

Community Profile Report

Susan G. Komen for the Cure®

San Diego Affiliate



4699 Murphy Canyon Road, Suite #207
San Diego, CA 92123
858-573-2760
www.komensandiego.org

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Community Advisory Panel

- Ana Navarro, PhD: SDSU-UCSD Cancer Partnership/Addressing cancer disparities through research, training and outreach
- Carleen Stoskopf, Sc.D.: Director, San Diego State University Graduate School of Public Health
- Julie Barone, MD: Oncology Associates of San Diego, Sharp Health Care
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In addition, the affiliate would like to thank all the individuals and organizations who supported the process by responding to our Survivor Survey or participated in our key informant interviews.

Executive Summary

Every two years, Susan G Komen affiliates are required to undertake a needs assessment and engage in a reflective process to ensure that their programs are meeting the needs in their communities. This report is the result of a participatory and collaborative process in which Komen San Diego staff worked with an advisory board of community members to review and collect data to develop recommended priority areas and issues. The information collected through the report should guide the following Affiliate activities:

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

The following is a summary of the key results from the research in San Diego County.

Methodology and Limitations

A brief description of data sources used, methodology and limitations by section follows.

- **Demographic and Breast Cancer Statistics:** Data from a variety of sources and years was used based on what was available. Data was collected from the California Cancer Registry, the California Health Interview Survey, Susan G. Komen National Data Collection Packets from Thompson Reuters, and Cancer Facts and Figures. Due to this, comparisons between sources may not be exact. Where possible, the most recent data was used.
- **Programs and Services:** This section includes data from the Susan G. Komen Data Packs, the Komen San Diego Breast Cancer Resource Directory (BCRD), and a Provider Survey. Efforts were made to ensure that all agencies and sites were included on the asset maps, but some agencies and sites may not be represented.

Approximately 210 individuals were invited to participate in the Provider Survey. One hundred and eighty two individuals completed the entire survey.

- **Exploratory Data:** Three target areas were selected for this data: minority women, young women, and providers. This data was collected through focus groups and interviews with stakeholders and breast cancer survivors. The minority women target area was broad and included eight subsets of women.

Overview of Demographic and Breast Cancer Statistics

The key findings below are drawn from basic demographic data on San Diego's population as well as breast cancer statistics for the County and State.

Key Findings

- **Ethnicity:** The majority of San Diego County is White (50.1%); 30.8% Hispanic/Latino; 10.4% Asian/Pacific Islander and 4.7% African American.¹
- **Gender:** The County had slightly more males (50.3%) than females (49.7%).²

¹ U.S. Census 2010

² Ibid.

- **Income:** The median household income for a family of four was \$62,468, with 8.7% of families earning below the poverty level.³
- **Age:** 44.3% of San Diego County women are over the age of 40.⁴
- **Incidence:** In a change from 2009's Community Profile, San Diego had a lower breast cancer incidence rate (104.49 per 100,000) than that of the State (119.40 per 100,000). Incidence was the highest among Whites (128.57 per 100,000), followed by African Americans (77.85 per 100,000), Incidence was also highest among women age 65+ (326.58 per 100,000), followed by women age 45-64 (199.87 per 100,000). The majority of incidences were Stage 1 (64.6%) followed by 27.7 in Stage 2 (this trend was similar for all ethnicities).⁵ San Diego County men also had lower incidence rates (0.76 per 100,000) than that of the State (0.87 per 100,000).
- **Mortality:** San Diego County women's breast cancer mortality rate (22.04 per 100,000) was above that of the State (20.20 per 100,000). San Diego mortality was the highest among Whites (28.59 per 100,000), followed by African Americans (20.51 per 100,000). San Diego County men also had lower mortality rates (0.11 per 100,000) than that of the State (0.16 per 100,000).⁶
- **Screenings with mammograms:** Nearly 34.4% of women over the age of 40 had not had an annual mammogram. Reasons given ranged from 'not having time' (9.4%) , choosing not to (5.2%) and didn't they needed one (2.5%). However, over half (50.7%) of San Diego County women who had never had a mammogram earned under \$40,000 per year and 22.3% were uninsured, suggesting that access to health care may be a deciding factor in having mammograms.
- **Regional differences in incidence and mortality:** The South Bay continues to be the place of highest incidence in San Diego County (zip 92155, 279.9 per 100,000), while Borrego Springs is ranked second (zip 92004, 166.1 per 100,000); and in descending order: San Marcos (zip 92078, 158.4 per 100,000), Rancho Santa Fe (zip 92067, 156.8 per 100,000); Point Loma (zip 154 per 100,000) and Allied Gardens/Del Cerro (zip 92120, 152.9 per 100,000).⁷
- **Race/Ethnic Differences in screening and early stage diagnosis:** Minority women (Asian-Americans, African-Americans, and Hispanics) in San Diego County were less likely to be diagnosed with breast cancer at an early stage than White women. These three minority groups were also less likely to receive mammograms compared to White women.⁸

Overview of Programs and Services

The findings below were informed by the asset maps, which were created using the Komen San Diego BCRD, and the Provider Survey Results. Findings are organized by service area.⁹

Key Findings

- **Education/outreach and screening:** These services were the most common services available throughout the County, although providers indicated that there was a need for additional resources for these services.

³ Ibid.

⁴ Susan G. Komen Data Packs, 2010.

⁵ California Cancer Registry.

⁶ Ibid.

⁷ San Diego Association of Governments, 2010.

⁸ Cancer Facts and Figures, 2010

⁹ The information in this section was collected from the Susan G. Komen Breast Cancer Resource Directory and the Provider Survey Results.

- **Diagnosis and treatment:** Diagnosis and treatment services were less common throughout the County. Just under 22% of providers responding to a survey reported that their programs offered diagnostic services, treatment, or post-operative or hospice care; these were the same services identified as most needing additional resources.
- **Support services:** Financial assistance for clients was commonly noted as a need: only 20.4% of respondents stated that they offer financial assistance and 39.6% noted offering insurance assistance.
- **Regional difference in services:** Overall, the North Coastal, North Inland, and East County regions lacked services, while the Central, North Central, and South regions were the most resourced. Although this may be related to population density within the regions, there were no diagnosis or treatment sites located in or near Borrego Springs (in North Inland) or Rancho Santa Fe (in North Coastal), two of the cities with the highest incidence and mortality rates in San Diego County.
- **Language capacity:** Providers frequently did not speak the language of their clients. Languages with the largest needs were Spanish, Tagalog, Vietnamese, Farsi, Somali, Cantonese, and Korean.

Overview of Exploratory Data

Based on some of the breast cancer statistics (including the high mortality rate among African Americans and the fact that minority women are less likely to be screened for breast cancer) as well as the personal and professional expertise of the Advisory Group, three target areas were selected for further study: 1) Minority Women (African-Americans, Latinas, Asian/Pacific Islanders) 2) Young Survivors, and 3) Breast Health Providers. Results for all three areas are summarized by theme below.¹⁰

It is of note that providers identified the homeless and disabled as being key, underserved target groups. Because these groups were not selected by the Advisory Group, additional information was not gathered.

Barriers to Accessing Breast Healthcare

- Lack of awareness and knowledge
- Financial barriers including insurance, transportation, and childcare
- Cultural barriers
- Emotional factors such as fear, denial, and stigma

Challenges in the Current Breast Healthcare System

- High cost of care
- Lack of qualified and diverse providers
- Lack of information
- Language barriers

Improving the System

- Increased advocacy and education
- Increased funding for services, particularly transportation and screening

¹⁰ All of the data in this section comes from the focus groups and interviews with stakeholders and breast cancer survivors.

- Increased knowledge and training for providers

Conclusions

This section includes key findings by target area. Data in this section was collected from a variety of sources including the breast cancer statistics, the Provider Survey, and exploratory data findings.

Target Area 1: Minority Women

- Minority women were less likely to receive clinical breast exams and mammograms¹¹
- Breast cancer was less likely to be detected at an early stage in minority women¹²
- African American women had high breast cancer mortality rates¹³
- Minorities and immigrant groups were identified by providers as needing additional resources¹⁴
- Financial barriers were a consideration for all minority groups, and some “under insured” women of all ethnicities.¹⁵
- Cultural barriers played a role in accessing care. Emotional considerations such as fear prevented many women from seeking treatment¹⁶

Target Area 2: Young Women

- According to the focus group participants and stakeholders, in addition to the fact that limited statistics were available for young women, this cohort is an understudied group
- Women under 40 needed additional resources for breast cancer¹⁷
- Current guidelines for breast cancer screening make it difficult for women under 40 to access care¹⁸
- Denial prevents women from seeking care¹⁹
- Financial barriers prevent women from accessing care²⁰
- Young survivors lacked information and support²¹

Target Area 3: Provider Intervention

- Providers lacked reliable and accurate information for breast cancer patients²²
- Newly-diagnosed breast cancer patients and Survivors believed that providers were not “current” on breast cancer protocols, nor were they culturally competent.²³
- Providers did not have staff to speak the language spoken by their clients^{24 25}

¹¹ California Health Interview Survey, 2008 and 2010.

¹² Cancer Facts and Figures, 2010.

¹³ California Cancer Registry.

¹⁴ Provider Survey, 2011.

¹⁵ Exploratory Data Findings.

¹⁶ Ibid

¹⁷ Provide Survey, 2009.

¹⁸ Exploratory Data Findings.

¹⁹ Ibid.

²⁰ Ibid.

²¹ Ibid.

²² Ibid.

²³ Ibid.

- Partnering with other agencies could help survivors navigate the system ²⁶

Areas for Future Research

- Investigation of the demographics of women in cities with high breast cancer incidence and mortality
- Exploration of the relationship between income and breast cancer incidence and mortality
- Further exploration of the factors impacting incidence, early detection, screening
- Evaluation of Komen San Diego's best practices
- Explore the needs of various minority groups in more detail

Action Plan

Susan G. Komen for the Cure® remains committed to fulfilling our promise to save lives and end breast cancer forever through empowering people, ensuring quality care for all, and energizing science to find the cures. Susan G. Komen for the Cure® is focused on **reducing breast cancer incidence and mortality within the next decade with increased emphasis on finding solutions for disparities in breast cancer across populations**. With funds raised by the Komen San Diego Affiliate, community grants will be made to support **outcome-based strategies and promising practices** to reduce disparities in breast cancer mortality in San Diego County.

Applicants are strongly encouraged to utilize the data within the 2011 Community Profile Report to implement strategies in one or more of the following areas that result in **documented links** of rarely screened or never screened women from the priority populations to breast cancer screening and diagnostic services, and **documented links** of women diagnosed with breast cancer from priority populations to treatment and/or treatment support services to ensure successful treatment outcomes.

Drawing from evidence-based information from the 2011 Community Profile, and other local and national studies, the San Diego Affiliate of Susan G. Komen for the Cure® has identified the following priority populations, geographic target areas and programmatic priorities for the 2011 Community Grants Program:

- **Financial and Navigation Issues:** Increase the availability of financial resources for diagnosis, treatment and post-treatment in San Diego County among uninsured and underinsured women. Partner or collaborate on resources to help patients and their families' access and navigate the resources that are available.
- **Providers:** Increase competency among providers for breast health protocols and cultural/linguistic sensitivity. Partner with professional organizations to study/create/implement culturally sensitive continuing education and track progress.
- **Underserved Populations:** Programs that seek to reduce late stage diagnosis and mortality among underserved groups of women. Many groups of women are currently at higher risk due to lack of education about breast health, cultural/linguistic barriers, lack of available diagnostic services and late stage diagnosis. There are proportionally more such underserved women in the African American, Latina, Pacific Islander, Asian, Lesbian/Transgender and Homeless communities.

²⁴ Provider Survey, 2010

²⁵ Exploratory Data Findings.

²⁶ Ibid.

- **Young Women at Risk:** Develop a better understanding of this population and its needs; to provide screening, diagnostic, treatment and support services for women under 40 with a family history or palpable mass; to decrease late stage diagnosis and mortality rate by increasing partnerships with organizations that predominantly serve young women, especially under served young women; to increase awareness of breast health and breast cancer and the availability of culturally appropriate and relevant breast health materials for young women.

Introduction

Affiliate History

The San Diego Affiliate of Susan G. Komen for the Cure® was founded in 1995, the same year as the first San Diego Race for the Cure®. In 2010, the Affiliate's Race for the Cure® was attended by 13,250 participants and raised more than \$1.3 million. Since its inception, the Komen San Diego Affiliate has raised and invested nearly \$10 million to support local breast health programs. In addition to funding community grants, the Komen San Diego Affiliate provides awareness and education about breast health and cancer, screening, early detection, and connects people to services and resources when dealing with a breast cancer diagnosis.

In addition to community grant funding, the Komen San Diego Affiliate provides awareness and education about breast health and cancer, screening, early detection, and connects people to services and resources when dealing with a breast cancer diagnosis. Through a Speakers Bureau Program, the Affiliate conducts interactive and culturally appropriate education presentations. The Affiliate also participates in health fairs and community based events where breast health materials and information are distributed. In addition, Komen San Diego has sponsored a number of breast health conferences each year including Mana San Diego's Dia de la Mujer, Bethel AME's Body & Soul and Sharp Hospital's Hablando de la Mujer.

For more information about Komen San Diego's programs and services, please call us at 858-573-2760 or visit www.KomenSanDiego.org.

Organizational Structure

Komen San Diego employs three full-time staff members, one part-time Affiliate Accountant and is governed by a 13-person volunteer Board of Directors. In addition, Komen San Diego relies on the generosity of more than 875 committed and dedicated volunteers who provide nearly 20,000 hours, and an estimated \$250,000 of volunteer work every year. Because we serve the community, we believe we must reflect the community. That's why the Affiliate's annual strategic plan contains inclusion targets for the Board of Directors, staff, vendors, grantees and volunteers.

Description of Service Area

San Diego County lies just north of the Mexican border – sharing a border with Tijuana – and is located along the Pacific Ocean in the far southwest corner of California. It is home to miles of beaches, a mild Mediterranean climate, and 16 military facilities hosting the United States Navy, the United States Coast Guard and the United States Marine Corps.

The County is made-up of six regions as determined by the Health and Human Services Agency (HHSA) – East, South, Central, North Central, North Inland, and North Coastal. In 2010, the population of San Diego County was 3,053,793, making it the second largest County in California, after Los Angeles County, and the median household income was \$62,468 with 8.7% of families earning below the poverty level.²⁷ The 2010 Census data indicated that San Diego County was majority Caucasian, with a 50.1% White population and a 30.8% Latina population. Additionally, 49.8% of the population was female. The majority of these women – 55.7% -- were under the age of 40.²⁸

Purpose of Report

Community Assessment is a priority for Susan G. Komen for the Cure because the basic philosophies on which the organization was founded hinge on the ability to "know" the communities it serves. Every two years, we take a "snapshot" of what's going on in San Diego County in terms of breast health. Who is being diagnosed? What stage? What is preventing them from accessing quality care and breast health services? How do we change that? We take the "snapshot" to make sure we are:

Responsive

An Affiliate's community assessment identifies specific ways Komen can be responsive to the needs of its service area and provide for those touched by breast cancer today.

Non-Duplicative

Komen carved its niche in the cancer environment by identifying and focusing on unmet needs. Community assessment allows each Affiliate to identify and focus on the needs in its service area and to carve its niche in the local breast cancer environment.

Collaborative

An Affiliate's community assessment helps to identify strategic partners in the local fight against breast cancer. Partners may be potential grant recipients, donors, volunteers and other community nonprofits.

