



COMMUNITY PROFILE REPORT

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2011

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TABLE OF CONTENTS

Executive Summary	5
Los Angeles County Affiliate of Susan G. Komen for the Cure®	5
Purpose of the Report and Methodology	5
Statistics and Demographic Review	5
Health Systems Analysis.....	7
Qualitative Data Overview	7
Conclusions and Affiliate Action Plan	8
Introduction.....	12
Affiliate History	12
Organizational Structure	13
Description of Service Area.....	13
Purpose of the Report.....	14
Breast Cancer Impact in Affiliate Service Area.....	15
Data Sources and Methodology	15
Overview of the Affiliate Service Area	16
Communities of Interest.....	18
Conclusions.....	21
Health Systems Analysis.....	23
Breast Health Continuum of Care.....	23
Methodology	24
Key Informant Interview Findings.....	25
Provider Survey Results.....	25
GIS Mapping.....	26
Barriers.....	27
Community Assets	28
Komen Los Angeles County Affiliate and Public Policy	29
Conclusions.....	31
Breast Cancer Perspectives in the Target Communities.....	32
Introduction and Methodology Overview.....	32
Surveys.....	32
Focus Groups	32
Review of Qualitative Findings	33
Survivor Surveys.....	33
Healthcare Provider Surveys.....	34
Survivor Focus Groups	35
Community Member Focus Groups.....	36
Conclusions.....	36
Conclusions.....	38
Review of the Findings	38
Conclusions and Response.....	39
Affiliate Action Plan	40
Works Cited.....	44

EXECUTIVE SUMMARY

Los Angeles County Affiliate of Susan G. Komen for the Cure®

The Los Angeles County Affiliate of Susan G. Komen for the Cure® was founded in 1996. Since that time, the Komen Los Angeles County Affiliate has raised over \$8.3 million to support local breast health programs through our community grants program. In the grant years of 2009 and 2010, the Affiliate invested over \$850,000 in community grants to Los Angeles County hospitals, clinics and non-profit community organizations. In addition to the grants program, the Affiliate offers trainings and leads education and information seminars about breast health, screening and early detection to the community. The Komen Los Angeles County Affiliate has six full time employees and engages consultants as needed. The Affiliate has an eleven member Board of Directors and over 1,000 registered volunteers, including public health interns.

Purpose of the Report and Methodology

The purpose of the biennial Community Profile is to present an overview of the state of breast cancer in Los Angeles County, and to provide a road map for granting priorities, program planning and service delivery for the Los Angeles County Affiliate and for the entire Los Angeles County breast health and breast cancer community.

Statistics and Demographic Review

The most current demographics and breast cancer data in Los Angeles County were derived from the following data sources: the U.S. Census Bureau; Los Angeles County Cancer Surveillance Program (CSP); the 2007 Los Angeles County Health Survey; and several other sources. The demographics category included data on age, race/ethnicity, annual household income, federal poverty level, primary language spoken at home, and education level completed. This data was based on the 2000 U.S. Census Bureau and the 2007 Los Angeles County Health Survey. The 2007 Los Angeles County Health Survey also provided data on health status, mammography screening history, access to care, and insurance status. Furthermore, the Los Angeles CSP is a population-based cancer registry for LA County, administered by the USC Keck School of Medicine and USC/Norris Comprehensive Cancer Center. It is a part of the state-wide population-based cancer surveillance system, California Cancer Registry (CCR), and the National Cancer Institute-funded Surveillance, Epidemiology, and End Results (SEER) program. The Los Angeles County Cancer Surveillance Program (CSP) provided age-adjusted incidence rates by race/ethnicity and mortality rates by race/ethnicity from 1988 to 2008.

Los Angeles County is home to approximately 10,147,329 people, according to the U.S. Census Bureau, making it the most populated county in the nation.¹ Los Angeles County is comprised of an extremely diverse population, with many cultures and ethnicities. As of 2007, English was not the primary language spoken at home for 45.5% of adults in LA County² and 40.7% of adults were born outside of the U.S.³ Many women in the county do not have access to adequate

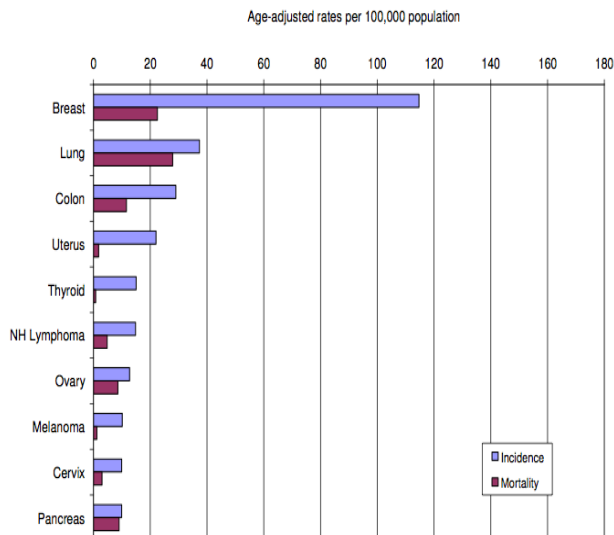
¹ <http://quickfacts.census.gov/qfd/states/06/06037.html>

² Los Angeles County Health Survey 2007

³ 2007 Key Indicators of Health

healthcare or services because of the cultural and language barriers they face. Regardless of race/ethnicity, breast cancer remains the most common cancer among all women in the county.⁴

Incidence and Mortality of Top 10 Common Cancers, All Races Combines, Females, Los Angeles County 2004-2008



The incidence rate of breast cancer in LA County, for women of all races, is 114.7 per 100,000, with non-Latino white females experiencing the highest incidence rate at 143.1 per 100,000, followed by African American females at 125.2 per 100,000, non-Latino Asian or Pacific Islander females at 98.5 per 100,000, and Latinas with the lowest incidence rate of 80.8 per 100,000.⁵ Breast cancer is the second leading cause of mortality among non-Latino White, African American, and Asian/Pacific Islander females, and is the leading cause of mortality among Latinas in LA County.⁶ In addition, studies have shown that timely screening may reduce mortality rates of breast cancer, thus breast cancer screening by mammography is an important indicator we looked at.⁷ The Los Angeles County Health Survey found that 73.7% of women 40 years or older reported

obtaining a mammogram in the past 2 years. Asian/Pacific Islander women have lower rates of breast screening compared to women of other ethnic groups, with only 66.9% reporting having had a mammogram in the past 2 years. Latino females closely followed with only 72.3% obtaining a mammogram in the past 2 years.⁸ In addition, only 54% of women with no insurance have had a mammogram in the past 2 years.⁹ Furthermore, 39% of women in LA County are diagnosed with later stage of invasive breast cancer.¹⁰ African American women have the highest percentage of late stage diagnosis with 45.9%, followed by Latino women at 45.1%, Asian and Pacific Islander women at 36.2%, and non-Latino White women at 35.9%.¹¹ African American women also have the lowest survival rate among all three stages of breast cancer (localized = 93.2%, regional = 72.0%, distant = 11.9%)¹².

⁴ University of California Keck School of Medicine Department of Preventive Medicine USC/CSP-Cancer in Los Angeles County: incidence and mortality by race/ethnicity 1988-2008.

⁵ University of California Keck School of Medicine Department of Preventive Medicine USC/CSP-Cancer in Los Angeles County: incidence and mortality by race/ethnicity 1988-2008.

⁶ University of California Keck School of Medicine Department of Preventive Medicine USC/CSP-Cancer in Los Angeles County: incidence and mortality by race/ethnicity 1988-2008.

⁷ Meeting the mammography screening needs of underserved women: the performance of the National Breast and Cervical Cancer Early Detection Program in 2002-2003 (United States).

Tangka FK, Dalaker J, Chattopadhyay SK, Gardner JG, Royalty J, Hall IJ, DeGroff A, Blackman DK, Coates RJ.

Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta, GA, USA

⁸ Los Angeles County Health Survey, 2007

⁹ Los Angeles County Health Survey, 2007

¹⁰ USC/Cancer Surveillance Program Los Angeles County-2nd dataset

¹¹ USC/Cancer Surveillance Program Los Angeles County (MSF0710) among women ages 20+, excl. unknown/borderline stages.

¹² USC/Cancer Surveillance Program Los Angeles County .Table 4. 5 year relative survival rate of women breast cancer (ages 20+) by stage/race in LAC in three time periods 1995-1999, 2000-2004, and 2005-2007

Health Systems Analysis

The county is divided into eight Service Planning Areas (SPAs): SPA 1 (Antelope Valley), SPA 2 (San Fernando Valley), SPA 3 (San Gabriel Valley), SPA 4 (LA Metro), SPA 5 (LA West), SPA 6 (LA South), SPA 7 (LA East), and SPA 8 (South Bay).¹³ The regions that contain the lowest percentage of women who have had a mammogram in the past 2 years are SPA 4 (Metro) and SPA 1 (Antelope Valley).¹⁴ SPA 6 had the highest percentage of women diagnosed with later stage of invasive breast cancer.¹⁵ Of all the Service Planning Areas, SPA 4 had the highest percentage of uninsured women (32.7%), which creates a barrier to accessing quality health care services and the timely receipt of appropriate screening and treatment services.

The 2011 Community Profile once again reveals some disturbing discrepancies in survival rates among different ethnic groups in women in Los Angeles County. This compelling information points to a need for increased cultural sensitivity and continued education and awareness. This county has such a large and diverse population which requires our work to be prioritized based on the unique characteristics that define the female population of Los Angeles. Of great interest to our Affiliate, is a strong and accessible breast health continuum of care model, which affects all women in our County regardless of their differing characteristics. The 2011 Community Profile provides us with the information needed to make decisions about resource allocation, priority populations and programmatic objectives.

2010 proved to be a challenging year for the underserved in California. Changes in the US Preventive Task Force Services guidelines recommending that screening begin at age fifty rather than forty caused confusion and concern for our community. Susan G. Komen for the Cure's screening recommendations consistently remain:

- Ask your doctor which screening tests are right for you if you are at higher risk;
 - Have a mammogram every year starting at age 40 if you are at average risk;
 - Have a clinical breast exam at least every 3 years starting at 20 and every year starting at 40;
 - Know what is normal for you and report any changes to your healthcare provider right away.
- Additionally, the freeze to new enrollments in Cancer Detection Programs: Every Woman Counts, the state-funded breast cancer screening program for uninsured women in California in 2010 created a barrier to mammography for uninsured and underinsured women. Because LA County's population comprises over a quarter of the entire state's population, the underserved in Los Angeles County have a great need for the continued existence of the state program.

Qualitative Data Overview

During 2010, the Komen Los Angeles County Community Profile team created and distributed Survivor and Healthcare Provider online surveys and conducted three focus groups with breast cancer survivors, two focus groups with community members, and conducted 26 key informant interviews. We used Survey Monkey to collect, review and analyze online survey data. We received 178 survivor surveys (172 in English, 6 in Spanish) and 50 healthcare provider surveys.

¹³ LA County Department of Public Health

¹⁴ Los Angeles County Health Survey, 2007

¹⁵ USC/Cancer Surveillance Program Los Angeles County-Table 2 Percentage of Women Diagnosed with later stage of Invasive Breast Cancer by Age, Race, and Service Planning Area (SPA), in Los Angeles County, 2000-2008.

Key informant interviews all stated a need for greater access to diagnostic and therapeutic care for the underserved, and a need for patient navigation to assist us in that process. Patient Navigators are health care professionals whose primary focus is to assist cancer patients, caregivers, and families in “bridging the gaps” within the health care system and decreasing barriers to care by utilizing resources¹⁶. Additionally, key informants expressed the need for assisting women into the county system and bringing healthcare providers together to work together to provide more of a safety net for uninsured and underinsured patients.

Focus group participants and survey respondents discussed the need for navigating patients, as well. They stressed the need for navigation along the continuum of care, starting with helping to make mammography screening and resources more available, as well as assisting patients to find answers to treatment questions and support services. There was also a trend that it was important to “have another set of ears” during doctor’s visits to advocate for patients and help patients remember all they need to know along the way. Another consistent theme was a general need for more breast health and breast cancer resources, and to publicize what is in existence and keep the information centralized and updated on a regular basis.

Conclusions

The lack of navigation and knowledge about what services and resources exist in Los Angeles County make it difficult for patients to access the continuum of care. Not only is there a lack of resources, but there is a lack of access to those resources that are in existence. Healthcare providers, community members and breast cancer survivors all referenced the need for assistance accessing the continuum of care at point of entry and throughout the continuum. Overall findings from the community highlighting the need for patient navigation services and increased access to different entry points along the continuum of care have already been incorporated into the 2011-2012 Komen Los Angeles County grant Request for Proposals.

