



The Susan G. Komen  
Breast Cancer Foundation  
Orange County Affiliate

# *2006 Community Profile*

## Summary of Findings

The Susan G. Komen Breast Cancer Foundation  
Orange County Affiliate  
3191-A Airport Loop Drive  
Costa Mesa, CA 92626  
(714) 957-9157  
[www.ockomen.com](http://www.ockomen.com)

## ACKNOWLEDGEMENTS

The Orange County Affiliate of the Susan G. Komen Breast Cancer Foundation would like to thank the Affiliate Board of Directors and the following people who participated in the work group, helped analyze the data, and proofread the report:

*Lianne Avila*, Education Committee

*Marie Blash*, Education Committee

*Lindsey Brengle*, Staff

*Rhena Carusillo*, Work Group Member

*Suzi Dempsey*, Work Group Member

*Ginny Espenship*, Board of Directors 2006, Work Group Member

*Mary Anne Foo*, Board of Directors 2006

*Paul Gibson*, California Department of Health Services

*Jane Hill*, Staff, Work Group Member

*Christine Hudson*, Staff, Work Group Member

*Carla Longfellow*, Race Committee, Work Group Member

*Sally Molnar*, Board of Directors 2005, Work Group Member

*Ellie Monroe*, Work Group Member

*Jane Ka'ala Pang*, Board of Directors 2006, Work Group Member

*Michele Patanella*, Staff

*Marica Pendjer*, Board of Directors 2006

*Deborah Ryan*, Education Committee

*Megan Stirrat*, Board of Directors 2006, Work Group Member

*Annie Stoeckmann*, Work Group Member

*Chris Tannous*, Board of Directors 2006

*Melissa Weisbach*, Work Group Member

*Karen Wolett*, Race for the Cure® Co-Chair 2006, Work Group Member

*Lisa Wolter*, Executive Director, Work Group Member

In addition, the Komen Foundation would like to thank all the individuals and organizations that completed the Programs and Services survey, and who participated in the key informant interviews. Thank you for sharing your knowledge and expertise.

***The mission of the Susan G. Komen Breast Cancer Foundation is to eradicate breast cancer as a life-threatening disease by advancing research, education, screening and treatment.***

The Komen Foundation recommends a 3-step approach to breast cancer screening that includes, depending upon a woman's age, a combination of mammography, clinical breast exams and breast self-exams.

- Annual mammograms beginning at age 40.
- Clinical breast exam at least every 3 years beginning at age 20, and annually from age 40 on.
- Monthly breast self-exam beginning by age 20.

Women with a family history of breast cancer or other concerns about their personal risk should consult with a health care provider. Screening tests may need to be done more often and/or started earlier than usual.

As part of a total approach to breast health, it is also important that women become familiar with their own bodies, play an active role in their own health, and develop a close partnership with their health care providers.

For more information, please visit [www.ockomen.com](http://www.ockomen.com).

PREPARED BY:  
Sandra Rose, MPH  
Director of Programs and Grants  
Orange County Affiliate of the Susan G. Komen Breast Cancer Foundation

## TABLE OF CONTENTS

<b>Executive Summary .....</b>	<b>5</b>
<b>Introduction .....</b>	<b>8</b>
<b>Demographics .....</b>	<b>11</b>
<b>Breast Cancer Statistics .....</b>	<b>14</b>
<b>Programs and Services Survey and Key Informant Results .....</b>	<b>24</b>
Programs and Services .....	24
Key Informants .....	27
Discussion .....	30
<b>Conclusion – Identified and Prioritized Gaps .....</b>	<b>33</b>

## **EXECUTIVE SUMMARY**

In 2006, the Orange County Affiliate of the Susan G. Komen Breast Cancer Foundation conducted a needs assessment of the breast health and breast cancer community in Orange County. The needs assessment is referred to as the Community Profile. The goal of the Community Profile is to gather information about the community for the purpose of identifying gaps in services and populations most in need of breast health care. This information is instrumental in guiding our Affiliate's activities such as grant making, fundraising and education outreach so as to not duplicate programs already in place and focus our efforts on addressing any unmet breast health and breast cancer needs. In addition, this information can be used by other organizations for program planning and service delivery, grant writing, and finding opportunities for expanded referrals and interagency collaborations.

The Community Profile includes:

- Demographics
- Breast cancer statistics
- An assessment of current breast health and breast cancer services
- A survey of the community's beliefs and attitudes about breast cancer through interviews with key informants

### **Demographics**

In 2005, the Orange County population was 3,074,722 million people. Nearly 48% of the Orange County population identified as White, slightly more than 33% is Hispanic, 15% is Asian, less than 2% is Black/African American and less than 1% is American Indian or Pacific Islander. (Source: California Department of Finance, 2005)

### **Breast Cancer Statistics**

In 2006 in Orange County, an estimated 1,890 new cases of breast cancer will be diagnosed. This estimated number of new cases is higher than any other county in the California, except for Los Angeles County. In 2006 in Orange County, an estimated 340 people are expected to die from breast cancer. Breast cancer is the second leading cause of cancer deaths among women, second to lung cancer. (Source: American Cancer Society, California Cancer Facts and Figures, 2006)

In California, nearly 77% of women aged 40 and over reported having had a mammogram within the past two years, according to the 2004 Behavioral Risk Factor Surveillance System. In California, women aged 40 and over are more likely to have had a mammogram within the past two years if they were older, had a higher income, and a higher level of education.

## **Programs and Services**

About 120 Programs and Services surveys were distributed to hospitals, breast centers, community based agencies, and other related organizations. Fifty-eight (58) surveys were returned.

- More than 90% (53) of respondents reported offering breast health education, and 35 of the 53 respondents reported offering community breast health education. In 2006, the Komen Orange County Affiliate funded half of the 35 respondents who reported offering community breast health education to support their efforts.
- More than 70% of respondents reported that Spanish was spoken by their staff.
- Four respondents reported that Chinese (Mandarin) was spoken by their staff. Two respondents reported that an Asian language besides Chinese, Vietnamese or Korean was spoken by their staff.
- Fewer than 10% of respondents reported offering ancillary services such as childcare, transportation and post-operative home care.
- Approximately 60% of respondents reported offering financial assistance to clients, of which 70% is through the Cancer Detection Program. It is unclear from this survey whether respondents offered financial assistance for those who do not qualify for the Cancer Detection Program.
- Eight respondents reported offering clinical trials.
- Two respondents reported offering financial assistance for basic living expenses to qualified individuals currently in treatment for breast cancer.

## **Key Informant Responses**

Forty (40) key informants were interviewed to get their insights about the women they serve and/or populations in greatest need of breast health regarding the following topics:

- Preferred sources of information about breast health and breast cancer
- Obstacles and barriers to routine breast health care
- Recommendations for improving the health care system to best meet the needs for breast health care and breast cancer treatment

Common themes for obstacles and barriers to routine breast health care emerged from the key informant interviews. Themes included:

- Financial barriers (e.g. lack of insurance or underinsured, can't afford to take off work due to lost wages, can't afford services)
- Information and education barriers (e.g. not aware of programs in the community, not aware of risk, myths and false information, "fear" of perceived costs associated with services and/or treatment)
- Systems barriers (e.g. no services for multi-lingual residents, lack of medical providers)

Common themes for recommendations to improve the current healthcare system include:

- Provide more education outreach through health fairs, home-setting workshops, health kiosks, forums, media, and public figures
- Increase ancillary services such as transportation assistance, in-home support care, psychosocial support services
- Provide more screening, including mobile mammography screening, and screening for underinsured/ uninsured women who do not qualify for state or federal programs
- Provide more patient navigators/care coordinators, including ethnic specific navigators, community-based navigators
- Focus on quality of life issues and quality of treatment
- Develop programs with a comprehensive approach to preventive health and risk reduction by including topics such as nutrition, exercise, mental health, etc.
- Increase number of providers who will provide treatment services to underinsured/uninsured people who do not qualify for state or federal programs
- Increase number of providers who accept MediCal patients
- Increase cultural competency among medical providers
- Advance research and clinical trials

## **Identified and Prioritized Gaps**

Overall there were three major categories of obstacles and barriers to routine breast health care that emerged from the key informant interviews for the majority of groups mentioned as in greatest need of breast health services. All three categories are considered Very High Priority. The categories in order are:

- Cost
- Education/awareness
- Fear

## **INTRODUCTION**

At the beginning of 2006, the Orange County Affiliate of the Susan G. Komen Breast Cancer Foundation conducted a needs assessment of the breast health and breast cancer community in Orange County. The needs assessment is referred to as the Community Profile. The goal of the Community Profile is to gather information about the community for the purpose of identifying gaps in services and populations most in need of breast health care. This information is instrumental in guiding our Affiliate's activities such as grant making, fundraising and education outreach so as to not duplicate programs already in place and focus our efforts on addressing any unmet breast health and breast cancer needs. In addition, this information can be used by other organizations for program planning and service delivery, grant writing, and finding opportunities for expanded referrals and interagency collaborations.

