast Cancer Incidence in the Service Area by county 2007-2011). Five counties in the service area had higher incidence rates than the state: Nassau (147.5/100,000), Suffolk (142.5/100,000), Westchester (140.2/100,000) Manhattan (137.9/100,000), Rockland (135/100,000) and Richmond (132/100,000). Three counties had lower incidence rates: Bronx (108.7/100,000), Kings (113/100,000) and Queens (114.5/100,000).
Figure 2.2. Breast Cancer Incidence in the Service Area 2007-2011 by County

This same general pattern is repeated in data from 2011 only and is shown in Fig 2.3 Breast Cancer Incidence in the Service Area by County, below.

Figure 2.3. Breast Cancer Incidence in the Service Area in 2011 only by County
Incidence rates in 2011 also varied by race/ethnicity. Whites had the highest incidence rate, 148.4/100,000, followed by Blacks/African-Americans (123.4/100,000); Hispanics/Latinos (95.5/100,000) and Asians/Pacific Islanders (94.6/100,000) (see Fig 2.4 Breast Cancer Incidence in the Service Area by Race/Ethnicity in 2011). Between 2007 and 2011, rates remained largely stable for Whites and Hispanics/Latinos (see Fig 2.5 Breast Cancer Incidence 2007-2011 by Race/Ethnicity). For Blacks/African-Americans rates increased slightly from 115.5/100,000 in 2007 to 123.3 in 2011. Rates also rose among Asians/Pacific Islanders, from 85.4/100,000 in 2007 to 94.6/100,000 in 2011 (NYSCR).

Figure 2.4. Breast Cancer Incidence in the Service Area in 2011 by Race/Ethnicity

![Breast Cancer Incidence by Race/Ethnicity, 2011](chart)

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Incidence Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Races</td>
<td>128.9</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>148.4</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>123.4</td>
</tr>
<tr>
<td>Non-Hispanic API</td>
<td>94.6</td>
</tr>
<tr>
<td>Hispanic</td>
<td>95.5</td>
</tr>
</tbody>
</table>

Figure 2.5. Breast Cancer Incidence 2007-2011 by Race/Ethnicity

![Breast Cancer Incidence by Race/Ethnicity 2007-2011](chart)

As they do in most populations, cancer incidence rates in the service area for 2011 increased with age. The cancer incidence overall was 128.9 but the rate for women younger than 50 years was 49.7 per 100,000; for women 50 years and older it was 336 per 100,000. Between
2007 and 2011 rates have remained stable see Fig 2.6 Breast Cancer Incidence 2007-2011 by Age below (NYSCR).

![Breast Cancer Incidence by Age, 2007-2011](image)

**Figure 2.6.** Breast Cancer Incidence 2007-2011 by Age

**Early Stage Diagnosis**

This section will review the percentage distribution of breast cancer cases in the service area by stage at diagnosis for each geographic area, race/ethnicity and age group.

In the period 2007-2011, 63.7 percent of breast cancers cases in the Komen Greater New York City service area were diagnosed at early or localized stage see Figure 2.7. Statewide 65.6 percent of cancers were diagnosed at localized stage in 2011 compared to 60.8 percent nationwide for the period 2004-2010 (NYSCR).

![Breast Cancer Stage at Diagnosis Distribution 2007-2011](image)

**Figure 2.7.** Breast Cancer Stage at Diagnosis Distribution 2007-2011

Over the period, there was a trend toward a slight increase in diagnosis at early stage from 62.2 percent in 2007 to 64.6 percent in 2011 as shown in Figure 2.8 (NYSCR).
Stage at diagnosis varied by county for the period 2007-2011; Westchester had the highest proportion of cases diagnosed at early stage (69.3 percent) see Figure 2.9, followed by Nassau (67.5 percent), Rockland and Manhattan (66.7 percent each), Richmond (65.4 percent), Suffolk (64.1 percent), Queens (61.8 percent), the Bronx (59.7 percent), and Brooklyn (57.9 percent) (NYSCR).
Early stage diagnosis varied by race/ethnicity as shown below in Figure 2.10; 55.7 percent of Blacks/African-Americans were diagnosed at an early stage, followed by Hispanics/Latinos (59.4 percent), Asians/Pacific Islanders (63.1 percent), and Whites (67.1 percent).

![Breast Cancer Stage Distribution by Race/ Ethnicity 2007-2011](image)

**Figure 2.10.** Breast Cancer Stage Distribution 2007-2011 by Race/Ethnicity

A similar trend was repeated between 2007 and 2011: Whites and Asians had the highest proportion of early stage cancers diagnosed followed by Hispanics/Latinas and Blacks/African-Americans (see Figure 2.11 below).

![Percent Diagnosed Local/Early Stage by Race/Ethnicity 2007-2011](image)

**Figure 2.11.** Percent Diagnosed Local/Early Stage 2007-2011 by Race/Ethnicity
Finally, more women 50 years and older were diagnosed with early stage disease (65.8 percent) than women under 50 years of age (57.1 percent). The trend of proportions of women diagnosed with early stage disease remained stable between 2007 and 2011 (not shown).

**Mammography Screening**

This section will review mammography screening in women 40 years old and over for the service area by geographic area, race/ethnicity and age group.

The proportion of women who reported having a screening mammography in the past two years was 78.4 percent in New York State and 74.0 percent in the US overall in 2012. Per the QDR, in the Komen Greater New York City service area the proportion of women who reported having mammographic screening was 80.6 percent. For the five New York City counties data were requested from the NYC Community Heath Survey for 2012. Using this data, 74.5 percent of women reported having had a mammogram in the past two years citywide. Mammography prevalence was variable between 2007 and 2012 in New York City (see Figure 2.12). Between 2007 and 2012 the net change was small (nearly half a percentage point from 73.9 percent prevalence in 2007 to 74.5 percent in 2012).

![Mammography Prevalence Trends](image)

**Figure 2.12.** Percentage Reporting Mammographic Screening 2007-2012

Mammography use varied by county. The QDR reports mammography use for the service area with the highest percentage of self-report in Nassau, Manhattan, Queens and Westchester County. A comparison of the two data sources (QDR and CHS) shows some differences in mammography use by county which probably reflects the different methodology and sampling of BRFSS versus CHS. From CHS (see Figure 2.13), the proportion of women who reported having had a mammogram was highest in Bronx (78.8 percent) followed by Brooklyn (76.9 percent), Staten Island (77.1 percent), Queens (72.7 percent) and Manhattan (69.5 percent).
Mammography use also varied by race/ethnicity. The highest proportion of women reporting a mammogram in the past two years were Black/African-American women (78.8 percent) followed by Hispanic/Latina (78.8 percent), White (70.4 percent) and Asian (68.5 percent) women (see Fig 2.14) (NYC CHS).

This trend has remained stable between 2007 and 2012 (see Fig 2.15). In the 2011 Community Profile, it was noted that White and Asian women had lower screening prevalence as compared to Black/African-American and Hispanic/Latina women. The persistence of this lower prevalence might indicate a need for increased interventions to combat low mammography use in these groups (NYC CHS).
Given the data on early stage diagnosis and death for Black/African-American and Hispanic/Latina women, the high rates of mammography screening via self-report seem counterintuitive. This may reflect processes after the screening mammogram takes place that constitute some sort of breakdown in care which promotes a delay in diagnosis. Or there could be a differential distribution of risk factors that increase the speed of tumor growth or that increase death from cancer. On the other hand, the high self-reported rates of mammography use among non-White women could reflect a reporting bias by women of color survey respondents. More optimistically, these elevated numbers might reflect the success of breast cancer prevention, education and outreach efforts of Komen, nonprofit organizations and health care providers.

Mammography use does not seem to have varied with nativity within New York City in 2012; 74.3 percent of US-born women and 74.8 percent of foreign-born women reported having a mammogram. Mammogram use varied with insurance status such that 77.6 percent of women with insurance reported having had a mammogram as compared to 51.1 percent in women without insurance.

**Death**

This section will review breast cancer death rates for the service area by geographic area, race/ethnicity and age group.

The overall breast cancer death rate in the Komen Greater New York City service area was 21.5 per 100,000 for 2007-2011, which was the last period for which data was available. This death rate was lower than the death for the state (21.7 per 100,000) and nation (22.6 per 100,000) for the period 2006-2010 (NYSCR).

Death rates varied by geographic area or county (see Fig 2.16 Breast Cancer Death 2007-2010 by county). Six counties in the service area had rates higher than the state death rate for the
period 2007-2011: Richmond (23.1/100,000), Rockland (23.1/100,000), Brooklyn (22.9/100,000), the Bronx (22.8/100,000), Westchester (21.3/100,000) and Nassau (20.9/100,000). Three counties had rates lower than the state; the county with the lowest rate was Queens (18.7/100,000), followed by Rockland (19.2/100,000) and Manhattan (21.5/100,000).

![Mortality by County 2007-2011](image)

**Figure 2.16.** Breast Cancer Death Rates in 2007-2011 by County.

As shown in Fig 2.17, the pattern of death rates in 2011 only had Brooklyn (23.8/100,000), Suffolk (22.4/100,000), Westchester (21.4/100,000) the Bronx (21.3/100,000) and Richmond (20.7/100,000) with the five highest rates followed by Manhattan (20.6/100,000), Rockland (20.5/100,000) Nassau (19/100,000) and Queens (17.8/100,000).
Death rates also varied by race/ethnicity (see Fig 2.18 Breast Cancer Death 2011 by Race/Ethnicity) in the service area. Blacks/African-Americans had the highest death rates at (29.2/100,000), followed by Whites (21/100,000) Hispanics/Latinos (15.6/100,000), and Asian/Pacific Islanders (9.7/100,000). Rates remained relatively stable between 2007 and 2011 (not shown).

Komen Greater New York City also requested data from New York City Vital Statistics Bureau for the period 2008-2012 and found a slightly different pattern than the service area. Citywide death was 20.5/100,000, quite close to the rate overall for the service area (see Fig 2.19). Death rates were nearly identical in the Bronx and Staten Island (22.4/100,000 each), Brooklyn.
(22.3/100,000), and Manhattan (22.0/100,000). Queens had the lowest death rate at 16/100,000.

### Figure 2.19. Death by NYC County 2008-2012

Death also varied by race/ethnicity in the city. Blacks/African-Americans had a death rate of 26.9/100,000, followed by Whites (23.7/100,000), Hispanics/Latinos (14.7/100,000) and Asians (7.9/100,000) as shown in Fig 2.20 below (NYC Vital Statistics).

### Figure 2.20. Death by Race/Ethnicity NYC 2008-2012

As it does in most other populations, breast cancer death rates also increased with age in the service area. In 2011, the death rate for women younger than 50 years was 4.5 per 100,000; for women 50 years and older it was 63.7 per 100,000. The death rates remained stable in these age groups between 2007 and 2011.
**Population Characteristics**

The Komen Greater New York City service area comprises nine counties with a total population in 2012 estimated to be 12,082,160 people (see Table 2.9 below). Of this population, approximately 6.3 million are women (see Table 2.10 below). The Komen Greater NYC service area includes some of the most populous counties in the country as well as the more rural county of Suffolk in Long Island. Seven of the nine counties in the Komen Greater NYC region are ranked in the top 10 most populous in the state. Brooklyn is the most populous county in the region, Manhattan is the most densely populated, while Queens is consistently rated the most diverse county in the country.

**Table 2.9. Population in the Komen Greater NYC Service Area by Race/Ethnicity**

<table>
<thead>
<tr>
<th>Source: 2012 Census Data Estimates</th>
<th>Bronx</th>
<th>Brooklyn</th>
<th>Manhattan</th>
<th>Nassau</th>
<th>Queens</th>
<th>Staten Island</th>
<th>Rockland</th>
<th>Suffolk</th>
<th>Westchester</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Population</td>
<td>1,386,364</td>
<td>2,465,467</td>
<td>1,596,735</td>
<td>1,338,712</td>
<td>2,235,008</td>
<td>460,730</td>
<td>311,687</td>
<td>1,493,350</td>
<td>949,113</td>
</tr>
<tr>
<td>White</td>
<td>312,055</td>
<td>(22.5%)</td>
<td>1,119,881</td>
<td>909,145</td>
<td>973,573</td>
<td>950,264</td>
<td>341,677</td>
<td>228,295</td>
<td>1,206,297</td>
</tr>
<tr>
<td>Black or African-American</td>
<td>481,739</td>
<td>(34.7%)</td>
<td>859,622</td>
<td>247,743</td>
<td>148,771</td>
<td>421,540</td>
<td>49,857</td>
<td>37,058</td>
<td>111,224</td>
</tr>
<tr>
<td>American Indian/Alaska Native</td>
<td>7,196</td>
<td>(0.5%)</td>
<td>8,247</td>
<td>5,012</td>
<td>2,310</td>
<td>9,475</td>
<td>1,695</td>
<td>911</td>
<td>5,366</td>
</tr>
<tr>
<td>Asian</td>
<td>49,489</td>
<td>(3.6%)</td>
<td>266,557</td>
<td>178,673</td>
<td>103,765</td>
<td>522,638</td>
<td>35,164</td>
<td>19,293</td>
<td>50,972</td>
</tr>
<tr>
<td>Asian Indian</td>
<td>13,741</td>
<td>(1%)</td>
<td>24,290</td>
<td>24,384</td>
<td>39,293</td>
<td>134,656</td>
<td>6,793</td>
<td>7,028</td>
<td>15,975</td>
</tr>
<tr>
<td>Chinese</td>
<td>8,189</td>
<td>(0.6%)</td>
<td>180,888</td>
<td>96,527</td>
<td>24,705</td>
<td>199,472</td>
<td>13,321</td>
<td>2,781</td>
<td>12,052</td>
</tr>
<tr>
<td>Filipino</td>
<td>5,614</td>
<td>(0.4%)</td>
<td>9,389</td>
<td>11,081</td>
<td>11,383</td>
<td>41,248</td>
<td>5,224</td>
<td>4,482</td>
<td>5,202</td>
</tr>
<tr>
<td>Japanese</td>
<td>564</td>
<td>(0.0%)</td>
<td>4,356</td>
<td>13,931</td>
<td>1,887</td>
<td>6,658</td>
<td>201</td>
<td>277</td>
<td>904</td>
</tr>
<tr>
<td>Korean</td>
<td>2,829</td>
<td>(0.2%)</td>
<td>7,940</td>
<td>18,860</td>
<td>12,385</td>
<td>63,219</td>
<td>3,207</td>
<td>2,199</td>
<td>5,627</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>3,560</td>
<td>(0.3%)</td>
<td>3,692</td>
<td>2,721</td>
<td>1,070</td>
<td>4,271</td>
<td>468</td>
<td>402</td>
<td>1,585</td>
</tr>
<tr>
<td>Other Asian</td>
<td>14,992</td>
<td>(1.1%)</td>
<td>36,002</td>
<td>11,189</td>
<td>13,076</td>
<td>73,114</td>
<td>5,950</td>
<td>2,124</td>
<td>9,647</td>
</tr>
<tr>
<td>Native Hawaiian/Other Pacific Islander</td>
<td>308</td>
<td>(0.0%)</td>
<td>1,372</td>
<td>804</td>
<td>81</td>
<td>1,356</td>
<td>213</td>
<td>130</td>
<td>495</td>
</tr>
<tr>
<td>Some Other Race</td>
<td>488,156</td>
<td>(35.2%)</td>
<td>225,107</td>
<td>192,325</td>
<td>81,435</td>
<td>260,286</td>
<td>28,006</td>
<td>18,159</td>
<td>82,965</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>497,620</td>
<td>(19.8%)</td>
<td>409,298</td>
<td>195,287</td>
<td>614,147</td>
<td>81,051</td>
<td>48,783</td>
<td>246,239</td>
<td>207,032</td>
</tr>
<tr>
<td>Mexican</td>
<td>93,124</td>
<td>(3.7%)</td>
<td>42,606</td>
<td>10,883</td>
<td>87,644</td>
<td>18,684</td>
<td>5,358</td>
<td>15,663</td>
<td>44,060</td>
</tr>
<tr>
<td>Puerto Rican</td>
<td>181,136</td>
<td>(7.2%)</td>
<td>113,269</td>
<td>30,865</td>
<td>116,277</td>
<td>37,517</td>
<td>12,650</td>
<td>58,549</td>
<td>41,836</td>
</tr>
<tr>
<td>Cuban</td>
<td>7,764</td>
<td>(0.3%)</td>
<td>10,461</td>
<td>6,506</td>
<td>12,408</td>
<td>1,831</td>
<td>1,191</td>
<td>4,310</td>
<td>5,287</td>
</tr>
<tr>
<td>Other Hispanic</td>
<td>215,596</td>
<td>(8.6%)</td>
<td>242,962</td>
<td>147,033</td>
<td>397,818</td>
<td>23,019</td>
<td>29,584</td>
<td>167,717</td>
<td>115,849</td>
</tr>
</tbody>
</table>

Susan G. Komen® Greater New York City
Table 2.10. Female Population of the Service Area by County

<table>
<thead>
<tr>
<th>County</th>
<th>Number of Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bronx</td>
<td>735,475</td>
</tr>
<tr>
<td>Kings</td>
<td>1,323,322</td>
</tr>
<tr>
<td>Nassau</td>
<td>691,554</td>
</tr>
<tr>
<td>New York</td>
<td>841,432</td>
</tr>
<tr>
<td>Queens</td>
<td>1,150,919</td>
</tr>
<tr>
<td>Rockland</td>
<td>158,808</td>
</tr>
<tr>
<td>Staten Island</td>
<td>241,441</td>
</tr>
<tr>
<td>Suffolk</td>
<td>758,682</td>
</tr>
<tr>
<td>Westchester</td>
<td>492,452</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>6,394,085</strong></td>
</tr>
</tbody>
</table>

*US 2010 Census Data

In the service area overall, Whites and Hispanics/Latinos are the largest racial/ethnic groups, followed by Blacks/African-Americans, but the Asian population continues to grow rapidly and shows the highest percentage increase since 2000. Some three million residents of the service area are foreign-born, and an estimated 775,000 are undocumented. In New York City alone, 41 percent of residents are foreign-born (US Census, American Community Survey, 2012 estimates). Of the NYC foreign-born population, 32.1 percent hail from Latin America, 27.5 percent from Asia, 19.4 percent from the non-Hispanic Caribbean, 15.9 percent from Europe and 4.2 percent from Africa (New New Yorkers, NYC Planning, 2013). The country of birth and relative contribution to the city’s foreign born population is shown in Table 2.11. Given this diversity throughout the Komen Greater New York City service area and linguistic isolation figures referenced in the QDR, culturally appropriate and linguistically appropriate services are required to adequately serve the needs of the population. This great need is underlined by the fact that NYC Planning estimates that there are 1.8 million New Yorkers who can’t communicate effectively with their health care providers in English.