The qualitative and quantitative data from the 2011 Community Profile also reveal that specific groups need our attention at specific points along the continuum of care. Examples are:

- Asian American/Pacific Islander community navigation and education may be of greater impact given that members of these ethnic groups have the lowest screening rates.
- There are high late-stage diagnosis rates among African Americans within Los Angeles County which supports the need to focus on targeting the African American community for screening and diagnostic tests. We also found that younger African American women have high incidence of later stage diagnosis and lowest survival of all groups, including a marked 5-year survival rate discrepancy compared to all other race/ethnicity groups. Reasons as to why we observed these numbers in young African American women are still inconclusive and will be something of focus in the 2013 Community Profile.
- Pacific Islanders would especially benefit from culturally and linguistically competent education and navigation because of cultural and linguistic barriers to accessing healthcare.
- Latinas consist of the highest number of uninsured women in LA County. There is no question that this adds to difficulty accessing care. For all women who speak English as a second language or who do not speak English, communication is a significant barrier to care.

¹⁶ http://www.cancerkansas.org/download/Cancer_Patient_Navigation_Toolkit.pdf

All of these factors have led us to the conclusion that we need to focus on access into and throughout the continuum of care with the help of patient navigation to improve survival rates for all women in Los Angeles County. The qualitative and quantitative data led us to focus on the following target communities, in order of priority:

- Women with low incomes and/or who are underserved, uninsured or underinsured
- African American women, with an emphasis on SPAs 6 and 8
- Latina women, with an emphasis on SPAs 3, 4 and 7
- Asian American and Pacific Islander women, with an emphasis on SPAs 3, 4 and 8
- Women under the age of 40

Affiliate Action Plan

The Los Angeles County Affiliate of Susan G. Komen for the Cure® intends to focus our efforts on increasing access to each phase of the continuum of care, and partnering with breast health leaders in LA County (hospitals, clinics, and community-based organizations) to help patients navigate the health care system. The ultimate goal of these efforts is to improve breast cancer outcomes and reduce breast cancer mortality.

Based on the needs identified in this report, the Komen Los Angeles County Affiliate has developed four priority goal areas to address within the next two years:

Comprehensive Goal: Assist our priority populations through the continuum of care by improving outreach and education, patient navigation services, collaborative efforts with community partners, and access to care.

Goal 1: To increase access to the continuum of breast care, Komen LA will provide comprehensive breast health outreach and education to our underserved priority populations in Los Angeles County.

Objective 1: By March 31, 2012 Komen Los Angeles County will prioritize funding grantees who have a demonstrated commitment to address the needs of the underserved priority populations identified by this community needs assessment.

Activity 1.1: Develop a list of additional agencies, including hospitals, clinics and community-based organizations, which serve our priority populations and have the capacity to join us in our fight against breast cancer.

Activity 1.2: Distribute Komen LA County's Request for Proposals (RFP) to at least 20 new organizations serving our priority areas that may not be familiar with Komen funding opportunities.

Activity 1.3: Modify RFP and grant scoring criteria to give proposed programs that are serving priority populations and geographic areas even greater preference.

Activity 1.4: Provide training and technical assistance (including instruction in program evaluation and impact measurement) to improve the capacity of potential grant applicants and current grantees to document their efforts and use of Komen funds.

Objective 2: By March 31, 2013, Komen Los Angeles County will increase breast health outreach and education efforts to our underserved priority populations.

Activity 2.1: Establish a team of at least 50 partners to provide comprehensive breast health outreach and education to Komen's priority populations through Worship in Pink, the African American Initiative and other community outreach initiatives.

Activity 2.2: Create and implement a data collection and tracking system to comprehensively capture the community's voice related to their breast health needs at 3 large-scale education events in the community.

Activity 2.3: Provide up to date breast health toolkits, including educational materials and local resources, to community partners and grantees to be utilized in their outreach and education efforts serving Komen LA County's priority populations.

Activity 2.4: Develop an interactive online guide of local breast health resources, programs and services available in Los Angeles County.

Goal 2: Lead the development of a comprehensive patient navigation program targeting our priority populations in partnership with community collaborators.

Objective 1: By March 31, 2012, Komen Los Angeles County will secure funding (in partnership with our community collaborators) to develop a patient navigation program addressing each component of the continuum of care model.

Activity 1.1: Design a comprehensive patient navigation program with collaborating organizations.

Activity 1.2: Apply for funding to support the implementation of this patient navigation model.

Objective 2: By March 31, 2013, Komen Los Angeles County will implement and promote Komen's patient navigation program to the community.

Activity 2.1: Pilot test the patient navigation model and evaluate its effectiveness.

Activity 2.2: Implement a comprehensive patient navigation program.

Activity 2.3: Create a marketing and social media campaign to increase the community's awareness of and knowledge about Komen's patient navigation program.

Goal 3: Cultivate Komen Los Angeles County’s collaborations and partnerships with community-based organizations and healthcare providers united in the fight against breast cancer.

Objective 1: By March 31, 2012, Komen Los Angeles County will strengthen our relationships with existing community partners and create new collaborative allies.

Activity 1.1: Komen Los Angeles County will continue to participate in ongoing coalitions to collectively address breast health disparities, improve outreach and education efforts, and increase patient navigation opportunities.

Activity 1.2: Komen Los Angeles County will evaluate their current partnerships to identify the strengths, impact, and effectiveness of existing collaborations and identify any priority area and service related gaps in these existing alliances.

Activity 1.3: Komen Los Angeles County will join additional community coalition efforts to create new relationships with hospitals, clinics and community-based organizations committed to the fight against breast cancer.

Objective 2: By March 31, 2013, Komen Los Angeles County will bring together local partners to create new opportunities for community collaboration.

Activity 2.1: Komen Los Angeles County will host an annual educational forum for hospitals, clinics and community-based organizations to share best practices, opportunities, and resources.

Activity 2.2: Recruit participants from the educational forum to participate in Komen Los Angeles County’s existing Medical Advisory Council to strengthen Los Angeles County’s breast health continuum of care network.

Goal 4: Reduce barriers and improve access to quality care for the medically underserved populations residing in Los Angeles County.

Objective 1: By March 31, 2012 Komen Los Angeles County will prioritize funding hospitals and community clinics that have a demonstrated commitment to reduce the barriers and improve access to quality care for our priority populations.

Activity 1.1: Komen Los Angeles County will fund healthcare providers that serve uninsured, symptomatic women under age 40 and men to improve access to the continuum of care and reduce breast cancer mortality.

Objective 2: By March 31, 2013, Komen Los Angeles County will address healthcare reform, as it relates to breast health, through our public policy efforts.

Activity 2.1: Work in conjunction with our California Komen Affiliate partners and local community organizations on local, state and federal policy issues related to healthcare reform and breast health legislation.

INTRODUCTION

Affiliate History

On February 18, 1996, the first Susan G. Komen Race for the Cure® was held in Los Angeles County. Over 4,000 people participated in that first Race for the Cure®. In July of 1996, the Komen Los Angeles County chapter was incorporated as a Komen Affiliate.

Over the past fifteen years, the Komen Los Angeles County Affiliate has raised over \$8.3 million to provide community-based grants to local organizations that provide breast cancer education and outreach, diagnostic services and supportive services. The Affiliate raises funds through events such as the Los Angeles County Susan G. Komen Race for the Cure. Twenty-five percent of the funds raised in Los Angeles County are allocated to fund national breast cancer research programs. A major focus of the Komen Los Angeles County Affiliate is to help uninsured and underinsured women and men who have symptoms of breast cancer and are facing barriers to accessing healthcare, particularly women and men under 40. During 2008-2009, the Komen Los Angeles County Affiliate gave over \$654,000 to fund community screening, diagnostic, treatment, and education services. During 2009-2010, the Affiliate invested over \$850,000 in community grants to Los Angeles County hospitals, clinics and non-profit community organizations.

In addition to providing community grants, the Affiliate also engages in targeted education and outreach initiatives throughout Los Angeles County. For example, the Affiliate organized an educational campaign through a faith-based initiative focused on priority populations. *Worship in Pink* event in 2010. ***Pink Sunday*** was held in October of 2009, and offered training to over 80 African American faith leaders and representatives. Participants were trained to be Komen Los Angeles County Pink Sunday Ambassadors and to organize breast cancer awareness events at their respective churches. In an effort to expand this initiative to other faith-based organizations, the Affiliate changed the name of this initiative to ***Worship in Pink***. In September of 2010, ***Worship in Pink*** had over twenty participants from faith-based institutions, including Korean, Latino Catholic, and African American churches, and Jewish synagogues. Supported by a grant from the Employees Community Fund of Boeing, the Affiliate developed a ***Worship in Pink*** educational toolkit for representatives to use at their own breast cancer awareness events, with educational materials, talking points and a slide presentation.

In 2010, the Komen Los Angeles County Affiliate also partnered with the Komen Orange County Affiliate on an “African American Initiative.” The Affiliates worked together to conduct a needs assessment in the South Bay area in Los Angeles County (an area that includes Long Beach, Hawthorne, Carson and other communities) and northern Orange County, to better understand high rates of late-stage diagnoses in that area. In 2011, the two Affiliates continue to work together on an action phase with a newly-formed Advisory Group of African American community leaders.

Additionally, in October 2010, the Komen Los Angeles County Affiliate organized a *Lynn Lectures: Mindfulness and Integrative Medicine* event, featuring a lecture by Jon Kabat-Zinn, Ph.D., entitled “Letting Everything Become Your Teacher: The Healing Power of Mindfulness.”

Over 1,200 community members attended this lecture on mindfulness-based stress reduction at UCLA's Royce Hall. Dr. Kabat-Zinn also provided a lecture about mindfulness during psychiatry grand rounds at the UCLA Semel Institute.

Organizational Structure

The Komen Los Angeles County Affiliate is staffed by six full time employees and is supported by a board of eleven directors, two fully engaged Advisory Councils (Medical Advisory Council and Young Women's Advisory Council), volunteer committees (including Race for the Cure, Public Policy, Grants, Volunteers, Outreach and Education, Marketing and Communication, and Fundraising), the Pink Tie Guys and Pink Divas and over 1,000 registered volunteers. The Affiliate also hosts a robust public health internship program. The Affiliate newsletter is distributed to almost 40,000 individuals in Los Angeles County.

Description of Service Area

With over 10 million inhabitants, Los Angeles County is the most populous county in California and in the United States. 50.4% of the population is female and 49.6% is male. Los Angeles County has an extremely diverse population; the race and ethnicity breakdown for adults in Los Angeles County is as follows: 41.7% are non-Latino White, of which, 76.4% reported only one race; 37% are Latino; 6.6% are African American; 1.2% are American Indian/Alaska Native; 12.7% are Asian; and 0.4% are Native Hawaiian/Other Pacific Islander. Only 2.6% identified themselves as having two or more races.¹⁷

Currently, Los Angeles County has 88 incorporated cities and many unincorporated areas.¹⁸ The Los Angeles County Department of Public Health divides Los Angeles County into eight geographic Service Planning Areas (SPAs). The Affiliate has utilized these SPAs and the research that has been conducted on these SPAs, to guide grant making and other education and outreach efforts.

(SPA 1 – Antelope Valley; SPA 2 – San Fernando Valley; SPA 3 – San Gabriel Valley; SPA 4 – Metro Los Angeles; SPA 5 – West Los Angeles; SPA 6 – South Los Angeles; SPA 7 – East Los Angeles; SPA 8 – South Bay)



According to the U.S. Bureau of Labor Statistics, the unemployment rate in Los Angeles County was 12.7% in December 2010, a slight rise from 2009, when it was 12.5%.¹⁹ The state of California has the second highest rate of unemployment in the country, with an unemployment rate of 12.5%. Often, loss of employment means loss in health benefits, which can seriously undermine the well-being of Los Angeles County residents. In 2007 (prior to the recent economic downturn), 1,999,372 individuals under the age of 65 were uninsured in Los Angeles

¹⁷ <http://quickfacts.census.gov/qfd/states/06000.html>

¹⁸ <http://ceo.lacounty.gov/forms/09-10%20cities%20alpha.pdf>

¹⁹ http://www.google.com/publicdata?ds=usunemployment&met=unemployment_rate&idim=county:CN060370&q=unemployment+rate+in+los+angeles+county

County; approximately 23% of the population. Furthermore, 30% of those uninsured are at or below 200% of the Federal Poverty Level (FPL).²⁰ Although Los Angeles County provides some programs and services to uninsured individuals, many are unaware of these services and thus, outreach and education is needed to spread the word about how to access existing resources.

Despite high numbers of uninsured individuals and the presence of other barriers to access to care, Los Angeles County is a county rich with healthcare resources. Los Angeles County is home to three National Cancer Institute-designated Comprehensive Cancer Centers: the City of Hope National Medical Center; the University of California at Los Angeles Jonsson Comprehensive Cancer Center; and the USC/Norris Comprehensive Cancer Center. In addition, there are American College of Surgeons-designated cancer centers, community cancer centers and community clinics providing care to people in Los Angeles County.

Purpose of the Report

The purpose of the biennial Community Profile is to provide an overview of the state of breast cancer in Los Angeles County, and to inform program planning and service delivery not only for the Affiliate, but for the entire Los Angeles County breast health and breast cancer community. The Community Profile prioritizes the Affiliate's fundraising, marketing and mission efforts, and provides a road map for our focus for the next five years. The Community Profile also provides clarity on our priority populations, programmatic objectives, and granting priorities.