### **Community Profile Components and Methodology**

The Community Profile includes:

- Demographics
- Breast cancer statistics
- An assessment of current breast health and breast cancer services
- A survey of the community's beliefs and attitudes about breast cancer through interviews with key informants

### **Demographics and Breast Cancer Statistics**

The demographics and statistics portions of the Community Profile were pre-populated by Komen Headquarters. This information is from the National Cancer Institute Surveillance, Epidemiology, and End Results (SEER) Program and the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System (BRFSS). Additional resources for demographic information cited in this report include the California Department of Finance, the 2006 Community Indicators Report, and the Orange County Health Needs Assessment (OCHNA). Additional resources for breast cancer statistics cited in this report include the California Health Interview Survey (CHIS) and OCHNA.

### **Programs and Services**

A survey of existing breast health and breast cancer services and programs was distributed to about 120 hospitals, breast centers, community-based agencies, and other related organizations. Surveys were distributed to Community Grant recipients, organizations involved with the Orange County Breast Cancer Coalition, Cancer Detection Program (CDP) providers, hospitals and organizations listed in the Orange County Breast Cancer Resource Guide, and agencies that attended a Community Needs assessment meeting hosted by the Komen Orange County Affiliate. Fifty-eight (58) surveys were returned.

The survey and database were developed by Komen Headquarters. Volunteers entered surveys into the database, and the Director of Programs and Grants was responsible for the initial review of the information. Members of the Education Committee, assisted by the Director of Programs and Grants, further reviewed the information and offered recommendations for next steps to the Orange County Affiliate Board of Directors.

Some limitations to this data are important to mention. The majority of providers who completed the survey are from nonprofit community-based organizations, community clinics, and Cancer Detection Program providers, where the focus may be more on prevention, health education, and working with underserved populations. Ideally, more providers from both public and private health care settings would have completed and returned the survey. In addition, certain topics and services such as “care”, “counseling” and “patient advocate” were subject to a broad interpretation of meaning.

## **Key Informant Interviews**

Forty (40) key informant interviews were conducted using an interview guide developed by Komen Headquarters. A list of key informants was compiled with input from the Board of Directors, Education Committee, staff, and agencies who attended a Community Needs assessment meeting hosted by the Komen Orange County Affiliate. Key informants were also asked to identify other people they considered to be knowledgeable about breast health and breast cancer services and needs in Orange County.

Key Informants were interviewed about women they serve and/or populations in greatest need of services to get their insight about the following topics:

- Preferred sources of information about breast health and breast cancer
- Obstacles and barriers to routine breast health care
- Recommendations for improving the health care system to best meet the needs for breast health care and breast cancer treatment

A work group, led by the Director of Programs and Grants, was formed to complete the key informant interview process. The work group was made up of 6 volunteers, 4 members of the Board of Directors, 2006 Race Co-Chair, 3 staff, and the Affiliate Executive Director. Training on the interview guide and basic interview skills were provided to the work group by the Director of Programs and Grants. The work group and Education Committee, led by the Director of Programs and Grants, were responsible for the initial review of the key informant responses. Common themes emerged from the key informant interviews and priority focus areas were identified to present to the Orange County Affiliate Board of Directors.

Identifying and selecting key informants can be challenging, and limitations related to the key informant process is important to mention. All key informant interviews were conducted in English, and therefore limited the participation of key informants whose primary language was one other than English. The ethnic groups included in this report are broad groups. This was particularly challenging to report for Asian groups, as many distinct groups were referenced in several interviews. In this report, Asian includes a number of Asian, Southeast Asian and Pacific

Islander nationalities. The definition and use of the term “community” varied from references to the general population to a specific group identified by the key informant. Lastly, it is important to keep in mind that information from the key informant interviews is not intended to generalize, but rather to understand more in-depth the issues that are being addressed.

## DEMOGRAPHICS

Orange County is located in southern California, bordered by the Pacific Ocean on the west, Los Angeles County to the north, San Diego County to the south, and Riverside and San Bernardino counties to the east.

### Population

In 2005, the Orange County population was 3,074,722 million people.<sup>1</sup> Table 1 shows that half of the Orange County population is made up of females. Orange County is the second largest county in California, and the fifth largest county in the nation.<sup>2</sup> Orange County is second only to San Francisco for the most densely populated county in California.<sup>2</sup> Orange County is denser than Los Angeles County, more than 2.5 times denser than Santa Clara and Sacramento counties, and five times denser than San Diego County, which has roughly the same population.<sup>2</sup>

Table 2 shows that nearly 48% of the Orange County population is White, slightly more than 33% is Hispanic, 15% is Asian, less than 2% is Black/African American, and less than 1% is American Indian or Pacific Islander. Figure 1 shows the race/ethnic break down for the female population in Orange County. Orange County is a “minority majority” county where no single racial or ethnic group comprises more than 50% of the total population.<sup>2</sup> According to the 2000 US Census, nearly 42% of the population in Orange County five years and older speak a language other than English at home, and nearly 30% of people living in Orange County are foreign born.

Figure 2 shows that 28% percent of the female population in Orange County is 19 and under, slightly more than 28% are between 20 – 39 years old and over 43% are 40 and older.

According to the 2004 Orange County Health Needs Assessment (OCHNA) Survey, 10.4% or approximately 233,000 Orange County adults aged 18 and over lacked health care coverage. Figure 3 shows the percentage of uninsured adults in Orange County by age groups. Well over half (54.5%) of the uninsured adult population in Orange County were Hispanic, followed by White adults (22.8%), Vietnamese adults (11%), and other Asian or Pacific Islanders (7.6%).<sup>3</sup> The cities with the highest estimated number of adults without health coverage are listed in order: Santa Ana, Anaheim, Costa Mesa, Westminster, Garden Grove, and Fullerton.<sup>3</sup>

According to 2000 US Census, in Orange County overall, 10.3% of persons lived below poverty. Nearly 20% of persons living in Santa Ana were below poverty, 14% in Anaheim, 13% in Costa Mesa, 14% in Westminster, 14% in Garden Grove, and 11% in Fullerton.

**Table 1. Orange County Population, 2005**

Sex	Number
Female	1,543,314
Male	1,531,408
<b>Population Total</b>	<b>3,074,722</b>

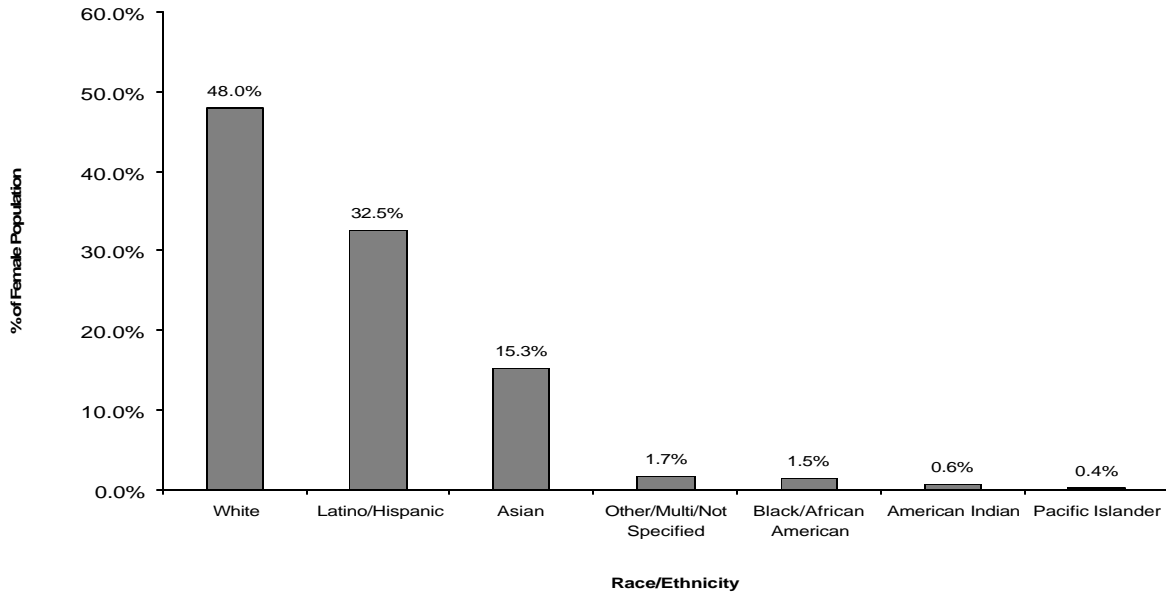
Source: California Department of Finance, 2005