Table 2.11. Foreign Born Population Rank and Percentage by Country of Birth, 2011

<table>
<thead>
<tr>
<th>Country</th>
<th>Rank Number</th>
<th>Percent Foreign Born Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dominican Republic</td>
<td>1</td>
<td>12.4</td>
</tr>
<tr>
<td>China</td>
<td>2</td>
<td>11.4</td>
</tr>
<tr>
<td>Mexico</td>
<td>3</td>
<td>6.1</td>
</tr>
<tr>
<td>Jamaica</td>
<td>4</td>
<td>5.5</td>
</tr>
<tr>
<td>Guyana</td>
<td>5</td>
<td>4.6</td>
</tr>
<tr>
<td>Ecuador</td>
<td>6</td>
<td>4.5</td>
</tr>
<tr>
<td>Haiti</td>
<td>7</td>
<td>3.17</td>
</tr>
<tr>
<td>Trinidad and Tobago</td>
<td>8</td>
<td>2.9</td>
</tr>
<tr>
<td>India</td>
<td>9</td>
<td>2.5</td>
</tr>
<tr>
<td>Russia</td>
<td>10</td>
<td>2.5</td>
</tr>
</tbody>
</table>

Source: Adapted from New Yorkers 2013, NYC Planning

The Hispanic/Latino population is increasingly heterogeneous; 90 percent of Hispanics/Latinos in the service area come from Puerto Rico, Dominican Republic, Mexico, Ecuador or Colombia (CLACS, 2008). Of these, the four Latin American countries (the Dominican Republic, Mexico,
Ecuador, and Colombia) were among the city’s top sources of immigrants: (New Yorkers, NYC Planning, 2013). In fact, most of the population of the Bronx (54.0 percent) is Hispanic/Latino, predominantly Puerto Ricans and Other Hispanic or Latino individuals, but a growing number of Mexicans as well. (US Census, American Community Survey, 2012 estimates).

The Black/African-American population of the service area is also more diverse than US Census categories fully capture. Nearly, one in four Black/African-American New York City residents is foreign born (Center for American Progress 2012). An even larger but hard to quantify proportion are first-generation Americans of Caribbean or African origin. Four Caribbean countries (Jamaica, Guyana, Haiti and Trinidad and Tobago) were among New York City’s top sources of immigrants: (New New Yorkers, NYC Planning, 2013). In Brooklyn, foreign-born individuals from the Caribbean comprise 30.0 percent of the borough’s foreign-born population, while Africans comprise 3.0 percent. In the Bronx, people from the Caribbean comprise 19.0 percent of the foreign-born population, while Africans comprise 10.0 percent. Finally, in Queens - 17.0 percent and 2.0 percent of foreign born are from the Caribbean and Africa respectively (New New Yorkers, NYC Planning, 2013).

In addition, more than a million Asians, also heterogeneous in national origin, live in the service area (Asian U for Equality 2011). Among Asians, the Chinese are the largest single subgroup. In parts of Queens and Brooklyn, the Asian American communities have grown since the 2009 Census estimates.

Household income varies tremendously across the service area. While Manhattan, Westchester, Nassau, Suffolk and Rockland counties reported higher household incomes, nearly 25.0 percent of households in the service area had incomes under $25,000 annually (US Census, 2010; 2012 estimates). Large numbers of individuals in the five boroughs/counties of New York City live below the poverty line.

**Limitations**

The quantitative data presented in this exploration are the latest available data. One key limitation is that the population of the service area is mobile, and that data may therefore change during the five-year planning period for this report. Further, although the Affiliate gathered the most complete data available, for some measures the sources had only limited data on some population subgroups. Lack of information on ethnic subgroups or counties with small populations of certain subgroups may make comparisons difficult. Differences in cancer data sources can also exacerbate the problem of comparing population subgroups across cancer variables.

However, the combination of the data from the QDR and this quantitative data exploration provide a rich and nuanced picture of the burden of breast cancer in the service area. As such the data help to identify the populations with the highest priority needs evidence-based breast cancer interventions.
**Selection of Target Communities**

**Justification**
The Affiliate selected the target communities based on the data on which population subgroups were most affected by breast cancer (priority populations) and which geographic areas were most affected with a high burden of disease (priority areas). This overlap between priority population and priority area pinpoints those target communities most in need of evidence-based cancer interventions.

**Conclusions from data**
According to both the QDR and this quantitative data exploration, across the Komen Greater New York City service area higher proportions of Black/African-American and Hispanic/Latina women than of women in other groups are diagnosed at late-stages and more Black/African-American women experience higher death rates. As a result the priority population(s) are:
- Black/African-American women
- Hispanic/Latina women

The QDR highlights the Bronx as a medium-high priority area, followed by Kings County, Richmond County, Rockland County and Suffolk County which were classified as medium priority. This data exploration echoes this pattern; the Bronx, Kings, Richmond and Rockland counties had the highest death rates in the service area. In addition this exploration also highlighted Suffolk County for its elevated death rates and high proportion of late-stage diagnosis. The exploration also highlighted Westchester County for its elevated breast cancer death. As a result the priority area(s) are:
- the Bronx/ Bronx County
- Brooklyn/ Kings County
- Staten Island/Richmond County
- Lower Hudson Valley: Rockland County and Westchester County
- Suffolk County

Based on the overlap of priority populations and priority areas the target communities are:
- Black/African-American and Hispanic/Latina women in
  - the Bronx/ Bronx County
  - Brooklyn/ Kings County
  - Staten Island/Richmond County
  - Lower Hudson Valley: Rockland County and Westchester County
  - Suffolk County

**Next Steps**
The goal of the Community Profile is to highlight the needs of women in the Komen Greater New York City service area. Toward this end, the Affiliate will perform an environmental scan to explore the health system as it currently exists. Particularly, to explore the health system infrastructure and its ability to serve the unique cultural, linguistic and social needs of Black/African-American and Hispanic/Latina women in the service area.
Some questions to explore:

- Why are the death and late-stage diagnosis rates so high if screening percentages are more than adequate?
- What are the specific barriers that prevent a patient from moving from screening to diagnosis, from diagnosis to treatment, and from starting to complete treatment? Are some of these barriers unique to women of certain demographic backgrounds (e.g., race/ethnicity, country of origin)?
- Whose responsibility is it to ensure that a patient completes the diagnostic or treatment plan? Primary care provider? Radiologist? Oncologist? Surgeon?
- What systems are used by hospitals and providers to prevent loss to follow up and failure to adhere to the diagnostic or treatment plan?
- Do the institutions that purport to serve women in the target communities provide the full range of diagnostic, treatment, and other services that breast cancer patients may need?
- Do those services meet generally accepted standards of quality?
- What barriers, if any, do patients in those communities face in accessing those services in a timely and culturally appropriate fashion?

We will use qualitative information and stakeholder interviews and focus groups to answer these questions and to describe the challenges faced by Black/African-American and Hispanic/Latina women in accessing screening and treatment for breast cancer.
Health Systems Analysis Data Sources

Mammography Centers
http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMOSA/mqsa.cfm

Hospitals
https://data.medicare.gov/Hospital-Compare/Hospital-General-Information/v287-28n3

Local Health Departments
http://www.naccho.org/about/lhd/

New York State Department of Health/Cancer Services Program
http://www.health.ny.gov/diseases/cancer/services/

Community Health Centers
http://findahealthcenter.hrsa.gov/Search_HCC.aspx

Free Clinics
http://www.nafcclinics.org/clinics/search

American College of Surgeons Commission on Cancer
http://datalinks.facs.org/cpm/CPMAccreditedFacility-Search.htm

American College of Radiology Centers of Excellence
http://www.acr.org/Quality-Safety/Accreditation/Accredited-Facility-Search

American College of Surgeons National Accreditation Program for Breast Centers (NAPBC)
http://napbc-breast.org/resources/find.html

National Cancer Institute Designated Cancer Centers
http://www.cancer.gov/researchandfunding/extramural/cancercenters/find-a-cancer-center

New York State Cancer Consortium
http://www.nyscancerconsortium.org/

NYS State of Health Enrollment Report
http://info.nystateofhealth.ny.gov/sites/default/files/NYSOH%202014%20Open%20Enrollment%20Report_0.pdf

The Komen Greater New York City (NYC) Affiliate assessed the data by reviewing what was in the Quantitative Data Report and then aligning it with the findings from the Health Systems Analysis data. It took approximately three weeks to complete the Health Systems Analysis Excel document. In addition to the resources listed, the Affiliate also looked at hospital and
clinic websites, GeMs data and reports from Komen Greater NYC grantees. The Affiliate looked at the population data and then evaluated whether there were any gaps in services in the areas of greatest need. The Affiliate also looked at recent magazine and newspaper articles regarding hospitals closings, service limitations, etc. The Affiliate also reviewed the mayor’s and governor’s websites for any relevant announcements about health care, the Affordable Care Act (ACA), etc. Conversations with key health care professionals familiar with the region (i.e., Grants, Policy and Education Committee members) also yielded useful information about the services identified in the analysis. The full analysis of the data took three weeks.

**Health Systems Overview**

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

![Breast Cancer Continuum of Care (CoC) Diagram]

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

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

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

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

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

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

**Summary of Health Systems Strengths and Weaknesses for each Target Community**

*Bronx County*

*Strengths* –

There are six hospitals, 67 community health centers and 26 mammography centers in the Bronx (Figure 3.2). Two of the six have multiple locations throughout the Bronx. The Cancer Services Program (NBCCEDP) for the Bronx is based at Lincoln Hospital Medical Center, one of the three Health and Hospitals Corporation (municipal) hospitals in the Bronx. Lincoln provides a host of treatment services – medical and radiation oncology. The Cancer Services Program includes 15 other providers who deliver screening and diagnostic services. Most of the hospitals, as well as at the community health centers were enrollment sites for the NY State of Health, New York’s health marketplace. The other hospitals (Jacobi, St. Barnabas, and Montefiore) are also part of the Cancer Services Program. The hospitals are fairly evenly distributed throughout the county but travel in the North Bronx can be difficult. While most of the southern sections of the Bronx are easily accessible by subway, the North Bronx is only
accessible by buses. In most cases, people traveling to hospitals in that part of the county have to take a subway and then transfer to a bus line. For example, Montefiore Hospital, one of the larger academic centers in the Bronx, can be reached by taking the subway and then switching to a bus, a trip that can take over an hour. Albert Einstein Medical Center, one of the regions’ National Cancer Institute-designated clinical cancer centers, is located on Montefiore’s campus. St. Barnabas has a mobile mammography van that travels to the economically depressed area surrounding the hospital.

According to the 2010 Census, over 50.0 percent of the population that reside in the Bronx is Hispanic. Many of the Hispanic/Latino residents have limited English and Spanish literacy. All of the medical facilities in the Bronx have bilingual staff to accommodate the language needs of the population.

Though the income level for many residents is below the poverty level, the Bronx is home to three municipal hospitals and a number of Federally Qualified Health Centers that will provide medical care regardless of insurance, income or citizenship status.

Weaknesses –
The Bronx is one of the poorest counties in the region with large numbers of undocumented women.

There are limited patient navigation programs in all of the hospitals. The quality of navigation also differs throughout the Bronx. In some facilities, the case manager is solely devoted to that role, and in others, it can be one of many duties. Support services are limited as well. Montefiore has a well-regarded peer support program but is located in the northern part of the Bronx and is not easily accessible by subway. There are limited support groups for Hispanics/Latinos and young women. SHARE, Self-Help for Women with Breast and Ovarian Cancer, one of the local information and support organizations operates a support group a few times a week in the Bronx.

There is a growing South Asian community in the Bronx however, because the community there is still quite small, there are few services available to them. The vast majority of South Asians in the affiliate service area is largely concentrated in Queens and has resided in that area for the last 20 years. In the last few years, because of overcrowding and diminishing affordable housing in Queens, the Bronx became home to an increasing number of South Asians, particularly Bangladeshi. Many Bangladeshi who moved to the Bronx are new immigrants, speak very little English, live below the Federal poverty line and have no real political connections to the community. (Many of the politicians in the Bronx focus their efforts on issues facing the large population of Hispanic/Latino constituents.) Additionally, unlike Queens, where there are neighborhoods with markets, restaurants, clothing shops, etc, with goods specific to South Asians, there are few places in the Bronx where the new residents can purchase goods.
specific to their culture. The population is new to the Bronx, is fairly isolated in small neighborhoods and has little political clout, so there are few South Asian grass roots organizations that can advocate for the needs of the Bangladeshi population.

Treatment options in the smaller hospitals can be limited. Many patients are referred to Lincoln which means they are expected to be sure they make appointments and keep those appointments even though they may not be near the community in which they live.

**Kings County**

**Strengths** –
The Cancer Services Program of Kings County operates out of Brooklyn Hospital and partners with the other hospitals and FQHCs in the county.

There are 13 hospitals and 49 health centers (Figure 3.3). The only comprehensive breast center in Kings County is located at Maimonides Hospital. The director of the center used to work at Memorial Sloan-Kettering Cancer Center. It provides a full range of treatment services for breast cancer all housed in one location. The three municipal hospitals are generally well run.

**Weaknesses** -
Kings County (Brooklyn) is one of the most populous counties in the state. Many of the hospitals are overcrowded and understaffed. Unfortunately one of hospitals, Long Island College Hospital (LICH), recently closed. This places an additional burden on Brooklyn Hospital, the only facility near LICH. There are three municipal hospitals in Brooklyn – Kings County/Downstate Medical Center, Woodhull and Coney Island Hospital. In October 2012, Coney Island sustained a considerable amount of damage during Hurricane Sandy. Flooding inundated the 371-bed facility, closing down pediatric inpatient services, the emergency and psychiatry emergency department, the nuclear medicine department, several operating rooms and countless other clinical areas. Patients scheduled for breast surgery at Coney Island had to be seen at other HHC facilities. Most were treated at Kings County/Downstate Medical Center. There were some difficulties accessing medical records for those patients because the electronic medical records system for the Health and Hospitals Corporation was down for a period of time. Most of the operating rooms and other departments were up and running sometime in 2013, however, the emergency department just re-opened in November 2014.

Kings County is unique in that there are few highways into the county and a few of the area’s hospitals are accessible only by bus. It takes a fair amount of time to travel from one side of the county to the other. There are few support services. Patients are often referred to Manhattan or to Queens since part of Kings County borders Queens. Patient navigation services are limited and differ in quality. Women of color who reside in Kings County have an extraordinarily high death rate which may be due to the difficulties in accessing treatment.

**Richmond County (Staten Island)**

**Strengths** –
There are two hospitals located at the northernmost part of the borough (Figure 3.4). According to the National Institute of Health/Health Systems Area data, Richmond University Medical Center is located in an economically depressed region of the county. The hospital is near the
Staten Island Ferry terminal. (The Staten Island Ferry is one of only two methods of reaching Staten Island. It is a system of ferries or boats that is operated by the New York City Department of Transportation.) According to the 2010 Census data, the community surrounding the ferry is over 60.0 percent Black/African-American and Hispanic/Latino and largely under and uninsured. Staten Island University Hospital is located some distance away from Richmond and serves a more affluent population. Both hospitals offer the full range of breast screening, diagnostic and treatment services, including medical oncology and radiation.

**Weaknesses**
Medical care for the medically underserved residents in Richmond County is limited. There are no municipal hospitals in the county. There are few community health centers. Richmond County is committed to serving the uninsured and underinsured but the two hospitals that serve that population have limited services because of budget shortfalls. The Richmond University Medical Center recently lost a number of staff due to layoffs. Transportation in the county is primarily by buses that operate on limited schedules. There is subway service, known as the Staten Island Railway, but there is no service to residents who live on the western and northern sides of the county. In some neighborhoods, bus service ends at six in the evening and residents have to depend on car service which can be quite costly. If residents wish to travel to Manhattan, they must do so either by ferry or over a bridge by bus or car. Many Richmond County neighborhoods feature steep hills making bus travel in the snow and ice virtually nonexistent.

There are few breast surgeons or oncologists in the county. The Black/African-American and Hispanic/Latino populations are small but most residents live at or below the Federal poverty line, are under and uninsured and suffer from other chronic conditions like diabetes and hypertension. Employment opportunities are few and there are limited support services.

**Suffolk County**

**Strengths**
There are 12 hospitals in Suffolk County (Figure 3.5). Most of them have comprehensive breast cancer services. Political officials in Long Island, in particular, those in Suffolk County have a history being supportive of the activities carried out by the breast cancer coalitions in the area. Some years ago, the National Cancer Institute launched a study, the Long Island Breast Cancer Study Project, to determine whether there were environmental factors that contributed to the higher than state average rates of breast cancer on Long Island. The breast cancer coalitions and Long Island’s legislators partnered with National Cancer Institute representatives to ensure that the study was carried out. At the time that the study began, Long Island legislators and hospital administrators recognized that hospitals needed to be able to provide a full range of screening, diagnostic and treatment services to the area’s residents. Several hospitals opened comprehensive breast cancer centers that include mammography screening and diagnostic services. Treatment for breast cancer varies as some treatment is delivered in doctor’s offices (chemotherapy) rather than in the hospital.

The Cancer Services Program for Suffolk County is based at Peconic Bay Medical Center located in Riverhead. Though it is a community hospital, leadership at Peconic Bay is committed to treating uninsured women.
**Weaknesses**
Most of the underserved population on the East End of Long Island of Suffolk County is geographically and culturally isolated. The public transportation system in Suffolk County is not extensive. Those without access to cars must travel one hour or more by bus to the larger towns. There is fragmented bus service and the buses that do run, do so sporadically. The bus system operates daily but service after 4:00PM is often hourly and in many cases, service ends at 8:00PM. For example, women who wish to receive their radiation treatments after work find it difficult to get home after their appointments because of limited bus service.

The hospitals are spread from one end of the county to the other but Eastern Suffolk is particularly underserved. The medical professionals call that area “the land of no.” There are few support services, no case management, few medical professionals and no transportation to get to the physicians who are there.

Medical care is spread throughout the county. It is not uncommon for a woman to have to travel 90 minutes one way for radiation appointments.

