

**susan g. komen.**  **COMMUNITY**  
PROFILE REPORT 2015



SUSAN G. KOMEN®  
ORANGE COUNTY

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# Executive Summary

## **Introduction to the Community Profile Report**

The purpose of the 2015 Community Profile (CP) Report is to provide information about the current status of breast health/cancer in Orange County. This report serves to inform Susan G. Komen® Orange County on breast health issues in the community through an informed process that includes stakeholder input and community members' participation. The data and information collected in this report will guide Komen® Orange County on: inclusion efforts in the breast cancer community; grant priorities; public policy efforts; outreach and education needs; and fundraising and marketing goals. This report outlines the status of breast health and services in Orange County and will serve as a road map for Komen Orange County on future strategic and program planning.

Komen Orange County was founded in 1991 in the same year the first Komen Orange County Race for the Cure® event was organized in the county. Now more than 20 years since its founding, Komen Orange County has raised and invested over \$35 million in breast cancer screening, education, support programs, and research. In 2014, Komen Orange County (OC) invested over \$1 million in grants to local organizations to ensure breast health services across the continuum of care are available to all people in the Affiliate service area's diverse communities. In addition, funding to safety net community clinics and hospitals provide breast cancer diagnostic services to individuals who do not qualify for state or federally funded programs.

In collaboration with community partners, Komen OC conducts special outreach activities and education initiatives to address breast health disparities among target populations at greatest risk of late-stage breast cancer diagnoses and mortality. Additionally, the Affiliate continues to advocate on policies that impact breast health care services and access to care. Komen Orange County has garnered special recognition and was named Affiliate of the Year for 2014, the highest honor among a network of over 100 Komen Affiliates worldwide.

The Affiliate has a diverse and multi-lingual staff and board. There is a 12-person board of directors; active committees made up of knowledgeable community leaders; and a staff of 12 professionals covering the areas of fundraising, community health, grants management, marketing, finance, and data management. The organization also relies on the generosity of more than 2,500 registered volunteers who provide nearly 23,000 hours, and an estimated \$400,000 of volunteer work every year.

The Affiliate service area encompasses Orange County, the third most populous county in California, and the second most densely populated county in the state, with over 3.1 million residents within only 948 square miles. Orange County is home to a diverse group of residents; 43.3 percent are Non-Hispanic White, 34.3 percent Hispanic/Latina, 18.0 percent Asian and Pacific Islanders (API), 1.6 percent African-American/Black and 2.8 percent other; the county's population will become increasingly diverse over the next 20 years (Orange County Health Profile, 2013). A mostly suburban county, Orange County is surrounded by four populous counties (Los Angeles, San Bernardino, Riverside and San Diego Counties).

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

The quantitative data in this report comprises of updated statistics from several sources including the California Cancer Registry (CCR); California Health Interview Survey (CHIS); Centers for Disease Control and Prevention (CDC); Health Resources and Services Administration (HRSA); North American Association of Central Cancer Registries (NAACCR);

Orange County Health Care Agency; and the US Census Bureau. The combined data present evidence on female breast cancer incidences, death rates, late-stage diagnosis, screening mammography, population demographics, and socioeconomic indicators. Review of the combined statistics was conducted to identify breast cancer disparities within Orange County to determine target communities and priority areas for the Affiliate.

Based upon complete review of the statistical and demographic information collected, four communities in Orange County were selected for further exploration: 1) African-American/Black women; 2) Asian and Pacific Islander women, specifically Chinese, Filipino, Japanese, Korean, South Asian, and Vietnamese; 3) Hispanic/Latina women; and 4) all women ages 65 years and older.

The data revealed that African-American/Black communities had an increasing trend for breast cancer incidence, late-stage diagnosis (8.1 percent), and a death rate considerably higher than Whites (30.2 per 100,000 versus 22.5 per 100,000) in Orange County. Among Asian and Pacific Islander communities, specifically Chinese, Filipino, Japanese, Korean, South Asian and Vietnamese, there are the highest invasive breast cancer incidence counts with Japanese and Filipinos having higher invasive breast cancer incidence rates than the general API population (176.3 and 199.1 per 100,000 compared to 169.7 per 100,000 for APIs )in the county. Hispanic/Latina women represent over one-third of residents in Orange County and also represent nearly a third of women ages 40 years and over that have never had a mammogram screening. Further, geographical areas that represent higher populations of Hispanic/Latinas also indicate other socio-demographic barriers to care, such as low health insurance coverage (less than the county's average of 82.3 percent).

In addition, women ages 65 and older are a growing population in the county and represent a priority group with the highest rates of breast cancer and death, across all races (153 per 100,000 among African-American/Blacks; 110.3 per 100,000 among non-Hispanic Whites; 75.9 per 100,000 among Hispanics/Latinas in OC; and 40 per 100,000 among Asian and Pacific Islanders). These four target groups will be the focus of the Affiliate's efforts over the next four years.

### **Health System and Public Policy Analysis**

The breast health continuum of care (screening, diagnosis, treatment and follow-up) was utilized as the framework to identify key assets, needs, and gaps in existing health services as they relate to each of the target communities selected. An inventory of services included an in-depth examination of the current grant slates, taking into account services that are provided to each of the target communities by health centers, and other community-based entities.

The CP Team also completed a review of publicly available data sources in Orange County. The following represents some of the resources used to complete the Health Systems Analysis:

- Cancer Detection Program Breast Cancer Early Detection Providers (BCEDP) list
- List of Community Based Organizations providing breast health information, education, and support services (including Komen grantees)
- List of public hospitals
- List of local support groups in Orange County, provided by the Orange County Health Care Agency (Local health department)
- Quality of Care (Certifications and Accreditations) resources websites for College of Surgeons, College of Radiology Centers of Excellence, College of Surgeons for National

Accreditation Program for Breast Centers, and National Cancer Institute (NCI)  
Designated Centers

As a result, the CP Team was able to determine that the Affiliate's service area has clinical providers across the continuum of care (CoC) throughout the county which serves the community, specifically in the following target communities African-American/Blacks, Asians and Pacific Islanders, Hispanics/Latinas and women 65 years and older.

The following reflects an overview of services across the CoC for all communities in Orange County:

**Screening/Patient Navigation:** Family PACT; Every Woman Counts (EWC); community clinics; hospitals, community-based organizations (CBOs)

**Diagnostic/Patient Navigation:** EWC; community clinics; hospitals, imaging centers, CBOs

**Treatment/Patient Navigation:** Breast and Cervical Cancer Treatment Program (BCCTP) providers; hospitals, CBOs

**Other Social Support Services within the CoC:** Breast Cancer Solutions; Breast Cancer Angels; CBOs; Faith-based organizations (FBOs) through churches, temples, and/or health/cancer ministries

**Outreach & Education/Follow-Up Care:** community clinics, hospitals, CBOs & health system providers to provide reminders and breast health education.

Furthermore, the CP Team also identified the following assets available in Orange County for women in each of the communities selected:

The **African-American/Black** community in Orange County has access to services across the breast cancer CoC. Patient navigation for breast health services is provided by community-health workers/advocates of a local community based organization, as well as by cancer nurse navigators at hospitals and health systems. Various social support services are provided through hospitals, health systems, community clinics, and the faith-based communities through churches and health ministries. Another local community-based organization provides financial support services throughout the county; and the Public Law Center provides legal information and resources throughout the county.

**Asians and Pacific Islanders** in Orange County have access to services across the breast cancer CoC. Patient navigation is provided through various community organizations. In addition, cancer nurse navigators at hospitals and health systems also provide patient navigation. In-language patient navigation is provided by community organizations for the Chinese, Korean, Vietnamese, Marshallese, Samoan, and Tongan communities. Information is lacking on in-language services for the Filipino, Japanese, and South Asian communities in Orange County. Various social support services are provided through hospitals, health systems, community clinics, and CBOs with support groups available in Chinese, Korean and Vietnamese. Another local community-based organization provides financial support services throughout the county; and the Public Law Center provides legal information and resources throughout the county.

The **Hispanic/Latina** community in Orange County has access to services across the breast cancer CoC. Patient navigation is provided through various community

organizations, as well as by cancer nurse navigators at hospitals and health systems. Services across the cancer continuum are available in Spanish throughout most facilities. Various social support services are provided through hospitals, health systems, community clinics, community-based organizations, faith-based organizations such as churches, and ethnic markets. Another local community-based organization provides financial support services throughout the county; and the Public Law Center provides legal information and resources throughout the county.

In Orange County, **women 65 years and older**, have access to services across the breast cancer CoC. Patient navigation is provided through various community organizations, as well as by cancer nurse navigators at hospitals and health systems. Various social support services are provided through hospitals, health systems, community clinics and community-based organizations. Another local community-based organization provides financial support services throughout the county; and the Public Law Center provides legal information and resources throughout the county.

While services are available, missing in the Health System Analysis is a review of the quality of services and the timeliness in which resources and services are made available to individuals seeking care. In addition, it may be that various service providers exist, however the individuals within the four target communities are unaware of these resources and more outreach is needed to inform individuals of available services.

As for public policy implications on the current health systems, with the roll out of the Affordable Care Act (ACA) and the health care marketplace, much remains undetermined in terms of access and utilization. Some have expressed concerns about the availability of health care providers to respond to an increase of 30 million insured Americans across the country. Some studies report not only a shortfall in health care providers, but also in the health care workforce as a whole, in responding to the ACA changes (Anderson, 2014). Though these concerns may be warranted, other efforts are taking place at all levels to ensure collaboration and partnership across providers (safety net providers, private providers, Medi-Cal providers, hospitals, and health systems) to ensure strategies to meet the changing needs of health care delivery (HRSA, 2014).

For the local Affiliate, it is estimated that 210,000 individuals in Orange County will remain uninsured. Nearly half will be ineligible due to their immigration status, meaning there will be a large number of uninsured individuals who are in need of breast health services and may need access to NBCCEDP/EWC or Affiliate resources to ensure timely and quality access to breast health services (Lucia et. al, 2015). The Affiliate will continue to work closely with its partners in health care and health policy to stay current on breast health needs in the service area and respond accordingly to provide support for access to care.

### **Qualitative Data: Ensuring Community Input**

Following the asset analysis, the needs of the four targeted communities were examined using a provider survey, key informant interviews and focus groups to collect qualitative data. Questions for the provider survey, key informant interview guide and focus group guide were linked to key questions that arose from the review of the quantitative data and health systems and public policy analysis.

Key areas of interest included gaps; challenges or barriers to breast health information and care; access to and utilization of breast health services; attitudes, beliefs and behaviors around

breast cancer and breast health services. The data collection tools also included questions about opportunities for Komen to develop and strengthen outreach efforts, partnership development, education/health promotion, and funding strategies in working with target communities. The rationale and details of each qualitative data collection method and ethics applied for each of the target communities: African-American/Black, Asian and Pacific Islander, Hispanic/Latina, and women 65 years and older, are found in the Qualitative Data section of this report.

Having gathered information from the community through the provider survey; key informant interviews and focus groups, the Affiliate found some common recommendations across all data sources.

Common recommendations that arose were:

- A need for ongoing education – general breast health, screening, and treatment information; Help to clarify screening guidelines; specific individualized risk must be taken into consideration specifically for older adults.
- An additional burden of cancer – financial costs, need for social support.
- A need to make the available breast health resources available to all.
- Importance for culturally and linguistically appropriate outreach, education and materials.
- Need for interpreter services
- Continued need for early detection services
- Opportunities for working with faith based organizations, community leaders, and senior centers.
- Social media is not highly used but marketing/outreach opportunities exist.
- All communities shared opportunities for partnership in outreach, education and bridging relationships with key leaders and organizations.
- Need for intergenerational messaging
- A continued need for Komen to promote breast health outreach, education, screening and treatment information. Need for grant-making organizations to look at innovative strategies for funding.

### **Mission Action Plan**

The following is the Mission Action Plan for Komen Orange County to address by March 31, 2019:

#### **Priority Need/Problem A:**

Based on quantitative data findings, over 6 percent of all women ages 40 and older in OC have not had a screening mammogram and an additional 12 percent have not had a mammogram within the last two years. ; Among the group that has not had a screening mammogram Hispanic/Latinos represent 28 percent; and Asians represent 33 percent; data is unstable for Pacific Islanders but a history in Orange County of high rates of late-stage diagnoses and death have been identified in previous CP's (2009 and 2011 CP Reports). However, the health systems and public policy analysis found that there are health services available across the county. In turn, the apparent gap in accessing these services was explored during the qualitative data collection process.

The qualitative data collection process revealed that there is a need for low- to no-cost screening options, continued need for access to early detection services, and information on available hours outside of “normal” business hours. It was also identified that there is a need for

the following: financial support, social support, interpreter services, navigation services to increase utilization, and transportation services.

As a result, the Affiliate concluded that many communities (including Asian and Pacific Islander, Hispanic/Latina, and women 65 years and older of all races) are not aware of the available services and are not able to access breast health screening services as a priority need/problem.

**Priority I:** Increase knowledge/awareness of available breast cancer screening services in OC that is culturally and linguistically appropriate for all target communities identified in the CP.

**Objective I-1:** By 2019, Komen OC will build a network of breast cancer navigation services that provide ethnic, language and cultural support in each of the Asian subgroups identified in the CP. To include at least five new collaborative partnerships of community-based organizations that serves these communities.

**Objective I-2:** By 2019, Komen OC will educate 6,500 Hispanic/Latina women annually in OC about available breast cancer screening service via grant partners and/or Unidos Contra Cancer de Seno Coalition.

**Objective I-3:** By 2019, Komen OC will participate in five senior-specific outreach events per year reaching women 65 years and older to increase awareness of breast health services/resources.

**Priority II:** Improve access to available breast cancer screening services in OC that is culturally and linguistically appropriate for all target communities identified in the Community Profile.

**Objective II-1:** By 2019, Komen OC will collaborate with community partners and/or Komen-funded grant partners to improve access to screening services for 650 Hispanic/Latina women per year (a total of 2,600) through patient navigation and screening mammography events.

### **Priority Need/Problem B:**

From all data collection methods in the qualitative data findings, it was determined that lack of education was the greatest problem with regard to disparities in screening mammography data. Specifically, in key informant interviews, many shared that education with targeted information – age-specific, language-specific, and breast cancer risks continues to be a need. In addition, education should include signs/changes in the breast and symptoms, available screening, treatment and diagnostic services, and age-specific screening guidelines/recommendations.

Furthermore, it was indicated that in-language access; information tailored to specific ages; intergenerational messaging; and education to the community with various health literacy levels are needed. Thus, there is a need for continued outreach and education about the risks, signs, symptoms and impact of breast cancer throughout the CoC in all the target communities identified in the CP.

**Priority III:** Increase breast health education to all target communities by developing in-language and appropriately tailored breast health information that will be comprehensible for various audiences to raise awareness of breast cancer and associated risk factors in these communities.

**Objective III-1:** By 2019, Komen OC will improve breast health education by recruiting and training 12 breast health advocates who are bilingual, bicultural and/or age-appropriate covering languages in Chinese, Korean, Spanish, Tagalog and Vietnamese to conduct breast cancer and provide education and information on breast health to the target communities.

**Objective III-2:** Annually through 2019, Komen OC will give priority (or add weighted value during review process) to grant applications that propose to provide evidence-based breast health education in specific languages and/or cultures and/or age-groups that are innovative and not duplicative.

**Priority Need/Problem C:**

African-American/Black women in OC are dying from breast cancer at a faster rate than White women in OC. In the quantitative data analysis, there is an increasing trend for late-stage diagnosis a rate of 8.1 percent per year and a higher death rate among African-American/Black women in comparison to Whites in OC, 30.2 per 100,000 versus 22.5 per 100,000.

From focus group sessions, participants shared that there are many reasons why African-American/Black women in OC do not have a mammogram regardless of having health insurance or not. They shared that there are barriers such as distrust of medical providers, lack of cultural and/or generational sensitivity. Other findings include messengers of breast health information need to represent the African-American/Black community, and address the complexities of the family dynamic. As a result of these findings, it was determined that the breast health needs among African-American/Black women in OC must be addressed.

**Priority IV:** Partner with organizations/agencies/professional associations to help address the diverse needs and barriers to motivate African-American/Black women in OC to learn more about risk factors and obtain breast cancer screenings.

**Objective IV-1:** By 2017, Komen OC will continue to build the OC African-American Breast Health Community Partnership that is representative of various communities, faith-based, and professional organizations; that is effective, sustainable and visible in the community to ensure engagement in activities such as breast health outreach and education, access to care and advocacy efforts.

**Objective IV-2:** Annually through 2019, Komen OC will increase knowledge and awareness of at least **1,200** African-American/Black women about breast health and available breast cancer screening services in OC through strategic partnerships and collaboration using culturally-competent and evidence-based strategies.

**Objective IV-3:** By 2019, Komen OC will encourage informed breast health care decision-making and motivate **300** African-American/Black women to action through patient navigation and mammography events via grant partners and/or the OC African-American Breast Health Community Partnership efforts.

**Priority Need/Problem D:**

Quantitative data found women 65 years and older have high death rates of breast cancer at 110.3 per 100,000 among non-Hispanic Whites; 153 per 100,000 among African-American/Blacks; 40.0 per 100,000 among Asian and Pacific Islander; and 75.9 per 100,000 among Hispanic/Latinas in OC. The age-adjusted death rate of breast cancer is 20.7 per

100,000 in OC. During the qualitative data collection process, the CP Team experienced challenges in recruiting participants that are knowledgeable and/or experienced in working with women 65 years and older. Of those that did participate, key informants shared that education continues to be one of the most pressing health needs for women 65 years and older. Specifically, information around individual risk and aging is vital. Other informants shared that there is a need for guidance on providing information for individualized plans pending age and health status, discussed repeatedly.

Financial support was also noted, older adults live on a fixed income and if they are diagnosed with cancer; the financial burden of cancer can be traumatic. They shared that Medicare does not cover all medical costs (such as gauze after surgery) and the need to cover medical costs out of pocket creates a burden on other daily needs such as finances for food, housing and transportation. Therefore, it was determined that not much is known about the breast health needs and standards of breast health care offered/utilized among women 65 and older.

**Priority V:** Build relationships and partner with organizations/agencies that specifically work with women 65 years and older in OC.

**Objective V-1:** By 2017, Komen OC will develop three new collaborative relationships with organizations that serve women 65 and older to understand and learn more about how to address their breast health needs and barriers to accessing care.

**Objective V-2:** By 2017, Komen OC will gather information from doctors who specifically serve the geriatric community to discover and understand the standards of breast health care for women 65 years and older.

#### **Priority Need/Problem E:**

Under the Health Systems and Public Policy Analysis section, some racial ethnic groups are falling short in terms of enrollment and utilization under ACA due to ineligibility or insurance opt outs; many women will continue to lack access to breast health screening services. Also, NCBCEDP/EWC still serves as a safety net program creating important access to care especially for uninsured. As a result, many individuals in OC will remain uninsured and/or medically underserved.

**Priority VI:** Ensure all individuals are able to access quality breast health care services through safety-net programs covering the entire cancer continuum of care.

**Objective VI-1:** Komen OC will advocate annually for the preservation of safety-net programs like EWC/BCCEDP through participation in public policy efforts such as legislative visits, lobby days with Komen Headquarters public policy team, the Komen California Public Policy Committee, and local public policy committee.

**Objective VI-2:** Komen OC will advocate annually for the removal of age- and gender-specific restrictions on programs like EWC/BCCEDP through participation of public policy efforts such as legislative visits, lobby days with Komen Headquarters public policy team, the Komen California Public Policy Committee, and local public policy committee to ensure that all are able to access breast health care services.

**Objective VI-3:** By 2019, Komen OC will advocate for the expansion of covered services and treatment timeline-protocols under programs like BCCTP, and/or other available programs/services.

**Objective VI-4:** By 2019, Komen OC will maintain the Komen Fund for Breast Health Care as a safety net of last resort to cover gaps in the continuum of breast health/cancer care.

**Objective VI-5:** Komen OC will identify and train at least three volunteers per year to serve on the local public policy committee to carry out public policy efforts focused on access to breast health care in response to the changes in the health care landscape.

**Disclaimer:** Comprehensive data for the Executive Summary can be found in the full Susan G. Komen® Orange County CP Report.

# Introduction

## **Affiliate History**

Susan G. Komen® Orange County was founded in 1991, the same year as the first Race for the Cure® in Orange County (OC). Dr. Dava Gerad, a female breast cancer surgeon, founded the Komen OC Affiliate. In its first year, the Komen® OC's Race for the Cure raised \$150,000 with the support of 3,800 participants. Twenty three years later in 2014, the Race was attended by over 20,000 participants and raised nearly \$2 million. Since its founding, Komen OC has raised and invested over \$35 million in breast cancer screening, education, support programs and research.

In 2014, Komen OC was named Affiliate of the Year, the highest honor given to one exceptional Affiliate within the network of over 100 Komen Affiliates worldwide. This is an affirmation of the outstanding dedication, commitment and leadership of the Komen OC's Board of Directors, staff, passionate volunteers and generous donors, all working together in the fight against breast cancer.

Komen OC is at the forefront of ensuring that life-saving breast health services are accessible to all people in the community, regardless of their age or background. Each year, the Affiliate helps thousands of women and men with little or no health insurance receive breast health education, screening, treatment and support. Through special outreach and education initiatives targeting populations at greatest risk; the Affiliate has been the convener on the dialogue of addressing breast cancer disparities with key community leaders that advise and guide the Affiliate's deliberate efforts in reducing breast cancer death in a manner that is culturally congruent within these target communities.

Komen OC also provides community grants for innovative projects that are strongly focused on the areas of breast health and breast cancer education, outreach, screening, patient navigation and survivorship to help underserved populations in OC. In 2014, more than \$1 million in grants was awarded to local organizations that serve the Affiliate service area's diverse communities. Additionally, the Komen Fund for Breast Health Care provides funds to local community clinics and hospitals that serve as the vital safety-net of breast cancer diagnostic services for uninsured and underinsured women and men; particularly for women under age 40, and/or ineligible for other state or federally-assisted programs. The participating clinics and health centers become the medical home to many women that utilize this program.

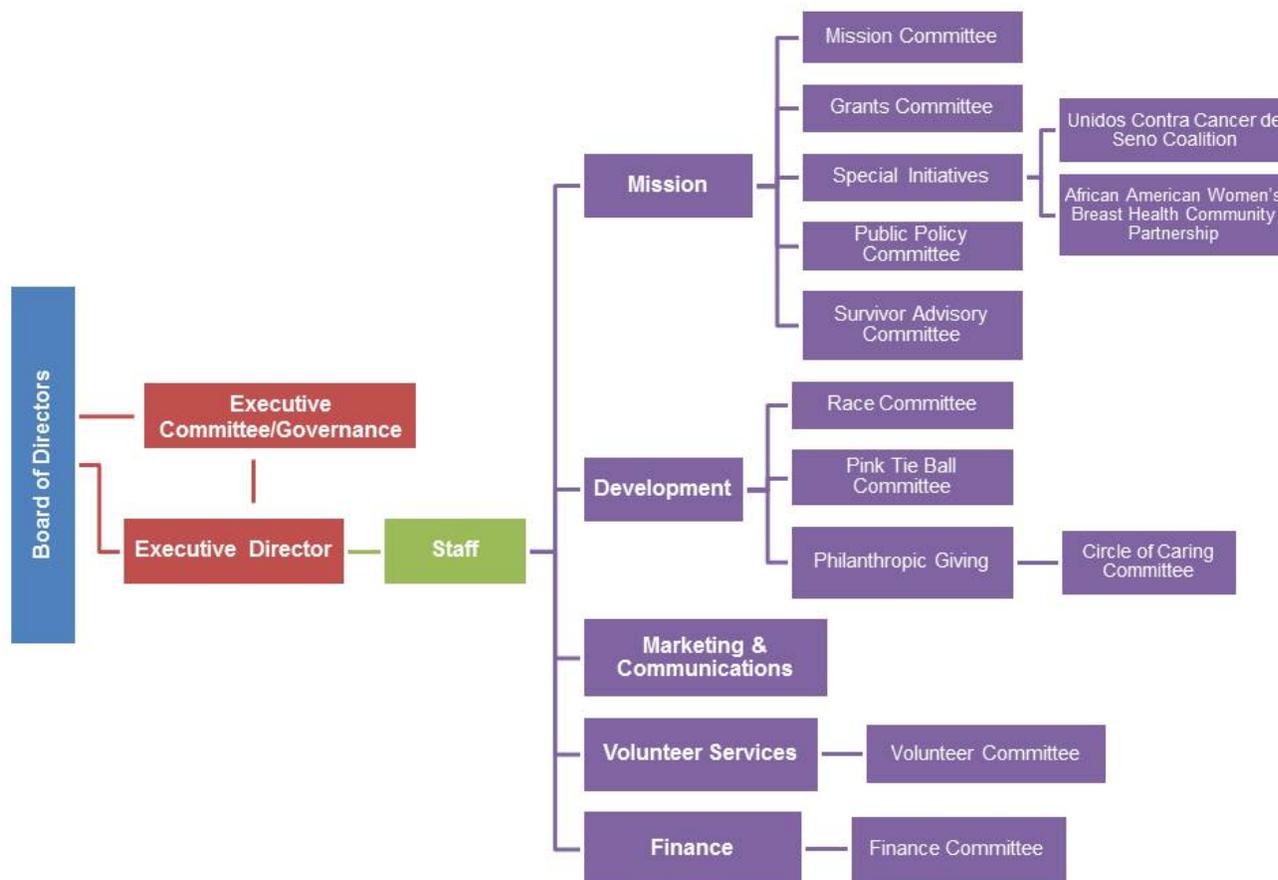
The Affiliate works in collaboration with several hospital systems in OC to provide free educational seminars for breast cancer survivors and co-survivors about the latest in breast cancer treatment; nutrition for breast cancer patients; the latest in breast reconstruction; among other relevant topics covered throughout the year. Furthermore, Komen OC provides new or gently used wigs and hats to women who have temporarily lost their hair due to breast cancer treatment.

The Affiliate is one of seven Affiliates that comprise the California Public Policy Collaborative that advocates on behalf of federal and state key legislative issues that impact breast health care services and access to care. For information about the Affiliate's programs and services please contact the office at (714) 957-9157 or visit [www.komenoc.org](http://www.komenoc.org).