²⁰http://smpbff1.dsd.census.gov/TheDataWeb_HotReport/servlet/HotReportEngineServlet?reportid=3358a9d3d93bd6a901040ca0fb46a7b0&emailname=saeb@census.gov&filename=sahie07_county.html

BREAST CANCER IMPACT IN AFFILIATE SERVICE AREA

1) **Data Sources and Methodology**

Los Angeles County demographics and breast cancer data was obtained from the following sources: U.S. Census Bureau, California Health Interview Survey (CHIS), statewide population-based cancer surveillance system – the California Cancer Registry (CCR), the Los Angeles County Cancer Surveillance Program (CSP), the Los Angeles County Health Survey, and 2007 Thomson Reuters estimates. While we used a breadth of data sources to ensure accuracy and reliability of the data, the most recent published breast cancer data is from 2007. We look forward to having access to more recent data for the 2013 Community Profile.

In terms of demographics, we used data from the 2007 Thomson Reuters data packs to examine the following variables among women in Los Angeles County: age, race, ethnicity, marital status, household size and income, federal poverty level, completed education level, foreign-born status, and language spoken at home. Thompson Reuters data is estimated using data compiled from the 2000 U.S. Census Bureau and 2007 CHIS findings.

In terms of variables related to overall health status as well as health behavior risk factors among women in Los Angeles County, we used findings from the 2007 California Health Interview Survey. The California Health Interview Survey is the nation's largest population-based random-digit dial telephone health survey; in 2007, this survey was conducted in six different languages and reached over 50,000 adults. Specifically, the data variables include:

- Access to care
- Insurance status
- Insurance status at or below the 200% federal poverty level (FPL)
- Mammography screening history
- Clinical breast exam history
- Breast self-exam status
- Having been diagnosed with breast cancer
- Main reasons for not having a mammogram

In addition to health status and health behavior data compiled from CHIS, we used estimates from Thomson Reuters PULSE healthcare survey to further examine rates of women in our service who received mammography and breast exams

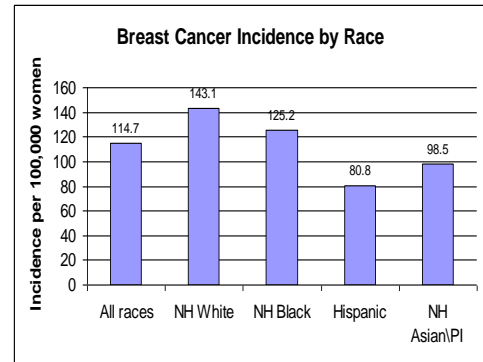
The Los Angeles County Cancer Surveillance Program (CSP), a population-based cancer registry administered by the University of Southern California Keck School of Medicine and USC/Norris Comprehensive Cancer Center, is a part of the larger California Cancer Registry, as well as the National Cancer Institute-funded Surveillance, Epidemiology, and End Results (SEER) program.

The 2007 Los Angeles County Health Survey, which is conducted by the Los Angeles County Department of Public Health Office of Health Assessment and Epidemiology, also provided valuable information for understanding both overall health behavior patterns. The survey's estimates are based on self-reported data by a representative, random sample of 7,200 Los Angeles County adults.

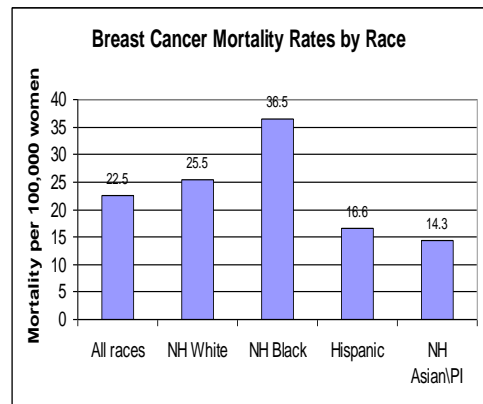
Overview of the Affiliate Service Area Over the coming year in California, it is estimated that there will be 23,640 new cases of breast cancer in women and approximately 165 new breast cancer cases in men. Approximately 25% of all new breast cancer cases (n = 5,865) are estimated to occur in Los Angeles County.²¹

Incidence and Mortality

Breast cancer continues to be the most common cancer among women in LA County, regardless of race/ethnicity. From 2004-2008, the age-adjusted incidence rate for all races combined was 114.7 per 100,000 women. It is expected to rise to 122.17 by 2014. Breast cancer is also the 2nd leading cause of cancer-related deaths for women. The mortality rate during the same time period was 22.5 per 100,000 women, second only to lung cancer.²²



There are distinct risk patterns for cancer incidence and mortality by race/ethnicity. Breast cancer is the most common cancer among non-Hispanic/Latino white, non-Hispanic/Latino black, Hispanic/Latino, and Asian/Pacific Islander women in LA County. White women had the highest incidence rate (143.1) followed by black (125.2) and Asian Pacific (98.5) women. Latino women had the lowest incidence rate (80.8). Breast cancer is the second leading cause of mortality among non-Hispanic/Latino white, African American, and non-Hispanic/Latino, Asian or Pacific Islander females, and is the leading cause of mortality among Latino females in LA County.²³ We also



know that mortality rates vary tremendously by race throughout LA County, and there is not a clear relationship between mortality and incidence rates. For example, although black women do not experience the highest breast cancer incidence rate, they do have the highest rate of death at 36.5 per 100,000. Mortality rates for this group of women are significantly higher than the average. It is critical that we determine the factors responsible for this disparity.

Breast Cancer Screening

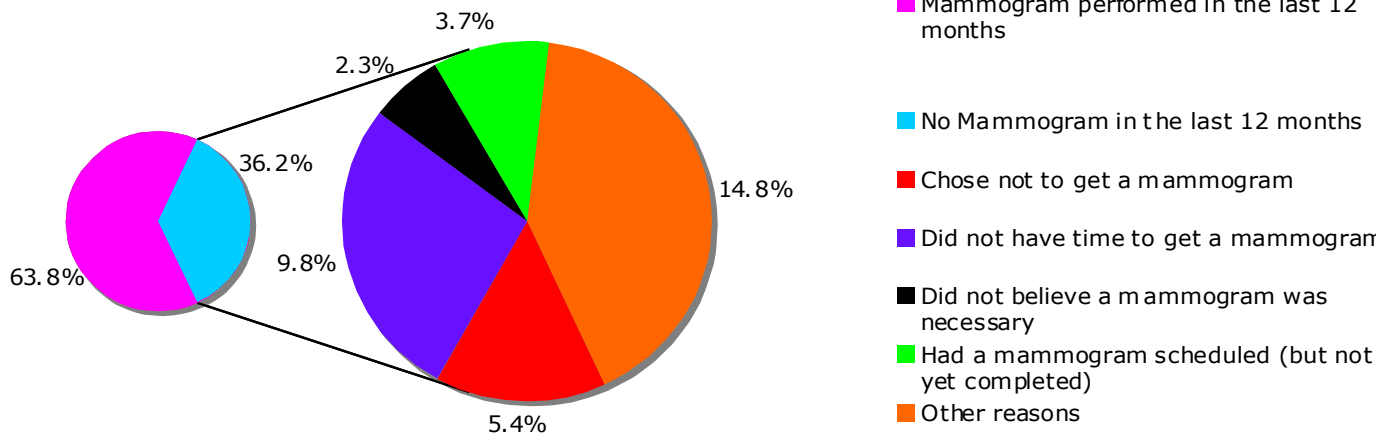
In 2009, in Los Angeles County, the population of women over 40 was 2,256, 461¹. The figure below shows that more than one third (36.2%) of these women had not received a mammogram in the last 12 months, .³¹ Findings from 2007 CHIS show that the most common reasons listed for not receiving a mammogram include: Not enough time (9.8%), chose not to receive mammogram (5.4%), did not feel they needed one (2.3%), and scheduled but had not received mammogram (3.7%).The remaining 14.8% listed other reasons³¹.

²¹ California Cancer Facts and Figures, California Cancer Registry

²² University of Southern California Keck School of Medicine Department of Preventive Medicine http://keck.usc.edu/en/Education/Academic_Department_and_Divisions/Department_of_Preventive_Medicine/Divisions/Epidemiology/Research/Cancer_Surveillance_Program/Cancer_Statistics/~/_media/Docs/Departments/Preventive%20Medicine/Epidemiology/rate882008.pdf

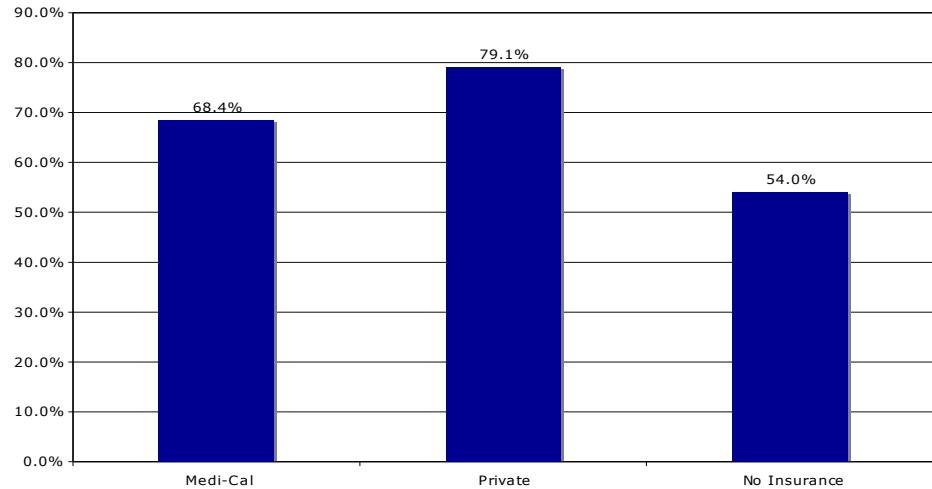
²³ University of California Keck School of Medicine Department of Preventive Medicine
 USC/CSP-CANCER IN LOS ANGELES COUNTY: INCIDENCE AND MORTALITY BY RACE/ETHNICITY 1988-2008.

Mammography for Females over 40 in Los Angeles County (2009)



As we know, early detection and regular screening is essential in effectively treating breast cancer. Studies show that having a regular source of care may help women obtain timely and appropriate screening services. Based on findings from the Los Angeles County Health Survey, only 85.3% of women in LA County have a regular source of care and 27.9% of women have difficulty accessing care.²⁴

Percent of Women (40-64 years old) Who Had a Mammogram in the Past 2 Years, by Type of Insurance, LACHS 2007



In addition, women without health insurance were even less likely to report receiving a mammogram in the past two years; this percentage was just 54% (n = 7,200). Twenty-two percent of all adults in Los Angeles County are uninsured.

Late Stage Diagnosis

Five-survival rates are related to the characteristics and stage (local, regional, distant) of breast cancer at diagnosis. Local breast cancer is an invasive cancer confined entirely to the breast. Regional is defined as a malignant cancer that either 1) has extended beyond the limits of the breast directly into surrounding organs or tissues; 2) involves regional lymph nodes by way of lymphatic system; or 3) has both regional extension and involvement of regional lymph nodes. Distant refers to a malignant cancer that has spread to parts of the body remote from the primary tumor.

²⁴ Los Angeles County Health Survey, 2007

In Los Angeles County there are significant and important age-related racial and geographic differences with regards to late stage diagnosis rates. The USC/Cancer Surveillance Program for Los Angeles County analyzed data among women over 20 years with breast cancer from 2000 to 2008. Results showed that 50.2% of women in the study were diagnosed with localized breast cancer.

Racial Differences in Late State Diagnosis Rates: Among women of all races, younger women (20-49 years) are more likely to be diagnosed with later stage of invasive cancer. Thirty-nine percent (39%) of women in Los Angeles County are diagnosed with later stages of invasive breast cancer.²⁵ African American women have the highest percentage of late stage diagnosis with 45.9%, followed by Latino women at 45.1%, Asian and Pacific Islander women at 36.2%, and non-Latino White women at 35.9%.²⁶ Furthermore, African American women have the lowest survival rate among all three stages of breast cancer (localized = 93.2%, regional = 72.0%, distant = 11.9%). White women had the highest survival rates (localized = 99.7%, regional = 87.0%, distant = 27.9%).²⁷

Geographic Differences in Late State Diagnosis Rates: As mentioned in the previous section, the county is divided into eight Service Planning Areas (SPAs): SPA 1 (Antelope Valley), SPA 2 (San Fernando Valley), SPA 3 (San Gabriel Valley), SPA 4 (Metro), SPA 5 (West), SPA 6 (South), SPA 7 (East), and SPA 8 (South Bay).²⁸ Disparities in state of diagnosis exist by region. SPA 6, which has the highest percentage of African Americans, had the highest rate of women with distant cancer (6.3%), while SPA 1, which is mostly Caucasian, had the lowest rate (3.3%). SPA 6 had the highest percentage overall of women diagnosed with a later stage of invasive breast cancer.²⁹ Other regions in LA County that contain high late-stage diagnosis rates are SPA 2 and SPA 4, which have high percentages of Latinos and Asian American/Pacific Islanders. The regions that contain the highest rates of late-stage diagnosis of breast cancer among African American women are SPA 6 and SPA 8. For Latina women, SPA 3, SPA 4 and SPA 7 are of greatest concern.

