

Executive Summary

Introduction to the Community Profile Report

Affiliate Overview

The Affiliate began as the Komen New Jersey Race for the Cure® in 1994. Recognizing the need for growth, key volunteers and Board members launched the Central and South Jersey Affiliate of Susan G. Komen® in January 2005. Since its inception, the Affiliate has invested over \$17 million in local non-profit organizations and hospitals through the community grants program, and has helped to fund \$3.9 million in research in New Jersey through the Susan G. Komen National Research Program.

The Central and South Jersey Affiliate raises funds to make grants to nonprofit organizations offering breast health and breast cancer-related projects to medically underserved individuals through its community grants program. The goal is to ensure a patient's needs are addressed throughout the entire continuum of care, including screening, diagnosis and follow-up care. In addition to community grantmaking, the Affiliate's other mission-related activities include local and national public policy efforts, community outreach in the form of breast health presentations, serving as a local resource for patients in need, and spearheading a multi-faceted initiative to reach breast cancer survivors.

The service area is both culturally and demographically diverse in terms of race and ethnicity, age, and wealth, and there are substantial issues apparent at the individual county level in terms of both demographic and socioeconomic statistics. Overall the service area is one of stark contrasts. There are densely populated urban centers such as Camden and New Brunswick that are home to an array of health care services including top quality hospitals and academic research institutions. There are also very rural pockets in South Jersey (in counties such as Salem) where there are higher proportions of undocumented populations, transportation challenges, and generally fewer health care resources overall, leading to medically underserved populations.

Purpose of the Report

The Community Profile presents a compelling look at the state of breast cancer in the Affiliate's 13-county service area, and is an invaluable tool for those working on the issue of breast cancer in New Jersey including hospitals, grassroots organizations, insurance companies, and politicians. It presents a comprehensive look at an array of breast cancer and demographic statistics, the distribution of health services by county, as well as the individual and systemic barriers patients face in navigating the Continuum of Care (CoC). Ultimately, the goal of this needs assessment is to drive the strategic operations of the Affiliate's mission work by targeting the areas of greatest need and establishing measurable goals and objectives for the Affiliate's work in these areas. Among its many functions, the *Profile* will be used to inform the Affiliate's inclusion efforts (within the service area and more specifically the target communities and populations), proposed education/outreach activities, proposed grantmaking, community organizing/engagement, advocacy/public policy efforts, marketing/communications plans, sponsorship/fundraising (i.e. development activities), and strategic and operational planning.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Based on an extensive statistical review, Susan G. Komen Central and South Jersey has chosen to target five communities (encompassing seven counties). Four counties will be grouped into two communities due to their similar population characteristics, creating a total of five target areas. The Affiliate will focus strategic efforts on the selected communities over the course of the next four years. The selected target communities are:

- Atlantic County
- Camden County
- Gloucester County
- Burlington and Monmouth Counties
- Salem and Cumberland Counties

The target communities were chosen because they have the most significant breast cancer-related issues as compared to other counties in the Affiliate service area. When selecting target communities, the Affiliate first considered counties classified in the quantitative data analysis as highest and high priority, as determined by Komen Headquarters. This classification of priority counties was primarily based on the projected time needed to achieve Healthy People 2020 (HP2020) health objectives for breast cancer late-stage diagnosis and mortality. The Affiliate also considered late-stage rates and trends, death rates and trends, incidence rates and trends, breast cancer screening proportions, socioeconomic conditions (e.g. income relative to the US poverty level, employment status, cultural barriers, lack of health insurance, and education), five-year relative survival rates, and population distribution and characteristics.

A brief summary of the findings from the Quantitative Data Report and the Additional Quantitative Data Exploration for each target community is provided below.

Atlantic County

Atlantic County has the highest death rate among Black women compared to all of the other counties in the service area. Atlantic County's five-year relative survival rate is considerably low in general and among Blacks. As compared to New Jersey and the Affiliate service area as a whole, a large percentage of the population is considered to be rural and medically underserved. Compared to other counties in the service area, Atlantic County has the second highest percentage of residents with no health insurance as well as incomes below 250 percent of the federal poverty level.

