SUSAN G. KOMEN®
CENTRAL NEW YORK
EXECUTIVE SUMMARY
Acknowledgments

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

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Introduction to the Community Profile Report

Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982 that promise became Susan G. Komen for the Cure®, launching the global breast cancer movement. Today, Susan G. Komen® is the world’s largest grassroots network of breast cancer survivors and activists. Komen Central New York became the thirteenth Komen Affiliate to be organized in 1991. In the beginning, the Affiliate’s major focus was education and support as it presented breast health awareness programs at universities, colleges, businesses, health fairs, community centers, and government agencies throughout CNY. In 1995, the Komen CNY expanded its outreach to administer the first CNY Race for the Cure®, held in Syracuse, New York, with Crouse Irving Memorial Hospital being the first major sponsor. The 1995 Race for the Cure allowed the Affiliate to award its first grant, the recipient of which was University Hospital, which used the funds to purchase a refrigerator for its breast cancer research program. Since then, the race has grown from 1,050 participants to more than 5,200 in 2014.

Susan G. Komen CNY grants funds to programs within the Affiliate’s service area that support the organization’s mission, to save lives and end breast cancer forever by empowering others, ensuring quality care for all and investing in science to find the cures. Today, looking toward its twenty-fifth year, Komen CNY is the outgrowth of a true grassroots ideal. Through its continued strong presence at health fairs, educational events, and seminars, the Affiliate reaches out to people of all backgrounds in the CNY service area.

Overview of the Affiliate Service Area
The service area of Komen CNY consists of seventeen rural and urban counties with a total estimated female population in 2010 of 1.25 million. The service area represents 12.6 percent of the total New York State female population; however the geographic area that Komen CNY covers is approximately 34 percent of the state. Approximately 50 percent of the population in the 17-county service area lives in Monroe and Onondaga Counties, which include the service area’s two largest cities, Rochester and Syracuse. Thus, the women whom Komen CNY serves are divided between urban and rural areas. Therefore, although Komen CNY focused this study on Monroe and Onondaga Counties, as they best represent the largest overall populations with the greatest needs in the Central New York service area, it also considered the needs of the extensive rural population in the other 15 counties.

Notable Highlights
Since 1991 Komen CNY has raised more than $5.5 million for local programs and more than $2.5 million for national research grants. During the 2013-2014 grant cycle, the Affiliate and its partners reached more than 12,000 women with breast health education, provided more than 1,000 no-cost screening mammograms for medically underserved CNY residents, detected 64 breast cancers in people who otherwise might not have had access to screening, and provided diagnostic and follow-up services for 87 people with breast cancer.

Purpose of the Community Profile Report
Komen Central New York’s promise to save lives and end breast cancer forever relies on information obtained through the Community Profile process. Every four years, Komen CNY
completes a comprehensive quantitative and qualitative analysis of Central New York’s breast health needs. This Community Profile ensures that the Affiliate’s work is targeted and non-duplicative, focusing Komen CNY’s grantmaking and education priorities. The Community Profile also ensures that efforts in the community stress inclusion, as it guides marketing and outreach and assists in the formation of goals and plans to carry out these goals.

This report describes the varied breast health needs in the Affiliate service area as well as potential areas in which Komen CNY’s may contribute to the promise of reducing breast cancer death. Potential opportunities and key interests have been drawn from analyses of breast cancer statistics and from policies and programs in CNY that may impact breast health. In addition, the Affiliate collected data from providers and key informants throughout CNY, focusing on target communities with the greatest breast health needs. After synthesizing data from various sources, this report presents data-driven priority areas from which Komen CNY intends to develop funding decisions for the years 2015-2016 and beyond.

**Quantitative Data: Measuring Breast Cancer Impact in Local Communities**

**Summary of the Quantitative Data Report**

The quantitative data report (QDR) for Komen CNY links evidence from sources including: North American Association of Central Cancer Registries (NAACCR), National Center for Health Services (NCHS), Centers for Disease Control and Prevention (CDC), to identify the highest priority areas for evidence-based breast cancer programs. The QDR is one of the key information sources that support the Community Profile with descriptive tables, maps, and identification of priority areas. Data are provided at the Affiliate-, County-, and State-levels, as well as for the United States as a whole on female breast cancer incidence (i.e. new cases) and death, late-stage diagnosis, mammography rates as well as demographics (e.g. age, race/ethnicity) and socioeconomic indicators such as income and education level.