This report is the result of a collaborative and participatory process led by the Komen San Diego staff and a Community Advisory Panel composed of local experts, breast cancer survivors and community members. The Community Advisory Panel members volunteered their time to review key data, comment on data collection protocols, and assist in identifying target populations and areas of concentration. The Community Advisory Panel selected the three target areas for deeper study. In addition, the Community Profile also relies on community members to support the effort by participating in surveys, interviews or focus groups.

²⁷ Susan G. Komen Data Packs

²⁸ 2009 California Health Interview Survey

Methodology and Limitations

Komen San Diego's staff and Community Advisory Panel created this Community Profile using various data sources. This section describes the methodology for each section of the report and also discusses the limitations of the data.

Demographic and Breast Cancer Statistics

This section includes demographic and breast cancer data for California and San Diego County. Data from the following sources and years was used because this was what was available when collecting this data:

- California Cancer Registry: Data was collected from the website in January 2011
- California Health Interview Survey (CHIS) 2005, 2007 and 2009
- Susan G. Komen Data Packs: These packs were provided to the San Diego Affiliate by National, who obtains them from Thomson Reuters
- Cancer Facts and Figures, 2010

One of the limitations in using data from various sources and years is that comparisons between sources and years may not be exact. The most recent data as well as consistent data sources were used where possible.

Programs and Services

This section includes data from Susan G. Komen Data Packs, a list of providers generated by Komen San Diego and based on the San Diego Breast Cancer Resource Directory, and a Provider Survey. In creating the asset maps, efforts were made to ensure that all agencies and sites were included on the maps, however some agencies and sites may not be represented.

The Provider Survey was administered online. Respondents were given the opportunity to respond between January 11, 2011 and January 18, 2011. Approximately 210 individuals were invited to complete the survey. Of these individuals, 182 completed the entire survey.

Exploratory Data

The exploratory data included interviews and focus groups. Questions for the protocols were adapted from Komen National's suggested questions, and included questions relating to barriers to breast healthcare access, the strengths and challenges of the current breast healthcare system, programs and services that could improve the system, and ways in which Komen San Diego could make an impact.

Key informant interviews were conducted with 25 individuals associated with hospitals, support groups, community clinics, patient navigation programs, and organizations with an expertise in minority women or young survivors. All individuals were selected because they focused on one or more of the target areas selected by the Community Advisory Panel. Four focus groups were conducted with target area populations: African-American survivors, Latina survivors, young survivors, and patient navigators. A fifth focus group was conducted with a group of Somali and Ethiopian women who were not necessarily breast cancer survivors.

One of the limitations of this section is that the target areas were broad. One of the target areas of study – minority women – includes different groups – African-American, Latina, Asian/Pacific Islander and immigrant women. Given that each group is so broad (for example, refugee women can include Somalis as well as Iraqis), this Community Profile identifies areas of need based on the

stakeholders, survivors, and community residents interviewed. However, these needs may not apply to all minority women. Additionally, there are likely needs women have that are not identified in this report. This is also the case for needs identified for young breast cancer survivors.

Demographic and Breast Cancer Statistics

This section includes key demographic and breast cancer statistics for San Diego County. Data from a variety of sources was used because this was what was available when collecting data. This was one of the limitations of this study, as was discussed in the Methodology and Limitations section. Demographic data is described based on the race/ethnic categories used by the Department of Health and Human Services and the United States Census Bureau. Statistics were presented to the Komen San Diego Affiliate Community Advisory Panel in January 2009. Selected key statistics are included in the Community Profile based on feedback from the Community Advisory Panel and the San Diego Affiliate.

Key Demographic Statistics

Key demographic statistics include gender, age, race/ethnicity, and income.

Gender

Data from the 2009 Demographic Snapshot provided by Komen National indicates that just under half (49.7%) of San Diego County's population is female, with a total of 1,526,742 women in 2009. Exhibit 1 shows a breakdown of gender by HHS region. The South region has the most females, with 54.1%.

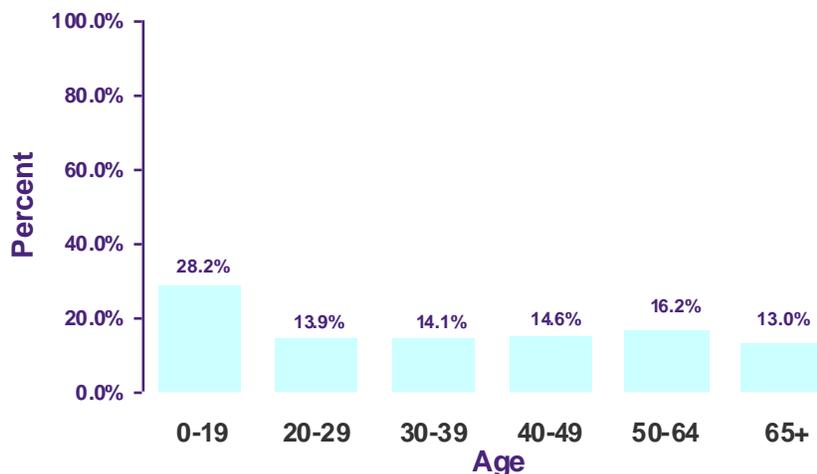
Exhibit 2 shows the age breakdown in San Diego County for the entire population as well as for females. Insurance companies generally cover an annual mammogram for a woman once she reaches 40 years of age. In San Diego County, 43.8% of women are over 40 years of age.

Exhibit 1: Gender by HHS Regions

	Male	Female
Central	54.3%	45.7%
East	49.0%	51.0%
North Central	47.4%	52.6%
North Coastal	50.6%	49.4%
North Inland	50.5%	49.5%
South	45.9%	54.1%
Countywide	49.7%	50.3%

Source: SANDAG Data Warehouse 2010

Exhibit 2: Percent of Females in Age Groups, San Diego 2010



Ethnicity

As Exhibit 3 indicates, countywide, the majority of the population (50.1%) was White²⁹, with Latinos being the second largest ethnicity (30.8%). San Diego County’s Latino population continues to grow faster than any other ethnicity. The only regions that did not have a majority White population were Central and South, which had the largest Latino populations compared to all the other regions. The largest Asian³⁰ population was concentrated in the North Central region at just over 18%, while the largest African-American³¹ population, at 10.5%, was in the Central region. In general, the Central region had the highest level of diversity, as evidenced in the relatively high percentage of all non-White ethnicities and the lower percentage of individuals identifying as white.

Exhibit 3: Ethnicity by HHS Region

	Latino	American Indian/Alaska Native	Asian	African American	White	Other single/ 2+ races
Central	32.2%	0.9%*	14.3%	10.5%	39.1%	2.9%
East	18.8%	0.8%*	4.0%	4.2%	69.4%	2.9%
North Central	7.9%	0.7%*	18.1%	3.0%	66.6%	3.8%
North Coastal	19.9%	0.7%*	5.0%	2.4%	68.6%	3.4%*
North Inland	17.2%	0.7%*	12.3%	1.4%	65.3%	3.1%
South	43.1%	0.2%*	12.1%	4.8%	35.2%	4.6%
Countywide	30.8%	0.6%	10.4%	4.7%	50.1%	3.4%

Source: SANDAG Data Warehouse 2010

Income and Insurance

The median annual income for a San Diego county family was \$62,468 (for a family of four) with 8.7% of families earning below the poverty level.³² Exhibit 4 shows County income by regions, and indicates that income in the Central was lower, with more people earning \$30,000 or less, compared to other regions. By contrast, over 20% of the population in each North Central, North Coastal, and North Inland earned over \$100,000 annually. Central, along with North Inland, had the highest rate of uninsured females compared to the entire County and other regions. Countywide, 11.7% of females were uninsured, while in Central 15.3% were uninsured and in North Inland 15.1% were insured.³³

²⁹ The data reviewed for this report frequently utilize the label of “White” to refer to the Caucasian population. Thus, this report has adopted the “White” label throughout.

³⁰ The data reviewed for this report presented the data both as “Asian” and “Asian/Pacific Islander.”

³¹ The data reviewed for this report call the African American population by various names including African American, non-Hispanic African American, and African-American. For the purposes of this report, we utilized the category as identified by the data source.

³² Susan G. Komen Data Packs prepared by Thomson Reuter

³³ 2005 California Health Interview Survey

Exhibit 4: Income by HHS Region

HHS Region	Under 15K	15K-30K	30K-50K	50K-70K	70K-100K	Over 100K
Central	19.2%	27.8%	18.8%	15.6%	9.6%	9.0%
East	8.7%	21.7%	21.4%	17.1%	17.2%	13.8%
North Central	7.5%	13.6%	20.0%	15.7%	21.1%	22.0%
North Coastal	10.6%	19.2%	16.2%	11.3%	16.8%	25.9%
North Inland	6.8%	16.4%	18.6%	17.3%	18.3%	22.6%
South	12.2%	15.5%	20.6%	23.4%	15.0%	13.3%
Countywide	10.6%	18.8%	19.2%	16.5%	16.6%	18.2%

Source: 2005 California Health Interview Survey

Key Breast Cancer Statistics

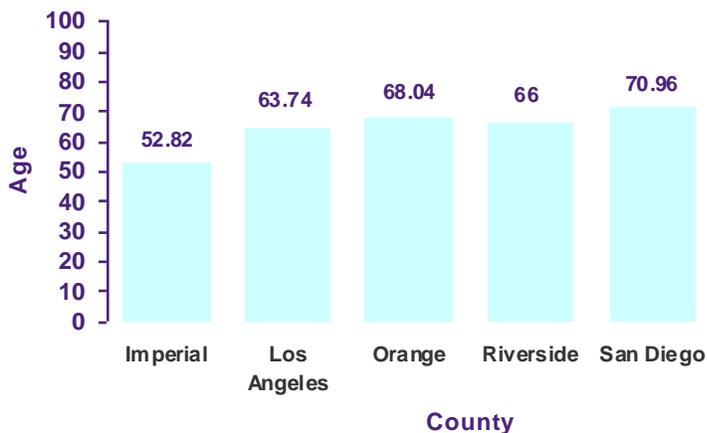
This section presents statistics in four parts: breast cancer incidence, mortality, early detection, and screening. Rates for incidence, mortality, and early detection are age adjusted and are presented as rates per 100,000 population. Using age-adjusted rates controls for differences in ages among different groups (ethnicities and counties, for example), and is beneficial when comparing groups to each other. Similarly, using the rate of disease per 100,000 allows for comparison between ethnic groups and counties as it controls for population differences.

Incidence

Breast cancer was the most common cancer among women in California, regardless of race/ethnicity. In 2011, it is expected that there will be 22,115 new cases of breast cancer for females in California. For males in 2011, there will be an expected 150 new cases. Additionally, of the 12,490 expected new cases of all cancers in San Diego County for 2011, 15.7% (1,960) are expected to be breast cancer.³⁴ San Diego has the highest incidence rate (163.95 per 100,000) compared to neighboring counties, as is shown in Exhibit 5. Its incidence rate is also above that of the State (151.82 per 100,000). Because they represent rates per 100,000, they control for population differences in groups, and allow for comparison between groups.

³⁴ California Cancer Facts and Figures, 2009

Exhibit 5: Average Annual Age-Adjusted Breast Cancer Incidence Rates for Females, by County 2001-2008



Source: California Cancer Registry

Within San Diego County, incidence rates vary, as is shown in Exhibit 6. The higher the incidence rates within a zip code, the darker the shade of pink. The five zip codes with the highest incidence rate are also indicated on the map below, and Exhibit 7 describes these five zip codes in greater detail, including the ethnic breakdown and median household income of these areas.

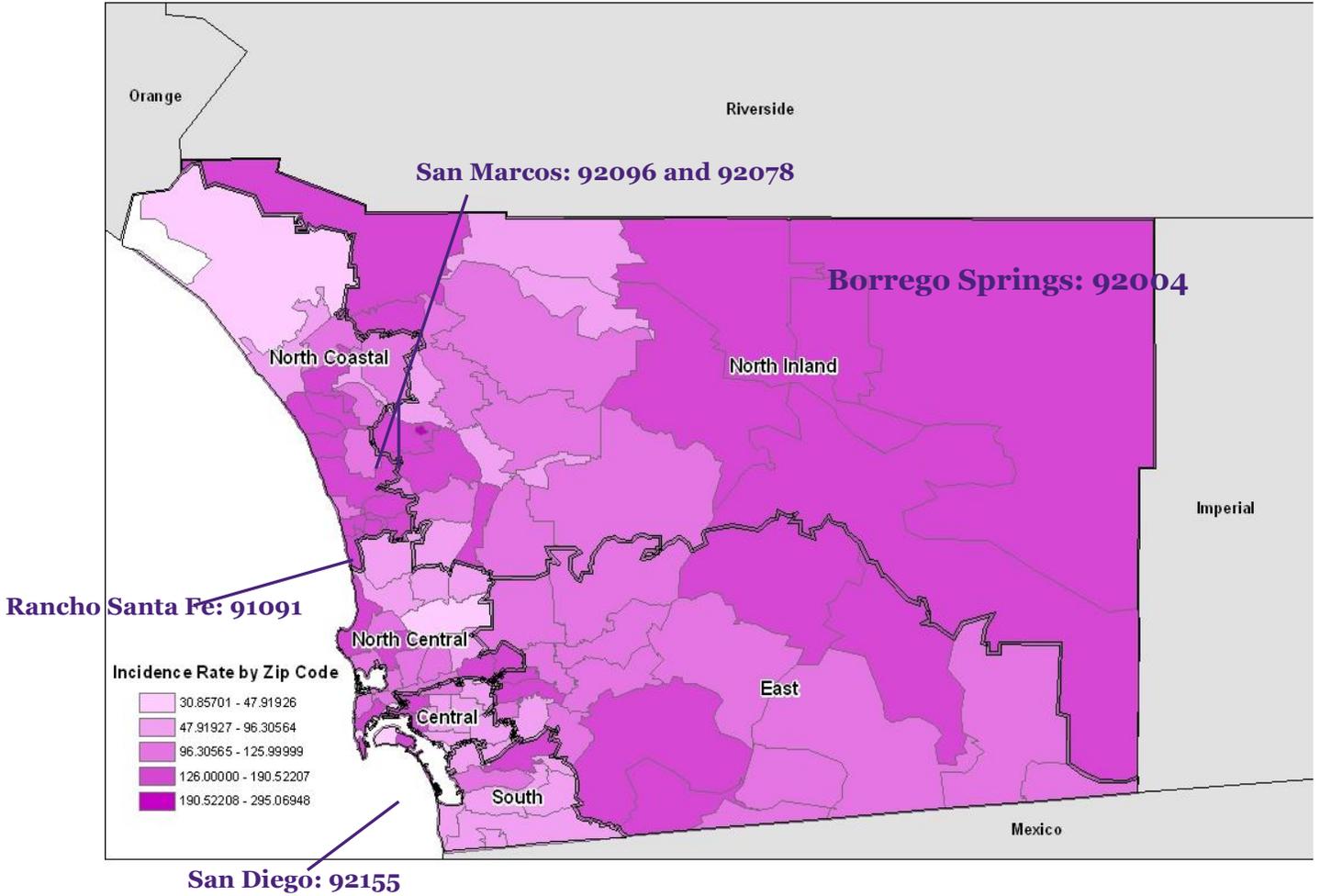
Although the zip code with the highest incidence rate was in South (the city of San Diego), out of the five zip codes with the highest incidence rate, three were in North Inland (the cities of San Marcos and Borrego Springs) and one was in North Coastal (the city of Rancho Santa Fe). The ethnic make-up of each city varies: San Diego was predominately White and Asian, San Marcos was primarily Hispanic and White, Rancho Santa Fe was primarily White, and Borrego Springs was predominately Hispanic and White. The median household incomes in these cities ranged from \$46,107 to \$210,547. Although the data indicates the ethnic make-up of and income of each city, it does not reveal the income and ethnicity of women in these regions with breast cancer. Thus, it is not possible to draw concrete conclusions about the specific needs of women in these cities. It is likely, however, that given the diversity, needs could vary. Some women in these areas, for example, may be in need of financial and insurance assistance, while others are in need of other types of support such as survivor support groups.