Camden County

Camden County has the highest late-stage diagnosis rate within the Affiliate service area. Black and Hispanic/Latina women are both faced with death rates that are substantially higher than the average rates of the Affiliate service area and New Jersey as a whole. Additionally, Hispanics/Latinas living in Camden County are experiencing the lowest five-year relative

survival rate among all counties in the Affiliate service area while a large percentage of Blacks are being diagnosed with breast cancer at a late-stage. The data show that only 69.2 percent of women (ages 50-74) living in Camden County reported mammography screening in the past two years. This is the lowest screening percentage in the entire Affiliate service area. Compared to other counties in the Affiliate service area, the county has a substantially higher percentage of residents with income below 250 percent the federal poverty level, no health insurance, and lack of employment.

Gloucester County

While Gloucester County has a fairly low incidence rate compared to the service area as a whole and to other counties within the service area, the death rate is high. The county currently has the third highest death and late-stage diagnosis rates in the service area, both of which are considerably higher than the average rates of the Affiliate service area and State of New Jersey. Black women of Gloucester County are suffering from a death rate that is notably higher than the average rates of the Affiliate service area and State of New Jersey. The data indicate that a considerably larger percentage of women ages 65 and older have experienced late-stage diagnoses in Gloucester County compared to the Affiliate service area and State of New Jersey. Despite better outcomes overall on socioeconomic indicators as compared to other counties in the Affiliate service area, Gloucester County has one of the lowest proportions of women ages 50-74 who reported obtaining screening mammography within the Affiliate service area.

Salem and Cumberland Counties

Salem and Cumberland Counties were chosen because of their high death rates, low screening prevalence, low five-year relative survival rates, and unique socioeconomic characteristics. In particular, Salem County has the highest death rate among all counties in the Affiliate service area, while Cumberland County is the poorest county in the service area. Both counties experienced low screening prevalence in the last two years among women ages 50-74, with Salem County having the second-lowest proportion of women screened in the Affiliate service area.

The majority of Salem and Cumberland Counties' residents live in rural and medically underserved areas. They are also among the top five counties with residents who have substantially lower unemployment, education and income levels. Major racial and age disparities also exist in both counties. Cumberland County has the largest Hispanic/Latina population and third largest Black population in the Affiliate service area. Although Salem County has a smaller concentration of Black and Hispanic/Latina women, the county has the third largest population of women ages 65 and older.

Burlington and Monmouth Counties

Both counties also have fairly high incidence rates with incidence trends increasing in Monmouth County. In Burlington County, the percentage of late-stage diagnoses is higher than

the service area as a whole and the State of New Jersey, and presents as an increasing trend. While Burlington presents with a fairly high percentage of women, ages 50-74, who obtained a screening mammogram in comparison to the rest of the service area, the percentage of women screened in Monmouth County is lower than the service area average and the State of New Jersey.

Although the majority of the population in both counties is White, together the counties make up a considerably large population of women who are over the age of 40 and who identify as Black and/or Hispanic/Latina. In Burlington County, the percentage of Black women diagnosed with late-stage breast cancer is considerably higher than White women diagnosed with late-stage breast cancer. Moreover, this percentage of Black women diagnosed with late-stage breast cancer is also higher than the Affiliate service area's percentage of Black women diagnosed with late-stage breast cancer. Likewise, in Monmouth County, the death rate for Hispanics/Latinas is substantially higher and the five-year relative survival rate lower than the average death and five-year relative survival rates of the Affiliate service area and State of New Jersey.

Health System and Public Policy Analysis

For each target community, the strengths and weaknesses of the health system and potential barriers to accessing services across the CoC were assessed. Key partnerships in the target communities and potential new partners to address needs and key issues were identified, as were other potential issues to explore in the Qualitative Analysis. The major strengths and weaknesses related to the health system are outlined by target community below.

Atlantic County

The Health Systems Analysis (HSA) revealed a wealth of breast health services available in Atlantic County addressing all facets of the CoC, including those that specifically target vulnerable populations in areas of great need (e.g. Atlantic City). However, a key concern identified was the unequal geographic distribution of resources, leaving the key question of the impact of accessibility (particularly for rural residents), including any transportation challenges, vital to address through the Qualitative Analysis.

Camden County

Although Camden County has several strong health systems, the HSA revealed a major weakness to be the availability of comprehensive breast care services beyond the concentrated pocket of hospitals. This creates an accessibility issue for those who live a significant distance away in areas where comprehensive breast care resources are not as readily available. There also appeared to be a general lack of resources available for those who cannot afford them. Questions were raised about the ability and willingness of poorer residents to travel for care to the few locations that do offer services, as well as other potential access issues, including transportation challenges, given the dearth of comprehensive resources available and accessible to a substantial portion of the county's residents.