## **Organizational Structure**

The Affiliate has a diverse and multi-lingual staff and board. There is a 12-person board of directors; active committees made up of knowledgeable community leaders; and a staff of 12

professionals covering the areas of fundraising, community health, grants management, marketing, finance, and data management. The organization also relies on the generosity of more than 2,500 registered volunteers who provide nearly 23,000 hours, and an estimated \$400,000 of volunteer work every year. The chart below (Figure 1.1) demonstrates the organizational structure; each committee is comprised of staff liaison(s) and volunteers.



**Figure 1.1.** Komen OC Organization Structure

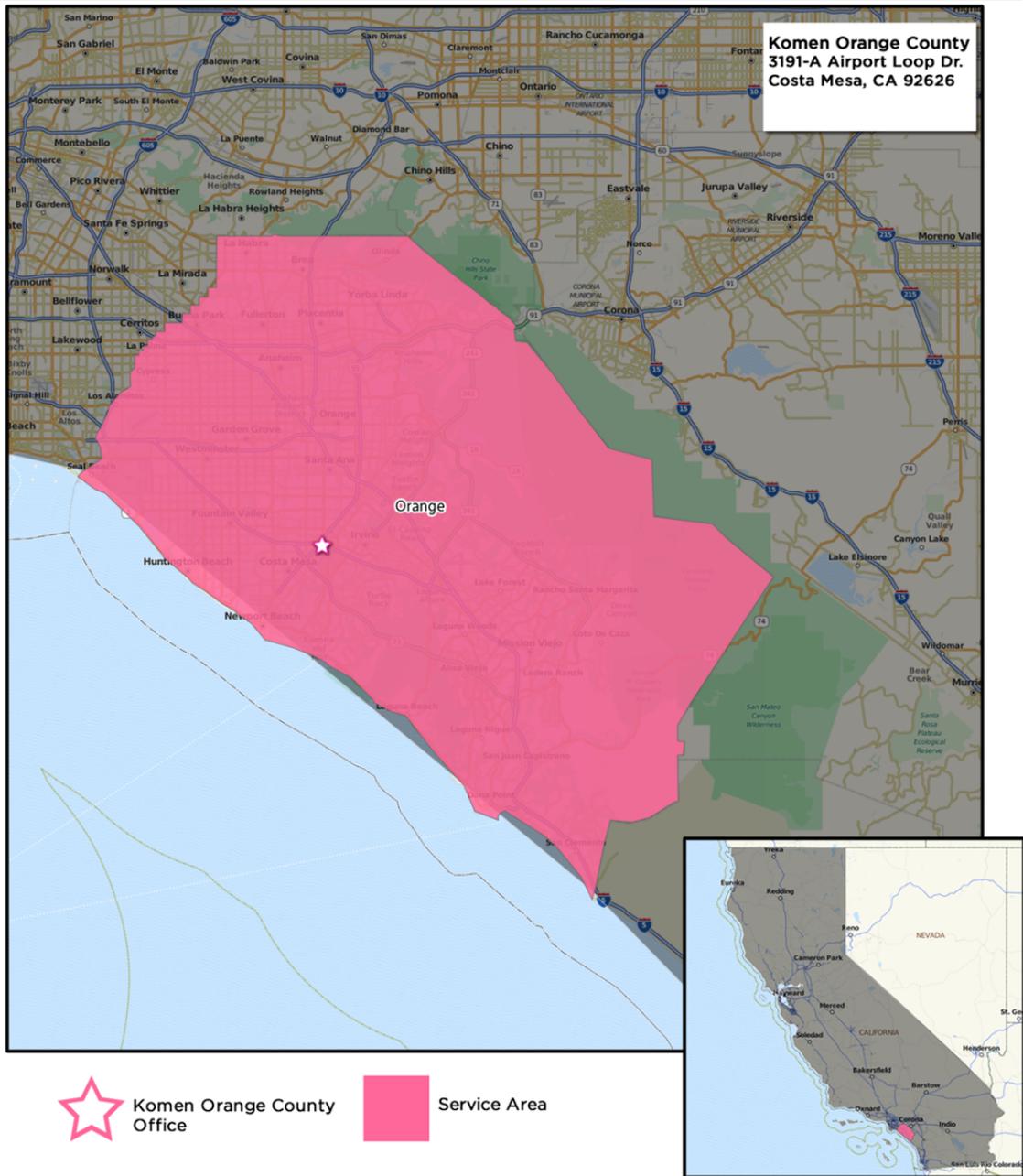
**Affiliate Service Area**

OC is the third most populous county in California, and the second most densely populated county in the state, with over 3.1 million residents within only 948 square miles. With 34 incorporated cities, OC is home to a diverse group of residents; 43.3 percent are Non-Hispanic White, 34.3 percent Hispanic/Latina, 18.0 percent Asian, 1.6 percent African-American/Black and 2.8 percent other; the county’s population will become increasingly diverse over the next 20 years (OC (OC) Health Profile, 2013). A mostly suburban county, OC is surrounded by Los Angeles County to the north, San Bernardino and Riverside Counties to the east, San Diego County to the south, and more than 42 miles of coastline on the Pacific Ocean (Figure 1.2).

OC is considered to be a “minority majority county” with a larger percentage of minorities than non-Hispanic White residents. Thirty percent of the population is foreign born and forty-six percent of the residents speak a language other than English at home (US Census, 2013). It is important to note that OC does not have a county hospital; therefore the area relies on a safety

net of community clinics, non-profit organizations and the Affiliate to collaborate and provide breast health care for uninsured women. Through the Affiliate’s grant programs and special initiatives/collaborative, these partnerships enable services to be provided ranging from outreach, education, clinical breast exams, mammography, patient navigation, diagnostics, and enrollment in state provided/ funded programs for treatment.

## KOMEN ORANGE COUNTY SERVICE AREA



**Figure 1.2. Susan G. Komen Orange County Service Area**

## **Purpose of Report**

Komen's promise is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures. To meet this promise, the Affiliate relies on information obtained through the Community Profile (CP) Report to guide the accomplishment of the promise in its communities. The CP relies on the generosity and dedication of key stakeholders at every step of the process. The report is produced by an advisory team of experts and professionals who volunteer their time to provide guidance on the process. In addition, the CP also relies on community members to support the effort by participating in surveys, interviews or focus group activities.

The information collected in the report guides the Affiliate through the following activities:

- Promotion of inclusion efforts in the breast cancer community
- Guidance in grant priorities
- Informing public policy efforts
- Determining outreach and education needs
- Informing fundraising and marketing efforts

This information can also be used by other community organizations for the following purposes:

- Program planning and service delivery
- Grant writing
- Opportunities for expanded referrals and inter-agency collaborations

In summary, the CP not only serves to inform the Affiliate, but the entire breast health/cancer community in OC. The final report provides a snapshot of breast health/cancer in the Affiliate's service area, and serves as a road map for future strategic and program planning. It will be shared with all community partners and health care systems and made available online through the Affiliate website.

# Quantitative Data: Measuring Breast Cancer Impact in Local Communities

## Quantitative Data Report

### Introduction

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

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

The following is a summary of Komen Orange County's Quantitative Data Report. For a full report please contact the Affiliate.

### Breast Cancer Statistics

#### Incidence rates

The breast cancer incidence rate shows the frequency of new cases of breast cancer among women living in an area during a certain time period. Incidence rates may be calculated for all women or for specific groups of women (e.g. for Asian and Pacific Islander women living in the area).

The female breast cancer incidence rate is calculated as the number of females in an area who were diagnosed with breast cancer divided by the total number of females living in that area. Incidence rates are usually expressed in terms of 100,000 people. For example, suppose there are 50,000 females living in an area and 60 of them are diagnosed with breast cancer during a certain time period. Sixty out of 50,000 is the same as 120 out of 100,000. So the female breast cancer incidence rate would be reported as 120 per 100,000 for that time period.

When comparing breast cancer rates for an area where many older people live to rates for an area where younger people live, it's hard to know whether the differences are due to age or whether other factors might also be involved. To account for age, breast cancer rates are usually adjusted to a common standard age distribution. Using age-adjusted rates makes it possible to spot differences in breast cancer rates caused by factors other than differences in age between groups of women.

To show trends (changes over time) in cancer incidence, data for the annual percent change in the incidence rate over a five-year period were included in the report. The annual percent change is the average year-to-year change of the incidence rate. It may be either a positive or negative number.

- A negative value means that the rates are getting lower.
- A positive value means that the rates are getting higher.
- A positive value (rates getting higher) may seem undesirable—and it generally is. However, it's important to remember that an increase in breast cancer incidence could also mean that more breast cancers are being found because more women are getting mammograms. So higher rates don't necessarily mean that there has been an increase in the occurrence of breast cancer.

**Death rates**

The breast cancer death rate shows the frequency of death from breast cancer among women living in a given area during a certain time period. Like incidence rates, death rates may be calculated for all women or for specific groups of women (e.g. African-American/Black women). The death rate is calculated as the number of women from a particular geographic area who died from breast cancer divided by the total number of women living in that area. Death rates are shown in terms of 100,000 women and adjusted for age.

Data are included for the annual percent change in the death rate over a five-year period. The meanings of these data are the same as for incidence rates, with one exception. Changes in screening don't affect death rates in the way that they affect incidence rates. So a negative value, which means that death rates are getting lower, is always desirable. A positive value, which means that death rates are getting higher, is always undesirable.

**Late-stage diagnosis**

For this report, late-stage breast cancer is defined as regional or distant stage using the Surveillance, Epidemiology and End Results (SEER) Summary Stage definitions (<http://seer.cancer.gov/tools/ssm/>). State and national reporting usually uses the SEER Summary Stage. It provides a consistent set of definitions of stages for historical comparisons.

The late-stage breast cancer incidence rate is calculated as the number of women with regional or distant breast cancer in a particular geographic area divided by the number of women living in that area. Late-stage incidence rates are shown in terms of 100,000 women and adjusted for age.

**Table 2.1.** Female breast cancer incidence rates and trends, death rates and trends, and late-stage rates and trends

Population Group	Incidence Rates and Trends				Death Rates and Trends			Late-stage Rates and Trends		
	Female Population (Annual Average)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of Deaths (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)
US	154,540,194	198,602	122.1	-0.2%	40,736	22.6	-1.9%	70,218	43.7	-1.2%
HP2020	-	-	-	-	-	20.6*	-	-	41.0*	-
California	18,413,837	23,266	122.0	-0.6%	4,251	21.9	-2.1%	8,287	43.5	-1.7%
Komen Orange County Service Area (Orange County – CA)	1,497,628	1,972	125.4	-0.7%	331	20.7	-2.5%	703	44.9	-2.0%
White	1,158,927	1,656	133.4	-0.6%	291	22.5	NA	592	48.1	-1.3%
African-American/Black	31,959	28	110.5	1.4%	7	30.2	NA	12	45.7	8.1%
American Indian/Alaska Native (AIAN)	17,944	3	21.3	-3.0%	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	288,797	254	83.7	1.7%	32	11.5	NA	89	29.3	-2.8%
Non-Hispanic/Latina	1,016,340	1,686	133.3	-0.5%	292	21.7	NA	579	46.7	-1.3%
Hispanic/Latina	481,288	285	95.8	-0.2%	39	14.5	NA	124	39.6	-3.3%

\*Target as of the writing of this report.

NA – data not available

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

Data are for years 2006-2010.

Rates are in cases or deaths per 100,000.

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

Source of incidence and late-stage data: North American Association of Central Cancer Registries (NAACCR) – Cancer in North America (CINA) Deluxe Analytic File.

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

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

### ***Incidence rates and trends summary***

Overall, the breast cancer incidence rate in the Komen OC service area was slightly higher than that observed in the US as a whole and the incidence trend was better than the US as a whole. The incidence rate of the Affiliate service area was **significantly higher** than that observed for the State of California and the incidence trend was not significantly different than the State of California.

For the United States, breast cancer incidence in African-Americans/Blacks is lower than in Whites overall. The most recent estimated breast cancer incidence rates for Asians and Pacific Islanders (APIs) and American Indians and Alaska Natives (AIANs) were lower than for Non-Hispanic Whites and African-Americans/Blacks. The most recent estimated incidence rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and African-Americans/Blacks. For the Affiliate service area as a whole, the incidence rate was lower among African-Americans/Blacks than Whites, lower among APIs than Whites, and lower among AIANs than

Whites. The incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

It's important to remember that an increase in breast cancer incidence could also mean that more breast cancers are being found because more women are getting mammograms.

### ***Death rates and trends***

Overall, the breast cancer death rate and death rate trend in the Komen OC service area were slightly lower than that observed in the US as a whole. The death rate of the Affiliate service area was not significantly different than that observed for the State of California.

For the United States, breast cancer death rates in African-Americans/Blacks are substantially higher than in Whites overall. The most recent estimated breast cancer death rates for APIs and AIANs were lower than for Non-Hispanic Whites and African-Americans/Blacks. The most recent estimated death rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and African-Americans/Blacks. For the Affiliate service area as a whole, the death rate was higher among African-Americans/Blacks than Whites and lower among APIs than Whites. There were not enough data available within the Affiliate service area to report on AIANs so comparisons cannot be made for this racial group. The death rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

### ***Late-stage incidence rates and trends***

Overall, the breast cancer late-stage incidence rate in the Komen OC service area was slightly higher than that observed in the US as a whole and the late-stage incidence trend was lower than the US as a whole. The late-stage incidence rate and trend of the Affiliate service area was not significantly different than that observed for the State of California.

For the United States, late-stage incidence rates in African-Americans/Blacks are higher than among Whites. Hispanics/Latinas tend to be diagnosed with late-stage breast cancers more often than Whites. For the Affiliate service area as a whole, the late-stage incidence rate was slightly lower among African-Americans/Blacks than Whites and lower among APIs than Whites. There were not enough data available within the Affiliate service area to report on AIANs so comparisons cannot be made for this racial group. The late-stage incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

### **Mammography Screening**

Getting regular screening mammograms (and treatment if diagnosed) lowers the risk of dying from breast cancer. Screening mammography can find breast cancer early, when the chances of survival are highest. Table 2.2 shows some screening recommendations among major organizations for women at average risk.

**Table 2.2.** Breast cancer screening recommendations for women at average risk\*

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

\*As of October 2015

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

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

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

- The number of women living in an area who the BRFSS determines should have mammograms (i.e. women age 50 to 74).
- The number of these women who actually had a mammogram during the past two years.

The number of women who had a mammogram is divided by the number who should have had one. For example, if there are 500 women in an area that should have had mammograms and 250 of those women actually had a mammogram in the past two years, the mammography screening proportion is 50.0 percent.

Because the screening proportions come from samples of women in an area and are estimates, Table 2.3 includes confidence intervals. A confidence interval is a range of values that gives an

idea of how uncertain a value may be. It's shown as two numbers—a lower value and a higher one. It is very unlikely that the true rate is less than the lower value or more than the higher value.

For example, if screening proportion was reported as 50.0 percent, with a confidence interval of 35.0 to 65.0 percent, the real rate might not be exactly 50.0 percent, but it's very unlikely that it's less than 35.0 or more than 65.0 percent.

In general, screening proportions at the county level have fairly wide confidence intervals. The confidence interval should always be considered before concluding that the screening proportion in one area is higher or lower than that in another area.

**Table 2.3.** Proportion of women ages 50-74 with screening mammography in the last two years, self-report

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
US	174,796	133,399	77.5%	77.2%-77.7%
California	4,347	3,512	81.8%	80.3%-83.2%
Komen Orange County Service Area (Orange County – CA)	294	249	84.5%	78.6%-89.1%
White	275	236	87.7%	82.0%-91.7%
African-American/Black	SN	SN	SN	SN
AIAN	SN	SN	SN	SN
API	SN	SN	SN	SN
Hispanic/Latina	34	27	82.4%	63.3%-92.7%
Non-Hispanic/Latina	260	222	85.0%	78.9%-89.6%

SN – data suppressed due to small numbers (fewer than 10 samples).

Data are for 2012.

Source: CDC – Behavioral Risk Factor Surveillance System (BRFSS).

**Breast cancer screening proportions summary**

The breast cancer screening proportion in the Komen Orange County service area was significantly higher than that observed in the US as a whole. The screening proportion of the Affiliate service area was not significantly different than the State of California.

For the United States, breast cancer screening proportions among African-Americans/Blacks are similar to those among Whites overall. APIs have somewhat lower screening proportions than Whites and African-Americans/Blacks. Although data are limited, screening proportions among AIANs are similar to those among Whites. Screening proportions among Hispanics/Latinas are similar to those among Non-Hispanic Whites and African-Americans/Blacks. There were not enough data available within the Affiliate service area to report on African-Americans/Blacks, APIs, and AIANs so comparisons cannot be made for these racial groups. The screening proportion among Hispanics/Latinas was not significantly different than among Non-Hispanics/Latinas.

## Population Characteristics

The report includes basic information about the women in each area (demographic measures) and about factors like education, income, and unemployment (socioeconomic measures) in the areas where they live. Tables 2.4 and 2.5 show this data for the US, the state, the Affiliate service area, and each of the Medical Service Study Areas (MSSAs) in the Affiliate’s service area. Demographic and socioeconomic data can be used to identify which groups of women are most in need of help and to figure out the best ways to help them.

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

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

- The race, ethnicity, and age data are based on the total female population in the area (e.g. the percent of females over the age of 40).
- The socioeconomic data are based on all the people in the area, not just women.
- Income, education and unemployment data don’t include children. They’re based on people age 15 and older for income and unemployment and age 25 and older for education.
- The data on the use of English, called “linguistic isolation”, are based on the total number of households in the area. The Census Bureau defines a linguistically isolated household as one in which no one over the age of 14 speaks English well or very well.

**Table 2.4.** Population characteristics – demographics

Population Group	White	African-American/Black	AIAN	API	Non-Hispanic/Latina	Hispanic/Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
US	78.8 %	14.1 %	1.4 %	5.8 %	83.8 %	16.2 %	48.3 %	34.5 %	14.8 %
California	75.1 %	7.3 %	2.0 %	15.6 %	62.5 %	37.5 %	45.5 %	31.5 %	13.1 %
Komen Orange County Service Area (Orange County –CA)	76.1 %	2.3 %	1.3 %	20.3 %	66.5 %	33.5 %	46.8 %	31.8 %	13.3 %
115.1 - Dana Point/ San Clemente/ San Juan Capistrano	83.6%	1.1%	1.4%	5.0%	76.9%	23.1%	54.5%	39.2%	16.8%
115.2a - Lake Forest East/ Mission Viejo Central and South	75.1%	2.1%	1.1%	13.6%	78.5%	21.5%	50.7%	33.2%	11.4%
115.2b - Coto de Caza/ Las Flores/ Mission Viejo Northwest/ Rancho Santa Margarita/ Trabuco Canyon	80.5%	2.2%	1.0%	11.9%	85.8%	14.2%	46.9%	27.7%	9.9%
115.2c - Aliso Viejo/ Laguna Hills/ Laguna Niguel	76.9%	2.1%	0.9%	14.7%	85.7%	14.3%	51.1%	33.2%	11.6%
115.2d - Laguna Beach/ Laguna Woods	77.3%	1.7%	0.9%	11.7%	79.5%	20.5%	66.3%	54.2%	33.4%
116a - Buena Park/ La Palma	42.7%	5.0%	2.0%	29.5%	58.3%	41.7%	43.9%	29.4%	11.9%

Population Group	White	African-American/ Black	AIAN	API	Non-Hispanic /Latina	Hispanic /Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
116b - Santa Ana Central	47.2%	1.9%	1.6%	5.0%	10.1%	89.9%	29.4%	16.9%	6.3%
116c - Anaheim West	46.3%	4.1%	1.6%	24.2%	52.2%	47.8%	41.6%	27.7%	11.8%
116d - Irvine South/ Newport Beach/ Newport Coast/ San Joaquin Hills	76.6%	1.2%	0.7%	18.8%	92.1%	7.9%	49.8%	35.5%	15.6%
116e - Cypress/ Los Alamitos/ Rossmoor	62.4%	3.3%	1.3%	26.2%	80.7%	19.3%	52.6%	35.9%	15.7%
116f - Fullerton Central and South	54.7%	2.7%	1.4%	22.9%	63.2%	36.8%	44.8%	30.3%	13.8%
116g - Santa Ana South	45.2%	1.9%	1.3%	8.9%	17.6%	82.4%	33.1%	19.6%	6.7%
116h - City of Orange South/ Santa Ana North/ Tustin Foothills/ Tustin West	58.5%	2.6%	1.4%	17.1%	56.6%	43.4%	42.3%	28.6%	12.8%
116i - Garden Grove South/ Santa Ana West	30.7%	1.3%	1.3%	42.7%	53.2%	46.8%	41.3%	27.1%	10.7%
116j - Fountain Valley/ Huntington Beach Central	60.6%	1.5%	1.2%	30.6%	84.7%	15.3%	54.3%	38.9%	18.5%
116k - Brea West/ Fullerton North/ La Habra	58.3%	2.2%	1.4%	19.6%	58.6%	41.4%	47.5%	32.6%	14.3%
116l - Anaheim Central	48.7%	3.2%	1.3%	11.4%	29.0%	71.0%	34.7%	21.4%	8.4%
116m - Brea East/ Placentia Central and North/ Yorba Linda	69.1%	2.4%	1.1%	19.3%	79.0%	21.0%	49.8%	34.2%	13.0%
116n - Anaheim Hills/ City of Orange East/ Villa Park	69.8%	1.8%	1.0%	18.0%	76.1%	23.9%	52.2%	35.6%	13.6%
116o - Irvine Central/ Tustin East	52.6%	2.6%	0.8%	38.9%	86.8%	13.2%	46.8%	30.5%	11.0%
116p - Costa Mesa	65.0%	2.3%	1.4%	13.1%	63.4%	36.6%	40.2%	26.3%	10.8%
116q - Anaheim East/ City of Orange North/ Placentia Southwest	58.2%	2.7%	1.7%	11.4%	45.5%	54.5%	38.9%	25.5%	10.3%
116r - Garden Grove North/ Stanton	43.1%	2.3%	1.3%	30.6%	53.4%	46.6%	41.9%	28.0%	11.7%
116s - Huntington Beach North/ Seal Beach East/ Westminster	38.2%	1.7%	1.2%	43.3%	70.8%	29.2%	45.1%	30.4%	13.1%
116t - Huntington Beach South	81.2%	1.1%	1.3%	12.9%	88.1%	11.9%	54.0%	38.0%	16.2%
116u - Huntington Beach West/ Seal Beach West	79.6%	1.3%	1.4%	13.7%	87.2%	12.8%	60.1%	45.6%	24.1%
116v - Foothill Ranch/ Irvine Northeast/ Lake Forest West/ Portola Hills/ Tustin East	55.0%	2.2%	0.7%	38.4%	88.9%	11.1%	43.9%	25.5%	8.3%

US, state, and county data are for 2011; MSSA data are for 2010.  
Data are in the percentage of women in the population.  
Source: US Census Bureau – Population Estimates and Census 2010.

**Table 2.5. Population characteristics – socioeconomics**

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistic-ally Isolated	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age: 40-64)*
US	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
California	19.2 %	14.4 %	35.6 %	10.1 %	27.2 %	10.3 %	5.0 %	16.7 %	20.2 %
Komen Orange County Service Area (Orange County – CA)	16.6 %	10.9 %	29.5 %	8.3 %	30.5 %	10.1 %	0.1 %	4.0 %	18.9 %
115.1 - Dana Point/ San Clemente/ San Juan Capistrano	8.4%	9.6%	NA	7.7%	16.7%	3.6%	0.0%	0.0%	14.8%
115.2a - Lake Forest East/ Mission Viejo Central and South	6.7%	5.9%	NA	7.3%	21.5%	3.6%	0.0%	0.0%	9.9%
115.2b - Coto de Caza/ Las Flores/ Mission Viejo Northwest/ Rancho Santa Margarita/ Trabuco Canyon	3.1%	3.7%	NA	6.5%	14.4%	2.6%	2.2%	0.0%	5.4%
115.2c - Aliso Viejo/ Laguna Hills/ Laguna Niguel	3.9%	5.4%	NA	7.9%	21.5%	3.7%	0.0%	0.0%	9.9%
115.2d - Laguna Beach/ Laguna Woods	8.4%	8.0%	NA	8.4%	23.1%	5.4%	0.2%	0.0%	10.8%
116a - Buena Park/ La Palma	20.1%	12.2%	NA	7.6%	37.5%	18.9%	0.0%	0.0%	19.8%
116b - Santa Ana Central	57.7%	26.3%	NA	10.6%	52.7%	34.8%	0.0%	87.4%	39.8%
116c - Anaheim West	26.4%	16.4%	NA	12.2%	40.6%	18.7%	0.0%	0.0%	24.6%
116d - Irvine South/ Newport Beach/ Newport Coast/ San Joaquin Hills	2.2%	10.6%	NA	6.9%	18.8%	3.2%	0.2%	0.0%	8.6%
116e - Cypress/ Los Alamitos/ Rossmoor	7.9%	6.5%	NA	7.4%	22.8%	7.4%	0.0%	0.0%	12.3%
116f - Fullerton Central and South	16.1%	14.4%	NA	10.5%	30.5%	10.5%	0.0%	0.0%	20.5%
116g - Santa Ana South	47.2%	18.3%	NA	10.1%	48.1%	23.8%	0.0%	17.9%	32.7%
116h - City of Orange South/ Santa Ana North/ Tustin Foothills/ Tustin West	19.0%	13.7%	NA	9.4%	30.7%	9.1%	0.0%	0.0%	19.2%
116i - Garden Grove South/ Santa Ana West	38.4%	20.5%	NA	11.8%	53.3%	27.1%	0.0%	0.0%	26.1%
116j - Fountain Valley/ Huntington Beach Central	9.9%	7.4%	NA	8.2%	27.5%	8.1%	0.0%	0.0%	10.9%

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistically Isolated	In Rural Areas	In Medically Underserved Areas	No Health Insurance (Age: 40-64)*
116k - Brea West/ Fullerton North/ La Habra	14.9%	10.4%	NA	8.6%	29.2%	10.8%	0.0%	0.0%	19.9%
116l - Anaheim Central	38.4%	22.1%	NA	13.1%	42.4%	21.3%	0.0%	0.0%	29.3%
116m - Brea East/ Placentia Central and North/ Yorba Linda	7.7%	6.5%	NA	7.9%	21.4%	4.3%	0.5%	0.0%	10.8%
116n - Anaheim Hills/ City of Orange East/ Villa Park	10.9%	6.7%	NA	7.5%	26.1%	5.7%	0.0%	0.0%	12.6%
116o - Irvine Central/ Tustin East	6.2%	8.5%	NA	7.5%	36.0%	9.7%	0.0%	0.0%	11.0%
116p - Costa Mesa	15.3%	14.7%	NA	8.7%	27.8%	7.3%	0.0%	0.0%	21.8%
116q - Anaheim East/ City of Orange North/ Placentia Southwest	25.0%	14.4%	NA	11.1%	32.6%	11.6%	0.0%	0.0%	21.4%
116r - Garden Grove North/ Stanton	28.7%	15.1%	NA	12.4%	42.7%	18.9%	0.0%	0.0%	23.0%
116s - Huntington Beach North/ Seal Beach East/ Westminster	25.9%	17.6%	NA	11.8%	44.4%	20.8%	0.0%	0.0%	20.9%
116t - Huntington Beach South	4.5%	6.2%	NA	7.1%	12.3%	2.5%	0.0%	0.0%	10.3%
116u - Huntington Beach West/ Seal Beach West	5.3%	7.0%	NA	9.2%	14.4%	4.0%	0.0%	0.0%	9.0%
116v - Foothill Ranch/ Irvine Northeast/ Lake Forest West/ Portola Hills/ Tustin East	3.0%	5.7%	NA	6.0%	31.3%	6.5%	0.2%	0.0%	7.0%

\* Health Insurance coverage data for MSSAs are for all ages.