**Table 2. Orange County Population by Race/Ethnicity, 2005**

Race/Ethnicity	Number	Percent
American Indian	18,509	.6%
Pacific Islander	11,206	.4%
Asian	457,790	15%
Black/African American	48,785	1.6
Hispanic	1,026,908	33.4%
White	1,458,545	47.4%
Other/Multi/Not Specified	52,979	1.7%
<b>Population Total</b>	<b>3,074,722</b>	

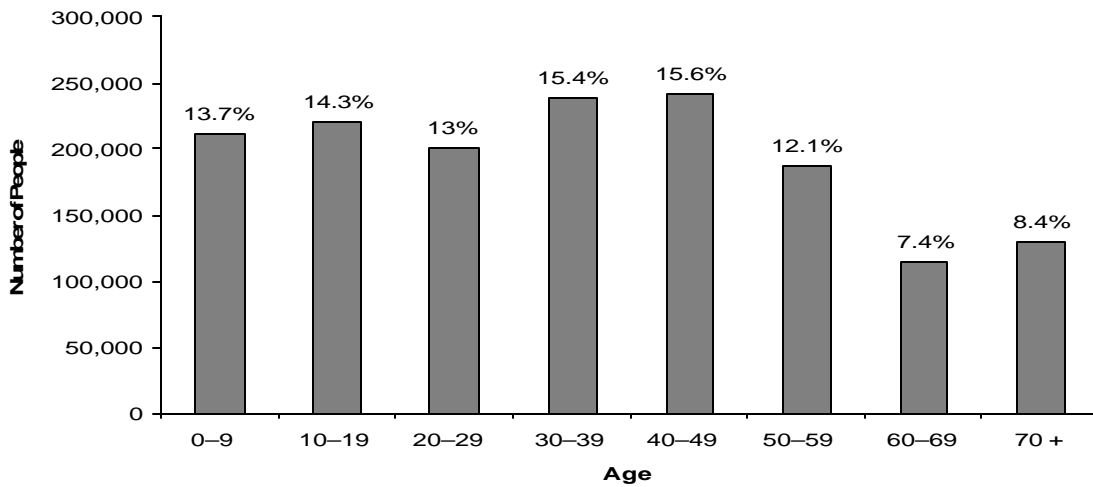
Source: California Department of Finance, 2005

**Figure 1. Orange County Female Population by Race/Ethnicity, 2005**



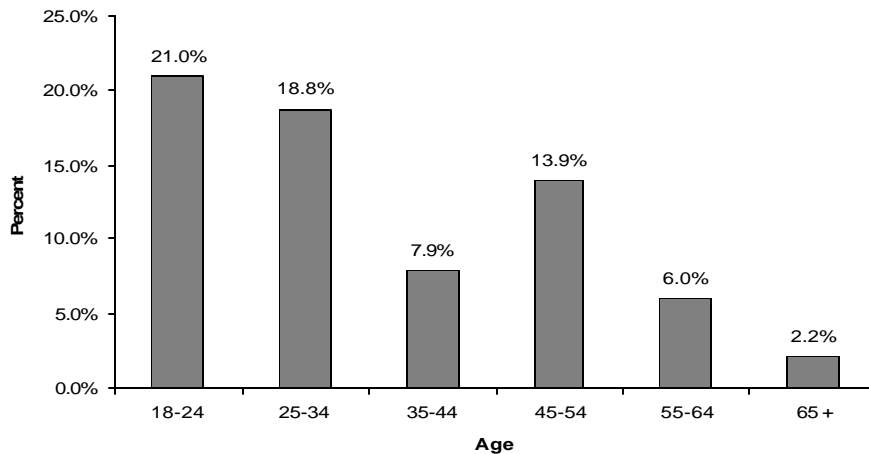
Source: California Department of Finance, 2005

**Figure 2. Orange County Female Population by Age Group, 2005**



Source: California Department of Finance, 2005

**Figure 3. Percent of Uninsured Adults in Orange County by Age Group, 2004**



Source: Orange County Health Needs Assessment, Spring Report 2005

For additional demographic and/or socio-economic information, please refer to the 2006 Community Indicators Report, released 3/06 by the Orange County Executive Office, the Orange County Health Needs Assessment, Spring Report, 2005, and/or the 2005 Orange County Progress Report published by the Center for Demographic Research.

---

<sup>1</sup> California Department of Finance, 2005

<sup>2</sup> Orange County 2006 Community Indicators

<sup>3</sup> Orange County Health Needs Assessment, Spring Report, 2005

## BREAST CANCER STATISTICS

An estimated 212,920 new cases of invasive breast cancer are expected to occur among women in the United States. An estimated 40,970 women will die from breast cancer. It is estimated that 1,720 men will be diagnosed and 460 men will die of breast cancer during 2006.<sup>4</sup>

Breast cancer is the most common cancer among women in California, regardless of race/ethnicity. In California, it is estimated that there will be 22,070 new cases of breast cancer among women, and over 4,000 deaths.<sup>5</sup>

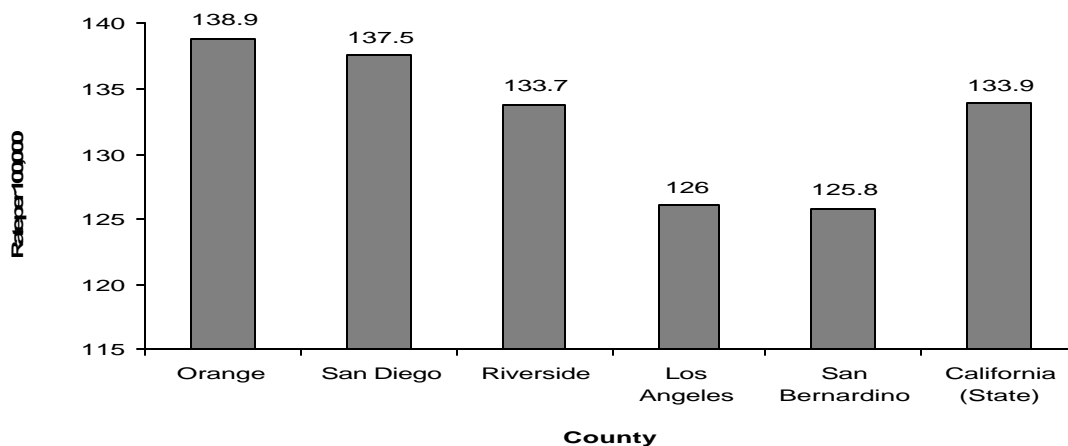
Table 3 shows that breast cancer incidence in Orange County has been relatively stable from 1999 – 2003. However, Figure 4 shows that Orange County has had a higher breast cancer annual incidence rate (138.9 per 100,000) than the state rate (133.9), and that of its surrounding neighboring counties, including Los Angeles County. In Orange County, it is estimated that 1,890 new cases of breast cancer will occur among women in 2006.<sup>5</sup> This number is higher than any other county in California except for Los Angeles County.

**Table 3. Number of Breast Cancer Cases by Year and Gender, Orange County, 1999–2003**

Year	Male	Female	Total Number
1999	12	1,910	1,922
2000	9	1,872	1,881
2001	15	1,876	1,891
2002	9	1,914	1,923
2003	9	1,805	1,814
<b>5-Year Total</b>	<b>54</b>	<b>9,377</b>	<b>9,431</b>

*Source: UCI Department of Epidemiology, Cancer Surveillance Program of Orange County*

**Figure 4. County Comparison of Breast Cancer Annual Incidence Rate, 1998–2002**



*Source: 2005 Orange County Health Needs Assessment Breast Health Report*

In 2006, in Orange County, it is estimated that 340 deaths due to breast cancer will occur.<sup>5</sup> Breast cancer is second to lung cancer as the leading cause of cancer-related deaths among women. (Source: Centers for Disease Control and Prevention) Table 4 shows the number of breast cancer deaths in Orange County from 1999 – 2003.

