



SUSAN G. KOMEN[®]
MIAMI/FT. LAUDERDALE
EXECUTIVE SUMMARY

Acknowledgments

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

Susan G. Komen® Miami/Ft. Lauderdale Board of Directors would like to extend its deepest gratitude to the Affiliate staff and the following individuals who participated on the 2015 Community Profile Team:

Paula Alexander-Delpech, PhD, ARNP

Assistant Professor/Service-Learning Fellow
Barry University, College of Nursing and Health Sciences

Karen A. Callaghan, PhD

Dean/Professor of Sociology
Barry University, College of Arts and Sciences

Kim V. Heard

Governance Chair - Board of Directors
Susan G. Komen Miami/Ft. Lauderdale

Sherri Martens-Curtis

Board President
Susan G. Komen Miami/Ft. Lauderdale

Sheila McKinney, MA

Graduate Assistant
Robert Stempel College of Public Health and Social Work

Kim Saiswick

Director, Community Benefit and Outreach
Holy Cross Hospital

A special thank you to the following entities for their assistance with data collection and analyses, as well as providing information included in this report:

- Barry University
- The Beautiful Gate
- Breast Health Center
- Cancer Support Community
- Church on the Way
- Clinica Luz Del Mundo
- Community Life Support
- Department of Health - Broward County
- Department of Health – Miami-Dade County
- First Assembly of God Church
- Florida Keys Area Health Education Center

- Gilda's Club South Florida
- Health Education, Prevention & Promotion
- Holy Cross Hospital
- Liga Contra el Cancer
- Lower Keys Community Health Center
- Open Door Health Center
- South Broward Hospital District d/b/a Memorial Health Care System
- Miami Springs Adult and Community Education Center at Riverside Elementary
- National Breast Cancer Prevention Project
- North Broward Hospital District d/b/a Broward Health Hospital
- Open Door Health Center
- Robert Stempel College of Public Health and Social Work
- Sisters Network
- St. John Bosco Clinic
- The Pride Center
- Womankind
- Women's Breast and Heart Initiative

Report Prepared by:

Susan G Komen® Miami/Ft. Lauderdale

1333 S. University Drive

Suite 206

Plantation, Florida 33324

Broward 954-909-0454

Miami-Dade – 305-383-7116

www.komenmiaftl.org

Executive Summary

Introduction to the Community Profile Report

Susan G. Komen® Miami/Ft. Lauderdale held its first Race for the Cure® in 1996 and was founded in 1999. After hosting a Race for the Cure in Miami for three years, a dedicated group of volunteers put together a plan to continue their hard work on a year-round basis and the Komen Miami/Ft. Lauderdale was born. The Affiliate serves over four million people in three counties in the southernmost point of Florida, including Broward, Miami-Dade and Monroe Counties. Since that time, the Affiliate has granted over \$9.3 million dollars into its local community through its community and small grants programs. Up to seventy-five percent of the Affiliate's net income goes toward funding grants to health care organizations, public health agencies and community groups that provide breast health education, breast cancer screening and treatment programs for uninsured, medically underserved women and men in Broward, Miami-Dade and Monroe Counties.

Currently, the Affiliate funds 27 local grantees with close to \$800,000 in funding, while funding approximately \$285,000 in Komen National Research Programs. The grantees range from large hospital systems to small support groups and free clinics. One of the Affiliate local grantees, Save Our Sisters (known as SOS) is a local dragon boat team that is making an international splash! This group of survivors recently hosted an international dragon boat festival with more than 3,000 breast cancer survivors and 105 teams from around the world. For survivors that are looking for a local support group that combines physical activity with the comradery of sister survivors, this group promotes healthy living and welcomes all survivors.