Area for Future Research: Cities with High Incidence and Mortality

Although Exhibit 7 reveals the demographic characteristics of the San Diego zip codes/cities with high incidence and mortality, it does not reveal the demographic characteristics of the women in these cities with breast cancer. Exploring these areas further would reveal more about the needs of women in these areas.

Exhibit 6: San Diego Incidence Rates by Zip Code

San Diego County Estimated 2007 Age-Adjusted Female Breast Cancer Incidence Rates by Zip Code



Source: Susan G. Komen Data Packs prepared by Thomson Reuters

Note: The zip codes and cities labeled on the map indicate the areas with the highest breast cancer incidence and mortality rates.

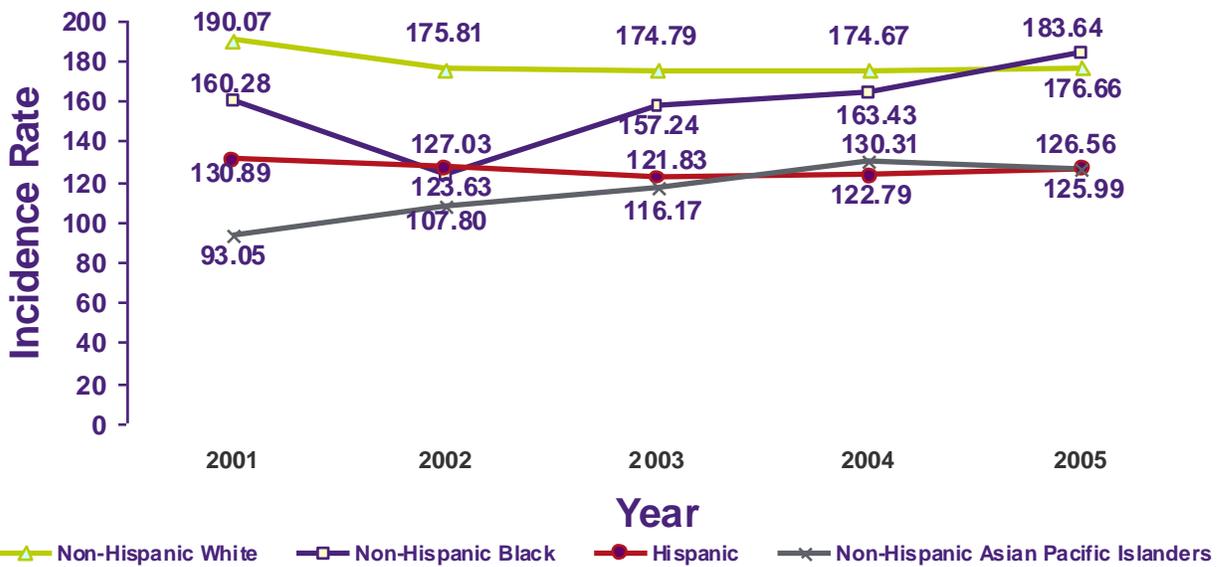
Exhibit 7: Profile of Zip Codes with the Top Five Breast Cancer Incidence and Mortality Rates

Zip Code	City	Incidence Rate Per 100k	Mortality Rate Per 100k	Overall Income		Overall Ethnicity for Zip Code				Overall Age Group for Zip Code					
				Median Income	Below Poverty Level	Asian	African American	Latino/Hispanic	White	Age 0-19	Age 20-29	Age 30-39	Age 40-49	Age 50-64	Age 65+
92155	San Diego (Silver Strand)	279.959	75.0321	\$92,593	0.0%	2.3%	0%	16.6%	80.4%	5.6%	4.3%	3.8%	5.0%	17.0%	64.4%
92004	Borrego Springs	166.132	40.0117	\$46,107	10.0%	0.4%	1.1%	38.3%	58.6%	20.6%	10.3%	9.5%	10.4%	20.9%	28.3%
92078	San Marcos (North)	158.429	38.5933	\$64,702	3.3%	5.8%	1.6%	21.2%	68.5%	24.7%	9.4%	9.8%	13.0%	16.2%	26.8%
92067	Rancho Santa Fe	156.818	34.9912	\$210,547	2.8%	4.3%	0.2%	3.7%	89.8%	24.0%	12.9%	4.2%	10.0%	29.0%	19.8%
92106	San Diego (Pt Loma)	154.047	35.1541	\$87,002	3.8%	3.2%	1.6%	8.3%	83.2%	20.0%	12.1%	11.7%	12.8%	23.9%	19.6%
92120	San Diego (Allied Gardens)	152.936	35.2775	\$73,922	1.9%	5.3%	2.9%	11.5%	76.6%	20.3%	10.9%	1.2%	14.0%	21.2%	21.7%

Source:

When explored by race/ethnicity the incidence rates varied from 2001-2005 for Non-Hispanic Whites, Non-Hispanic African Americans, Hispanic/Latinos, and Non-Hispanic Asian/Pacific Islanders (see Exhibit 8). Overall, incidence rates were the highest among African Americans, followed by Whites, Hispanics, and Asian Pacific Islanders. Examining the trends for the past five years more closely, incidence rates for White females and Hispanics decreased, while incidence rates for African Americans and Non-Hispanic Asian/Pacific Islanders increased. Given the fact that incidence rates were highest for Whites and African Americans, and increased for Asian/Pacific Islanders, these communities may be in need of more education and services.

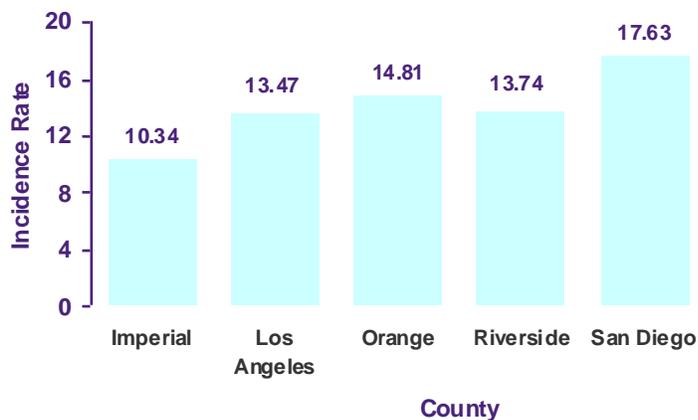
Exhibit 8: San Diego County Female Age-Adjusted Breast Cancer Incidence Trends by Race/Ethnicity



Source: California Cancer Registry
In Situ (Non Invasive) Incidence

The rate of breast cancer diagnosed in situ, at an early stage, when the cancer is non-invasive, can be an indication of early detection and screening. Exhibit 9 shows the rate of non-invasive (in situ) breast cancer incidence diagnoses for San Diego and neighboring Counties. Compared to neighboring Counties, San Diego had the highest rate of breast cancer in situ incidence, higher than that of the state, meaning that there is a higher incidence of breast cancer diagnosed at an early stage in San Diego County. It is important to note that because San Diego's overall incidence rate (Exhibit 5) is higher, its in-situ incidence rate is higher. High in situ incidence does not imply that women in San Diego with breast cancer are necessarily being diagnosed sooner than women in other parts of the County. Rather, it implies that per 100,000 women, more women in San Diego are diagnosed with non-invasive breast cancer. The section on screening and early stage diagnosis provides more information on the percentage of women being screened and diagnosed at an early stage.

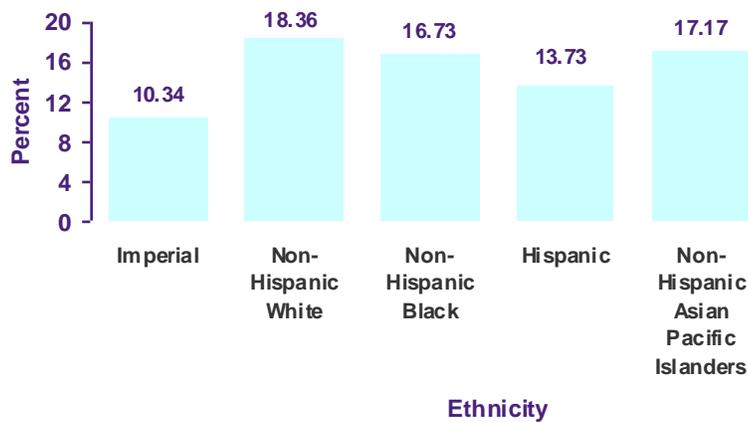
Exhibit 9: Average Annual Age-Adjusted Breast Cancer *In Situ* Incidence Rates for Females, 2001-2008



Source: California Cancer Registry

Exhibit 10 shows the in situ incidence trends by ethnicity for San Diego County. In situ incidence trends were similar to incidence trends, with African Americans and Whites having the highest in situ incidence, followed by Hispanics and Asian/Pacific Islanders. From 2001-2008, in situ incidence increased for Hispanics and Asian/Pacific Islanders but decreased for Whites. From 2003-2005, in situ incidence increased for African Americans.

Exhibit 10: San Diego County Female Age-Adjusted Breast Cancer In Situ Incidence Trends by Race/Ethnicity * 2001-2008



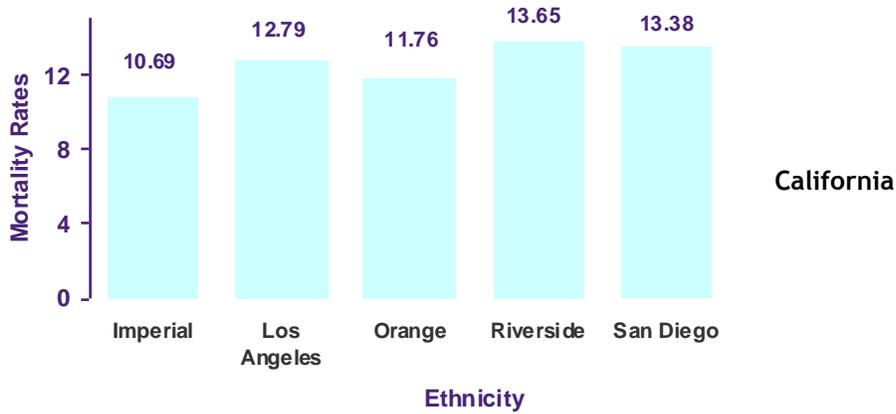
Source: California Cancer Registry

* No data for 2004 NH African American and 2003 NH API. Counts are suppressed if fewer than 15 deaths were reported in the specific category.

Mortality

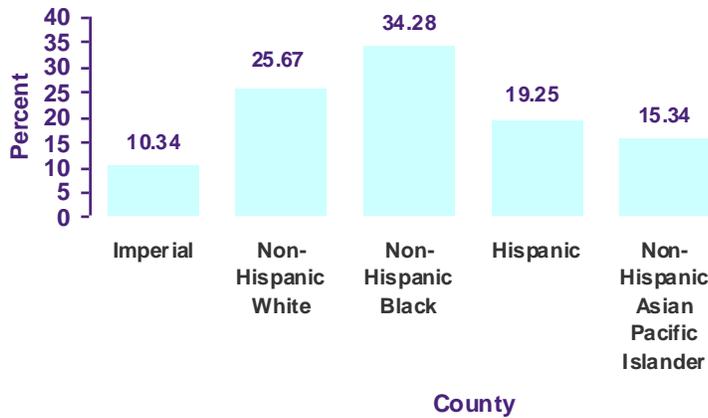
Exhibit 11 shows breast cancer mortality trends from 2001 through 2008 for females in San Diego by race/ethnicity. Mortality rates for African Americans were the highest, followed by Whites, Hispanics, and Asian Pacific Islanders. From 2001 to 2005, mortality rates for White females and Asian/Pacific Islanders decreased, while rates for African Americans and Hispanics increased. It is important to note that in 2005 the mortality rate for African Americans was more than double that of any other race. Increased treatment resources may need to be directed to the African American and Hispanic community to address the increase in mortality as well as the especially high mortality rate in the African American community.

Exhibit 11: Average Annual Age-Adjusted Breast Cancer Mortality Rates for Females 2001-2008



Source: California Cancer Registry

Exhibit 12: 2001-2008 San Diego County Female Age-Adjusted Breast Cancer Mortality Trends by Race/Ethnicity *



Source: California Cancer Registry

* No data for 2004 NH African American and 2003 NH API. Counts are suppressed if fewer than 15 deaths were reported in the specific category.

Area for Future Research: Income and Breast Cancer

This community profile examines breast cancer incidence, mortality, early screening and detection by race, but does not examine the majority of these statistics by income level. Additionally, even in cases where income is briefly explored, the relationship between race and income is not accounted for. Research that explores income more thoroughly would be beneficial in determining what types of services and support women need.

The percent of breast cancer diagnosed at an early stage is an indication of screening and early detection. This data represents percentages of women, and the population size for each group

varies. According to Cancer Facts and Figures (see Exhibit 13), in San Diego County, 71% of White women were diagnosed with breast cancer at an early stage (stage 1) compared to 65% of African Americans, 63% of Hispanics, and 68% of Asian/Pacific Islanders. Statistics for San Diego County were comparable to data for the entire state. Another data source, the Susan G Komen Data Packs, divided ethnic groups into three categories – White, African American, and other – and this data indicated that a greater percentage of African Americans in San Diego County were diagnosed at an early stage (52.2%) compared to Whites (65.4%) and other (63.2%). This data also revealed that a higher percentage of African Americans were diagnosed at stage 4 (8.0%) compared to Whites (4.2%) and other races (4.2%), which likely contributes to the high breast cancer mortality rate among African American women. Both data sources suggest that early detection resources were needed in minority communities, especially the African American and Hispanic communities.

Exhibit 13: Percent of Women Diagnosed with Breast Cancer at Early Stage (Stage)

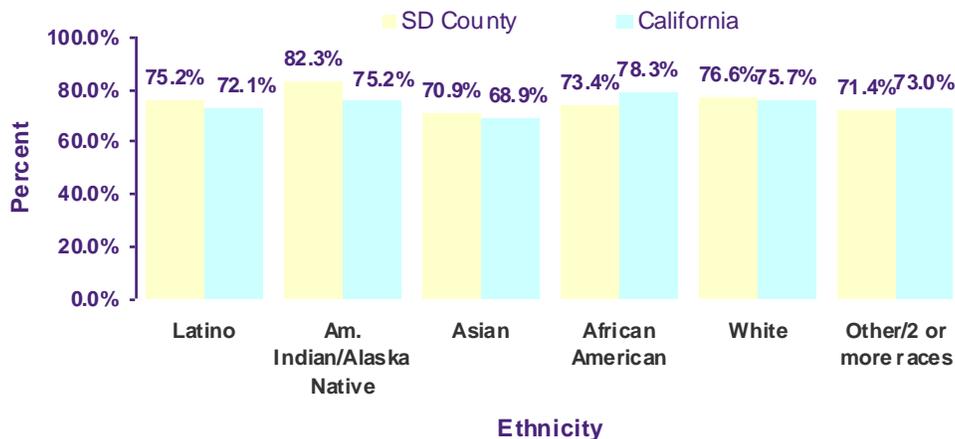
	NH White		African American		Hispanic		Asian/Pacific Islander	
	Cases	%Early	Cases	%Early	Cases	% Early	Cases	%Early
San Diego	3,860	71%	157.14	65%	126.19	63%	121.59	68%
California	39,581	70%	1,647	61%	3,813	63%	2,713	70%

Cancer Facts and Figures, 2010.