Communities of Interest

After a careful review of the demographic and breast health data, the Komen Los Angeles County Affiliate identified the following five priority populations (in priority order):

- Women with low income and/or who are underserved, uninsured or underinsured
- African American women, with an emphasis on SPAs 6 and 8
- Latina women, with an emphasis on SPAs 3, 4, 6 and 7
- Asian American and Pacific Islander women, with an emphasis on SPAs 3, 4 and 8
- Women under the age of 40

²⁵ USC/Cancer Surveillance Program Los Angeles County-2nd dataset

²⁶ USC/Cancer Surveillance Program Los Angeles County (MSF0710) among women ages 20+, excl. unknown/borderline stages.

²⁷ University of Southern California Keck School of Medicine Department of Preventive Medicine

http://keck.usc.edu/en/Education/Academic_Department_and_Divisions/Department_of_Preventive_Medicine/Divisions/Epidemiology/Research/Cancer_Surveillance_Program/Cancer_Statistics/~/_media/Docs/Departments/Preventive%20Medicine/Epidemiology/rate882008.pdf

²⁸ LA County Department of Public Health

²⁹ USC/Cancer Surveillance Program Los Angeles County-Table 2 Percentage of Women Diagnosed with later stage of Invasive Breast Cancer by Age, Race, and Service Planning Area (SPA), in Los Angeles County, 2000-2008.

These targeted "communities" were chosen based on gaps in the continuum of care for specific groups, low screening rates, high late-stage diagnosis rates, high mortality rates and access issues. Below is a detailed discussion of the characteristics and major concerns within each of these targeted areas.

Geographic Communities of Interest

Each of the targeted Service Planning Areas (SPAs) in LA County has their own unique population characteristics and composition.

- SPA 3: More than half the female population of SPA 3 is comprised of Latina and Asian women. Nearly 40% of women over the age of 40 live at or below 200% of the federal poverty level (FPL), and 27.6% need a mammogram.
- SPA 4: 51% of women are either Latina or Asian. More than half of the women over 40 live at or below 200% of FPL and nearly 32% need a mammogram. Nearly 33% of women are uninsured in SPA 4.
- SPA 6: This area has the highest percentage (62%) of women living at or below 200% of the FPL and 79% of women are either black (42.6%) or Latina (36.1%). Nearly 29% of women are uninsured.
- SPA 7: 38.3% of women are Latina and nearly 44% live at or below 200% of the FPL.
- SPA 8: This area is most diverse, with 37.9% non Latina white, 22.3% Latina, 15.1% black and 14.6% Asian women. More than one in three women lives at or below 200% of the FPL.

INDICATOR ³⁰	SPA 1	SPA 2	SPA 3	SPA 4	SPA 5	SPA 6	SPA 7	SPA 8
Uninsured women (18-64)	12.9%	17.3%	22.8%	32.7%	8%	28.8%	24.5%	16.5%
Mammogram in past 2 years – women 40+	70.9%	75.4%	72.4%	68.5%	78.5%	72.0%	77.0%	73.3%
Women - Difficulty accessing care	29%	23%	31%	34%	14%	39%	29%	24%
Women - No regular access to care	13%	13%	14%	22%	15%	14%	17%	11%
Women over 40 at or below 200% of FPL	36.8%	24.1%	38.8%	52.6%	17.8%	62%	43.7%	35%

The region that contains the lowest percentage of women who have had a mammogram in the past 2 years is SPA 4. Significant socioeconomic factors potentially exist in SPA 4, 6, & 7. Of all the SPAs, SPA 4 has the highest percentage of uninsured women (32.7%), which may be a barrier in accessing quality health care services and thus, the timely receipt of appropriate screening and treatment services. Finally, as stated previously, SPA 6 has the highest percentage overall of women diagnosed with a later stage of invasive breast cancer.

Low Income, Underserved, and Uninsured/Underinsured Women

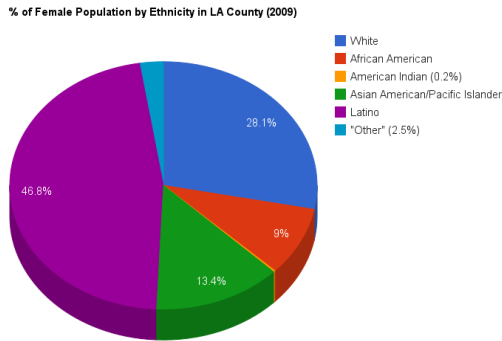
Social, economic and environmental conditions all play a role in the observed health disparities among women in LA County. LA County was home to 2,244,183 families in 2009, with 14.8% of these families having an income below the federal poverty level. The median household income was \$53,787. There are pockets throughout the county where socioeconomic conditions correlate with health insurance status and health outcomes. For example, nearly 50% of LA's Latina women report household incomes less than 100% of the federal poverty level.³¹ Insurance status is also an important aspect of breast health. In 2009, 20.3% of all females and 27.1% of females between the ages of 18-64 were uninsured in LA County.³²

³⁰ Sources: Healthy People 2010, Los Angeles Public Health (2007)

³¹ <http://www.lapublichealth.org/owh> (Health Indicators 2010)

³² Thomson Reuters data

Insurance status mapping data shows there are concentrated pockets of uninsured adults in SPAs 4, 6, 7 and 8. Latinas consist of the highest number of uninsured women in Los Angeles County. All uninsured individuals face difficulties accessing care. In addition, only 54% of women without insurance have had a mammogram in the past 2 years.³³

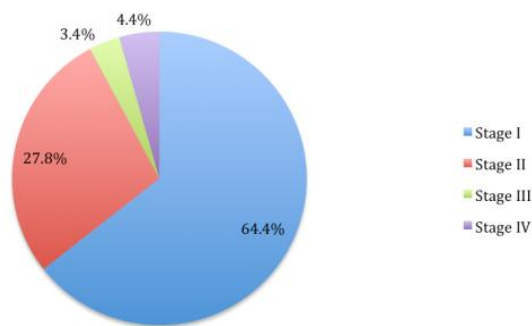


The figure on the left displays the racial and ethnic composition of the female population in LA County. Asian/Pacific Islander women represent 13.4% of the female population, Latino women represent 46.8% and African Americans represent 9.0%. These three ethnicities are our target communities due to their propensity towards breast cancer. See below for a detailed explanation.

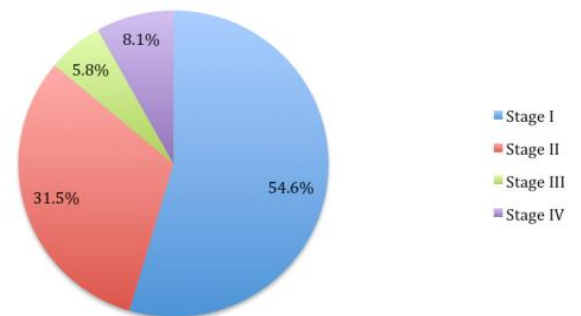
African American Women

Perhaps the greatest health disparities are present among black women, who have far higher mortality rates from many chronic diseases (including breast cancer) than other women in the County. Breast cancer is the most common diagnosed cancer in African American women in LA County. 28.8% of all cancers in African American women are breast cancer. Despite the high prevalence, 23.9% of African American women 40 years or older have not had a mammogram in the past 2 years and 7.7% (17,000) of African American women age 40 and over have never had a mammogram. The highest incidence of breast cancer in African American women occurs in SPA 6. For reasons that are not well understood, black women have an increased chance of having breast cancer diagnosed at a later stage. For this group, 13.9% of cancers are diagnosed at stage 3 or stage 4 compared to 7.8% for all women combined in California.

Incidence of Breast Cancer in All Women in California (2009)



Incidence of Breast Cancer in Black Women in California (2009)



Latina Women

Breast cancer is also the most common cancer among Latinas in LA County. 26.1% of all cancers in Latinas are breast cancer. In addition, 27.7% of Latinas 40 years or older have not had

³³ Los Angeles County Health Survey, 2007

a mammogram in the past 2 years³⁴ and 22.9% of Latinas age 20 and over, in LA County, do not examine their breasts for lumps. The highest incidence of breast cancer in Latinas occurs in SPA 3, 4, and 7. In addition, Latinas report the poorest self-rated health status among all ethnic groups. Compared to all other groups, they report poorer access to care, with 34.6% lacking health insurance, and 40% reporting difficulty accessing medical care. Some factors believed to contribute to this disparity include a high level of poverty and low level of education.³⁵

Asian/Pacific Islander Women

Given the heterogeneity of the Asian/Pacific Islander (API) population, health disparities are only readily apparent when examining individual ethnic groups within the larger population. For example, Vietnamese women have much higher rates of poverty compared to other Asian groups (over 2/3 live in households with incomes less than 200% FPL). Korean women have the poorest self-rated health status with less than 1/3 reporting excellent/very good health.³⁶ In addition, breast cancer continues to be the most common cancer among all API women in LA County. Close to 1 in 50 women of Asian/Pacific Islander descent in LA County have been diagnosed with breast cancer. 26.0% of all cancers in API women are breast cancer. Again disparities exist within this population. For example, 34.5% of all cancers in Filipino women are breast cancer, 37.0% of all cancers in Japanese women are breast cancer, 28.7% of all cancers in Chinese women are breast cancer, and 21.0% of all cancers in Korean women are breast cancer. In addition to this high genetic propensity, API women are much less likely to schedule regular mammograms. More than 1 in 10 (10.6%) API women over 40 in LA County have never had a mammogram, and 33.1% of API women 40 years or older have not had a mammogram in the past 2 years. Among API subgroups, Chinese women rank the highest in those who have never had a mammogram. The highest incidence of breast cancer in API women occurs in SPA 3.

Women Under 40

California's breast cancer incidence rate (44.60) for women between the ages of 18-44 is the 4th highest in the U.S. In fact, 12% of all breast cancers occur in women under the age of 44 in the US.³⁷ Women under 40 are at a distinct disadvantage when it comes to their breast health, and early screening in particular. Breast screening guidelines have historically recommended that women over the age of 40 receive annual mammograms. These guidelines make it much less likely for a younger woman to receive breast screening, even if symptomatic or at high risk. The USC/Cancer Surveillance Program for LA County found that amongst all races, women ages 20 to 49 have the largest percentage of women diagnosed with a later stage of invasive cancer.

Conclusions

Demographic and statistical data collected through the U.S. Census Bureau, California Health Interview Survey (CHIS), California Cancer Registry (CCR) and Los Angeles County Cancer Surveillance Program (CSP), were analyzed by the Community Profile team to determine the current breast health landscape among women in Los Angeles County. Overall findings revealed that the San Gabriel Valley area (SPA 3), the Los Angeles Metro area (SPA 4), the

³⁴ <http://www.lapublichealth.org/owh>

³⁵ LA Public Health (Health Indicators 2010)

³⁶ LA Public Health (Health Indicators 2010)

³⁷ Surveillance, Epidemiology, and End Results (SEER) Program, 17 SEER Registries, 1973-2005, Division of Cancer Control and Population Sciences, National Cancer Institute, 2008.

South Central Los Angeles area (SPA 6), the East Los Angeles area (SPA 7), and the South Bay area (SPA 8) face issues of fewer screenings, higher incidences of late stage breast cancer diagnosis, higher levels of poverty, and lower levels of education as compared to the rest of Los Angeles County. Based on this information, the Community Profile team came to a consensus to continue to focus on the aforementioned target communities.

This data analysis also revealed that there may be specific groups that need our attention at particular points along the continuum of care. Examples are:

- Asian American community navigation and education may be of greater impact, given that members of these ethnic groups have the lowest screening rates. Pacific Islanders may particularly benefit from culturally\linguistically competent education and navigation due to cultural and linguistic barriers to accessing healthcare. There are high percentages of Asian women in SPA 3 (27.5%), SPA 4 (25.3%), and SPA 8 (14.6%).
- There are high late-stage diagnosis rates among African Americans, which supports the need to focus on screening and diagnostic tests for this population. Younger African American women have a high incidence of later stage diagnosis and the lowest survival of all groups, including a marked 5-year survival rate discrepancy compared to all other ethnic groups. There are high percentages of African American women in SPA 6 (42.6%) and SPA 8 (15.1%).
- Latinas report high levels of poverty and comprise the highest number of uninsured women in LA County. These factors may add to difficulty accessing care. There are high percentages of Latinas in SPA 3 (28.2%), SPA 4 (26.1%), SPA 6 (36.1%), and SPA 7 (38.3%).