Several physicians in Suffolk County no longer accept Medicaid so women are forced to go to Nassau County, which can be quite the hardship.

The major medical center in Suffolk County is at Stonybrook Medical Center which is a state-run facility, and serves as the safety net hospital for the county. It is located in Western Suffolk County and is approximately two to two and a half hours from people who live in Eastern Suffolk.

**Hudson Valley (Westchester and Rockland Counties)**

*Strengths* –
There are 14 hospitals in the two counties of the Lower Hudson Valley (Figure 3.6). Westchester Medical Center is the safety net hospital for that county. Rockland County’s underserved usually go to Nyack Hospital, Good Samaritan Hospital or the multiple health centers in the county. Treatment services at the area hospitals are comprehensive, particularly in Westchester County. Rockland County is rather small so medical care is fairly easy to get to – if you have a car. There are ACA enrollers based at two of the hospitals in this region. There is a Memorial Sloan-Kettering Cancer Center satellite center in Westchester County so people do not have to travel to Manhattan to access care from a National Cancer Institute-designated comprehensive cancer center.

*Weaknesses* –
Transportation in Rockland County is limited. There are buses but they run sporadically. There aren’t many oncologists in the area forcing many to travel to Westchester or Manhattan. The Cancer Services Program serves five counties including Rockland and Westchester.
Figure 3.2. Breast Cancer Services Available in Bronx County
Figure 3.3. Breast Cancer Services Available in Kings County
Figure 3.4. Breast Cancer Services Available in Richmond County
Figure 3.5. Breast Cancer Services Available in Suffolk County
Figure 3.6. Breast Cancer Services Available in Lower Hudson Valley
Summary of Key Mission Partnerships For Each Target Community

Existing Partnerships

New York State Cancer Consortium (NYSCC) – The New York State Cancer Consortium is the comprehensive cancer control coalition for the state. The Affiliate is a member organization and the Director of Grants has served as the co-chair of the Steering Committee for the Consortium for some years. Membership on the coalition allows the Affiliate to participate in state-wide conversations with others across the state regarding the cancer control needs of the medically underserved populations in the region.

Greater Brooklyn Health Council - The mission of the Greater Brooklyn Health Council to create an agenda for action and unity to reduce public health disparities and improve the health of Brooklyn, New York State’s most populous county. The Affiliate has partnered with the council on events focused on health disparities and breast health. A breast health program held at Woodhull Hospital, a Brooklyn facility, was co-hosted by the Affiliate, the council and New York Langone Medical Center. Affiliate staff also attends monthly council meetings to stay abreast of issues that affect Brooklyn residents. Council representatives have served as key informants for the qualitative assessment portion of the Affiliate’s Community Profile.

American Cancer Society (ACS) - The Affiliate has partnered with both local ACS and division level representatives on all policy related issues for the last several years. The Coalition to Save Cancer Screening, an ad hoc group that mobilizes when the need arises is co-chaired by the Affiliate and ACS advocacy staff. ACS staff are also members of the Steering Committee for the New York State Cancer Consortium, mentioned above. When the new comprehensive cancer control plan was released, ACS, the Affiliate, and fellow Steering Committee members, traveled the state to talk to health care professionals about the benefits of using the plan to assist with cancer control planning.

Leukemia and Lymphoma Society (LLS) – The Affiliate has partnered with LLS on public policy initiatives. The Affiliate and LLS collaborated on a legislative strategy to amend the insurance law to cover costs for oral chemotherapy. Additionally, LLS is also represented on the Steering Committee for the NYSCC. LLS and the Affiliate are co-authors on an article about physician’s knowledge of clinical trials. The article was recently accepted for publication.

Cancer Education and Early Detection Advisory Council – The New York State Cancer Detection and Education Program Advisory Council, a legislatively mandated (through NYS Public Health Law 2904-a) body of health care professionals from across the state has, as part of its mission, to make recommendations to the Department of Health regarding the promotion and implementation of programs under section 2406 and 2409 of the Public Health Law, including the Cancer Services Program.

Komen Greater NYC’s mission staff person has been a member of the Council since 2008. Participation on the council gives the Affiliate with the ability to provide input on policy issues related to breast health.

Memorial Sloan-Kettering (MSK) Cancer Center Regional Network – Some years ago, Memorial
Sloan-Kettering Cancer Center began expanding into areas outside of Manhattan with the goal of providing high quality cancer care in suburban settings. The network is also known as the Suburban Outpatient Treatment Centers. Leadership at MSK felt that patients in Long Island and Westchester and Rockland Counties would prefer to be treated closer to home. The administrator for the regional network and the Affiliate partnered on events held at the MSK facilities at Commack (Long Island), Sleepy Hollow (Westchester) and West Harrison (Westchester/Rockland) Hospitals. The events, designed for the public, focused on breast health and clinical trials.

*New York University Langone (NYU) Medical Center/Perlmutter Cancer Center* – The New York University Langone Medical Center is the academic partner for Bellevue and Woodhull Hospitals, two of the municipal hospitals in the Affiliate’s service region. The patient population at both facilities is largely medically underserved. The director of breast surgery at NYU holds an annual Women of Color breast health event that attracts large numbers of Black/African-American and Hispanic/Latina women. The Affiliate has participated and financially supported this event for the last several years. The Affiliate has also co-hosted a breast health event at Woodhull in partnership with other community collaborators and NYU. Additionally, NYU is represented on the Affiliate’s medical advisory committee.

*Babylon Breast Cancer Coalition* – The Babylon Breast Cancer Coalition is one of several coalitions in Suffolk County focused on providing support and financial assistance to medically underserved women. Over the years, members of the coalition have served on the Grants, Policy and Education Committee, a subcommittee of the Affiliate’s Board. In 2013, the Affiliate and the coalition co-sponsored a small event at a Long Island-based university focused on the ACA and the implications for the medically underserved communities in Suffolk County.

*Southampton Breast Cancer Coalition* – The Southampton Breast Cancer Coalition is similar to the Babylon group described above in that it too provides services and assistance with everyday living for medically underserved populations. The Southampton group is based on the East End of Suffolk County, an area that has long been a major focus of the Affiliate’s granting program. It is located at the tip of the Island and is geographically isolated. The medically underserved population there comprises the large Hispanic/Latino population that work there during the spring and summer months as temporary workers. The Affiliate has partnered with the organization on events to promote the availability of Komen’s granting programs as well as on breast health events that include the other Long Island based breast cancer coalitions. Representatives of the coalition have served as key informants as part of the qualitative assessment for the Affiliate’s Community Profile.
FORCE – FORCE is a Brooklyn based advocacy coalition that formed to address disparities in employment and health care. The Affiliate has partnered with FORCE representatives on a number of smaller events focused on the implications of the ACA on Brooklyn residents.

National Coalition of Cancer Survivorship – The National Coalition of Survivorship’s mission is to advocate for cancer patients to ensure that all have access to high quality care. The Affiliate, in conjunction with the New York State Cancer Consortium, has partnered with local chapters of the coalition on development of survivorship plans in New York State.

Redes en acción – The Redes en accion program is a grantee of the National Cancer Institute’s Center to Reduce Cancer Health Disparities initiative. The program is based in Brooklyn and focuses on Hispanics. The Affiliate has partnered with Redes staff on breast health events for the last several years. The Affiliate’s mission staff was instrumental in supporting the nomination of a Redes representative for the Steering Committee for the New York State Cancer Consortium thus ensuring that the needs of Hispanics/Latinos are addressed by the comprehensive cancer control plan.

LatinaSHARE – SHARE, Self Help for Women with Breast and Ovarian Cancer, is an organization that provides support services for women with breast and ovarian cancer. LatinaSHARE is specifically focused on the support needs of Hispanic/Latina women throughout the affiliate’s service area. For three years, LatinaSHARE and the Affiliate co-sponsored a Long Island based breast health program in English and Spanish. The program attracted over 100 Hispanic/Latina women each year it was held. Additionally, representatives from LatinaSHARE provide input to the Affiliate’s granting program on issues specific to the Hispanic/Latino population.

SAPNA (the letters refer to a Bangladeshi word that does not have an English translation) – SAPNA is a South Asian grass roots organization that was initially called the Westchester Square Partnership. The name derives from its location in the Bronx, an area called Westchester Square. The organization was formed in 2013 to address the needs of the new Bangladeshi population that moved to the Bronx in recent years. SAPNA is a new Komen partner. The Affiliate and SAPNA have held two small events to assess the health care needs of the South Asian population in the Bronx.

Public Health Solutions – Public Health Solutions is a non-profit research agency that uses a community-based participatory approach to research in the medically underserved communities in the Affiliate’s service area. The Affiliate and Public Health Solutions representatives have partnered in recent years on the development of the Community Profile. Additionally, the Affiliate also partnered with the group during the roll out of the NY State of Health by jointly sponsoring webinars to review the ACA to Komen partners and grantees.

SAGE (Services and Advocacy for GLBT Elders) – SAGE is a Brooklyn based coalition focused on the needs of the older LGBT population. The Affiliate partnered with SAGE representatives on two breast health events held at local community based organizations. The focus was to
promote the importance of breast cancer screening in the LGBT population and distribute audience appropriate screening resources. SAGE representatives have also served as key informants for the qualitative assessment of the Community Profile.

_Fighting Cancer_ - Fighting Cancer is an organization based on the East End of Suffolk County. The goals of the organization include providing resources to the underserved populations that reside in the area. The Affiliate has partnered with Fighting Cancer recently on the rollout of the NY State of Health. Two programs were held at Fighting Chance's office in Long Island. The Affiliate identified a Spanish speaking individual who helped translate during the programs.

_Woodhull Hospital_ – Woodhull Hospital is one of the 11 municipal hospitals in the Affiliate’s service area. It is based in Brooklyn and serves a fairly large medically underserved population. The Affiliate co-hosted breast health programs held at Woodhull over the last two years. Woodhull did not have a history of holding programs for community members yet the two programs attracted close to 100 women at each. The speakers spent a considerable amount of time after the program continuing to answer questions from the audience. Partnering with the facility has provided the Affiliate entrée to a population eager for information.

_Future Partnerships_

_Maimonides Medical Center_ – Maimonides located in Brooklyn is a comprehensive breast center in Kings County. The population they serve includes the large Orthodox Jewish population in the Borough Park section of Brooklyn and the Caribbean-born Black population in Crown Heights. The Affiliate will continue its efforts to partner with the breast center representatives at Maimonides on breast health events. Currently, the director of the breast center is the chairperson for the Affiliate’s medical advisory committee.

_Hispanic Federation_ – The Hispanic Federation is a national organization focused on the needs of Hispanics. The Komen Affiliate will be working with the organization on breast health programs.

_Montefiore Medical Center/Buddy BOLD Program_ – The BOLD program is a peer navigator program in the Bronx. Their navigator model is unique in that survivors serve as the navigators for the newly diagnosed.

_Caribbean Women’s Society_ – The Caribbean Women’s Society is based in Brooklyn and provides social service assistance to women from Jamaica, St. Vincent, Trinidad and Tobago. The death rate for breast cancer in the Caribbean-born population, along with Black/African-American women is alarmingly high. The Affiliate has attended a few events sponsored by the organization and noted the large numbers of women who seem to participate. The organization has been receptive to partnering on future events.

_Kingsbrook Jewish Medical Center_ – The Kingsbrook Jewish Medical Center is based in the Flatbush area of Brooklyn. Flatbush is home to a large segment of the Caribbean-born
population. As noted above, the breast cancer death rate for the population served by Kingsbrook is quite high.

**Haitian Women’s Society** – The Haitian Women’s Society is based in the Flatbush/Crown Heights section of Brooklyn. The organization focuses their attention on the Haitian population which has increased dramatically after an earthquake hit Haiti some years ago.

**Hudson River Health Care** – The Hudson River Health Care is a nonprofit system of FQHC community health centers that provide care to residents of the Hudson Valley as well as Nassau and Suffolk counties. Though it is a small area, there are pockets of extreme poverty in Upper Westchester and Rockland Counties. Most of the population resides in an area where there is no other health care facility.

**Public Policy Overview**

The NYSDOH Cancer Services Program (CSP) oversees the delivery of comprehensive breast, cervical and colorectal cancer screening and diagnostic services to eligible uninsured and underinsured New Yorkers through local screening programs implemented by state-funded CSP contractors. The goal of the CSP is to reduce morbidity and mortality from breast, cervical and colorectal cancers in New York State.

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) in New York State is known as the Cancer Services Program or the CSP and is overseen by the New York State Department of Health (NYSDOH)/Bureau of Cancer Prevention and Control. The NYSDOH Cancer Services Program (CSP) oversees the delivery of comprehensive breast, cervical and colorectal cancer screening and diagnostic services to eligible uninsured and underinsured individuals in NYS through local screening programs. The CSP contractors are expected to develop relationships with regional providers (e.g., hospitals, clinics, health care providers) and community-based organizations to conduct outreach to priority populations. They also provide screening, diagnostic and case management services; conduct public education programs; and carry out data management and quality assurance activities. There is a Project Director for each CSP and are usually based at hospitals. The CSPs in the Komen Greater NYC region, referred to by the NYSDOH as the “metro” region CSPs, report to locally based Department of Health (DOH) Regional Managers. There are two Regional Managers in the region who work closely with the CSP contractors and their credentialed providers to provide oversight, guidance and technical assistance.

The CSP provides services to all 62 counties in the State of New York. There are a total of 36 CSPs in the state. Contractors are funded in five year cycles after responding to a Request for Application (RFA) released by the New York State Department of Health. The current contractors were selected and funded in 2013. In the Komen Greater New York City region, there is one CSP for each of the counties/boroughs of New York City and for Nassau and Suffolk Counties (Long Island); Rockland and Westchester Counties are served by the Cancer Services Program of the Hudson Valley which also serves Ulster, Dutchess and Putnam Counties.
Though each program can be reached by local telephone numbers, New York State added a toll free referral line for the CSPs several years ago for easier access. That number, 1-866-442-CANCER (2262), is answered by staff who ask general questions about special accommodation needs, eligibility and residence zip code and then provides the number of the local CSP and then offers to transfer the caller directly to the program.

The eligibility criteria include women who are 40 years of age or older, uninsured or underinsured (defined as those financially unable to meet their co-payments or deductibles or whose insurance does not provide coverage for breast cancer screenings) and whose household incomes are at or below 250.0 percent of the federal poverty level (FPL). Women with household incomes above 250.0 percent of the FPL who meet all other eligibility criteria are also eligible for services, if they are unable to afford cancer screenings. The program is open to all age eligible women regardless of citizenship status. The program will provide screening to high risk women who are under 40. Those women have to provide an "attestation of risk" document completed by a medical provider who has utilized one of the commonly used risk assessment tools.

Case management has been an integral part of the CSP since the federal legislation for the NBCCEDP was reauthorized to include this component in 1998. Clients found to have abnormal screenings are provided with case management services to ensure that they receive timely diagnosis, appropriate follow-up care and access to necessary treatment. Case management increases client adherence to screening, diagnostic and treatment services, and ensures clients receive support to obtain needed services. The CSP requires that a direct, personal level of support be available to assist clients to address barriers that might delay or prevent their care. Barriers to care include transportation issues, lack of child or elder care, language and cultural barriers, fear and misunderstanding of clinical recommendations and psychosocial issues related to the emotional burden of cancer.

In addition to the funds from the Centers for Disease and Control (CDC) the CSP also receives funds from New York State.

**Access to the Medicaid Treatment Cancer Treatment Program (MCTP)**

Contractors (local health departments, community-based organizations or health providers and institutions) also facilitate the enrollment of eligible men and women in the New York State Medicaid Cancer Treatment Program (MCTP) for breast cancer. The NYS MCTP is a Medicaid program for eligible persons who are found to be in need of treatment for breast cancer. Beginning in 2008, contractors were required to create and implement a referral system to Medicaid facilitated enrollers to screen CSP clients for eligibility for public insurance programs. The process for enrollment into MCTP is far more stream lined than for regular Medicaid. A person can access the MCTP through a number of ways – she can contact a partnership directly, call the toll-free state number, or through a hospital’s financial screening department. Through whatever manner the person chooses, they would be put in contact with a Designated Qualified Entity (DQE) who would assist them in completing the application either in their office or at a location convenient to the client.

All Contractors have DQEs on staff, as do most hospitals associated with the contractors as well. Some hospitals that do not have a formal relationship with the partnership. MCTP applications
are sent by the DQE directly to the NYSDOH CSP MCTP Coordinator in Albany for review. These applicants can have an answer within days. With regular Medicaid the local area Medicaid office is involved with the application process. That process can take weeks to months to complete. Once an uninsured woman is diagnosed, she is assessed for Medicaid eligibility. If a woman is screened in one of the municipal hospitals (the Health and Hospitals Corporation) in New York City, that assessment happens at the point of screening.

The New York City Health and Hospitals Corporation (HHC) is an integrated health care system of hospitals, neighborhood health centers, long-term care, nursing homes and home care -- the public safety net health care system of New York City. The corporation includes 11 hospitals that accept any and all patients regardless of whether they have insurance or citizenship status. Women in need of treatment who are not citizens are enrolled into Emergency Medicaid and may be referred to one of the HHC facilities. Prior to 2009, only women who were enrolled into the CSP were able to access treatment through the MCTP. That meant that a woman who was not enrolled into the CSP but happened to be screened at a CSP provider, was diagnosed and met all other eligibility requirements, was not able to access treatment through the MCTP. Komen Greater NYC launched a media campaign and caused an outcry among women’s health activists about the unfairness of that practice. The negative publicity brought the issue to NYS legislature and through legislation the policy was revised. Now any woman screened at a CSP provider regardless of whether she’s a CSP patient can be enrolled in the MCTP.

**Relationship between the CSPs and Medicaid**

CSP staff based at the New York State Department of Health is in constant contact with staff in the state Medicaid office to ensure that the process of enrolling patients into the MCTP runs smoothly. The DQE’s based at each site meet regularly with the CSP Project Directors to review new policies and guidelines.

**Affiliate’s Relationship with the Cancer Services Program**

Komen Greater NYC has had a long, mutually beneficial relationship with the Cancer Services Program. The Affiliate’s mission staff attends meetings for each CSP in the region. Affiliate staff is kept apprised of the program’s policy and guidelines changes. Affiliate staff is in constant contact with the CSP’s Regional Managers as well as the Project Directors and attend the regional meetings held specifically for the metro CSPs.