Related to early detection is screening, including clinical breast exams and mammograms. It is important to note that screening data includes only women age 30 or older or women age 40 or older (see graphs and narrative for specifics). Overall, 75.5% of San Diego County women received clinical breast exams in the past year, which was slightly higher than the overall California percentage of 74.1%.

Exhibit 14 shows the percentage of women who received a clinical breast exam by ethnicity. In San Diego County, American Indian/Alaskan Native (82.3%) most commonly received clinical breast exams, followed by Whites (76.6%), Latinos (75.2%), African-Americans (73.4%), and Asians (70.9%). The low rate of clinical breast exams in the Asian/Pacific Islander and African-American community may indicate the need for increased education about the importance of annual doctor's visits.

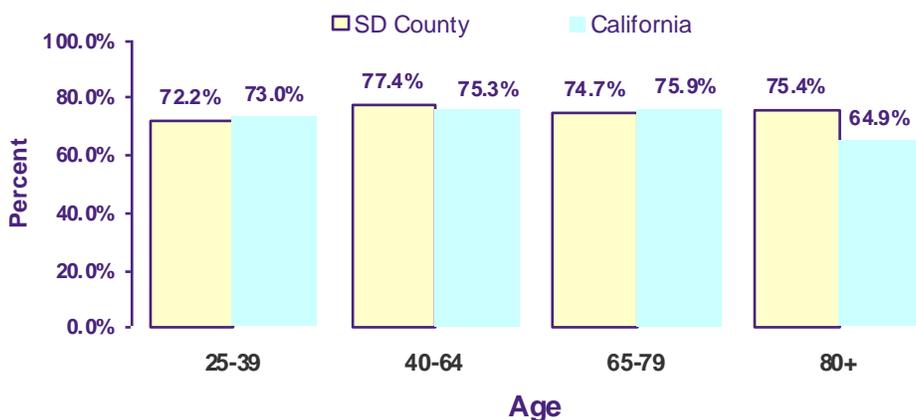
Exhibit 14: Clinical Breast Exam Performed in the Last 12 Months by Race/Ethnicity



Source: 2009 California Health Interview Survey
 Note: Includes women 30 years or older

Exhibit 15 shows the percent of women who received clinical breast exams by age groups. In San Diego County, the group with the fewest women screened was women ages 25-39 and the group with the most women screened was women ages 40-64. This suggests that younger women were either less likely to visit the doctor annually or were not receiving the same care at the doctor, and indicates a need for increased education for both younger women and providers about the importance of clinical breast exams for all age groups.

Exhibit 15: Clinical Breast Exam Performed in the Last 12 Months by Age Group



Source: 2009 California Health Interview Survey
 Note: Includes women 25 years or older

Exhibit 16 shows the percentages of women age 40 or older who had mammograms within the past two years, more than two years ago, and never by ethnicity. Similar to California as a whole, results indicate that 24.1% of San Diego women never had a mammogram. The ethnic groups that are least likely to have mammograms were Latinos, Asians, women of two or more races, and American-Indians/Alaskan Natives. Over 30% of women in each of these groups said they had never had a mammogram. On the other hand, Native-Hawaiian/Pacific Islanders, Whites, and African-Americans

were most likely to have mammograms, with at least 65% having one within the past two years. The low rate of mammogram use in Asian, Latino, and American-Indian communities indicates a need for increased education about the importance of receiving annual mammograms.

Exhibit 16: Mammogram Screening History, 2009

	San Diego County			California		
	Never	Within 2 Years	More than 2 Years	Never	Within 2 Years	More than 2 Years
White	18.2%	68.8%	13.0%	17.2%	69.4%	13.4%
Latino	37.3%	51.8%	10.9%	33.7%	54.9%	11.5%
African-American	20.5%	66.3%	13.2%	17.5%	69.0%	13.5%
Asian	35.3%	53.9%	10.8%	27.3%	57.1%	15.5%
Native Hawaiian/Pacific Islander	14.8%*	85.2%	--**	12.3%*	68.2%	19.5%*
American-Indian./Alaskan Native	30.5%*	66.9%	--**	17.2%	66.2%	16.7%
Two or More Races	33.7%	48.7%	17.6%*	29.0%	58.2%	12.9%
All	24.1%	63.7%	12.2%	23.2%	63.6%	13.2%

Source: 2009 California Health Interview Survey

Note: Includes women age 40 or older

*Percentage statistically unstable **Estimate less than 500 people

The ethnicity of women who receive clinical breast exams versus mammograms varied slightly. With the exception of American Indians, White women were more likely than minority women to be screened. Latinos were more likely to have clinical breast exams than African-Americans and Asians, but less likely to have mammograms than these two groups. Asians were among the least likely to have either clinical breast exams or mammograms compared to other ethnicities. Next to

White women, African-Americans were the most likely to receive a mammogram, while they were less likely than American Indians, Whites, and Latinas to receive clinical breast exams.

Income and Region

In addition to the impact of ethnicity, data also indicated that just over half (50.7%) of women in San Diego County who had never had a mammogram earned under \$40,000 per year and 22.3% were uninsured, suggesting that access to health care may be a deciding factor in having mammograms. Additionally, regionally, North Coastal had the highest percentage of women receiving clinical breast exams (79.5%), followed by North Inland (77.7%), North Central (77.2%), South (75.1%), East (72.3%), and Central (68.9%).³⁵ Further research is necessary to explore the relationship between ethnicity, income, and region.

³⁵ 2005 California Health Interview Survey

Demographic and Breast Cancer Statistic Implications

Exhibit 17 summarizes incidence, mortality and in situ incidence in San Diego County and California. As was discussed in this section, incidence and in situ incidence rates were the highest for White women, while mortality was the highest for African American women. In fact, mortality among African American women was almost double the rate for any other ethnic group. Trends indicated that while incidence decreased in the Hispanic community, mortality increased. The opposite was true for Asian/Pacific Islanders, for whom incidence increased and mortality decreased.

Exhibit 17: State and San Diego County Age-Adjusted Breast Cancer Incidence, Mortality, and In Situ Incidence Rates for Females, 2001-2005

	Incidence		Mortality		In Situ Incidence	
	San Diego	California	San Diego	California	San Diego	California
Non-Hispanic White	178.43	174.47	27.31	26.00	33.40	30.90
Non-Hispanic African American	157.63	147.32	35.51	34.74	31.44	24.61
Hispanic	125.36	105.73	18.83	17.10	25.22	18.15
Non-Hispanic Asian/Pacific Islander	115.75	112.65	15.59	14.14	25.96	24.25
All	163.95	151.82	25.28	23.68	31.77	27.11

Source: 2005 California Health Interview Survey

This data coupled with the fact that minority women, particularly African-Americans, were less likely than White women to be diagnosed at an early stage indicates a need for increased education and screening in minority communities. Asians, Latinos, and African-Americans were less likely to receive clinical breast exams and mammograms compared to White women, with the receipt of mammograms being particularly low in the Asian/Pacific Islander and Latino communities. There was also evidence that women under the age of 40 were less likely to receive clinical breast exams compared to older women, which suggests a need for increased education in this cohort.

Regionally, the South region (in the city of San Diego), North Inland (Borrego Springs and San Marcos), and North Coastal (Rancho Santa Fe) had the highest incidence and mortality rates. Ethnicity and income within these cities varied. Overall, additional research about how ethnicity and income relate to one another, in addition to the ethnicity and income of the women with breast cancer residing in the high incidence areas of San Diego is needed.

Based on the data presented in this section as well as the expert opinions and experiences of stakeholders and the advisory group members, the Community Advisory Panel chose to focus on three target areas:

1. Minority women (including African-Americans, Latinas, Asian/Pacific Islanders, Native Americans and immigrant women) with a focus on the low income and un/underinsured;
2. Young survivors (women diagnosed before the age of 40) with a focus on the low income and un/underinsured; and
3. Breast healthcare providers

Programs and Services

The programs and services section of the report includes asset maps detailing the types of providers and services available across the County. It also reports the results of the Provider Survey. The purpose of this section is to illustrate the assets within the County and highlight areas of need, especially as related to the three selected target areas: 1) Minority women (including African-Americans, Latinas, Native Americans, Asian/Pacific Islanders, refugee women, immigrants, lesbians, and transgender women and men) with a focus on the low income and un/underinsured; 2) Young survivors (women diagnosed before the age of 40) with a focus on the low income and un/underinsured; and 3) breast health care providers.

As was discussed in the Methodology and Limitations section, the asset maps were created using data from the Susan G. Komen Data Packs as well as a list of providers generated by Komen San Diego and based on the San Diego Breast Cancer Resource Directory. The Provider Survey was developed based on preexisting surveys provided by Susan G Komen National and then modified to address San Diego specific issues of concern by the Community Advisory Panel. The following section highlights the needs and assets in San Diego by programs and services, and then by population.

Needs and Assets by Programs and Services

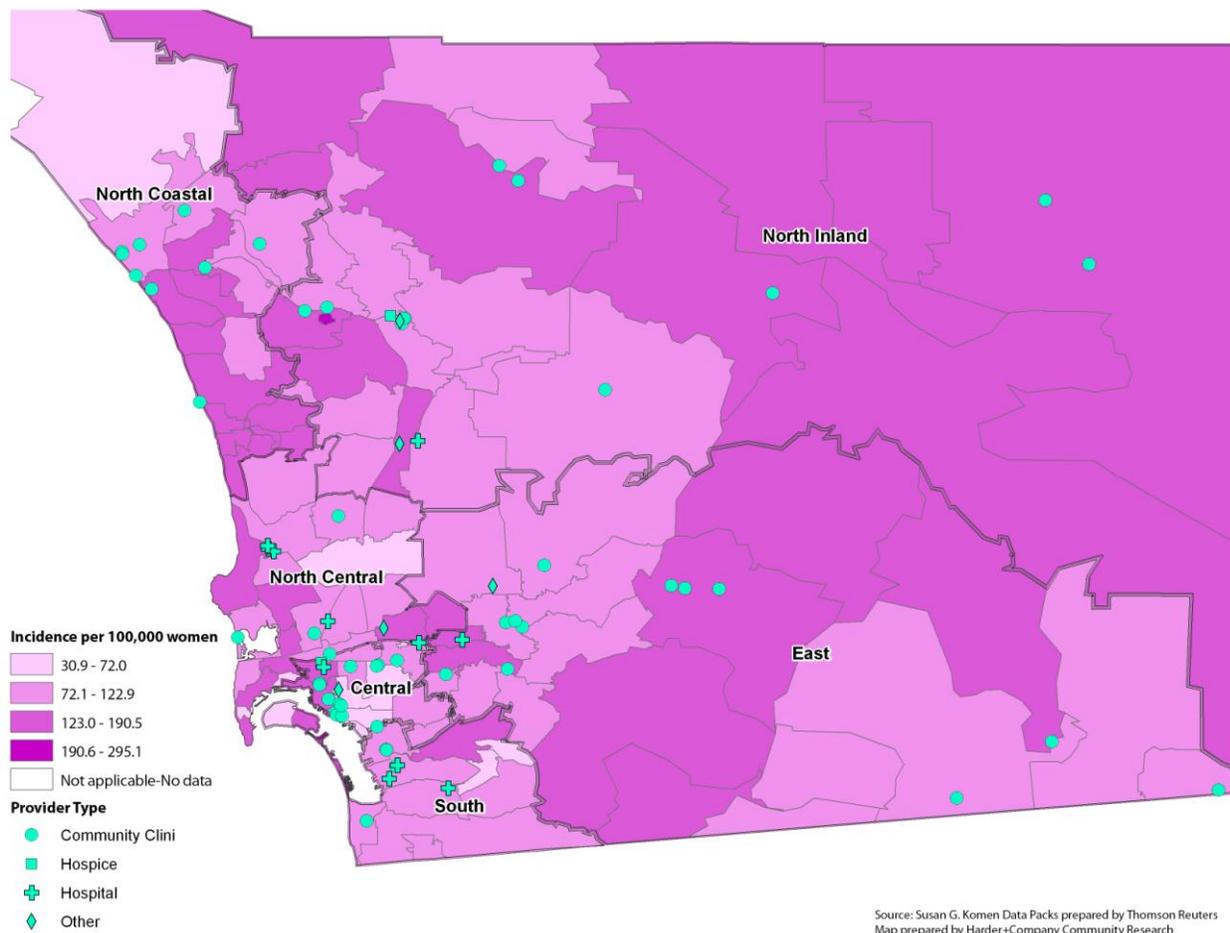
This section uses maps and Provider Survey results to illustrate the types of services provided in the County and to identify needed services. The various types of services include prevention (education/outreach), screening, diagnostic, treatment, support services, and financial assistance. Availability of many services corresponds to regional population density: Central has the highest population density, followed by South, North Central, North Coastal, East and North Inland.³⁶

³⁶ County of San Diego Healthy and Human Service Strategic Planning & Operational Support: Office of Strategy Management. Ethnic Composition and Population Density of San Diego County. San Diego. 2007.

Asset Maps

Exhibit 18 shows the providers offering direct services (screening, diagnosis, and treatment) throughout San Diego County. Overall, community clinics are the most common direct service provider type, followed by hospitals. Hospice care is much rarer, with only two providers in the County. Direct services were located throughout the County, but were sparser in North Inland and East, which corresponds to the population density in these regions. It is important to note that the cities/zip codes with the highest incidence and mortality rates had direct services within the zip code or in a nearby zip code. However the only direct services available in North Coastal, North Inland, and East were screening services; diagnosis and treatment were not available in these three regions.

Exhibit 18: San Diego County 2007 Age-Adjusted Female Breast Cancer Incidence Rate and Direct Services Provider Type



In terms of education/outreach and screening Exhibit 19 shows these services and programs by incidence. Education/outreach and screening occurred throughout the County, with the majority of providers offering both screening and education/outreach. Services were sparser in North Inland and East, which corresponds to the population density in these regions, compared to other regions. As was the case with direct services, the cities/zip codes with the highest incidence and mortality rate offered screening, education, and outreach within the zip code or a nearby zip code.