Data are in the percentage of people (men and women) in the population.

Source of health insurance data: US Census Bureau – Small Area Health Insurance Estimates (SAHIE) for 2011 and American Community Survey (ACS) for 2008-2012.

Source of rural population data: US Census Bureau – Census 2010.

Source of medically underserved data: Health Resources and Services Administration (HRSA) for 2013.

Source of other data: US Census Bureau – American Community Survey (ACS) for 2007-2011 and 2008-2012.

### **Population characteristics summary**

Proportionately, the Komen OC service area has a slightly smaller White female population than the US as a whole, a substantially smaller African-American/Black female population, a substantially larger Asian and Pacific Islander female population, a slightly smaller American Indian and Alaska Native (AIAN) female population, and a substantially larger Hispanic/Latina female population. The Affiliate’s female population is slightly younger than that of the US as a whole. The Affiliate’s education level is slightly lower than and income level is slightly higher than those of the US as a whole. There are a slightly smaller percentage of people who are unemployed in the Affiliate service area. The Affiliate service area has a substantially larger percentage of people who are foreign born and a substantially larger percentage of people who

are linguistically isolated. There are a substantially smaller percentage of people living in rural areas, a slightly larger percentage of people without health insurance, and a substantially smaller percentage of people living in medically underserved areas.

The following MSSAs have substantially larger API female population percentages than that of the Affiliate service area as a whole:

- 116a - Buena Park/ La Palma
- 116c - Anaheim West
- 116e - Cypress/ Los Alamitos/ Rossmoor
- 116i - Garden Grove South/ Santa Ana West
- 116j - Fountain Valley/ Huntington Beach Central
- 116o - Irvine Central/ Tustin East
- 116r - Garden Grove North/ Stanton
- 116s - Huntington Beach North/ Seal Beach East/ Westminster
- 116v - Foothill Ranch/ Irvine Northeast/ Lake Forest West/ Portola Hills/ Tustin East

The following MSSAs have substantially larger Hispanic/Latina female population percentages than that of the Affiliate service area as a whole:

- 116a - Buena Park/ La Palma
- 116b - Santa Ana Central
- 116c - Anaheim West
- 116g - Santa Ana South
- 116h - City of Orange South/ Santa Ana North/ Tustin Foothills/ Tustin West
- 116i - Garden Grove South/ Santa Ana West
- 116k - Brea West/ Fullerton North/ La Habra
- 116l - Anaheim Central
- 116q - Anaheim East/ City of Orange North/ Placentia Southwest
- 116r - Garden Grove North/ Stanton

The following MSSAs have substantially older female population percentages than that of the Affiliate service area as a whole:

- 115.2d - Laguna Beach/ Laguna Woods
- 116j - Fountain Valley/ Huntington Beach Central
- 116u - Huntington Beach West/ Seal Beach West

The following MSSAs have substantially lower education levels than that of the Affiliate service area as a whole:

- 116b - Santa Ana Central
- 116c - Anaheim West
- 116g - Santa Ana South
- 116i - Garden Grove South/ Santa Ana West
- 116l - Anaheim Central
- 116q - Anaheim East/ City of Orange North/ Placentia Southwest
- 116r - Garden Grove North/ Stanton
- 116s - Huntington Beach North/ Seal Beach East/ Westminster

The following MSSAs have substantially lower income levels than that of the Affiliate service area as a whole:

- 116b - Santa Ana Central
- 116c - Anaheim West
- 116g - Santa Ana South
- 116i - Garden Grove South/ Santa Ana West
- 116l - Anaheim Central

- 116s - Huntington Beach North/ Seal Beach East/ Westminster

The following MSSAs have substantially lower employment levels than that of the Affiliate service area as a whole:

- 116c - Anaheim West
- 116i - Garden Grove South/ Santa Ana West
- 116l - Anaheim Central
- 116r - Garden Grove North/ Stanton
- 116s - Huntington Beach North/ Seal Beach East/ Westminster

The MSSAs with substantial foreign born and linguistically isolated populations are:

- 116a - Buena Park/ La Palma
- 116b - Santa Ana Central
- 116c - Anaheim West
- 116g - Santa Ana South
- 116i - Garden Grove South/ Santa Ana West
- 116l - Anaheim Central
- 116r - Garden Grove North/ Stanton
- 116s - Huntington Beach North/ Seal Beach East/ Westminster

The following MSSAs have substantially larger percentage of adults without health insurance than does the Affiliate service area as a whole:

- 116b - Santa Ana Central
- 116c - Anaheim West
- 116g - Santa Ana South
- 116i - Garden Grove South/ Santa Ana West
- 116l - Anaheim Central

## **Priority Areas**

### ***Healthy People 2020 forecasts***

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

HP2020 has several cancer-related objectives, including:

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

To see how well the Komen OC service area is progressing toward these targets, the report uses the following information:

- County breast cancer death rate and late-stage diagnosis data for years 2006 to 2010.
- Estimates for the trend (annual percent change) in county breast cancer death rates and late-stage diagnoses for years 2006 to 2010.
- Both the data and the HP2020 target are age-adjusted.

These data are used to estimate how many years it will take for the Affiliate to meet the HP2020 objectives. Because the target date for meeting the objective is 2020, and 2008 (the middle of the 2006-2010 period) was used as a starting point, an area has 12 years to meet the target. Death rate and late-stage diagnosis data and trends are used to calculate whether an area will meet the HP2020 target, assuming that the trend seen in years 2006 to 2010 continues for 2011 and beyond.

**Identification of priority areas**

The purpose of this report is to combine evidence from many credible sources and use the data to identify the highest priority areas for breast cancer programs (i.e. the areas of greatest need). Classification of priority areas is based on the time needed to achieve HP2020 targets in each area. These time projections depend on both the starting point and the trends in death rates and late-stage incidence.

Late-stage incidence reflects both the overall breast cancer incidence rate in the population and the mammography screening coverage. The breast cancer death rate reflects the access to care and the quality of care in the health care delivery area, as well as cancer stage at diagnosis.

There has not been any indication that either one of the two HP2020 targets is more important than the other. Therefore, the report considers them equally important.

Counties are classified as follows (Table 2.6):

- Counties that are not likely to achieve either of the HP2020 targets are considered to have the highest needs.
- Counties that have already achieved both targets are considered to have the lowest needs.
- Other counties are classified based on the number of years needed to achieve the two targets.

**Table 2.6.** Needs/priority classification based on the projected time to achieve HP2020 breast cancer targets

		Time to Achieve Late-stage Incidence Reduction Target				
		13 years or longer	7-12 yrs.	0 – 6 yrs.	Currently meets target	Unknown
Time to Achieve Death Rate Reduction Target	13 years or longer	Highest	High	Medium High	Medium	Highest
	7-12 yrs.	High	Medium High	Medium	Medium Low	Medium High
	0 – 6 yrs.	Medium High	Medium	Medium Low	Low	Medium Low
	Currently meets target	Medium	Medium Low	Low	Lowest	Lowest
	Unknown	Highest	Medium High	Medium Low	Lowest	Unknown

If the time to achieve a target cannot be calculated for one of the HP2020 indicators, then the county is classified based on the other indicator. If both indicators are missing, then the county is not classified. This doesn't mean that the county may not have high needs; it only means that sufficient data are not available to classify the county.

**Affiliate Service Area Healthy People 2020 Forecasts and Priority Areas**

The results presented in Table 2.7 help identify whether an area is likely to meet the HP2020 breast cancer targets.

- For counties in the “13 years or longer” category, current trends would need to change to achieve the target.
- Some counties may currently meet the target but their rates are increasing and they could fail to meet the target if the trend is not reversed.

Trends can change for a number of reasons, including:

- Improved screening programs could lead to breast cancers being diagnosed earlier, resulting in a decrease in both late-stage incidence rates and death rates.
- Improved socioeconomic conditions, such as reductions in poverty and linguistic isolation could lead to more timely treatment of breast cancer, causing a decrease in death rates.

The data in this table should be considered together with other information on factors that affect breast cancer death rates such as screening percentages and key breast cancer death determinants such as poverty and linguistic isolation.

**Table 2.7.** Intervention priorities for Komen OC service area with predicted time to achieve the HP2020 breast cancer targets and key population characteristics

Population Group	Priority	Predicted Time to Achieve Death Rate Target	Predicted Time to Achieve Late-stage Incidence Target	Key Population Characteristics
Orange County - CA	Medium Low	1 year	5 years	
115.2d - Laguna Beach/ Laguna Woods	NA	NA	NA	Older
116a - Buena Park/ La Palma	NA	NA	NA	%API, %Hispanic/Latina, foreign, language
116b - Santa Ana Central	NA	NA	NA	%Hispanic/Latina, education, poverty, foreign, language, insurance, medically underserved
116c - Anaheim West	NA	NA	NA	%API, %Hispanic/Latina, education, poverty, employment, foreign, language, insurance
116e - Cypress/ Los Alamitos/ Rossmoor	NA	NA	NA	%API
116g - Santa Ana South	NA	NA	NA	%Hispanic/Latina, education, poverty, foreign, language, insurance, medically underserved

<b>Population Group</b>	<b>Priority</b>	<b>Predicted Time to Achieve Death Rate Target</b>	<b>Predicted Time to Achieve Late-stage Incidence Target</b>	<b>Key Population Characteristics</b>
116h - City of Orange South/ Santa Ana North/ Tustin Foothills/ Tustin West	NA	NA	NA	%Hispanic/Latina
116i - Garden Grove South/ Santa Ana West	NA	NA	NA	%API, %Hispanic/Latina, education, poverty, employment, foreign, language, insurance
116j - Fountain Valley/ Huntington Beach Central	NA	NA	NA	%API, older
116k - Brea West/ Fullerton North/ La Habra	NA	NA	NA	%Hispanic/Latina
116l - Anaheim Central	NA	NA	NA	%Hispanic/Latina, education, poverty, employment, foreign, language, insurance
116o - Irvine Central/ Tustin East	NA	NA	NA	%API, foreign
116q - Anaheim East/ City of Orange North/ Placentia Southwest	NA	NA	NA	%Hispanic/Latina, education
116r - Garden Grove North/ Stanton	NA	NA	NA	%API, %Hispanic/Latina, education, employment, foreign, language
116s - Huntington Beach North/ Seal Beach East/ Westminster	NA	NA	NA	%API, education, poverty, employment, foreign, language
116u - Huntington Beach West/ Seal Beach West	NA	NA	NA	Older
116v - Foothill Ranch/ Irvine Northeast/ Lake Forest West/ Portola Hills/ Tustin East	NA	NA	NA	%API

NA – data not available.

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

## **Data Limitations**

The following data limitations need to be considered when utilizing the data of the Quantitative Data Report:

- The most recent data available were used but, for cancer incidence and death, these data are still several years behind.
- For some areas, data might not be available or might be of varying quality.
- Areas with small populations might not have enough breast cancer cases or breast cancer deaths each year to support the generation of reliable statistics.
- There are often several sources of cancer statistics for a given population and geographic area; therefore, other sources of cancer data may result in minor differences in the values even in the same time period.
- Data on cancer rates for specific racial and ethnic subgroups such as Somali, Hmong, or Ethiopian are not generally available.
- The various types of breast cancer data in this report are inter-dependent.
- There are many factors that impact breast cancer risk and survival for which quantitative data are not available. Some examples include family history, genetic markers like HER2 and BRCA, other medical conditions that can complicate treatment, and the level of family and community support available to the patient.
- The calculation of the years needed to meet the HP2020 objectives assume that the current trends will continue until 2020. However, the trends can change for a number of reasons.
- Not all breast cancer cases have a stage indication.

## **Quantitative Data Report Conclusions**

### ***Medium low priority areas***

The Komen OC service area is in the medium low priority category. OC is expected to take one year to reach the death rate HP2020 targets and five years to reach the late-stage incidence rate HP2020 target.

## **Additional Quantitative Data Exploration**

### **Demographics & Poverty Levels**

In 2013, OC had a population of 3,114,363 people, as reported by the United States (US) Census Bureau. About 50.5 percent of the population or approximately 1,556,311 individuals in OC are women (US Census Bureau, 2014). Of this total population of over three million, 43.3 percent were Non-Hispanic White, 34.3 percent Hispanic/Latina, 18.0 percent Asian, 1.6 percent African-American/Black and 2.8 percent other (Orange County (OC) Health Profile, 2013).

This population represents approximately 23.6 percent under the age of 17, 38.1 percent individuals that are 18-44 years of age, 26.1 percent individuals 45-64 years of age, and 12.3 percent individuals 65 years of age or older (OC Health Profile, 2013). About 24.1 percent of the households in OC earn \$34,999 or less; 40.0 percent earn between \$35,000 and \$99,999, and 35.9 percent earn \$100,000 or more; with the median household income in OC in 2011 being \$72,293 (OC Health Profile, 2013). This is higher than the state and national median household of \$57,287 and \$50,502, respectively (OC Health Profile, 2013). However, between 2008 and 2012, 11.7 percent of OC's population reports living below poverty (US Census Bureau, 2014).

In OC, about 16 percent of residents 25 years and older had less than a high school diploma, 29.1 percent of residents 25 years and older had some college education or an associate’s degree, and 36.7 percent of residents 25 years and older had a bachelor’s degree or higher (OC Health Profile, 2013). While the overall county reports having insurance at about 82.3 percent or higher, some cities in OC are much lower and are far from the Healthy People 2020 goal of 83.2 percent of the population being covered by insurance (OC Health Profile, 2013). Table 2.8 represents cities in OC with less than 82.3 percent health insurance coverage, which is the county’s overall coverage rate.

**Table 2.8.** Rates of health coverage (insurance) in OC by Cities, 2009-2011

City	Percent with Health Insurance, 2009-2011
Westminster	82.1%
Orange	81.3%
Tustin	81.1%
San Juan Capistrano	80.8%
Buena Park	80.0%
Fullerton	79.7%
La Habra	77.8%
Garden Grove	77.5%
Costa Mesa	77.3%
Anaheim	77.0%
Stanton	71.9%
Santa Ana	65.7%

Source: Orange County Health Profile, 2013.

Anaheim is the most populated city in the county representing about 11.2 percent of the county’s population (OC Health Profile, 2013). Santa Ana, Irvine, Huntington Beach and Garden Grove follow as the second through fifth most populated cities in the county (US Census Bureau, 2014). By 2020, it is anticipated that the county population will rise to 3,198,279 (OC Health Profile, 2013).

In California, from 2005-2009, breast cancer was the most common newly diagnosed type of cancer among females among Non-Hispanic White, African-American/Black, American Indian/Alaska Native (AIAN), Chinese, Filipino, Native Hawaiian, Hispanic, Japanese, Cambodian (Kampuchean), Korean, Laotian/Hmong, Pacific Islander (includes Micronesian, Melanesian, and Polynesian, specifically noting Chamorro/Guamanian, Tahitian, Samoan, Tongan, Fiji Islander, and New Guinean), South Asian and Vietnamese women (Cook et al., 2013). Breast cancer is the most common cancer among women and the second leading cause of cancer deaths among women in OC (OC Health Profile, 2013).

### **Mammography Screening Behavior**

Mammogram screening data from the California Health Interview Survey (CHIS, 2011-2012), shows that women 50 years and older are reporting high rates (nearly 80 percent or higher) of having had a mammogram within the past two years. Table 2.9 reflects the screening history by five-year age groups for mammograms within the past two years. CHIS 2011-2012 also reports that 22 percent of women ages 40-44 have never had a mammogram in OC; this is an important age group to begin developing healthy screening behaviors. In addition to this, 13.8 percent of all women in OC reported having no insurance during the entire past year in CHIS 2011-2012 data. The uninsured represent a population for outreach and education about early detection,

based on Komen’s screening recommendations, as well as assistance in linkages to screening services, where appropriate.

**Table 2.9.** OC Mammogram Screening, within the last two years among women 40 and older

Age Groups	Mammogram screening history - 2 years or less		
	Est. N	%	95% C.I.
40-44 years	80,000	71.5	(59.9 - 83.1)
45-49 years	79,000	77.2	(65.2 - 89.2)
50-54 years	89,000	88.7	(81.3 - 96.1)
55-59 years	106,000	85.6	(78.3 - 92.8)
60-64 years	58,000	90.4	(83.2 - 97.6)
65-69 years	40,000	83.8	(74.4 - 93.2)
70-74 years	29,000	84.8	(77.1 - 92.6)
75 years and older	79,000	78.4	(71.3 - 85.4)

Source: 2011-2012 California Health Interview Survey  
 \* = statistically unstable

Since Komen recommends mammography screening starting at age 40, Table 2.10 represents data from CHIS with a specific focus on screening behavior by race for women 40 years and older in OC. CHIS 2011-2012 data showed that 81.7 percent of all women 40 years and older in OC reported having a mammogram within the last two years. Of these women, 84 percent are currently insured. Among the various racial groups the following reported having had a mammogram within the last two years, among Non-Hispanic White women 85.6 percent, Hispanic/Latina women 80.8 percent, African-American/Black women 62.1 percent, and Asian women 71.8 percent. Data were not available for Native Hawaiian/Pacific Islanders and AIAN in OC. In addition, 6.2 percent or 42,000 women (confidence interval (4.1 - 8.3), reported never having had a mammogram.

While data show screening percentages above or near those in California, the US and Healthy People 2020 goals (81.1 percent) for all races, non-Hispanic Whites and Hispanics/Latinas, screening percentages are lower among African-Americans/Blacks and Asians. As well, while much of the data is statistically unstable, Table 2.11 reflects mammogram screening among women 40 years and older in OC, showing that even among smaller population groups such as African-Americans/Blacks, AIANs and Native Hawaiians/Pacific Islanders (NHPI); screening percentages within the last two years are low comparatively to non-Hispanic Whites. This may point to a need to continue to promote and encourage prevention and early detection, particularly among diverse communities in OC.

**Table 2.10.** Mammogram Screening History within the last two years, among women 40 years and older, OC, CA

Race	Currently Insured	Not Currently Insured	All
All Races	84.00% (80.6 - 87.3) 502,000	66.20% (51.2 - 81.3) 58,000	81.70% (78.2 - 85.2) 560,000
Non-Hispanic White	87.20% (84.1 - 90.3) 319,000	51.80% (26.1 - 77.5) 9,000	85.60% (82.3 - 88.9) 328,000
Hispanic/Latino	83.20% (73.5 - 92.8) 81,000	76.7%* (57.7 - 95.7) 42,000	80.80% (71.7 - 90.0) 123,000
African American/Black	70.8%* (36.5 - 100.0) 7,000	-	62.10% (29.6 - 94.6) 7,000
Asian	74.40% (63.9 - 84.9) 85,000	49.0%* (18.4 - 79.5) 6,000	71.80% (61.8 - 81.7) 91,000
Native Hawaiian/Pacific Islander	Data Not Available	Data Not Available	Data Not Available
American Indian/Alaskan Native	-	-	-

**Source:** 2011-2012 California Health Interview Survey, via AskCHIS March 25, 2014.

95 percent confidence intervals are displayed in blue

\* Red Asterisk means statically unstable

- (hyphen) = Estimate is less than 500 people

**Table 2.11. Mammogram Screening History by Race for Women 40 and older in OC, CA**

Race - OMB/Department of Finance (2011)	2 years or less			More than 2 years ago			Never had a mammogram			TOTAL		
	Estimated N	%	95% CI	Estimated N	%	95% CI	Estimated N	%	95% CI	Estimated N	%	95% CI
Hispanic/Latino	123,000	80.8	(71.7 - 90.0)	17,000	11.3*	(4.2 - 18.5)	12,000	7.9*	(1.5 - 14.2)	152,000	100.0	n/a
Non-Hispanic White	328,000	85.6	(82.3 - 88.9)	40,000	10.4	(7.5 - 13.4)	15,000	4.0	(2.3 - 5.7)	384,000	100.0	n/a
African American/Black	7,000	62.1*	(29.6 - 94.6)	3,000	24.4*	(0.0 - 54.4)	2,000	13.5*	(0.0 - 37.7)	11,000	100.0	n/a
American Indian/Alaskan Native	-	-	-	-	-	-	-	-	-	-	-	-
Asian	91,000	71.8	(61.8 - 81.7)	22,000	17.5	(8.5 - 26.6)	14,000	10.7*	(4.1 - 17.2)	127,000	100.0	n/a
Native Hawaiian/Pacific Islander	1,000	100.0*	(100.0 - 100.0)	-	-	-	-	-	-	1,000	100.0	n/a
Two or More Races	9,000	92.0*	(79.6 - 100.0)	1,000	5.9*	(0.0 - 17.4)	-	-	-	10,000	100.0	n/a
All	560,000	81.7	(78.2 - 85.2)	83,000	12.1	(9.2 - 15.0)	42,000	6.2	(4.1 - 8.3)	685,000	100.0	n/a

Source: 2011 California Health Interview Survey  
 \* = statistically unstable

**Population Characteristics – Socioeconomics, Geography and Subgroup Data**

Population characteristics of race/ethnicity and socioeconomic data (age, education, less than HS education), income levels (income below 100 percent of the Federal Poverty Level), employment (unemployed status), foreign born status, linguistic isolation status (all adults in the household have difficulty with English), and insurance status (for those between 40 and 64 years of age) were considered for all cities in OC, noted in Table 2.12, below. These indicators may reflect geographic communities that have barriers to access to quality breast health care. Data in the Affiliate’s Quantitative Data Report were organized into a table by these characteristics. Six Medical Service Study Areas (MSSAs) were identified with five or more characteristics that may warrant consideration for focused efforts. Table 2.12 denotes a value of 1 if the socioeconomic category was present in the MSSA and a value of 0 if it was not identified through the quantitative data report. The total column is the summation of the various socioeconomic indicators, a total of eight that were represented in the MSSA. MSSAs with five or more indicators or population characteristics were noted to the far left of the table. These MSSAs represent portions of the cities of Anaheim West, Garden Grove South/Santa Ana West, Anaheim Central, Huntington Beach North/Seal Beach, East/Westminster, and Santa Ana South. These areas represent diverse racial/ethnic groups including a higher than overall service area population of API women and/or a larger than overall service area population of Hispanic/Latina women. Three additional geographic areas for consideration are those noted by the pink-bordered boxes, which have high populations of older women, for whom breast cancer is a greater risk; the cities represented by these MSSAs are Fountain Valley/Huntington Beach Central, Huntington Beach West/Seal Beach West, and Laguna Beach/Laguna Woods.

In addition to the data provided to Komen OC by Headquarters, the local affiliate also requested incidence and death rates by age, race, and ethnic subgroups for OC. A data request was made to the California Cancer Registry for more specific county level data, if available. Data

were prepared by the Cancer Registry of Greater California, for years 2005-2011 (as available) in OC for female invasive breast cancer incidence rates by age and race, female invasive breast cancer death rates by age and race, and female invasive breast cancer incidence and death counts by age and Asian subgroup; and data from 2005-2010 for female invasive breast cancer incidence rates and death rates by age and Asian-Subgroup for California (California Cancer Registry, 2014). The local Affiliate sought this additional data because OC is a diverse county and it was important for the Affiliate to try to gather a detailed picture of the breast health status of OC. The data were used to supplement and support the quantitative data report provided by Komen Headquarters and to reflect a more detailed understanding of OC's diversity in population. While age, race, and ethnicity data were obtained, data could not be correlated to geographic areas and are not specific to cities within OC; this limitation was due to time and resources.

As well, data for race subgroups for Non-Hispanic Whites and African-American/Blacks were not readily available, not allowing for a deeper understanding of these subgroups, in OC. Apart from these limitations, the data did help illuminate some deeper information about OC's breast health among diverse communities. Overall, the data revealed that breast cancer incidence and death rates were highest among those 65 and older for all racial groups (where data were available), with rates highest among Non-Hispanic Whites and African-American/Blacks; reinforcing the importance of focusing on communities with older women (Tables 2.13 and 2.14).