In addition to oversight by the New York State Department of Health, the CSPs are advised by the New York State Cancer Education and Early Detection Advisory Council, a legislatively mandated (through NYS Public Health Law 2904-a) body of health care professionals from across the state. Komen Greater NYC’s mission staff person has been a member of the Council since 2008. The role of the council is to advise the commissioner regarding provision of information to consumers, patients, and health care providers relating, but not limited to, breast, cervical, prostate, testicular and ovarian cancer, including signs and symptoms, risk factors, the benefits of prevention and early detection, guideline concordant cancer screening and disease management, options for diagnostic testing and treatment, new technologies, and survivorship. The council meets twice per year.
Affiliate and the Cancer Services Program – Next Four Years

Komen Greater NYC mission staff will continue to strengthen the relationship with the Cancer Services Program by regularly attending all CSP-related state level and local meetings and involving CSP staff in Komen Greater NYC-sponsored educational events. As an example, Komen Greater NYC co-hosted a breast health educational program with the New York University Langone Medical Center in April 2013. Two of the speakers on the panel were from area CSPs and were invited by Komen Greater NYC staff. Affiliate staff is in the planning stages for events to celebrate Komen Greater NYC’s 25th anniversary in 2015. One of those events will be a symposium to be held in March. A planning committee for that event will include CSP staff.

In May, 2015, CSP leadership, in conjunction with other state wide leaders, including Komen Greater NYC, will be hosting a day long Cancer Prevention Summit. Meetings to plan the summit started in May, 2014 and are held twice a month. This event will feature both national and international speakers who will address not only breast cancer but general cancer prevention and risk reduction.

The New York University Langone Medical Center co-sponsors an annual “Women of Color” forum at which Komen Greater NYC has participated for the last six years. The forum, scheduled for early October, targets Black/African-American and Hispanic/Latina women. Komen Greater NYC will be a panel speaker and is financially supporting the event.

Komen Greater NYC staff will continue to include CSP staff as part of the reviewer panels for the community grants for the next several years.

Komen Greater NYC staff will continue to actively participate in the Cancer Education and Early Detection Advisory Council for the next five years (the average tenure for a Council member).

Komen Greater NYC will continue participate in state-wide coalitions, e.g., Breast Cancer Disparities Roundtable, that addresses issues that impact breast health and the work of the CSPs. The Breast Cancer Disparities Roundtable, a coalition of health professionals from within five counties/boroughs of NYC, has been working on several projects that involve CSPs. One, a research project to look at treatment adherence among patients from two area hospitals that has been in progress since 2012, is scheduled to end in late 2014. Another project was just completed that assessed wait times at mammography facilities.

State Comprehensive Cancer Control Coalition - New York State Cancer Consortium

The New York State Cancer Consortium (www.nyscancerconsortium.org) (NYSCC) was formed in 2005 and charged with developing and implementing the New York’s Comprehensive Cancer Control Plan (Plan). The New York State Department of Health is one of 67 state, tribe and territorial programs participating in the National Comprehensive Cancer Control Program, funded by the Centers for Disease Control and Prevention (CDC). The NYSCC strives to bring together representatives from the public and private sectors engaged in research; surveillance; prevention; early detection; education; diagnosis and treatment; management; support; rehabilitation and palliative care to address problems relating to cancer in New York State. The
State’s comprehensive cancer control plan was revised in 2012 and can be found at http://www.nyscancerconsortium.org/documents/NYSCompCancerPlan2012-2017-FINAL.pdf.

**The breast cancer objectives are as follows:**

1. By 2017, increase the proportion of women who receive breast cancer screening based on the most recent guidelines by at least 5.0 percent. (Baseline, 2010: 77.7 percent women aged 40 to 74 years who have received a mammogram in the past two years. Source: BRFSS)

2. By 2017, reduce the rate of female breast cancer identified at late-stages to 41.7 cases per 100,000 females (Baseline, 2005-2009: 44.4 cases per 100,000. Source: NYSCR)

The NYSCC Steering Committee (SC) is responsible for overseeing the implementation and evaluation of the New York State Comprehensive Cancer Control Plan and oversight of the activities of the Consortium. The Komen Greater NYC mission staff person is one of the co-chairs for the NYSCC Steering Committee. She has been a SC member since 2005 and has been co-chair since 2009. The role of the co-chairs is to provide guidance and direction to the SC and the associated committees. As mentioned earlier in this document, staff from the New York State Department of Health/Bureau of Cancer Prevention and Control that oversees the Cancer Services Program are also the State Department of Health representatives on the Steering Committee.

Komen Greater NYC was instrumental in reviewing the revised plan, particularly the section on early detection. When the new version of the plan was released the Komen Greater NYC staff person, along with other key SC members, presented at meetings around the state to encourage use of the plan and how it might be used to support local cancer control efforts and discussed the benefits of joining the Consortium. In addition to serving on the Steering Committee, the Komen Greater NYC staff person is on the Communication, Membership, Nominations and Clinical Trials committees.

During 2013/2014, the members of the Clinical Trials committee conducted a short research study querying both patients and health care providers from around the state about participation in clinical trials. Partnering with local medical associations and the American Cancer Society and the Leukemia and Lymphoma Society, the members of the group designed two questionnaires which were administered to participants via email.

**Komen Greater NYC and the New York State Consortium – Next Four Years**

Over the next four years, Komen Greater NYC will continue to play a key role on the Consortium. The current plan expires in 2017 so the revisions will start at the end of 2016. As in years past, the Komen Greater NYC mission staff person has agreed to participate on the ad hoc committee in charge of Plan revisions. The new plan will be unveiled in early 2018. The mission staff person’s term as the co-chair will end in mid-2015 but will continue to be a member of the SC. In 2015/2016, the Clinical Trials group will conduct another project focused on primary care physicians and their knowledge of clinical research.
Affordable Care Act (ACA) – NY State of Health
New York opened its Health Plan Marketplace, the NY State of Health, on October 1, 2013, allowing New Yorkers to shop for and enroll comprehensive health plans. Though there was some backlash about the implications of the ACA on the middle class, in general, both state and local legislators on both sides of the aisle supported the development of the health exchange to provide New Yorkers with access to health insurance. The Marketplace is an integrated exchange, allowing for one-stop shopping for Medicaid, Child Health Plus and Qualified Health Plans. Sixteen health insurers offered coverage to individuals and ten insurers offered plans to small businesses.

State Action on Medicaid
With the implementation of the Affordable Care Act, New York expanded Medicaid eligibility levels to 138.0 percent FPL for all eligible New Yorkers. Since New York’s eligibility levels already largely met this new federal standard, this expansion affected single and childless adults whose eligibility had been set at 100.0 percent FPL. As projected, a relatively small percentage (13.0 percent) of the persons who enrolled in Medicaid through the Marketplace was newly eligible as a result of the Medicaid expansion. In an effort to help undocumented women undergoing cancer treatment, there was an option to enroll patients into Emergency Medicaid.

Number of Uninsured Prior to and After the Mandate
There were approximately 2.2 million uninsured individuals in New York State prior to the opening of the NY State of Health. At the time the Marketplace opened, department of health officials projected that 1.2 million individuals would become newly insured. There are an estimated 775,000 undocumented individuals in the Komen Greater NYC service area. It is important to note that these uninsured individuals are ineligible to enroll into health care because of their citizenship status. As of April 15, 2014, 1,319,239 New Yorkers had completed applications and 960,762 had enrolled in coverage through the NY State of Health. Of those who enrolled, 81.0 percent stated that they did not have health insurance at the time they applied. Medicaid and Child Health Plus enrollees were the least likely to report being insured.

Of the nearly one million who enrolled, 55.0 percent were enrolled into Medicaid which indicates that these were the people who could benefit most from the Affordable Care Act. More than half (52.0 percent) of the enrollees live in New York City; 14.0 percent live in Long Island and 34.0 percent live in the other regions of the state. NY State of Health officials felt that the negative publicity that plagued the ACA, nationwide impacted the enrollment levels at the local level. The vast majority of those who ultimately enrolled into the NY State of Health did so after January 1, 2014, a full three months after enrollment opened. There was a massive promotional campaign that launched in September, 2013, but most people indicated that they found out about the NY State of Health through word of mouth or when they visited one of the community organizations that served as enrollment sites.

The NY State of Health trained and certified almost 9000 people to provide free, in person enrollment assistance at convenient times to New Yorkers applying for coverage through the Marketplace. There were 643 navigators, 3,999 certified application counselors and 4,318 brokers. The navigators and counselors were largely based at community based organizations, Federally Qualified Health Centers, advocacy organizations and hospitals.
Implications of ACA on the Cancer Services Program eligibility and utilization

Patients who purchased the Bronze tier, the least expensive option, find that once diagnosed with cancer, they are unable to afford the high deductible for treatment which leaves CSP staff often struggling to find viable options for treatment for those patients.

Komen Greater NYC conducted a short survey of the CSPs in the region in June, inquiring about the patient population they are seeing, post-ACA. Of those CSPs located in the five counties/boroughs of New York City, undocumented individuals comprise the majority of the women screened for breast cancer. The other CSPs in the region report that several women state that while enrolling into the NY State of Health was an option, many found that even with subsidies, they still are unable to afford the premiums. As of July 1014, none of the CSPs have reported a decline in the number of patients they see monthly. Even with the implementation of the ACA, CSP leadership suggests that it will not reach everyone. An estimated 10.0 percent of men and women ages 50-64 will continue to remain uninsured in New York State. From April 1, 2015 through March 31, 2015 approximately 28,514 people received at least one-program funded cancer screening, a slight decrease from the previous year. Contractors in the New York City region serve a high proportion of clients who are not eligible to enroll in the state’s exchange, thus experiencing little to no effect on numbers screened.

For the immediate future, the eligibility requirements for the CSP will not change. Individuals underinsured or uninsured are eligible to be screened through the CSP providers. There are still too many people uninsured, too many unable to access insurance because of citizenship status or because of high co-pays or premium costs. The MCTP remains in place with no expected changes to how women access it.

Implications for Health Care Providers

Conversations with physicians in the Komen Greater NYC reveal that not all are enamored of the NY State of Health. While they understand the need to insure as many people as possible, the fallout from that goal, in their view, will be detrimental to the quality of care delivery. The NYS State Cancer Consortium conducted a brief survey of physicians after open enrollment began in October 2013. The questions (Komen Greater NYC staff assisted with the questionnaire design) were open-ended and posed questions about their thoughts on Medicaid, health care and access to care. Many stated that though they accept Medicaid, they prefer not to because the payments are rather low. So many new enrollees are insured by Medicaid, however some physicians feel that having insurance provides those patients with a false sense of security. There may not be specialists who will take Medicaid, particularly the Medicaid managed care plans. For example, Memorial Sloan-Kettering Cancer Center, one of the premier cancer centers in the country, does not accept the Medicaid managed care plans; only straight Medicaid. Patients may be able to have their surgery done by a surgeon in a practice who accepts Medicaid. Then that physician may refer the patient to a medical oncologist colleague in the same medical practice who does NOT accept Medicaid. The patient now has to seek care in another facility and see physicians unfamiliar with his/her care. Will that patient follow up with a completely new physician? Maybe – maybe not. There are exceedingly high death rates in the Komen Greater NYC region for select population groups. Health care experts
speculate that some patients are not treatment adherent because of this sort of fractionation of care.

New York State is in the middle of a new initiative that grew out of the Medicaid Redesign campaign that took place a few years ago. The Delivery System Reform Incentive Payment Program or DSRIP is the main mechanism through which New York State will implement the suggestions from the Medicaid Redesign team. DSRIP’s purpose is to fundamentally restructure the health care delivery system by reinvesting in the Medicaid program, with the primary goal of reducing avoidable hospital use by 25.0 percent over five years. Up to $6.42 billion dollars are allocated to this program with payouts based upon achieving predefined results in system transformation, clinical management and population health. Physicians in the Komen Greater NYC region who were surveyed through the New York State Cancer Consortium questionnaire described above are cautiously optimistic that this will help contain costs.

In addition to the Medicaid issues, some physicians state that some of the health plans offered in the Marketplace pay too little and/or restricts the prescriptions the physician writes or the tests he/she orders. Or the physician may be within a patient’s network but the hospital at which the doctor practices is not.

Suffolk and Rockland counties have suffered from a shortage of oncologists for the last few years. It is becoming increasingly difficult to get an appointment with the few breast surgeons and medical oncologists that remain. If a patient is successful in getting an appointment, in an effort to see as many patients as possible, the physician is so rushed that patients are unable to ask all of their questions.

Physicians in the Komen Greater NYC region support the spirit in which providing access to health care insurance to all was designed. They just aren’t sure that they can provide the level of care required to meet the needs of so many people. They clearly don’t have the resources to meet the increased demand for their services.

**Implications of the ACA for the Affiliate**

Komen Greater NYC has gone to great lengths to understand the implementation of the ACA in the region. During meetings with grantees, colleagues in the region, survey results, etc., it has become clearer that education and case management and/or patient navigation services are needed by the newly insured. As mentioned earlier, the numbers of undocumented individuals in the region continues to grow so there will always be a substantial population of uninsured. The Affiliate’s role is to closely monitor the enrollment numbers, the issues facing medical professionals and modify the granting programs to address some of these needs.

**Affiliate’s Public Policy Activities**

**Examples of Komen Greater NYC’s Public Policy Activities**

Komen Greater NYC, in conjunction with the American Cancer Society, lobbies local legislators during the fall months to continue the efforts of the Cancer Services Program. Komen Greater NYC staff attends in-person meetings between September and December with legislators to
both educate and impress upon them the importance of continued state funding. The Governor releases his draft budget in late December/early January. Additionally, all of the NYS Affiliates sign on to a letter addressed to the Governor about the CSPs and maintenance of funding.

When Komen Headquarters releases the August recess public policy toolkit, Komen Greater NYC contacts the Congress members via email and telephone.

All local and Congressional leaders are invited to the Race and given a platform on which to talk to the participants about working with Komen Greater NYC.

**Potential Future Local and/or State Public Policy Activities**

In the recent past, Komen Greater NYC was an active member of the Coalition to Save Cancer Screening. The group comprised local advocacy organizations and CSP directors and worked collaboratively on maintaining the state funding. Though the coalition disbanded sometime in 2013, Komen Greater NYC and the American Cancer Society will re-form the group. The major focus will be to ensure that the CSPs continue their work in light of the ACA.

**Health Systems and Public Policy Analysis Findings**

**Needs in Target Community Related to Health Systems and CoC**

The bulk of the needs in the Komen Greater NYC region are focused on patient navigation, support, survivorship and access to quality care. Transportation is also a much needed service for those living in Richmond, Suffolk, Rockland and Westchester Counties. The CoC highlights the need for education to patients and medical providers regarding the importance of treatment completion. That may involve encouraging health care providers to ensure that once patients leave their care, there is some level of follow up. The barriers seem to be related to limited options in electronic medical records. A crucial need includes eliminating those systems barriers that prevent patients from moving from point A (surgery) to point B (chemotherapy and/or radiation). Kings County continues to suffer from a lack of access to medical care. The hospitals are strong and provide comprehensive services but are overcrowded. Hospital officials and medical personnel observe that patients can spend hours in waiting rooms waiting for medical appointments.

**Key Partnerships**

The key partnerships with the Cancer Services Program, the Cancer Education and Early Detection Council and the New York State Cancer Consortium provide the Affiliate with access to state level decision making regarding cancer control. The Affiliate has the opportunity to participate in those discussions that affect policies for breast screening/breast cancer.

Partnering with the American Cancer Society and the Leukemia and Lymphoma Society on public policy issues increases the Affiliate’s leverage with local legislators. Local legislators have looked to the Affiliate as a resource for breast cancer/breast health information. The Affiliate will continue to strengthen those relationships with additional advocacy staff at those organizations.
Partnering with the cancer centers like Memorial Sloan-Kettering, and New York University Langone Medical Center and community hospitals like Woodhull Hospital on educational programs and other events increases the visibility of the Affiliate within the region thereby reaching more people and potential donors.

Collaborating with a varied number of community based organizations like the Greater Brooklyn Health Council, Fighting Cancer and SAGE that reach multiple audiences provide the Affiliate with an extended reach into populations that do not proactively seek breast health information.

Representatives from LatinaSHARE and Redes en accion provide access to information about issues specific to the Hispanic/Latino population not only for the Affiliate but also for the Affiliate’s state level partners. The Affiliate plans to link those two partners with the Hispanic Federation to work on breast health activities. The Affiliate has also suggested that representatives from the Hispanic Federation may wish to work with the other New York based Affiliates.

Creation of survivorship plans has been a topic at several meetings of the New York State Cancer Consortium. Though the plans are a required part of discharge planning for cancer patients, many health care professionals in the state are struggling with how best to create and ensure the use of the plans. The Affiliate and the local chapter of the National Coalition of Cancer Survivorship are partnering to address many of the concerns by seeking best practices and engaging the companies that provide the electronic medical record systems used by local hospitals. Several health care professionals believe that the survivorship plans can be created by adding features to the electronic medical form.

Working with representatives from the Babylon and Southampton Breast Cancer coalitions provide the Affiliate with insight into the needs of the medically underserved in parts of Long Island. The coalitions often provide breast cancer patients with assistance with concrete needs like funds for utility bills, provision of housekeeping services and babysitters. Occasionally the coalitions provide assistance for unique needs that are not typically covered by other organizations. For example, the Babylon group bought a prom dress for the daughter of a patient unable to afford the cost. The coalitions are often the best source of information about the needs of the medically underserved in Long Island.

Engaging in activities that involve representatives from the Caribbean Women’s Society, the Haitian’s Women’s Society and the Kingsbrook Jewish Medical Center will provide the Affiliate with access to women who, along with African-Americans, have an increased rate of death from breast cancer. The Affiliate has meetings scheduled to meet with the representatives in January and February 2015.

Partnering with the Hudson River Health Care offers additional opportunities for the Affiliate to reach individuals who reside in those pockets of extreme poverty in Westchester and Rockland Counties. Preliminary conversations with representatives from the network have been promising and the Affiliate hopes to hold a few small events at the health centers within the network. The Affiliate also hopes that the relationship with the Hudson River Health Care results in an increase in the number of applications from the two counties, particularly Rockland County. The Affiliate
rarely receives more than two to three applications from Rockland County based organizations.

