



# COMMUNITY PROFILE REPORT

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2011



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The information in this Community Profile Report is based on the work of Inland Empire Affiliate of Susan G. Komen for the Cure® in conjunction with key community partners. The findings of the report are based on a needs assessment public health model but are not necessarily scientific and are provided "as is" for general information only and without warranties of any kind. Susan G. Komen for the Cure® and its Affiliates do not recommend, endorse or make any warranties or representations of any kind with regard to the accuracy, completeness, timeliness, quality, efficacy or non-infringement of any of the programs, projects, materials, products or other information included or the companies or organizations referred to in the report.

## Acknowledgements

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# Executive Summary

## Introduction

Nancy Brinker promised her dying sister, that she would do everything possible to end breast cancer forever. In 1982, that promise became the Susan G. Komen Breast Cancer Foundation now known as Susan G. Komen for the Cure® and launched the global breast cancer movement. Today, Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists and the largest source of nonprofit funds dedicated to curing breast cancer at every stage. Komen has more than 120 Affiliates around the globe working to meet unmet breast health needs. Through events like the Komen Race for the Cure®, the organization engages people in the breast cancer movement and raises funds to discover and deliver the cures for breast cancer.

Nationally, 80 percent of what's spent goes toward mission (research, education, screening, treatment) and 20 percent goes to administrative and fundraising costs. To date, Komen has invested more than \$1.9 billion in breast cancer research and community programs and promises to invest another \$2 billion by 2017.

Komen has transformed how the world talks about and treats this disease, helping to turn millions of breast cancer patients into breast cancer survivors. Virtually every major advance in breast cancer research had been touched by a Komen grant and now has personalized treatment options instead of a one-size-fits-all approach to breast cancer care. By working together with scientists and advocates around the world, the organization is moving closer to our goal of discovering and delivering the cures.

Susan G. Komen for the Cure's vision is a world without breast cancer. Many countries are where Komen was in 1982 – a culture of silence in which the disease is not addressed or treated. In order to increase breast cancer awareness, Komen trains breast cancer advocates around the world and funds culturally sensitive, sustainable education and breast health programs globally.

Advocacy plays a crucial role in the U.S., where Komen serves as a committed partner with policy makers to ensure access to services and continued research funding for breast cancer.

In 1998, the Inland Empire Affiliate pledged that it would do all it could to provide needed resources and improve breast health/breast cancer in the communities within their service area of Riverside (includes the Coachella Valley) and San Bernardino Counties. In 1999, the Affiliate held its first "Susan G. Komen Inland Empire Race for the Cure®." Funds raised from this event are granted, to local organizations who offer programs for the uninsured/underinsured women and families. The Komen Promise: to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures is supported by many dedicated individuals and community partnerships wanting to make a difference.

75 percent of the funds raised by the Affiliate remain in the Inland Empire via grants to nonprofit organizations that offer for education, screening, diagnostic services and

treatment support programs while 25 percent supports breast cancer research. Since the 1999 inaugural Komen Inland Empire Race for the Cure®, the Affiliate has funded nearly \$5 million in grants to meet the Inland Empire needs for the uninsured/underinsured residents and over 1 million to the Susan G. Komen for the Cure Award and Research Grant Program.

In order to meet our Promise, a Community Profile assists the affiliate by identifying gaps in services and unique target areas of need within the service area. The Community Profile serves as a “road map” for the Affiliate’s education, outreach and granting strategies. The Community Profile includes analysis of community data as well as voices of those living in the area.

The Inland Empire Affiliate serves more than 4 million people residing in Riverside and San Bernardino Counties, hosting 27,000 square miles of diverse geographic terrain from mountains and valleys to below sea level in the desert. The majority of the population is concentrated in the southwestern area of both counties. Many miles of the service area are national parks, military and desert.

## **Statistics and Demographic Review**

In 2009, the estimated population of the Inland Empire was 4,219,766. The two largest racial/ethnic groups are Hispanic (46.0%) and White, non-Hispanic (38.1%); 7.1% are Black, non-Hispanic. One in four adults 25+ (25.3%) did not graduate from high school; 24.9% possess a high school degree. The unemployment rate is 7.8% (compared to 5.6% in the United States).<sup>1</sup> Please note that the unemployment rate and percentage of uninsured/underinsured may be higher due to current hard economic times.

There are approximately 2 million women living in the Inland Empire. Within the female population the breakdown is: Hispanics 43%; White 41.2%; Black 7.2%; Asian Pacific Islanders 5.4%; American Indian 0.5%; all other 2.6%. The median household income in the Inland Empire is \$56,343, with 11.6% of households having income below poverty level.

It is estimated that 15.9% of Riverside County females are uninsured; this is slightly lower than the female uninsured rate in San Bernardino County of 18.5%. When considering females between 18 and 64 years of age, 21.9% in Riverside and 24.8% in San Bernardino County are uninsured.<sup>2</sup> The majority of Hispanic (71.3%), Black (63.2%), American Indian (57.3%), and “other” females are under the age of 40.

For uninsured/underinsured women 40 and over, with an income at or below 200% of the federal poverty, the State of California Cancer Detection Program: EWC (Every Woman Counts) helps underserved women receive free breast cancer screening and diagnostic services through diagnosis as well as cervical cancer prevention for women who qualify. Cervical cancer screening is provided to women 25 and older. CDP: EWC is funded by a federal grant and state tobacco tax revenue. For those who are diagnosed with breast cancer, the State of California provides Breast and Cervical

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Cancer Treatment Program (BCCTP). The BCCTP provides cancer treatment for eligible low-income California residents who are screened by Cancer Detection Program: Every Woman Counts (CDP:EWC) or Family Planning, Access, Care and Treatment (Family PACT) programs and found to be in need of treatment for breast and/or cervical cancer.

In order to fill the gap in services for symptomatic uninsured/underinsured women less than 40 years of age, Komen Inland Empire Affiliate grant recipient programs provide diagnostic breast health services to those with need.