**Table 2.12. Komen OC Socioeconomic Data**

Category	Anaheim West	Garden Grove South/Santa Ana West	Anaheim Central	Garden Grove North/Stanton	Huntington Beach North/East Seal Beach/Westminster	Santa Ana South	Santa Ana Central	Buena Park/La Palma	Anaheim East/Orange North/Placentia SW	Fountain Valley/Central Huntington Beach	Irvine Central /Tustin East	Brea West/Fullerton North/La Habra	Cypress/Los Alamitos/Rossmore	Foothill Ranch/Irvine NE/Lake Forest W/Portola Hills/Tustin East	Huntington Beach West /Seal Beach West	Laguna Beach/Laguna Woods	Orange South/Santa Ana North/Tustin Foothills/Tustin West
Population of API female population higher than the overall service area	1	1	0	1	1	0	0	1	0	1	1	0	1	1	0	0	0
Population of Hispanic/Latino female population larger than that of overall service area	1	1	1	1	0	1	1	1	1	0	0	1	0	0	0	0	1
Older woman	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1	1	0
Lower Education	1	1	1	1	1	1	1	0	1	0	0	0	0	0	0	0	0
Lower Income	1	1	1	0	1	1	0	0	0	0	0	0	0	0	0	0	0
Lower Employment	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0
Foreign born/Linguistic Isolation	1	1	1	1	1	1	1	1	0	0	1	0	0	0	0	0	0
40-64 without health insurance	1	1	1	0	0	1	1	0	0	0	0	0	0	0	0	0	0
<b>Total</b>	<b>7</b>	<b>7</b>	<b>6</b>	<b>5</b>	<b>5</b>	<b>5</b>	4	3	2	2	2	1	1	1	1	1	1

If the population characteristic was identified in the quantitative data report (QDR), the category was given a value of 1; if not a value of 0. The final row represents the number of population characteristics identified in the MSSA out of the possible 8 areas identified by the QDR.

**Table 2.13.** Female Invasive Breast Cancer Incidence Rates by age and race, OC, 2005-2011 Combined

	Age	Rate	Lower CI	Upper CI	Pop
Non-Hispanic White	20-39	32.1	28.8	35.6	1,133,190
	40-64	249.6	242.6	256.8	1,877,251
	65+	487.3	472.8	502.2	928,780
African American/Black	20-39	36.2	20.7	58.5	50,097
	40-64	209.9	174.5	250.4	58,474
	65+	383.1	283.8	506.8	13,041
Hispanic/Latino	20-39	17	14.6	19.7	1,120,941
	40-64	153.4	144.7	162.4	806,221
	65+	315.9	290.1	343.3	177,138
Asian/Pacific Islander	20-39	25.6	21.8	30	605,671
	40-64	169.7	160.1	179.7	683,061
	65+	208.9	189.8	229.5	209,770
American Indian	20-39	^	^	^	8,840
	40-64	173.8	108.7	263.8	12,175
	65+	^	^	^	3,422

Rates are per 100,000 and age-adjusted to the 2000 US Std Population (19 age groups - Census P25-1130) standard; Confidence intervals (Tiwari mod) are 95% for rates.

^ Data suppressed due to confidentiality purposes

Source: California Cancer Registry

**Table 2.14.** Female Invasive Breast Cancer Death Rates by Age and Race, OC, 2005-2011 Combined

	Age	Rate	Lower CI	Upper CI	Pop
Non-Hispanic White	20-39	2.2	1.4	3.3	1,133,190
	40-64	25.8	23.7	28.2	1,877,251
	65+	110.3	103.7	117.3	928,780
African American/Black	20-39	^	^	^	50,097
	40-64	43.4	28.3	63.8	58,474
	65+	153	89.7	243	13,041
Hispanic/Latino	20-39	2.2	1.4	3.4	1,120,941
	40-64	21.5	18.3	25.1	806,221
	65+	75.9	63.3	90.2	177,138
Asian/Pacific Islander	20-39	1.8	0.9	3.2	605,671
	40-64	17.9	14.9	21.4	683,061
	65+	40	31.7	49.9	209,770
American Indian	20-39	0	0	42.9	8,840
	40-64	^	^	^	12,175
	65+	^	^	^	3,422

Rates are per 100,000 and age-adjusted to the 2000 US Std Population (19 age groups - Census P25-1130) standard; Confidence intervals (Tiwari mod) are 95% for rates.

^ Data suppressed due to confidentiality purposes

Source: California Cancer Registry

Subgroup data for Asians in OC also revealed additional communities of importance. Tables 2.15 and 2.16 report high frequency counts and incidence rates for Asian subgroups. Frequency counts for breast cancer incidence were considerable for Chinese, Japanese, Filipino, Korean, and Vietnamese women (greater than 100 cases from 2005-2011) in OC for women ages 40-64; this may be a result of improved screening percentages in the county. In addition, Table 2.16 shows Filipinos 40-64 and Japanese 65 and older had the highest rates of invasive cancer. This specific subgroup data is important to help reflect the diversity of ethnic subgroups in the county. While Asian subgroup frequency counts for incidence were considerable; overall breast cancer incidence rates were markedly higher for those aged 65 and older with high rates (229.5, 254.3 and 292.7 per 100,000 from 2005-2010, combined) respectively among South Asian, Filipino, and Japanese women 65 years and older in OC. These rates are far higher than those noted among the total API race group data for the same time period (208.9 per 100,000 for those 65 and older).

**Table 2.15.** Female Invasive Breast Cancer Incidence Counts by Age and Asian-subgroup, OC, CA, 2005-2011.

		2005	2006	2007	2008	2009	2010	2011	2005-2011
<b>Chinese</b>	20-39	^	^	^	^	^	^	^	18
	40-64	22	21	39	25	26	24	21	178
	65+	5	6	10	17	8	6	11	63
<b>Japanese</b>	20-39	^	^	^	^	^	^	0	11
	40-64	16	15	12	16	19	12	11	101
	65+	18	8	^	20	13	11	13	83*
<b>Filipino</b>	20-39	^	^	5	5	^	^	^	24
	40-64	23	24	40	36	23	48	28	222
	65+	9	8	9	12	11	9	10	68
<b>Korean</b>	20-39	^	^	^	^	^	^	^	22
	40-64	20	16	21	12	22	29	22	142
	65+	6	^	5	11	9	13	9	53*
<b>Vietnamese</b>	20-39	8	6	5	6	9	7	10	51
	40-64	35	39	35	45	49	64	52	319
	65+	12	13	14	11	13	18	12	93
<b>Laotian</b>	20-39	0	0	0	0	0	0	0	0
	40-64	^	0	0	0	0	^	0	^
	65+	0	0	0	0	0	0	0	0
<b>Hmong</b>	20-39	0	0	0	0	0	0	0	0
	40-64	0	0	0	0	0	0	0	0
	65+	0	0	0	0	0	0	0	0
<b>Cambodian</b>	20-39	0	0	0	0	0	0	0	0
	40-64	0	^	0	^	0	^	^	7
	65+	0	0	0	0	0	0	0	0
<b>Thai</b>	20-39	0	0	0	0	0	0	0	0
	40-64	^	^	^	0	^	0	^	7
	65+	0	^	^	0	^	0	0	^
<b>Pacific Islander</b>	20-39	0	^	^	0	0	0	0	^
	40-64	^	^	5	^	^	^	5	21
	65+	^	^	^	^	0	^	5	14
<b>South Asian</b>	20-39	0	^	^	7	0	^	^	15
	40-64	8	5	13	12	11	15	18	82
	65+	7	5	^	^	^	^	6	32

^ Statistic not displayed due to fewer than 5 cases.

\* Please note: This total value does NOT include the cell with <5 counts for confidentiality purposes.

Source: California Cancer Registry

**Table 2.16.** Female Invasive Breast Cancer Incidence Rates by Age and Asian-subgroup, OC, CA, 2005-2011 Combined.

		Rate	Lower CI	Upper CI	Pop
Chinese	20-39	19.5	17	22.2	1,169,310
	40-64	140.8	134.8	146.9	1,476,372
	65+	190.7	179.1	202.9	525,947
Japanese	20-39	23.4	18.2	29.5	294,428
	40-64	176.3	163.5	189.8	394,024
	65+	292.7	271.6	315.1	251,170
Filipino	20-39	21.6	19	24.5	1,163,539
	40-64	199.1	192	206.5	1,426,168
	65+	254.3	240.5	268.7	492,415
Korean	20-39	19.8	16	24.3	459,549
	40-64	129.4	119.6	139.8	496,678
	65+	132.5	115.8	151.1	168,711
South Asian	20-39	18.3	15	22.1	623,739
	40-64	136.4	125.2	148.4	402,987
	65+	229.5	200.5	261.7	103,140
Vietnamese	20-39	23	19.2	27.3	560,476
	40-64	138	128.6	147.8	581,522
	65+	157.8	138.8	178.7	159,696
Laotian	20-39	12.2	4.4	25.8	65,943
	40-64	75.2	52.3	104.6	46,205
	65+	75.5	34.1	145.3	11,497
Hmong	20-39	^	^	^	78,733
	40-64	44.8	25.6	72.8	35,743
	65+	^	^	^	10,237
Cambodian	20-39	15.6	7.7	27.6	94,640
	40-64	86.9	67	110.9	73,265
	65+	59.1	29	107.4	18,084
Thai	20-39	21.8	12.2	36.1	67,645
	40-64	154.2	127.1	185.4	72,631
	65+	170.3	107.1	260.9	14,481

Rates are per 100,000 and age-adjusted to the 2000 US Std Population (18 age groups - Census P25-1130) standard; Confidence intervals (Tiwari mod) are 95% for rates.

^ data suppressed due to confidentiality purposes

Source: California Cancer Registry

Lastly, while past data have shown high rates of late-stage diagnoses and death among Pacific Islanders, the data were suppressed due to small counts (fewer than five cases per year for years 2005-2011 each, except for 2007 and 2011, per the California Cancer Registry). It is possible that individuals of Pacific Islander descent were misclassified in their race or ethnic group. As well, data referenced earlier for screening by race among women 40 years and older showed that this population is screening very low as compared to other races, pointing to a need for increased screening utilization (note, Table 2.11). This is also true for African-American/Black, AIAN (for whom there is even less data) and mixed race individuals in OC.

### **Selection of Target Communities**

Based on the review of data from the Quantitative Data Report, the California Cancer Registry (CCR), and the California Health Interview Survey (CHIS), the CP Advisory Team has identified the following communities as target areas to focus on:

- African-American/Black Women
- Asian and Pacific Islander Women specifically Chinese, Filipino, Japanese, Korean, South Asian and Vietnamese
- Hispanic/Latina Women
- Women 65 years and older

Reviewing incidence, death and late-stage data (Table 2.1) the aforementioned groups were identified as important for consideration due to age-adjusted rates and/or trends for OC. African-American/Black communities had an increasing trend for breast cancer incidence and late-stage diagnosis and had a death rate higher than Whites in OC. APIs also had an increasing trend for breast cancer incidence with subgroup data (specifically Chinese, Filipino, Japanese, Korean, South Asian and Vietnamese) showing far higher incidence rates than those noted for the total API race group. Hispanic/Latino women who represent over 1/3 of the county's population also represent 1/3 of women 40 years and over that have never had a mammogram. Table 2.10 notes that a majority of Hispanic/Latina women (80.8 percent) are getting mammogram screenings within the past two years, however a large number of them are also uninsured. In addition, Table 2.8 and 2.12 also reflect cities and similar MSSAs that represent populations of Hispanic/Latinos with low insurance coverage and other socio-demographic barriers to care, such as low education, low income, low employment and linguistic isolation that may compound the barriers that they face in accessing screening. These data highlight African-Americans/Blacks, API and Hispanic/Latino communities as important communities for consideration for focused efforts by Komen OC.

In addition to these specific racial groups, Komen OC also identified women ages 65 and older as a priority group. Breast cancer is a disease of the aging and the aging population in OC continues to grow, representing about 12.3 percent of the population today and projected to grow to over 20 percent of the county's population by 2030 (OC Health Profile, 2013). Tables 2.13 and 2.14 highlight the higher rates of breast cancer incidence and death for women, across all races, ages 65 and older. With a growing older population, it will continue to be imperative to ensure access to breast health screening, diagnostics, and treatment so that the incidence and death trends do not grow linearly with the aging population.

The data revealed some key geographic pockets of need regarding breast health in OC. While the Affiliate recognizes that individuals live in specific communities, areas where they receive breast health information, screening and services may not be specific to their geographic

dwelling; as a result the Affiliate does not want to limit the work only to specific geographic areas.

The data show that there are promising practices for early detection and maintenance of healthy screening behaviors, however all communities face varying levels of disparities in utilization of screening, incidence, late-stage diagnosis, and death, with some age groups and geographic areas facing additional barriers to access. OC has favorable screening percentages overall, but in looking deeply at the data there is continued need for awareness raising, education, behavior change, and screening maintenance to eradicate breast cancer as the second leading cause of cancer deaths in the county.

# Health Systems and Public Policy Analysis

Komen OC will use the Health Systems and Public Policy Analysis to identify clinical assets as well as gaps for access to care for breast health services. The Analysis will also review existing health policies and public policies and a review of health coverage programs, reviewing eligibility and access to screening, diagnostics, treatment, and follow up care for breast health in OC. This will include a review of the Affordable Care Act, coverage enrollment and implementation of screenings under ACA, and state and federally supported programs such as Every Woman Counts/National Breast and Cervical Cancer Early Detection Program. An assessment of the health system landscape for the priority communities, and current policies (including potential changes) in regards to access, screening, diagnostics and treatment will be noted.

## **Health Systems Analysis Data Sources**

The Health System Analysis was completed from a review of publicly available data sources in OC. The following represents the resources used to complete the Health Systems Analysis:

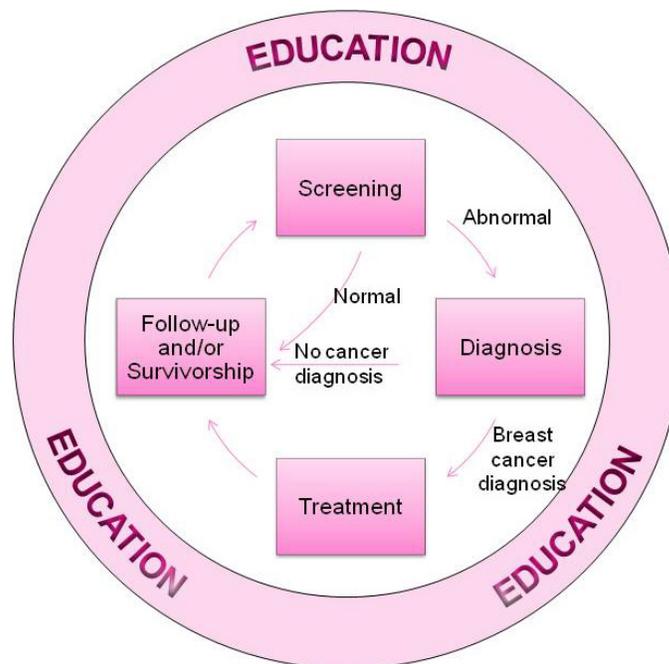
- Cancer Detection Program Breast Cancer Early Detection Providers (BCEDP) list
- List of Community Based Organizations providing breast health information, education, and support services (including Komen grantees)
- List of licensed Community Clinics (via the Coalition of OC Community Clinics, [www.coccc.org](http://www.coccc.org))
- List of Family PACT providers
- List of Faith Based communities in targeted communities
- List of FDA certified Mammography Centers in geographic areas associated with targeted communities
- List of ethnic based resources (such as churches, markets, community-based organizations, etc.) in OC matched to targeted communities and geographies of high population
- List of public hospitals
- List of local support groups in OC, provided by the OC Health Care Agency (Local health department)
- Census data for targeted communities
- Quality of Care (Certifications and Accreditations) resources websites for College of Surgeons, College of Radiology Centers of Excellence, College of Surgeons for National Accreditation Program for Breast Centers, and National Cancer Institute (NCI) Designated Centers
- Quantitative Data report from Komen Headquarters
- Subject expertise (e.g. community based organizations, resources, clinical providers, and support groups, etc.) from Komen staff
- Subject expertise (e.g. community based organizations, resources, support groups, clinical providers, imaging centers, etc.) from members of the CP Advisory Team

The data collected from the resources noted above, were input into the Health Systems Analysis spreadsheet in association with the four target communities of African-American/Black, Asian and Pacific Islanders, Hispanic/Latinas and women 65 years and older selected by the CPCP Team. The CP Team chose not to base the Health Systems Analysis by general geographic areas, however emphasized the focus on key areas with high population sizes for the four target populations. The African-American/Black community analysis focused on the cities of Fullerton, Anaheim, Buena Park, La Palma and Santa Ana West. The areas of focus for Asians and Pacific Islanders were Anaheim West, Garden Grove South, Santa Ana West, Anaheim Central, Huntington Beach North, Seal Beach East, Westminster, Fountain Valley, and Huntington Beach Central. For the Hispanic/Latina community areas of focus were Anaheim

West, Garden Grove South, Santa Ana West, Anaheim Central, Garden Grove North, Stanton East, Westminster, Santa Ana South and Santa Ana Central. For women 65 and older, the analysis included Fountain Valley, Huntington Beach Central, Huntington Beach West, Seal Beach West, Laguna Beach, and Laguna Woods. Large hospitals, health systems, and the local health department overlap in serving all of these communities and were noted as assets for each community.

After data were entered for these four target communities, the Team reviewed the data for any missing information and confirmed accreditation or FDA certification status as quality of care indicators. Additional information on local resources such as providers, imaging centers, community-based organizations, and social support resources were included following the framework of the cancer continuum of care (CoC) to identify any potential assets and/or gaps in breast health services within the Affiliate’s service area.

**Health Systems Overview**



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

The CoC (Figure 3.1) addresses screening through diagnosis, treatment, and follow up care as the typical process an individual would use to navigate through the health care system for their breast health needs. Figure 1 illustrates the general process for normal and abnormal screening results and the maintenance of healthy early detection behaviors for ongoing screening for women 40 years and older. The Affiliate’s services area has clinical providers across the CoC throughout the county that serves the community, specifically the four target communities African-American/Blacks, Asians and Pacific Islanders, Hispanics/Latinas and women 65 years and older.

The data reveal that there are providers for screening; diagnostic; treatment; and social support services, including in-language programs/services. The following reflects an overview of services across the CoC for all communities:

**Screening/Patient Navigation:** Family PACT; Every Woman Counts (EWC); community clinics; hospitals, community-based organizations (CBOs)

**Diagnostic/Patient Navigation:** EWC; community clinics; hospitals, imaging centers, CBOs

**Treatment/Patient Navigation:** Breast and Cervical Cancer Treatment Program (BCCTP) providers; hospitals, CBOs

**Other Social Support Services within the CoC:** Breast Cancer Solutions; Breast Cancer Angels; CBOs; Faith-Based organizations (FBOs) through churches, temples, and/or health/cancer ministries

**Outreach & Education/Follow-Up Care:** community clinics, hospitals, CBOs & health system providers to provide reminders and breast health education.

In particular, the county has providers that are part of California's Breast and Cervical Cancer Early Detection Partnership (BCCEDP) network, which helps create access to screening, diagnostic and treatment services for women who are uninsured or under-insured. The data also highlights key local organizations that provide social support services, such as patient navigation and support groups, to ethnic and/or age specific groups in the community. Lastly, the county has providers certified by the American College of Surgeons, American College of Radiology for Breast Imaging Centers, American College of Surgeons National Accreditation for Program for Breast Centers (NAPBC) and a NCI Designated Cancer Center, which demonstrates quality of care indicators that were factored into the analysis as assets within the cancer CoC.

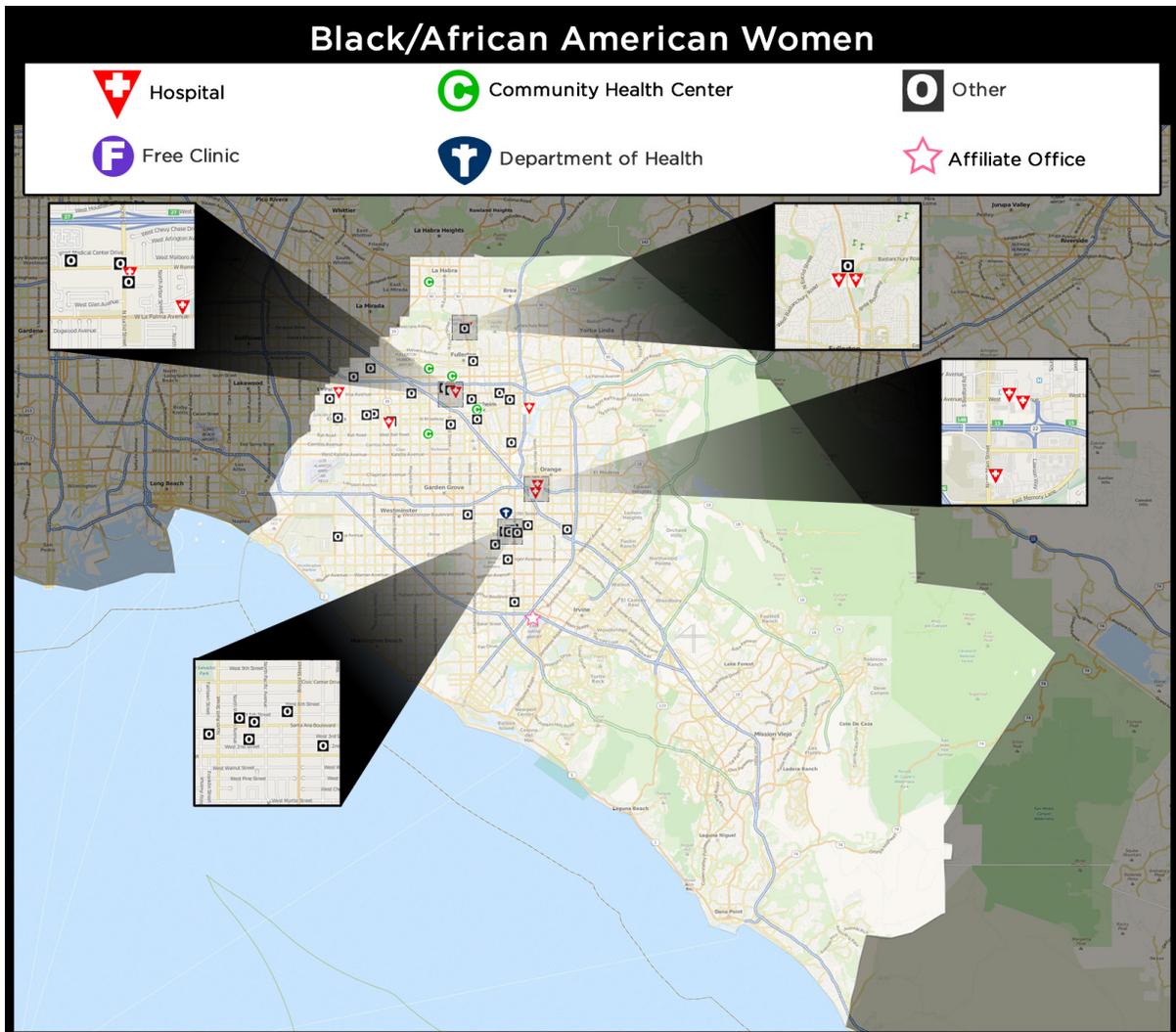
The **African-American/Black** community in OC has access to services across the cancer CoC. Patient navigation for breast health services are provided by community-health workers/advocates of the G.R.E.E.N Foundation, a local community based organization, as well as by cancer nurse navigators at hospitals and health systems (Figure 3.2). Various social support services are provided through hospitals, health systems, community clinics, and the faith-based communities through churches and health ministries. Breast Cancer Solutions, a local community-based organization, provides financial support services throughout the county; and the Public Law Center provides legal information and resources throughout the county.

**Asians and Pacific Islanders** in OC have access to services across the CoC. Patient navigation is provided through various community organizations, such as the Asian American Senior Citizens Service Center; OC Asian and Pacific Islander Community Alliance; OC Korean American Health, Information, and Education Center; Vietnamese American Cancer Foundation; and Pacific Islander Health Partnership (Figure 3.3). In addition, cancer nurse navigators at hospitals and health systems also provide patient navigation. In-language patient navigation is provided by community organizations for the Chinese, Korean, Vietnamese, Marshallese, Samoan, and Tongan communities. Information is lacking on in-language services for the Filipino, Japanese, and South Asian community in OC. Various social support services are provided through hospitals, health systems, community clinics, and community-based organizations with support

groups available in Chinese, Korean and Vietnamese. Breast Cancer Solutions, a local community-based organization, provides financial support services throughout the county; and the Public Law Center provides legal information and resources throughout the county.

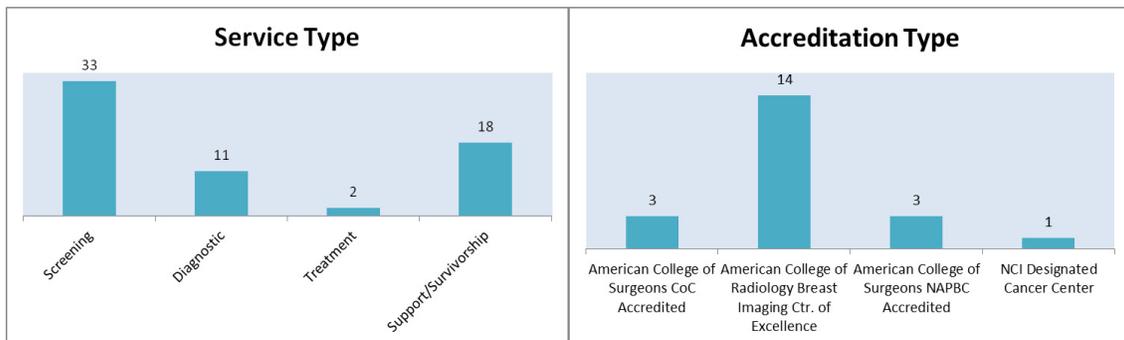
The **Hispanic/Latina** community in OC has access to services across the cancer CoC. Patient navigation is provided through various community organizations, such as Latina Health Access, as well as by cancer nurse navigators at hospitals and health systems (Figure 3.4). Services across the cancer continuum are available in Spanish throughout most facilities. Various social support services are provided through hospitals, health systems, community clinics, community-based organizations, faith-based organizations such as churches, and ethnic markets. Breast Cancer Solutions, a local community-based organization, provides financial support services throughout the county; and the Public Law Center provides legal information and resources throughout the county.