The QDR reveals an Affiliate service area with more than 1.2 million women spread over approximately 34 percent of the land area of New York State (US Census Bureau). A small number of populous urban counties are surrounded by many sparsely populated rural counties. Monroe and Onondaga Counties, centered around the cities of Rochester and Syracuse, respectively, include nearly 52 percent of the female population of the Affiliate service area. The racial composition of women in the service area is 88.3 percent White, 8.8 percent Black/African-American, 2.3 percent Asian-Pacific Islanders and 0.6 percent American Indian/Alaskan Native. Ethnically, approximately four percent of women are classified as Hispanic/Latina. Out of the entire Affiliate service area, a large proportion of Black/African-American women reside in Monroe and Onondaga Counties.

The highest age-adjusted death rate from breast cancer in the service area is seen in Monroe County. In addition, the breast cancer incidence rate is significantly higher in Monroe County than the service area as a whole. For these reasons, Monroe County was assigned the “highest priority” based on predicted time to achieve Healthy People 2020 (HP2020) targets for both age-adjusted death rate and late-stage diagnosis rate. As noted, Monroe and Onondaga Counties also have high concentrations of Black/African-American women, who have higher age-adjusted death rates and late-stage diagnosis rates than the corresponding rates in the USA, New York State and Komen CNY service area. Additionally, Black/African-American women are historically disadvantaged regarding health care in general and breast cancer care in particular,
(Hunt et al, 2013; Shavers & Brown, 2002) and have been the focus of Komen CNY’s efforts over the years. Komen CNY is committed to continuing to serve this population.

One rural county, Seneca County, stood out in the QDR due to a high age-adjusted death rate and strong trends for accelerating death and late-stage diagnosis rates. Seneca County was also identified as a highest priority area based on HP2020 targets. The remainder of the CNY service area is predominantly rural and suffers from poverty, poor access to health care and transportation problems. The Affiliate has and will continue to meet the needs of women in these areas; however, the Community Profile Report will emphasize the target communities with the highest population densities and proportions of historically underserved women, as well as the rural county with the most alarming breast health trends.

**Target communities selected for further exploration**

Target communities selected by Komen CNY as focus areas for this report include Monroe County, Black/African-American women in Monroe and Onondaga Counties and Seneca County. Monroe County was selected because of its high breast cancer death and incidence rate and because of its worsening trends with respect to HP2020 targets. In addition, Monroe County is home to a high proportion of Black/African-American women, who have high death and late-stage diagnosis rates, and who are historically underserved by the health care system. Onondaga County, too, has a high proportion of Black/African-American women. This population has historically been the focus of many of Komen CNY’s efforts to improve awareness of, and access to, breast cancer prevention and treatment services. Finally, Seneca County, owing to its high death rate and identification as a priority area for HP2020 targets, was also selected as a target community by Komen CNY.

**Health Systems and Public Policy Analysis**

**The Continuum of Care**

The breast cancer continuum of care represents an ongoing process that may be initiated with screening, which is preferable, or with diagnosis. Women with a positive screen result should receive prompt, high-quality diagnosis and, if necessary, treatment services. A negative screening result or a diagnosis that does not include breast cancer should be directed to follow-up care that includes later screening at age- and risk-appropriate intervals.

**Strengths and Weaknesses of the Continuum of Care in Target Communities**

The two most populous target communities, Monroe and Onondaga Counties, feature academic medical centers with high-quality cancer care. Despite these apparent strengths, elevated late-stage diagnosis and death rates among Black/African-American women persist, suggesting that this population may not be receiving the best diagnostic and treatment care.

Other strengths in these two counties include a strong Cancer Services Program in Monroe County that provides frequent screening and education events designed to introduce underserved women into the continuum of care, while Onondaga County boasts a new Cancer Care Center at Upstate Medical University. Both counties have state-of-the-art mammography facilities in proximity to some communities with poverty.

Despite these advantages, not all neighborhoods with large concentrations of underserved women enjoy ready access to high quality preventive care, and some care that is accessible uses outdated technology. In addition, changes in large health systems within these
communities threaten to disrupt the networks of care that are available for the underserved. In addition, there are pockets of refugees, particularly in Onondaga County, whose health needs are poorly understood. In both counties, deficits in health literacy and cultural issues constitute additional barriers to high-quality breast cancer care and greater coordination is needed to introduce underserved women into and through the continuum of care.

Seneca County, the third target community, has a small population (35,000) and limited health services. The county is largely rural and lies between the two largest Finger Lakes in CNY. The county has no hospital and just one facility for screening mammography, located in the north. A federally qualified health center opened in the southern part of the county serving the poor rural population in this area. Strengths include access to excellent health facilities for those with the means to travel to them and strong collaboration among health care providers and the Cancer Services Program (CSP). Lack of health services within the county and the necessity for women to travel long distances to receive care are the main weaknesses in this area.