## **Health Systems Analysis**

The methods used to conduct the health systems analysis included a variety of individual surveys. Individual surveys targeted the following populations: survivors, young survivors, medical providers, and the community in general. Participants included men and women, ranging from age 13 to 83, and represented White, Hispanic, Black/African American, American Indian/Alaska Native, Asian/Pacific Islander, and Other race/ethnicities. 490 surveys were analyzed for the purpose of this Community Profile. The Affiliate collaborated with Loma Linda University, School of Public Health to research programs and services in our service area for asset mapping purposes.

Through careful analysis of the data, we found that gaps and barriers throughout the continuum of care exist in the target communities. Target communities were determined through the use of surveys. Target communities identified as a priority include High Desert residents, African American women, medical and clinical trial providers, as well as breast cancer survivors. The gaps and barriers in these target communities include access to resources and education, on-going support after treatment, as well as post-cancer follow-up issues.

Surveys have indicated that providers are least likely to offer alternative therapies, palliative/end-of-life care, pain management, long-term treatment, reconstruction, durable medical goods, lymphedema therapy, and managing side-effects. Additionally, nearly 80% of medical providers and their staff lack knowledge regarding breast cancer clinical trials. In order to fill the gaps and overcome these barriers, the Affiliate will continue to be engaged within the community, influence policy, foster partnerships, and provide quality education to our constituents, including medical providers, breast cancer advocates, volunteers, and staff.

Key findings of the analysis indicate that the incidence and mortality patterns throughout the High Desert reveal a failure to detect breast cancer early in the natural history of the disease. These are the current issues and barriers facing women and influencing their access to screening, treatment, and other services. The key findings which may be contributing to the high incidence, prevalence, and mortality rates include distribution of resources, level of education, level of income, stage of diagnosis, and insurance coverage. Challenges facing the Affiliate include location of main office and resource office, number of staff, size of service area, and number of able facilities to conduct needed services for underserved populations.

## **Quantitative and Qualitative Data Overview**

The methods used to collect community data for qualitative purposes included an African American women focus group and survivor focus group, as well as individual surveys consisting of survivors, young survivors, and the community in general. Participants included men and women, ranging from age 13 to 83, and represented White, Hispanic, Black/African American, American Indian/Alaska Native, Asian/Pacific Islander, and Other race/ethnicities. 490 surveys were analyzed for the purposes of the Community Profile.

The reoccurring themes throughout the focus groups and surveys identified an increased need for education and outreach services, utilizing a community ambassador, to include faith-based gatherings such as churches, as well as improve breast health education in schools. Focus groups and surveys also identified a lack of resources and support services throughout the continuum of care, particularly during follow-up care post treatment and clinical trials, as well as a lack of knowledge surrounding where to obtain resources and support services.

## **Conclusions**

The Inland Empire Affiliate has identified gaps and barriers to access throughout its Affiliate service area. It is clear that education remains a priority for all ages, ethnicities, and communities. Additionally, there is an increased need for clinical trials knowledge and enrollment, for healthcare professionals, as well as the public at large. Furthermore, there is an increased need for services throughout the continuum of care for those who have been diagnosed with breast cancer. After careful consideration, the Affiliate has established the following 2011 and 2013 Goals and Objectives/Action Plan to guide its' efforts and ensure quality, efficiency, and effectiveness.

### **Inland Empire Affiliate Goals & Objectives / Action Plan**

Goal 1: Increase education and outreach efforts throughout the Inland Empire.

Objective 1: Breast health: By March 31, 2013, we will have expanded education and outreach efforts to include faith-based organizations, college campuses, special events, and other venues as determined by completion of internal quarterly reports.

Objective 2: Advocacy and public policy: By March 31, 2013, we will have met with local legislatures to inform them about Community Profile data, breast health issues and policy, as well as increase our grass-roots lobbying campaigns, as demonstrated by completion of internal quarterly reports.

Objective 3: Komen: By March 31<sup>st</sup>, 2013, we will have launched a Mission Communications campaign to increase knowledge about Susan G. Komen for the Cure® and the Inland Empire Affiliate of Susan G. Komen for the Cure®, as demonstrated by completion of internal quarterly reports.

Goal 2: Increase knowledge and awareness of clinical trials.

Objective 1: Partner with clinical trials providers: By March 31<sup>st</sup>, 2013, we will have networked and provided outreach to clinical trials providers within the service area, as demonstrated by completion of internal quarterly reports.

Objective 2: Medical Providers: By March 31<sup>st</sup>, 2013, we will have partnered with a medical facility and have conducted a minimum of two professional clinical trials education seminars and one public clinical trials education seminar, as demonstrated by completion of internal annual reports.

Objective 3: Pilot a consortium for clinical trials discussions: By March 31<sup>st</sup>, 2013, we will have implemented a consortium to engage medical providers and clinical trial providers to discuss current clinical trials retention and recruitment options throughout the service area to enhance clinical trials enrollment, as demonstrated by completion of internal quarterly reports.

Goal 3: Improve the continuum of care for those diagnosed with breast cancer, as well as include enhancing programs and services available for co-survivors.

Objective 1: Increase the Affiliate's knowledge of the continuum of care within the service area: By March 31<sup>st</sup>, 2013, we will have designed, distributed, and collected English and Spanish language surveys from low-income, ethnically diverse populations within the service area to increase our knowledge of the continuum of care within those communities, as demonstrated by the 2013 Community Profile Report.

Objective 2: Increase knowledge and access to resources: By March 31<sup>st</sup>, 2013, we will have planned a continuum of care resource guide for the community, as demonstrated by internal quarterly reports.

Objective 3: Increase co-survivorship support: By March 31<sup>st</sup>, 2013, we will have increased activities to enhance the role of co-survivors, including resources and support for the co-survivors needs during their love one's journey.

### **Future Considerations**

The Inland Empire Affiliate would like to make special mention of areas of potential focus for the following 2013 Community Profile. These areas may include:

- Young survivors
- Native Americans
- Asian Americans
- Women with disabilities

- Women who partner with women
- Senior women
- Palliative Care/End of Life Care
- Pain Management
- Rehabilitation and breast cancer as a “chronic disease”
- Physical therapy
- Lymphedema support
- Psychosocial support
- Collaboration/partnering efforts with:
  - o In-home care
  - o Meals to breast cancer families
  - o Cleaning for a Reason
  - o Fresh and Easy
  - o 215
  - o Community organizations/special service groups
- Collaboration with border Affiliates (Arizona and Nevada) to identify current breast health outreach programs and determine if new strategies for outreach and reducing barriers to access of services are needed

# Introduction

## Komen History

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The Inland Empire Affiliate was the recipient of the 2008 Service/Charitable Organization of the Year by the Temecula Valley Chamber. This award recognized the Affiliate’s generosity and philanthropic efforts that benefit many women and families throughout the community.