In OC, **women 65 years and older**, have access to services across the cancer CoC. Patient navigation is provided through various community organizations, as well as by cancer nurse navigators at hospitals and health systems (Figure 3.5). Various social support services are provided through hospitals, health systems, community clinics and community-based organizations. Breast Cancer Solutions, a local community-based organization, provides financial support services throughout the county; and the Public Law Center provides legal information and resources throughout the county.



### Statistics

Total Locations in Region: 48



**Figure 3.2.** Breast Cancer Services Available in African-American/Black Target Communities in OC

# Asian American/Pacific Islander Women



Hospital



Community Health Center



Other



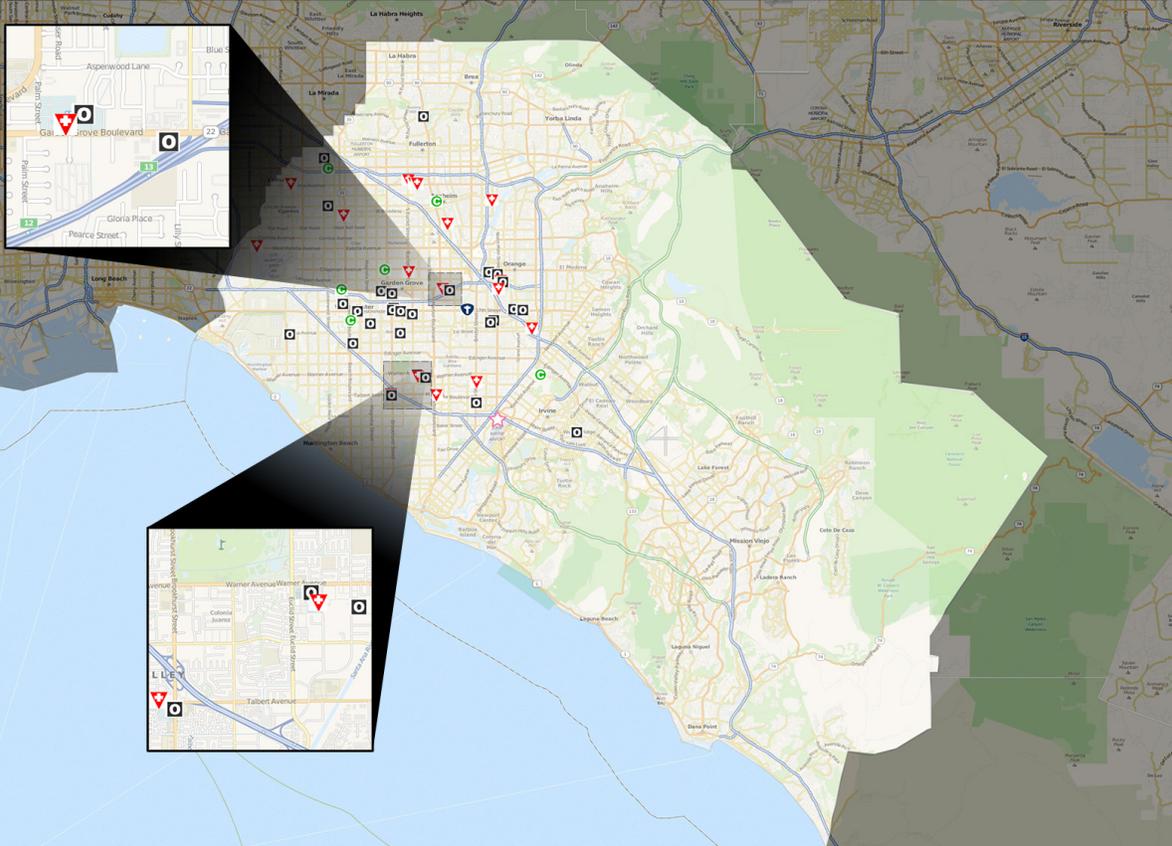
Free Clinic



Department of Health

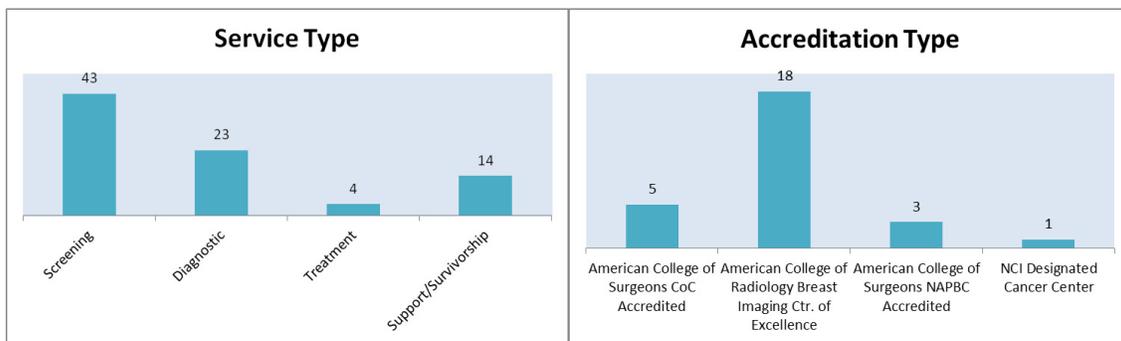


Affiliate Office



## Statistics

Total Locations in Region: 56



**Figure 3.3.** Breast Cancer Services Available in Asian American/Pacific Islander Target Communities in OC

# Hispanic/Latina Women

 Hospital
 

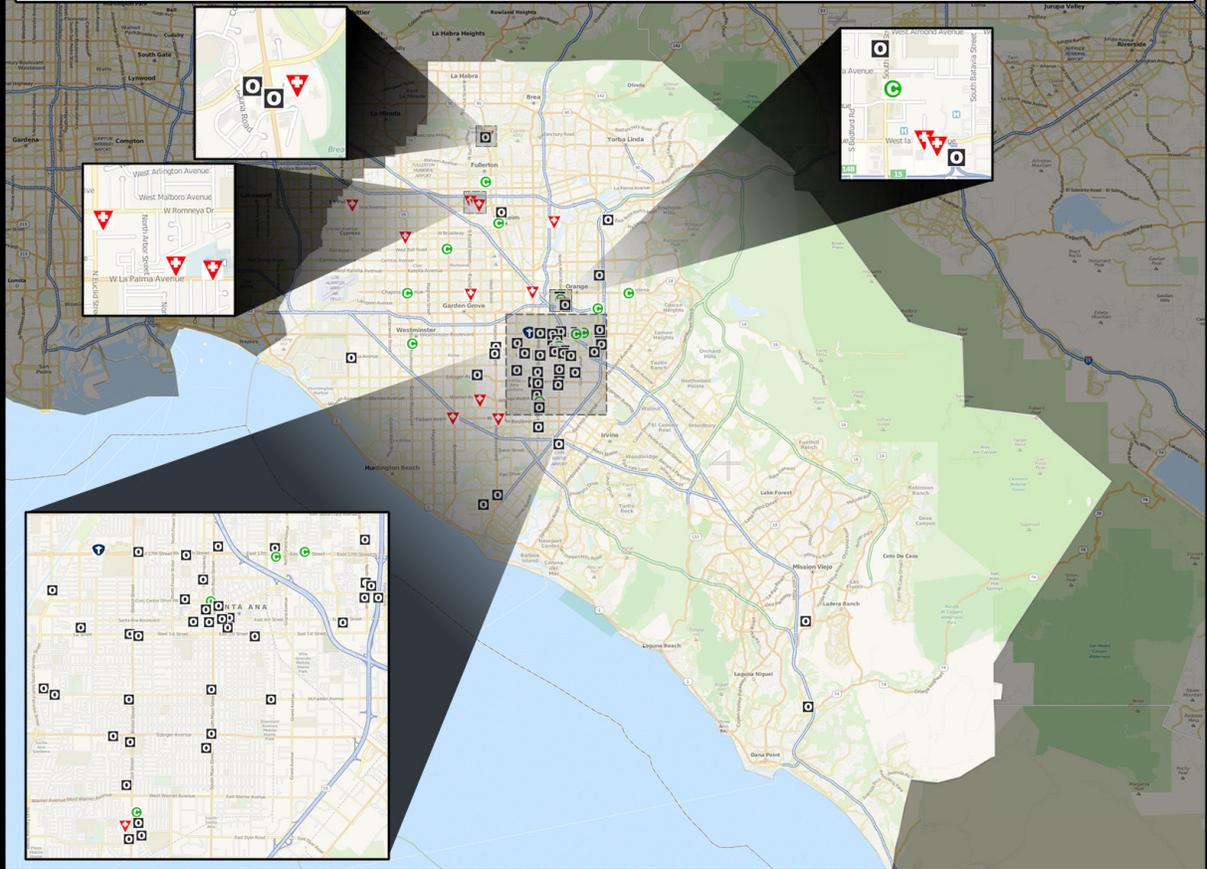
 Community Health Center
 

 Other

 Free Clinic
 

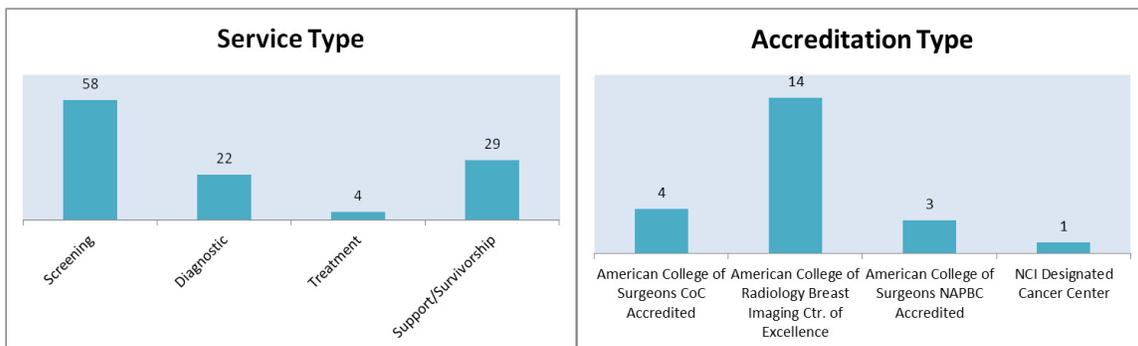
 Department of Health
 

 Affiliate Office

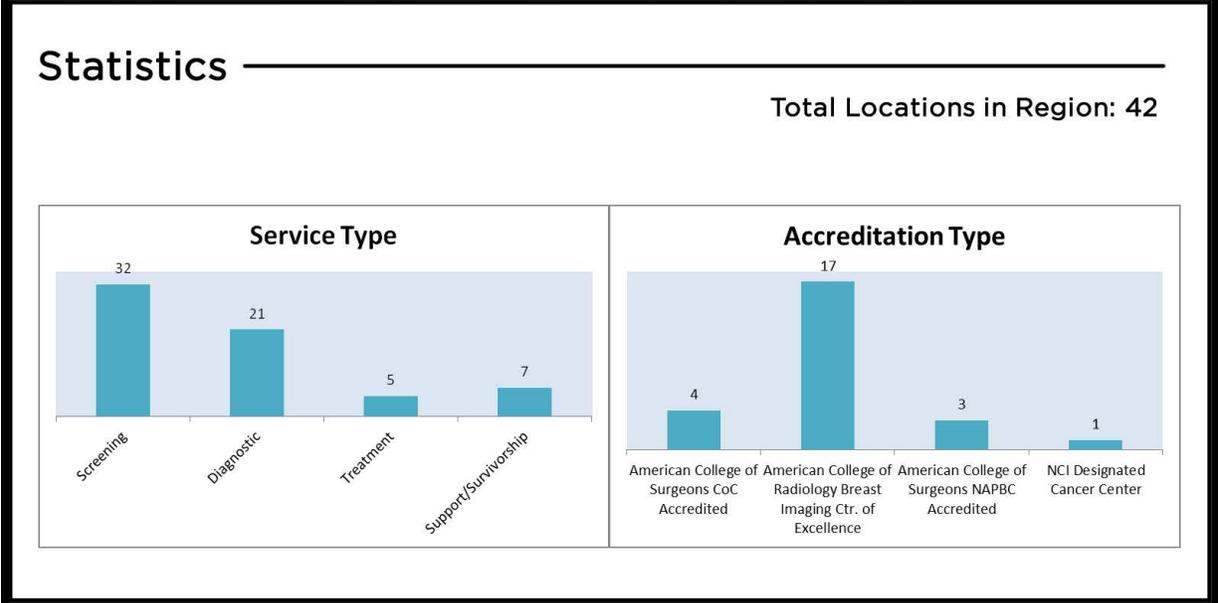
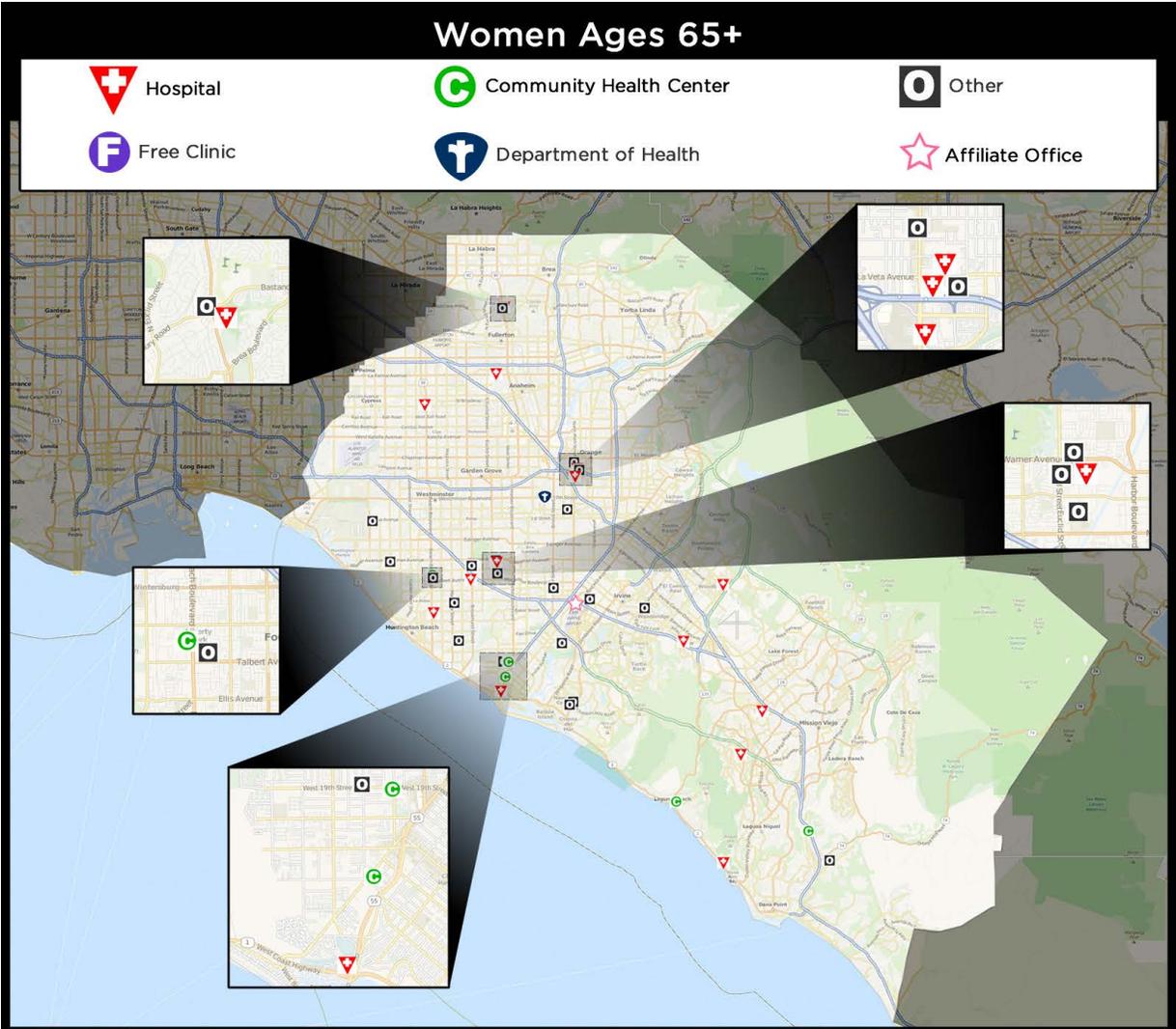


## Statistics

Total Locations in Region: 88



**Figure 3.4.** Breast Cancer Services Available in Hispanic/Latina Target Communities in OC



**Figure 3.5. Breast Cancer Services Available in Women 65+ Target Communities in OC**

Overall, the four communities have available services across the cancer CoC, as well as support information and services. In-language services across the entire continuum are limited; however there are some key community organizations providing leadership for in-language support services to clients seeking breast health care. While services are available, what is missing in the Health System Analysis is a review of the quality of services and the timeliness in which resources and services are made available to individuals seeking care. This information will be explored through the qualitative data collection process. In addition, it may be that various service providers exist, however the individuals within the four target communities are unaware of these resources and more outreach is needed to inform individuals of available services.

The OC Affiliate works diligently to build partnerships throughout the community with community-based organizations, clinical providers, hospitals and health systems, and key stakeholders to create access to breast health services throughout the service area. In recent years, specific efforts have been undertaken to increase and/or improve access to breast health services for communities with the highest level of needs for breast health access, which include but are not limited to communities that represent African-American/Blacks, Hispanic/Latinas, Native Hawaiians/Pacific Islanders, and women that are uninsured.

The OC Affiliate continues to identify areas of greatest need and strives to develop partnerships throughout the community to increase and improve access to breast health services, for example:

**African-American/Black Women:**

Over the last 18-months the local OC Affiliate has worked with six other Affiliates in California to develop an African-American Initiative to address breast health disparities of African-American/Blacks in California. Moreover, the OC Affiliate has successfully established a coalition, known as the African-American Women’s Breast Health Community Partnership, comprised of leaders and advocates of the African-American community to guide the Affiliate’s mission-related work and identify effective strategies for awareness-building, education, outreach, and linkage to breast health screening services to reduce the rates of late-stage diagnosis and the number of breast cancer deaths. The development of this partnership includes the participation of key leaders in the African-American/Black community providing opportunities to learn and engage with individuals that represent faith- and community-based organizations, survivor groups, clinicians, academic faculty/researchers and sorority groups.

These community leaders provide guidance and input on upcoming efforts for breast health outreach, education, and access to screening services through strategic planning activities to ensure cultural and age-appropriateness. Through the leadership of the African-American Women’s Breast Health Community Partnership, the Affiliate can make a greater impact on addressing the burdens of breast cancer in the African-American/Black community. Qualitative findings from the CP for African-American/Blacks in OC will include input and participation from members of the Partnership, as well as the development of the Mission Action Plan to include effective and strategic goals, objectives, and methodical approaches in addressing the needs of the African-American/Black community.

**Asian and Pacific Islander Women:**

In the Asian and Pacific Islander community, the Affiliate has strong partnerships with community-based organizations (CBOs) that provide education and screening linkages. The Affiliate has funded many of these CBOs and continues to have positive working relationships with them. In particular, the local Affiliate works with organizations that serve the Chinese, Korean and Vietnamese communities of OC. The local Affiliate has identified Filipino, Japanese and South Asian communities as additional communities of interest for developing further resources and contacts. The Affiliate is looking to identify key leaders for these communities and to build relationships with organizations that serve and/or represent these communities. The Affiliate is aware that there are some health and professional organizations for the Filipino and South Asian community and will make efforts to reach out to them to identify possible linkages to the communities in OC. The Affiliate will also reach out to CBOs serving these communities, based in neighboring Los Angeles County, to identify if individuals are seeking breast health services from these organizations. Komen OC also has strong ties to Pacific Islander serving organizations in OC and will continue to strengthen these relationships to address the needs of the Asian and Pacific Islander community.

**Hispanic/Latina Women:**

In recent years, the Affiliate has made great efforts to reach and better serve the Hispanic/Latina community of OC. The Affiliate provides leadership for the Unidos Contra el Cancer de Seno Coalition (Unidos), as well as help to convene “Cafecitos”, a coffee chat type support group for Latina women going through treatment of breast cancer. Unidos was established in 2009 to address breast cancer disparities between Latinas and non-Latinas in OC. Additionally, one of the goals of the coalition was to address late-stage diagnosis among Latinas by increasing breast cancer awareness through education and linkage to screening services. Unidos is comprised of representatives from non-profit organizations, health care systems, hospitals, the health department and local businesses. An example of a business partnership is working closely with the local Northgate Gonzalez and Tula markets, where many members of the community shop for groceries, to provide outreach and education about early detection of breast cancer and reduce barriers to access by hosting screening events at these ethnic supermarkets. While these organizations have made great strides to improve the breast health of Latinas in OC, more work is needed; and Komen OC continues to identify effective strategies and strategic partnerships to serve the Hispanic/Latina community.

**Women 65 years and older:**

Efforts among women 65 years and older for the OC Affiliate is integral to ongoing work to ensure women have information, resources, and linkages to breast health services in a timely manner. As breast cancer is a disease of the aging and OC’s baby boomer population is growing, the local Affiliate has continually made efforts to ensure outreach and education to women 65 years and older and to encourage continued screening. This target group has not been identified in previous Community Profile reports as a target community of focus. Therefore, the Affiliate will utilize the qualitative data collection process to identify other needs and barriers within this community and look to strategically build partnerships to reduce and eliminate such barriers.

Strengthening and developing partnerships is an important ongoing role for the local Affiliate. Having targeted the four communities of African-American/Blacks, Asian and Pacific Islanders, Hispanic/Latinas and women 65 years and older, Komen OC will continue to identify key

strategic partners to make available access to breast health services and to effectively meet the needs identified by these communities. Relationships with community-based organizations, clinical providers and hospital/health system leaders, such as the Pink Tie Guys (prominent, influential businessman and health care leaders in OC asked to bring awareness of breast cancer to the forefront of the business world and communicate a powerful statement that everyone must be committed to finding a cure), will continue to be one of the local Affiliate's key strategies. As other potential partners are identified, Komen OC will work to develop and strengthen these relationships.

### **Public Policy Overview**

*The National Breast and Cervical Cancer Early Detection Program (NBCCEDP)* supports, the provision of clinical breast exams, mammograms, Pap tests, pelvic exams, diagnostic testing, and referrals to treatment for low income and uninsured women. The program is supported by the Centers for Disease Control and Prevention, which provides a federal grant to each state (CDC, 2014).

In California, the program is referred to as *Every Woman Counts (EWC)*, and receives funding support from general state funds and through state tobacco tax revenue. EWC is part of the *Department of Health Care Service's Cancer Detection and Treatment Branch (CDTB)* and is separate from Medi-Cal (California's Medicaid Program). *The mission of the EWC is to save lives by preventing and reducing the devastating effects of cancer for Californians through education, early detection, diagnosis and treatment, and integrated preventive services, with special emphasis on the underserved (DHCS: EWC, 2014).*

The eligibility requirements for EWC are the following:

- Uninsured or underinsured
- Income at or below 200 percent FPL
- Must be between the ages of 40-64 for breast care services
- Proof of California residency
- Not eligible for any other state or federally funded programs, such as Medi-Cal

In California, oversight for EWC services is provided through regional contractors throughout the state. A statewide 1-800 number is available for inquiries regarding eligibility and referrals for services. The phone line is available Monday through Friday from 8:30am to 5:00pm and provides language assistance in English, Spanish, Mandarin, Cantonese, Korean and Vietnamese. Additionally, the EWC website provides a search portal for women and providers to identify local EWC services in their area. Individuals can enroll on-site at local EWC provider offices and health centers (DHCS; EWC, 2014).

If breast cancer is found, treatment is provided to eligible individuals through the *Breast and Cervical Cancer Treatment Program (BCCTP)*. BCCTP provides full-scope Medi-Cal to low income and uninsured women who meet the federal eligibility criteria. The state-funded BCCTP only provides cancer treatment and related services to individuals, including men, who do not meet the federal criteria. The State BCCTP program provides no cost breast cancer treatment services for up to 18 continuous months. The application and required documents for the BCCTP program are available in eleven languages, including English, Spanish, Vietnamese, Cambodian, Hmong, Armenian, Cantonese, Korean, Russian, Farsi and Laotian. Individuals can request an application for enrollment through the state BCCTP phone number or enroll through certified application assistants at health centers and hospitals (CDPH; BCCTP, 2014).

The OC Affiliate works with the local Breast Cancer Early Detection Partnership (BCEDP) through the OC Health Care Agency. Staff of both programs are in contact and aware of each other's programs and services. The local BCEDP program staff support enrollment of providers into the program to ensure access to services throughout OC. In the past the Affiliate has provided education about any updates and/or changes in policy that effect access to NBCCEDP to local community members, and continues to share information about relevant policy changes as information becomes available.

The OC Affiliate is also an active member of the Komen California Collaborative Public Policy Committee (KCCPPC), which is comprised of representatives from all seven California Affiliates. The KCCPPC has relationships with the Department of Health Care Services and EWC Administration, and closely monitors the program in terms of potential budgetary impacts, changes to eligibility, and screening recommendations. The local Affiliate, along with other members of the KCCPPC, will continue to strengthen relationships with legislators, DHCS staff and EWC Administration.

The *California Dialogue on Cancer* (CDOC) is a statewide cancer coalition, established by the California's Comprehensive Cancer Control Program in 2002. It is comprised of stakeholders and representatives from community organizations working together to reduce the burden of cancer in the state of California. CDOC was created to develop and implement California's Comprehensive Cancer Control Plan (CCCP).

The California Cancer Control Plan for 2011-2015 addresses the cancer continuum and includes primary prevention, early detection and screening, treatment, quality of life and end-of-life care. It also addresses cross-cutting issues such as advocacy, eliminating disparities, research, and surveillance.

The two breast cancer objectives for the plan are:

- 1) By 2015, increase the prevalence of women 40 years and older who report having both a mammogram and a clinical breast exam (CBE) within the prior two years by 7.5 percent, from a baseline prevalence of 79.1 percent to 85 percent (CDOC, 2014).
- 2) By 2015, increase the proportion of early-stage diagnoses of breast cancer among all women by 29 percent, from the baseline proportion of 69 percent to 89 percent (CDOC, 2011).