Exhibit 19: San Diego County 2007 Age-Adjusted Female Breast Cancer Incidence Rates and Provider Type (Education, Outreach, and Screening)

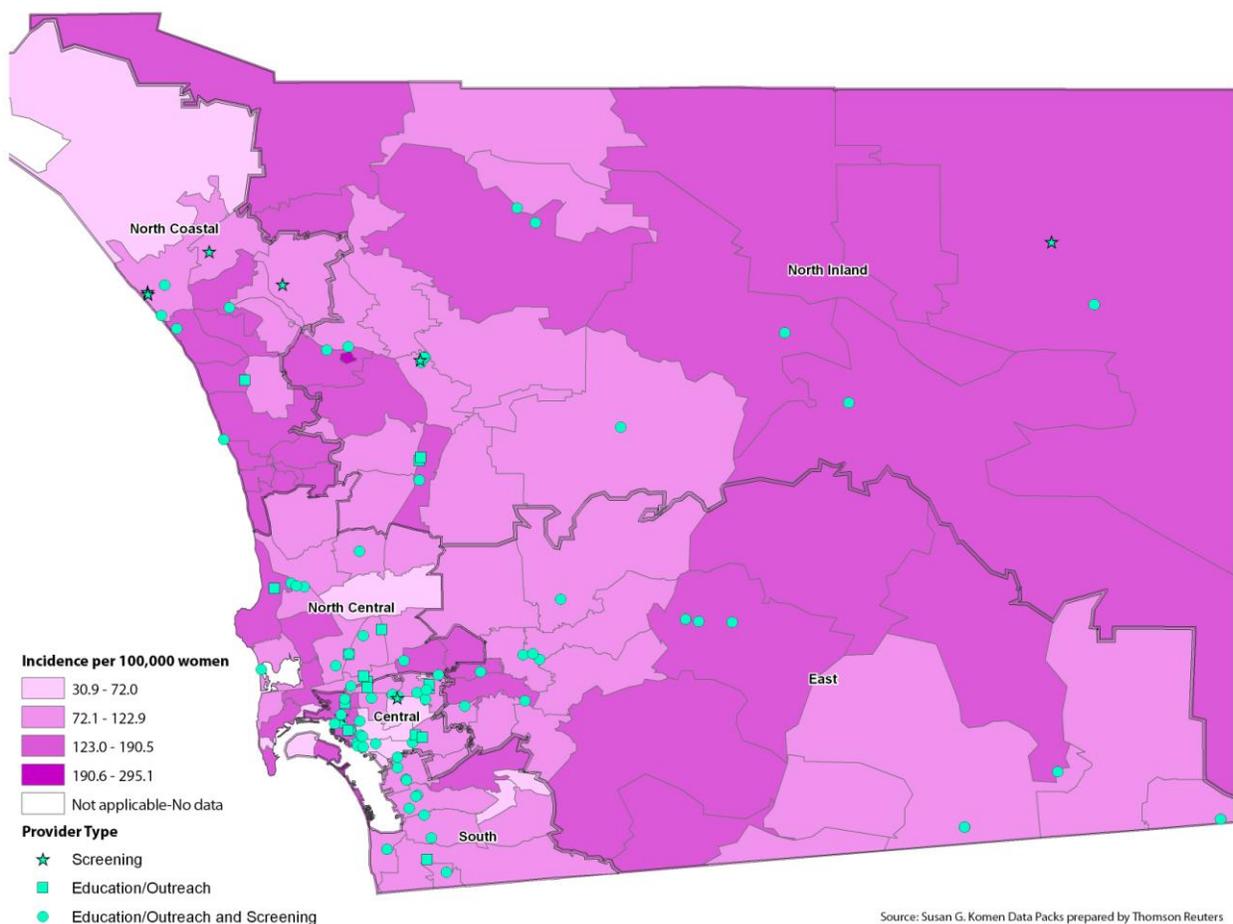


Exhibit 20 shows diagnosis, treatment, and hospice sites throughout the County. As the map indicates, diagnosis and treatment services were generally offered by the same providers, and there were only two providers offering hospice services in the County. There were no diagnosis or treatment sites in or nearby Borrego Springs or Rancho Santa Fe, two of the cities with a high incidence and mortality rate.

Exhibit 20: San Diego County 2007 Age-Adjusted Female Breast Cancer Incidence Rates and Provider Type (Treatment)

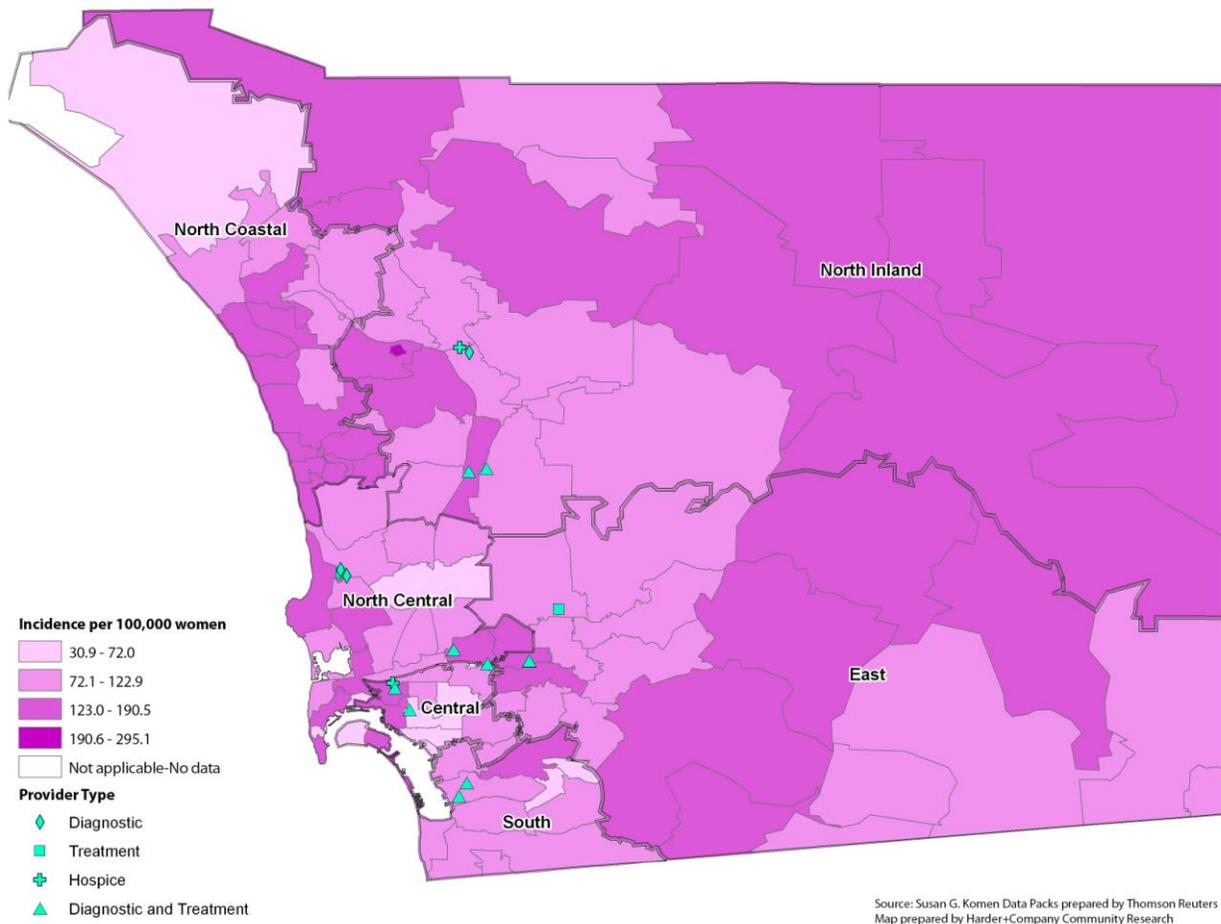
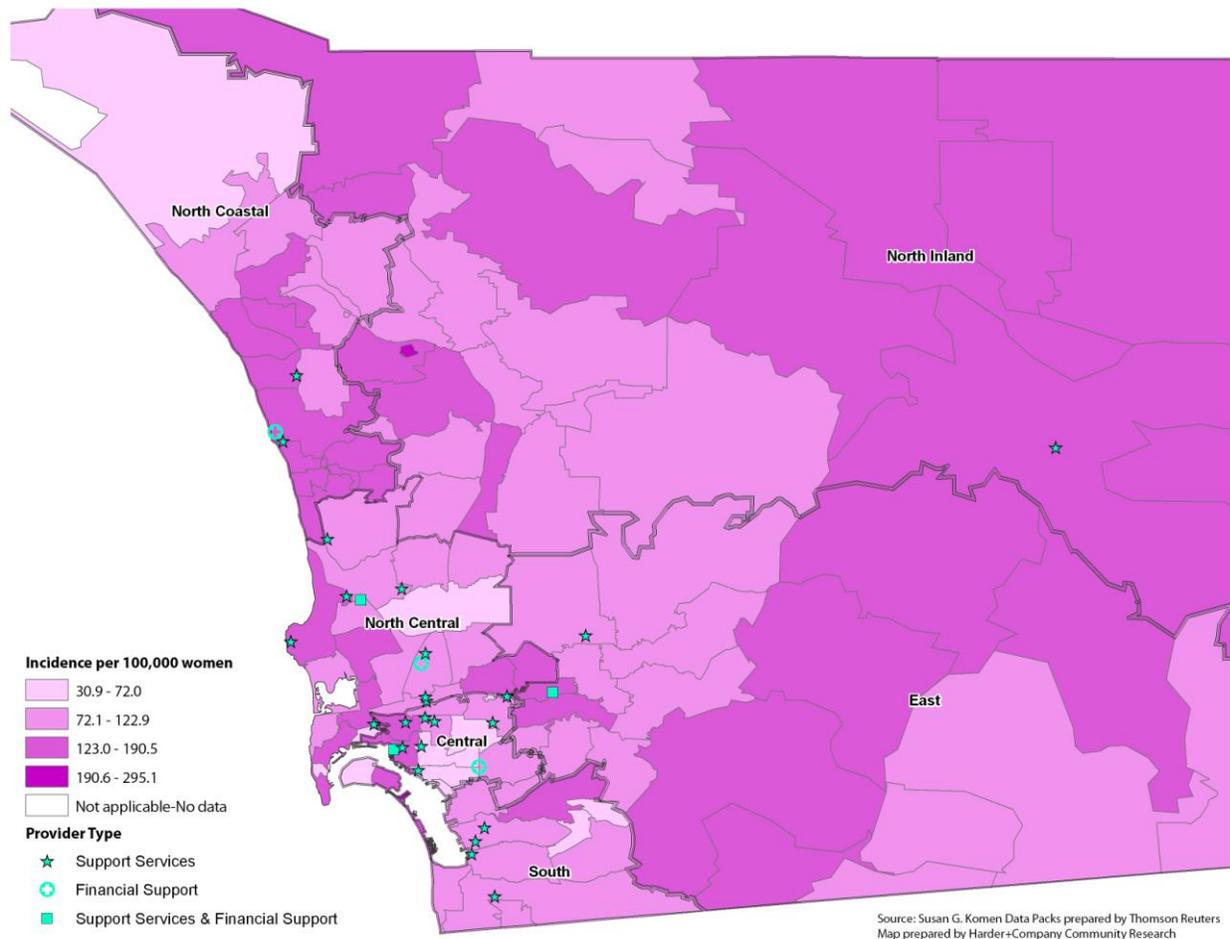


Exhibit 21 shows support and financial services available to breast cancer survivors. The majority of providers are based in Central, North Central, and South. Only a few providers offered financial support, while general support services are more common. This map shows only administrative sites for many of the support services; however some of these services may be available throughout the County.

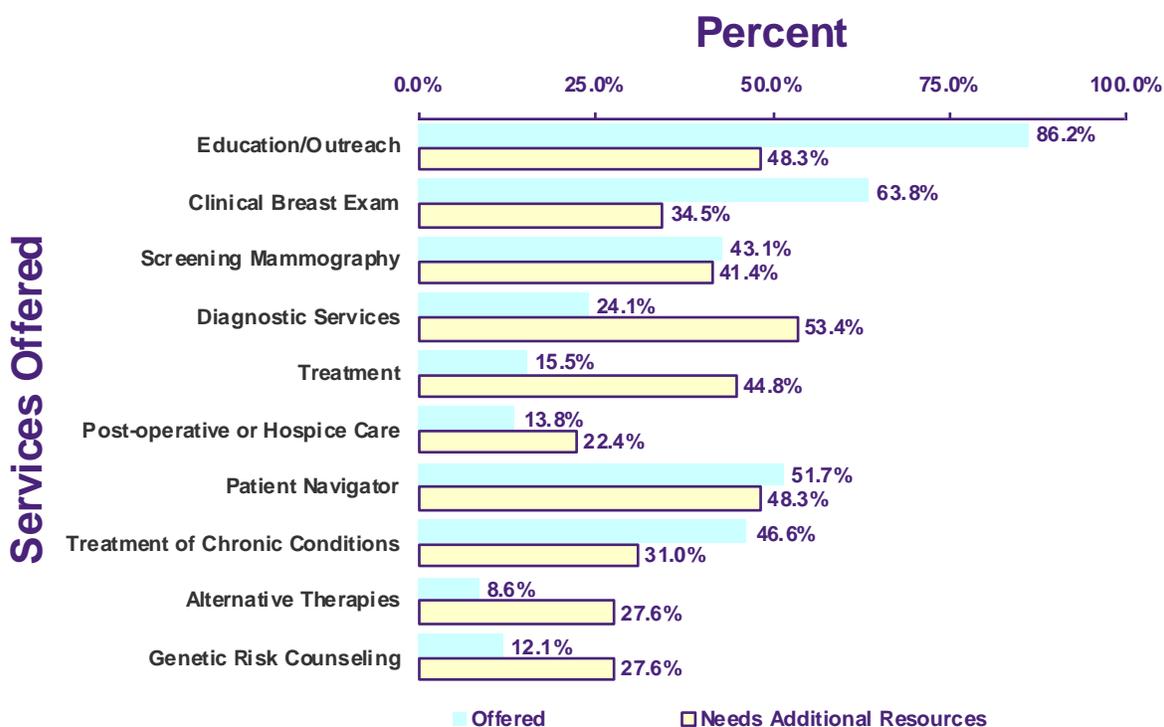
Exhibit 21: San Diego County 2007 Age-Adjusted Female Breast Cancer Incidence Rates and Support Services



Providers' Perspectives

Providers were asked which services were offered by their agencies and which services they thought needed more resources. According to the results, education/outreach and clinical breast exams were the most common services offered by providers (see Exhibit 22), which corresponds with the number of education/outreach providers throughout the County. It is important to note that less than 25% of respondents reported that their programs offered diagnostic services, treatment, or post-operative or hospice care. These findings correspond with the asset maps. Additionally, diagnostic services, education/outreach, patient navigation, and treatment were the areas identified as most needing additional resources.

Exhibit 22: Breast Health Education, Screening and Medical Services Offered (N=58) *



*Responses are not mutually exclusive.

Providers also indicated which types of support services and assistance they offered and felt needed additional resources. As is shown in Exhibit 23, support groups were the most commonly offered support service, while financial support and meals were least common. Compared to education, screening, and treatment, fewer providers overall offered support services (15.5%–86.2% compared to 1.7%–44.8%). However, none of the providers indicated that support services needed additional resources. Financial assistance, on the other hand, was noted as an area in need of additional resources by over three-fourths (75.9%) of survey respondents (see Exhibit 24). Yet, only 20.7% of respondents noted that they offer financial assistance and 39.6% noted offering insurance assistance. This corresponds with the asset maps, which indicate that only two providers offer financial support in the County.