**Organizational Structure**

Our Affiliate currently has four staff members an Executive Director, Mission Programs Manager, Development & Communications Manager, and Administrative and Financial Associate. The staff reports to the Executive Director, and the Executive Director reports to the Board of Directors of the Affiliate. Currently, 8 members serve on the board of directors for the Affiliate.

The Inland Empire Affiliate Board of Directors

Sandra Finestone, Psy.D. <i>Board President</i>	Debbie Gilligan <i>Board Secretary / Race Chair</i>
Jacquín Davidson <i>Board Treasurer</i>	Dorcy Bowman Rose <i>Communications Chair</i>
Barb Killian <i>Volunteer Chair</i>	Micki Greenspan <i>Desert Liaison Chair</i>
Natalee Boggs <i>Youth Ambassador</i>	Herb Killian <i>Member at Large</i>

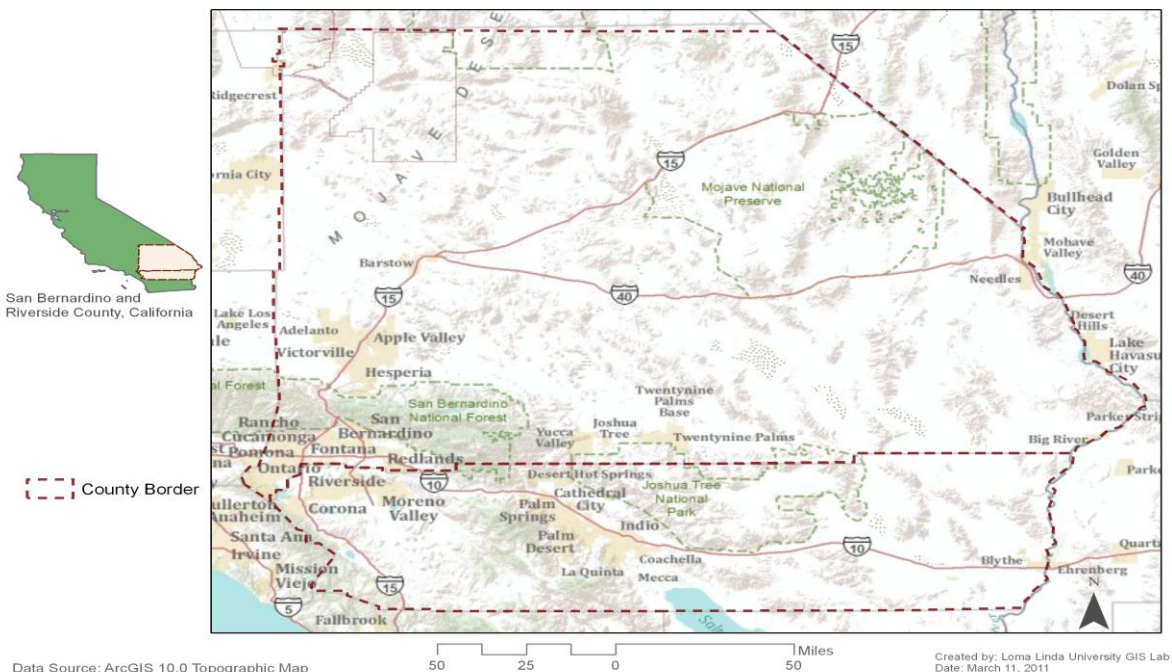
## Description of Service Area

The Inland Empire Affiliate's service area includes San Bernardino and Riverside Counties (including Coachella Valley and Mojave Desert) totaling approximately 27,000 square miles. Unlike most metropolitan areas that have grown up around a central city, the Inland Empire is composed of many small and medium sized cities as well as unincorporated communities that together form the 14th-largest metropolitan area in the nation. Los Angeles County and Orange County border the Inland Empire to the West; Inyo and Kern to the North, San Diego and Imperial County to the South and the States of Arizona and Nevada to the East. The Inland Empire stretches from the Los Angeles County - San Bernardino County border through the San Bernardino Valley, encompassing the San Bernardino Mountains and the high and low deserts to the Nevada and Arizona state lines. Figure 1 shows an outline of San Bernardino and Riverside Counties. Suburban sprawl, centering around the cities of Riverside, San Bernardino, and Ontario, spreads out to form a unified whole with the Greater Los Angeles area, with further development encroaching past the mountains into the outlying desert areas. The San Bernardino valley floor houses roughly over 80% of the total human population in the Inland Empire. San Bernardino is the largest county in the contiguous United States.

Elevations range from 11,499 feet (3,505 m) at the top of the San Gorgonio Mountain to 220 ft (-67.1 m) below sea level at the Salton Sea. The San Bernardino mountains are home to the San Bernardino National Forest and the resort communities of Big Bear Lake, Lake Arrowhead, and Running Springs. The Santa Ana River extends from Mt. San Gorgonio for nearly 100 miles (160 km) through San Bernardino, Riverside, and Orange Counties before it eventually spills into the Pacific Ocean. While temperatures are generally cool to cold in the mountains it can get hot in the valleys. In the desert resort of Palm Springs, near Joshua Tree National Park, summer temperatures can reach well over 110 degrees.

The developed area of the Inland Empire consists of the following valleys: Chino Valley, Coachella Valley, Cucamonga Valley, Menifee Valley, Murrieta Valley, Perris Valley, San Bernardino Valley (largest valley in the Inland Empire), Temecula Valley (known as Southern California Wine Country), and Victor Valley. The Inland Empire is popular for recreational activities such as skiing the San Bernardino Mountains, biking, hiking, and camping in both the mountains and deserts. Additionally, resident and visitors enjoy off road vehicle entertainment, Nascar Racing, boating, tennis, and golf. The famous resorts of the Coachella Valley such as Indian Wells, La Quinta, Rancho Mirage, Palm Springs and Palm Desert are located in eastern Riverside County.