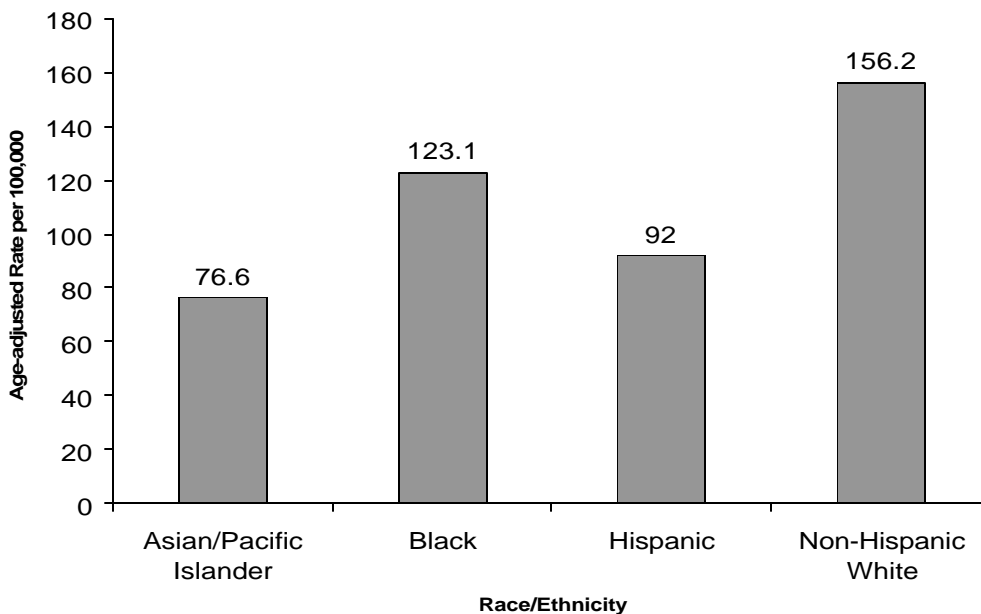
**Table 4. Number of Breast Cancer Deaths by Year and Gender, Orange County, 1999–2003**

Year	Male	Female	Total Number
1999	0	304	304
2000	2	300	302
2001	3	323	326
2002	3	320	323
2003	6	352	358
<b>5-Year Total</b>	<b>14</b>	<b>1,599</b>	<b>1,613</b>

Source: UCI Department of Epidemiology, Cancer Surveillance Program of Orange County

Figure 5 shows that the five-year average annual age-adjusted breast cancer incidence rates for females in Orange County from 1999 – 2003 was highest among White women (156.2 per 100,000), followed by Black/African American women (123.1 per 100,000), Hispanic women (92 per 100,000) and Asian/Pacific Islander women (76.6 per 100,000).

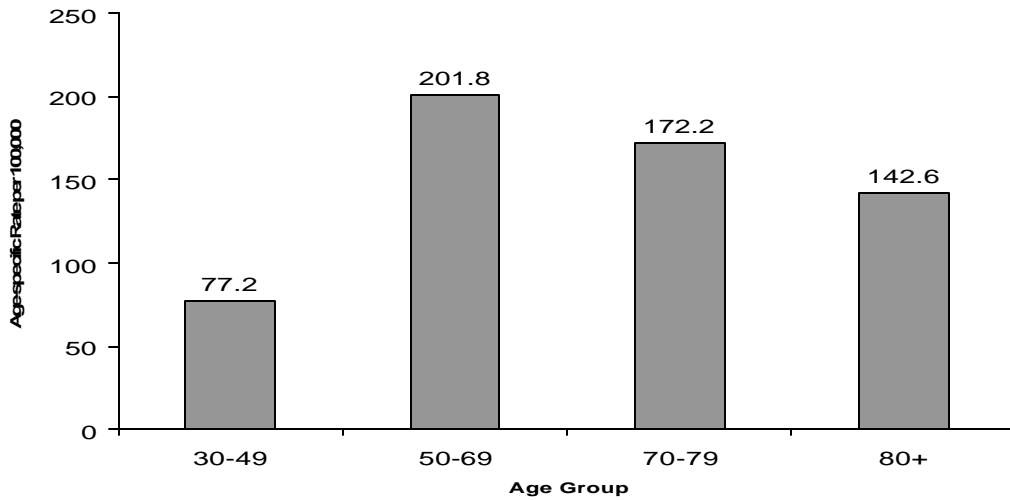
**Figure 5. Five-year Average Annual Age-Adjusted Breast Cancer Incidence Rates for Females, by Race/Ethnicity, Orange County, 1999–2003**



Source: UCI Department of Epidemiology, Cancer Surveillance Program of Orange County

Figure 6 shows the five-year average annual age-specific breast cancer incidence rates for Asian/Pacific Islander females in Orange County from 1999 – 2003. Among this group, 50 – 69 year olds have the highest incidence rate (201.8 per 100,000).

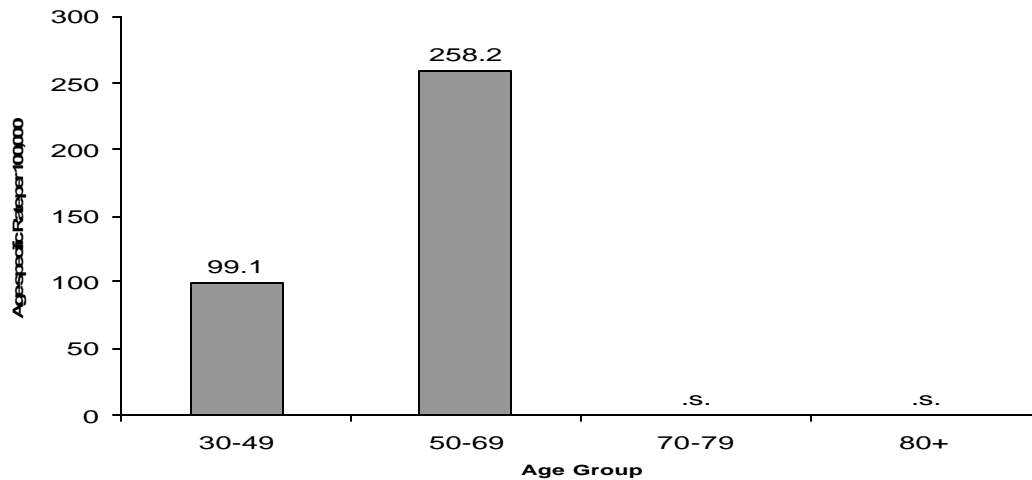
**Figure 6. Five-year Average Annual Age-Specific Breast Cancer Incidence Rates for Asian/Pacific Islander Females, Orange County, 1999–2003**



Source: UCI Department of Epidemiology, Cancer Surveillance Program of Orange County

Figure 7 shows the five-year average annual age-specific breast cancer incidence rates for Black/African American females in Orange County from 1999 – 2003. Among this group, 50 – 69 year olds have the highest incidence rate (258.2 per 100,000).

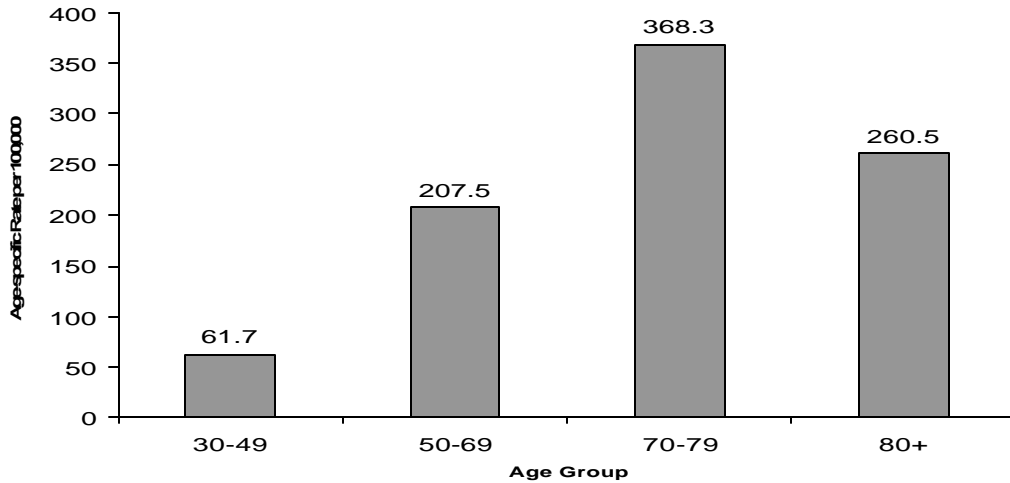
**Figure 7. Five-year Average Annual Age-Specific Breast Cancer Incidence Rates for Black/African American Females, Orange County, 1999–2003**



Source: UCI Department of Epidemiology, Cancer Surveillance Program of Orange County

Figure 8 shows the five-year average annual age-specific breast cancer incidence rates for Hispanic females in Orange County from 1999 – 2003. Among this group, 70 – 79 year olds have the highest incidence rate (368.3 per 100,000).