Exhibit 23: Support Services Offered and Needing Additional Resources (N=58) *

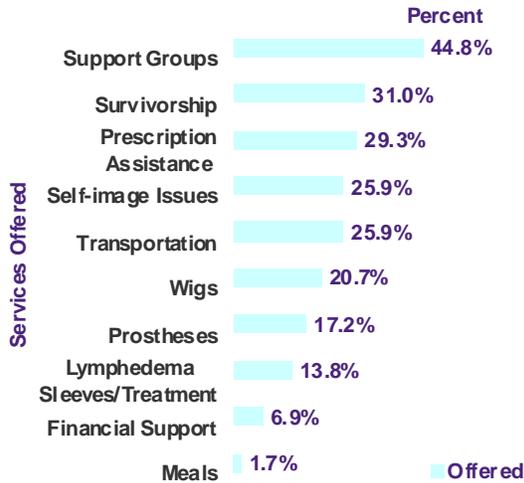
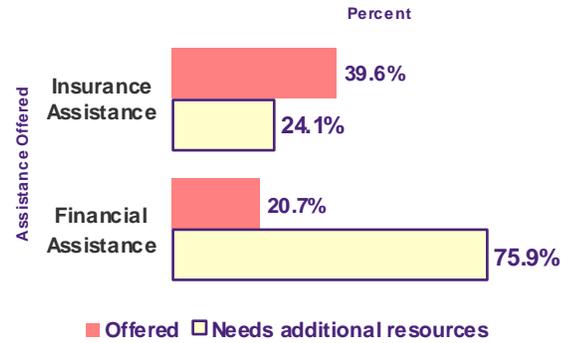


Exhibit 24: Assistance Offered and Needing Additional Resources (N=58) *

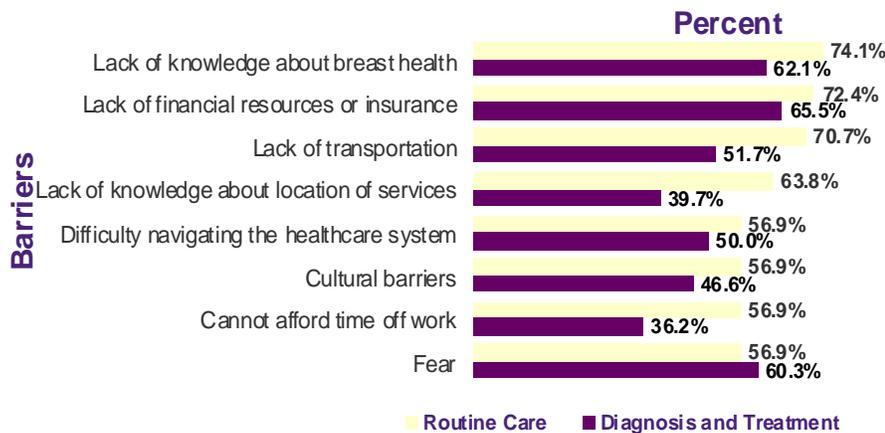


*Responses are not mutually exclusive.

Barriers to Care, Diagnosis, and Treatment

Providers were asked to identify barriers to receiving routine care as well as diagnosis and treatment. Overall, providers identified more factors as barriers to receiving routine care than in diagnosis and treatment. Exhibit 25 shows the top five barriers for each type of care. Common barriers include lack of knowledge about breast health, lack of financial resources, lack of transportation, difficulty navigating the healthcare system, and fear.

Exhibit 25: Primary Barriers to Routine Care and Diagnosis and Treatment (N=58)*



*Responses are not mutually exclusive.

Needs by Population

Minority Women

The provider survey asked respondents about the needs of individuals from various racial/ethnic groups as well as the needs of immigrants. The top five groups identified as most needing resources are shown in Exhibit 26 and Exhibit 27. Most providers identified Mexicans as the ethnic and the immigrant group most in need of resources (the survey separated Mexicans from other Latinos in order to collect more specific information). Other racial/ethnic groups in need of resources were African American/African Americans, Whites, Filipino, and Other Latinos. Immigrant groups in need of resources included Vietnamese, Somali, Filipino, and Iraqi/Kurdish/Chaldean.

Exhibit 26: Top 5 Ethnic Groups Needing Resources (N=58) *

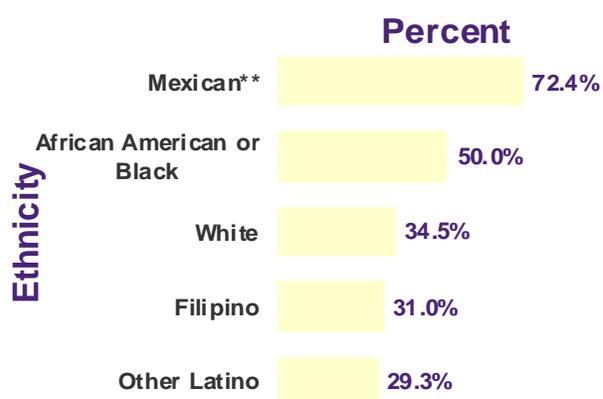
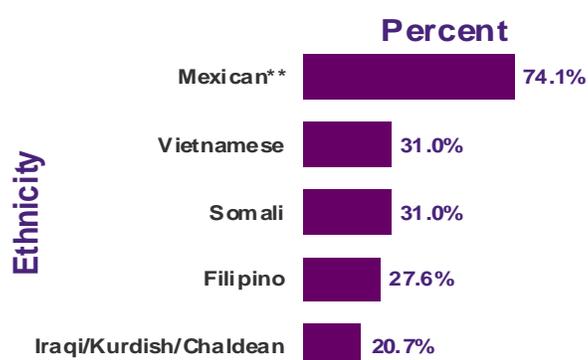


Exhibit 27: Top 5 Immigrant Groups Needing Resources (N=58)*



*Responses are not mutually exclusive.

**Mexicans were separated from other Latinos in order to collect more specific information

The data also indicated that there was a gap in the languages spoken by clients versus the staff at the agency for every language listed in the survey. The largest gap was in Spanish, with 86.2% of clients speaking the language and only 58.6% of providers speaking the language. Other notable gaps (with more than 15% of the clients speaking languages the staff did not) were Tagalog, Vietnamese, Farsi, Somali, Cantonese, and Korean. The ways in which language barriers affect breast cancer survivors is discussed in the following section; however, additional quantitative data is necessary to determine how language impacts breast cancer incidence, mortality, early detection, and screening.

Additionally, providers were asked about the following special groups – breast cancer survivors, homeless, persons with disabilities, lesbians, men, and transgender individuals. Breast cancer survivors (75.9%), the homeless (70.7%), and disabled (69.0%) were the groups most commonly served by providers. Up to 20.7% of providers reported focusing on any one group. By far, the homeless (63.8%) were the special group providers noted were most in need of additional resources (see Exhibit 28), and may be a target area for exploration in the future. Other groups in need of resources were breast cancer survivors (37.9%), persons with disabilities (29.3%), lesbians (17.2%) and transgender men and women (17.2%). One limitation of this data is that these percentages are based on provider's experiences, opinions, and perceptions. For example, only 17.2% of providers noted that lesbians and transgender men and women needed additional resources, but given that

only 62.1% of the agencies responding served this group, it may be that many respondents were unfamiliar with lesbians needs.

Young Women

Providers were asked about services for women by age group. Women of all ages were serviced by at least 90% of the providers responding to the survey. About half of all providers focused on women under 40. Additionally, when asked which age group was in need of resources, 60.3% reported that women under 40 needed more resources (see Exhibit 29), and slightly more (63.8%) reported that women over 40 needed more resources. Less than half of providers noted that women 50+ and 60+ needed more resources. Thus, women under the age of 40 and from 40-50 are most in need of resources.

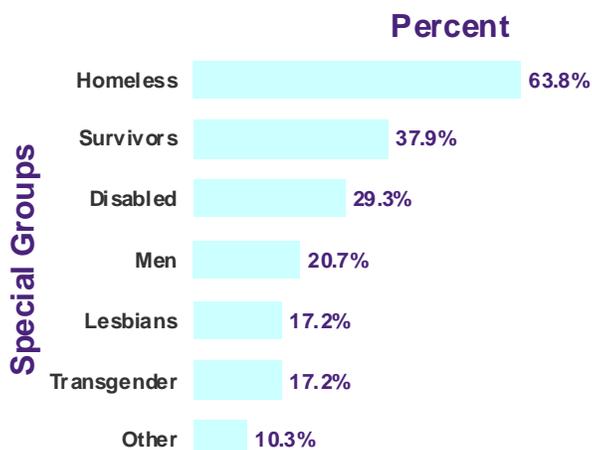
Affiliate Grantees

During the 2009-2010 fiscal year, the San Diego Affiliate invested \$565,000 to support 12 organizations and programs addressing the breast health needs of breast cancer survivors, and underserved racial/ethnic or other high-risk populations. Grants were provided in three main areas:

diagnostics/screening/treatment, education and outreach and breast cancer services. Komen San Diego's grants cover every step of the breast health journey – from education,

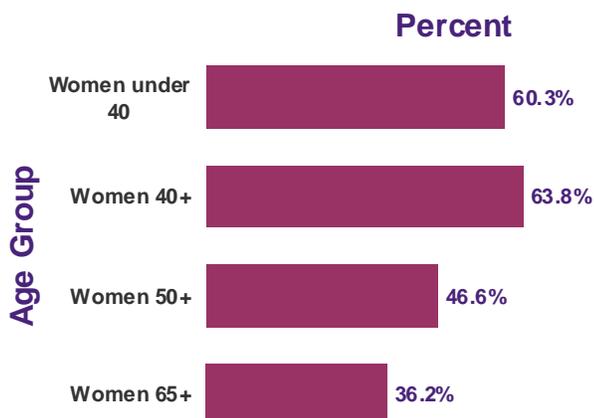
outreach, mammograms and diagnostics, to surgeries, chemotherapy, radiation and material and financial support like meals, mortgage payments, child care, prosthetics and wigs.

Exhibit 28: Special Groups Needing Resources (N=58) *



*Responses are not mutually exclusive.

Exhibit 29: Women Needing Resources by Age Group (N=58) *



*Responses are not mutually exclusive.

Best Practices and Evidence-Based Programs

Developing and implementing culturally sensitive and practical breast health education projects have shown to be effective in changing breast health behaviors among Latina women in South San Diego County. Three San Diego County organizations have created and implemented a health outreach initiative using the “Promotoras Model.” Promotoras are community health workers on staff to help bridge access to care for early breast cancer detection. These programs send bilingual women to speak with other women about the importance of early screening and direct them to community clinics. They have shown to be an effective way to reach women previously “unreachable” – and

caused positive breast health behaviors. One example is the PODER Program (*Promotoras Outreach, Detection, Education and Referral*) at San Ysidro Health Center. PODER is a breast and cervical cancer education and screening program designed to increase the rate of breast exams, mammograms and pap-tests for low-income, uninsured Latinas on the US/Mexico Border. The program uses multiple strategies to increase screening rates. Included in these strategies are increased community education and outreach; linking women directly from classes to appointments; coordinating with a local hospital for special screening days and providing intensive case management. The program is evaluated through education pre/post tests, a general screening survey, conducting focus groups and random patient satisfaction survey's. Since the beginning of the program, over 8,500 qualifying women have been screened, and according to the screening survey, over 30.8% of women who participated had not had a mammogram or pap-test in more than 2 years. Information collected via focus groups, letters, and a recent survey of randomly selected women showed that prior to the program many women were unaware of either the importance of these services, and if they were aware, had no knowledge that funding was available to pay for them. Many women also mentioned they received mammograms as a result of the convenience offered in PODER. The program overall has been successful in raising awareness in the community of the importance of yearly screening, reducing the failure rates associated with mammogram referrals and getting women who have not been screened services for the first time.

Two other San Diego County programs – led by Dr. Georgia Sadler at UCSD John Moores Cancer Center - seek to change behaviors by reaching “women where they live.” Much of Dr. Sadler’s research has focused on increasing the representation and participation of minorities in cancer research and awareness programs, including Komen for the Cure-funded cancer awareness programs for the Asian/Pacific Islander community in which Asian American college students are trained to communicate cancer prevention and early detection information to shoppers at Asian grocery stores. Sadler has also headed innovative research projects such as the African American Cosmetologists Promoting Health Program, which is concerned with reducing the disproportionately high mortality rates for breast cancer and diabetes among African Americans, and studies related to women coping with fatigue following breast cancer, problem-solving for couples coping with prostate cancer, and African Americans dealing with post-cancer treatment fatigue.

In addition, the use of bilingual and bicultural Patient Navigators has become increasingly more common in San Diego County and has been shown to be effective in motivating and increasing access to breast health care among underserved and ethnically diverse populations. Key responsibilities common for Community Health Navigators include: outreach and education in trusted and convenient community locations, assistance with making appointments and filling out paperwork, translation and interpretation, arrangements for childcare, transportation, and emotional support. Many of Komen San Diego’s current grantees use patient navigators, but the need for patient navigation far outweighs the resources.

Area for Future Research: Evaluating Best Practices

Evaluation of the impact Komen San Diego programs and best practices have had on breast cancer trends countywide, as well as regionally, among women from various ethnic groups and incomes, has not been conducted. This type of research would assist Komen San Diego in creating new programs and expanding existing programs.

Partnerships and Grant Opportunities

Each quarter since 2008, the Affiliate has convened a group of breast health leaders and community organizations as the first ever San Diego County Regional Breast Health Coalition. The Coalition meets quarterly for education, problem-solving and to surface shared issues and concerns. In addition, the Affiliate has partnered with the American Cancer Society and other Cancer-related organizations in San Diego County to form the first ever Access to Cancer Care Working Group. The goal of this group is to break down barriers keeping all San Diegans from accessing quality health care.

Public Policy Perspectives

In December 2009, the Every Woman Counts program (California's only free mammography and cervical screening program for uninsured women) closed its doors suddenly leaving more than 250,000 women at risk in the State. The seven California affiliates of Susan G. Komen for the Cure fought back...and through a strategic plan of attack that combined grassroots advocacy, media support, legislative visits and more, the Senate and Assembly voted unanimously to reopen the program. The Collaborative works to build community coalitions, enlist online advocates, gather petition signatures and pay visits to their legislators. Now, it's more important than ever to continue our fight in state capitals across the country. The women we represent deserve a chance at survival, and we will continue to work with the California Affiliate Collaborative and members of our community to help as many people as we can in San Diego County.

Program and Service Data Implications

The implications described below are based on the asset maps as well as the provider survey results. The data indicates that although there were providers that offered education/outreach throughout the County, increased outreach is necessary. Lack of knowledge about breast health was identified by providers as one of the main barriers to both routine care and diagnosis and treatment. Treatment services also need additional resources, according to 44.8% of providers, as do screening and diagnosis services, according to about a third of providers. The need for treatment is also evidenced by the fact that less than 25% of providers who responded to the Provider Survey reported offering these services. The lack of treatment was especially pronounced in Borrego Springs and Rancho Santa Fe, cities that have high breast cancer incidence and mortality rates, yet limited diagnosis and treatment services. Support services (support groups, wigs, transportation, etc) were the only areas no providers reported as needing additional resources. However, financial assistance, insurance assistance, and patient navigations services were reported as needing resources.

The provider data supports the need for more resources to be directed to the three target areas identified by the Community Advisory Panel:

1. **Minority women (including African-Americans, Latinas, Asian/Pacific Islanders, Native American and Immigrants).** Minority groups were widely identified as needing more resources, particularly Latinas, African-Americans and Filipinos. Immigrant groups identified as needing more resources were Mexican, Vietnamese, Somali, and Filipinos.

2. **Young survivors (women diagnosed before the age of 40).** About 60% of providers noted that women under the age of 40 needed more resources.
3. **Breast health care providers.** Collectively providers reported serving populations who speak a wide variety of languages that represent the variety of immigrant and refugee populations in San Diego County. In all cases there was a gap between the percent who reported serving populations who speak each language and the percent who reported having staff that are able to speak each language. Also, the need for additional services to meet the demand indicates the ongoing need to build breast health care provider capacity.

Exploratory Data

The exploratory data gave the San Diego Affiliate the opportunity to further delve into the key areas of concern identified by the Community Advisory Panel. This section includes the results from key informant interview and focus groups which focused on the three target areas identified by the Community Advisory Panel: 1) Minority women, 2) Young survivors, and 3) breast health care providers.

Data for this section was compiled using focus groups and key informant interviews. Results for the focus groups and the key informant interviews are reviewed in this section by each of the three target areas.