Komen Miami/Ft. Lauderdale plays an active role in the local cancer community by collaborating with the Florida Cancer Control and Research Advisory Council (CCRAB), which was established by the Florida Legislature in 1979 with the purpose of advising the Legislature, Governor and Surgeon General on ways to reduce Florida's cancer burden. The Affiliate is also active in the Komen Florida Public Policy Collaborative with two staff members actively participating in all Collaborative monthly meetings and projects. The Affiliate Executive Director is the current Chair for the Collaborative. The Komen Florida Public Policy Collaborative is made up of representatives of the six State of Florida Susan G. Komen Affiliates with the goal of addressing issues and legislation that are critical to breast cancer issues in the State of Florida.

The 2015 Community Profile Report will allow the Affiliate to define specific strategies to address gaps and barriers to accessing critical breast health services as well as help in assessing the availability and quality of those services. Pinpointing the population that is most at risk of dying of breast cancer or late stage diagnosis and comparing the service area data to the Healthy People 2020 breast cancer targets helps determine the priority areas of the Affiliate. By determining set priorities in each Affiliate service area, this report will allow the Affiliate to make data-driven decisions about how to use its resources in the best way while making the greatest impact. The findings in this report will not only direct future Affiliate grants funding, but also impact public policy initiatives, community mobilizing activities and the development of strong collaborations and partnerships throughout the service area. This will create synergy between the Affiliate's Mission-related strategic plans and operational activities.

The Community Profile Report will be hosted on the Affiliate website for community review as well as shared with the extensive database of donors, volunteers, current and past grantees, county and state health departments, healthcare systems, community organizations, cancer collaborative and legislators in the service area.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

The findings from the Quantitative Data Report that were reviewed and analyzed by Susan G. Komen Miami/Ft. Lauderdale were geared toward making the Affiliate service area compliant with the Healthy People 2020 initiative. Healthy People 2020 is a major federal government initiative that provides specific health objectives for communities and the country as a whole. The Affiliate analyzed the statistics provided for the Affiliate service area and identified four priority targets based on the time needed to meet Healthy People 2020 targets for breast cancer, as well as other local priorities based on community knowledge not included in the statistics or data given in the Quantitative Data Report.

The selected priority target communities for the Affiliate are:

- Broward County: Black/African-American females and women who partner with women
- Miami-Dade County: Women who are linguistically isolated/foreign born
- Monroe County

Broward County has a substantially higher Black/African-American female population than the other two counties in the service area with a slightly higher percentage of residents who are unemployed. While the Affiliate service area as a whole has a substantially higher percentage of the population age 40-64 living without health insurance (32.6 percent), Broward County has a substantially larger percentage of this population without health insurance than the United States average of 16.6 percent.

There is limited data on women who partner with women, however, according to the Williams Institute Florida Census Snapshot of 2010, Broward County ranks number two in the state in same sex couples with an estimated 11.33 per 1,000 households. Broward County also has three out of the top four cities in the state rankings of highest percentage of same sex couples per 1,000 households. Women who partner with women are believed to have a higher risk of breast cancer than other women because they usually have more risk factors. They are less likely to bear children or to have children earlier in life and have a higher obesity and alcohol use rate.

Upon review, none of the three counties in the Affiliate service area have a combined Highest or High Needs priority classification based on the projected time to achieve Healthy People 2020 breast cancer targets. Two of these communities do have a highest rating of thirteen years or longer on one of the components of the Healthy People 2020 breast cancer targets.

Miami-Dade County is the most populous county in the Affiliate service area with over half of the Affiliate service area population. Miami-Dade County is currently on track to meet the Healthy

People 2020 breast cancer death rate target and was projected to meet the late-stage incidence target goal in two years. Miami-Dade County is made up of 65 percent Hispanic/Latina residents with 51.2 percent being foreign born and 26.7 percent being linguistically isolated. It is imperative that Komen Miami/Ft. Lauderdale continue to find ways to impart breast health information and materials that communicate in the various languages and learning styles of this demographic, as well as embrace the different cultures present to effectively service this priority area.