## San Bernardino and Riverside County



Map provide by Loma Linda University, School of Public Health, Health Geoinformatics Program

### Military Presence

March Joint Air Reserve Base (ARB) located in Riverside County, California between the cities of Riverside and Moreno Valley is the home to the Air Force Reserve Command's largest air mobility wing of the 4th Air Force<sup>1</sup>. March ARB is also home to units from the Army Reserve, Navy Reserve, Marine Corps Reserve and the California Air National Guard.

The Naval Surface Warfare Center (NSWC) located in Corona, is a division of the U.S. Navy organization under the oversight of NAVSEA. NSWC consists of 10 major divisions.

The Marine Corps Air Ground Combat Center (MCAGCC), also known as 29 Palms, Twentynine Stumps, or simply the Stumps, is the United States Marine Corps' largest base. Officially known as Twentynine Palms Base, California is located adjacent to the city of Twentynine Palms in southern San Bernardino County, California.

Fort Irwin is located approximately 37 miles northeast of Barstow in the High Mojave Desert, midway between Las Vegas, Nevada and Los Angeles, California. Fort Irwin serves as a National Training Center and Army base.

## Education in the Inland Empire

### Universities

University of Redlands, California State University, San Bernardino, California Baptist University, University of California Riverside, Claremont Colleges, The Peter F. Drucker and Masatoshi Ito Graduate School of Management, Loma Linda University, University of La Verne, University of La Verne College of Law, La Sierra University, and California Polytechnic State University, Pomona.

### Junior Colleges

Crafton Hills College, Riverside Community College, San Bernardino Valley College, College of the Desert, Chaffey College, Copper Mountain College, Victor Valley Community College, Palo Verde College, Barstow Community College, Mt. San Jacinto College, and Community Christian College.

## Casinos/Native American Healthcare Clinics

**Unique to the Inland Empire is the number of gaming/ casinos throughout the service area.** A total of 12 casinos exist in Riverside County and 3 in San Bernardino County (Figure 2). Noted on the map below are Indian clinic sites in relationship to the casinos. Little is known about breast cancer within the American Indian ethnicity. Initial conversations have begun with Tribal Councils in hopes of gaining more understanding. This may be an area of focus for the next Community Profile.

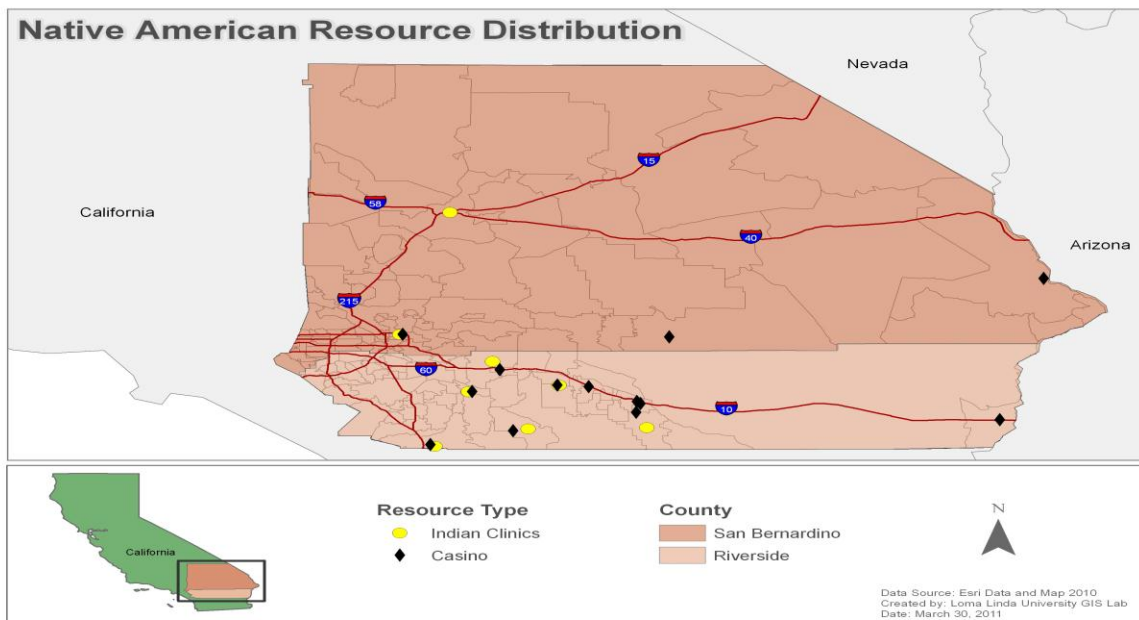


Figure 2. Native American Resource Distribution, Casinos and Indian Clinics  
Map provide by Loma Linda University, School of Public Health, Health Geoinformatics Program

## Purpose of the Report

The Community Profile will update demographics and breast cancer statistics in order to identify new and/or previous gaps in services and barriers to access within our service area. New gaps and barriers will be analyzed to pin point “target areas” where Komen’s

efforts will have the most impact. These gaps in services are incorporated into the annual RFA (Request for Application) as possible pilot or continued projects of importance, therefore establishing focused education and granting priorities. An important component of the profile is to document existing resources so that efforts supported by Komen are non-duplicative. The Community Profile serves as the “road map” for the Affiliate through 2013.

It is essential to be aware of available community assets that can be evaluated for future partnerships and collaborations. Working together for solutions that improve health disparities, access to services and reducing mortality from breast cancer is vital.

This document is available not only for health organizations, but donors, businesses and the population at large, to understand the breast health needs in their community and how they can assist the Affiliate and further the Komen Promise: to save lives and end breast cancer forever by empowering people, ensuring quality of care for all and energizing science to find the cures.

# Breast Cancer Impact in Affiliate Service Area

## Methodology

Data presented in this section were obtained by the Health Assessment Resource Center (HARC) from a custom module designed and created by Thomson Reuters in collaboration with Susan G. Komen for the Cure®.