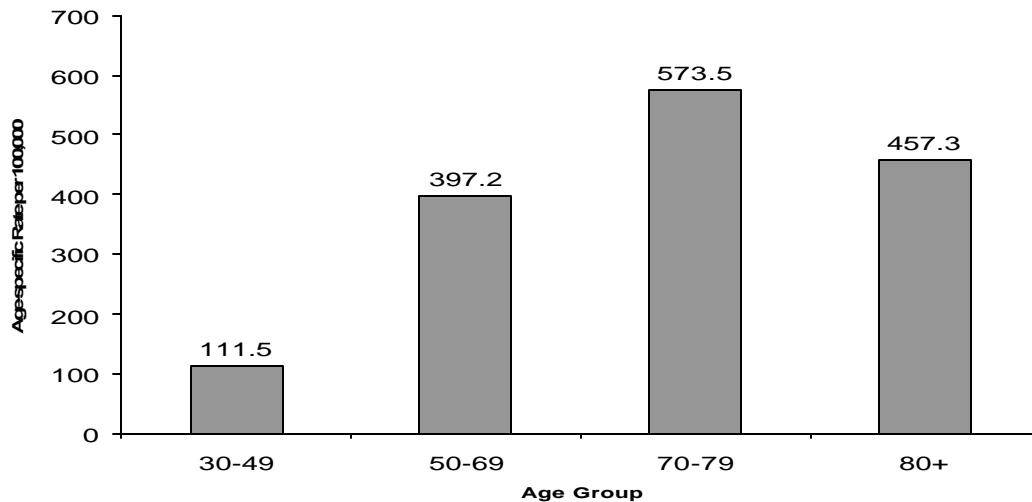
**Figure 8. Five-year Average Annual Age-Specific Breast Cancer Incidence Rates for Hispanic Females, Orange County, 1999–2003**



*Source: UCI Department of Epidemiology, Cancer Surveillance Program of Orange County*

Figure 9 shows the five-year average annual age-specific breast cancer incidence rates for non-Hispanic White females in Orange County from 1999 – 2003. Among this group, 70 – 79 year olds have the highest incidence rate (573.5 per 100,000).

**Figure 9. Five-year Average Annual Age-Specific Breast Cancer Incidence Rates for Non-Hispanic White Females, Orange County, 1999–2003**



*Source: UCI Department of Epidemiology, Cancer Surveillance Program of Orange County*

Table 5 shows the percent of breast cancer diagnosed at early stage (*in situ* or localized) for Orange County in 2002.

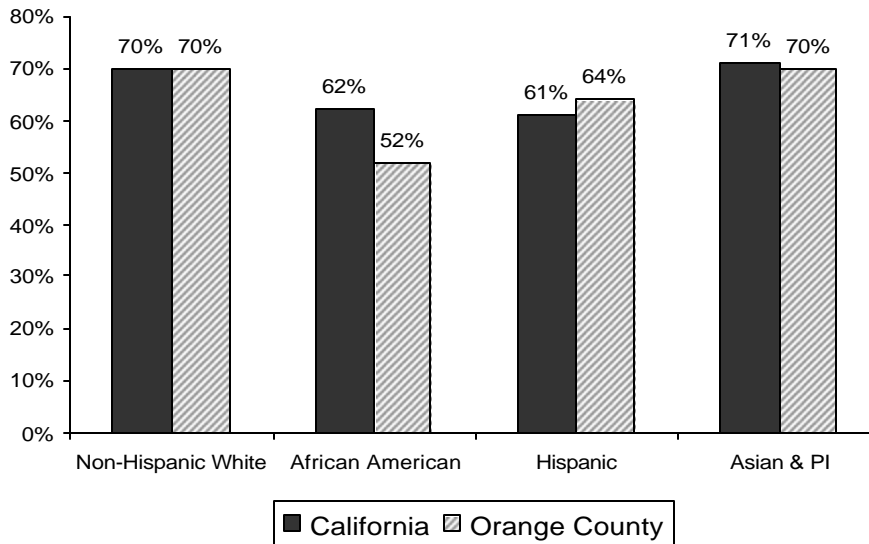
**Table 5. Percent of Breast Cancer Diagnosed at Early Stage, 2002**

	Non-Hispanic White		African American		Hispanic		Asian & Pacific Islander	
	Total Cases	% Early	Total Cases	% Early	Total Cases	% Early	Total Cases	% Early
Orange County	1,788	70%	33	52%	227	64%	211	70%

Source: California Cancer Registry, CA DHS. Printed in the American Cancer Society California Cancer Facts & Figures, 2006

Figure 10 shows the percent of breast cancer diagnosed at an early stage (*in situ* or localized) for females in Orange County compared to the state in 2002.

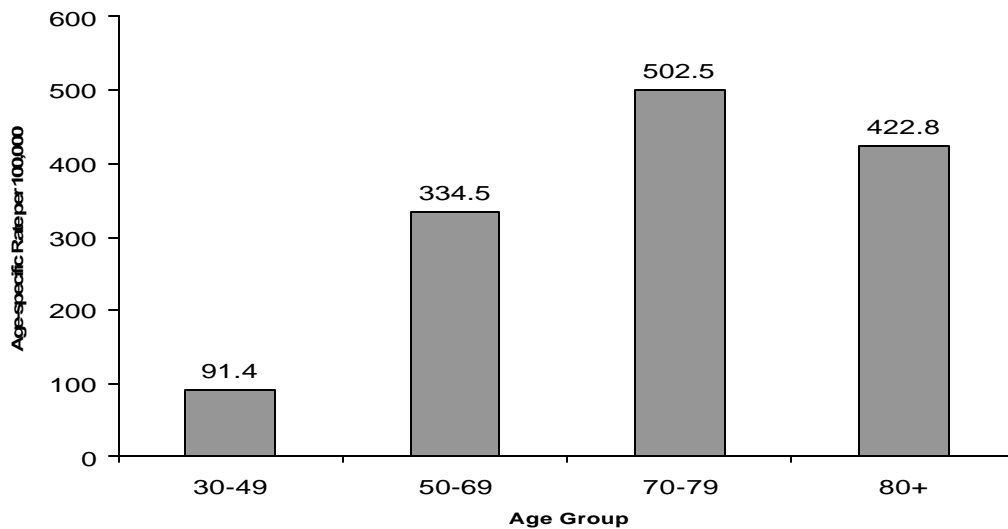
**Figure 10. Percent of Breast Cancer Diagnosed at Early Stage, California and Orange County, 2002**



Source: California Cancer Registry, CA DHS. Printed in the American Cancer Society California Cancer Facts & Figures, 2006

Figure 11 shows that the five-year average annual age-specific and age-adjusted breast cancer incidence rates for females in Orange County from 1999 – 2003 was highest among 70 – 79 year olds (502.5 per 100,000), followed by 80 and older (422.8 per 100,000), 50 – 69 year olds (334.5 per 100,000), and 30 – 49 year olds (91.4 per 100,000).

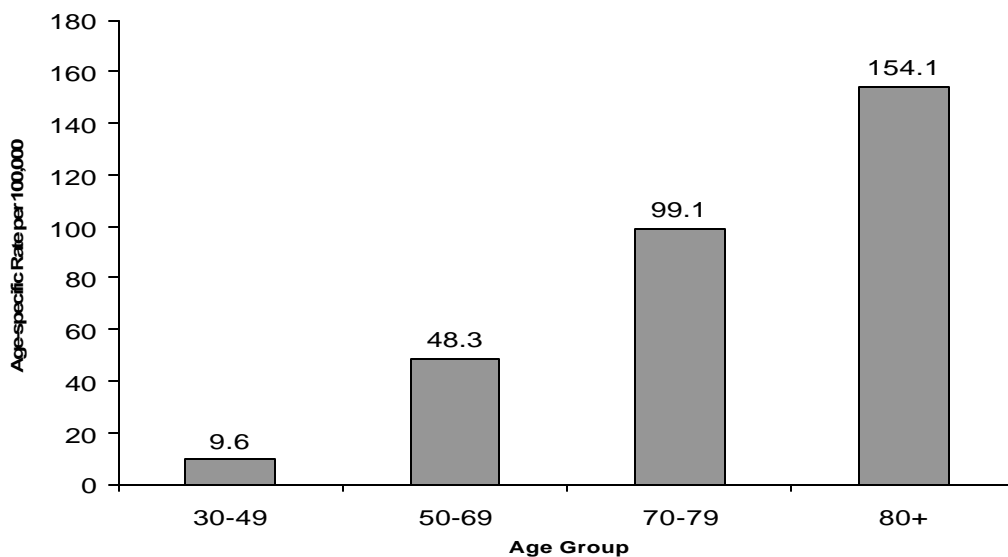
**Figure 11. Five-year Average Annual Age-Specific and Age-Adjusted Breast Cancer Incidence Rates for Females, Orange County, 1999–2003**



Source: UCI Department of Epidemiology, Cancer Surveillance Program of Orange County

Figure 12 shows that the five-year average annual age-specific and age-adjusted breast cancer mortality rates for females in Orange County from 1999 – 2003 was highest among women 80 years and older (154.1 per 100,000), followed by 70 – 79 year olds (99.1 per 100,000), 50 – 69 year olds (48.3 per 100,000), and 30 – 49 year olds (9.6 per 100,000).