Monroe County is the southernmost county in the United States and Florida with the Florida Keys, a chain of low lying islands connected to the mainland by U.S. Highway 1, which ends 150 miles south of Miami in Key West. Due to the geographical layout of Monroe County, medical access is limited with 100 percent of the population listed as living in medically underserved areas. Monroe County has a projected time of 13 years or longer to meet the Healthy People 2020 death rate target goal, but currently is on track to meet the late-stage incidence target goal. The Monroe County death rate and trend of 25.1 per 100,000 is substantially higher than the Healthy People 2020 rate of 20.6 per 100,000 as well as the Komen Miami/Ft. Lauderdale service area rate of 21.1 per 100,000.

Health Systems and Public Policy Analysis

For two of the counties in the Komen Miami/Ft. Lauderdale service area, Broward and Miami-Dade Counties, the number and location of hospital systems, free clinics and supporting organizations are abundant. The Affiliate currently partners with more than 20 organizations in each of these two counties to provide breast health services and to ensure that the continuum of care is met for these populations. In both of these counties, the Affiliate is working to educate the population on the available resources and strengthen the patient navigation network. While the Affiliate partners through its grants program with 17 hospitals in Broward County and 18 hospitals in Miami-Dade County, there are still a few that have no connection to the Affiliate. Three of the hospital systems currently have new Cancer Institutes under construction so the outlook for more breast cancer dedicated services in both of these counties are bright.

Monroe County is comprised of three main segments; upper, middle and lower keys. While there is at least one hospital and one community health center in each segment, most of the other breast health services are located in Key West or on the mainland Miami. This translates into a three to four hour drive for most residents. Screening services are available in 86 percent of the health centers in Monroe County but only 27 percent provide diagnostic tests and a mere 18 percent provide treatment options. As such, providing easy access to the full continuum of care is a major concern of the Affiliate.

The Komen Miami/Ft. Lauderdale service area is comprised of the number one and number two most populated counties in the State of Florida. Greater emphasis needs to be placed on Public Policy efforts and developing those political and impactful relationships. The Komen Florida Public Policy Collaborative will be discussing ways to enhance the mission and build stronger relationships with state politicians at the annual collaborative meeting. With the successful

passing of the Oral Parity Bill in 2014, the Collaborative has taken a leadership role in the cancer arena in the State. Each Florida Affiliate has taken steps to educate and train the staff and volunteers to ensure that the message is a cohesive one and stays within the guidelines of the National Advocacy Policies.

Qualitative Data: Ensuring Community Input

The questions that were asked of participants were selected based upon the contextual nuances documented in the Quantitative Data and Health Systems and Public Policy Analysis reports. These reports offered a visual representation of the available services throughout the regional area and documented the gaps of services and proximity of the resources to the breast cancer hot spots in the region. The questions asked were designed to build on the previous reports by presenting the community perspective on how effective these services are when it comes to meeting the needs of the women in the region and the extent that the services offered meet the screening, diagnostic and treatment needs to overcome breast cancer.

The Komen Miami/Ft. Lauderdale Community Profile Team decided to approach the Qualitative Data by focusing on two data collection methods: key informant interviews and focus groups. The team developed a “Qualitative Question Bank” that addressed access to care, barriers, disparities, survivorship and healthcare system issues (i.e. bottleneck, capacity and timeliness issues). A number of additional resources were developed to aid in the data collection process such as scripts, focus group invitations, consent and demographic forms. These were also professionally translated into both Spanish and Creole to assist in the data collection of the priority area of linguistically isolated/foreign born population in Miami-Dade County.

Of the four priority areas of the Komen Miami/Ft. Lauderdale service area, disparities were most evident between two distinct groups. The first group being the linguistically isolated and foreign born women of Miami-Dade County, who were newly immigrated into the United States. These women remain outside the local continuum of care for many reasons including the inability to communicate with providers, fear of discovering breast cancer, cultural norms that do not promote health prevention activities, immigration status and lack of education about breast cancer prevention.

The second disparate group represents Black/African-American women in Broward County that remain outside of the continuum of care. Black/African-American women are more likely to be diagnosed with late-stage breast cancer than White women. Particular segments of this county have rates of late-stage diagnosis that not only exceed other regions of the county, but also that of state and national rates. This group relayed several reasons as to their reluctance to engage in the healthcare system such as competing priorities, lack of insurance or financial resources, fear and culture of silence.