The KCCPPC participates in the CDOC stakeholder meetings and is part of the email distribution network to receive information related to training opportunities and other pertinent updates. CDOC is in the process of developing a new strategic plan for 2015 and the KCCPPC will be involved in the planning sessions to inform objectives and activities for breast cancer.

In 2010, California was the first state in the nation to enact legislation to implement the provisions of the federal Affordable Care Act (ACA), creating *Covered California* (Covered California, 2014). This health care marketplace was established to increase access to affordable and quality health care. California also decided to expand its Medi-Cal Program to cover individuals at or below 138 percent of the federal poverty level. California has the greatest number of uninsured of all the states with over 7 million uninsured (CFHC, 2014). By 2014, 2.6 million Californians were eligible to access financial assistance through *Covered California* to pay for their health insurance, and 1.4 million were newly eligible for Medi-Cal (Covered California, 2014). However, a large number of individuals (nearly 3 million) will remain

uninsured in California (CHFC, 2014). Approximately 703,000 will be eligible to Medi-Cal and not enroll; 959,000 will be undocumented and ineligible for insurance coverage; and 1.4 million will be eligible for coverage through *Covered California* and not enroll (CHFC, 2014). Of this 1.4 million, 577,000 will be eligible for subsidy but will not take it and 832,000 are not eligible for the subsidy (CFHC, 2014).

As of March 31, 2014, a total of 1,395,929 consumers enrolled in plans statewide and a total of 1.9 million California residents enrolled in Medi-Cal. A report by the Commonwealth Fund, estimates that roughly 1 in 4 people who were uninsured last in 2013, now have received coverage, with the state of California having the highest expansion in coverage. The percentage of Californians without health insurance was cut in half, from 22 percent a year ago to 11 percent by the end of June 2014 (Collins, Rasmussen and Doty, 2014).

The ACA through its marketplace health plans cover the following preventive health services for women, specific to breast health, without charging the patient a co-payment or co-insurance:

- 1) Breast Cancer Genetic Test Counseling (BRCA) for women at higher risk for breast cancer,
- 2) Breast cancer mammography screenings every 1 to 2 years for women over 40, and
- 3) Breast cancer chemoprevention counseling for women at higher risk<sup>7</sup>.

However, individuals who remain uninsured, due to ineligibility or opting not to purchase coverage, will not have access to these preventive health services for women. As a result, the NBCCEDP/EWC program will still be needed to provide clinical breast exams, mammograms, diagnostic testing for women and referrals to treatment for women (Levy, Bruen and Ku, 2014). While the overall number of women eligible to services through NBCCEDP will likely decrease, due to ACA and Medicaid expansion, a large number of women will remain uninsured and will still rely on EWC and BCCTP services for breast cancer screening and treatment. Additionally, while mammography is a covered benefit under ACA, there will still be women that purchased a higher deductible health plan and have large out of pocket costs as it relates to breast cancer diagnostic care and treatment.

While much excitement has surrounded the ACA and the roll out of the health care marketplace, a lot remains undetermined in terms of access and utilization. Some experts in the community have expressed concerns about the availability of health care providers to respond to an increase of 30 million insured Americans across the country. Some studies report not only a shortfall in health care providers, but also in the health care workforce as a whole, in responding to the ACA changes (Anderson, 2014). While these concerns may be warranted, other efforts are taking place at all levels to ensure collaboration and partnership across providers (safety net providers, private providers, Medi-Cal providers, hospitals, and health systems) to ensure strategies to meet the changing needs of health care delivery (HRSA, 2014).

For the local Affiliate, there will remain a large number of uninsured individuals who are in need of breast health services and may need access to NBCCEDP/EWC or Affiliate resources to ensure timely and quality access to breast health services. The Affiliate will continue to work closely with its partners in health care and health policy to stay abreast of the breast health needs in the Affiliate service area and respond accordingly in providing support for access to care.

The local Affiliate is actively involved in public policy activities at the state and local level and stays apprised of key public policy issues in the service area. The Affiliate participates on the

KCCPPC monthly calls, attends both state and national lobby days, and meets with local legislators regularly to educate on pertinent breast health issues and maintain relationships.

Moreover, the Affiliate works with the local Cancer Coalition for the county, the OC Cancer Coalition (OC3) and attends its bi-monthly meetings. OC3 works with the state cancer coalition and participates in its annual convening to learn best practices and lessons learned and to network with other colleagues in cancer education, prevention, screening, and advocacy. The local Affiliate intends to continue participation with OC3 and the State Coalition and provide leadership on breast health issues.

### **Health Systems and Public Policy Analysis Findings**

In conclusion, the analysis highlighted in-language social support, legal and financial services for those facing cancer in OC. While the county has available resources across the cancer CoC, the Affiliate is not clear that the target populations are aware of the accessibility of resources. The local Affiliate is interested in utilizing the qualitative data collection process to understand the availability and use of breast health resources and to identify any additional gaps not illuminated by the Health Systems Analysis. This additional layer of data will help to contextualize the needs and level of needs faced especially by the target communities.

Komen OC recognizes the tremendous number of organizations and individuals that partner with the Affiliate to ensure access to quality and timely breast health services in OC. Relationships with individuals/advocates, faith- and community-based organizations, the local health department, universities, hospitals, research organizations, businesses (small and corporate) and other philanthropic organizations will continue to be critical in order to maintain and strengthen the reach of resources for individuals in OC. As new partners are identified, there is more to learn about resources and building collaborations to support the community's breast health needs.

While there have been many positive accomplishments in California, and more individuals have health coverage through Medi-Cal and Covered California, there are still populations that are falling short of other racial/ethnic groups in terms of enrollment and utilization. The local Affiliate and its grantees will work to ensure constituents are aware of the available coverage options to increase enrollment of OC residents into comprehensive health coverage. Moreover, the Affiliate is highly concerned that there will be women left behind without coverage. The Affiliate in collaboration with the KCCPPC will need to ensure that EWC and BCCTP remain viable and well-funded. Finally, the local Affiliate will need to work closely with OC3 and other local coalitions to ensure women know about and have access to local EWC providers in the county.

# Qualitative Data: Ensuring Community Input

## **Qualitative Data Sources and Methodology Overview**

Komen OC focused on using a provider survey, key informant interviews and focus groups to collect qualitative data from the community among the four target communities selected. Questions for the provider survey, key informant interview guide and focus group guide were linked to key questions that arose from the review of the quantitative data and health systems and public policy analysis. Key areas of interest included many gaps; challenges or barriers to breast health information and care; access to and utilization of breast health services; and attitudes, beliefs and behaviors around breast cancer and breast health services. The data collection tools also included questions about opportunities for Komen to develop and strengthen outreach efforts, partnership development, education/health promotion, and funding strategies in working with target communities. The following includes the rationale and details of each qualitative data collection method and ethics applied for each of the target communities: African-American/Black, Asian and Pacific Islander, Hispanic/Latina, and women 65 years and older.

## **Qualitative Data Overview**

### **Provider Survey**

The CP Team recognized the potential overlap in responses and respondents when reviewing all qualitative data collection methods with regard to the target communities selected and the providers that would participate; as a result, a provider survey was determined to be the best method for collecting data that explored access and utilization of breast health services. A provider survey comprised of 18 questions was developed based on areas of interest from the quantitative data review, health system and public policy analysis, and input from the Advisory Team members. The survey was drafted and then developed via Survey Monkey and distributed via email to nearly 2,000 providers in OC. The distribution list included community organizations, physicians in family practice, general preventive medicine, geriatrics, family practice, internal medicine, obstetrics & gynecology, breast surgeons, breast oncologists, radiologists and nurse practitioners. The total list was 2,000 emails. In order to calculate sample size the Affiliate used a sample size calculator from the website of MaCorr Research ([www.macorr.com/sample-size-calculator.htm](http://www.macorr.com/sample-size-calculator.htm)) and set a population size of 2,000 with a 95 percent confidence level and 10 percent confidence interval. The calculation yielded a sample size of 92, which was the goal; however the Affiliate was able to achieve close to a 90 percent confidence level and 10 percent confidence interval, with a sample size of 64.

The provider survey was sent to organizations and providers serving all four target communities: African-American/Black, Asian and Pacific Islander, Hispanic/Latina and women 65 years and older. The survey was available at [www.surveymonkey.com/s/breasthealthneeds](http://www.surveymonkey.com/s/breasthealthneeds). The Affiliate disseminated the survey via the email distribution list and allowed the link to be open for responses for 60 days (starting September 4, 2014 and closing November 14, 2014). The survey link was sent out multiple times and the Affiliate received 64 responses for a response rate of 3.2 percent. The sample was of convenience identified through the health system analysis and a list of health providers in OC. These individuals were invited to respond to the provider survey because they provided breast health services to any of the four target communities.

Survey data were gathered online and filtered into Excel spreadsheets via Survey Monkey. Data were analyzed based on the set of 18 survey questions, yielding quantitative and qualitative responses.

Sixty-four respondents answered the provider survey and shared information about the services that they provide as well as gaps and challenges in access to breast health services in the community. Respondents represented diverse organization types and organizational roles; most organizations provided services to Hispanics/Latinas, Asians and Pacific Islanders, low-income individuals, non-Hispanic Whites and the uninsured in OC; most provide services to women ages 30 and older; and provide, order and refer breast health services across the cancer continuum.

While respondents shared that they provided in-language breast health materials (predominantly in Spanish and then Vietnamese), not surprisingly they also said that more language services are needed throughout the community and culturally and linguistically sensitive outreach and education is needed.

Gaps in breast health services included:

- Access to care, including available surgeons that accept low cost reimbursement or Komen treatment funds;
- Awareness and a lack of education about breast health;
- Financial support;
- Insurance coverage gaps;
- Challenges with the Affordable Care Act (ACA) and navigating the health system once enrolled and eligible for services;
- A need for language access and culturally sensitive services;
- Transportation needs;
- A lack of ancillary and supportive services;
- Services outside of standard business hours (for example after hours, weekends and walk-in flexibility); and
- Services for the uninsured.

When asked about communities being served with the most pressing barriers the uninsured, low-income communities and the Hispanic/Latina community had the highest responses.

The top responses in order for key barriers to receiving breast health services are:

- People are too busy with work (cannot take time off);
- The health system is too difficult to navigate;
- People are busy taking care of family;
- Language barriers in accessing care;
- Fear that a mammogram is painful or uncomfortable;
- A lack of reliable transportation;
- Not sure where to go;
- Other health issues take a priority;
- Cost of getting treatment; and
- Cultural barriers.

Lastly, when asked about key suggestions for strategies and programs for Komen the following were shared: continued outreach and education to various communities; providing transportation support with bus passes or rides; collaborating with local providers and hospitals; developing a multi-cultural education team – providing outreach in other languages; working with faith-based organizations and senior adult centers; addressing gaps still remaining even with health care reform; disaggregating Asian and Pacific Islander data; and continued outreach efforts and screening services for low-income and at-risk women.

## **Key Informant Interviews**

Key informant interviews were a second method of data collection for the Asian and Pacific Islander (API) community and women 65 years and older. Key informant interviews were selected for this group to be able to gather diverse perspectives of the needs of these target communities. Particularly for the API community, with diverse subgroups, this method allowed for meeting with key leaders and organizations serving very specific subgroups to address their specific needs. For women 65 years and older, this method allowed for meeting with individuals with different roles serving women 65 years and older and to hear the different perspectives they had in serving this community – such as those who are providing education and risk reduction, screening, and those working with diagnosed clients through survivorship. Komen OC used a convenience sampling from the Health System Analysis to recruit potential interviewees; referrals from interviewees for other resources for interviews were also solicited. The Affiliate was able to identify key organizations serving specific API subgroups for OC, however quickly found that some key subgroups were not served by any formal organizations in OC – such as the Filipino, Japanese and South Asian communities. As a result, the Affiliate reached out to colleagues in neighboring Los Angeles County as well as leaders in OC for recruitment. The Affiliate also found that while there are many service organizations for women 65 years and older in OC, few specifically had knowledge regarding breast health needs for the community. The Affiliate’s goal was to conduct twelve key informant interviews per target community.

Fifteen interviews were completed from August 25<sup>th</sup> through October 27<sup>th</sup>. Interviews were conducted in English with a note taker present and all but one session was audio recorded. The session that was not audio recorded was conducted via telephone. All notes were evaluated by reviewing the audio recording and making sure that no key elements were missing. Two members of the CP team then separately reviewed the notes and coded the interviews to identify key categories and themes. The team of interviewers met and shared the themes and condensed the findings to a code list. All interviews were then reviewed again and themes were recorded based on the code list. Data analysis was performed with hand coding and checked for accuracy using inter-rater reliability. Common findings were then evaluated between the interviews and focus groups. Verbal and signed consent was collected from all participants. A demographic survey was also collected from all participants. Survey notes were coded and a log with identifiers was used by only one of the research team members, to ensure confidentiality. Consent forms and demographic surveys are stored in a locked cabinet at the Komen offices; demographic surveys do not provide any identifiers.

## ***Asian and Pacific Islander Communities***

Ten interviews were conducted in the API community with a focus on the Chinese (3), Filipino (1), Japanese (2), Korean (2), South Asian (2), Vietnamese (2) and Pacific Islander (1) communities. Please note that some individuals were able to speak about multiple communities due to their experience and background working with and serving multiple communities. Individuals worked with community based organizations or clinical providers in the community. Of the ten interviewees, two were male and eight were female with ages ranging from 20-79, all identified as non-Hispanic Asians. The following represents their organizational roles: three Executive Directors, one Chief Operating Officer, one Physician, one Nurse Navigator, one University/Faculty member, and three community-based organization staff in the role of outreach or program manager.

With a rich diversity of subgroups in OC, key informant interviews were selected so that representatives serving and working with the diverse Asian and Pacific Islander subgroups could be invited to participate in the data collection process. A few interviewees also shared

insight on working with the Filipino and Japanese communities, though no known resources for specifically serving these populations around breast health was identified or available in OC. The completed interviews offers a rich platform of information around breast health for Asian and Pacific Islander communities; however the information gathered is not generalizable to all Asian and Pacific Islander subgroups in OC.

#### *The most substantial breast health needs for API women*

Key informant interviewees noted that education about breast health continues to be a substantial breast health need in the community. In particular, participants discussed general breast health awareness (general breast health and risks) and knowledge about screening guidelines as important topics for education. Among the aging, it was noted that education on the importance of re-screening was important. In addition to general breast health education, participants shared that it was important to have information and education on treatment options, how to access screening services and insurance coverage. Interviewees also noted that having in-language materials and interpreters at clinical sites was important to ensure accessible services for clients. In relation to interpretive services, a few interviewees also mentioned the importance of navigation support for patients through the continuum of care, including assistance for health care reform programs. Other areas where education can be provided is in addressing specific communities and sharing risk specific to ethnic subgroups, addressing fear of screening, discussing prioritization of women's health (many women prioritize family responsibilities above their own health), and providing social support so that women feel they can access services.

#### *Challenges or barriers to breast health*

In regard to challenges or barriers to breast health, top issues shared were transportation needs, language access, and not having enough time for prioritizing one's health. Distance to a provider was shared as a barrier in allowing for access to care; some community members must rely on public transportation which can be confusing and time consuming; for those using public transportation there are other associated needs, such as needing to bring children with them or having caretaking responsibilities at home for children or elder family members; and some individuals rely on the schedules of others, especially elders, limiting their ability to access services. In discussing language access, interviewees shared that clinical sites tend to have poor phone interpretation services; there is a lack of in-language materials; and language access is needed throughout the process from making appointments, completing registration materials and paperwork to the actual medical encounter with the provider. This service is often fragmented and not available throughout the entire process of the continuum of care. A few participants noted that individuals they have interacted with share a lack of time being a barrier to accessing breast health; this includes women working multiple jobs with long hours, not being able to take time off from their jobs for health care appointments; busy meeting multiple basic needs; and an inability to take multiple days off to see a physician and to go elsewhere for diagnostic or follow up care, as needed.

In addition to these top issues several other challenges and barriers to care were noted. These included: a lack of social support – particularly, who to turn to other than their family; immigration status; reluctance to practice screening because of the discomfort of mammograms; a lack of understanding of the western health care setting; and cultural stigma, beliefs around karma, and cultural modesty (e.g. the importance of gender concordance with a provider in addressing women's health).

### *Gaps in Breast Services*

Participants also shared their perceptions about the accessibility of breast health care for the community. Overall, interviewees felt that those with health coverage, including Medi-Cal and state sponsored programs, had good access to care.

However, there are key gaps in breast health services for the community. Top gaps in services, similar to those shared as substantial needs, are the gaps in education, language access, and health coverage/access. Interviewees continuously expressed the importance of education, and an understanding of risks, signs and symptoms and screening guidelines. The lack of appropriate and consistently available language services to access and navigate health services were mentioned as a gap that hinders patient compliance. Lastly, while health care reform was referenced and should improve health access, interviewees shared that because this is new there is a great deal of confusion, and because individuals are assigned to specific health plans, local community navigators are not necessarily able to provide the same level of navigation support for clients.

Interviewees also shared that a portion of the population is not accessing care. This tends to be among “newcomers” – recent immigrants who have not received general outreach or education about breast health and risks.

Additionally, interviewees shared that navigation support, language interpretation, transportation assistance and the sharing of survivor stories or testimonials were good best practices to help increase utilization by community members.

### *Utilization*

While interviewees felt that breast health services were accessible in the community, eight of 10 interviewees believed that actual utilization in the community was low. Reasons shared for this belief were very similar to the barriers and challenges mentioned in previous sections. However, it is important to mention a small number of interviewees felt that there was high utilization in the community. Many believed this for those linked with a regular provider, health coverage, and communities, such as the Vietnamese that have providers, community clinics, programs and patient navigators that facilitate access to screenings. Among this population, patients are generally compliant and follow through on referrals for screenings. For some private clinics, the patient is also compliant due to efforts from the clinic to meet quality measures for screenings (e.g. Health care Effectiveness Data and Information Set (HEDIS) measures).

### *Behavior*

In discussing behavior and individuals of influence on breast health screening, interviewees mentioned peers and the media as top influencers. Especially among peer breast cancer survivors, those that have experienced breast cancer are influential in promoting screening behavior. Media was also highly popular especially through the use of culturally specific and appropriate public service announcements and programming from the home country. Other influencers of breast health screening behavior are physicians, other health care providers, community programs, community elders/gatekeepers, community navigators, spiritual leaders, family members, and individuals themselves once they understood their own potential risk.

Participants mentioned the importance of in-language materials and in-language education to reach diverse communities. Community sites, such as senior centers and faith-based organizations, were also referenced as good places to share information and resources on breast health.

### *Educational Messaging*

Interviewees believed that education continues to be a high need in the community – as a result the Affiliate asked them for suggestions around educational messaging, messengers and locations for messages. Participants reported that targeted and age appropriate messages that are language specific are important and will help to convey important breast health information. Cultural considerations in terms of images, design, and color to reflect salience to the audience is also of great importance. In addition to having appropriate translations, it's important to understand that various languages also have nuances that must be considered to reach diverse groups within the different ethnic communities in OC. It's important to have educational messaging in multiple formats and platforms – not just print materials. Participants also shared that because many Asian Pacific Islander communities are collective in nature, educational messages can be framed around family health and wellbeing and the importance of a woman taking care of her own health so that she can continue to care for and support her family. Packaging the message as a family approach to include spouses and children and even grandparents could be most effective. Participants also suggested leveraging messaging to men to support the women in their lives, allowing the men an opportunity to be educated and engaged in the process.

Participants shared a number of individuals as possible messengers in the community. This included physicians/providers and health care workers; gatekeepers and community leaders; peers, especially survivors; family members; local ethnic media broadcasters, and celebrities from the diverse communities. They also shared the importance of providing intergenerational messaging and promoting an intergenerational conversation about breast health and breast cancer.

Possible sources or locales for information dissemination, participants felt strongly about reaching the community where they are – where they work, play, pray and gather. Examples of these locales are ethnic markets, senior centers, halaus, people's homes (e.g. mahjong groups, gardening clubs), community events, restaurants, factories, and faith-based organizations (e.g. mosques, temples, churches). Participants felt it important to integrate into existing social networks to provide information and education and to provide in-language materials and information.

### *Screening Guidelines and Breast Health Knowledge*

Almost all interviewees discussed confusion around screening guidelines for the community. Participants shared how community members are confused about when to start screening to establish their baseline mammograms, how often to re-screen and how long to continue screenings. Adding to the confusion of the screening guidelines provided in the community health plans, particularly HMOs, also note that mammography screening is optional after age 74 and this adds to the confusion regarding screening recommendation for the aging.

Ultimately, women are unaware of their own individual risk, and standard guidelines do not help with clarifying the best practice for early detection, as shared by some interviewees. The informant also shared, the confusion around guidelines gets used as an excuse for not practicing any screening in some communities, such as the Vietnamese.

A few interviewees also shared that the move from promoting monthly breast self-examinations was very confusing to community members and while breast awareness is still promoted, the lack of a method or technique to understand one's own breast has added to the confusion in the community.

### *Breast Health Attitudes & Beliefs*

In discussing the overall community's knowledge of breast health and breast cancer; about 50 percent of participants felt that there was high knowledge in the community and the other 50 percent felt there was low knowledge in the community.

Those who believed the knowledge level was high noted that this was the case because these women are insured and compliant or have had access to education and resources. However, while many may be highly knowledgeable that is not reflected in their behavior. In some cases, the knowledge supports the confusion of screening guidelines, people have some knowledge about when to begin screening but express they have other life priorities.

Other informants shared that in general, the community had medium to low overall knowledge about breast health. Most may know what a mammogram is and should do it but not details of risks, symptoms, etc. An informant also shared that a lack of knowledge is not just present among community members but also among providers. Many informants believed some physicians are not keeping up to date on screening guidelines and information on risk assessment, and as a result, patients lose trust when they interact with these providers in the community.

In addition to general breast health knowledge, the Affiliate asked about insights into the notion of breast cancer in diverse communities. Informants shared that fear and silence about breast cancer in the community continues to be an ongoing struggle. "Cancer is bad" – it's a death sentence and still very scary. Some communities still do not speak publicly about experiences with cancer due to cultural or individual beliefs. For instance, in some communities there is a stigma associated with cancer, in general, and one does not share it in public because it can bring negative feelings and connotations for the family. Cancer is also related to karma and there is taboo around discussing women's body parts. In some communities a cancer diagnosis is not shared to protect the viability of marriage for the children of those living with cancer. Conversely, these same communities also shared that more and more there is awareness and compassion about cancer; that when a diagnosis is shared there is an outpouring of community support. There are also community wide efforts, such as in the Native Hawaiian community, to acknowledge and share the cancer experience by utilizing community leaders, such as *kuma hula* (revered hula instructors), to respectfully discuss breast cancer with dignity and pride.

Some pervasive attitudes in the community are that *"it has to hurt to be breast cancer,"* cancer is costly and so *"what do I do if something is found,"* and *"...I'm not sexually active so it can't be breast cancer."* *"It's a white person's disease and I am not at risk if I do not take contraceptive pills or hormones (HRT)."*

Breast health and breast cancer beliefs vary across communities. Misconceptions still persist about not being diagnosed since there is no family history, either you get breast cancer because you do or do not breast feed, injuries to the breast cause breast cancer, *"you will get breast cancer from the radiation in the mammogram screenings,"* *"mammograms flatten your breast;"* *"I'm too old to have it;"* *"breast size affects your cancer risk;"* *"being around people with breast cancer will increase your chance of getting breast cancer;"* and *"it happens to other women, not Asians."*

In regard to diagnosis and treatment, there also exists varying beliefs. This includes the *"US health care system makes money from unnecessary treatment,"* *"radiation treatment is close to the heart and will cause other illness or disease,"* *"once the breast is removed everything is okay,"* and *"chemotherapy will kill you not the cancer itself."* As a result, these beliefs influence

behaviors for screening and treatment in diverse communities. In addition, the US model of offering treatment options and discussing options is not culturally appropriate for all communities. A few respondents shared that health decision making in the US is very individual and this does not take into consideration the collective family process of many diverse communities; while this is changing, it is still acknowledged as a challenge in working with diverse communities.

There are also misunderstandings in the community that treatment is the same for every woman, and people do not recognize that there are various factors such as age, stage and location of the mass that influence the recommended treatment options. As a result, community members are not informed or prepared for follow up treatment and care. Many are left confused about what to expect next in their treatment. A few respondents specifically addressed the need for more information and discussion about the implications of treatments and procedures to provide patients with more information and support; too often patients believe one procedure will cure them. There are serious concerns for those diagnosed with cancer; many reiterated the need to provide more information to patients about treatment options and plans, and what to expect throughout the entire process. For instance, some patients believed they could immediately return to work as usual after surgery and did not realize they had limited physical capacity/movement.

While these beliefs do not reflect the overall majority, they persist in the community and continue to be shared and passed on. As a result, respondents shared the importance of continued education and discussion of myths and misconceptions at each phase of the continuum of care.

All respondents shared that there were not any particular trends for risk reduction procedures in the community; to their knowledge there was little to no discussion around this except for the recent news about Angelina Jolie.