Nielsen Claritas, Inc. provides updated U.S. Census demographic data and related information used by many healthcare professionals. Nielsen Claritas demographic estimates are based on the 2000 U.S. Census and are available at the national, designated market area (DMA), core based statistical area (CBSA), state, county, ZIP Code, census tract, and block group levels. For this report, 2009 data are used.

Unfortunately, some data, such as mortality rates for different racial/ethnic groups, only distinguish between Caucasian/White, Black, and “other” so data for Hispanic/Latino and Asians cannot be reported.

### Asset Maps

The San Bernardino and Riverside County maps were created using the desktop version of ArcGIS 10 by Loma Linda University, School of Public Health, Health Geoinformatics Program. Geographic layers including boundaries, zip codes, and census tracts were imported from the 2000 census data. Demographic layers including total population were imported from the 2010 estimates of the 2000 census data. Feature layers including health clinics, public health facilities, cancer hospitals, mammogram centers, hospitals, Native American clinics, and casinos were received as an Excel file from Susan G. Komen for the Cure®, cross referenced for accuracy and updates, and imported and geocoded in ArcGIS. Demographic data used in the choropleth maps were calculated using the percent of females per census tract and normalized by the total population (males and females). Drive time distance estimates were calculated using ArcGIS Business Analysis, polygons were grouped and merged according to travel time, and the modified shapefile was imported into the project maps.

## Overview of Affiliate Service Area

In 2000, the estimated population of the Inland Empire was 3,257,409. This increased to 4,219,766 in 2009 (a 29.5% increase). In 2014, it is estimated that the population will increase by 14.0% to 4,811,977. Fifty percent of the population is male and 50% is female. The two largest racial/ethnic groups are Hispanic (46.0%) and White, non-Hispanic (38.1%); 7.1% are Black, non-Hispanic. One in four adults 25 years of age or more (25.3%) did not graduate from high school; 24.9% possess a high school degree. The unemployment rate is 7.8% (compared to 5.6% in the United States).<sup>3</sup>

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In 2009, 10.8% of families in Riverside County and 12.5% of families in San Bernardino County have incomes that are below the poverty level. Overall, 11.6% of families in the Inland Empire have family incomes below the poverty level. The median family income in the Inland Empire is \$56,343 (\$57,154 in Riverside and \$55,478 in San Bernardino).<sup>4</sup> One topic of concern for the Affiliate is the distribution of services throughout remote location (see Figure 3). As one can see from the map below, there are large portions throughout Riverside and San Bernardino County that do not encompass a facility nearby. The Affiliate hopes to collaborate with border states, Nevada and Arizona, to enhance future breast health access along border towns.

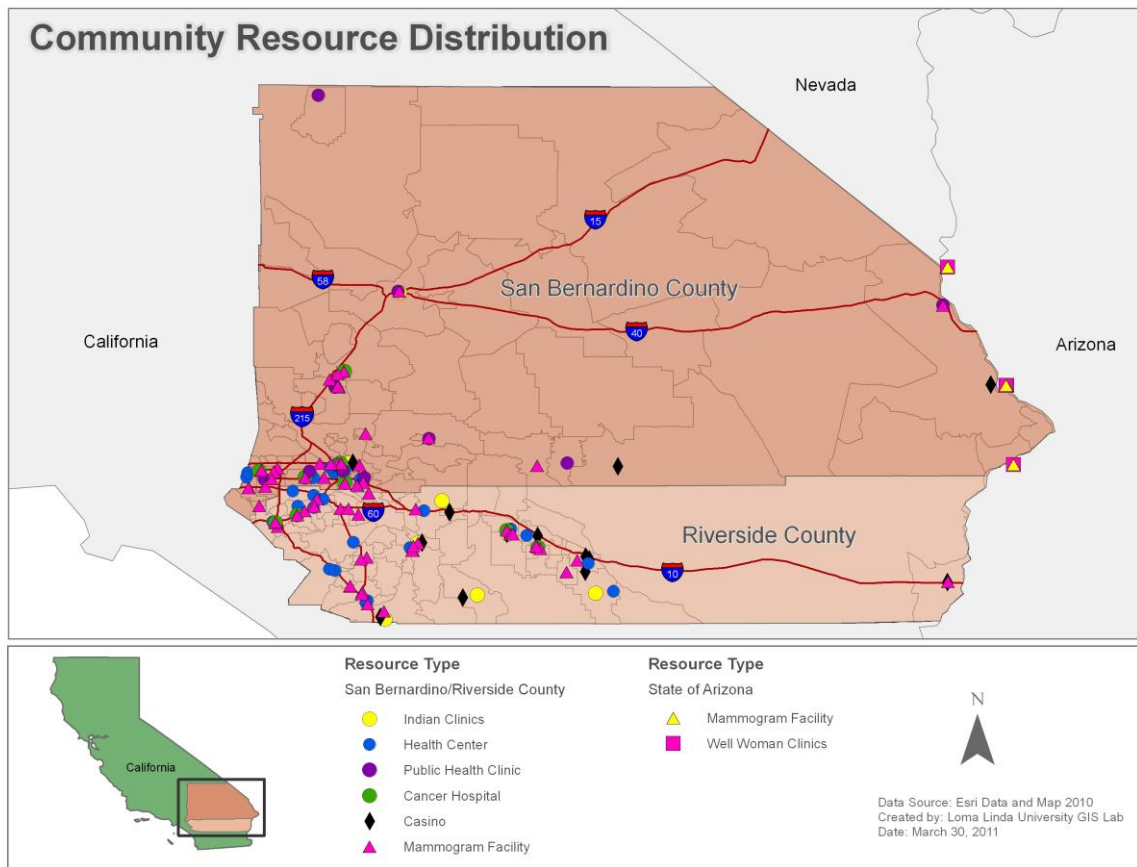


Figure 3. Community Resource Distribution throughout Affiliate Service Area and Bordering States  
 Map provide by Loma Linda University, School of Public Health, Health Geoinformatics Program

### The Area's Female Population

It is estimated that 15.9% of Riverside County females are uninsured; this is slightly lower than the female uninsured rate in San Bernardino County of 18.5%. When considering females between 18 and 64 years of age only, 21.9% in Riverside and 24.8% in San Bernardino County are uninsured.<sup>5</sup>

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Figure 4 shows the distribution of the area’s female population by age and race/ethnicity. The majority of Hispanic (71.3%), Black (63.2%), American Indian (57.3%), and “other” females are under the age of 40. As these women age, it may put increased pressure on area providers for breast health services and increasing health care costs. The map below (Figures 5 and 6) display the percentage of female African American and Hispanic populations in relation to the distribution of community resources within the Affiliate’s service area.