Women who partner with women in Broward County felt that most healthcare professionals were lacking in cultural competency training. By simply altering the type of questions asked on an intake form and being culturally sensitive, most healthcare providers could not only receive

more accurate and relative information on their patients but could provide more data on the needs of this segment of the population. With the passage of same sex marriage laws in Florida, becoming more culturally competent is a priority to be able to address the needs of this population.

For Monroe County the findings suggested that while the number of available local resources for breast health diagnosis and treatment was a deterrent to receiving breast health care, lack of trust in the local healthcare facilities and/or providers were just as important. In a community with few resources available, any negative word of mouth stories can have a major impact.

All groups express that fear and cultural behavior is a barrier to obtaining breast health services. While the Affordable Care Act has allowed more people the ability to enroll in affordable health insurance coverage, many of these plans are not being accepted by healthcare providers. With the exception of women who partner with women in Broward County, all groups touched upon the lack of insurance or financial resources for breast health service and treatment as a barrier to proper care.

Mission Action Plan

For the Affiliate as a whole, both the late-stage incidence rate and death rate are higher amount Black/African-American women than White women, and Broward County, in particular, is home to a relatively large Black/African-American population. Even though there are more than enough breast cancer screening, diagnostic and treatment resources readily available, there appears to be a universal unawareness of those resources in the Black/African-American community. The same findings appeared within the women who partner with women population, but they felt that a lack of sensitivity to their lifestyle was a barrier to care.

Komen Miami/Ft. Lauderdale needs to provide breast health education and information on available resources to Black/African-American women in Broward County to ensure that screening information and practices will not only be effectively received, but also acted upon. The Affiliate needs to provide cultural competency training for health care providers and staff working with the LGBT community in Broward County.

Miami-Dade County population is 65 percent Hispanic/Latina, while another large percentage are Haitian/Caribbean. Of that number, 51.2 percent are foreign-born and 26.7 percent are linguistically isolated, both of which are significantly higher than the national average. There are an abundance of local health centers and free clinics, however women in this community could not readily identify where to get free/low-cost services. The second problem area that this report has uncovered is the large population of undocumented women in Miami-Dade County who are fearful of being deported if they seek health care services.

Komen Miami/Ft. Lauderdale needs to increase breast health provider information outreach and education to the linguistically isolated/foreign born population of Miami-Dade County as well as

inform this population of providers who screen and treat the undocumented population without regard to immigration status.

Monroe County has good support with screening facilities and availability. The bigger issue appears when diagnosis and treatment support is needed. Most of the women expressed a lack of trust in the local medical community that stemmed from a lack of reliable medical resources. Komen Miami/Ft. Lauderdale needs to increase the number of health service providers available in Monroe County by establishing and funding, health system partnerships to increase access to services.

The objectives of Komen Miami/Ft. Lauderdale are as follows:

Broward County – In FY16, meet with service providers that work with the Black/African-American and the LGBT communities to develop an action plan on how to improve breast cancer outreach, cultural competency and education. The Affiliate will develop an outline of education and competency needs to be addressed to ensure that the community needs are met. By starting with the Affiliate’s grantees that are education and service providers there will be a partnership in accomplishing these goals and changes. Including these needs as part of the mandatory grants workshops this fall should give a measurable outcome by the end of the next grants cycle.

Miami-Dade County – In FY16, meet with breast health service providers that work with linguistically isolated/foreign-born women to develop an action plan on how to improve breast cancer outreach in the target community and for FY17 update the Affiliate grants RFA to include outreach requirements for anyone serving this population.

By FY17, develop new collaborative relationships with local groups (i.e. embassies, consulates, immigration groups, etc.) who work with the undocumented population of Miami-Dade County and then survey community health centers in the county to establish a resource list for undocumented patients.

Monroe County – By FY17, meet with local breast health providers in Monroe County to establish, and possibly fund, patient-navigation programs targeting women diagnosed with breast cancer as well as encourage more providers to apply for Komen Miami/Ft. Lauderdale grant funding.