Gloucester County

The HSA revealed that Gloucester County appears to have a fair amount of resources overall, including several hospitals that provide access to care along the CoC. However, a key concern identified in the HSA was the unequal geographic distribution of resources in this community, leaving the key question of accessibility (particularly for rural residents), including any transportation challenges, vital to address in the Qualitative Analysis. Additionally, strategies for improving access to comprehensive programs, particularly for those with transportation challenges coming from other screening and diagnostic facilities in the region, was also identified as a key issue to further explore.

Burlington and Monmouth Counties

The HSA revealed that both counties appear to have an abundance of resources that address all facets of the CoC. However, given that the majority of the resources appeared to be located in specific pockets in each county, the question of accessibility issues (particularly for rural residents), including any transportation challenges, was vital to answer through the Qualitative Analysis in order to assess the potential impact. Additionally, the findings suggested a need for programs targeting Hispanic/Latina women in Monmouth County and additional programs targeting Black women Burlington County, given the issues of late-stage diagnoses and survival rates in these populations.

Salem and Cumberland Counties

The HSA revealed that this target community has a dearth of resources compared to the other target communities. Salem County has little to no resources available that span the entire CoC, and the few that do exist in Cumberland are concentrated in the northern portion of the county. In Salem County, there are no places to go for biopsies or treatment, and residents must travel to Vineland (in Cumberland County). In Cumberland County, Vineland is the only location providing treatment. Besides the NJCEED sites, there really are no programs for vulnerable populations to receive free or reduced cost care.

Public Policy Implications

The Affiliate's policy work in the past has primarily revolved around meeting key advocacy priorities established by Komen Headquarters. The Affiliate will continue to focus on meeting these priorities as they are established each year, given that these are the key priorities for breast cancer care established through a national issue vetting process. The Affiliate will continue to monitor key aspects of the public policy realm that greatly impact breast cancer, including the New Jersey Cancer Education and Early Detection (NJCEED) Program funding and the Affordable Care Act (ACA), as it unfolds over the next few years. The Affiliate's biggest policy goal is to establish relationships with a few key legislators. The findings from this assessment will be an important tool and conversation piece for developing these relationships,

as well as a call to action to address the most vital issues outlined in the target communities. Additionally, the Affiliate will continue collaborating with NJCEED screening sites primarily through its community grants program, and will continue to hold influential roles on state coalitions and workgroups to help influence policy at a broad level.

Health Systems Analysis Conclusions

In general, the findings indicate that in the more resource-rich target communities, addressing needs should involve focusing on integrating existing resources and combining efforts when possible. In those target communities where there are less resources overall, the issues get a bit more complex, drawing the focus instead to how to maximize impact with a dearth of resources. The Affiliate will consider convening a coalition of key players in each of the target communities to address these issues collaboratively. It will also be important to ensure that all programs and resources connect women with the necessary care at every phase of the CoC, and that all collaborative efforts and partnerships attempt to focus, when possible, on providing targeted programs that reach the most vulnerable populations identified.

Qualitative Data: Ensuring Community Input

The purpose of the qualitative data is to further explore the breast health and breast cancer issues highlighted by the Quantitative Data Analysis and the Health Systems and Public Policy Analysis. The qualitative data provide insight into the community perspective as to what is working, what is not working, and what the various barriers are that lead to gaps in access, utilization and quality of services.

The Affiliate developed a specific set of assessment questions to address the key variables identified. Questions were specifically developed to further explore disparities in care, access, and utilization. For each target community, the Affiliate asked a generic set of questions about barriers to care (both individual and systemic) along the continuum of care and the strengths and weaknesses of the health system. Additionally, for each community, supplemental questions were asked to explore specific issues identified that were unique to that county. The general assessment questions asked were:

- What are the greatest issues in the community related to breast health and breast cancer?
- What are the specific groups (racial/ethnic and geographic) that do not get the services they need in the community, and why?
- What barriers (individual or systemic) are faced at each stage of the continuum of care, and in transitioning through the stages? Why do they exist? What strategies are currently in place and/or need to be in place to address these barriers?
- What are the strengths and weaknesses of the health system and what new programs, resources, and policies are needed to deliver breast health more effectively?

The primary methods employed to collect data in each county were key informant interviews and document review. The key findings related to the qualitative data are outlined by target community below.