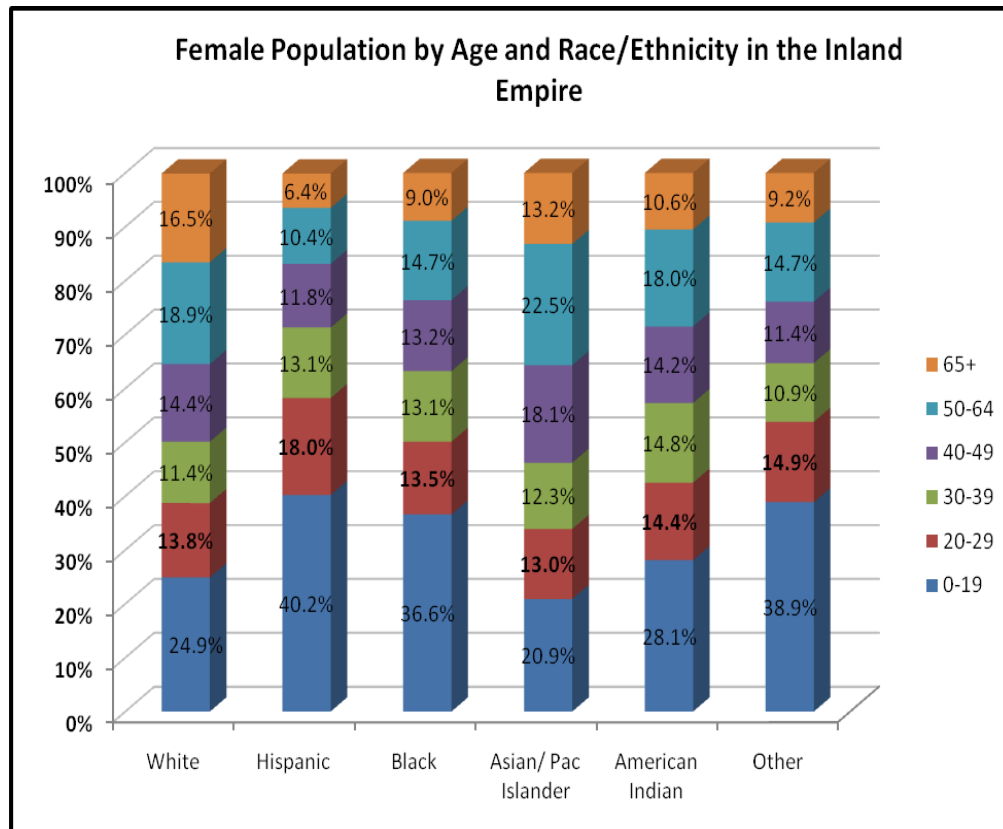


Figure 4. Female Population by Age and Race/Ethnicity in the Inland Empire  
 Data provided by © 2009, Claritas Inc., © 2010 Thomson Reuters. All Rights Reserved.  
 Graph developed by Health Assessment Resource Center, 2011.

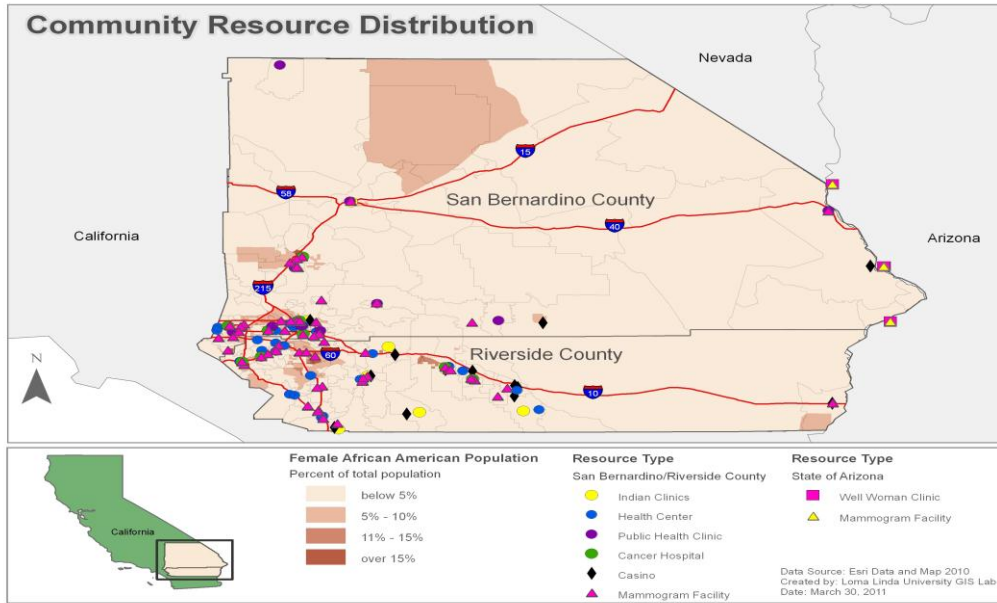


Figure 5. Female African American Population and the Distribution of Community Resources  
Map provide by Loma Linda University, School of Public Health, Health Geoinformatics Program