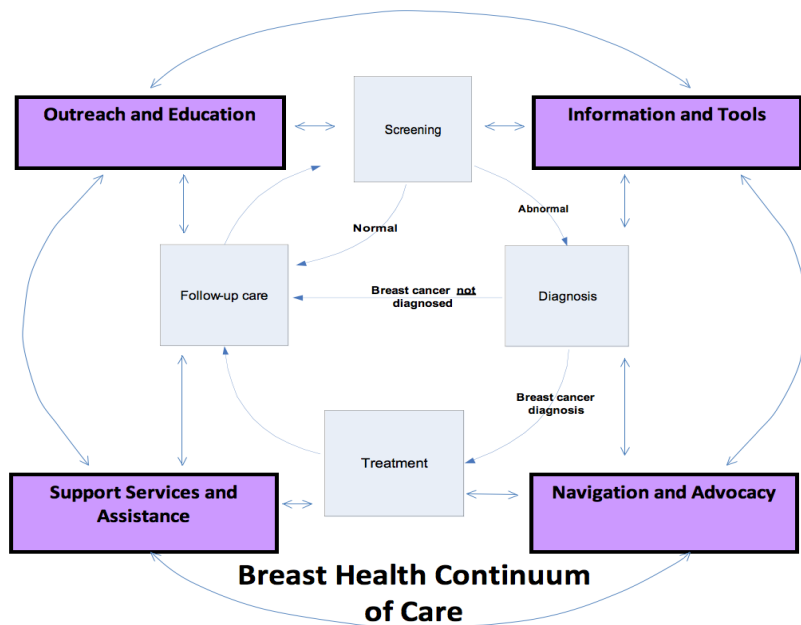
A careful review of demographic information and breast health statistics lead us to areas and populations where substantial health disparities exist. What this information does not explain are the specific barriers and gaps (e.g., lack of resources, access, cultural, linguistic) facing women in LA County as they pertain to and impact breast health. The following health systems analysis and qualitative studies will shed further light on these issues.

HEALTH SYSTEMS ANALYSIS

Breast Health Continuum of Care

The breast health continuum of care is the basis for our 2011 Community Profile, particularly for our health systems analysis. In addition to using this model as a foundation to organize our Community Profile, the continuum of care model ultimately drives all of our Affiliate's programs and services, including our fundraising and marketing efforts. This model outlines the entry point of a woman into the cycle of screening, diagnosis, treatment and follow-up care as well as how a woman typically transitions through the healthcare system. The breast health continuum of care is the process by which individuals move through their recommended breast health screening, and if necessary, breast cancer experience. This model acts as a guide to help understand why some women do not receive regular screening and why others who are screened do not move through each phase of the model in a timely manner.

The ideal continuum of breast care model would begin with healthcare providers and preventive health agencies providing outreach and education about recommended breast health screening to empower women to move into the continuum of care to screening. Then, healthcare providers and health agencies provide women with the information and tools they need along with their screening results, and women either move forward to diagnostic testing or go back into yearly screening adherence. Once diagnostic testing is completed, women move into routine follow-up and screening or move forward to treatment, if diagnosed with breast cancer. Navigation and patient advocacy is helpful throughout the continuum, but is especially important from diagnosis to treatment. Once women are in the treatment phase of the continuum, they should receive support services and assistance. Once treated for breast cancer, women will need to continue their follow-up care, especially in the first five years post-diagnosis. After five years, women benefit from regular, routine screening, support, and management.



Methodology

In an effort to collect information about the health system and the continuum of breast health in Los Angeles County, the Affiliate collected quantitative data from the Cancer Surveillance Program, Thomson Reuters, Office of Women's Health and CHIS to review demographic variables and areas of high late-stage diagnosis, high incidence, and high mortality.

The Affiliate also conducted a robust literature review of breast health and breast cancer studies in Los Angeles County. We collected qualitative data through key informant interviews, surveys and focus groups to understand factors that contribute to high incidence, mortality and late-stage diagnosis rates. Findings from this review of the literature informed the creation of our survivor and provider surveys, focus group facilitation guide, and our key informant interview guide. For a review of our findings from our survivor surveys and focus groups, please see the following section.

In addition to a review of the literature, we collected qualitative data through provider surveys and key informant interviews with breast health experts in LA County. The qualitative data instruments were created to understand issues affecting breast care delivery for women in our target community, specific issues and barriers that exist in LA County, how women move through the continuum of care, and concerns facing survivors. We conducted 28 key informant interviews in-person and via telephone, with breast health providers and researchers throughout the county. Furthermore, we used Survey Monkey to conduct online provider interviews and received 50 complete provider surveys.

To assess the programs and resources in our community, we worked with a Geographic Information System (GIS) mapping expert to create maps of poverty level and insurance status as well as asset maps of resources by Service Planning Areas. The Service Planning Area data came from the Los Angeles County Department of Health Services, demographic statistics came from the Thomson Reuters data, and zip code boundaries were acquired from the Los Angeles County Department of Regional Planning. Data points representing hospitals, community clinics, support groups, Komen LA County grants awarded, and other breast health community assets were based on research conducted by the Komen Los Angeles County Affiliate. Bus route data was acquired from: Antelope Valley Transportation Authority, City of Santa Clarita, City of Santa Monica, and Metro. Street data acquired from the U.S. Census Bureau's TIGER database (2009) and city boundary data acquired from Los Angeles County Department of Regional Planning.

Lastly, we analyzed the public policy environment within California and Los Angeles County to highlight how policy impacts each stage of the continuum of care.

Limitations: Although we had a relatively small sample of providers, they represent a diverse group of hospitals and health systems throughout Los Angeles County.

Key Informant Interview Findings (n = 28)

We conducted eight key informant interviews with representatives from the three NCI-designated cancer hospitals, three county facilities, the Los Angeles County Department of Women's Health, and the Cancer Surveillance Program at USC. As part of our joint African American Initiative project with Komen Orange County, we also conducted twenty key informant interviews with African American leaders in the community, including healthcare providers, church representatives and leaders of community-based organization. There were five consistent themes from the key informant interviews:

- 1) Patient Navigation and Patient Advocacy throughout the continuum of breast health care, with a focus on following patients through their experience over time;
- 2) Access to timely diagnostic and therapeutic care to reduce late-stage diagnosis, with a focus on reaching the underserved, ethnically diverse groups, and high-risk younger women;
- 3) Komen taking a leadership role to bring together key leaders and partners in the healthcare and faith-based communities, and community-based organizations;
- 4) Communication and decision-making tools for providers and patients, and culturally appropriate messaging about early detection; and
- 5) Prevention and healthy behavior change with a focus on diet and exercise.

When asked what Komen Los Angeles County's priorities should be, we heard:

Patient Navigation:

"The navigation component is essential: to have the awareness of how to access the system, and have somebody who can help access the treatment, all the way through the continuum of care."

Outreach and Education:

"Education of how to obtain low cost screening exams and mammography to the local community and where to go."

"Access to care for uninsured or poorly insured individuals; Access to timely diagnostic and therapeutic care; Access to multidisciplinary care."

Healthcare Capacity:

"Capacity for actually getting a screening mammogram, diagnostic services, treatment (surgical oncology services) Are there enough providers?"

When asked who Komen Los Angeles County should partner with, we heard:

"Providing that infrastructure between area medical centers is really important... being able to develop a network to create pathways for care. There are amazing organizations that come together naturally and foster that spirit of partnership to help patients."

"I think what's also important is infrastructure within health systems and then within their own medical center. Once a patient is diagnosed with breast cancer, they have limited resources to provide treatment. So having a direct referral is always important, creating those links."

Provider Survey Results (n = 50)

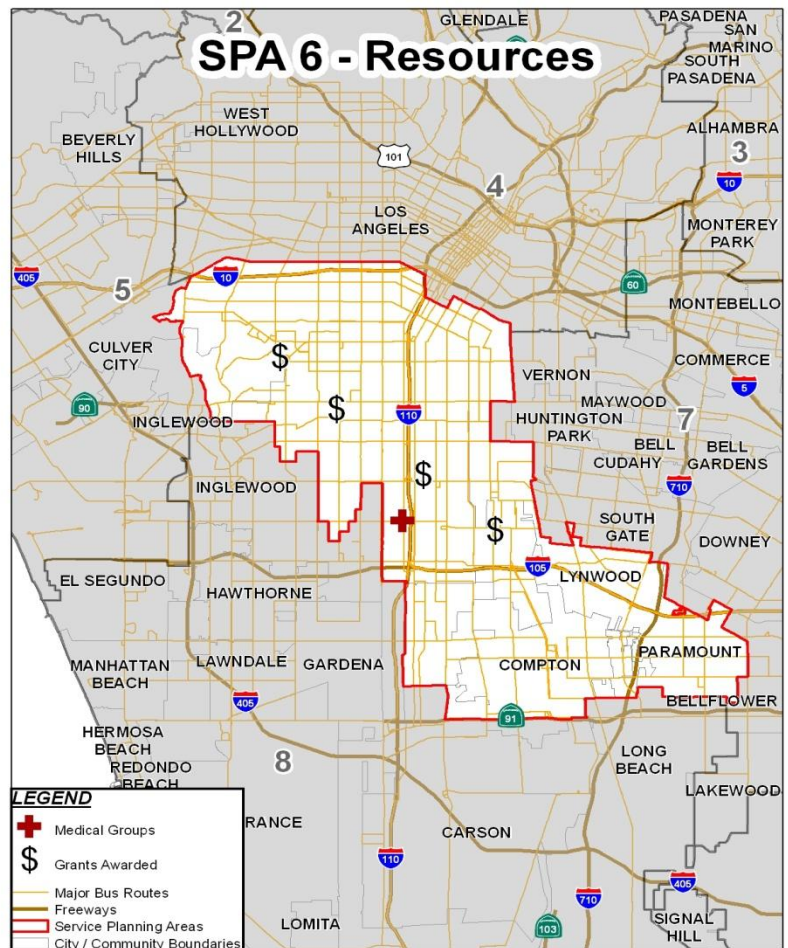
Leaders and Partnerships in the Community: Provider respondents recognized Komen Los Angeles County and several of our grantees and partners as navigators and leaders in Los Angeles County that could help build a network. We asked "What partnerships exist in Los Angeles County to navigate women through the continuum of care? What further collaborative efforts are needed?" We heard that additional collaborative efforts are needed on both the macro and micro level, and there was strong support for Komen Los Angeles County establishing a

navigation network committee with leaders from the area hospitals and medical centers to understand the needs of the uninsured patient population.

When we asked, “What role can the Los Angeles County Affiliate of Susan G. Komen for the Cure take in building a stronger continuum of care network within our County?” Themes that emerged from this question included increased outreach and education, especially for low-income women, acting as a liaison to create alliances and collaborations between community organizations to build a stronger continuum of care, and creating a resource guide of available services throughout LA County.

GIS Mapping

Asset mapping was conducted with the help of two Community Profile Team members. One of the volunteers validated an existing list of healthcare provider agencies, including hospitals and clinics that provide breast health services and treatment centers for breast cancer patients, some of which are Komen Los Angeles County Affiliate grantees. The other volunteer, a GIS mapping expert from LA County, created maps using this list of County programs and resources, as well as public transportation routes. The resources map showed us that SPA 6 is the geographic area lacking the most breast health resources, including the fewest hospitals that provide cancer services. The transportation routes showed that while options for public transportation exist throughout LA County, transportation may still be a barrier for low-income women and for women who must travel several miles from their home to receive care



Barriers

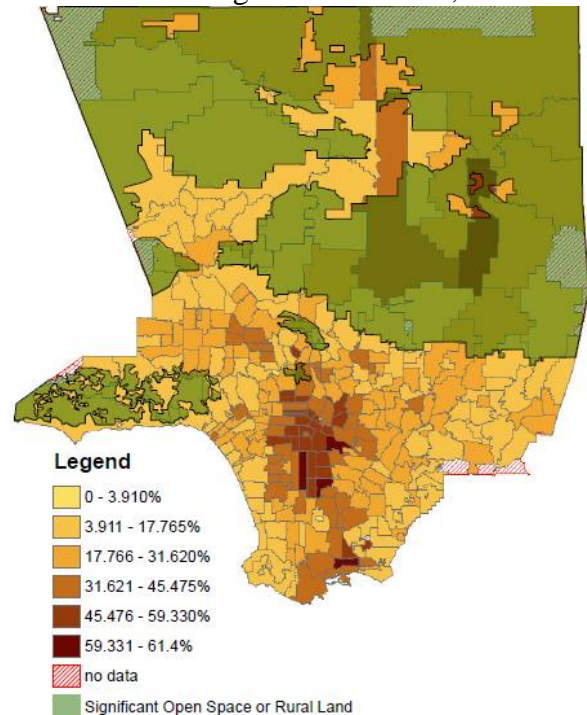
Based on our literature review, key informant interviews and provider interviews, we examined barriers to accessing health systems in LA County including: lack of insurance; lack of access to screening and diagnostic tests; lack of understanding or knowledge of how to access the healthcare system, with a specific focus on accessing the public County system; language barriers; public transportation; financial barriers; childcare and taking time off work, lack of knowledge; lack of health insurance; fear of pain/discomfort; distrust of the healthcare system; lack of information on how to access the system; and lack of awareness of the various free and low cost services and programs available.