Atlantic County

The Qualitative Analysis identified the most frequently cited issues in the community related to breast health and breast cancer, which included financial barriers, a lack of education, competing priorities, and transportation barriers. Many of these issues were also given as potential explanations for the high death rate among Black women. The main reason why so much of population is considered to be medically underserved, despite having a wealth of resources in the area, was primarily attributed to access in general, and more specifically to transportation barriers (including insufficient distribution of bus routes and poor access to public transportation), and a lack of services and providers (particularly specialists) available.

Camden County

The Qualitative Analysis identified the most frequently cited issues in the community related to breast health and breast cancer as a lack of education, language barriers, fear, transportation barriers, financial barriers, and competing priorities. Many of these issues were highlighted as potential explanations for why this county experiences high late-stage diagnoses, low screening rates, and issues related to survival and late-stage diagnoses among minority populations. The potential impact on breast health outcomes of the existence of population heavy areas where there are no resources available was noted as a key issue as well. The most substantial weakness of the health system identified was a lack of navigation, which was also acknowledged as the most common cause of delay in progression through the continuum of care.

Gloucester County

The Qualitative Analysis found that the most frequently cited issues in the community related to breast health and breast cancer were access (including transportation barriers, and particularly for rural populations), lack of education (among patients and conducted by providers), and fear. Many of these issues were given as potential explanations for why this county experiences high death rates among Blacks and high late-stage diagnoses among those 65 and older. The most commonly cited reasons as to why some of the key breast health statistics are so poor despite a relatively low incidence of breast cancer and unremarkable socioeconomic indicators, were a lack of trust in the health system and issues of competing priorities among the working poor. Access to early screenings was described as one of the most pressing issues for the community, particularly given the low screening rates.

In terms of issues related to access, just as the findings from the HSA suggest, it appears as though the major resources are concentrated mostly in the northern region of the county. Thus, accessing treatment can be particularly problematic for those who live a distance away, including those rural populations in the most southern portions of the county. Overall, the findings indicate a lack of transportation resources that can be attributed to a number of different issues including a lack of buses, a lack of awareness about availability, and inconvenient

transportation schedules. A lack of vehicle access was cited, particularly for undocumented farm workers.

Burlington and Monmouth Counties

The Qualitative Analysis identified that the most frequently cited issue in the community related to breast health and breast cancer was access to care, with a specific emphasis on transportation barriers due to the sprawling and in some instances rural nature of this community. Accessibility issues cited included the geographic proximity of health care facilities (e.g. they are too spread out to access and not evenly distributed) and other transportation challenges (e.g. inconvenient times and stops, no walkable access to public transportation, and not enough routes).

Other issues cited often in both communities were a lack of education about breast health and fear. Financial/insurance barriers were also highlighted as key issues specifically in Monmouth County, while language barriers were highlighted in Burlington County. These were the issues most commonly cited as potential explanations for why these counties experience issues related to poor breast health outcomes, particularly among minority populations.

Salem and Cumberland Counties

The Qualitative Analysis results identified that the most frequently cited issues in the community related to breast health and breast cancer were a lack of education and transportation barriers. Other issues mentioned frequently included a lack of screening and financial barrier/insurance issues (particularly among undocumented populations), and to a lesser extent fear and competing priorities. Many of these issues were cited as potential explanations for why this community experiences poor breast health outcomes, particularly among minority populations.

The most substantial weakness of the system was identified to be access, with an emphasis on the geographic location of services. Access issues identified included the unequal distribution of services, a lack of providers, and transportation barriers. There was consensus in the Qualitative Analysis findings on a number of issues identified in the HSA, with the chief finding being that there are few resources available to address breast health across the entire continuum in this community. There was also agreement on a number of other potential access issues identified in the HSA including that:

- There are no resources that offer biopsies, treatment or follow-up services in these counties, and that this impacts breast health/breast cancer in the area.
- There are not enough resources for poor populations to receive free or reduced cost care, due to sparse, unequal distribution throughout the county.

Mission Action Plan

The key findings presented above for each of the target communities provide an overview of the triangulation of the findings conducted for each of the key components of the *Profile* analysis (Quantitative, Health Systems and Public Policy, and Qualitative). These findings provided the

basis for the Mission Action Plan, which is intended to serve as a strategic and targeted roadmap for the Affiliate's Mission work.

The Mission Action Plan was developed to focus on addressing three key problem areas identified in all of the target communities: education and outreach, access, and financial coverage, as well as crosscutting issues identified that impact all aspects of the Mission Action Plan. The priorities and measurable objectives are intended to address more specific issues identified related to each of the problem areas in the target communities, and are specific to certain target communities where the findings indicate a need to be. A short summary of each of the problem areas, including priorities and objectives, is provided below.