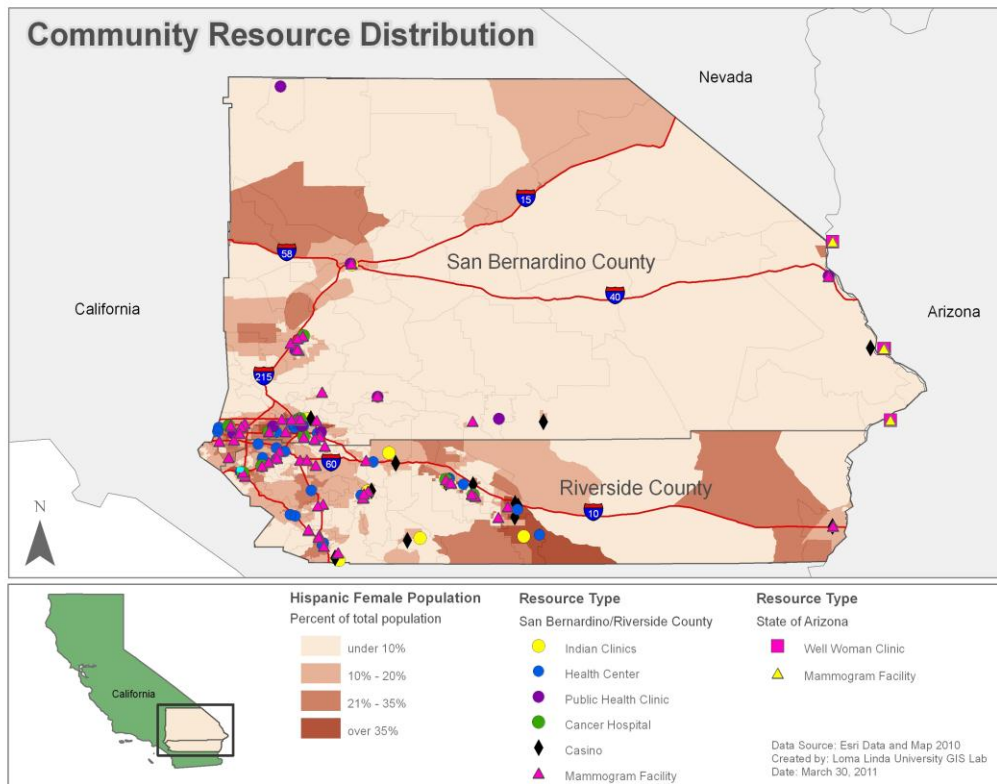


Figure 6. Hispanic Female Population and the Distribution of Community Resources  
Map provide by Loma Linda University, School of Public Health, Health Geoinformatics Program

## Breast Cancer in Females<sup>6</sup>

### Screening

Data from 2009 show that of the 825,372 women 40 years of age or older in the Inland Empire, 302,086 (36.6%) did not have a mammogram in the last 12 months.<sup>7</sup> Figure 7 examines the female population over the age of 40 distribution throughout the service area.

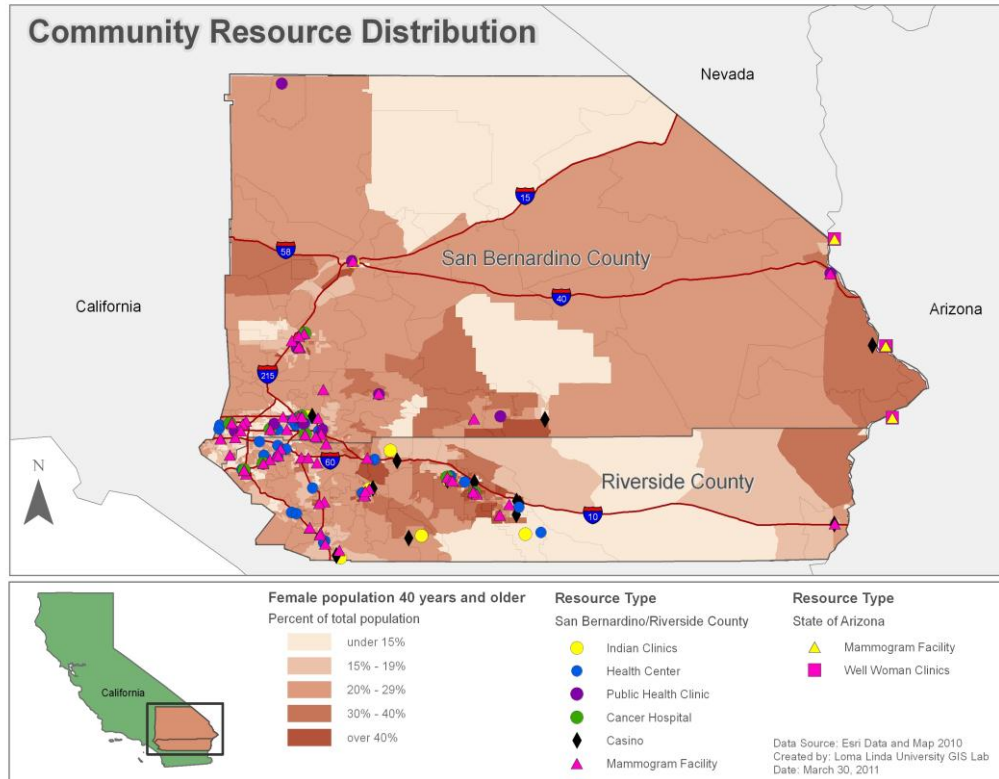


Figure 7. Female population 40 years and older and the distribution of resources.  
Data provided by © 2009, Claritas Inc., © 2010 Thomson Reuters. All Rights Reserved.  
Graph developed by Health Assessment Resource Center, 2011.

### Mortality

The breast cancer mortality rate per 100,000 females is 20.09 in Riverside County, 17.02 in San Bernardino County, and 18.59 for the Inland Empire (both counties combined). These are close to the mortality rate of 20.20 per 100,000 females in California, which ranks fifth out of the 51 states and the District of Columbia for having the lowest mortality rate (behind Rhode Island, South Dakota, Nebraska, and Minnesota). In 2009, 392 women in the Inland Empire died from breast cancer.<sup>8</sup>

<sup>6</sup> The incidence rate for males is 0.7 in the Inland Empire, compared to 90.4 for females; thus, this report focuses on women in the Inland Empire.