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

The efforts that Komen Greater NYC has made in advocating for the Cancer Services Program has had a direct impact on breast health care in the region. The conversations with legislators during those legislative visits have resulted in flat vs. reduced funding for the CSPs. Continued access to the much needed CSPs means that medically underserved women will still be able obtain breast health care. Developing relationships with local legislators either through events, theirs or the Affiliate’s, has also led to the legislators’ increased awareness of the needs of their constituents. And finally, participation on the Cancer Education and Detection Council provides the Affiliate a voice to ensure that policies remain in place that provide much needed CSP services to medically underserved.

The expansion of Medicaid through the NY State of Health has benefitted several individuals in the region. Now those previously uninsured are able to access health insurance. The expansion of oral chemotherapy coverage in New York has also benefitted patients who were unable to afford to pay for their prescription medications. The breast density issue, though fraught with controversy, did encourage women to ask their doctors more questions about their mammograms and follow up testing. In general, the public policy issues in New York State facilitate collaboration between multiple partners and address much needed issues among the communities served.

**Affiliate’s Policy Work**

Komen Greater NYC’s mission staff has been at the forefront of every public policy issue related to breast health care over the last several years. As stated earlier, through a media campaign and distribution of a white paper, entitled, “Through the Wrong Door,” the Komen Greater NYC encouraged the New York State legislators to modify the CSP policy regarding access to the Medicaid Cancer Treatment Program. In the past, only women who were screened within the CSP were able to access treatment through the MCTP. That meant that women who may have been screened by a CSP provider but were NOT actually enrolled in the CSP were not able to access the MCTP. Due to the Affiliate’s efforts, all eligible women screened by a CSP provider can now be treated through the MCTP.

In addition to CDC funding, the CSP was also a line item on the New York State legislative budget. As a result of the economic downturn that affected New York State in 2008, funding for the CSPs was in danger of being reduced.

In 2011, the Affiliate and representatives from the local chapters of the Leukemia and Lymphoma Society (LLS) partnered to address the issue of parity in insurance coverage for oral chemotherapy in the state. The two groups discussed strategies to educate legislators about the issue and how best to influence those same legislators. The Affiliate identified patients whose care had been affected by the high costs of oral chemotherapy, spoke with legislators that were Komen supporters and encouraged the other NYS Komen Affiliates to get involved. As a result of the efforts of the Affiliate and LLS, the insurance law was amended to cover the costs associated with oral chemotherapy.
In 2011, the Affiliate began working with representatives from the local chapter of Are You Dense (AYD) a grass roots organization focused on breast density and breast cancer. At that time, there was a nationwide call to insist that doctors inform women with dense breasts that they should seek additional screening. According to AYD and its supporters, mammography was an insufficient screening tool for women with dense breasts and the addition of an ultrasound should be standard of care. Their intention was to amend the public health law to add language that would address increasing awareness about breast density and add ultrasound as the next step in the screening process. The Affiliate, in consultation with Komen Advocacy Alliance colleagues and the other Komen Affiliates in New York wrote a letter and a modified version of the proposed bill that focused on increasing awareness about density and eliminated the language regarding ultrasound. In 2012, the Governor passed Public Health Law NY AB 9586.
Qualitative Data: Ensuring Community Input

Qualitative Data Sources and Methodology Overview

Methods

Rationale for Data Collection Strategy
Key informant interviews were conducted to assess ideas, opinions, and perceptions about barriers and facilitators of breast cancer care across the continuum (screening, diagnostic follow-up, treatment and survivorship) to elicit key factors operating at the level of the individual, health care provider and health system. Key informant interviews were selected as the best way to collect expert information to contextualize and expand the findings from the quantitative data and health system analyses.

The second method of data collection was Document Review. Per the instructions from Komen Headquarters, ten articles focused on the two target communities, Blacks/African-Americans and Hispanics/Latinas, were reviewed by Affiliate staff.

Data Collection Tool Development
The Affiliate, in conjunction with the Community Profile Team, developed a key informant interview guide that included a series of open-ended questions and prompts about breast cancer screening and treatment, and barriers and facilitators to accessing breast care along the cancer continuum. Grounded Theory, a methodological approach that generates theoretical categories from collected data, guided the key informant interviews and analysis. In this way, data collection, analysis, and interpretations were directed by the observed data. After the initial interviews, the Qualitative Data Collection Team met to determine if the guide would need to be modified for the subsequent interviews to include additional questions and explore the themes that had surfaced. Data collection was performed by the Qualitative Data Collection Team composed of the Greater New York City (NYC) Affiliate mission staff person, a Community Profile consultant and two graduate student interns.

Sampling

Document Review
The Affiliate reviewed 40 journal articles selected after the Affiliate conducted three literature searches through PubMed using search terms that included “system and provider barriers to breast cancer treatment for Black/African-American and Hispanic/Latino women,” “delay of care for vulnerable populations with abnormal breast cancer screening” and “access to care for Black/African-American and Hispanic/Latina women.” The journals selected included the Journal of the National Comprehensive Cancer Network, Breast Cancer Research and Treatment, Cancer, the American Journal of Preventive Medicine, and Preventive Medicine. After reviewing the 40 articles, the Affiliate staff selected ten that best supported the findings identified in the key informant interviews. Excerpts and comments specific to the findings from each article were collected in a master document compiled by two graduate student interns. Some of the articles focused on issues specific to both Black/African-American and Hispanic/Latino populations in urban settings.
**Key Informant Interviews**

In consultation with Komen Headquarters it was determined that three informants per region would be sampled for a total of 15 informants. The five regions were as follows:

- Bronx/ Bronx County
- Brooklyn/ Kings County
- Staten Island/Richmond County
- Lower Hudson Valley: Rockland County and Westchester County
- Suffolk County

Initially, a purposive sampling strategy was used to identify informants who had intimate knowledge of the health care environment facing Hispanics/Latinas and women of African descent as well as a deep understanding of the various ethnic sub-communities in the downstate region. The Community Profile Team generated a list of health care and social service agencies serving Hispanics/Latinas or women of African descent over 40 years old in the five regions of interest. Key informants were invited to participate if they worked at an agency serving Hispanics/Latinas or women of African descent. Interviews were conducted in English. Key informants were invited via an introductory letter explaining the purpose and the voluntary aspect of the study. A follow-up call was made and an email was sent to secure participation. Of the 85 informants invited to participate over more than a month of follow up, only 20 indicated an interest in participating, and the team succeeded in conducting interviews with only 15 during the period the Affiliate had designated for interviews. This response rate resulted in a convenience sample technique.

**Data Collection**

The key informant interviews were conducted by phone in November and December 2014. Interviews lasted approximately an hour. Interviewers obtained verbal consent to participate from each informant. The chart entitled “Key Informant Descriptors” lists the organization names, role, ethnicity, gender and credentials of the key informants, the number of years each key informant has been with the respective organizations, the target population, and the counties served by each organization.

Fifteen key informants participated in the in-depth interviews. All informants were women, and all worked at agencies involved in the care and support of women affected by cancer and serving Hispanic/Latina and women of African descent.

Of the 15 informants, six worked in an agency that had operations in Bronx, six in Suffolk, five in Brooklyn, three in Staten Island, and two in Lower Hudson Valley; several agencies had operations in more than one county.

The informants included administrators as well as clinicians; among them were four nurses, one psychologist, and one social worker. In addition, one of the administrators was also a breast cancer survivor. Informants had a mean of nine years (range: 1-20 years, median of 6.5 years, and mode of six years) of experience in their respective roles. Of the 15 informants, eight were Hispanic/Latinas or women of African descent.
Fourteen of 15 interviews were conducted by one graduate student intern and the other by the Komen Greater NYC mission staff person. The interviews were recorded on audio tape, and were then transcribed by three members of the data collection team. The verbatim transcripts were reviewed for accuracy by the main interviewer, and final transcripts were generated.

Anonymity of sources was protected by omitting identifying data about the informant on transcripts. Audiotapes were destroyed after 30 days.

Qualitative Data Overview

Data Analysis
The consultant reviewed the verbatim final transcripts to identify major ideas and themes. After transcription, each response (sentence or group of sentences) was coded using codes that emerged in the following domains: patient (knowledge, emotions, cultural beliefs, economic barriers, work, family) provider (hours, provider knowledge, cultural competence, patient navigation, collaboration, outreach) and health system (insurance, equipped facilities, system capacity). The Qualitative Data Collection team then met to discuss major themes and relationships among themes. After initial identification of themes, the consultant reexamined the data and identified additional constructs, reorganized and labeled existing themes, and described relationships among themes. To assist in drafting this report, themes were categorized by types of factors that influence receiving timely and effective care at the level of the individual, health care provider and health system and those factors that act as barriers.

Patient Level Factors
At the patient level, factors enabling care were education and family support. Barriers to care were the competing priorities of work and family demands.

Education
All informants suggested that education was critical to getting women into breast cancer screening, as well as maintaining engagement in diagnosis or treatment. Informants described two main areas of knowledge that education could improve: knowledge of cancer prevention and knowledge of resources for care.

“In terms of facilitators [of screening], one, obviously for me is education, knowledge. In terms [of] facilitating the process, in addition to understanding the benefits and the process, is the ability to have access-- understanding where and how. Education and understanding the risk and the importance of screening; Understanding, knowledge and access to that information.” (#6)

A study led by researchers at the Icahn School of Medicine/Mount Sinai Medical Center compared screening adherence using two educational outreach messages followed by navigation support to increase breast and cervical cancer screening for 1,333 Hispanic/Latina women in Arkansas, Buffalo and New York City. The intervention group received education
about breast screening and the control group received diabetes education. After the initial education, participants were contacted periodically and offered navigational assistance. Mammography screening increased with the addition of the navigation. The authors conclude that the specific health messaging may not have been as critical to increasing screening behaviors. It was the cultural and language specific outreach into the community which disseminated resources about accessing services that had more of an impact on increasing screening.

Other knowledge domains that informants identified as facilitating care were “how to use insurance,” how to navigate care, and what to expect during diagnosis and treatment. Managing expectations and providing guidance about the importance of diagnosis and treatment were described as critical to keeping women adherent to care plans.

“In facilitating it [diagnostic follow-up], it is the education for the patient. Making sure the patient understands the procedures, all the risks, everything that goes into having that procedure. One of the things I think that might hinder a patient from returning is the fear in not understanding what that process is, fully understanding the extent of the abnormality. If the physician can say that in a way to ease the fears of a patient, it would facilitate the patient in coming back, coming back in a timelier manner, and also completing all the recommendations.” (#3)

“Education, understanding what the nurses are doing or why you are doing chemotherapy, why you are doing radiation, why is it important to take hormonal treatment regularly. We do have a lot of women who are on the 5-year hormonal treatment, maybe about 40.0 percent who do not take as it is prescribed, which reduces its effectiveness in preventing recurrence.”(#2)

Informants described at length the various emotions that could act as obstacles to care. The most cited emotion was fear. Although informants described various types of fear, the most cited was fear of a breast cancer diagnosis. In addition, most informants mentioned fear of deportation as a common barrier for immigrants, especially undocumented Hispanics/Latinas and women of African descent. Other fears described were fear of “feeling sick” as a result of treatment, fear of bodily changes and fear of rejection by partners. Other emotions that were described as interfering with care-seeking behavior were worry, anxiety, shame and feeling overwhelmed. One informant summarized the powerful role education can play in addressing fear:

“…but if these barriers are addressed effectively, patients will be coming in. They will be sacrificing whatever fear they do have in order to do something that is beneficial to them or their family. I always tell the individuals… that “the 20 minutes of fear that you have for this appointment is not worth the 20 years if negative findings could come up if you weren’t to take care of this right now.”” (#1)
In addition to addressing emotional barriers, informants described the various cultural barriers addressed through education. Many informants described a fatalism linked to religion, such that cancer was viewed as a curse from God. For others cancer was viewed as fated and as such something that only God could treat. This theme emerged especially in discussion about women of African descent. One informant said: “We find that the Haitian community, which is also a large population, sometimes wants to “give it to God” as opposed to doing the follow up necessary.” Informants noted that this fatalism was also high among Hispanics/Latinas as “many women come from Central America; they associate it [cancer] with immediate death.” Several informants described the challenges of serving West Africans and Muslims, noting that “our patients are Muslim and cannot see a male doctor...We have to find a female clinician to see the patients.”

Objectives of a study led by L.R. Chavez examined the demographic and other predictors of fatalistic beliefs among Hispanic/Latina women and non-Hispanic White women and assessed the impact of those beliefs on the use of cancer screening services. Ninety-four Hispanic/Latina and 27 White women were selected for ethnographic interviews and 803 Hispanic/Latina and 422 White women were selected for a telephone survey. The study showed that Hispanic/Latina immigrants were more likely than US-born Hispanics/Latinas or White women to have fatalistic beliefs. Immigration, education levels and insurance status predicted fatalistic beliefs.

Researchers in St. Louis, Missouri investigated perceived barriers to mammography among underserved women in an urban setting. Over 9,000 registrants in the Siteman Cancer Center Mammography Outreach Registry, which was developed in 2006 to evaluate mobile mammography’s effectiveness among the underserved, were asked why they thought women did not get mammograms. Approximately 2500 Black/African-Americans and 3000 Hispanics/Latinas were included in the study. Fear of cost, mammography-related pain and bad news were the most commonly reported barriers. The results of the study are underscored by key informants who cite fear as a major obstacle to care.

**Family Support**

All informants described family support as the second most important factor in care. For instance:

“Sometimes, a family would push and remind to keep the appointments. Sometimes, we can’t get in touch with our patients, and we do have a relative on record, so contacting the relative to relay the message that we are trying to get in touch with the patient, so they have that extra person to say, “hey, you need to call someone back in regards to your testing.” (#4)
**Competing Priorities**

On the other hand, family responsibilities were identified as "competing priorities" for women.

“I think family plays a role. That is one of the main messages. As I mentioned before, that is one of the ways we get our message to the women. Women usually take care of everybody else and kind of leave their own health on the backburner. If they are not healthy, they can’t take care of their families. Usually when you bring that family theme and how important it is for them to be healthy so that their families can be healthy as well and be taken care of, that is definitely something that would help them. (#14)

The caregiving role and the difficulty of securing and paying for childcare emerged as important barriers to screening, diagnosis and treatment. Women often struggle with family and work demands. Many have to take time off from work to obtain care. As one informant put it “Patients have difficulty getting time off work. In order to get their screenings, they have to choose between making money to support themselves versus their health.” Another informant stated:

“…because the priority is taking care of your family-- putting food on the table for the family as opposed to going to follow up with this abnormal concern. Cost- plays a huge factor in medical follow up of any kind. If there is a cost out of pocket and there is a concern about maintaining the household like paying rent, or paying for a metro card, and feeding your family then follow up will not be a priority. I’ve seen that happen… if there is an issue with being able to financially support your family, they chose to support their family.” (#6)

A study was conducted by Samantha Hendren, et al., to better understand the barriers to cancer care and to determine which Black/African-American, Hispanic/Latino and non-Hispanic White patients have a greater need for assistance from a patient navigator. The study took place in a large academic center and three community hospitals in Buffalo, New York. Community health workers (CHWs) assisted newly diagnosed breast and colorectal cancer patients and collected information about patients’ barriers. The most commonly identified barriers to care included many mentioned by key informants - a lack of social support, insurance/financial concerns and difficulties with communicating with health care providers. Those patients who had more complex barriers and who reported a greater need for assistance were Black/African-American and Hispanic/Latino and in most cases, were unemployed. An increase in the number of barriers led to delays in treatment. The Community Health Workers reported that some barriers were time-intensive. Problems such as transportation, unstable housing, health insurance concerns and identifying interpreters prevented patients from being able to focus on their treatment. Additionally, patients reported a reluctance to query their physicians about their treatment leading to a lack of understanding about their care. The CHWs accompanied patients to their doctor’s appointments to provide comfort and support to the patients and help to ensure patient understanding of the doctor’s comments. The authors conclude that the study’s Black/African-American and Hispanic/Latino cancer patients’ barriers to care are far more complex than just transportation or insurance coverage problems. They suggest that patient
navigation programs are well-suited to address the barriers but navigators may require additional training to be able to handle more difficult problems presented by their patients. Programs may need to focus more resources on the highest-risk patients because the service is resource-intensive. Several key informants discussed the difficulty in trying to arrange medical appointments around patients’ work schedules, identifying legal representatives to help with patients’ housing and social service problems and juggling patients’ child care issues while they are trying to ensure that patients adhere to their treatment schedules. These problems complicate treatment adherence and recovery.

**Provider Level Factors**
At the health care provider level, interview participants described factors enabling care as cultural competence, patient navigation and extended hours of operation and appointment availability. A barrier to care was providers’ lack of knowledge of health care resources.

**Patient Navigation**
Patient navigation emerged as one critical way that health care providers overcome both patient level barriers (knowledge, cultural beliefs, language, competing priorities) and provider level barriers (hours of operations, appointment availability) to care. Patient navigation was described by informants as a way of providing “family-like support”.

“The navigation … it helps these women to interpret, provide support and follow up with them, and they become a family member. So, it depends whether they have family here and the family dynamics. (#13)

Patient navigators are a critical part of the health care team and provide the support that can stand in lieu of family support. Support provided by patient navigators ensures that women complete diagnostic follow-up or enter into treatment.

“Having support, whether it is family being supportive, or having a lay navigator to help them through the process will facilitate. Will facilitate better following up of their care. Having a lay navigator say, “Ok, there is an abnormal finding,” and for that person to explain what is going on and kind of help them to the next step – “this is what is going to happen, these are the possibilities, I have been at this point before and now we’re going to talk to the oncologist.” Family is very supportive but also having that person who has been through this process themselves plays a really strong role.” (#2)

“Having support definitely facilitates treatment. Whether it is family or having a navigator companion, like a treatment companion, definitely helps facilitate the treatment.” (#2)

“Then you can get them the support they need. Some people have a family, a good support system. Emotional support. Some patients don’t and giving them the access to say to them, you may want to talk to somebody who has been through what you’re going through, you can talk about what you’re going through. These things that you’re feeling, the things that you’re thinking, it’s normal. But when you’re first diagnosed, everything is
so new, you don’t know what normal is. So you need these other support systems. A support system would be great. “ (#11)

Informants described multiple dimensions by which patient navigators facilitate care. The patient navigator role includes educating women, answering questions, translating medical terminology, providing encouragement or emotional support, scheduling appointments, making reminder calls, language interpretation, filling out paperwork, facilitating insurance coverage and providing concrete support to overcome economic barriers (like financial assistance to secure childcare or cover the cost of transportation to appointments).