Komen Miami/Ft. Lauderdale Service Area - In the Komen Miami/Ft. Lauderdale service area as a whole, the percentage of residents living at 250 percent below the poverty line is higher than the national average, as is the unemployment rate. The percentage of residents living with no health insurance is nearly double that of the national average. When considering the implications of the Affordable Care Act (ACA), of particular concern are the residents who fall in the “Medicaid Gap”, undocumented women who are not eligible for the ACA, and women who are uninsured/underinsured. A common theme among the service area is the cost of care and lack of insurance. Even for those with insurance, many have been denied care because of the

lack of physicians or service providers accepting their insurance or the financial burden of high deductibles. While screening services are often available to this population for free, if diagnosed with breast cancer there are very few resources available for treatment and other costs that occur with a breast cancer diagnosis. The Affiliate needs to increase funding to providers for diagnostics and treatments in the service area.

By 2018, a key funding priority in the Affiliate RFA will be funding free or low-cost treatment programs in the service area while meeting with treatment partners to try and negotiate lower costs for breast cancer treatment options.

Broward County

Problem Statement: For the Affiliate as whole, both the late-stage incidence rate and death rate are higher among Black/African-American women than White women, and Broward County, in particular, is home to a relatively large Black/African-American population. The health system analysis found that breast cancer screening, diagnostics and treatment options are readily available throughout the county. However, breast cancer survivors and health care providers indicated that among the Black/African-American population there is a universal unawareness of breast cancer and the available breast health resources in the community. If women do not understand the risk and nature of the disease, they will not know what health information and/or services to seek out.

Priority: Provide education on breast health and available resources to Black/African-American women in Broward County, so as to ensure that screening information and practices will not only be effectively received, but also acted upon.

Objectives

- In FY16, meet with service providers in Broward County that work with the Black/African-American community to develop an action plan on how to improve breast cancer outreach and education in this target community.
- By 2017, update Affiliate RFA to include outreach requirements for anyone serving the Black/African-American community in Broward County.

Problem Statement: Very little statistical data on women who partner with women is available. However, because women who partner with women are less likely to bear children and exhibit riskier lifestyle choices such as alcohol use and obesity, they are believed to have more risk factors for breast cancer than other women. Broward County ranks second in the state in same sex couples, and is home to three of the top four cities in the state with the highest percentage of same sex couples. According to the health system analysis, two of these cities have hospitals within the city, and the third has one within five minutes of the city limits. Community partners felt that geographically the services are in place, but that there is a lack of sensitivity among health care providers when it comes to working with the LGBT community.

Priority: Provide cultural competency training for health care providers and staff working with the LGBT community in Broward County.

Objectives

- By 2016, meet with key LGBT community leaders to determine best practices that should be put in place in all health care facilities serving the LGBT community in Broward County.
- By 2017, fund a cultural competency “train the trainer” program to be disseminated to all providers serving the LGBT community in Broward County.

Miami-Dade County

Problem Statement: In the target community of Miami-Dade, 65.0 percent of the residents are Hispanic/Latina, while another large percentage are Haitian/Caribbean. Of that number, 51.2 percent are foreign-born and 26.7 percent are linguistically isolated, both of which are significantly higher than the national average. Statistics show that Hispanics/Latinas tend to be diagnosed with late-stage breast cancers more often than Whites. Due to cultural norms and language barriers, the Haitian/Caribbean population faces high late-stage diagnosis rates as well. The health system analysis indicated that there is an abundance of health centers throughout Miami-Dade County, including free clinics which are particularly important in this population, with a vast majority of them providing screening and diagnostic services. However, women in the community could not readily identify where to get free/low-cost services, while providers expressed that unlike other communities where medical resources are lacking, in Miami-Dade it is education and health literacy that are lacking.

Priority: Increase breast health outreach to foreign-born/linguistically isolated communities in Miami-Dade County.