Target Area 1: Minority Women

Minority women who were African-American, Latina, Asian/Pacific Islander and immigrant women were included in this target area. Stakeholders and focus group participants were asked about the characteristics of women who are least likely to receive breast healthcare services, the strengths and weaknesses of the current system, and how the system could be improved. The results below address each of these issues by minority group. Although many of the themes are similar (and are discussed at the end of this section), each group faces unique barriers and challenges. Given the data collection challenges described above, the exploratory data contains more information on African-Americans and Latinas compared to other minority groups.

African-Americans

African American women in San Diego are more likely than all other women to die from breast cancer. Their tumors often are found at a later, more advanced stage. So, there are fewer treatment options. Provider surveys and focus groups considered that some reasons for this may include not being able to get health care or not following-up after getting abnormal test results. One focus group participant said “her people” distrust the health care system, and that “doctors” may not have the best interests of African Americans at heart. Still others said culturally, there is a belief in some communities that a breast cancer diagnosis is “fate” and that one’s religious beliefs would either intercede or not – depending on “God’s plan.”

“Our community has no idea that there are organizations that will pay for your rent and other needs while you go through your treatment.”

– African-American Survivor

As in the 2009 Community Profile, African-American women noted that advocacy was needed in their community in order to improve the system, and that African-American survivors should participate in the education and outreach in order for it to be most effective. They noted that breast cancer information should have images of African-American women; ads should be available in frequented meeting places such as churches, beauty shops, nail salons, and local merchants. They also thought that Komen could partner work with the African American Nurses Association, the North County African American Health Coalition, and the San Diego African-American Association in order to improve their advocacy efforts.

“I have two daughter’s who searched for a lot of information so I had all the information before the surgery.”

– Latina Survivor

Latinas

Key barriers to access among Latina women included low utilization of preventative healthcare, lack of knowledge, language and cultural barriers, financial barriers, and fear. Stakeholders indicated that Latinas were less likely to visit the doctor regularly and often used the emergency room for medical care. This was partly due to the fact that they were underinsured or uninsured and did not

have transportation to facilities. Additionally, Latinas lacked knowledge about how to access healthcare resources in an increasingly complex medical system. One survivor noted: “I had to keep skipping my chemo appointments – how was I going to get there? I work two jobs and take a bus everywhere. It’s practically impossible to be sick in San Diego County.”

Cultural and language barriers included the fact that many providers did not speak Spanish and that many women came from families where men make decisions about healthcare and did not allow the women to receive breast screenings or pap smears, especially if the physician is male. Cultural barriers were especially true for recent immigrants. Patient navigators noted that many Mexican women did not feel empowered to take care of themselves, and that they were afraid of seeking health care because they were afraid of being deported if in the United States illegally.

Once diagnosed with breast cancer, the key challenges in navigating the system were the cost and quality of care and cultural barriers.

In improving the current system for the Latino community, stakeholders noted that the *promotora* (community health worker) model, as well as patient navigation programs had been successful and could be considered best practices. They also noted that more free programs were needed due to the current economic climate. Survivors noted that increased education and outreach was noted, and that Komen should work with the Mexican consulate to reach the community and approach individuals one-on-one as opposed to in a group setting. All participants noted that outreach and education needed to occur in Spanish and by Latina survivors and/or health providers.

“They told me I needed to pay \$2,000 to get my operation. Where was I going to get that in less than 24 hours?”

- Latina Survivor

Asian/Pacific Islanders

For this community, the primary barriers to accessing care were cultural. Stakeholders noted that many Asian/Pacific Islander women, especially older women, stayed within their community, and did not have access information about breast cancer. Women also tended to be more private and were embarrassed about receiving breast care screening and/or felt guilty about allowing someone to

touch their breasts. Once diagnosed with breast cancer, women were hesitant to seek treatment for multiple reasons. First, they faced challenges related to insurance and the high cost of care. Specifically, stakeholders noted that women were afraid of losing their health insurance if identified as having a pre-existing condition. Second, women relied on alternative medicines and distrusted western medicine. Finally, mastectomies were not culturally acceptable among this community.

Regarding system improvement, stakeholders identified the need for increased education and outreach, and additionally suggested involving students from the University of California in San Diego as well as Asian physicians. They also suggested that Komen partner with Samoan, Tongan, and other Pacific Islander groups and also have a presence at community festivals.

Refugees

This section includes information for the Iraqi, Burmese, Somali, and Ethiopian refugees. For refugee populations, the key barriers to accessing care were lack of knowledge and cultural barriers. Most refugees did not know what mammograms were or how often they were recommended. When they arrived in the United States, they were enrolled in Medi-Cal. However, making medical appointments was their responsibility, and in most refugee cultures, preventative healthcare was not common.

Focus group participants noted that they would only see a doctor if they experienced breast pain. There was a stigma associated with visiting the doctor because it indicates that there is a medical problem. Although refugees received health screening upon arriving in the United States, the focus was on infectious diseases and breast cancer screening was not required.

When asked to identify challenges of the current healthcare system, stakeholders and focus group participants felt the system was unsuccessful in meeting their needs. The primary challenge was language. Although Medi-Cal was supposed to pay for interpreters, it was difficult to find individuals capable of translating. Focus group participants noted that in City Heights (a neighborhood in San Diego where the majority of Somali residents live), there were only two people at the community clinics who could speak Somali. Additional challenges included navigating the system given that it was so complicated and included visits to multiple doctors and transportation.

Like the other minority groups, refugee communities needed more education about breast cancer, especially in their native language. One stakeholder noted that educational workshops about women's health would be "wonderful." Focus group participants also suggested that Komen partner with the Chaldean Middle Eastern Services Agencies to improve education and services as well as utilizing Somali television for education and outreach.

Komen's Contribution to Minority Women

Komen was praised for their involvement in and support of minority communities. The following were noted as suggestions of ways to increase their contribution.

- + Continue and increase support of tailored survivor groups
- + Continue and increase support of universal as well as tailored outreach, clinical services and community programs
- + Strengthen partnerships with community groups and government agencies
- + Increase Komen presence at community events
- + Fund services (screenings, treatment, and support services)
- + Diversify Komen leadership
- + Increase visibility of Komen Board

Target Area 2: Young Survivors (Women Diagnosed Before the Age of 40)

The data presented here was collected through one focus group with young survivors as well as key informant interviews with individuals who worked with survivors.

Women diagnosed with breast cancer before the age of 40 faced many challenges in their efforts to receive effective breast health services. Insurance companies generally cover annual mammograms if patients are over the age of 40, thus young survivors often have to visit multiple doctors and provide proof of family history of breast cancer before they can receive a mammogram. In one woman's words, "My friend is a student and she doesn't have a lot of insurance. She's not sure what she's going to do. She can't get a mammogram so she's kind of letting it go." Also, denial is a factor for young survivors in accepting the fact that they may have breast cancer. Young women may find it hard to believe that breast cancer could affect them at such a young age. Thus, many young survivors do not do breast self exams or if they find a lump, they may not follow-up.

In addition to the challenges of being accurately diagnosed, young survivors also identified the following weaknesses of the current breast health care system:

- **Quality of providers.** Young survivors often went to several doctors before finding one that worked best for them. Additionally, health care providers were unaware of resources for young survivors because they have so few young patients. In one woman's words: "My coordinator told me I was the youngest person she'd ever sat down with and told that they had breast cancer. She was at a loss. She didn't know where to direct me. There wasn't anybody to explain things and navigate the process."
- **Cost of care.** Young survivors also indicated that the high cost of care was a problem, as was interacting with insurance companies for payment. In one woman's words, "When I got diagnosed it was difficult. I definitely had to make a lot of phone calls. It was like my second job." Women also noted that they felt that hospitals discharged them too quickly after surgeries.
- **Lack of information and support.** Young women diagnosed with cancer faced unique issues that the current healthcare system is not sensitive to. The main issue was fertility. According to one woman, "Unless you go out of your way to protect your fertility, they want to get started so quickly that you don't really have an option." Other issues included dating, caring for young children, school, and breast reconstruction.

"I had at least 30 years on everyone in my doctor's office. I was at least 30 years younger than everyone else."

– Young Survivor

As for current strengths of the system, women noted that there were plenty of breast reconstructive options and that finding a qualified plastic surgeon to do the surgery they wanted was not a problem. Additionally, insurance companies generally cover reconstructive options. In one woman's words, "I was worried – is insurance going to cover this now? To have a double mastectomy with reconstruction – I was told that it's my right to do that. That's awesome!" Additionally, survivors noted that the availability of free massages and acupuncture through the San Diego Cancer Center was beneficial.

When asked how the current system could be improved, most participants felt that increased education and outreach was needed at college campuses. They believed that young survivors

needed to realize that breast cancer was something that could happen to them, so that they could be more effective advocates for themselves. Additional improvements are outlined in the textbox below.

Target Area 3: Breast Health Providers

In addition to focusing on minority women and young survivors, Komen identified providers as a target area. Through stakeholder interviews with providers and through all of the focus groups with minority women and young survivors three main areas emerged as key areas for providers:

- **Cultural competency.** All of the target areas groups indicated that providers were not culturally competent in addressing the unique needs of varying communities. Each community had various needs as is described below:
 - **African-Americans** felt providers were racist, utilized a “one size fits all” approach, and did not share information about all of their options with them.
 - **Latinas** often did not speak English and often came from male-dominated cultures.
 - **Native Americans** often relied on natural treatments or believed that illness was fate.
 - **Asian/Pacific Islanders** commonly relied on eastern medicine, and were often private and embarrassed about having their breasts examined by a stranger. Additionally, they faced language barriers.
 - **Refugees** also generally came from more private cultures and faced language barriers since few providers had staff who could speak their language.
 - **Lesbians** were often afraid of disclosing their sexual orientation and working with judgmental provider. Additionally, lesbians were less likely to seek women’s healthcare, especially if they were not planning on having children.
 - **Transgender men and women**, like Lesbians, were often afraid of facing judgmental healthcare providers and revealing their sexual orientation. Additionally, female to male transgender individuals often neglected their female body parts.
 - **Young survivors** noted that providers were not aware of or sensitive to the unique needs of young women, including childcare and fertility.

This data indicates a need for providers to be more sensitive to the varying needs of women,

Komen’s Contribution to Young Women

Participants believed that Komen’s financial contribution to young survivors was key and hoped for continued support. They specifically noted that they appreciated being invited to participate in various events. They noted that one way Komen could reach out to young survivors is to make their marketing materials more appealing to young women, perhaps by branding “a portion of themselves for young women and young breast health in general.”

Specific programs and services needed included workshops addressing the needs of young survivors (diet/nutrition, fertility, undergoing treatment with young children, dating, and reconstructive options), more support groups for young survivors in San Diego (including support groups in Spanish and other languages), and increased outreach on college campuses.

to make materials available in multiple languages, and to have staff that can speak the languages in the communities they serve.

- **Increased Knowledge and Training.** All respondents, and particularly young survivors, noted that they did not receive enough information about their options when they visited their doctor. Young survivors specifically noted that often they brought information to their providers, who frequently had less information than the survivors did. This indicates a need for providers to be more informed about various treatments and support services available across the County.
- **Increasing partnerships.** Respondents noted that providers, non-profits, and government agencies should work together to spread the word and provide effective services. Sometimes, agencies compete with one another for funding, but a collaborative approach would be more effective in fighting breast cancer.

Exploratory Data Implications

The following section summarized the exploratory data for all groups by theme: accessing breast healthcare, challenges in the current system, and improving the system.

Accessing Breast Healthcare

Barriers to receiving effective breast health care access were similar for all women in the target areas and included the following:

Lack of awareness and knowledge. Many women were aware of the importance of preventative healthcare in general, and preventative breast healthcare specifically. They did not know how to do self breast exams and did not receive annual mammograms as recommended. Young women, particularly, were unaware that breast cancer could affect them, while lesbians and transgender men and women were less likely to seek women’s healthcare because they did not utilize contraception and generally were not trying to become pregnant.

Financial barriers. Many women were uninsured or underinsured, which often meant that they did not receive breast health screenings or visit the doctor regularly. Transportation was also an issue for many women, especially those who lived in more remote areas of the County where mammograms were not easily available.

Cultural barriers. Cultural barriers varied, depending on the group; each minority group had unique needs, as did young survivors, but providers were often unaware of what these were and did not know how to communicate with women from diverse backgrounds.

Emotional factors. Emotional factors include fear, denial, and stigma. Many women were afraid of visiting the doctor because of the stigma attached to being sick, and lesbians and transgender men and women were particularly hesitant to reveal their sexual orientation to providers. Additionally, illegal immigrants often avoided accessing health care due to the fear of being deported, while young women were often in denial about the fact that breast cancer could affect them.

Challenges in the Current Breast Healthcare System

As was the case with the barriers to accessing care, the challenges in the current system were similar for all women and are described below.

- **Cost of care.** Often, women did not have insurance, or sufficient insurance, to address their breast health needs. Even those who were insured often paid high out of pocket costs and had to “fight” with insurance companies for payment.
- **Quality of providers.** Overall women agreed that providers were not culturally competent and often went to see more than one physician before finding one that they wanted to work

with. Some women noted that they wanted to see female doctors and others wanted to be treated by a physician of the same race.

- **Lack of communication and information.** Participants reported that physicians often did not provide women with enough information, which made it more difficult for them to make the best choices for themselves and their breast health care. This was particularly an issue for African-American women and young survivors.
- **Language barriers.** Language barriers were challenges for Latinas, Asian/Pacific Islanders, and refugees. Often, informational material is not available in their native languages, and providers cannot speak their language.

Improving the System

Various suggestions were made for improving programs, services and the system overall.

- **Increased advocacy and education.** The primary need was for advocacy and education efforts tailored to reach each group. Education efforts should reflect the target population. For example, brochures should have images of minority women, lesbians, and young survivors, and survivors of various backgrounds should participate in advocacy efforts.
- **Increased funding.** A need for transportation funding was noted by stakeholders and focus group participants. Patient navigators suggested providing bus tokens. There is also a need for more screening services, especially in more remote areas of the County.
- **Increased knowledge and training for providers.** Providers could benefit from a variety of training including language and cultural competency. They could also learn more about the various services and resources available to breast cancer survivors so that they can more effectively refer women.
- **Increased partnerships.** Providers could partner with more agencies and organizations in order to enhance outreach efforts as well as service delivery. This would also improve the support services available to women.

Conclusions

According to the American Cancer Society, 2011 will see the first decline in cancer deaths in over 70 years. Despite these gains, these trends remain elusive for San Diegans who are poor and who lack English language proficiency, lack health insurance or otherwise have inadequate access to timely, high-quality cancer detection services.

It is a cruel irony that the San Diego region is home to some of the most distinguished healthcare research and clinical facilities in the country, yet inadequate access to healthcare is pervasive. One need not look far to see why. Fewer than half of all San Diegans have job-based health insurance. Approximately 15.2% of the population under 65 years of age (an estimated 463,415) is uninsured, with estimates of the uninsured in the South region at 21.1%. The Southern regions have the largest number of MediCal beneficiaries at 19.4% (San Diego Healthcare Safety Net Study 2005). These disparities are exacerbated by the fact that unlike most California counties with a large urban population, San Diego has no public hospital or

county-run primary care community health center. Instead, it relies on a contracted network of private, not-for-profit providers with reimbursement rates less than one half of what they are in other California counties.

Evidence suggests that breast cancer can be prevented and the prospects for survival will continue to improve if patients have access to diagnostic services and early treatment. The California Breast Cancer screening rates amongst the uninsured are 20% despite the efforts targeting the medically underserved through the Cancer Detection Program (aka “Every Woman Counts”). Numerous studies document major disparities in primary cancer prevention as well as a fragmented care continuum among the safety net providers in the nation, state and county’s minority and poorer populations. In FY 10, SMHCV provided over 15,500 screening mammography visits to a diverse population of patients (11% Asian/Pacific Islander, 66% Hispanic; 18% White; 3% African American; 2% other).