“Patient navigation. When you use a patient navigator assigned at the facility who is specifically assigned to follow up with the breast abnormalities, that is the process that works well. I have seen the patient navigation program at the facility that I work at that goes above and beyond trying to follow up with screening abnormalities. From the phone calls to reaching out to the patient, to the counseling of the patient and easing of fears, to making home visits when the demographics might be wrong. I think the population that we work with, a lot of them have demographics that change rapidly so the home visits, the phone calls, the telegrams, that patient navigation piece, I feel, is essential in following up with patients and getting them back in a timely manner.” (#3)

“We have a whole referral system for specialists and specialty services, and our centers are now set up so that we basically facilitate their next appointments, and we validate that they are making their next appointments, and there is a reminder system for it. In addition, our breast health center itself has a navigator who makes sure that those individuals are followed up on, and they make that appointment and that if they require additional treatment services, it is easily arranged for them. It is easy to make it for the individual, makes it more likely that they will do it and show up for it. If you tell someone that they have an abnormal finding, their brain shuts down, and if you tell them that it is their responsibility to figure out how to make that appointment, it’s probably not going to happen. It is easier for us to handle it and make sure when their next appointment is.” ( #7 )

“The hospitals, doctors, and patient navigator as well as programs such as support programs play a role. They call, make sure they have their appointment, make sure that all of the paperwork is done. If they need any help with the paperwork, we ask them to fax or email it to us or ask the doctor to directly email it to us. We help them fill out anything they are comfortable with us helping them fill out. We walk them through the process, handholding. We take it very seriously. Some women do not want to go to treatment, so we try to give them as many support groups as possible. We may have someone come it to talk to them. Just so we can give them every available option.” (#15)

Although informants uniformly stressed the importance of navigators, their opinions on responsibility for ensuring diagnostic follow-up and treatment adherence were varied. The vast
The majority of informants suggested that diagnostic follow-up was timely and of high quality. When asked which health care provider was responsible for ensuring diagnostic follow-up, the majority laid the responsibility on the primary care physician; the second most common answer was the “team,” meaning some combination of the primary care provider and/or radiologist, nurses, and others involved in patient care. When asked which health care provider was responsible for diagnostic delay, some said the primary care physician, others the “team,” and others the radiologist. A few others said, “it depends.” Finally, when asked which health care provider was responsible for ensuring treatment adherence, many chose the primary care physician, but an equal number of informants chose specialists (surgeons/oncologists) or a non-specific “team.” Several informants noted that private primary care doctors were overburdened, had too many patients scheduled daily, and often were not staffed with caseworkers or patient navigators to help manage the necessary follow-up.

According to several published sources, patient outreach and assistance programs have been shown to improve rates of early detection and follow through to biopsy and treatment. The programs are a low cost way to provide supplemental services during treatment for breast cancer. In a study conducted by Anne M. Stey et al, the authors defined comprehensive patient assistance programs as programs having professional staffing and volunteer staffing with a not-for-profit status that offer a wide range of services that include counseling, educational lectures, peer support groups and financial assistance. The study population included 333 women with primary early stage breast cancer treated surgically at eight New York City hospitals. Twenty-one percent were Black/African-American and 31.0% percent were Hispanic. Twenty-four percent spoke primarily Spanish. All of the women had an average of 14 years in education; 29.0 percent had Medicaid/Medicare health insurance and 3.0 percent were uninsured. Other study participants included 64.0% percent who had private insurance. The women were given a choice to utilize one of the patient assistance programs. White patients, patients with private health insurance, those with 1.5 years more advanced schooling and women who were English-speaking tended to use the patient assistance programs most often. The findings of the study showed that the quantity of needs was related to socio-demographic factors with greater needs among women who are poor, unmarried, minority, foreign-born, Spanish speaking and women with low educational attainment. Those women had an average of one additional need as compared to other women in the study. The authors concluded that “that existing comprehensive patient assistance programs are a low cost way to provide information, emotional support and assistance to obtain insurance, medication and transportation for women with new breast cancer.” They further conclude that patient assistance programs provide an opportunity for vulnerable communities to connect to needed services. This statement is supported by the findings from the key informant interviews.

Nina Bickell et al conducted a study to determine whether connecting women to patient assistance programs would reduce the underutilization of adjuvant treatment. Black/African-American and Hispanic/Latina women from New York City hospitals were divided into intervention and usual care groups. The intervention group received patient assistance programs such as counseling and peer support while the usual care group received an informational pamphlet. Interestingly, the results showed that both groups demonstrated high
rates of adherence to adjuvant treatment. The authors suggest that perhaps simply prompting patients about the availability of assistance programs increases the chances that patients will take advantage of those programs. However, the study did highlight the deficiencies of some patient assistance programs for those patients with particular challenges. Patient assistance programs are often limited financially in providing access to funds to supplement rent, medication payments or transportation. At a six month follow up, 6.0 percent of patients in the study reported that they were unable to obtain assistance for these more practical types of needs. Several of the key informants mentioned these intractable problems experienced by the more vulnerable clients they serve.

A study led by Sarah W. Primeau et al, studied the association between social service barriers and timely diagnostic resolution after a cancer screening abnormality among 760 Black/African-American, Hispanic/Latina and White breast cancer patients across six urban community health centers in Boston. The majority had no or public insurance. The authors identified social service barriers that “presented obstacles to meeting life’s most basic needs” such as housing, employment challenges, childcare issues, and income. Subjects with no barriers were compared to those with several social service barriers on their time to diagnostic resolution. Those with two or more barriers were more likely to be Hispanic, younger and have public or no health insurance. The women with multiple barriers had the longest time to resolution as compared to the other group. Navigators contacted patients by telephone after the subjects had been informed that they had an abnormal breast screening finding. The authors concluded that with the introduction of navigation, there was an increase in the timeliness of diagnostic care after abnormal breast screening but those patients with multiple social service barriers took a longer time to resolution. They state that social service barriers are often so complex and frequently require intervention beyond the scope of a patient navigator. The authors echo a suggestion given by one of the key informants that partnerships that integrate legal services and advocacy into the health care team have the potential to “expand the capacity of existing patient navigation programs to identify and address social service barriers.”

Cultural Competence
Informants all suggested that cultural competence is a key promoter of breast cancer screening, diagnosis and treatment. A key idea expressed by all the informants was that cultural competence was defined by an ability to understand a woman’s needs and her culture.

“You have to understand people’s experience and values. Having an understanding of why someone is not going for their mammogram or why they are afraid, especially when you are working with immigrant populations. Each culture has its own values and understanding those values can either give you the trust or not, and that’s important. In the process, if you want people to hear your message and take action, you need to gain their trust. And, if you don’t understand their culture, values, where they are coming from, you are not likely to get that trust then. So it is very important to be culturally sensitive to understand where they are coming from and also understanding their reactions in their behavior. That helps a lot. It also helps you plan their next steps if someone shows resistance to your message, understanding where that behavior is
coming from can help you plan where you are going and what you are going to say next. That is very important to be culturally sensitive towards the people." (#14)

In addition to understanding, informants identified a provider’s ability to place a woman at ease, inspire a feeling of connectedness and trust as a critical component of cultural competence. A key way that health care providers inspire that trust and confidence is by providing information that is “relatable”. About half of the informants directly linked being bicultural (from the same culture as the woman) with being able to provide information that is relatable.

“Patients/customers/clients are more apt to listening and receiving information from those they think they relate to and who understand their background, which maybe come from the same cultural background as they do.” (#3)

Informants also highlighted the importance of the ability to speak in a woman’s mother tongue:

“It plays a big role because when reaching out in the community, there are so many different cultures... A lot of times when I’m out there, a lot of them want their own to talk to them. Either that or I don’t speak the language. And if there is someone who speaks their language and knows their culture, they know exactly what to say to encourage them to come... So it [cultural competence] plays a big role. I am not as effective as someone who does speak the language.” (#8)

Informants also highlighted the consequences of lacking cultural competence. Health care providers who lack cultural competence and do not inspire trust can deter patients from adhering to treatment.

“It is huge. You have to understand the people you are working with. You have to understand how to talk to people, to understand their beliefs about cancer, beliefs about screening. You really need to know these things so that you can explain what you are doing as a doctor or a psychologist in breast cancer. Talking about the curse from God or punishment, those are the real things that we have to deal with. So you have to understand where the people are coming from otherwise you can’t connect with the patients, and with a lot of oncologists, if they can’t form that relationship with the patient, they [patients] will stop the treatment. They are less motivated to go to the treatment because they feel that the person is not on their side. Or, they go to treatment but the treatment or screening experience is very difficult. You can improve the quality of life, whatever the process is. The cultural competence is vital! Particularly in an urban area with people from all over the globe.” (#2)

A literature review described in an article by Susan Mott-Coles et al., discusses providers’ self-rated skills in communication practices when working with Black/African-American and Hispanics/Latinas diagnosed with breast cancer. The review reveals how providers lack the ability to communicate with patients and fail to incorporate cultural beliefs into breast cancer care and treatment. The poor communication and failure to address cultural beliefs can result in
poor patient outcomes. The authors highlight a study of providers’ perceptions of how they address the cultural beliefs of Black/African-American and Hispanic/Latina women with breast cancer. Interviews with physicians, inpatient and clinic nurses, mammography and ultrasound technicians showed that they used the same approach for all patients, regardless of race, ethnicity or culture but felt they practiced culturally competent care. The authors of the article conclude that increased and improved cultural competence education is recommended for providers at all levels as a first step toward increasing culturally competent communications.

All informants agreed that bilingual medical providers were preferable to interpreters. Although all informants acknowledged that interpretation services were available, many reported that it was difficult to obtain timely access to interpreters. Often, the only method of interpretation available was a phone interpretation system. The informants differed in their assessments of the quality of interpretation. A majority of informants noted that most women didn’t feel comfortable with interpreters, whether in person or over the phone and that many therefore brought in family members to interpret.

“The biggest challenge is that it creates a disconnect. I hear our members talk often about this need to develop a trusting relationship with their medical team and how that really makes a huge difference in their stress and anxiety, and they really want to feel that they are being cared for. Certainly, when you have an interpreter it becomes difficult. Our members who do have an interpreters talk about it, ‘cause we’ve asked how that might impact in their communicating, and they do say that it is difficult. It is hard for them to know if it is really received, and it is hard them to feel that there is this strong connection between them and their direct provider because there is an interpreter.” (#6)

A review of the English language literature on cancer care from 1980-1998 was conducted by a team led by J.S. Mandelblatt in an article from 1999 and cited barriers at both the provider and system level. Though somewhat dated, the conclusions in the paper have also been cited by the key informants. The authors report that providers are often ill-prepared to communicate the complexities of cancer care to their diverse populations. Gaps in training in patient-physician communication constitute “an unaddressed barrier to cancer care.” The authors also posit that the growth of managed care represents a major potential system barrier or facilitator to better access to care. Several key informants report the difficulty in obtaining continuity of care for their patients because of insurance coverage. The surgeon may take the Medicaid managed care plan a particular patient is on but the medical oncologist the patient is referred to may not accept the same plan. Patient navigators report difficulties in identifying specialists who will both accept the patient’s insurance AND who are located in an area the patient can easily access.

A study led by Yihang Liu to assess the impact of patient-provider communication on adherence to tamoxifen and aromatase inhibitors 36 months after breast cancer diagnosis in a low-income population of women in California, also found that patient-centered communication, which involves exploring patients’ ideas and concerns, and assesses and responds to their emotions
and understanding, was associated with ongoing treatment. The researchers state that interventions at the provider level to improve their ability to communicate with their low income patients greatly impacts patients’ adherence to treatment.

**Extended Hours**

Finally, extended hours of operation were mentioned as a key way to improve access to care along the continuum. Most informants acknowledged that most health care provider facilities do a poor job of providing expanded access. For example one informant stated “I think we can be better about being more open with hours that would work better for a working woman or a woman with family responsibilities.” All informants considered providing extended hours of operation (outside of 9am to 5pm Monday to Fridays) a critically important way to ensure that women can participate in breast cancer screening, diagnosis and treatment and do not have to choose between meeting their health care needs and addressing the competing priorities of work and family.

“A lot of the women that we help in the community have multiple jobs and taking a day off from work to go to the doctor is not really feasible. They have to make their decisions, “If I don’t go to work then I won’t get paid for that day. I may lose my job and my boss will not give me the permission to go.” So they just don’t take the time off. It comes to maybe evenings or the weekend as their only option. A lot of women ask me if they can come for mammogram on a Saturday. That plays an important role. Unfortunately, a lot of facilities don’t really have that service.” (#14)

“Most places, I feel, are open normal business hours, like 9 to 5. Being able to be open later, having a doctor that is more flexible is important because family is huge to these women—they have lots of kids, they have things that take up their time, so being able to talk to a physician past those hours is something that they are looking to do.” (#1)

Informants highlighted the consequences of not having extended hours of operation. For many women this lack of flexibility translates into not getting timely screening, follow-up or treatment.

“Talking to some of our patients, they are struggling to work or they have to work with their families’ hours. If there aren’t weekend hours available for patients to be seen, it may delay their screening and their treatment because they have to wait ‘til their family member gets there. Or, taking time off the work to go to the treatment appointments or there are no evening appointments after 6 pm; that is going to make it a challenge. You know for some of the people they work in the evening and they come early. If there aren’t late hours available or some weekend hours, that increases the likelihood of someone not coming for their screening and treatment.” (#2)

Some informants suggested that, especially for those women undergoing treatment for breast cancer, the inability to schedule appointments at night or on weekends can result in decreased adherence to treatment.
“It is a real challenge for our members who are working. They have to take time off to be able to go to their treatment sessions and this causes a tremendous amount of stress. There seems to be sometimes not as much compliance among those who are working vs. those who are not due to the hours of health care institution.” (#6)

Even if women can come for treatment on weekdays, limited facility hours of operation deprive many patients of the critical social support of family members during treatment.

“I know that if you are going through treatment sometimes if you’re not feeling well and you have to sit there during chemo, sometimes it’s good to have someone you know or a family member with you. If you have to be there between 9-5, that may not be the case. You may have to drive yourself – push yourself to drive back home. You don’t have that option. If you’re not working, ok but people can’t miss work on a regular basis. It’s not like it’s a onetime thing. People say, ok I can miss this day from work because I haven’t missed work in the last six months. But when you’re talking about a chronic illness, you’re talking about all these different appointments throughout the week, throughout the month for an extended period of time. Having different hours would facilitate that. Sometimes something as simple as having somebody hold your hand when you’re having a treatment – not that it’s any clinically going to make a difference but it just gives you that “I can handle this today” on a day when you think you can’t handle it.” (#11)

**Increased Appointment Availability**

Many informants noted that while some facilities have extended hours of operation which serve to increase access to screening and treatment, those appointments are booked quickly.

“Actually, some of our centers do have flexible hours. We do have one office that provides a few appointments on Saturdays. You know that works out a lot, but they book up so fast. Most of the offices are 9 to 5 or 8 to 4, so for the working people, that doesn’t work for them. It’s always good to try to get a Saturday, but they are booked out. It would be better to have more weekends or after hour appointments. Not a lot of our providers at the moment have flexible hours.” (#15)

In short, the demand for flexible hours exceeds the supply of available appointments.

“When it comes to the screening process, dealing with different places, you get different responses. There are some organizations where I can call, and it will be no problem, “I can get you right on the calendar, I can make an appointment right away.” And then some take you through hoops. It can be very discouraging for someone that doesn’t know the whole process. Especially, if you have a language barrier and you are trying to do all of these things. Then at some point, you just give up because all of this is way too hard. I need my prescription, call my primary care physician, but I do not have a primary care physician, so now what do I do? Who do I call? I have nobody else to reach out to. Those are some of the things that make it harder. There are some hospitals that make it
easier, they will take care of XYZ, and it is a little easier for them, so they are not as discouraged." (#9)

Appointment availability seems to be a problem for all types of medical providers. One informant highlighted a particular problem within the public hospital system in New York City:

“Making sure the appointments are available, the times and days... Making sure there are enough appointments available. In the HHC facilities, for them - if someone doesn’t make their appointment, they forgot or whatever, they usually have weeks to wait to get another. So if they could somehow change that so that way if someone misses an appointment, they could get seen quicker than 3-4 weeks out.” (#10)

**Provider Knowledge of Resources**

By providing culturally competent care, patient navigation services, and extended hours of operation, health care providers can overcome some of the most difficult barriers women face. However, one in three informants suggested that provider lack of knowledge is a persistent obstacle to women accessing care. They indicated that providers are unable to educate women about available services and to refer women to the appropriate resources.

One informant responding to a question on how health care providers encourage screening replied:

“Doctors by providing the information on screening, when a women should get screened, by informing patients of different places and different programs that would provide those screenings. If cost is an issue, knowing how to refer them to programs where they can get free or low cost screenings. I think the more that a patient understands, the more the patient is willing to get the screening”. (#3)

Another informant highlighted the importance of provider knowledge in facilitating treatment

“The health care provider needs to be aware of what the patient can be referred to. If something abnormal comes up and they do need treatment, so education for the health care provider and being able to convey that information to the patient. Like who they should be referred to if the treatment isn’t going to happen on site and any other counseling services that they could refer them to as well.” (#1)

**System Level Factors**

At the health system level, informants described factors enabling care, such as comprehensive insurance, funds for low cost and free care and community outreach. Barriers to care cited were health facility shortage areas and poorly equipped facilities.

**Insurance**

Informants suggested that care insurance availability and methods to reduce out-of-pocket costs for women facilitate access to care.
“Cost is important. I think 75.0 percent of the time, it’s something that patients are worried about. “How am I going to be able to pay for this? How is it going to be covered? I don’t have health insurance.” So being able to provide that to a patient is part of the battle.”(#1).