Public Policy Environment and Implications
The public policy environment affects the relationship between Komen CNY and state and local agencies that provide access to breast health services for uninsured and underinsured women in the Affiliate service area. Another consideration includes the recently implemented Affordable Care Act (ACA) and how that may alter the landscape for breast health care.

Women without private health insurance can receive breast health services through a complex network of federal, state and local agencies. Screening services are available through the National Breast and Cervical Cancer Early Diagnosis Program (NBCCEDP), which is administered by County-level Cancer Services Programs (CSPs). Coverage for breast cancer diagnosis and treatment is available for Medicaid enrollees through the Medicaid Cancer Treatment Program (MCTP). Enrollment in the NBCCEDP occurs through county departments of social services, working with local CSPs, who assist qualified enrollees in the process of applying for MCTP through Medicaid. Medicaid applications are processed at the state level through the Office of Health Insurance Programs (OHIP). Not surprisingly, given the complexity of this process, many women in need of breast cancer services fall through the cracks in the system and do not receive the high-quality care that they need. Komen CNY collaborates with county CSPs and with health care providers directly to provide a safety net for women who are unable to access breast health preventive, diagnosis and treatment services.

Under the ACA, New York State has participated in the expansion of Medicaid coverage, which will allow more women to receive health insurance coverage through marketplace exchange programs. A number of private health insurance providers will participate in the exchange program and will offer coverage at the bronze, silver, gold and platinum levels. Breast cancer prevention services, notably screening mammography, are included in all of these plans. As a result of the ACA, the NBCCEDP should expand eligibility to offer screening and coordination services to women who remain uninsured, i.e. who may not qualify for Medicaid. The ACA will also alter the environment for providers of breast health care, including primary care physicians who counsel women to seek preventive services and radiologists who provide prevention services such as mammography. Demand for preventive services such as mammography is expected to increase due to expanded eligibility under the ACA and due to the aging of the female population in Komen CNY service area. Reimbursement structures may change in
unpredictable ways for these providers as they work to meet the increased demand for preventive services. Thus, the ACA represents a “wild card” in the public policy landscape which will be scrutinized diligently by agencies involved in breast health care, including Komen CNY.

Conclusions Regarding the Health System and Public Policy Analysis findings
Although the safety net for breast cancer prevention and treatment may expand under the ACA, Komen CNY anticipates that the need to provide services for women who “fall through the cracks” in the system will persist. This need is expected to be most pressing in minority communities that include historically underserved women. Furthermore, some providers of breast health services may decline to take Medicaid enrollees due to low reimbursement, resulting in reduced access to needed care for these women. In addition, the fragmented nature of the health care system will continue to create barriers for uninsured or underinsured women in need of breast cancer prevention and treatment services. These will continue to be focus areas for Komen CNY to enable all women who are in need of breast health services to obtain them.

Qualitative Data: Ensuring Community Input

Key questions and variables that were explored in the target communities
The Affiliate recognizes and understands the importance of involving the community it serves in addressing issues related to breast cancer prevention, diagnosis and treatment. Accordingly, the Affiliate enlisted the help of multiple community leaders in the target communities. Key assessment questions were similar for Monroe and Onondaga Counties, but assessment questions were unique for the rural agricultural population of Seneca County. Due to elevated late-stage diagnosis and death among Black/African-American women in Monroe and Onondaga Counties, the Affiliate questioned where in the continuum of care the system was failing. What were barriers relating to knowledge, culture, health literacy, trust, geography and belief systems that blocked access to high-quality care. In rural Seneca County, which had the highest breast cancer death rate in the Komen CNY area, the Affiliate wanted to know where, when and how women were accessing and receiving breast health services through the continuum of care.

Data Collection Methods Used
In order to learn from those most knowledgeable about women in the Affiliate’s target communities, the Affiliate looked to key informants from among providers and support programs. These key informant Interviews were the main qualitative method chosen to explore barriers to access and utilization that contribute to poor breast cancer outcomes. Through this process, the Affiliate sought to gain in-depth knowledge of issues and relationships among different cultural groups in the Affiliate’s target communities. In order to triangulate findings from key informant interviews, an electronic survey was also sent to a broad range of providers in the Affiliate service area, but there were too few responses to provide meaningful information.