### *Future Opportunities*

Key informants shared a great wealth of information for future opportunities for Komen to work with and engage diverse communities in OC. Overall, there was a desire for more outreach and education, especially in-language; support for male breast cancer survivors (though low in number, more must be done); more survivor resources for different communities, in-language support groups; an assessment of opportunities for financial support or changing eligibility requirements so that more individuals have access to breast health care; and engaging leaders of these diverse communities with Komen to discuss community need. Respondents felt it was important to know and understand the diversity of ethnic groups, as well as within ethnic groups to recognize the rich diversity, which influences knowledge and behavior. The following are some notes for the specific communities interviewed in this assessment:

#### For Chinese community

- The community is everywhere in OC in mosques and temples
- It's important to serve in a sensitive way
- Chinese support group needs – especially in language
- Support groups for male BC survivors
- Provider network for breast surgeons

#### For Taiwanese community

- Language and print have to be considered
- Mammograms are a starting point for other medical needs

#### For Filipina community

Need to outreach to them because there are currently no efforts happening in Orange County  
Work through churches, ballroom dancing, finance people, and nurses association

#### For Japanese community

Need to outreach to them because there are currently no efforts happening in Orange County  
Outreach via newspaper, social media, the Japanese language schools, restaurants, and Japanese companies like Toshiba and Maruchan

#### For Korean community

Broaden the income eligibility criteria so the interviewee's organization can serve more women  
Reach out to women under age 40  
By working with Korean churches, it will help build trust in the community  
Have more outreach and awareness of services and programs provided by Komen

#### For Pacific Islander community

Komen should consider a strategy for males and their long-term survivorship

- In OC, there are 4-6 male breast survivors
- A small tea or gathering on how to address their needs

Work through the gatekeepers  
Have salient images, colors, and faces—visible cues that are relevant to diverse groups of PI communities  
Large print for elders

#### For South Asian community

Outreach to South Asian community regardless of the type of community organization  
Targeted community outreach and messaging – understand the diversity of community in terms of native geographic regions and religious beliefs  
Utilize assets in the community to link educational campaigns – e.g. pink sari and pink candleholders; give free incentives to engage and educate  
Bring South Asian women on the Advisory Board  
Get Bollywood stars engaged to conduct outreach and raise awareness  
Work with the Los Angeles and Bay Area Affiliates of Komen to outreach to and engage the South Asian community

#### For Vietnamese community

More education and targeting of younger women

- Educating young women about their risks will spread across generations

Radio and television shows are the way to reach the community  
For those with low health coverage and public supported programs, fragmented health care system requires taking a lot of time off from work  
Need help for patients who have insurance, but with high deductibles

They encouraged conducting more outreach to various diverse community groups and looking at the unusual suspects who could provide innovative ideas for outreach and linkages such as working with Chinese language schools to reach age appropriate women for screening education. They also wanted to recognize that some organizations are pan-ethnic and work with multiple subgroups and the importance of recognizing this diversity and the associated

financial support to be successful in changing knowledge and behavior to improve screening access and utilization in the community. Many communities felt there was an overall need to expand funding to address the needs of the diverse communities in OC.

A few informants also made recommendations for consideration in changing the review process for grant applications and looking at possibly developing capacity building opportunities to support smaller, yet diverse communities, with high diagnoses rates and/or death. A few respondents recognized that not all communities are ready to receive grants and provide appropriate reporting and such, but that there could be resources invested to help build capacity to serve these communities not currently served by any existing grantees. A few comments were shared that *“the same groups are always getting the funding,”* reflecting an opportunity to review the selection criteria and process and to consider different priorities or innovative practices to best serve OC’s diverse communities. One respondent noted that *“there are lots of needs from various communities; however it does not feel that the API community is a priority population and their needs are not being considered.”* A few respondents specifically noted that there is not enough focus on the Asian and Pacific Islander communities and few grants are awarded to serve these communities. There are limitations in being able to meet the entire needs of the API communities with the number of grantees awarded.

Informants also recognized that the current process and trainings are good and clear and Komen is doing a nice job, however they want to remind Komen of the depth of diverse communities in OC that need to be served and the importance of disaggregating data; even disaggregating Asians and Pacific Islanders.

In building stronger and deeper relationships in the various communities, respondents suggested that Komen works to build stronger partnerships with key community leaders and community-based organizations.

When asked if there was anything else they wanted to share, informants noted that continued educational resources and material in print were important- especially for diverse communities. There is a continued and ongoing need for increased breast health awareness. Sharing stories and testimonials is important and powerful as well. Komen can help to continue to share information, data and research with the community.

A few respondents also were very pleased to see that the needs assessment was examining more than just API as an aggregate group. They are *“pleased to see Komen going beyond looking only at the needs of the largest population in Orange but to also look at the needs of Japanese, Filipina and South Asian women.”* *“Taiwanese women are also being overlooked,”* as are *“Pacific Islanders, who need to be disaggregated from APIs.”* Respondents acknowledged the importance of recognizing these diverse communities and wanted to convey that this awareness and knowledge collection about these communities should also be shared with Komen Headquarters so as to better understand the *“over 28 Pacific Islander groups and over 60 Asian groups that are our community.”* In addition to rich opportunities for outreach and engagement of diverse communities, some respondents also mentioned the importance of expanding research to diverse communities and ensuring representative samples in studies around lifestyle and behavioral risk factors.

Lastly, a few respondents requested technical support from Komen in helping their organizations to establish good tracking tools (for Komen grants reporting as well as for their organizations) and resources, such as a directory for breast surgeons in the OC area.

### ***Women 65 Years and Older***

Five interviews were conducted around the needs of women 65 years and older in OC. Individuals worked with community based organizations or were clinical providers in the community. All five interviewees were women with ages ranging from 40-69, one identified as Latina and four identified as non-Hispanic White. The following represents their organizational roles: two physicians, one executive director, one health care/hospital/clinical staff, and one clinical nurse navigator.

While this was one of the four target communities, identifying key informants in the community that served this community and had knowledge and expertise around breast health and breast cancer issues was challenging. The Affiliate identified multiple organizations that serve individuals 65 years and older and a handful of them declined participation because they did not feel that they served a representative sample of women 65 years and older, and could not speak about breast health or breast cancer needs.

While the Affiliate faced this challenge, the Affiliate was also able to conduct five rich interviews that revealed the following information in the community. Please note that because of the small sample size this information may not be generalizable for all women 65 years and older throughout OC. However, among this small group there was much similarity about the strengths, challenges and needs of women 65 years and older in OC.

#### ***The most substantial breast health needs for women 65 years and older***

Interviewees shared that education continues to be one of the most substantial health needs for women 65 years and older. Specifically, information around individual risk and aging is vital. Participants shared that there are mixed messages in the community regarding the value and importance of mammograms as people age. There is a need to continuously promote and provide health education and to help clarify any confusion that may be present in the community regarding screening guidelines. Guidance on providing information for individualized plans pending age and health status was discussed repeatedly. In addition to breast health education, participants shared that there was a need to provide information on how to navigate through health care reform (including accessing coverage and utilization of coverage, once assigned to a plan), as well as ensuring education to providers with the most updated research and information.

In addition to education being a substantial breast health need in the community for women 65 years and older, transportation support; financial support; social support; resources for basic needs such as food and housing; and addressing language and cultural beliefs were other important areas shared by informants. In particular to financial support, participants noted that older adults live on a fixed income and if they are diagnosed with cancer; the financial burden of cancer can be traumatic. They shared that Medicare does not cover all medical costs (such as gauze after surgery) and the need to cover medical costs out of pocket creates a burden on other daily needs such as finances for food, housing and transportation.

#### ***Challenges or barriers to breast health***

In discussing challenges or barriers to breast health, interviewees shared that for some women 65 years and older there are no health barriers because they are covered by Medicare and are compliant patients, following through on screenings if referred by their provider. However, other interviewees shared that even with Medicare coverage, there can be barriers to breast health, such as transportation (to and from appointments, especially in the use of public transportation), language, health coverage (some have limited coverage and Medicare does not cover all costs), a lack of family and/or social support, immigrant status, and a belief that mammograms are

painful. Additionally, fear of going through a lengthy list of procedures, anxiety about not knowing their results and projecting concerns for additional health or financial needs, delay in communication and coordination of care, and a cultural fear of going to the doctor were other barriers mentioned. As a result, even though the interviewees feel that breast health care is accessible for this community, some may not be utilizing these services and will not access care until they are symptomatic. In addition among this target community, the greater challenge appears to be the belief that “*they are too old to get cancer*” and if they have lived this long without cancer “*chances are they are not going to get it.*”

### *Utilization*

Overall interviewees felt that breast health utilization was high in the community, especially among those with Medicare. Informants shared that the insured population that has received education on breast health is proactive about accessing and utilizing screenings, in fact; often request that the providers refer them for their annual screenings. Again, this was the perception for those with coverage and access to health care.

### *Gaps in Breast Services*

Informants were asked to share what they felt were key gaps in breast health services in OC, and most shared that education was lacking, especially around screening guidelines and knowing what is normal, and transportation assistance. Additional gaps in services were social support for those diagnosed with breast cancer, support for those with financial needs, and a lack of health care options. In particular, there was mention of a need for low cost alternatives for screening, to ensure even those uninsured can access screening.

In addition to the aforementioned, informants shared that those who are dealing with other primary cancers (not breast) did not have guidance or information about recommendations for their breast screening during or after their cancer treatment. They shared that their clients were never provided information around screening guidelines while going through cancer treatment for other primary cancers. In addition to the lack of recommendations and guidance from providers, interviewees also shared that while in some instances providers offered recommendations for screening to clients, there is truly never any follow up to ensure that these practices are engaged and maintained over time; this was noted as an important gap in the continuum of health care.

### *Behavior*

Interviewees were asked to discuss how they felt people were influenced regarding breast health behaviors. Most felt that health care providers and the media played prominent roles in influencing health and screening behaviors. Providers and medical experts were the main sources for those who were insured and had health coverage. In terms of media sources, interviewees shared that the news, newspapers and the Internet had roles in influencing behavior. In particular, Dr. Oz was noted as a source of information. In addition to these key resources, peers, especially breast cancer survivors and spiritual leaders were also individuals with influence on impacting individual behavior.

### *Social Media*

The Affiliate was interested in understanding the role of social media among women 65 years and older. Most interviewees noted that their patients/clients (who were 65 years and older) tended not to use social media and rarely accessed the Internet. Most still read print media and saw newspapers as a reliable source for information. Some shared that their patients do utilize social media but predominantly for social purposes, such as Facebook and keeping in touch with family, but did not utilize social media or the Internet as a health resource. Where

individuals did utilize the Internet, they would access medical websites and ask for support in using this form of information from their friends and children. Other sources of information for this community include, but are not limited to their community groups, health fairs, bridge club, bowling leagues, AARP, Westways and other magazines (trade magazines, for example O), and church groups.

### *Educational Messaging*

Through the interview process the Affiliate spoke to participants about educational messaging and messengers. Half shared the need to continue to provide education on risk factors, especially among older women and to promote annual screenings. One informant discussed the importance to consider addressing and breaking down myths around breast health. Participants felt that peers, friends and providers were great messengers to share breast health information; they also suggested intergenerational dialogue among women and the use of local resources such as the TV channel at Laguna Woods to specifically reach this population. Television news spots (public service announcements) in various languages were particularly supported by the interviewees. When asked where best to provide educational messages, all participants mentioned utilizing faith based organizations (churches, synagogues and temples), health centers, social gathering sites/clubhouses, and to go *“where the people already are”*, such as the senior centers, locales providing senior services, the mall, shops, ethnic markets, rosaries and the post office. Lastly, one interviewee shared that maximizing the physician waiting room for education should be considered.

### *Screening Guidelines and Breast Health Knowledge*

Since education was shared as a substantial need in the community, informants also discussed whether or not there was confusion in the community around screening guidelines and the knowledge level for breast health in the community. All noted that there was some confusion in the community around breast health and the confusion varied around the effectiveness of mammograms, as well as how often one should be screened. A few respondents shared that people thought mammograms were controversial in general and may not get screened for that reason. Other reasons for confusion or non-screening behavior includes people are not sure when to start screening, to establish their baselines, and how often to continue screening, especially with aging. While Susan G. Komen recommends avoiding using the term, *“preventive screening,”* most of the confusion remains around messaging that emphasizes prevention, as opposed to breast cancer screening for early detection. Regardless, there is not enough clarity in the screening guidelines, which is causing many to feel upset and/or misinformed when they are diagnosed with cancer. *“As soon as they hear that someone is screened all the time and still get breast cancer many respond in disbelief that it happened to them.”*

In regard to breast health knowledge in the community four of five interviewees felt that the knowledge level was high and patients are aware of signs and symptoms, particularly noting changes to their breast, that women are educated and empowered to ask for their screenings and know where and how to get a mammogram. However, even though knowledge is high one interviewee noted, *“they are aware but something gets in the way of acting on that awareness.”*

### *Breast Health Attitudes & Beliefs*

In particular to women 65 and older, four of five of the participants shared that individuals they interacted with or treated, did not feel that they had individual risk and since they had not yet been diagnosed with breast cancer, they did not have continued risk. *“It’s not going to happen to me.”* Respondents also noted that the patients/clients they see believe that breast cancer is treatable, *“gone is the notion that breast cancer is a death sentence.”* In particular, *“this*

*generation seems to embrace cancer more and understand that there are good treatment options, there is power in knowing there are options.”*

The overall consensus was with aging, people felt they had less risk, *“it’s not going to happen to me, if I’ve come this far in age.”* A few of the respondents shared that their patients accept the provider recommendation unequivocally, and continue with screening. In fact most women in this age group, especially those who are White, *“know what they are supposed to do; entitled to screening; and many want to keep screening (e.g. 80+); however not everyone is this way.”* Most informants noted that those with coverage in this age group tend to be aware of screenings and healthy lifestyle behaviors; though pending their health and age may or may not engage in screenings.

Of particular interest, among this age group all respondents shared that patients will consider comfort and quality of life in treatment decisions, one participant noting *“most women as they age will choose a mastectomy; it’s a phase in their life when they are less likely to do reconstruction. They just want to take it out and not think about it.”*

Informants shared that most patients and individuals that they interacted with focused on other health concerns, such as stroke prevention and healthy lifestyles addressing diet and alcohol use rather than focusing on breast health. This reiterates the notion that if they have aged and not experienced breast cancer it was not likely to happen to them.

There is a tendency to assume older adults have Medicare and family support, however even those with these resources may be in need of additional support when they are diagnosed with breast cancer. The informants also shared that not all individuals have good relationships with their family and friends or will not ask for help from them once diagnosed with breast cancer. In addition to this, respondents shared anecdotes from cancer patients who were overwhelmed by the language and academic nature of their health records and did not fully understand what was happening to them, and that providers were not taking the time to help the patient understand what was happening to and with them. A patient shared how the provider gave test results but the medical terminology was foreign to the patient and did not understand what any of the information meant. In particular, one respondent shared that there are guidelines that patients must be informed, however no one takes the time to make sure the patient truly understands the information, and *“...so notification is completed but to what end?”* This highlighted the continued opportunity for open and clear patient and provider communication.

### *Future Opportunities*

Informants were asked to share recommendations on strategies and opportunities for Komen to strengthen relationships and partnerships in this community.

In regards to strategies, there were suggestions to conduct more outreach, especially to continue screening at 65 years and older; provide promotional education and incentives for screening at 65 and older like those the Affiliate provides to engage those 40 years and older. Increase Komen visibility in the community, especially among the older adult population. Increase the availability of information and education for screening, especially for those 75 years and older, and help better communicate the services provided by grantees. Lastly, it was recommended that Komen have greater visibility, it appeared that breast health was not as prominent and mainstream as other issues such as Alzheimer’s and the ALS ice bucket challenge – seek an opportunity to have a strong and visible spokesperson in mainstream media.

Specific recommendations for the grantee process was to reach out to more groups serving women 65 years and older and to look at opportunities to partner with them to better serve this community – potential resources are the Council on Aging, Senior Centers, Assisted Living Centers, Alzheimer’s Association, Office of Aging, faith based groups, OCHCA, primary care providers, Leisure World, and local hospitals (gerontology departments). There was also interest in tracking outcomes over time and rendering the return on investment of Komen’s dollars into grantees; “...especially focused on did patients maintain behaviors; what are the impacts of the seeds we have planted, not just looking at volume of services.”

There was a suggestion to have more in-language materials available in the community and at the Komen offices so that all people, regardless of their backgrounds, felt welcome. Suggestions were for Komen to continue to provide education and information and help communities understand their risk (e.g. diversity in age and race/ethnicity), keep messaging about women’s health relevant and present in the news, (“*women’s health should be kept front and center*”), and to keep efforts such as the Komen Tissue Bank present and engage community in research studies and loop back to share findings and progress.

### **Focus Groups**

Focus groups were a third method of data collection used for the African-American/Black and Hispanic/Latina communities. A total of five focus groups were conducted; two focus group sessions were conducted in English for the African-American/Black community, and three focus group sessions were conducted: two in Spanish and one in English for the Hispanic/Latina community. There was a note taker in all focus groups sessions. The Spanish language focus group sessions were audio recorded and then transcribed from Spanish to English. On average focus groups were approximately two hours and seven minutes with the shortest focus group being two hours long; and the longest focus group being two hours and 25 minutes. Verbal consent was requested from all participants. A demographic survey was also collected for all participants; these surveys are stored in locked cabinets at the Komen OC office.

### ***African-American/Black Community***

Two focus groups were held with the African-American/Black community with 16 participants. All participants were female. Participants included general community members and one breast cancer survivor. Of the 16 participants, three participants reported being in the 30-39 age group and 13 reported being in the 40-49 age group. All identified as African-American/Black and all but one had health insurance coverage. Of the participants, six reported being affiliated with a community-based organization while the remaining 10 had no organizational affiliation. Each group session had a facilitator and a note taker. The average session lasted 2:17 minutes. All focus groups were conducted in English with a note taker and were audio recorded. The same guide was used as the Key Informant Interviews to solicit discussion around breast health and breast cancer in OC.

### ***Accessibility of breast health care for the African-American/Black Community***

The focus group discussions opened up with a discussion around the accessibility of breast health services for African-American/Black women in OC. Participants shared that resources were available, especially among those with health insurance; however many are not accessing care. For some women who are insured, they are not accessing care because they believe they have no familial history and are not at personal risk. For some, insurance coverage is restrictive, limiting access to care especially for high-risk women under 40 years of age; for others, they don’t practice preventive health and only go to see a provider when they are symptomatic; while some women don’t have health coverage at all. For those who lack private or public insurance, they are unaware of resources available to them and do not know where to

go. Several participants who were aware of the importance of screening shared that they don't go because mammograms are painful; they fear knowing what's wrong; believe that with age and decreases in estrogen levels, screenings are not necessary; and they have heard providers tell them that if they are under 40 they do not need to practice any type of screening.

### *Challenges or barriers to breast health*

In discussing barriers to breast health care, participants named: a lack of health coverage or insurance (again alluding to no coverage for women under 40); different types of insurance and the coverage restrictions that affect having access to quality care; not knowing when screenings are needed; misinformation (such as believing mammograms are no longer needed after a hysterectomy); limited financial resources; beliefs that mammograms are painful beliefs that there are less associated risks as women age; fear of an abnormal result, and distrust of medical providers. Some participants specifically noted a lack of internal motivation and self-neglect as reasons for why women do not access screenings – in particular they noted that women prioritize family responsibilities and take care of everyone else's needs first. Like other groups, many African-American/Black women are caring for their aging parents and their children. A few participants also noted that specifically in OC the African-American/Black community is scattered and there is a lack of a safety net and social support network for this community, especially for Black/African-American senior citizens.

### *Gaps in Breast Services*

In addition to challenges or barriers to breast health, participants also spoke about gaps in breast health services. There is a lack of education and knowledge about breast health and community specific risks among women and providers. Participants shared that some women also lacked knowledge of familial risk, as breast cancer is not generally discussed among family members. One participant shared she was adopted and has no familial history for reference, so she is diligent about obtaining her test results and with asking her provider questions.

Participants also shared that women in the community are not accessing services because they do not know where to go for screenings, there are limited resources for African-American/Black women under age 40 there is a lack of trust in medical providers, there is an overall lack of Black/African-American providers in OC who women can identify with, and there is a belief that *"what I don't know won't hurt me."*

### *Utilization*

The majority of focus group participants felt that utilization of breast health services in the community was low. Two individuals mentioned high utilization – one of which was a cancer survivor; both of these individuals did mention that high utilization tended to be among those with a regular provider.

Among the low utilization group, participants shared: that misinformation was high; there is a strong belief that mammograms are painful; there is a lack of knowledge about risk in the African-American/Black community; women are not aware of the available resources and don't know where to go for breast health services, especially women who are not connected to a community social network such as a church; some women don't want to go due to lack of internal motivation; and older African-American/Black women feel that they do not need to continue screening after a certain age.

### *Behavior*

When asked who are influencers on breast health behaviors, participants stated physicians and health care providers, including African-American/Black ; personal health care experiences (positive and negative); family, friends, peers, survivors, spouses and partners; and influential

people who are on television. One participant also noted specifically that many people place faith in God and may or may not practice screening behaviors as a result of their belief, leaving their destiny in God's hands.

### *Social Media*

Participants shared that many people use social media, especially because it is free; in particular people use Facebook, texting and push notifications and applications on smart phones. However, they also noted that generally older African-American/Black women do not use social media in any form, including accessing health information.

### *Educational Messaging*

Participants felt that education and raising awareness around breast health information was important. They suggested informational pamphlets and resource guides, texting screening reminders for mammograms on people's birthdays, making announcements in church, sharing survivor testimonies, and having women educate themselves so they can provide information via word of mouth. Participants also suggested the use of social media, public television service announcements focusing not only on younger women but also their family members, and having culturally appropriate messages to personally appeal to the viewer. They recommended targeting the younger generation but also tailoring messages for women in different age groups. Participants shared the importance of promoting dialogue and discussion about breast health and breast cancer so that it becomes less and less of a taboo in the community. They also proposed targeting men to engage with their partners and spouses and to support them when there is a diagnosis.

Participants laid great emphasis on the need to provide statistics and information specific to the African-American/Black community and sharing how more African-American/Black women are dying from breast cancer compared to any other racial group. One participant also suggested the promotion of modifiable behaviors such as diet; and promoting healthy alternatives as opposed to telling people "*they are eating wrong.*" Another participant also suggested letting community members know that treatment costs far more than screening and making this an impetus for action. In regard to faith, most participants mentioned that messages should acknowledge faith and church and still remind people that they need to get screened. Among some older African-American/Black women, there is an acceptance that "the doctor is always right," so several participants spoke about the importance of empowerment—equipping themselves with knowledge and being informed about their own health. Participants suggested that African-American/Black women be their own advocate and ask their provider questions, but at the same time, women should not rely solely on their provider for information; they should seek out reliable educational resources on their own. Lastly, participants suggested that when African-American/Black women educate themselves, they can share the information with other women in the community.

Potential messengers for delivering these messages in the community are peers, family and friends, spouses and partners, survivors, leaders and members of health ministries, celebrities (both male and female), athletes, and spiritual leaders.

Participants suggested potential locations for outreach and education are churches, health fairs, social organizations, markets, unemployment offices, emergency rooms, hairdressers and barbershops, and gyms.

### ***Screening Guidelines and Breast Health Knowledge***

Participants felt that the knowledge level in the community is inconsistent and varied. Community members may be getting information from outdated or unreliable resources and contributing to the confusion about screening guidelines and risks. Participants shared that many believe with age there is less risk and at a certain age mammograms are no longer needed, that if one has a hysterectomy they no longer need a mammogram, and that screenings are not necessary. There is some confusion about risks associated with breast density. They concurred that generally speaking messaging around breast health was confusing.

### ***Breast Health Attitudes & Beliefs***

Participants shared that persistent beliefs in the community are that *“mammograms are painful,” “screenings are not necessary,” “I have health insurance but I just don’t want to go,”* or breast health or breast cancer is not discussed at all. Early detection and risk reduction does come up if there is a known family risk or if a co-worker mentions that they are getting their screenings.

Other persistent community beliefs are that underwire bras cause breast cancer, husbands will leave if their wives are diagnosed with breast cancer, and African-American/Black women do not think that they are high risk or experiencing late-stage diagnoses with high death rates. Some believe there are advancements in cancer treatment so, *“if I get it, there will be treatment and I’ll be ok.”*

### ***Future Opportunities***

Participants had many ideas around strategies or programs that Komen could engage in to better reach and serve the African-American/Black community. They suggested the use of social media utilizing celebrities as messengers; partnering with African-American/Black churches; working with local pastors; working with social networks such as Delta Sigma Theta Sorority, Inc. OC Chapter, the National Coalition of 100 Black Women, Inc. OC Chapter, the OC Heritage Council, and the National Pan-Hellenic Council, Inc.; reaching out to younger African-American/Black women’s groups and sponsoring local social events and chapters; setting up free mammogram screening events; and providing simple information check lists.

One participant shared that she thought Komen was only a research organization, prompting an opportunity to help the community better understand the services and programs offered by Komen.

Participants saw education and outreach opportunities not only with community members (resource lists for where to get care, provider lists), but also having educational seminars that continuing education credits on how to be more culturally sensitive when working with the African-American/Black community was suggested. Participants also suggested working with local high schools and college-aged youth to provide information particularly to nursing students and allied health professionals.

Lastly, participants suggested Komen provide more outreach about grant funding opportunities and to help individuals and organizations understand the grant application process.

### ***Hispanic/Latina Community***

Three focus groups were held with the Hispanic/Latina community with 33 participants. All participants were female. Participants included general community members and breast cancer survivors. All participants identified as Hispanic/Latina; three reported being 30-39 and 29 reported being 40 and older; 18 reported having health insurance; 12 were breast cancer

survivors with six currently in treatment; and 24 preferred primarily speaking in Spanish. Participants were predominantly community members without organizational affiliations; three were associated with community based organizations; one with a university and four with a county or government agency. Each session had a facilitator and a note taker. The average session lasted two hours. Two focus groups were conducted in Spanish, one with cancer survivors; notes were taken in Spanish and then translated into English. The other group was conducted in English with a note taker. All groups were audio recorded. The same guide was used as the Key Informant Interview Guide to formulate a focus group discussion guide with six key areas – attitudes regarding health, experiences with accessing health care, understanding breast cancer awareness and attitudes, the most appropriate media vehicles for education, motivations for health behavior change and how participants perceived Susan G. Komen.

### *Attitudes on health*

Focus group participants shared with us their thoughts and insights on breast health in OC. Attitudes regarding health were to eat healthy/well and to exercise. Just under half of the participants noted that eating well was important to staying healthy and well and was useful in protecting good health. In terms of exercise, the participants mentioned walking, hiking, running and dance (including traditional Mexican dance) as modes to stay healthy. Participants also shared the importance of sleeping well, maintaining emotional wellness, not smoking, having a social support network and having fun as ways to stay healthy.

### *Access to health and health information*

In general, participants received information on health issues by reading journals, articles, magazines and online resources. They also gathered information by watching television and listening to the radio. A handful shared that they were proactive by having annual exams and mammograms.