**Figure 12. Five-year Average Annual Age-Specific and Age-Adjusted Breast Cancer Mortality Rates for Females, Orange County, 1999–2003**



Source: UCI Department of Epidemiology, Cancer Surveillance Program of Orange County

## Mammography Utilization

Participation in annual mammography screening and treatment of the disease at its earliest stages offers the best opportunity for decreasing breast cancer mortality and improving survival.<sup>4</sup> According to the CDC, mammography screening every 1 – 2 years for women age 40 and older could reduce mortality by approximately 20 – 25% over 10 years. Mammography is the best way to detect breast cancer in its earliest, most treatable stage – an average of 1 to 3 years before a woman can feel a lump. Mammography also locates cancers too small to be felt during a clinical breast examination.<sup>5</sup>

According to the 2004 Behavioral Risk Factor Surveillance System (BRFSS), in California, 76.5% of women aged 40 and older had a mammogram within the past two years. Table 6 shows a break down of women by age group, Table 7 shows a break down of women by income, and Table 8 shows a break down of women by education who reported having had a mammogram within the past two years.

**Table 6. Percent of Women 40+ Who Have Had a Mammogram within the Past Two Years by Age Group, California, 2004**

Age	Yes	No
40 – 49	67.8	32.2
50 – 59	79.3	20.7
60 – 64	82.5	17.5
65 +	82.8	17.2

*Source: Centers for Disease Control and Prevention, 2004 BRFSS*

**Table 7. Percent of Women 40+ Who Have Had a Mammogram within the Past Two Years by Income, California, 2004**

Age	Yes	No
Less than \$15,000	68.9	31.1
\$15,000 – 24,999	72.5	27.5
\$25,000 – 34,999	77.9	22.1
\$35,000 – 49,999	78.7	21.3
\$50,000 +	80.2	19.8

*Source: Centers for Disease Control and Prevention, 2004 BRFSS*

**Table 8. Percent of Women 40+ Who Have Had a Mammogram within the Past Two Years by Education, California, 2004**

Age	Yes	No
Less than H.S.	74.0	26.0
H.S. or G.E.D.	76.3	23.7
Some post – H.S.	76.4	23.6
College graduate	78.2	21.8

Source: Centers for Disease Control and Prevention, 2004 BRFSS

Table 9 shows that a majority of Orange County women 40 years and older have had a mammogram at least once in her lifetime, according to the California Health Interview Survey. According to the same report, the percent of Orange County women 40 – 49 years old who have had a mammogram in the last 2 years or less was 66.1%, women 50 – 59 was 81.6%, women 60 – 64 was 91%, and women 65 and older 81.3%.

**Table 9. Percent of Women 40+ Who Have Ever Had a Mammogram, Orange County, 2003**

Age	Yes	No
40 – 49	78.8	21.2
50 – 59	93.4	*
60 – 64	99.1	*
65 +	97.2	*

\*Statistically unstable (limitation of the sample collected in this survey)

Source: California Health Interview Survey, 2003

Table 10 shows the percent among Orange County women 40 years and older who reported ever having had a mammogram that had a mammogram in the last 2 years or less by age group and race/ethnicity. Among the groups reported in this table, the lowest percent of women who had a mammogram in the last two years or less are Asian women 40 – 49 years old (43%), followed by Asian women 50 – 59 years old (64%) and Hispanic women 40 – 49 years old (67.1%).

**Table 10. Percent of Women 40+ Whose Most Recent Mammogram was Within 2 Years or Less, by Age Group and Race/Ethnicity, Orange County, 2003**

Age	Hispanic	Asian	African American	White
40 – 49	67.1	43.0	*	71.4
50 – 59	74.5	64.0	*	85.5
60 – 64	*	93.0	*	92.1
65 +	84.3	75.8	*	80.8

\*Statistically unstable (limitation of the sample collected in this survey)

Source: California Health Interview Survey, 2003

Table 11 shows the percent among Orange County women 40 years and older who reported ever having had a mammogram that had a mammogram in the last two years or less by age group and federal poverty level. Among the groups reported in this table, the lowest percent of women who had a mammogram in the last two years or less are 40 – 49 year olds between 200 – 299% FPL (44.2%), followed by 40 – 49 year olds between 100 – 199% FPL (55.1%) and 50 – 59 year olds between 0 – 99% FPL (60.9%).

**Table 11. Percent of Women 40+ Whose Most Recent Mammogram was Within 2 Years or Less, by Age Group and Federal Poverty Level (FPL), Orange County, 2003**

Age	0-99% FPL	100 – 199% FPL	200 – 299% FPL	300% + FPL
40 – 49	61.4	55.1	44.2	73.2
50 – 59	60.9	79.7	81.3	84.2
60 – 64	83.4	*	100.0	95.3
65 +	84.5	82.4	73.0	82.3

*\*Statistically unstable (limitation of the sample collected in this survey)*

*Source: California Health Interview Survey, 2003*

Table 12 shows the percent of Orange County women 20 years and older who had a doctor examine their breasts for lumps within the past 12 months by age group and race/ethnicity. Among the groups reported in this table, the lowest percent of women who had a doctor examine their breasts for lumps within the past 12 months are Asian women 40 – 49 years old (47.2%), followed by Hispanic women 20 – 29 years old (55.3%), and Asian women 50 – 59 years old (55.5%).

**Table 12. Percent of Women 20+ Who Had a Doctor Examine Their Breasts for Lumps Within the Past 12 Months by Age Group and Race/Ethnicity, Orange County, 2003**

Age	Hispanic	Asian	African American	White
20 – 29	55.3	*	*	79.3
30 – 39	59.0	60.5	*	75.1
40 – 49	58.8	47.2	*	69.3
50 – 59	72.6	55.5	*	76.1
60 – 64	*	77.9	-	77.7
65 +	73.9	*	*	62.2

*\*Statistically unstable (limitation of the sample collected in this survey)*

*- no data*

*Source: California Health Interview Survey, 2003*

Table 13 shows the percent of Orange County women 20 years and older who examine their own breasts for lumps by age group and race/ethnicity. Among the groups reported in this table, the lowest percent of women who examine their own breasts for lumps are White women 20 – 29 years old (53.5%), followed by Asian women 40 – 49 years old (57.8%), and Asian women 50 – 59 years old (59.2%).

**Table 13. Percent of Women 20+ Who Examine Their Own Breasts for Lumps by Age Group and Race/Ethnicity, Orange County, 2003**

Age	Hispanic	Asian	African American	White
20 – 29	75.8	75.1	*	53.5
30 – 39	83.8	61.4	*	79.4
40 – 49	69.8	57.8	*	76.7
50 – 59	69.9	59.2	*	74.3
60 – 64	*	87.6	-	61.2
65 +	77.0	*	*	69.3

*\*Statistically unstable (limitation of the sample collected in this survey)*

*- no data*

*Source: California Health Interview Survey, 2003*

For additional information about mammography utilization, please refer to the California Health Interview Survey, the Orange County Health Needs Assessment and/or the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System.

---

<sup>4</sup> American Cancer Society Facts & Figures 2006

<sup>5</sup> American Cancer Society California Facts & Figures 2006

## PROGRAMS AND SERVICES SURVEY AND KEY INFORMANT RESULTS

### Programs and Services Survey (N = 58)

While the Programs and Services Survey was short and somewhat broad, this assessment provides a “snapshot” of breast health and breast cancer programs and services in Orange County. This information can help identify both strengths (assets) and gaps (needs) in services. In addition, this information can be used for improved program planning and service delivery, and for finding opportunities to better work collaboratively to reach more people.

The following section is a profile of the organizations that completed the survey.

(Note: Respondents were asked to check all that apply, and so totals for many of the tables do not add up to the total number of respondents. This also makes drawing conclusions somewhat difficult and interpretations may vary.)