Objectives

- In FY16, meet with service providers in Miami-Dade County that work with linguistically isolated/foreign-born women to develop an action plan on how to improve breast cancer outreach in this target community.
- By 2017, update Affiliate RFA to include outreach requirements for anyone serving linguistically isolated/foreign-born women in Miami-Dade County.

Problem Statement: Miami-Dade has a large population of undocumented women, who are not accounted for in the Census data due to their illegal immigrant status. These women, who are most often Hispanic/Latina and/or Caribbean/Black, both have higher late-stage incidence rates than White women. The health system analysis found that the health systems exist in the community; however, there is a shortage of centers in South Miami-Dade, where a large immigrant population resides. Women in the community and health care providers indicated that immigration status was a true challenge because undocumented women feel like there is no place to go, and worry that if they disclose their illegal status they will be deported. Added to

that, with the abundance of paperwork required at free clinics, the system becomes a burden to them, oftentimes making the requirements for free service too cumbersome.

Priority: Identify health care providers in Miami-Dade County that offer services to women regardless of immigration status, and work on streamlining both the communication of these services and the registration process to receive services.

Objectives

- By 2017, develop new collaborative relationships with local groups (i.e. embassies, consulates, immigration groups, etc.) who work with the undocumented population of Miami-Dade County.
- By 2017, survey community health centers in Miami-Dade County to establish resource list for undocumented patients.

Monroe County

Problem Statement: In the target community of Monroe County, the death rate is higher than both the Affiliate as a whole and the state. Due to its geographical layout, 100.0 percent of the population is listed as living in medically underserved areas. Monroe also has a higher percentage of residents living with no health insurance when compared to the national average. The health system analysis revealed that the county as a whole is severely lacking in medical resources. Though there appears to be one hospital in each segment of the county, the bulk of the health centers and free clinics are in the Lower Keys, which would mean a three hour drive for those living in the Upper Keys. Of the small number of centers that do exist, only 27.0 percent provide diagnostic services and 18.0 percent provide treatment. Survivors and providers alike felt that there is good support at the screening stage, but if breast cancer is diagnosed, there is nowhere to go locally for support. Most of the women expressed a lack of trust in the local medical community that stemmed from a lack of reliable medical resources.

Priority: Increase the number of health service providers available in Monroe County by establishing, and funding, health system partnerships to increase access to services.

Objectives

- By 2017, meet with local providers to establish, and possibly fund, patient-navigation programs targeting Monroe County women diagnosed with breast cancer.
- In FY16, heavily promote and host at least two grant writing workshops in Monroe County, to encourage more health care providers to apply for Komen funding.

Service Area (Broward, Miami-Dade, Monroe)

Problem Statement: In the service area as a whole, the percentage of residents living at 250 percent below the poverty line is higher than the national average, as is the unemployment rate. The percentage of residents living with no health insurance is nearly double that of the national average. When considering the implications of the Affordable Care Act (ACA), of particular

concern are residents who fall in the “Medicaid Gap,” undocumented women who are not eligible for the ACA, and women who are uninsured/underinsured. A common theme among the service area is the cost of care and lack of insurance. For those insured under the ACA, many have been denied care because not all physicians accept the insurance. While those with no insurance at all said the cost of services was prohibitive and often battles out with other basic needs (food, housing, child care, etc.). Providers agreed that the service area suffers from being underinsured and/or lacking the financial resources to follow through with care. And that while screening services are often available to this group for free, if an uninsured/underinsured woman is diagnosed there are very few places to go for treatment.

Priority: Increase free or low-cost treatment options available to uninsured/underinsured women in the Susan G. Komen Miami/Ft. Lauderdale service area.

Objectives

- By 2018, a key funding priority in the Affiliate RFA will be funding free or low-cost treatment programs in service area.
- By 2018, meet with treatment partners to try and negotiate lower costs for breast cancer treatment options in the Affiliate service area.

Disclaimer: Comprehensive data for the Executive Summary can be found in the 2015 Susan G. Komen® Miami/Ft. Lauderdale Community Profile Report.