“Medical insurance and the quality of medical insurance translates to having a larger balance to pay in terms of copay and out of pocket expenses. Sometimes, that deters those who are not in a situation where they don’t have comprehensive health insurance to not really be assertive in obtaining screenings. If they don’t feel that there are any symptoms, then the mentality is, “I am not going to incur any additional cost unless I am symptomatic.” So out of pocket expenses become stressors, which I think deters from prophylactic measures.”(#6)

The looming spectre of cost affects women’s care seeking behavior for screening, diagnosis and treatment. The fear of incurring out-of-pocket costs discourages women from seeking care. One informant commented:

“Women feel that, “What is the point of getting screened. If they find something I can’t get treated any way, I can’t afford it.” Sometimes, women need additional testing, being an MRI or CAT scan and not having access to these services becomes a problem too. Our social worker helps a lot of those women as much as she can…And, for women without health insurance, it is a huge challenge, and they are not getting quality care or the treatment compared to someone that might have insurance or might have access to better quality care. It is just unfortunate that there are so many disparities and differences in that quality just because someone can’t afford it.” (#14)

Even when women have overcome initial obstacles to screening, it becomes an additional hurdle to complete diagnostic care or treatment with those attendant costs for the additional care. One informant echoing a client viewpoint shared: “Okay, I got my mammogram and it cost this much or my insurance covered that, but after that, would it cover the treatment as well?” Several informants shared stories about the consequences of underinsurance especially as it relates to treatment:

“If you have insurance but only have a certain kind of Medicaid, a facility might not take that type of Medicaid, so you may have to travel to get to a different facility or different physician in order to have that treatment. That could be a barrier to a lot of women. Certain surgeons do not take insurance. You’ll pay them then submit for coverage. So the cost could be a huge barrier to women.” (#9)

Worry about the cost of treatments prevents women from adhering to the treatment plan. Several informants spoke of the dire consequences including women abandoning treatment altogether or skipping doses of medication:
“If these people are paying out of pocket for treatments that are ridiculously expensive, they aren’t going to go through with the treatment. Because why would they spend money on something that may or may not help me when I could be using that money on my family and their future and their well-being.” (#1)

“The insurance is not comprehensive enough to cover the expenses to a point that they can afford out of pocket. Or maybe the copay for all these visits is just too much, and they can’t afford it. It is not efficient insurance to cover all their expenses, so they start cut back. Sometimes, they skip some of the dosages.” (#6)

Stephanie B. Wheeler led a team that wrote an article summarizing the existing literature exploring reasons for racial disparities in breast cancer death with an emphasis on treatment disparities and opportunities for future research. Their focus was on Black/African-American and Hispanic/Latina women and reviewed biologic and non-biologic differences in breast cancer. Based on their review, the researchers state that “poor quality care persists among minority groups.” In addition, “inequities in treatment that lead to disparate health outcomes may have been essentially ignored resulting in widening gaps in outcomes between groups.” The authors suggest that there are a number of physician and facility level factors that affect the quality of care to varying degrees. The factors include environmental (geographic location), organizational (radiotherapy on site, caseload severity), institutional affiliations (academic and teaching status), provider (physician training, research alliances) that may be more or less problematic for patient subpopulations. They conclude that high quality treatment of breast cancer requires a multidisciplinary approach that necessitates coordination across multiple providers and health care settings. They further conclude that ensuring that all patients regardless of race, ethnicity or income level access that level of quality care has to be addressed at the policy level.

**Funding for Free or Low Cost Care**

A key method to reduce out-of-pocket costs for women is funding streams that provide free or low-cost screenings and breast cancer care in situations of underinsurance. All informants mentioned the critical role of the Cancer Services Program in providing care for underinsured women as well as undocumented women unable to benefit from new insurance under the Affordable Care Act.

“Of course, our relationship with the Cancer Services Program is crucial. Women don’t have a lot of options when it comes to breast cancer screening or the Cancer Services Program, so they are crucial in the process. It wouldn’t make a lot of sense for us to bring the message and say, “Yes, go for your mammogram every year” if we are not able to tell women that if you are uninsured, we can help you. It completes the process for us and it makes sense. It binds everything together when we are able to send the women there for the screening.” (#14)
Several informants mentioned Emergency Medicaid as another way to cover women ineligible for other coverage. At the same time, multiple informants acknowledged the limitations of the Emergency Medicaid program:

And for patients who are not even eligible, it’s a balancing act because through Emergency Medicaid it will cover some treatment, it doesn’t cover everything that you need. It doesn’t cover scans, it doesn’t cover any injections, Neupogen, Epogen, anything like that. So now have to go to a place that has financial assistance to cover the services not covered under Emergency Medicaid. Then it’s also trying to educate providers about Emergency Medicaid that it’s not just services that you get in an emergency room. That’s another barrier we see out here. So it’s been hard and we’re still working at it. But so far we have been able to work around things. So between the Emergency Medicaid and financial assistance, the patient is still going to owe money but the amount they will owe will not be hundreds of thousands of dollars vs. Thousands of dollars. (#11)

**Community Outreach**

Additionally, informants suggested that health systems that foster community outreach and welcome community input promote breast cancer screening, diagnosis and treatment. Community outreach is critical in educating women and increasing knowledge about available resources.

“I think people’s perception of cost may be—there is not cost barrier because of the grant that we have—but individuals will perceive that there is a cost barrier because they aren’t aware of the programs that we have here. Even now, after having several years of being out in the community, they don’t realize that you can have free screenings. It’s kind of sad when we diagnose breast cancer.” (#9)

Active community outreach helps health systems, particularly hospitals; publicize the availability of free or low-cost screening, diagnosis, and treatment to serve women who are not normally in hospital or medical settings.

“We go to places where women are—food pantries, churches. These are the people that rarely go for health screening. These are the people that are basically… you rarely run into them. So I think just having a program like this…. But we also have other programs like Cancer Support Team, and other support systems in the county. …. I think programs like this help women go for their screenings. Not only because we do it step by step for them, but we also counsel them, motivate, and figure out what’s wrong. We try to make every effort possible to give them what they need”. (#15)

Community outreach also helps support breast cancer prevention education and promotes a general culture of prevention.
“Knowledge is always the big one. Really educating people why you should have this test and why it is important. And knowing your own body--very basic things. If you feel strange, go and check it out. Probably, kind of having a better relationship with the health care team. It is difficult because “who knows what doctor we are seeing,” so possibly a better connection with the community and their local hospitals would foster people in deterring “ok I am not feeling well, or I notice something strange…and maybe I should ask my doctor about it.” For the institutions, to seem less intimidating, more community connected and integrated, so people can go and ask their questions and feel comfortable with their doctor. ...Definitely, the community outreach portion is very important. I think it is vital. To really pick a hospital and make it really part of the community--the hospital, the clinics, the doctors. Ultimately, you want to think of them as a family, that they can go to these people for information. I am convinced that they are concerned about my health care and not just another dollar sign. I think that is what people want to know. Reaching out to the community, giving knowledge and making things accessible--that is definitely what hospitals and providers can do.” (#2)

The article authored by Lina Jandorf et al., which was referenced earlier cited the importance of educational messaging coupled with community outreach to increase cancer screening percentages among Hispanics/Latinos.

**Health Facility Shortage Areas**

Informants identified persistent barriers to care as geographically dispersed facilities for screening, diagnosis and treatment, and lack of public transportation, particularly in Suffolk County, the Lower Hudson Valley, and Staten Island.

“Foremost is having providers in the community that you have access to. Suffolk County, especially the East End, the layout is very different than other counties. Providers are sometimes very spread out. Transportation is a big issue on the out on the east end if you don’t have transportation. Makes it very hard because there may be one bus but in order to get to the bus, you may be very far from that one bus route.” (#11)

Distance from health facilities was also mentioned for certain parts of southern Brooklyn and the northern Bronx. These findings echo Affiliate findings from the Health Systems and Public Policy Analysis.

**Poorly Equipped Facilities**

In some areas, the available facilities are not fully equipped for timely and effective diagnosis and treatment.

“The second issue with the services is that there is no public transportation in this area for people to get to the services that are even available. While people don’t think of Long Island as being a rural area, on some level it is very rural when it comes to real concrete services like these...There is no comprehensive cancer center there, and there is no
clinical cancer center in that particular area on Eastern Long Island. Stonybrook will be the largest University Medical Center, and that is a long way for people to go and get treatment. While there are efforts to improve the local hospital, it is very very slow to improve the cancer services of the local hospital. (#12)

While the above excerpt highlights this gap in Suffolk County, other informants highlighted this gap in the Bronx, Brooklyn and other counties in the service area and echoed findings from the Health Systems and Public Policy Analysis.

Special Needs of Immigrants
Throughout the interviews, the unique challenges faced by immigrants especially undocumented immigrants, were frequently cited. As one informant stated: “I think the individual who is an immigrant or doesn’t have a residential status has a very difficult time getting screening.”

Addressing Unique Barriers through Education
Many informants spoke of the critical role of education in addressing specific barriers faced by immigrants. Education is critical to addressing the fear of diagnosis and fatalism engendered by coming from countries where there are few resources to treat cancer.

“Immigrants have various issues and problems like immigration, finances, the issues of living in a country where there was no support where everyone did have cancer and died and the assumption is that you get cancer and you die. When they come here they learn through community and we reach them and let them understand and understand health care, advocate and speak out and use the resources that are available, there is a life after cancer is diagnosed. “(#13)

In addition, immigrants are often afraid to seek care because of fear of deportation. As one informant shared: “Some barriers would be….an individual’s immigration status because they have a fear of whether they are going to be deported because they came in to see a doctor or get a mammogram”.

Education is also critical to allaying fears that the undocumented may have about paying for medical services. And outreach and education allow providers to link women to resources for free and low cost care:

“When we’ve encountered it [cost as a barrier], a lot of our undocumented feel it will put them on the radar screen and there will be a cost and they don’t have insurance. But we do participate in the CSP, so we make them eligible for free breast screenings. So cost is really a factor in our community. It is a matter of reaching those populations that are afraid to put themselves on a radar screen by having a preventative screening”. (#7)
**Importance of Cultural Competence**
Several informants throughout the service area also highlighted the critical role of cultural competence when dealing with immigrant women.

“Absolutely, especially in the new immigrant population that exist on Long Island. We certainly need people to be able to speak the person’s language and understand their culture and understand the meaning of illness for them and what treatment will mean for them, and what decisions they have to make actually living in this country, so I think it is really important to have people who understand that and those services and speak their language and understand and make it more available on an even different level for people who are new immigrants and dealing with so many other issues that are here, besides making services available to them. The importance of that as important as it is, any place, especially when the services are limited, then it becomes even more crucial to capture people in the moment.” (#12)

Health care providers must not only understand cultural and linguistic barriers but understand the particular economic barriers facing low income, immigrant workers:

“It is a complicated issue. Having the knowledge and having things available in the language that the people in the Bronx are speaking. It is quite often you find English speakers and we need more Spanish speakers, and we have completely monolingual Spanish patients who if you are trying to explain that there is breast cancer diagnosis, they don’t understand. It increases their fear, and they are less likely to come for treatment, and they come when there is a stage four cancer and there is not much we can do. Part of what makes people less likely; there are a lot of undocumented workers and they are afraid, if they come where is the money going to come from for treatment. No insurance. If something happens to them, are they going to get treated? If they come for treatment are they going to be reported, so that is one of the issues in the Bronx. So it is monetary, education, cultural factors like cancer is a curse from God and some of the belief systems. It requires a lot of education tailored to them by people in the community. That tends to work better, something you have in common with others like common culture, common goals to make it easier. Maybe having someone who has been through the process before will encourage people to go step-by-step through the screening through the abnormal findings to further testing, diagnosis and then oncology work up if that is necessary.” (#2)

Several informants spoke of the consequences of not providing culturally competent care to immigrants particularly delays in care:

“Language plays a major role. It can make the difference between women getting the appointment or not getting the appointment, women understanding or not understanding the result even going for their appointments or following up after their appointments. A lot of women have to call for their appointments but no one speaks their language. They hang up and no appointment is made, and you lose the person. They get really
intimidated… To have someone to speak their language [is important] because we are aware that it could deter the woman from even making that appointment. It is like series of steps, making an appointment is one of the first steps in that process. If the women don’t get anyone in their language, most women will not make that appointment.” (#14).

A Challenging Coverage Landscape
Several informants spoke of the challenging insurance and coverage landscape for providing care for immigrants especially the undocumented. Informants noted that there are funding streams to support care for the undocumented like the Cancer Services Program:

“One of the barriers that people do look into is their health insurance. Something that they are worried about is immigration status and being able to have that coverage. So being able to provide a mammogram at very low cost or free is key and important for these patients. That’s why our collaboration with Cancer Screening Program is so effective and helpful.” (#1)

Informants also acknowledged other programs to provide care for this vulnerable group but they highlighted the limitations of these programs.

“Our programs are free, so that is how we deal with their care at least. The hospitals support that, for us to provide the free care… They do have the social workers and insurance teams to figure out a way to support patients. There are limitations with undocumented workers, that is what we have been seeing mostly. That has been taking an uptake in needing treatment and how we can get them the care when they can’t get insurance or they can’t get Medicaid etc etc. They [social workers] try their utmost to find some program. But it’s not available to everyone who has need, unfortunately”. (#2)

“We are trying to figure out additional ways to reach out to the undocumented, uninsured populations. Our challenge here is that we have the free screening; we have CSP programs for screenings, and then if there is an abnormality, that funds for a follow-up screening. But if it actually becomes cancer, they require more intense treatment. We process them through our financial assistance program, but in general, there is not a lot of financial support from that point forward. They require oncology treatments, induction treatments”. (#7)

“I think we need to address the immigration issue, access to insurance. I know that there is emergency health insurance, but then again the fear of enrolling in the system and becoming noticeable becomes a real deterrent.” (#6)

Finally, multiple informants spoke of “the pocket of population that is out here that is still undocumented therefore not eligible for insurance” under the Affordable Care Act.
**Need for Holistic Survivorship Care**

Participant interviews suggest that survivorship needs are a key though sometimes underserved need for women with a breast cancer. A key theme that emerged was that women require “holistic care” addressing biopsychosocial needs including: 1) a medical provider responsible for a follow-up care plan; 2) emotional support in the form of psychological counseling and/or support groups; 3) a provider capable of addressing social needs and providing concrete services in the aftermath of a cancer diagnosis.

“I think that should be a multidimensional approach. She is gonna need not only the medical team reinforcing the importance of coming back for treatment and all that, but also someone who works with her on identifying and overcoming any barriers. Identifying things like transportation, child care issues, her job situation, living situation. And someone who works with her on psychological level, works with family... You need kind of that multi-level approach to identify the psychological and social barriers.” (#14)

In addition, informants suggested the critical role of wellness groups including yoga, nutrition and exercises classes as critical tools for self-care and to support women in the survivorship period.

“The supportive care is the basics of knowing when she has to go for follow up appointments, having that all laid out for her. And, it is also about planning life after cancer. A lot of women that I speak with are like, “Ok I have been diagnosed, and I have had my treatment and the treatment has finished, and now I am out there in the open, I am all alone now.” They have their doctors and everyone, but now they are done, and they are out. They don't know what to do…. How do I rebuild my life after cancer? So that is when they need a lot of supportive care whether it is coming to wellness groups. Wellness groups that have nutrition workshops, yoga, mind and body groups, support groups that help you build your sense of self, recovering from broken relationships. A plan for the future. Trying to return to work-- how do you return to work and talk to an employer if you have long term disabilities from the treatment? That is really the supportive care they need after they complete their treatment.” (#2)

**Qualitative Data Findings**

The Affiliate developed a key informant interview guide that included questions to elicit barriers and facilitators to accessing breast care along the cancer continuum. Thus, the findings of the qualitative data analysis link directly to the key questions generated as a result of Quantitative Data Reports and Health Systems and Public Policy Analysis.

The Affiliate identified specific barriers that prevent a patient from moving from screening to diagnosis, from diagnosis to treatment, and from initiating to completing treatment. Factors enabling care at the patient level are education and family support. While the competing priorities of work and family demands served as barriers to accessing care along the continuum. At the health care provider level, interview participants described factors enabling care as
provider cultural competence, provision of patient navigation services and extended hours of operation and increased appointment availability. Barriers to care were lack of provider knowledge of health care resources. At the health system level, comprehensive health insurance, funds for low cost and free breast care and community outreach enabled care along the continuum. And barriers to care were health facility shortage areas as well lack of equipped multi-modality facilities.

Stephanie Wheeler’s article on disparities in breast cancer treatment posits that the barriers related to health systems and providers have to be addressed at both the institutional and policy level. Until changes occur at those levels, the disparities will persist. Regardless of advances in cancer treatment, Blacks/African-Americans and Hispanics/Latinos will continue experience poor outcomes.

Since the analysis was focused on women of African descent and Hispanics/Latinas the Affiliate did not find that these barriers were unique to certain demographic subgroups of these populations. The patterns that emerged seemed to globally effect this population. The Affiliate also found that lower income women and immigrants had the same problems but to a greater degree. That is, lower income women of African descent or Hispanics/Latinas would be more sensitive to insurance or cost barriers and competing priorities. And immigrant women would be more sensitive to issues related to cultural competence, require enhanced patient navigation and special programs to deal with being uninsured. Informants did highlight the particular need for culturally competent services directed to Haitians, West Africans (especially Muslim subgroups) and to Hispanics/Latinas more generally.

Informants laid the responsibility to ensure that a patient completes the diagnostic and or treatment plan on the primary care provider. However, there was a disconnect between this theme and the resources and time that private primary care providers have at their disposal to ensure follow-up. Most informants noted that private primary care doctors’ offices were overburdened and often lacked bilingual staff, access to phone interpretation services or staff to act as patient navigators.

The articles by Stey, Bickell and Primeau highlight the importance of utilizing patient navigators in both screening and treatment settings. The authors also cite the difficulty that navigators experience in dealing with the more complex problems that many Blacks/African-Americans and Hispanics/Latinos present in addition to their health care issues. Patient navigation programs are often under-resourced making it difficult to assure that patients’ needs are met.

The literature review by Mott-Coles cited that underserved patients of color have difficulty in communicating with their physicians which can lead to non-adherence to treatment. Those difficulties are often related to providers’ lack of understanding of their patients’ cultural norms. The authors conclude that cultural competence education is critically needed not only at the mammography and ultrasound technologist level but providers need to be culturally competent to ensure that they provide high quality care to their patients.
Informants noted that patient navigators are the primary method employed by hospitals to prevent loss to follow up and promote adherence to diagnostic and treatment plans.

Institutions within the five regions also have varying levels of capacity to provide the full range of diagnostic, treatment, and other services that breast cancer patients may need. In the five regions, most navigation programs that exist in a county are Cancer Services Program patient navigation programs. Outside of this federally and state supported system there are few robust patient navigation programs. Further, as highlighted in both this qualitative analysis and Health Systems and Public Policy Analysis there are health facility shortage areas in Suffolk County, southern Brooklyn, northern Bronx, and Staten Island. Not only are these regions without facilities but the facilities that are present do not provide the full range of diagnostic and treatment services. Please refer to the health facility map for more detail on those health care facilities with accreditations from the American College of Surgeons Commission on Cancer, American College of Radiology Breast Imaging Center of Excellence and National Cancer Institute designated Cancer Center. For example, Bronx has an NCI designated cancer center, while Brooklyn, Staten Island, Suffolk County and Lower Hudson Valley have none. Whether the pattern of health care facilities of high clinical quality is a driver of persistent health care disparities as described by the Quantitative Data report warrants further study and exploration by the Affiliate and other stakeholders.