Summary of the Qualitative Data findings
Key informant interviews revealed three salient themes about impediments to the continuum of care that were common to both urban women of color (Monroe and Onondaga Counties) and rural mainly White women (Seneca County). These commonalities included pervasive poverty, lack of all preventive medical practices in general, and an urgent need for medical homes for all.
In urban Monroe County, key informants highlighted barriers to high-quality breast cancer care among women of color who are faced with poverty and poor access to health care in general. These barriers include care facilities that are not conveniently located, lack of diversity among care providers, prohibitive cost of deductibles for follow-up diagnoses, low health-related knowledge and literacy levels, fatalistic health beliefs, and lack of a coordinated system to assist women through the continuum of care. Residents of Onondaga County face similar life circumstances and barriers to high-quality cancer care. Prevention is a low priority among women who struggle to make ends meet in their everyday lives. Here too, health-related knowledge and literacy are limited, women frequently seek advice from unscientific resources, and many women do not have strong relationships with primary care medical providers. Although the health insurance picture may be changing as a result of the ACA, many women in both Monroe and Onondaga counties historically have lacked health insurance, and there is much uncertainty about how changes brought on by the ACA will affect access to breast cancer care in these communities.

Barriers identified by key informants in Seneca County are also related to poverty and lack of primary care. In this rural county many women face social isolation and transportation difficulties, often putting off health care needs until they are in crisis. Many women do not prioritize their own health and do not regularly visit primary providers. Despite availability of free or low-cost prevention services through CSPs, many women refuse to take advantage of these because they consider them to be "hand-outs".

Key informants in all three target communities described dedicated providers who work tirelessly and creatively to bring underserved women into the continuum of care. This was evidenced, for example, by Rochester screening days that offer free services such as massages, and Seneca County providers who coordinate their efforts to find medical homes for at-risk women.

Interviews during this Community Profile cycle focused heavily on understanding barriers to mammography screening because, as the first line of defense, early detection is the best tool to combat breast cancer death and morbidity. Future investigations in Komen CNY could be enhanced by learning directly from at-risk women about their experiences with the continuum of care. The Affiliate also needs timely methods to evaluate the availability, affordability, and utilization of breast health services in various communities that are undergoing rapid consolidations in health care.
Mission Action Plan

Monroe County

Problem
According to the Central New York Quantitative Data Report, urban Black/African-American women in the target community of Monroe County have high breast cancer death rates compared to the Affiliate service area and the state as a whole, and lack of breast health services in proximity to where they live. In addition, the Qualitative Data Analysis indicated that they lack access to medical homes and have few opportunities to participate in screening activities.

Priority
- Facilitate access to consistent, high quality primary health care and increase opportunities to participate in breast cancer screening for urban, Black/African-American women in Monroe County.
- Reduce economic barriers to urban Black/African-American women’s ability to access quality breast health services in Monroe County.

Objectives
- In FY 16-17 a key funding priority will be to develop and/or improve navigation services to facilitate movement through the continuum of care - from primary care and screening through post-treatment support - for women of color provided by urban Black/African-American women in Rochester/Monroe County.
- In FY 16-17, encourage through funding the development of a program to train community peers to advocate and educate Black/African-American women in Rochester/Monroe County to increase access to breast cancer screening services.

Seneca County

Problem
According to the CNY Quantitative Data Report, Seneca County has a high age-adjusted breast cancer death rate as well as a significant positive increase in the death rate of 21.4 percent annually. The Health Systems and Public Policy Analysis indicated that there are limited health facilities due to the sparse rural population and geographic barriers that prohibit convenient and timely care. In addition, the Qualitative Data Analysis suggested that social isolation in this rural environment is common, and that there may be a reluctance to accept free or reduced cost services due to the perception that these are “handouts”.

Priority
- Increase the availability and accuracy of information for women in Seneca County regarding the importance of early screening for and treatment of breast cancer and the services accessible to them.

Objective
- In FY 16-17, hold one training session in Seneca County to teach providers how to apply for grants that would address the amount and quality of breast cancer education and navigation services.
Black/African-American women predominantly in Onondaga and Monroe Counties

**Problem**
In the context of longstanding disadvantages regarding health care in general and breast cancer services in particular, Black/African-American women continue to experience high late-stage diagnosis and death rates, as indicated in the Central New York Quantitative Data Report. The Health Systems and Public Policy Analysis and the Qualitative Analysis reveal that even in those areas where services are close to where they live, Black/African-American women in Onondaga and Monroe Counties face other barriers include fatalism, low health expectations, and competing health, psychosocial and economic problems.

**Priority**
- Partner with community-based outreach/health organizations to effectively promote breast health education and services including breaking down cultural barriers for Black/African-American women in Onondaga and Monroe Counties.

**Objectives**
- In FY 16-17, reach out to two predominantly Black/African-American faith-based organizations in Onondaga and Monroe Counties to hold breast health community outreach presentations.
- In FY 16-17, a key funding priority will be to encourage grant applications that address evidence-based and culturally appropriate approaches to moving women through the continuum of care in Onondaga and Monroe Counties.

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