Percent of Uninsured Females (ages 18-64) by Zip Code

This map shows that there are concentrated pockets of uninsured adults in SPAs 4, 6, 7 and 8. Latinas are the highest percentage of uninsured women in Los Angeles County.

The graph below shows that SPA 6 has the highest number of women who have difficulty accessing care with 39%, followed by Next are women in SPA 4, with 34%. SPA 4 also has the largest number of women with no regular source of care.

Lack of access to quality health care services affects the prevention and timely detection and treatment of diseases such as breast cancer. One of the barriers to accessing health care is lack of health insurance coverage. Individuals without health insurance are less likely to obtain health care and consequently are more likely to have poor health status³⁸, to be diagnosed at later stages of disease, and to die.³⁹ A recent survey conducted in 2009, found that 20.3% of females in Los Angeles County were uninsured and approximately 27.1% of uninsured females were between the ages of 18-64.⁴⁰ Since early detection is important in effectively treating breast cancer, having a regular source of care may help women obtain timely and appropriate screening services. It was found, however, that only 85.3% (n=7,200) of women in Los Angeles County have a regular source of care and 27.9% of women in Los Angeles County have difficulty accessing care.⁴¹



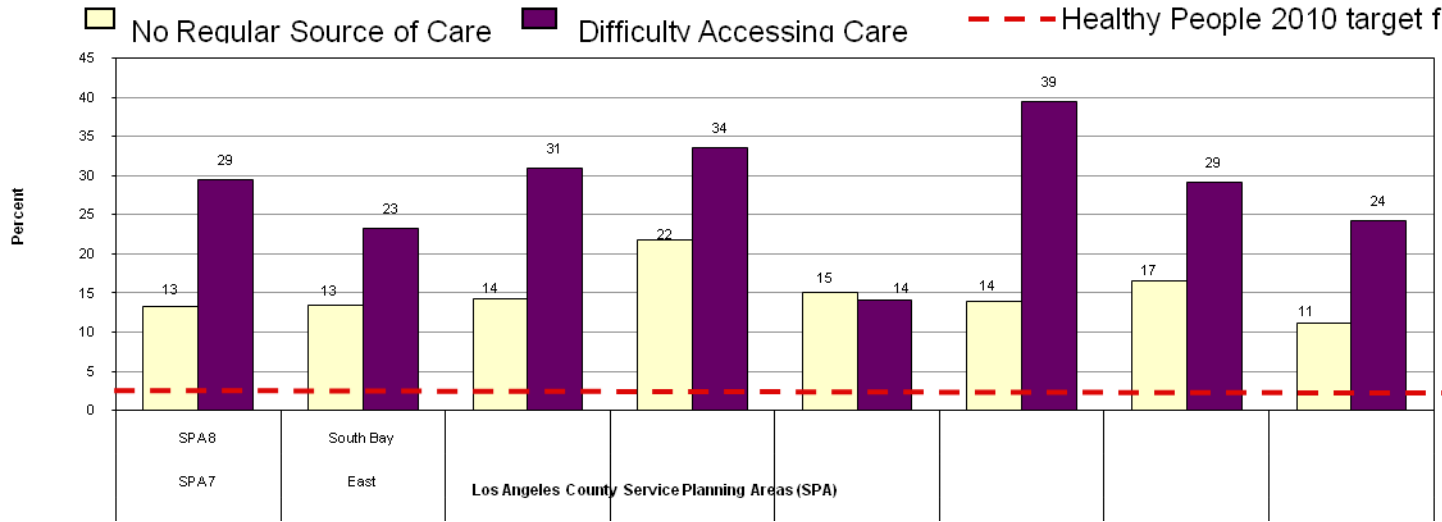
³⁸ <http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=1>

³⁹ Wilper, et al "Health Insurance and Mortality in U.S. Adults," American Journal of Public Health; Vol. 99, Issue 12, Dec 2009 and Hadley J. Sicker and poorer--the consequences of being uninsured: a review of the research on the relationship between health insurance, medical care use, health, work, and income. Med Care Res Rev June 2003 vol. 60 no. 2 suppl 3S-75S

⁴⁰ Uninsured Females by County: Ranked by 2009 Female Population (Desc). © 2009, Claritas Inc., © 2010 Thomson Reuters. All Rights Reserved

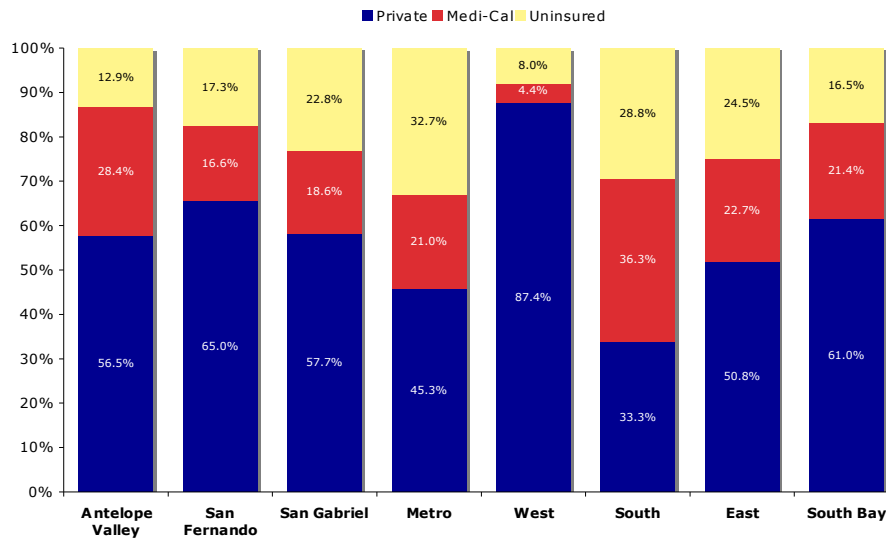
⁴¹ Los Angeles County Health Survey, 2007

Women in Los Angeles County with No Regular Source of Care and Difficulty Accessing Care by Service Planning Area, 2007 ¹



The table below shows that SPA 4 has the highest percentage of women who are uninsured (32.7%). SPA 6 has the second highest percentage of women who are uninsured (28.8%).

Insurance Types for Los Angeles County Women (18-64 years old) by Service Planning, LACHS 2007



Community Assets

The Komen Los Angeles County Affiliate has a number of existing partners in our Affiliate service area. We have close partnerships with : the County of Los Angeles Department of Women’s Health and the Department of Public Health; the University of Southern California Cancer Surveillance Project; each NCI-designated cancer hospital in the County; ACoS-accredited cancer hospitals; community-based organizations focusing on healthcare and services for the underserved; community clinics and public health programs at local universities; the

Cancer Support Community affiliates and other survivor support groups in the community; community advocacy organizations; legislators; and faith-based community leaders. The Affiliate has the potential to create future partnerships with healthcare providers at each institution and continue to convene community stakeholders, businesses, and legislators to improve access to care in LA County.

The Komen Los Angeles County Affiliate is a member of the ACCESS for LA Coalition. ACCESS (Access to Cancer Care, Education, Services & Support) for LA is a coalition to reduce the barriers to access to cancer care in Los Angeles County. . The Affiliate is also a member of the SPA 4 Breast Cancer Task Force that specifically aims to improve breast health outcomes in SPA 4, with a focus on reaching the Asian American/Pacific Islander population. The Affiliate is also a leading member and facilitator of the newly-formed Komen Community Partnership that aims to improve breast health outcomes in SPA 8 among African American women. The Affiliate participates on the Latino Task Force, the Asian American Task Force and the African American Task Force in LA County.

While the Komen Los Angeles County Affiliate provides community grants to a large number of organizations providing diverse programs and services throughout Los Angeles County, the Affiliate cannot possibly begin to meet the immense need of the community. Grantees currently provide community education and outreach, diagnostic services and supportive services to breast cancer patients in all eight SPAs. However, grantee programs are typically limited in nature by focusing on specific geographic areas, ethnic and age populations, and are usually limited to the funds provided by the Affiliate grant.

The Komen Los Angeles County Affiliate changed its grant RFP for 2011-2012, to ensure that partnership, collaboration and innovation are central to proposed grant projects. The Affiliate strives to partner with our current and former grantees and community partners through a variety of avenues to develop access and navigation throughout the continuum of care. Working together, the Affiliate and our community partners can make a greater impact on reducing barriers, empowering and engaging the community to access care, and navigating and supporting patients along the way.

Komen Los Angeles County Affiliate and Public Policy

The seven Komen Affiliates in California host a Komen California Collaborative Public Policy Committee. Members of the committee consist of representatives from each Affiliate and include the Affiliates' Public Policy Committee Chairs. The Committee holds bi-weekly conference calls to monitor and discuss California and federal legislative initiatives and determine Komen's support for legislative and public policy. During 2010, the Collaborative took a position of support for the following bills:

- AB 1640 (Evans, Nava – co-sponsored by the Komen California Collaborative) – Reinstate the Every Woman Counts program
- SB 836 (Oropeza) – Reinstate the Every Woman Counts program
- AB 113 (Portantino) – Improve access to mammography screening

The Komen California Collaborative Public Policy Committee also coordinated California Lobby Days in Sacramento in 2007, 2008, and 2009. On February 1, 2009, Komen

representatives from California attended meetings with State Senators and Assembly members to educate officials about the importance of the Every Woman Counts (EWC) program and to voice opposition to additional program cuts during ongoing state budget negotiations, as well as oppose the US Preventive Services Task Force recommendations to change the breast cancer screening guidelines.

The US Preventative Services Task Force Guidelines

The US Preventative Services Task Force (USPSTF) is a non-federal commission funded and appointed by the government to make recommendations for health care policy based off of data provided by the AHRQ and other agencies. The USPSTF makes recommendations on a multitude of health care issues, including breast cancer.

In 2009, the USPSTF made two suggestions that are contradictory to Komen's positions on breast health and breast screenings. First, the USPSTF suggested that mammograms may only be necessary every other year, as annual screenings may have no benefit. Komen acknowledges that different organizations assess the same data in different ways, which results in differing suggestions. Komen suggests that the individual woman decide with her doctor how often she should undergo testing. The second suggestion made by the USPSTF is that women between the ages of 40-49 consult with their personal physician on when to begin mammograms. Komen has stood firm that women should begin to have annual mammograms starting at 40, as breast screening is the best way to save lives through early detection and timely treatment of breast cancer. As Komen had feared, the release of the USPSTF's recommendation decreased the amount of mammograms from women 40-49. This is of utmost concern, as having regular screenings is one of the best ways to catch breast cancer at its earliest stages. The American College of Radiology and the American Cancer Society stand in solidarity with Komen's suggestions and continue all efforts to change the USPSTF'S recommendations for the appropriate time to start mammograms. The confusion created by these guideline changes reinforces the need for effective community education and outreach on breast health.

Cancer Detection Program: Every Woman Counts

In December 2009, it was announced that as of January 1, 2010, *Every Woman Counts* (EWC), the state's breast and cervical cancer screening program for low-income uninsured and underserved women, would have its funding frozen. As a result, 1.2 million women were denied access to vital breast cancer screening services..

EWC is a joint program of the California Department of Public Health and the U.S. Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program. Although EWC cut screening for women ages 40-49 and any woman above the age of 49 who was a new enrollee, one third of women diagnosed with breast cancer are under age 50⁴².

Unfortunately, women with low incomes, who are uninsured or underinsured — like those eligible for EWCs — are more likely to skip potentially life-saving cancer screenings, which may lead to later diagnoses and lower survival rates. After 10 months of the Komen California

⁴² <http://www.cdph.ca.gov>

Collaborative advocating to reinstate funds for EWC, Governor Arnold Schwarzenegger signed the budget, including funding to fully reinstate EWC programs throughout the state. Since January 1, 2011, clinics and providers have been able to enroll women into the program and provide breast cancer screening and diagnostic follow-up to women above the age of 40.

When the Patient Protection and Affordable Care Act (health care reform) was signed on March 30, 2010, improved access to breast cancer screenings, diagnosis and treatment became available to uninsured and insured Americans. Although most changes will not be implemented until 2014, many citizens have more services available at present. Under the Affordable Care Act, individuals with certain individual and group health insurance coverage (including self-insured plans) and individuals with Medicare, can get access to preventative services (such as annual mammography for women over the age of 40 and BRCA genetic counseling for women at higher risk) without having to pay a co-payment, co-insurance, or a deductible. It is important to educate women about these new provisions and encourage them to access free preventative services⁴³. Additionally, the Affordable Care Act states that mammograms, genetic counseling and breast cancer chemoprevention must be included in all health care coverage plans by 2014.

Promoting prevention and access to early detection is critical to the Komen Los Angeles County Affiliate, as well as to ensure that breast cancer survivors and those who will have to battle breast cancer have the coverage they need.