As another example of varying levels of capacity to provide the full range of services that patients may need, informants uniformly pointed to the fact that most facilities do not have enough bilingual let alone bicultural clinical providers. Further, these facilities must then resort to in person or phone interpretation systems. Informants suggested that interpretation was of varying quality. Often, there is difficulty accessing timely interpretation services resulting in the use of phone systems. Often, women are not comfortable with interpreters leading to reliance on non-professional interpretation in the form of family members. Further, this lack of bilingual clinical providers result in decreased trust in medical providers and has the potential for poor cancer outcomes.

As a result of these barriers described above, women of African descent and Hispanics/Latinas in the region face considerable and persistent barriers to accessing services in a timely and culturally appropriate fashion.

**Limitations of the Qualitative Analysis**

Although focus groups with community women would generate rich contextual data, gathering a large enough sample of women and focus groups with enough Hispanics/Latinas and women of African descent was not feasible. According to the guidelines for focus groups, the Affiliate would have had to conduct three to four groups per geographic region x four regions x two target populations for a total of approximately 24-32 focus groups. The Affiliate did not think the considerable cost and effort involved to gather such a large sample would have been justified by the amount of information that would have been learned. Moreover, focus groups would not have provided the depth and breadth of information about health systems that the Affiliate obtained from expert clinicians and public health practitioners in the field.
Key limitations of this key informant study arise from the fact that the Affiliate employed a convenience sample. Convenience samples may be biased because of the over-representation or under-representation of groups. As a result, the informants may not be representative of all the human service agencies that serve women of African descent and Hispanics/Latinas. Further, because all the informants worked at agencies dealing with breast cancer care, they probably knew more about the ideas, opinions, and perceptions of women who have been successfully engaged in care than of those who are more marginalized. Finally, the sample was vulnerable to response bias because many of the informants were former or current Komen grantees. The Affiliate tried to include human service agencies outside the breast cancer realm as well as informants who had never received Komen funding, but none of these agencies responded to requests. For those who did respond, it was particularly challenging to schedule interviews. Several interviews were rescheduled multiple times.

Limitations associated with the document review included limited access to journal articles. More than half of the articles identified were unavailable as full text copies to the general public. A member of the Community Profile Team based at a medical center with access to the medical library’s online catalogue was able to send all of the articles to the Affiliate. Though the articles selected did, for the most part, reinforce the findings of the key informants, the Affiliate was not able to identify articles to address all of the factors identified by the key informants.

Conclusions
Based on the findings of the Health Systems and Public Policy Analysis and this analysis, the Affiliate recommends that the Komen Greater NYC and other stakeholders undertake the following:

- **Recommendations at the Patient Level**
  - *Patient Education*- support programs that provide culturally competent breast cancer prevention education provided by bicultural and bilingual personnel. Education should have a special focus on increasing patient knowledge of free and low cost resources for breast cancer care. Education should focus on how to choose insurance plans under the Affordable Care Act. In addition, education should focus on how to navigate care for those newly insured under the Affordable Care Act.
  - *Financial Assistance*- support programs that provide concrete financial assistance to reduce the economic barriers to care faced by working women and women with caregiving roles including but not limited to providing financial assistance for childcare, transportation and time off from work.

- **Recommendations at the Health care Provider Level**
  - *Patient Navigation Services*- support programs that allow for patient navigation programs at a wider range of facilities. A special focus of support should be patient navigation programs in community health care settings like private primary care provider offices or federally qualified health centers (FQHCs). In
addition, another special focus of support should be patient navigation programs in nontraditional community settings where the hard to reach congregate.

- **Cultural Competence**- support programs that increase the number of bilingual clinical providers or clinical providers that learn to speak a foreign language in their clinical practice. Also support programs to hire more bilingual and bicultural clinical providers. Support programs that provide for reimbursement for and formalized training, professional development, credentialing for medical interpreters.

- **Provider Knowledge**- support programs that educate providers about the availability of resources for free or low cost breast care services including but not limited to education about Cancer Services Program, Emergency Medicaid, Medicaid Cancer Treatment Program and other funding sources.

- **Extended Facility Hours**- support rapid cycle quality improvement programs linked to changing practice and reorienting to more patient-centric care that recognizes the competing priorities that women face. These quality improvement programs should focus on providing extended hours of operation (outside of the traditional Monday to Friday 9am to 5pm paradigm) and increased appointment availability for breast care along the continuum.

- **Recommendations at the Health System Level**
  - **Insurance**- support advocacy around comprehensive insurance and reducing out of pocket costs for women. Support initiatives that encourage health care providers to accept Medicaid. Support increased mass media campaigns targeted to consumers providing education and concrete educational tools on how to choose insurance products in the NY State of Health exchange. Support advocacy and initiatives to explore how Medicaid Redesign Team DSRIP funding can be used to support breast cancer care along the continuum.
  - **Funding for Free or Low Cost Care**- support advocacy for continued funding for the Cancer Services Program. Support advocacy that highlights the unique needs of the undocumented especially the need for health insurance products or coverage geared to this population. An important advocacy goal to support would be ensuring administrative action by New York State on recommendations of the Medicaid Redesign Committee regarding streamlining Emergency Medicaid. Support advocacy for continued funding for charity care or other funding streams to compensate safety net health systems that provide care to the undocumented.
  - **Community Outreach**- support programs that sustain active and novel community outreach strategies to difficult to reach populations. Special emphasis should be given to projects targeted to immigrants of African descent and Hispanics/Latinas, as well as undocumented immigrant populations from these groups.
  - **Health Facility Shortage Areas**- support advocacy for funding to support multi-modality care in these shortage areas. Support convening a workgroup of the NY State Cancer Consortium or Cancer Education and Advisory Council to study
health facility shortage areas in the five regions and map community assets with high degrees of clinical quality (those facilities with accreditations from the American College of Surgeons Commission on Cancer, American College of Radiology Breast Imaging Center of Excellence and National Cancer Institute designated Cancer Center). Support programs that enhance provider collaboration in these shortage areas and help connect women to available, high quality resources. Support demonstration programs and initiatives that facilitate referral between primary care physicians, radiologists, surgeons and oncologists in these health facility shortage areas.
**Breast Health and Breast Cancer Findings of the Target Communities**

The proportion of women who reported having a screening mammography in the past two years was 78.4 percent in New York State and 74.0 percent in the United States overall in 2012. Per the Quantitative Data Report, in the Affiliate’s region the proportion of women who reported having mammographic screening was 80.6 percent.

Given the data on early stage diagnosis and death for Black/African-American and Hispanic/Latina women, the high rates of mammography screening via self-report seem counterintuitive. This may reflect processes after the screening mammogram takes place that constitute some sort of breakdown in care which promotes a delay in diagnosis.

The Affiliate’s Quantitative Data Report identified the Bronx County as a medium-high priority service area. The county has a relatively large Black/African-American and Hispanic/Latina population. In addition, with low education levels, high poverty rates, high unemployment, and a large number of households with limited English proficiency, the Bronx County has high breast cancer death rates and a large proportion of women diagnosed at late-stage disease. Those residents with limited English proficiency are often linguistically isolated in their communities. The Bronx County also has large numbers of uninsured residents. Kings County, which is the most populous county in the greater New York City region and has the largest Black/African-American population in the Affiliate’s region at nearly 900,000 residents, was selected as a medium priority.

Across the Affiliate’s region, Black/African-American women had consistently higher death rates than other racial groups. Black/African-American and Hispanic/Latina women were both found to have higher late-stage diagnosis incidence rates. As a result of these findings, Black/African-American and Hispanic/Latina women have been identified as priority populations in the Affiliate’s region. Based on the overlap of priority populations and priority areas, the target communities are Black/African-American and Hispanic/Latina women in the Bronx, Kings, Richmond, and Suffolk Counties and Hudson Valley (Rockland and Westchester Counties). The Bronx, Kings, Richmond and Rockland Counties had the highest death rates in the Affiliate’s region. In addition Suffolk County was selected because of the elevated death rates and high proportion of late-stage diagnosis among medically underserved women. Westchester County was selected because of the elevated breast cancer death among Black/African-American women.

These are the questions identified in the Quantitative Data Report:

- Why are the death and late-stage diagnosis rates so high if screening rates are more than adequate?
- What are the specific barriers that prevent a patient from moving from screening to diagnosis, from diagnosis to treatment, and from starting to completing treatment? Are some of these barriers unique to women of certain demographic backgrounds (e.g., race/ethnicity, country of origin)?
• Whose responsibility is it to ensure that a patient completes the diagnostic or treatment plan? Primary care provider? Radiologist? Oncologist? Surgeon?
• What systems are used by hospitals and providers to prevent loss to follow up and failure to adhere to the diagnostic or treatment plan?
• Do the institutions that purport to serve women in the target communities provide the full range of diagnostic, treatment, and other services that breast cancer patients may need?
• Do those services meet generally accepted standards of quality?
• What barriers, if any, do patients in those communities face in accessing those services in a timely and culturally appropriate fashion?

Health Systems Analysis Findings
The Affiliate’s Health Systems and Public Policy Analysis findings highlight New York’s commitment to ensuring that medically underserved populations gain access to quality care. The Cancer Services Program (CSP), the State’s NBCCEDP program, is deeply entrenched in the communities of color and provides much needed navigation and case management services. The Medicaid Cancer Treatment Program accepts women who have seen a Cancer Services Program provider but may not have been enrolled in the CSP. There is no plan to eliminate the Cancer Services Program and it continues to be supported by New York’s legislators.

The New York State of Health, New York’s insurance Marketplace, has enrolled over one million people since it opened in 2013. The bulk of those individuals enrolled in Medicaid. Over 90.0 percent of those who enrolled stated that they were uninsured in the year prior to enrollment, thus highlighting the benefit of the Affordable Care Act. There were over 900 community navigators based at community based organizations who provided assistance with enrollment. One of the major drawbacks, though, to the large numbers of Medicaid enrollees is the dearth of physicians in the Affiliate’s region that will accept Medicaid. Physicians state that the payments are too low. This is particularly problematic in Suffolk and Rockland Counties where there is a shortage of oncologists. Additionally, some physicians state that some of the health plans offered in the Marketplace pay too little and/or restricts the prescriptions the physician writes or the tests he/she orders. Or the physician may be within a patient’s network but the hospital at which the doctor practices is not.

Uninsured and undocumented residents in the region benefit from being able to obtain care from the 11 municipal or safety-net hospitals operated by the Health and Hospitals Corporation (HHC) in the region. The HHC hospitals will see any patient regardless of ability to pay or citizenship status. However, because of the inability for many to pay for care and reduced Medicaid reimbursement, the HHC hospitals have faced severe financial shortfalls in the last several years leading to reductions in services. There are also gaps within the HHC system. In an effort to eliminate duplication of services within the hospitals, patients may have to obtain care at two or more facilities. For example, a patient may be screened and have had her breast surgery at a hospital in Manhattan, get her radiation therapy at a facility in the Bronx and then, be referred to yet another Manhattan facility for her chemotherapy. Additionally, there are no
HHC hospitals in Richmond County. Richmond residents often travel to Brooklyn or even New Jersey for their care.

The state’s comprehensive cancer control coalition, the New York State Cancer Consortium actively collaborates with the New York State Department of Health, insurance providers and the oncology community. Issues related to medical workforce shortages and oral chemotherapy parity have been championed by Consortium leadership. The Affiliate is involved not only in the Consortium but also is a member of the Cancer Education and Detection Advisory Council, a legislatively mandated group that provides oversight to the NBCCEDP program. The Affiliate’s involvement in state-wide activities like those described above helps to increase the Affiliate’s visibility in the oncology community.

**Qualitative Data Report Findings**
In the Qualitative section, the Affiliate identified specific barriers that prevent a patient from moving from screening to diagnosis, from diagnosis to treatment, and from initiating to completing treatment. Factors that enable care at the patient level are education and family support while the competing priorities of work and family demands served as barriers to accessing care along the continuum. At the health care provider level, factors that enabled care were provider cultural competence, provision of patient navigation services and extended hours of operation and increased appointment availability. Barriers to care were lack of provider knowledge of health care resources. At the health system level, comprehensive health insurance, funds for low cost and free breast care and community outreach enabled care along the continuum. Barriers to care were health facility shortage areas as well lack of equipped multi-modality facilities. For example, Kings County has several large hospitals that provide comprehensive medical services however, the hospitals are constantly overcrowded. For those living in Richmond and Suffolk Counties and the Hudson Valley, transportation is a major barrier to care. Patients without cars have to travel long distances on inadequate public transportation systems. Providing comprehensive patient navigation and support and eliminating systems barriers that prevent patients from moving from point A (surgery) to point B (chemotherapy and/or radiation) is crucial. New York has also struggled with development of survivorship plans making treatment completion a continuum of care priority. Health care professionals from around the region state that survivorship care plans can be generated through the electronic medical records (EMR), but EMR vendors state that it will be very costly to update the various EMR systems.

**Mission Action Plan**

1. Black/African-American and Hispanic/Latina women continue to be diagnosed with breast cancer at late-stages. Black/African-American women have higher death rates than other demographic groups. Problem Statements: Black/African-American women in the Bronx, Kings, Richmond, Westchester and Rockland Counties have the highest death rates in the Komen Greater New York City area. Suffolk County has the highest proportion of late-stage breast cancer diagnosis for Black/African-American women.
**Priority** - After reviewing the QDR, reduce the number of late-stage diagnoses and high death rates among Black/African-American, Hispanic/Latina and other vulnerable women in Bronx, Kings, Richmond, Westchester, Rockland, and Suffolk Counties.

**Objectives**

- By December 2015, update the 2016 Komen Greater NYC RFA to reflect the funding priority of Black/African-American, Hispanic/Latina and other vulnerable women in these counties.
- In 2016, identify and meet with at least two new community-based organizations that target Black/African-American, Hispanic/Latina or other vulnerable women in these counties.
- By January 2016, develop partnerships with ten community-based organizations in Bronx, Kings, Richmond, Rockland and Suffolk Counties that serve Black/African-American and Hispanic/Latina women in an effort to increase the number of grant applications for Screening Coordination and Support & Treatment.
- By February 2017, reach out to current and potential partners to discuss the need to fund more patient navigation programs that ensure early screening, detection and treatment for Black/African-American and Hispanic/Latina women in Bronx, Kings, Richmond Rockland, Westchester and Suffolk Counties.

2. Programs need to be culturally competent and sensitive in providing bilingual and bicultural personnel and materials for Hispanic/Latina women.

**Priority** - Increase access to culturally competent breast health programs among undocumented immigrants, immigrants of African descent, and Hispanics/Latinas in Bronx, Kings, Richmond, Rockland, Westchester and Suffolk Counties.

**Objectives**

- By December 2015, update the 2016 Komen Greater NYC RFA to reflect the funding priority of culturally competent programs that provide bilingual/ bicultural personnel and materials for Bronx, Kings, Richmond, Rockland, Westchester and Suffolk Counties.
- By July 2016, convene a meeting or webinar of current and past Komen-funded patient navigation programs and other interested stakeholders to discuss best practices in outreach to diverse communities and cultural competency.
- By February 2016, make staff of current and past Komen Greater NYC-funded programs aware that Komen materials are available in: Spanish, Arabic, Korean and Russian.
3. Health care providers need to be educated on the availability of free and/or low-cost breast care resources in their area to promote facility and provider collaboration.

**Priority -** Increase provider education regarding the availability of free and low-cost breast services, and encourage and facilitate provider and facility collaboration to providers that serve Black/African-American and Hispanic/Latina patients.

**Objectives**
- By December 2015, update the 2016 Komen Greater NYC RFA to reflect the increased need for provider education about local breast care services such as CSP, Emergency Medicaid, the New York State of Health and the Medicaid Cancer Treatment Program for providers that serve Black/African-American and Hispanic/Latina women the Bronx, Kings, Richmond, Westchester, Rockland and Suffolk Counties.
- By July 2016, convene a meeting or webinar of current and past Komen Greater NYC-funded patient navigation programs and other interested stakeholders to discuss provider outreach, education, and collaboration best practices.

4. Vulnerable populations such as undocumented immigrants, immigrants of African descent, and Hispanics/Latinas have limited access to support and patient navigation programs.

**Priority -** Support advocacy around comprehensive insurance and reducing out of pocket costs for women in the Affiliate’s service area. Support advocacy and initiatives to explore how better use the Medicaid Redesign Team-designated Delivery System Reform Incentive Payment (DSRIP). Support advocacy for funding to support multi-modality care in Health Facility Shortage Areas particularly in Suffolk, Rockland and Westchester Counties to address limitations in care in those areas.

**Objectives**
- By 2016 and beyond, continue to advocate for continued funding of the Cancer Services Program by educating local legislators through grassroots lobbying.
- By July 2016, convene a meeting of Komen partners to discuss development of mass media campaigns targeted to consumers providing education and concrete educational tools on how to choose insurance products in the NY State of Health exchange.
- By January 2016, lobby the members of the New York State Cancer Consortium to adopt this issue as an area of focus as the new Comprehensive Cancer Control Plan is developed.
- By July 2016, convene a workgroup that will work on ensuring administrative action by New York State on recommendations of the Medicaid Redesign Committee regarding streamlining of Emergency Medicaid.
- By January 2016, convene a workgroup of the NY State Cancer Consortium or Cancer Education and Advisory Council to study health facility shortage areas in the
five regions and map community assets with high degrees of clinical quality (those facilities with accreditations from the American College of Surgeons Commission on Cancer, American College of Radiology Breast Imaging Center of Excellence and National Cancer Institute designated Cancer Center).

- By January 2016, identify and support programs that enhance provider collaboration in these shortage areas and help connect women to available and high quality resources.
- By April 2016, identify demonstration programs and initiatives that facilitate referral between primary care physicians, radiologists, surgeons and oncologists in these health facility shortage areas by collaborating with Komen GNYC partners and stakeholders.
- By April 2016, support advocacy for funding to support multi-modality care in these shortage areas by collaborating with the Cancer Education and Early Detection Advisory Council.
References


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