Minority women were less likely to be diagnosed with breast cancer at an early stage and less likely to be screened and given mammograms in comparison to non-minority women. An ability to communicate with Spanish speaking patients is also identified as an important need in reaching Latinas. This is both a language and cultural issue and affects both screening efforts and follow-up services for breast cancer survivors.

Breast cancer mammography screening has been shown to reduce breast cancer mortality by 30-40%.³⁷ However, ethnically diverse populations often remain “underserved” in the traditional health care system.³⁸ Multiple differential consequences operating in the complex United States healthcare system may add to the cause of this discrepancy. The report, “Cancer Screenings in California, Findings from the 2001 California Health Interview Survey,” found that women who report that they do not speak English well or do not speak English at all are less likely to be screened (65.7% vs. 76.9%). This is a likely reason why non-English speakers tend to have higher death rates, a result of lower screening rates.

Women who are unable to interact effectively with social and health service agencies and providers tend not to get the preventive services they need.³⁹ Many women from ethnically diverse backgrounds experience increase risk of breast cancer and may not access these services. These women may not be fully informed about current recommendations for annual screenings and may not have information on accessing diagnostic services when they experience a symptom of breast cancer, such as a lump or nipple discharge⁴⁰. Also, research indicates that they may be afraid or believe that mammography screening causes cancer or they may have had a bad experience with a healthcare provider.⁴¹

³⁷ Fletcher, S, Black, W, Harris, R, Rimer, Shapiro (1993). Report of the International Workshop on Screening for Breast Cancer. *Journal of National Cancer Institute*, 85, 1644-1656; Kelsey, J.L. (1993). Breast cancer epidemiology: Summary and future directions. *Epidemiologic Reviews*. 15 (1). 256-263.

³⁸ Bobo, J, Dean D, Stovall, C, Mendez M, Caplan L 1999. Factors that may discourage annual mammography among low-income women with access to free mammograms: a study using multiethnic, multiracial focus groups. *Psychology Rep*; 85:405-16; Peek, Monica., & Han, Jini. Disparities in screening mammography current status, interventions, and implications. *J Gen Intern Medicine* 2004; 19: 184-194.

³⁹ Ponce, N, Etzioni D, Spencer B, Brown, E, Chawla, N. Cancer Screening in California: Findings from the 2001 California Health Interview Survey. Los Angeles: UCLA Center for Health Policy Research; 2003.

⁴⁰ Nunez, A, Robertson C.. Multicultural considerations in women’s health. *Medical Clinics of North America* 2003;87:5; Jibaja-Weiss M, Volk R, Kingery P, Smith Q, Holcomb, J.. Tailored messages for breast and cervical screening of low income and minority women using medical records data. *Patient Educ Couns* 2003; 50: 123-32.

⁴¹ Lopez, Ellen., Eng, Eugenia., David, Elizabeth., & Robinson, Naomi. 2005 Quality-of-life concerns of African American breast cancer survivors within rural North Carolina: Blending the techniques of photo voice and grounded theory. *Qualitative Health Research* 2005; Volume 15.

Susan G. Komen for the Cure'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 Komen San Diego Affiliate relies on information obtained through the Community Profile Report to guide the accomplishment of the promise in its communities.

Key Findings

Key findings are presented by target areas and include data from all sections of the Community Profile.

Target Area 1: Minority Women

- **Minority women were less likely to receive clinical breast exams and mammograms.** Asians, Latinos, and African-Americans were less likely to receive clinical breast exams and mammograms compared to White women. The receipt of mammograms was particularly low in the Asian and Latino communities.
- **Breast cancer was less likely to be detected at an early stage in minority women.** African Americans, Hispanics, and Asian/Pacific Islanders were less likely to be diagnosed with cancer at an early stage compared to White women.
- **Minority women had high breast cancer mortality rates.** The mortality rate for African Americans was about 75% higher than any other ethnic group. Although White women had the highest incidence and in situ incidence rates in San Diego County, African Americans had the highest mortality rate. For Hispanic women, the incidence rate decreased from 2001-2005, however mortality increased.
- **Breast cancer incidence and mortality were highest in the city of San Diego, Borrego Springs, San Marcos and Rancho Santa Fe.** The four zip codes with the highest incidence and mortality rates were in these cities.
- **Minorities and immigrant groups were identified by providers as needing additional resources.** The race/ethnic groups most identified as needing more resources were Mexicans, African-Americans, Whites, Filipinos, and other Latinos. Immigrant groups most identified as needing resources were Mexican, Vietnamese, Somali, Filipino, and Iraqi/Kurdish/Chaldean.
- **Lesbians were identified as needing additional resources by only about 17% of providers.** The relatively low number of providers noting that this group needed additional services may be a reflection of the fact that only about 62% of providers work with lesbians.
- **Lack of awareness and knowledge were barriers to receiving care for African-Americans, Latinas, Asian/Pacific Islanders, Native Americans, immigrants and refugees.** Providers, focus group participants, and stakeholders expressed that lack of knowledge was a huge barrier. Based on the provider survey about 74% said it was a barrier to routine care while 62% said it was a barrier to diagnosis and treatment.
- **Financial barriers were a consideration for all minority groups, including lesbians and transgender men and women.** Financial barriers related to insurance, childcare and transportation were the key challenges. Lesbians and transgender men and women were less likely to be insured because they did not receive domestic partnership benefits. Even insured women faced challenges in navigating the system and often have to pay large out-of-

pocket costs. About 72% of providers noted finances as a barrier to routine care and 66% noted finances as a barrier to diagnosis and treatment.

- **Cultural barriers played a role in accessing care.** Cultural barriers varied but were an issue for all minority groups seeking healthcare. Many cultures did not discuss breast cancer or did not have a culture of preventative medicine. Lesbians were less likely to receive routine women's healthcare because they were less likely to attempt pregnancy or be on contraceptives. About 57% of providers said that cultural factors were a barrier to seeking routine care and 47% said they were a barrier to seeking treatment.
- **Emotional considerations such as fear prevented many women from seeking treatment.** Many women were afraid of visiting the doctor, and also had numerous fears related to cancer such as losing their hair and having mastectomies.

Target Area 2: Young Women

- **Young women were an understudied group.** On health surveys, questions pertaining to clinical breast exams were only asked of women over 30 while questions pertaining to mammograms were only asked of women over 40. Compared to older women, there is much less information about breast healthcare for young women.
- **Women under the age of 40 were less likely to receive clinical breast exams.** Compared to older women, women between 30 and 40 were less likely to have received a clinical breast exam within the year.
- **Women under 40 needed additional resources for breast cancer.** About 60% of providers reported that young survivors needed additional resources.
- **Current guidelines for breast cancer screening make it difficult for women under 40 to access care.** Guidelines recommend that a woman receive an annual mammogram once she turns 40. Thus, young survivors often had to show proof of family history and/or visit multiple doctors before they received a mammogram or a diagnosis.
- **Denial prevents women from seeking care.** Denial was often a factor for women under 40. Women in their 20s and 30s found it harder to believe that breast cancer was a reality for them, thus they did not do self breast exams. Even if they thought they found a lump, they might delay seeking additional treatment due to denial.
- **Financial barriers prevent women from accessing care.** Like older women, women under 40 face battles with insurance companies if they are insured. Additionally, students may have been less likely to have adequate insurance. Also, unique to young women was the fact that they had younger children and had the additional cost of childcare during treatment.
- **Young survivors lacked information and support.** Women under 40 with breast cancer had particular concerns such as fertility options, dating, child rearing, and reconstructive options. Many providers lacked information for young survivors and did not know where to refer them.

Target Area 3: Provider Intervention

- **Providers lacked information for survivors.** Many survivors noted that their doctors did not share or have information about the treatment process and their various options. The young survivors, in particular, felt that they brought new information to their providers. Providers could benefit from increased training in order to expand their knowledge and/or their ability to communicate this knowledge.
- **Survivors believed that providers were not culturally competent.** Cultural competency, as it is discussed here, related to a providers ability to communicate with, interact with, and treat women from diverse backgrounds. Providers may lack a basic understanding of different minority groups thus approach all patients the same way. Some survivors believed that providers were racist and judgmental, while others simply perceived them as insensitive.
- **Providers did not have staff to speak the language spoken by their clients.** Provider survey data indicated that there was a gap in the languages spoken by clients versus the staff at the agency for every language listed on the survey. The largest gap was in Spanish, with 86.2% of clients speaking the language and only 58.6% of providers speaking the language. Other notable gaps (with more than 15% of the clients speaking languages the staff did not) were in Tagalog, Vietnamese, Farsi, Somali, Cantonese, and Korean. This was validated by the refugee focus group where women noted that there were only two Somali-speaking staff members working at the clinics in City Heights, the community with the largest Somali population in San Diego.
- **Partnering with other agencies could help survivors navigate the system.** Stakeholders and focus group participants noted that providers should increase their partnerships and work more collaboratively with one another. One benefit of doing this would be that providers would be able to refer survivors to various support services and provide greater assistance in navigating the healthcare system.

Areas for Future Research and Study

- **Investigation of the demographics of women in cities with high breast cancer incidence and mortality.** This report includes a profile of the five zip codes/cities with the highest breast cancer incidence and mortality; however it does not include specific information about the women in these areas with breast cancer. Research to further explore this may reveal more about how to meet the needs of women in these cities.
- **Exploration of the relationship between income and breast cancer incidence and mortality.** This report primarily focuses on the relationship between race and breast cancer incidence and mortality, and additional research about how income affects breast cancer, as well as the relationship between income and race, would be beneficial in creating programs for women. While the focus groups and interviews explored the affect of income on accessing the system, most of the focus group participants had private insurance, and thus were not as familiar with the challenges lower income, uninsured women may face. Additionally, the homeless were identified by providers as a population in need of services; however, they were not a target area for this report.
- **Further exploration of the factors impacting incidence, early detection, screening.** Some of the breast cancer statistics appeared to be contradictory. For example, although African American women were least likely to be diagnosed with breast cancer at an early stage compared to Asian and Latina women, they were more likely to receive mammograms.

Similarly, Asians were less likely to receive mammograms than White or African American women, but still had lower breast cancer incidence and mortality rates than both groups. This suggests that other factors may impact early detection.

- **Evaluation of Komen San Diego's best practices.** Komen San Diego's best practices include utilizing the *Promotoras* Model and the use of bilingual and bicultural patient navigators. Evaluation to determine the impact of these programs and best practices would assist Komen San Diego in creating and expanding programs.
- **Explore the needs of various minority groups in more detail.** Minority women were one of the target areas selected for this Community Profile, and eight different groups were included in this group. Because this target area was so broad and the number of focus groups and interviews were limited, the information collected likely does not capture the needs of all minority women. Related to the needs of minority women, is the impact language barriers have on breast cancer incidence and mortality.

Susan G. Komen for the Cure® Action Plan

Susan G. Komen for the Cure® remains committed to fulfilling our promise to save lives and end breast cancer forever through empowering people, ensuring quality care for all, and energizing science to find the cures. Susan G. Komen for the Cure® is focused on **reducing breast cancer incidence and mortality within the next decade with increased emphasis on finding solutions for disparities in breast cancer across populations.** With funds raised by the Komen San Diego Affiliate, community grants will be made to support **evidence-based strategies and promising practices** to reduce disparities in breast cancer mortality in San Diego County.

Applicants are strongly encouraged to utilize the data within the 2011 Community Profile Report to implement strategies in one or more of the following areas that result in **documented links** of rarely screened or never screened women from the priority populations to breast cancer screening and diagnostic services, and **documented links** of women diagnosed with breast cancer from priority populations to treatment and/or treatment support services to ensure successful treatment outcomes.

Susan G. Komen for the Cure, San Diego Priorities (in alphabetical order)

Drawing from evidence-based information from the 2009 Community Profile, and other local and national studies, the San Diego Affiliate of Susan G. Komen for the Cure® has identified the following priority populations, geographic target areas and programmatic priorities for the 2010 Community Grants Program:

- **Financial and Navigation Issues:** Increase the availability of financial resources for diagnosis, treatment and post-treatment in San Diego County among uninsured and underinsured women. Partner or collaborate on resources to help patients and their families' access and navigate the resources that are available.
- **Providers:** Increase competency among providers for breast health protocols and cultural/linguistic sensitivity. Partner with professional organizations to study/create/implement culturally sensitive continuing education and track progress.
- **Underserved Populations:** Programs that seek to reduce late stage diagnosis and mortality among underserved groups of women. Many groups of women are currently at higher risk due to lack of education about breast health, cultural/linguistic barriers, lack of available diagnostic services and late stage diagnosis. There are proportionally more such

underserved women in the African American, Latina, Pacific Islander, Asian, Lesbian/Transgender and Homeless communities.

- **Young Women at Risk:** Develop a better understanding of this population and its needs; to provide screening, diagnostic, treatment and support services for women under 40 with a family history or palpable mass; to decrease late stage diagnosis and mortality rate by increasing partnerships with organizations that predominantly serve young women, especially under served young women; to increase awareness of breast health and breast cancer and the availability of culturally appropriate and relevant breast health materials for young women.

PROGRAMMATIC PRIORITIES

Successful programs will focus on improved access to of the priority populations quality breast health services within the geographic target areas identified in the Community Profile.

Priority will be given to projects that impellent strategies in one or more of the following areas that result in **documented** links of rarely screened or never screened women from the priority populations to breast cancer screening and diagnostic services, and **documented** links of women diagnosed with breast cancer from the priority populations to treatment and/or treatment support services to ensure successful treatment outcomes.

- Improving access to screening, re-screening, and diagnostic services among priority populations with an emphasis in the geographic target areas identified in the Community Profile by reducing cost and infrastructure barriers.

Examples of Activities:

- Guiding patients through the breast health system to facilitate and increase access to quality care
 - Transportation and childcare
 - Linking to free and low-cost services
 - Patient advocacy
 - Interpretation services
 - Helping women find providers near where they live
 - Conducting provider training on cultural and linguistic aspects of priority populations
 - Working with providers to ensure rarely or never screened women have access to services
- Evidence based and/or innovative outreach and education interventions among priority populations with an emphasis in the geographic target areas. Successful projects will result in **documented** improvements in knowledge, attitudes and behavior among program participants; and in **documented** links of program participants to breast cancer screening services.

Examples of Activities:

- Educational interventions aimed at increasing awareness of risk of getting breast cancer, the benefits of early detection, knowledge of available

breast health services and eligibility criteria, and ability to access and utilize breast health services.

- Culturally and linguistically competent educational approaches that motivate and directly link rarely or never screened women to breast health services.
 - Community-based outreach and education (i.e. alternative hours, services provided at locations where priority populations live, work, play and worship)
- Improving access to quality treatment and treatment support services by women from priority populations and with an emphasis in the geographic target areas diagnosed with breast cancer leading to **documented** successful treatment outcomes.

Examples of Activities:

Guiding patients through the breast health/cancer system to facilitate and increase access to quality care.

- Assistance in obtaining support services.
- Transportation and childcare
- Patient advocacy
- Interpretation services
- Financial assistance
- Working with healthcare community and insurance companies to improve access to timely quality treatment and support services for women from the priority populations
- Investigate the demographics of women in cities with the highest breast cancer incidence and mortality; exploration of the relationship between income and breast cancer incidence and mortality and exploring the needs of various minority groups in more detail.