In discussing experiences with accessing health care the cost of care and time were the two most mentioned issues. In terms of cost, participants shared that not having resources to pay for visits, tests and medications were barriers to health care; one participant noting that health care is expensive. Even those with coverage noted that health plans are expensive and often individuals had high deductibles. One participant shared that she had delayed visits because of the cost of insurance. Long wait times was the second most mentioned challenge to accessing health care with participants sharing that they had to wait as much as six to eight weeks for an appointment and sites which provided free to low cost access were full. One participant also shared that it was a challenge to take time off work for health appointments. A lack of coverage also served as a barrier in accessing care for participants, in addition to a lack of information, such as where to go for care, and distance to clinics. About half of the respondents had cancer or a health condition that caused them to be more aware of their own health and the need and importance of staying healthy; a few individuals also alluded to family members having had cancer or a chronic disease and using this knowledge to stay healthy and well.

For those with health coverage, most were satisfied or very satisfied with their care and did not have many barriers. They cited reminders from doctor's offices as being helpful in having a positive health care experience. Another participant shared that even though she had insurance coverage, alternative care (such as acupuncture) was limited and that was a barrier to care.

The mixed experiences shared by participants led to recommendations by participants as to what to do to ensure better care. Participants suggested changing providers, if you are currently not satisfied with your provider, becoming your own advocate – seeking out resources, self-education to be more informed, demanding test results and answers and asking questions

in the medical visits. They strongly advocated not relying on others to provide information and resources but seeking out resources until answers were found.

#### *Experiences with accessing health care*

In regard to knowledge about screening, 60 percent of participants noted that they were aware of a need for annual screening starting at age 40. While most knew to start screening at 40, one participant honestly shared she didn't know why she was supposed to start screening at age 40. Others shared that even though they knew to have annual screenings they screen every other year because of pain, discomfort, and soreness associated with mammograms. Lastly, while the majority of participants mentioned a need for an annual screening or check up, they noted that if one has a family history or is symptomatic they should be screened more frequently.

A majority of participants also shared that they did not have challenges with accessing or utilizing health care; these individuals tended to have health insurance. However, others shared some challenges with accessing health care such as cost, the level of quality of care with different types of insurance plans, and a lack of time to go to visits and follow up – no time, multiple appointments. One participant noted the importance of advocating for oneself and ensuring you get what you need. And another shared that complementary or alternative care is not covered by many insurance plans

#### *Experiences with accessing health care among cancer survivor participants*

In sharing their health care experiences, cancer survivors felt that their doctors did not take the time to explain things to them and give them treatment options. In fact, most reported that they felt the doctor decided what was best for them and persuaded them into the choices they suggested. Overall, they felt poorly treated by the breast surgeon; however they reported feeling supported by their local community clinic. All participants also reported having difficulty with health coverage through their breast cancer experience; in particular one woman struggled with coverage because of her legal status and was not authorized with continued treatment for her second diagnosis.

In addition to sharing their poor health care experiences, the participants also shared challenges after diagnoses. Two reported having a lack of information, not having insurance coverage, and not *“understanding what was being done to me.”* This reinforced the earlier comment that the survivors felt the doctors made the choices about treatment for them. One participant also poignantly shared that one of the greatest challenges after diagnoses was that *“people don't know how to act around you when they know that you have cancer.”* This addressed not only one's individual response to the diagnoses but how to grapple with the feelings and emotions of others around them. Given these challenges, the participants recommended that other women in the community be informed about breast health, have annual mammogram screenings, and recognize that *“life goes on.”*

Among cancer patients, other perspectives, especially in regard to the diagnosis were shared.

#### *Diagnosis experience*

Cancer survivor participants shared that when they were diagnosed they cried and were in shock, somewhat paralyzed by the news. One woman shared that she *“questioned, why me; I'm the first one in my family so I didn't understand why me.”* In spite of feeling lost and shocked they reported feeling strength and support from their children, co-workers and nurses they interacted with. However, they also reported that after diagnosis they were not able to find information, especially for a Spanish language support group. One participant shared however,

that she found comfort in volunteering for the American Cancer Society and speaking with other newly diagnosed women.

#### *Understanding breast cancer awareness and attitudes*

When asked what first comes to mind when breast cancer is mentioned about half of the participants responded with fear; about ¼ stated that they thought of death and others mentioned terror and anguish. One individual shared that they felt “...it would never happen to me,” and another “...it’s a club I don’t really want to join.” The most commonly mentioned sign or symptom was cysts, lumps, and pain in the breast. Less frequently mentioned symptoms were a change of color in the breast, breast secretions, fatigue and weakness. A majority of respondents also shared that anyone can get breast cancer, men or women, and it does not discriminate, “.....anybody regardless of income, education or ethnic group, it can be anyone.”

#### *The most appropriate media vehicles for education*

In discussing media vehicles for education, participants shared television, Internet, newspaper, radio and print materials such as brochures as good mediums. Participants also suggested providing education at clinics, health fairs, bus stops, on buses, and in department stores. Lastly, participants shared that celebrity voices about breast health would heed attention – suggested celebrities for messaging included Amari Lopez, Daniela Romo, Lorena Rojas, Luis Fonsi’s wife (an actress), Soraya and local sheriff Sandra Hutchens.

#### *Motivations for health behavior change*

Participants were asked to share what motivations contributed to them engaging in healthy behavior change. Participants shared that they wanted peace of mind, hence early detection; and practiced healthy behaviors because of their children, love of oneself and to live longer. Others shared that individuals have to internalize the importance and take action and that it’s very hard to ask others to change behaviors. Two respondents suggested utilizing social media to motivate younger individuals to take action for healthier lifestyles.

#### *How participants perceived Susan G. Komen*

In regard to perceptions about Susan G. Komen, all participants noted that the pink ribbon means women’s cancer and is a reminder for everyone to get checked. Susan G. Komen is a familiar organization that has a foundation in research and has funds and walks for awareness and testing. All women expressed a need for group support during their illness and shared that information should be provided to community members via the Internet, brochures and in clinics and via organizations such as Avon, Mary Kay and Macy’s. Most importantly that the message is not out there and not reaching everyone and more must be done!

Cancer survivors also shared similar perceptions about Susan G. Komen; particularly noting that the pink ribbon symbolizes breast cancer. Of the participants each had volunteered and become involved with Komen or the American Cancer Society and believed this involvement and engagement was helpful to their breast cancer experience. Lastly, two of the cancer survivors shared that two organizations that provide financial support through the breast cancer experience were very helpful; they mentioned Breast Cancer Angels and Breast Cancer Solutions. This reiterates comments made in key informant interviews about the additional financial burdens of cancer and the need for more than just medical support through the breast cancer journey.

## **Qualitative Data Findings**

Having gathered information from the community through the provider survey; key informant interviews and focus groups, the Affiliate found some common recommendations across all data sources. Most particularly that there is:

- A need for ongoing education – general breast health, screening, and treatment information; help to clarify screening guidelines; specific individualized risk must be taken into consideration specifically for older adults
  - Need for ethnic specific community data to convey risks
  - Disaggregating data to help diverse communities recognize their specific risks
- An additional burden of cancer – financial costs, need for social support
- Breast health resources are available, but not accessible to all
  - Health coverage/residual uninsured
  - Need simple resource materials – e.g. where to go for screenings, who are providers
- Importance for culturally and linguistically appropriate outreach, education and materials
  - Going to where the community already eats, works, plays and prays
  - Targeted and age appropriate messaging to diverse communities
- Need for interpreter services
- Continued need for early detection services
  - Including low to no cost options
  - Noting risks among diverse communities
  - Promoting screening guidelines
- Opportunities for working with faith based organizations, community leaders, and senior centers
- Social media is not highly used but marketing/outreach opportunities exist
- Komen does good work – keep it up, need more of it
  - However, not all communities are aware of Komen and the services and programs provided by or supported by Komen
- Things are working but need more of everything as women are continually being diagnosed or re-diagnosed/recurrence
  - More education and support for women once diagnosed about care plans, after treatment care plans and physical adjustments as a result of surgery
- There is still a disconnect between education and behavior – especially in regard to pain and fear as a barrier to screening
- There is a need to identify providers for care, specifically surgeons and specifically in South County
- All communities shared opportunities for partnership in outreach and education and bridging relationships with key leaders and organizations
  - Very specific opportunities were provided for the target communities and subgroups within these communities
  - Partnership opportunities also abound with clinical providers and hospitals
- Need for intergenerational messaging
- A continued need for Komen to promote breast health outreach, education, screening and treatment information
- Grantmaking opportunities should look at innovative strategies and additional organizations for funding

## **Limitations**

Challenges were faced in the implementation of all qualitative data collection methods. The Affiliate had a low response rate to the provider survey, even though there was a large group from which the Affiliate solicited participation and gathered support from key leadership organizations in the community. Participation may have been low due to a lack of interest or importance in completing the survey or a lack of time to complete the survey.

The Affiliate also faced challenges in recruitment for both focus groups and key informant interviews. While resources and service providers existed for most of the target populations, it was challenging to find a large number of focus group participants and key informants that wanted and could participate in the data collection process to discuss breast health and breast cancer. For focus groups the Affiliate had a great challenge in reaching out to the African-American/Black community and securing focus group participation. While the Affiliate recognizes this is a small population in OC it leveraged relationships with key leaders and organizations and still struggled to identify interested participants. Low participation may be associated with the lack of public dialogue about breast health in this community. While the Hispanic/Latina community is far larger in OC, the Affiliate also faced some challenges in focus group recruitment; this may have been associated with the time, date and locations of focus groups which may not have been convenient for participants; though the Affiliate made great efforts to accommodate suggested schedules for high recruitment.

Lastly, for key informant interviews, the Affiliate faced the greatest struggle in identifying informants that could speak about breast health and breast cancer specifically for women 65 years and older. While the Affiliate outreached to a large number of senior and older adult service programs, many declined participation because they did not feel that they had expertise and extensive knowledge around breast health or breast cancer, and that when their clients had needs they had appropriate referral resources.

The challenges noted above place limitations on the generalizability of the data to all target communities in OC. The time frame in which the Affiliate had to identify and recruit participants also limited the ability to more robustly recruit and gather survey responses; however, even with these challenges the Affiliate believes that it has gathered a representative and convenient sample of perspectives to more deeply understand the concerns, issues and needs of the four target communities. The data combined from the quantitative data analysis, health systems and policy analysis, and qualitative data collection has provided rich information on the local communities and allowed the Affiliate to dive deeper into looking at communities with high needs regarding breast health and cancer.

Most importantly, this process allowed the Affiliate to reconnect and strengthen ties with local community leaders and organizations who will continue to be pivotal partners as the Affiliate continues to make strides to reduce breast cancer in OC.

# Mission Action Plan

## **Breast Health and Breast Cancer Findings of the Target Communities**

### **Summary Findings from Quantitative Data Report**

The Quantitative Data Report reflects breast health disparities with regard to rates of late-stage diagnoses, death rates and screening behavior among specific communities in OC, California. For instance, African-American/Black women in OC are experiencing an increasing trend for breast cancer incidence and late-stage diagnosis, with a death rate that is considerably higher than White women (30.2 per 100,000 versus 22.5 per 100,000). Moreover, Asian and Pacific Islander communities demonstrate an increasing trend for invasive breast cancer incidence, specifically Chinese, Filipino, Japanese, Korean, South Asian and Vietnamese women have the highest rates of invasive breast cancer when compared to Asian and Pacific Islander as an aggregate group. Although the data are unstable for Pacific Islanders there is a history of high rates of late-stage diagnoses and death (see page 43, Quantitative Data section).

Likewise, both Asian and Pacific Islanders and Hispanic/Latina communities represent the highest numbers of women age 40 and older who have never had a screening mammogram (see page 15). In addition, the data revealed women age 65 years and older having the highest rates of breast cancer deaths across all racial/ethnic categories in the county. Upon analysis of the statistics from the Quantitative Data Report, as well as data from the California Cancer Registry and the California Health Interview Survey (CHIS) for OC, the Affiliate identified and selected four target communities of focus: Asian and Pacific Islanders, African-Americans/Blacks, Hispanics/Latinas and women 65 years and older.

### **Summary Findings from Health Systems and Public Policy Analysis**

The analysis of health systems and public policy highlight several key findings. Overall breast health screening services are available throughout the county, however based on the CHIS data; it was becoming evident that the availability and accessibility/utilization of breast cancer screening services were not congruent to one another, as the data suggest. It was determined that this was an area that needed further exploration and one of the key questions asked during the qualitative data collection process.

During the public policy analysis, the National Breast and Cervical Cancer Early Detection Program/Every Woman Counts program was identified as an area of concern. As a safety net program for many uninsured women, this program enables many medically underserved and/or uninsured women to access screening and diagnostic breast health services. Additionally, the implementation of the Affordable Care Act has theoretically made access to health care more attainable; however, more data are needed to understand the full impact of California's health insurance exchange on access to and utilization of the entire breast health continuum of care.

Unfortunately, some racial/ethnic groups are still falling short in terms of enrollment and utilization under the state's health insurance exchange, and while more individuals are becoming insured, it is expected that 210,000 individuals will remain uninsured in OC, with nearly half not eligible to coverage due to immigration status (Lucia et al, 2015). Other factors such as individuals being ineligible for financial subsidies will leave people vulnerable and they will need to depend on the availability of safety-net programs/services.

### **Summary Findings from Qualitative Data Report**

Through rich focus group discussions and key informant interviews, the qualitative data present important insight into each of the target communities regarding many gaps; challenges or barriers to breast health information and care; access to and utilization of breast health services; and attitudes, beliefs and behaviors around breast cancer and breast health services. Across

all target communities, the greatest need is for continued and ongoing breast health education (including breast health risk factors, signs and symptoms; community specific risks; available screening, diagnostic and treatment services; and age specific screening guidelines and recommendations). OC has a diverse population, not just of cultures but of generations, and nearly all of the participants emphasized the importance of tailored messages that are culturally and age appropriate. It was shared that these considerations are essential to ensure effectiveness and salient messages in these target communities. It was also shared that there is an interest and need to use intergenerational messaging across all of the target communities.

Among African-American/Black women in OC, many are not getting mammograms whether or not they have health insurance. In focus group sessions, it was shared that messengers of breast health information need to represent the African-American/Black community. In addition, the delivery of breast health messages needs to factor in the complexities of the African-American/Black family dynamics. The use of social media, African-American/Black churches, local pastors and social network organizations such as sororities or professional associations, efforts to reach groups that are mostly comprised of young African-American/Black women and the availability of free screening events were shared as effective ways to make an impact on the breast health disparities within this community in OC.

Among women 65 years and older, information about individual risk and aging is vital. Available low-cost breast health surgeons are more limited, especially in South OC where it was found to have a higher concentration of people 65 years and older. While the needs of women 65 years and older were found to be similar across all target communities, it was determined that not much is known about the standards of breast health care offered and utilized from the key informants interviewed. However, financial support was identified as a critical need because older adults live on a fixed income and not everything is covered under Medicare.

Another identified need and/or gap in service, is the need for in-language outreach and education as an important mechanism to reach different communities. A substantial gap identified is the lack of disaggregated quantitative data, specifically for Asian and Pacific Islander communities. By disaggregating the data, this will uncover actual health disparities within Asian subgroups, as well as, Pacific Islander subgroups.

Barriers in access to breast health care services include the lack of financial means and/or support, social support; transportation; in-person interpreter services; and continuity of care challenges with limited patient navigators/case managers for monolingual patients. Basic needs such as food and housing are needed especially while women are under treatment. In all target communities, there is a continued need for low or no cost screening, diagnostic and treatment options, especially for those without health coverage. In addition, diagnostic breast health procedures such as ultrasounds and biopsies are costly and difficult for uninsured women who are younger than 39 years of age and/or undocumented to access these vital breast health services. As well, available hours for breast health services outside of normal/regular business hours are also needed.

The data collection tools also included questions about opportunities for Komen to develop and strengthen outreach efforts, partnership development, education/health promotion and funding strategies in working with target communities. In terms of outreach, it was shared that the Affiliate needs to strengthen the connection between education, increasing awareness, and behavior change. Throughout the data collection process, one key recommendation was apparent throughout, which was to strengthen, build and leverage partnerships in the community in order to increase credibility, trust and recognition of Susan G. Komen. Other

recommendations centered on improving the Affiliate's grantmaking opportunities; to strongly consider innovative strategies; opportunities to help build capacity; and fund new (to the Affiliate) and/or diverse organizations.

### **Mission Action Plan**

The Mission Committee engaged in a strategic process to develop an action plan covering April 1, 2015 to March 31, 2019. Key findings from the quantitative, qualitative, health systems and policy analysis were presented. From this discussion evolved the development of eight problem/need statements. The statements were presented to the committee along with rationale of the problem/need and sample solutions. Each committee member individually developed priority statements and multiple solutions they deemed relevant and appropriate in addressing each of the need/problem statements. All the ideas/solutions were grouped by programmatic similarity, i.e., partnerships, outreach and education, grantmaking, etc.; and then the committee engaged in dialogue to discuss the resolutions gathered.

Thereafter, the committee participated in a voting process to narrow eight of the need/problem statements down to five; prioritizing the highest problems/needs for the Affiliate to address in the next four years. The group provided rationale for the five problem/needs statements, which received the majority of the votes. Further discussion about the justification for the three problem/need statements that received the least number of votes included concerns about feasibility and the problem/need is bigger than Komen to address locally.

As a result, the following Mission Action plan involved the input of the CP Advisory Team, Mission Committee (includes key representatives in grant-making, public policy and the Affiliate's special initiative efforts focused on two of the target communities selected), staff and the Board of Directors to help the Affiliate formulate priority statements and S.M.A.R.T. objectives for each of the priority areas.

#### **Priority Need/Problem A:**

Based on quantitative data findings, over six percent of all women ages 40 and older in OC have not had a screening mammogram and an additional 12 percent have not had a mammogram within the last two years. Among the group that has not had a screening mammogram Hispanic/Latinos represent 28 percent; Asians 33 percent and; data is unstable for Pacific Islanders but a history in OC of high rates of late-stage diagnoses and death have been identified in previous CPs (2009 and 2011 CP Reports). However, the health systems and public policy analysis found that there are health services available across the county. Therefore, the apparent gap in accessing these services was explored during the qualitative data collection process.

The qualitative data collection process revealed that there is a need for low- to no-cost screening options; continued need for access to early detection services; and information on available hours outside of "normal" business hours. It was also identified that there is a need for the following: financial support, social support, interpreter services, navigation services to increase utilization, and transportation services.

As a result, the Affiliate concluded that many communities (including Asian and Pacific Islander, Hispanic/Latina, and women 65 years and older of all races) are not aware of the available services and are not able to access breast health screening services as a priority need/problem.

**Priority I:** Increase knowledge/awareness of available breast cancer screening services in OC that is culturally and linguistically appropriate for all target communities identified in the CP.

**Objective I-1:** By 2019, Komen OC will build a network of breast cancer navigation services that provide ethnic, language and cultural support in each of the Asian subgroups identified in the CP (see page 66-69, Qualitative Data section) with at least five new collaborative partnerships of community-based organizations that serve these communities.

**Objective I-2:** By 2019, Komen OC will educate 6,500 Hispanic/Latina women annually in OC about available breast cancer screening service via grant partners and/or Unidos Contra Cancer de Seno Coalition. (see page 54, Health Systems and Public Policy Analysis).

**Objective I-3:** By 2019, Komen OC will participate in five senior-specific outreach events per year reaching women 65 years and older to increase awareness of breast health services/resources.

**Priority II:** Improve access to available breast cancer screening services in OC that is culturally and linguistically appropriate for all target communities identified in the CP.

**Objective II-1:** By 2019, Komen OC will collaborate with community partners and/or Komen-funded grant partners to improve access to screening services for 650 Hispanic/Latina women per year (a total of 2,600) through patient navigation and screening mammography events.

**Priority Need/Problem B:**

From all data collection methods in the qualitative data findings, it was determined that the lack of education was the greatest problem with regard to disparities in screening mammography data. Specifically, in key informant interviews, many shared that education with targeted information – age-specific, language-specific, and breast cancer risks continues to be a need. As well, education should include signs/changes in the breast and symptoms, available screening, treatment and diagnostic services, and age-specific screening guidelines/recommendations.

Moreover, it was indicated that in-language access; information tailored to specific ages; intergenerational messaging; and education to the community with various health literacy levels are needed. Thus, there is a need for continued outreach and education about the risks, signs, symptoms and impact of breast cancer throughout the continuum of care in all of the target communities identified in the CP.

**Priority III:** Increase breast health education to all target communities by developing in-language and appropriately tailored health information that is comprehensible for various audiences to help raise the awareness of breast cancer and associated risk factors in these communities.

**Objective III-1:** By 2019, Komen OC will improve breast health education by recruiting and training 12 breast health advocates who are bilingual, bicultural and/or age-appropriate covering languages in Chinese, Korean, Spanish, Tagalog and Vietnamese to conduct breast cancer and breast health education and information to all target communities.

**Objective III-2:** Annually through 2019, Komen OC will give priority (or add weighted value during review process) to grant applications that propose to provide evidence-based breast health education in specific languages and/or cultures and/or age-groups that are innovative and not duplicative.

**Priority Need/Problem C:**

African-American/Black women in OC are dying from breast cancer at a faster rate than White women in OC. In the quantitative data analysis, there is an increasing trend for late-stage diagnosis at a rate of 8.1 percent per year and a higher death rate among African-American/Black women than whites in OC, 30.2 per 100,000 versus 22.5 per 100,000 (see page 20, Quantitative Data section).

Additionally, from focus group sessions, participants shared that there are many reasons why African-American/Black women in OC don't have a mammogram regardless of whether or not they have health insurance. However, many shared that there are barriers such as distrust of medical providers, lack of culturally and/or generational sensitivity. Other findings include messengers of breast health information need to represent the African-American/Black community, and address the complexities of the family dynamic (see page 73-77, Qualitative data section for more information). As a result of these findings, it was determined that the breast health needs among African-American/Black women in OC must be addressed.

**Priority IV:** Partner with organizations/agencies/professional associations to help address the diverse needs and barriers to motivate African-American/Black women in OC to learn more about risk factors and obtain breast cancer screenings.

**Objective IV-1:** By 2017, Komen OC will continue to build the OC African-American Breast Health Community Partnership (see page 53, Health Systems and Public Policy Analysis) that is representative of various community, faith-based, and professional organizations; that is effective, sustainable and visible in the community to ensure engagement in activities such as breast health outreach and education, access to care and advocacy efforts.

**Objective IV-2:** Annually through 2019, Komen OC will increase the knowledge and awareness of at least **1,200** African-American/Black women about breast health and available breast cancer screening services in OC through strategic partnerships and collaboration using culturally-competent and evidence-based strategies.

**Objective IV-3:** By 2019, Komen OC will encourage informed breast health care decision-making and motivate **300** African-American/Black women to action through patient navigation and mammography events via grant partners and/or the OC African-American Breast Health Community Partnership efforts.

**Priority Need/Problem D:**

Quantitative data found women 65 years and older have high death rates of breast cancer at 110.3 per 100,000 among non-Hispanic Whites; 153 per 100,000 among African-Americans/Blacks; 75.9 per 100,000 among Hispanics/Latinas; and 40 per 100,000 among Asians and Pacific Islanders in OC (see page 40, Quantitative Data section). The age-adjusted death rate of breast cancer is 20.7 per 100,000 in OC. Moreover, during the qualitative data collection process, the CP Team experienced challenges in recruiting participants that are knowledgeable and/or experienced in working with women 65 years and older. Of those that

did participate, key informants shared that education continues to be one of the most substantial health needs for women 65 years and older. Specifically, information around individual risk and aging is vital. Other informants shared that there is a need for guidance on providing information for individualized plans pending age and health status was discussed repeatedly.

Financial support was also noted, older adults live on a fixed income and if they are diagnosed with cancer; the financial burden of cancer can be traumatic. They shared that Medicare does not cover all medical costs (such as gauze after surgery) and the need to cover medical costs out of pocket creates a burden on other daily needs such as finances for food, housing and transportation. Therefore, it was determined that not much is known about the breast health needs and standards of breast health care offered/utilized among women 65 and older.

**Priority V:** Build relationships and partner with organizations/agencies that specifically work with women 65 years and older in OC.

**Objective V-1:** By 2017, Komen OC will develop three new collaborative relationships with organizations that serve women 65 and older to understand and learn more about how to address their breast health needs and barriers to access.

**Objective V-2:** By 2017, Komen OC will gather information from doctors who specifically serve the geriatric community to discover and understand the standards of breast health care for women 65 years and older.

#### **Priority Need/Problem E:**

Under the Health Systems and Public Policy Analysis section, some racial/ethnic groups are falling short in terms of enrollment and utilization under ACA due to ineligibility or insurance opt outs; many women will continue to lack access to breast health screening services. As well, NCBCEDP/EWC still serves as a safety net program creating important access to care especially for uninsured. Thus, many individuals in OC will remain uninsured and/or medically underserved.

**Priority VI:** Ensure all individuals are able to access quality breast health care services through safety-net programs covering the entire cancer continuum of care.

**Objective VI-1:** Komen OC will advocate annually for the preservation of safety-net programs like EWC/BCCEDP through participation of public policy efforts such as legislative visits, lobby days with Komen Headquarters public policy team, the Komen California Public Policy Committee, and local public policy committee.

**Objective VI-2:** Komen OC will advocate annually for the removal of age- and gender-specific restrictions of programs like EWC/BCCEDP through participation of public policy efforts such as legislative visits, lobby days with Komen Headquarters public policy team, the Komen California Public Policy Committee, and local public policy committee, to ensure that all are able to access breast health care services.

**Objective VI-3:** By 2019, Komen OC will advocate for the expansion of covered services and treatment timeline-protocols under programs like BCCTP, and/or other available programs/services (see page 55-56, Health Systems Analysis for more information).

**Objective VI-4:** By 2019, Komen OC will maintain the Komen Fund for Breast Health Care as a safety net of last resort to cover gaps in the continuum of breast health/cancer care (see page 14, Introduction section for information regarding the Komen Fund for Breast Health Care).

**Objective VI-5:** Komen OC will identify and train at least three volunteers per year to serve on the local public policy committee to carry out public policy efforts focused on access to breast health care in response to the changes in the health care landscape.

This action plan is intended to create synergy between Mission-related strategic plans and the Affiliate's operational activities.

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