Problem Area: Education and Outreach

The most substantial weakness identified in all target communities was a pervasive lack of education about breast health and breast cancer, as well as about the availability of existing resources and programs. A lack of education was also the most frequently cited reason for potential delays at various stages of the continuum of care that can contribute to poorer health outcomes. The priorities established to address this problem area focused on:

- Increasing provider (including physicians, social workers, and navigators) awareness about the lack of comprehensive, consistent, and coordinated information available for patients about breast health, breast cancer, and community resources.
- Improving patients' knowledgebase of breast health and breast cancer information and of existing community resources to empower patients to more effectively navigate the CoC.
- Supporting culturally and linguistically appropriate educational programs designed to meet the unique needs of minorities and other at-risk populations.

Many measurable objectives were developed to address the priority areas outlined above.

Objectives focused on a number of key areas including:

- Developing collaborative solutions with key provider groups and professional organizations through coalition-based activities.
- Developing targeted educational campaigns aimed at providers.
- Revising the community grants program's RFA to include support and/or requirements for:
 - Breast cancer patient navigators.
 - A detailed plan illustrating how programs are meeting needs at all phases of the CoC.
 - Innovative and evidence-based outreach efforts that target Black, Hispanic/Latina, undocumented populations, and those 65+ in specific counties based the need identified.
- Developing and maintaining Affiliate-based initiatives (e.g. a web-based Resource Guide and Affiliate educational events) to address a dearth of educational resources and information.

Problem Area: Access

All target communities identified numerous issues related to the uneven distribution of resources. Access issues are most pervasive in the rural and underserved target communities of Atlantic, Cumberland, and Salem, which have a dearth of resources overall. Transportation barriers inherent in all counties compound the challenges related to the distribution of resources and include complex systemic challenges such as unsafe access, limited hours, and insufficient distribution of bus routes. Challenges cited related to accessing providers include a lack of specialists available, a lack of physicians accepting Medicaid, a lack of primary care providers to initiate referrals, and a lack of providers who speak the appropriate language. The priorities established to address this problem area focused on:

- Increasing access to providers at all phases of the CoC in order to improve access to vital services integral to improving health outcomes in the target communities.
- Enhancing provider and patient communication as it relates to linguistic challenges.
- The importance of connecting with a primary care home as a regular source of care.
- Addressing the awareness about and availability of transportation to screening, diagnostic, and treatment services.

Many measurable objectives were developed to address the priority areas outlined above. Objectives focused on a number of key areas including:

- Developing collaborative solutions with key provider groups, health systems, and the NJCEED program through coalition-based activities.
- Revising the community grants program's RFA to include support and/or requirements for:
 - A detailed plan illustrating linguistically competent and appropriate programs.
 - Innovative and collaborative approaches that mobilizing existing resources to comprehensively address transportation issues.
 - Connecting all patients to a primary care home.

Problem Area: Financial Coverage

Financial and insurance barriers were identified as major problems at all phases of the continuum, with the most frequently mentioned barrier being support for services beyond screening as well as for out-of-pocket costs. The most pervasive financial issues were identified in Atlantic, Cumberland, and Camden Counties, where there are a myriad of issues related to poverty, educational attainment, and unemployment. The priorities established to address this problem area focused on:

- Decreasing disparities in care by supporting the needs of vulnerable populations identified as those experiencing extensive barriers to care, including financial difficulties.
- Exploring innovative and collaborative approaches to meeting the extensive need for coverage for care beyond screening, including treatment.
- Continually evaluating and responding to the changing health care landscape as a result of the ACA.

Many measurable objectives were developed to address the priority areas outlined above. Objectives focused on a number of key areas including:

- Developing collaborative solutions with key provider groups, health systems, and the NJCEED program through coalition-based activities.
- Addressing policy issues related to financial coverage for follow-up care for low-income populations.
- Revising the community grants program's RFA to include support and/or requirements for:
 - Coverage for services beyond screening (including co-pays, deductibles, prescriptions, and premiums).
 - Formal commitments to provide care by partner organizations making and accepting referrals, to ensure patients do not fall through the cracks.
 - A financial counseling component for those in need of financial assistance.
 - Free mammography screenings in communities with the lowest screening rates.
 - Coverage for care for specific vulnerable populations in certain communities, including undocumented populations and casino workers.
- Hosting Affiliate-based initiatives (e.g. targeted education and screening events) to improve access to free screenings in specific communities.