The review of current breast health screening and breast cancer services and programs in Los Angeles County highlights the need to prevent the medically underserved, uninsured, and underinsured populations from “falling through the cracks” while pursuing screening, diagnostic testing, treatment, and support services for breast cancer. The following areas of need have been identified and implemented into the goals and objectives for the Affiliate and the Request for Proposals.

Conclusions

The health systems analysis section demonstrated that there are challenges to accessing care in Los Angeles County. The Affiliate plans to prioritize all activities for the upcoming year and focus our work on building community partnerships in the health care system. We also plan to continue being a resource to the community and provide grant monies to our community partners and build relationships with the grantees to help us improve access to the breast health continuum of care. Komen Los Angeles County will continue to work closely with the other Affiliates in the California Collaborative Public Policy Committee to advocate for the Every County Program to continue, and to improve and expand access to the Breast and Cervical Cancer Treatment Programs (BCCTP). It is important to get the community perspective on what the barriers to the health system mean to them. The next section examines qualitative responses from the focus group and survey participants to glean ways to address barriers and get the community perspective on the ease of access into and throughout the continuum of care.

⁴³ www.healthcare.gov/law/about/provisions/services/lists.html

BREAST CANCER PERSPECTIVES IN THE TARGET COMMUNITIES

Introduction and Methodology Overview

During 2010, the Komen Los Angeles County Community Profile team created and distributed Survivor and Healthcare Provider online surveys, conducted six focus groups with breast cancer survivors and community members, and conducted 25 key informant interviews to assess breast cancer perspectives within LA County. All qualitative data was reviewed by qualitative data experts on our Community Profile team.

We wanted to get a comprehensive overview of our community's knowledge, attitudes, and beliefs about breast cancer and the continuum of care. In addition, we wanted to hear from community members, survivors, and breast cancer experts on how to more effectively reach our community and we wanted to learn about survivors' experiences during diagnosis, treatment, and follow-up care as well as services available to them during these phases of the continuum of care. We will outline key findings and themes in an attempt to understand the assets and gaps in the continuum of care process in Los Angeles County as well as highlight potential solutions and key activities Komen Los Angeles County can undertake to meet these outlined needs.

Surveys (Survivors and Healthcare Providers)

Survivor and Healthcare Provider surveys were sent to our survivor's database (500+ survivors), our grantees and community partners, our 25-member Community Profile Team, and our 20-member Medical Advisory Council for distribution. In addition, we promoted the surveys through our website and social media sites (Facebook, Twitter). Surveys were distributed and completed online through the survey tool Survey Monkey. To date, a total of 178 survivors and 50 providers completed a survey, which is an estimated 20% response rate. Unfortunately, many of our partner healthcare providers cited HIPAA compliance issues and were unable to distribute our surveys to their patients without IRB approval.

Survivor surveys included information on demographics, diagnosis, obstacles to diagnosis and treatment, treatment plan, and follow-up care. Additionally, The Community Profile team wanted to get information on support services offered during treatments, the greatest needs of women in treatment and survivorship, and how Komen Los Angeles County can fill those gaps. Provider surveys included information on their organization's patient demographics and breast health services (outreach/education and screening/diagnostics services). In addition, we asked providers to discuss additional resources that would increase their organization's capacity to support women through the breast health continuum and what role the LA County Affiliate could take in building a stronger continuum of care network within our County. We included all providers of breast health services, including physicians, nurses, and staff at breast health community organizations.

Focus Groups (Survivors and Community Members)

Komen Los Angeles County conducted three focus groups with 15 breast cancer survivors total. We conducted two focus groups with 16 African American community members in the Greater

Long Beach Area. The Community Profile Team created a focus group guide and each focus group was facilitated by an experienced focus group facilitator. Two 60-minute focus group with breast cancer survivors in November 2010 explored survivor's diagnosis information, healthcare experiences, advice to other women, and perceptions of Susan G. Komen for the Cure. In addition to these two focus groups conducted directly by the LA County Affiliate, two survivor 90-minute focus groups with African American survivors and one 90-minute focus group with African American community members were conducted in September 2010, as part of the African American Breast Health Initiative. Focus groups were audio-taped and transcribed; we will present the main themes that emerged during these focus groups.

Review of Qualitative Findings

Survivor Surveys (n=178)

Demographics: The survey was distributed to survivors throughout Los Angeles County and respondents represented each geographic area in the County. The majority of our survivor respondents were age 40 years and older (93%) and Caucasian (65%). Further breakdown of race and ethnicity show 13% of respondents were Latino, 10% Asian American/Pacific Islander, and 7% African American. While we attempted to reach minority and non-English speaking women through our grantees, the majority of respondents spoke English as their primary language. The income range of respondents was fairly equally distributed; incomes between \$50,000 and \$74,999 were most common, followed by \$75,000-\$99,999 and \$150,000+. Importantly, the majority of respondents had insurance: 86.8% private insurance, 14.9% Medicare, and 0.8% other government program, while only 4.1% were uninsured.

Diagnosis: The majority of respondents were first diagnosed between 40-49 years (40.5%) and 50-59 years (29.7%). However, we also had many young survivors complete the survey; 14.4% were diagnosed with breast cancer before age 39. Most survivors were diagnosed with Stage 1 breast cancer (32.5%), followed by Stage 2 (28.9%), and Stage 3 (21.1%).

Mammography Experience: Seventy-nine percent of respondents reported that getting their mammogram was very easy or easy, while only 6% reported that getting their mammogram was difficult or very difficult. Additionally, 75.7% reported that had no problems seeking a mammogram. Of those who reported difficulty obtaining mammography services, respondents highlighted issues about not knowing where to get screened, fear of breast cancer, fear/distrust of the medical system, long waiting times for appointments, and lack of insurance. This skew toward ease of mammography screening may be largely due to the large proportion of English-speaking and privately insured individuals in our sample. Focus group findings will help to further elucidate obstacles women experience when seeking a mammogram as well as the best strategies to reduce these barriers for women.

Treatment Experience: Nearly 80% of respondents stated they had no problems getting treatment after being diagnosed with breast cancer. Among respondents who reported difficulties obtaining treatment, the following obstacles were most commonly reported: fear of treatment (11.5%), didn't know where to get treatment (6.2%), fear/distrust of the medical system (5.3%). Our respondents' treatments included: mastectomy (64.5%), chemotherapy infusion (61.1%), lumpectomy (56.6%), and whole breast radiation (46.0%).

Follow-up Care and Support Services: Most respondents have received follow-up care since being treated for breast cancer. Eighty-three percent continue to visit their oncologists, 77% receive blood tests, and 70% receive mammograms and breast exams. Additionally, the majority of survivors indicated they were offered support services during or after treatment. Nearly 80% of respondents reported they were offered support group services and/or mentor services, 50% were offered wigs or hats, 36% were offered exercise programs, and 32% were offered counseling services. Only 25% of respondents were offered patient navigation support and almost 10% of survivors were offered no support services. Notably, many respondents stated they sought their own support services, including creating their own support groups and seeking resources from the Wellness Community. Respondents found support groups, exercise programs, and complementary therapies (acupuncture, massage, Reiki, yoga, Tai Chi, etc) most beneficial.

Community Needs: The online survey responses of our survivor respondents provided the Komen Los Angeles Affiliate important feedback about the needs of the community and what Komen can do to address those needs. We asked our respondents to discuss what they feel are the greatest needs for women in treatment and breast cancer survivors, as well what breast health resources are missing for survivors and those still undergoing treatment. Our respondents provided rich information and suggestions on topics such as how to seek financial assistance to help pay for treatment and support services, getting timely follow-up care after getting a mammogram, the importance of providing education and awareness on early detection, and promoting continuity of care.

In general, our respondents felt that the following breast health resources were missing during and after treatment: financial support, in-language materials, patient navigation/case management, complementary and alternative treatments, and emotional and mental health services. The survivors offered suggestions about what the greatest needs are within our community and what Komen Los Angeles County can do to fill those needs. They include:

- *Providing a list of resources all in one place*
- *Offer financial assistance to help pay for treatment and support services*
- *Provide education and awareness on early detection*
- *Promote continuity of care through patient navigation and mobile mammograms*

Over and over, we heard that navigation through the continuum of care would benefit everyone.

Healthcare Provider Surveys (n=50)

Our provider respondents represented a diverse sample of breast health organizations with Los Angeles County, including: LA County Office of Women's Health, Cancer Support Community, UCLA Olive View Medical Center, Torrance Memorial Breast Diagnostic Center, City of Hope, USC Norris, St. Mary Medical Center and others. The majority of respondents represented community-based organizations, federally-qualified health clinics, local hospitals, and academic institutions. Additionally, our respondents worked in various roles, including oncologists, nurses, case managers, breast health navigators and physicians. This breadth of representation created a richer and well-rounded picture of the state of breast cancer in LA County.

Breast Health Services Offered: Nearly 90% of respondents reported their organization provided outreach and education. A majority of the organizations provided supportive services, patient

navigation, and screening and diagnosis services. Many respondents reported their organizations provided in-language services, including Chinese, Khmer, Russian, Spanish, Thai, and Vietnamese.

Follow-up Care/Survivorship Issues: The following type of support services were reportedly offered by respondents: support groups during treatment (45%); support groups after treatment (41%); wellness activities, such as fitness programs, yoga, and meditation (33%); and services for caregivers or family members (26%). Unfortunately, nearly 29% of respondents stated their organization provided no support services for breast cancer patients, survivors, and/or family members.

Community Needs: We asked providers what type of programs are needed in their community that would help improve the delivery of breast health services. In addition, we asked providers to discuss additional resources that would increase their organization's capacity to support women through the breast health continuum of care. We received similar responses for each question. Providers overwhelmingly reported that financial assistance, patient navigation, transportation services, and interpreting services were integral resources that are needed in their communities. In addition, a few providers reported the need for exercise and healthy cooking programs and services scheduled on the weekends or during the evening to meet the needs of working families.

Komen Los Angeles County also asked providers to discuss best practices to empower women to seek breast health services. Providers listed the following ways to effectively empower women to seek services: increase access through mobile services and low-cost services, educate about breast cancer and what women can do to improve their health, utilize lay health worker outreach using the Promotora model, and provide information on available community resources. Community-based outreach and linking people directly with services was highlighted as a best practice to empower women to seek services, as well.

Survivor Focus Groups (n=15)

The majority of women were receiving annual physicals and annual mammograms, which was how many of them found their breast cancer. Interestingly, social norms and prompting from friends were a big factor that prompted participants to seek mammography services. For example, one participant stated *"All my friends were having them and I wanted to be a part of the fit girls club."* Most reported they received excellent care, but they all agreed that a team approach would have been better. When asked, "How would you encourage women like yourselves to get screened for breast cancer?" every participant mentioned education about mammograms. In addition, women mentioned lack of insurance and financial burden as important barriers to seeking mammograms. For example, even, the "low cost" \$25 mammogram could be half of a woman's food budget. We also asked women what was "the most important piece of advice they could offer women." Survivors offered recommendations to other breast cancer patients, including taking a tape recorder with them and listening to it with their family when they got home, as well as bringing someone with them to their appointments to listen and take notes.

Community Member Focus Groups (n=16)

Themes from the community member focus groups mirrored many of the themes and findings that emerged from the survivor and healthcare provider surveys, survivor focus groups, and key informant interviews. Women in these focus groups felt that cancer, especially colon and breast cancer were important health issues that concerned them.

Breast Cancer Knowledge and Attitudes: A common response when asked about breast cancer was the thought of pain, breast removal, and chemotherapy. Most women were well-informed of mammography screening recommendations and were aware of signs and symptoms of breast cancer, including lumps in the breast or under the arm, leaky discharge, nipple inversion, swelling, and pain. All women who were over 40 years age had gotten at least one mammogram in their lives, however, many women did not receive yearly mammograms. Reasons for not receiving annual mammograms included fear of pain and discomfort and/or lack of insurance.

Effective Messages to Reach African American Women: All participants agreed that increasing awareness was essential and that promoting free services would be beneficial. They stressed having information and services at community events, using mobile clinics, and providing incentives would increase breast cancer awareness and screening in their community. In addition, they mentioned the following channels to promote breast cancer education: flyers/posters and billboards; television, radio, and magazine advertisements; and sending information home with the children. In addition, they recommended placing education materials in parks and recreation centers, churches, libraries, grocery stores, and hair salons. Lastly, the women reported that focus groups and community forums should be held more frequently in the African American community.

Conclusions

Throughout our analysis of the qualitative data we collected, a number of key issues repeatedly emerged. Breast cancer is an important health concern in the community, but continued outreach and education, especially to low-income and vulnerable populations, is necessary.

Information from our qualitative data collection also highlight the need to better link the services offered by breast health organizations in LA County to the needs reported by survivors and community members. While many survivors noted the importance of complementary and alternative therapies, such as exercise programs, yoga, and meditation as well as support services for family members and caregivers, very few of our provider respondents highlighted their importance or availability. The importance of patient navigation emerged from all respondents as a potential solution to addressing barriers and lack of access to the continuum of care.