**Table 14. Type of Organization**

Type of Organization	Number
Nonprofit	43
Medical Facility	21
Grassroots	11
Social Services	8
Mammography Facility	7
Educational Institution	5
For Profit	4
Mobile Mammography	1
Government Institution	1

**Table 15. How Do Clients Pay for Services?**

Method of Payment	Number
Medicare	22
State-funded insurance	21
Federally funded Cancer Detection Program	15
Sliding Scale	14
Low-cost for women who qualify	14

**Table 16. Languages (other than English) Spoken by Staff**

Language	Number
Spanish	42
Vietnamese	18
Korean	9
Chinese	4
Other	10

**Table 17. Languages (others than English) of Publications**

Language	Number
Spanish	38
Vietnamese	21
Korean	7
Chinese	6
Other	4

**Table 18. Where Program Activities Take Place**

Locations	Number
At our agency location	40
Health fairs	26
Other community agencies	21
Churches/temples	18
Community/recreation centers	16
Colleges/universities	10
Adult education facilities	7
Senior citizen homes	7
Homeless shelters	4
Domestic violence shelters	4
Day laborer locations	1

**Table 19. Populations Served**

Group	Number
Low-income	32
Uninsured/underinsured	24
Long term survivors	18
Homeless women in shelters	9
Incarcerated women	3

The following section is a profile of services offered by organizations that completed the survey.

**Table 20. Care**

Type of Care Service	Number
Post-operative care/in hospital	5
Hospice	4
Post-operative home care	2

**Table 21. Counseling**

Type of Counseling Service	Number
Family	12
Genetic risk	9
Children w/a parent w/breast cancer	8

**Table 22. Education Information**

Locations	Number
Breast Self-Exam Training	34
Community Education	35
Resource Center/Library	16

**Table 23. Financial Assistance**

Type of Assistance	Number
Cancer detection program	24
Other	15

**Table 24. Mammography**

Type of Screening	Number
Screening mammography	20
Diagnostic mammography	13

**Table 25. More Screening**

Other	
Clinical Breast Exam (CBE)	26
Ultrasound	11
Surgical Biopsy	10
CT Scan	9
Sentinel Node Biopsy	9
Image Guided Breast Biopsy	9
Nuclear Medicine	9
PET Scan	8
MRI	7
Scintigraphy	5
Computer Aided Detection (CAD)	5
Ductal Lavage	4
Breast Mapping	3

**Table 28. Treatment**

Type of Treatment	Number
Medical Oncology	10
Tumor Board	10
Chemotherapy	9
Radiation Oncology	9
Plastic Surgery	9
Surgery	9
Second Opinion	9
Physical Rehabilitation/Therapy	9
Lymphedema Specialty Services	7
Pain Management	8
Wound Care	8
Biological Therapy	5
Transplant	3
Bone Marrow/Stem Cell	2

**Table 26. Prosthesis/Wardrobe/Grooming**

Type of Service	Number
Hats and turbans	10
Wigs	9
Breast prosthesis	5
Wardrobe	2

**Table 27. Referral Services**

Type of Referral Service	Number
Patient Advocate	18
Patient Navigator Services	12

**Table 29. Support Groups**

Type of Support Group	Number
Women with Recurrent Breast Cancer	8
Young Women	5
Peer	5
Latina	5
Metastatic Support Group	4
Family/Care Giver	4
Children w/a parent w/breast cancer	3
African American	3
Korean	2
Peer Support for Men	2
Chinese	1

**Table 30. Other Services**

Type of Service	Number
Nutritional Services	10
Breast Reconstruction	8
Clinical Trials	8
Transportation	6
Political Advocacy	5
Complementary Therapies	4
Child Care	2

### **Key Informant Responses (N = 40)**

The information from the key informant interviews are a reflection of views captured through a systematic process. This information can help identify populations in greatest need of breast health services, focus resources to be responsive to unmet breast health needs, and identify strategic partners in the local fight against breast cancer.

#### **Health Concerns**

Key informants were asked to rate by severity health issues in the community. The most frequently mentioned issues, in order, were:

- Cancer
- Heart disease/hypertension
- Stress
- Diabetes
- Nutrition
- Substance abuse

#### **Sources of Information**

Key informants were asked about the community's preferences for sources of information for general health and breast health information.

- Medical doctors were mentioned most often as the most credible people for health information, followed by other health care providers such as nurses, health educators and allied health professionals.
- Medical doctors were mentioned most often as the person to whom someone in the community would most likely go to for breast health information, followed by friends.
- Newspaper and television were mentioned most often as the most effective ways to disseminate breast health information, followed by radio, Internet, brochures and pamphlets, and one-on-one.

#### **Screening Services**

Key informants were asked where low-income or underserved women go for their routine breast healthcare such as breast cancer screening and exams.

- Community or public clinics were mentioned most often followed by specific references to the Cancer Detection Program and YWCA.

Key informants were asked which groups of women they think are having mammograms now that didn't have them two years ago.

- Asian, Hispanic/Latina, and women 40-49 were mentioned most often as having mammograms now that didn't two years ago.
- Increased outreach and education were the most frequently mentioned reasons for what has motivated these groups of women to get mammograms.

#### **Groups in Greatest Need**

Key informants were asked to identify which groups (racial, ethnic, cultural, age, income, etc.) have the greatest need for breast health and breast cancer services.

- Asian, Hispanic, uninsured/underinsured, and women under 40 were mentioned most often as groups in greatest need of breast health and breast cancer services. Among Asian groups, Vietnamese women were mentioned most frequently.

#### **Obstacles and Barriers**

The reasons people don't get breast health care can be complicated. They include problems of access, cost, fear, misinformation or inaccurate beliefs, and/or cultural and behavioral characteristics.

The common themes of obstacles and barriers to routine breast health care that emerged from the key informant interviews for the four groups most frequently mentioned as in greatest need of breast health and breast cancer services are highlighted on page 27.

- Lack of insurance, inadequate transportation assistance to get to medical appointments, childcare barriers, and fiscal inability to take time off from work for screening and wellness care were common themes for all four groups.
- Information and education barriers related to low perception of risk, myths and false information, and fear associated with perceived costs of services and treatment were common themes for all four groups.
- For Asian and Hispanic women, cultural and language barriers were reported to impede their understanding and acceptance of breast health care services.

These factors are not mutually exclusive, and their cumulative effect contributes to the delay in detection, diagnosis and treatment.

#### **Health Care System**

Key informants were asked to rate how successful the present healthcare system is in meeting the needs for breast health care and breast cancer treatment.

- A significant number of key informants reported that the current healthcare system is inadequate when it comes to providing risk factor and prevention information.
- Responses from key informants were equally distributed among those who believed the current healthcare system is inadequate, adequate and moderately successful when it comes to providing early detection and screening.

Impacted Population: Asian
<p><b>Access</b></p> <ul style="list-style-type: none"> <li>No services for multilingual residents</li> <li>Limited hours of operation (clinic, hospital, etc.)</li> <li>No public transportation</li> <li>Lack of medical providers</li> </ul>
<p><b>Cost</b></p> <ul style="list-style-type: none"> <li>Cannot afford childcare</li> <li>Cannot afford to take off work (lost wages)</li> <li>Cannot afford transportation</li> <li>Cannot afford services</li> <li>Uninsured or underinsured</li> <li>Poverty (concern with basic survival – food, etc.)</li> </ul>
<p><b>Fear</b></p> <ul style="list-style-type: none"> <li>Fear of going to the doctor</li> <li>Fear of having cancer</li> <li>Fear of test results</li> <li>Fear of losing a breast</li> </ul>
<p><b>Education/Awareness</b></p> <ul style="list-style-type: none"> <li>Not discussed or recommended by doctor</li> <li>Not aware of programs in the community</li> <li>No information about preventive care</li> <li>Lack of education, literacy</li> <li>Not aware of risk</li> <li>Myths and false information</li> </ul>
<p><b>Cultural/Behavioral</b></p> <ul style="list-style-type: none"> <li>Embarrassment, modesty</li> <li>Procrastinates or forgets</li> <li>Other health problems more urgent</li> </ul>

Impacted Population: Hispanic/Latina
<p><b>Access</b></p> <ul style="list-style-type: none"> <li>Location of services too far away</li> <li>Limited hours of operation (clinic, hospital, etc.)</li> <li>No public transportation</li> <li>Lack of medical providers</li> </ul>
<p><b>Cost</b></p> <ul style="list-style-type: none"> <li>Cannot afford childcare</li> <li>Cannot afford to take off work (lost wages)</li> <li>Cannot afford transportation</li> <li>Cannot afford services</li> <li>Uninsured or underinsured</li> <li>Poverty (concern with basic survival – food, etc.)</li> </ul>
<p><b>Fear</b></p> <ul style="list-style-type: none"> <li>Fear of going to the doctor</li> <li>Fear of having cancer</li> <li>Fear of test results</li> <li>Fear of accessing the system (immigration issues)</li> </ul>
<p><b>Education/Awareness</b></p> <ul style="list-style-type: none"> <li>Not aware of programs in the community</li> <li>No information about preventive care</li> <li>Lack of education, literacy</li> <li>Not aware of risk</li> <li>Myths and false information</li> </ul>
<p><b>Cultural/Behavioral</b></p> <ul style="list-style-type: none"> <li>Embarrassment, modesty</li> <li>Procrastinates or forgets</li> <li>Other health problems more urgent</li> </ul>