The Affiliate encountered some unforeseen obstacles that created limitations in our data set. The Affiliate hoped to conduct more focus groups, but learned that offering incentives and publicizing our focus group opportunities more heavily would draw a greater number of participants. Additionally, the Affiliate plans to hold in-language focus groups to reach a more diverse sample for the next Community Profile project. The Affiliate encountered barriers in getting survivor and community surveys out to the community, as well. The Community Profile team (including healthcare providers and community-based organization representatives)

informed the Affiliate that HIPAA laws prevented them from assisting us in gathering surveys from their patient population and the population they serve. The Affiliate was advised to seek IRB approval at a university to conduct our qualitative research in the most effective manner. Because of these unforeseen difficulties, the Affiliate was not as successful as desired in documenting the underserved community's voice. For the 2013 Community Profile, the Affiliate will consider partnering with a university or medical center to seek IRB approval, and put a qualitative data gathering system in place.

The Affiliate strives to work with the diverse, medically underserved Los Angeles community, acknowledging that cultural differences and barriers, socioeconomic status, geography and other factors impact healthcare and access to care. The Affiliate plans to focus on being the number one resource for the community to access care and help the community navigate through the continuum of care in Los Angeles County. We strive to increase awareness, promote early detection and screening, and advocate finding a cure.

CONCLUSIONS

Review of the Findings

Our quantitative and qualitative data collection and analysis process uncovered vast amounts of critical breast health related data. What became readily apparent when reviewing this body of data was the emergence of a number of key themes\focus areas that will take priority in our planning efforts. The four broad focus areas include 1) Health Disparities, 2) Patient Navigation, 3) Collaborations, Linkages, and Partnerships, and 4) Access to Care. These issues will form the foundation of our Affiliate's work over the coming years. A review of the major findings in each of these focus areas is provided below.

Significant Health Disparities For Certain Populations

A comprehensive quantitative review of available health data in Los Angeles County highlighted glaring breast health disparities among certain groups of women. Breast cancer continues to be the most common cancer among women in our county, regardless of race/ethnicity. A demographic-focused review of breast cancer data indicated that incidence and mortality display distinct risk patterns by race/ethnicity in LA County. In addition, this data analysis revealed unique behavioral, cultural, and socio-economic factors for each group that may correlate with overall breast health and related outcomes. We also uncovered important geographic-based differences within some of our county's Service Planning Areas (SPAs).

By race\ethnicity, significant disparities exist for African American women (*high late state diagnosis rates, highest overall rate of death, younger women have lowest survival rates*), Asian\Pacific Islander women (*lowest breast screening rates of all ethnic groups, significant cultural\linguistic barriers to care*), and Latina women (*high levels of poverty, highest number of uninsured women, 40% reporting difficulty accessing medical care*). Geographically, the San Gabriel Valley area (SPA 3), the Los Angeles Metro area (SPA 4), the South Central Los Angeles area (SPA 6), the East Los Angeles area (SPA 7), and the South Bay area (SPA 8) face issues of fewer screenings, higher incidences of late stage breast cancer diagnosis, higher levels of poverty, and lower levels of education as compared to the rest of Los Angeles County. Finally, age-related differences exist as well. Younger women (ages 20-49) have the largest percentage of women diagnosed with a later stage of invasive cancer. California's breast cancer incidence rate (44.60) for women between the ages of 18-44 is the 4th highest in the U.S. It is imperative that we address these health disparities.

Patient Navigation

During our health systems analysis review, multiple key informants clearly and repeatedly indicated that a critical missing breast health component is patient navigation\advocacy throughout the continuum of care. Informants expressed the need for a concerted focus on following patients through their experience over time. Additional qualitative data sources (survivor surveys and community focus groups) revealed similar concerns. We learned that only 25% of survivor survey respondents had been offered patient navigation during their treatment, and all respondents agreed it would have been a helpful resource. The importance of patient

navigation emerged from all survey and focus group respondents as a potential solution to addressing barriers and lack of access to the continuum of care.

Strengthened and Increased Collaborations, Linkages, and Partnerships

Another significant theme arising from the data was the LA community's desire for increased collaborations, linkages and partnerships between the varied breast health organizations in the county. Provider survey respondents recognized Komen-LA County (and several of our grantees and partners) as navigators and leaders that could help build a comprehensive network of care. Respondents indicated that additional collaborative efforts are needed on both the macro and micro level. There was strong support for our Affiliate to establish a navigation network committee with leaders from area hospitals and medical centers, and act as a liaison to create alliances and collaborations between community organizations. The ultimate goal would be to create clear pathways to care for patients.

Access

A review of the qualitative and health systems analysis data indicates there exist numerous barriers (e.g., cultural, linguistic, financial, knowledge of resources) to breast health care for certain populations of women in our county. Access to and education around timely diagnostic and therapeutic care can play a significant role in decreasing late stage diagnosis rates. There is a decentralized community-based network of health care providers delivering breast health care to low-income, uninsured patient populations. Survey respondents and focus group participants referenced the need for centralized information on all available breast health resources in the county. The lack of navigation support and knowledge about what services and resources exist in Los Angeles County make it difficult for patients to access the continuum of care. In addition, major policy and insurance-related changes have impacted screening access for many women. Respondents would like Komen to continue in its advocacy role.

Conclusions and Response

The above findings highlight the breadth and complexity of breast health needs in LA county. Certain populations within our county experience significant health disparities. Patient navigation resources are lacking, and both providers and community members are requesting increased access to this critical support. The decentralized nature of breast health programs creates an uncertain pathway to care for many women in our county. A comprehensive network of care is needed. Finally, there exist numerous barriers (e.g., cultural, financial, policy-related, knowledge\education) related to access and entry into the continuum of care.

In response to these findings, Komen Los Angeles County Affiliate is embarking on a number of focused initiatives over the coming years with the ultimate goal of decreasing disparities and improving access to (and navigation through) the continuum of care. As one significant step towards improved overall access and increased patient navigation resources, our Affiliate will convene a major educational forum for breast health organizations (BHO) and healthcare providers. The vision for this event is to create an unparalleled opportunity for networking, best practice sharing, and information dissemination. To improve access, key healthcare providers\BHO will be asked to share their top practices as they relate to overall system\process improvement, patient tracking\navigation, and innovative approaches to care. In addition, we

will provide a venue for LA County providers\organizations to learn more about breast health resource (e.g., support groups, patient navigators, health\nutrition offerings, equipment\prosthesis) availability in their service areas and local communities. We wish to convene this forum on an annual basis, and will implement an ongoing participant feedback and evaluation component to gather data on the impact of this event. By working together, sharing best practices, and increasing knowledge about available supports\services our partners will collaboratively strengthen the existing breast health system in the county.

We are also initiating a number of other additional plans\projects to address these priority areas. Our RFP for 2011-2012 has been substantially modified to ensure we more directly address these identified issues through our grant-making process. To ensure we are reaching the desired targeted populations, we have recently added a required data collection\participant tracking tool to our granting process. Over time, this tool will enable the grantees and Komen itself to more accurately and effectively measure impact in our priority communities. We also plan to provide project development, grant-writing, and evaluation plan\outcomes workshops to increase the capacity of those organizations working in our targeted areas and with our targeted populations. To better uncover and hear the "voice" of the underserved women in our communities, we will be working closely with our partner programs (e.g., Worship in Pink, African American Initiative) to reach these women and obtain their perspectives on breast health needs and barriers. Access to care for the underserved also remains a critical focus area. Our Affiliate will begin work on an interactive Internet-based breast health resource guide for the county. We will be working with community partners to conceptualize, fund, and implement an innovative patient navigation project aimed at our priority populations (e.g., African American, Latino, and Asian) most in need of this support. Additionally, we will also continue and strengthen our advocacy work around insurance decisions and policy changes as they affect breast health. What follows are the specific goals\objectives of our 2011-2013 Action Plan.

Affiliate Action Plan

The Los Angeles County Affiliate of Susan G. Komen for the Cure® intends to focus our efforts on increasing access to each phase of the continuum of care, and partnering with breast health leaders in LA County (hospitals, clinics, and community-based organizations) to help patients navigate the health care system. The ultimate goal of these efforts is to improve breast cancer outcomes and reduce breast cancer mortality.

Based on the needs identified in this report, the Komen Los Angeles County Affiliate has developed four priority goal areas to address within the next two years:

Comprehensive Goal: Assist our priority populations through the continuum of care by improving outreach and education, patient navigation services, collaborative efforts with community partners, and access to care.

Goal 1: To increase access to the continuum of breast care, Komen LA will provide comprehensive breast health outreach and education to our underserved priority populations in Los Angeles County.

Objective 1: By March 31, 2012 Komen Los Angeles County will prioritize funding grantees that have a demonstrated commitment to address the needs of the underserved priority populations identified by this community needs assessment.

Activity 1.1: Develop a list of additional agencies, including hospitals, clinics and community-based organizations, which serve our priority populations and have the capacity to join us in our fight against breast cancer.

Activity 1.2: Distribute Komen LA County's Request for Proposals (RFP) to at least 20 new organizations serving our priority areas that may not be familiar with Komen funding opportunities.

Activity 1.3: Modify RFP and grant scoring criteria to give proposed programs that are serving priority populations and geographic areas even greater preference.

Activity 1.4: Provide training and technical assistance (including instruction in program evaluation and impact measurement) to improve the capacity of potential grant applicants and current grantees to document their efforts and use of Komen funds.

Objective 2: By March 31, 2013, Komen Los Angeles County will increase breast health outreach and education efforts to our underserved priority populations.

Activity 2.1: Establish a team of at least 50 partners to provide comprehensive breast health outreach and education to Komen's priority populations through Worship in Pink, the African American Initiative and other community outreach initiatives.

Activity 2.2: Create and implement a data collection and tracking system to comprehensively capture the community's voice related to their breast health needs at 3 large-scale education events in the community.

Activity 2.3: Provide up to date breast health toolkits, including educational materials and local resources, to community partners and grantees to be utilized in their outreach and education efforts serving Komen LA County's priority populations.

Activity 2.4: Develop an interactive online guide of local breast health resources, programs and services available in Los Angeles County.

Goal 2: Lead the development of a comprehensive patient navigation program targeting our priority populations in partnership with community collaborators.

Objective 1: By March 31, 2012, Komen Los Angeles County will secure funding (in partnership with our community collaborators) to develop a patient navigation program addressing each component of the continuum of care model.

Activity 1.1: Design a comprehensive patient navigation program with collaborating organizations.

Activity 1.2: Apply for funding to support the implementation of this patient navigation model.

Objective 2: By March 31, 2013, Komen Los Angeles County will implement and promote Komen's patient navigation program to the community.

Activity 2.1: Pilot test the patient navigation model and evaluate its effectiveness.

Activity 2.2: Implement a comprehensive patient navigation program.

Activity 2.3: Create a marketing and social media campaign to increase the community's awareness of and knowledge about Komen's patient navigation program.

Goal 3: Cultivate Komen Los Angeles County's collaborations and partnerships with community-based organizations and healthcare providers united in the fight against breast cancer.

Objective 1: By March 31, 2012, Komen Los Angeles County will strengthen our relationships with existing community partners and create new collaborative allies.

Activity 1.1: Komen Los Angeles County will continue to participate in ongoing coalitions to collectively address breast health disparities, improve outreach and education efforts, and increase patient navigation opportunities.

Activity 1.2: Komen Los Angeles County will evaluate their current partnerships to identify the strengths, impact, and effectiveness of existing collaborations and identify any priority area and service related gaps in these existing alliances.

Activity 1.3: Komen Los Angeles County will join additional community coalition efforts to create new relationships with hospitals, clinics and community-based organizations committed to the fight against breast cancer.

Objective 2: By March 31, 2013, Komen Los Angeles County will bring together local partners to create new opportunities for community collaboration.

Activity 2.1: Komen Los Angeles County will host an annual educational forum for hospitals, clinics and community-based organizations to share best practices, opportunities, and resources.

Activity 2.2: Recruit participants from the educational forum to participate in Komen Los Angeles County's existing Medical Advisory Council to strengthen Los Angeles County's breast health continuum of care network.

Goal 4: Reduce barriers and improve access to quality care for the medically underserved populations residing in Los Angeles County.

Objective 1: By March 31, 2012 Komen Los Angeles County will prioritize funding hospitals and community clinics that have a demonstrated commitment to reduce the barriers and improve access to quality care for our priority populations.

Activity 1.1: Komen Los Angeles County will fund healthcare providers that serve uninsured, symptomatic women under age 40 and men to improve access to the continuum of care and reduce breast cancer mortality.

Objective 2: By March 31, 2013, Komen Los Angeles County will address healthcare reform, as it relates to breast health, through our public policy efforts.

Activity 2.1: Work in conjunction with our California Komen Affiliate partners and local community organizations on local, state and federal policy issues related to healthcare reform and breast health legislation.

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