Impacted Population: Underinsured/ uninsured
<p><b>Access</b></p> <ul style="list-style-type: none"> <li>No public transportation</li> <li>Lack of medical providers</li> </ul>
<p><b>Cost</b></p> <ul style="list-style-type: none"> <li>Cannot afford childcare</li> <li>Cannot afford to take off work (lost wages)</li> <li>Cannot afford transportation</li> <li>Cannot afford services</li> <li>Uninsured or underinsured</li> <li>Poverty (concern with basic survival – food, etc.)</li> </ul>
<p><b>Fear</b></p> <ul style="list-style-type: none"> <li>Fear of having cancer</li> <li>Fear of test results</li> <li>Fear of the procedure, pain</li> <li>Fear of losing a breast</li> </ul>
<p><b>Education/Awareness</b></p> <ul style="list-style-type: none"> <li>Not aware of programs in the community</li> <li>No information about preventive care</li> <li>Lack of education, literacy</li> <li>Not aware of risk</li> </ul>
<p><b>Cultural/Behavioral</b></p> <ul style="list-style-type: none"> <li>Procrastinates or forgets</li> </ul>

Impacted Population: Women under 40
<p><b>Cost</b></p> <ul style="list-style-type: none"> <li>Cannot afford childcare</li> <li>Cannot afford to take off work (lost wages)</li> <li>Cannot afford services</li> <li>Uninsured or underinsured</li> <li>Poverty (concern with basic survival – food, etc.)</li> </ul>
<p><b>Fear</b></p> <ul style="list-style-type: none"> <li>Fear of having cancer</li> <li>Fear of test results</li> <li>Fear of losing a breast</li> </ul>
<p><b>Education/Awareness</b></p> <ul style="list-style-type: none"> <li>Not aware of programs in the community</li> <li>Not aware of risk</li> <li>Myths and false information</li> </ul>
<p><b>Cultural/Behavioral</b></p> <ul style="list-style-type: none"> <li>Procrastinates or forgets</li> </ul>

- Diagnosis and treatment were often reported as adequate or moderately successful.
- After treatment care, support and research were often rated as inadequate.

### **Recommendations**

Common themes for recommendations to improve the current healthcare system include:

- Provide more education outreach through health fairs, home-setting workshops, health kiosks, forums, media, and public figures
- Increase ancillary services such as transportation assistance, in-home support care, psychosocial support services
- Provide more screening, including mobile mammography screening, and screening for underinsured/uninsured women who do not qualify for state or federal programs
- More patient navigators/care coordinators, including ethnic specific navigators, community-based navigators
- Focus on quality of life issues and quality of treatment
- Develop programs with a comprehensive approach to preventive health and risk reduction by including topics such as nutrition, exercise, mental health and wellbeing, etc.

- Increase number of providers who will provide treatment services to underinsured/uninsured people who do not qualify for state or federal programs
- Increase number of providers who accept MediCal patients
- Increase cultural competency among medical providers
- Advance research and clinical trials

### **Discussion**

#### **Strengths and Assets Related to Programs and Services**

A number of strengths and assets related to breast health and breast cancer programs and services emerged from this assessment.

- More than 90% (53) of respondents reported offering education, and 35 of the 53 respondents reported offering community breast health education. Increased outreach and education were the most frequently mentioned reasons for what has motivated some medically underserved populations to get mammograms. In 2006, the Komen Orange County Affiliate funded half of the 35 respondents who reported offering community breast health education to support their efforts.
- Compared to the overall demographic profile of Orange County, it appears from the data collected that Hispanic and Vietnamese clients are well served in

regards to languages used in services provided. More than 70% of respondents reported that Spanish was spoken by staff at their organizations, and 66% offered publications in Spanish. More than 30% of respondents reported that Vietnamese was spoken by their staff at their organizations, and 36% offered publications in Vietnamese.

- The majority of key informants reported that diagnosis and treatment services were adequate, moderately successful or successful.
- For many low-income and underserved populations, community clinics are where they go for routine breast health care. Specific references were made to the Cancer Detection Program and YWCA. In 2006, the Komen Orange County Affiliate funded four community clinics, the YWCA North Orange County, and several community-based organizations that work in conjunction with Cancer Detection Program providers to support their early detection and screening programs.

#### **Possible Gaps and Needs Related to Programs and Services**

Several themes related to possible gaps and needs in breast health and breast cancer programs and services emerged from this assessment that warrants further examination.

- Fewer than 10% of respondents reported offering ancillary services such as childcare, transportation and post-operative home care. Key informants frequently mentioned a

need for increasing ancillary services such as transportation, in-home support care, and psychosocial support services. Cost (of services, child care, and transportation) was identified as a major barrier for populations in greatest need of breast health services. Only two respondents reported offering financial assistance for basic living expenses to qualified individuals currently in treatment for breast cancer.

- Approximately 60% of respondents reported offering financial assistance to clients, of which nearly 70% is through the Cancer Detection Program. It is unclear from this assessment whether financial assistance is offered for those who do not qualify for the Cancer Detection Program. Underinsured women and those without insurance who do not qualify for state or federal programs were mentioned frequently as a population that may be falling through the cracks, and not receiving information about breast health and resources for free or low-cost screening.
- Eight respondents reported offering clinical trials. The need for increasing access and awareness of clinical trials was brought up by a few key informants.
- Four respondents reported that Chinese (Mandarin) was spoken by their staff. Only two respondents reported that an Asian language besides Chinese, Vietnamese, or Korean was spoken by their staff. For many Asian groups, lack of services for monolingual residents

was identified as a major barrier to access.

- The majority of respondents reported that program activities take place at their agency location. According to many of the key informants, lack of transportation is a barrier for some populations, and so they may not be able to get to the agency location to receive services. Table 18 shows areas and locations that may be underserved where populations in need of breast health services can be found, and organizations can take their services directly to those people.
- While a moderate number of organizations reported serving low-income populations, only 40% of respondents reporting serving underinsured/uninsured populations. This population was identified by several key informants as a group that may be falling through the cracks as many do not qualify for state or federal programs. According to the data in this report, incarcerated women and women in shelters appear to be populations that are underserved.
- Screening mammography remains the best tool for early detection, and it appears from this data that there is still a need for increased screening services.

## CONCLUSION – IDENTIFIED AND PRIORITIZED GAPS

Overall there were 3 major categories of obstacles and barriers to routine breast health care that emerged from the key informant interviews for the majority of groups mentioned as having the greatest need for breast health services in Orange County. The categories in order are: cost, education/awareness and fear.

It can be very challenging for low-income, underserved women to get adequate and timely breast health care, and especially for those women who do not qualify for state or federal programs. Lack of insurance, inadequate transportation assistance to get to medical appointments, childcare barriers, and fiscal inability to take time off from work for screening and wellness care are cost-associated barriers that contribute to the disconnect of service utilization. To address issues of cost may require structural/environmental changes. These types of intervention may require significant resources, community mobilization and advocacy. Meanwhile, child care and transportation costs may be suggested areas for types of assistance incentives covered in the Komen Orange County Affiliate Community Grants Program. Increasing awareness of the Komen Orange County Affiliate Treatment Grant and Clinical Research Funding Trials programs may help to address cost barriers related to diagnostic and treatment services. Although addressing factors related to cost can be a significant undertaking, because it is a major obstacle and barrier to breast health care, it is considered a Very High Priority.

While significant progress has been made in providing breast health information, factors related to education/awareness still need to be addressed. It was often suggested in the key informant interviews to make breast health information relevant to the priority groups by providing clear, consistent, simple messages in their primary language. Common themes for messages included increasing perception of susceptibility for those who do not consider themselves at risk, and increasing the perception of benefits of early detection and screening to offset the barriers or obstacles for women who do not consider breast health a priority. A common thread throughout the assessment was the important role of education and outreach in the fight against breast, and it is considered a Very High Priority.

Lastly, it is interesting to note that the issue of fear was explained as related to cost and/or education/awareness. In regard to cost, the fear of having breast cancer was related to how an individual was going to pay for the cost of treatment services and the potential loss of income due to illness. In regard to education/awareness, the fear of having breast cancer was related to the belief that it was an automatic death sentence and that nothing could be done. It was suggested that some individuals would rather not know and therefore not get breast health care. Since early detection saves lives, and fear was identified as a major obstacle and barrier to breast health care, “fear” as is it understood in this context is considered a Very High Priority.

In closing, all the categories of obstacles and barriers that were addressed in the key informant interviews are interrelated and should not be considered in isolation. Multiple factors influence behavior, and therefore, a variety strategies are needed to appeal to all different populations.