<sup>7</sup> Thomson's PULSE Healthcare Survey

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The mortality rate for Caucasian/White females in the Inland Empire is 25.86; it is 21.25 for Black/African American females and 6.49 for females classified as “other.” Unfortunately, these data are not available to separate out Hispanic and Asian females.<sup>9</sup>

### Prevalence

Prevalence is defined as the number or percent of people alive on a certain date in a population who previously had a diagnosis of the disease. It includes new (incidence) and pre-existing cases and is a function of both past incidence and survival.<sup>10</sup> The prevalence rate in the Inland Empire is 0.3% (7,093 women out of 2,109,831). California’s prevalence rate is 0.4%. The average age of women in this group, 57.8, is similar to the national average of 59.0 and California’s average of 58.2.<sup>11</sup>

### Incidence

A cancer incidence rate is the number of new cancers of a specific site/type occurring in a specified population during a year, usually expressed as the number of cancers per 100,000 population at risk. That is,

$$\text{Incidence rate} = (\text{New cancers} / \text{Population}) \times 100,000$$

The numerator of the incidence rate is the number of new cancers; the denominator is the size of the population. The number of new cancers may include multiple primary cancers occurring in one patient. The primary site reported is the site of origin and not the metastatic site. In general, the incidence rate would not include recurrences. The population used depends on the rate to be calculated. For cancer sites that occur in only one sex, the sex-specific population (e.g., females for cervical cancer) is used.<sup>12</sup>

The incidence rate for females is 94.6 in Riverside County and 86.0 in San Bernardino County (90.4 in the Inland Empire; it is estimated to rise to 93.2 in the year 2014).<sup>13</sup> Looking at females in the Inland Empire by age group, the incidence rates are 0.03 for females 0-17, 34.80 for females 18-44, 193.14 for females 45-64 and 319.35 for females 65 years of age or older. The incidence rate for males is 0.7 in the Inland Empire.<sup>14</sup>

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<sup>10</sup> National Cancer Institute SEER definition.

<sup>11</sup> © 2009, Claritas Inc., © 2010 Thomson Reuters. All Rights Reserved

<sup>12</sup> National Cancer Institute SEER definition

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### Stage of Diagnosis

The incidence by stage for the Inland Empire shows that 64% are Stage 1, 28.1% are Stage II, 3.5% are Stage III, and 4.4% are Stage IV. These are very similar to the state figures of 64.4%, 27.8%, 3.4%, and 4.4% and the national figures of 64.2%, 27.7%, 3.5%, and 4.6%, respectively for Stage I, II, III, and IV.

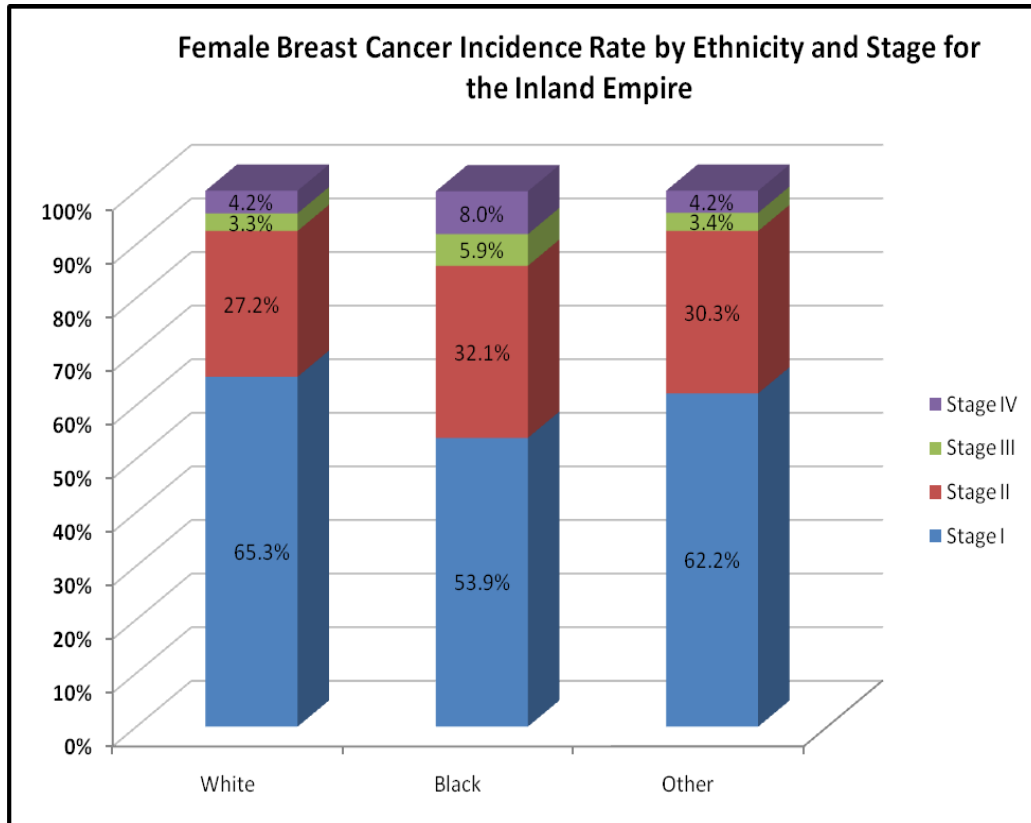


Figure 8. Female Breast Cancer Incidence Rate by Race/Ethnicity and Stage in the Inland Empire Health Assessment Resource Center, 2011.

### **Communities of Interest**

The Inland Empire Affiliate has identified the Black/African American community, as well as the communities throughout the High Desert as communities of interest due to the lack of resources available within these communities, as well as the high mortality rates, high incidence rates, and stage of diagnosis rates that are currently available.

#### **African American Women**

The incidence rate for White women by stage indicates that 7.5% of breast cancers for White women are Stage III or Stage IV; the comparable figure for African American women is 13.9%, almost twice as high. These data are shown in Figure 8 above.

## High Desert Population

The High Desert is defined as the cities of Adelanto, Apple Valley, Baker, Barstow, Fort Irwin, Hesperia, Ludlow, Lytle Creek, Needles, Newberry Springs, Phelan, Pinon Hills, Victorville, and Wrightwood. In 2009, the population was 432,758 with approximately equal numbers of males (49.7%) and females (50.3%). In 2009, it is estimated that 13,668 families (13.0%) have incomes below the Federal poverty level . Of females in the high desert, 47.3% are White, 37.7% are Hispanic, and 8.2% are Black. Five of the cities (Adelanto, Apple Valley, Barstow, Fort Irwin, and Victorville) contain more than 7.1% African American women (7.1% of Inland Empire residents are African American).<sup>15</sup>

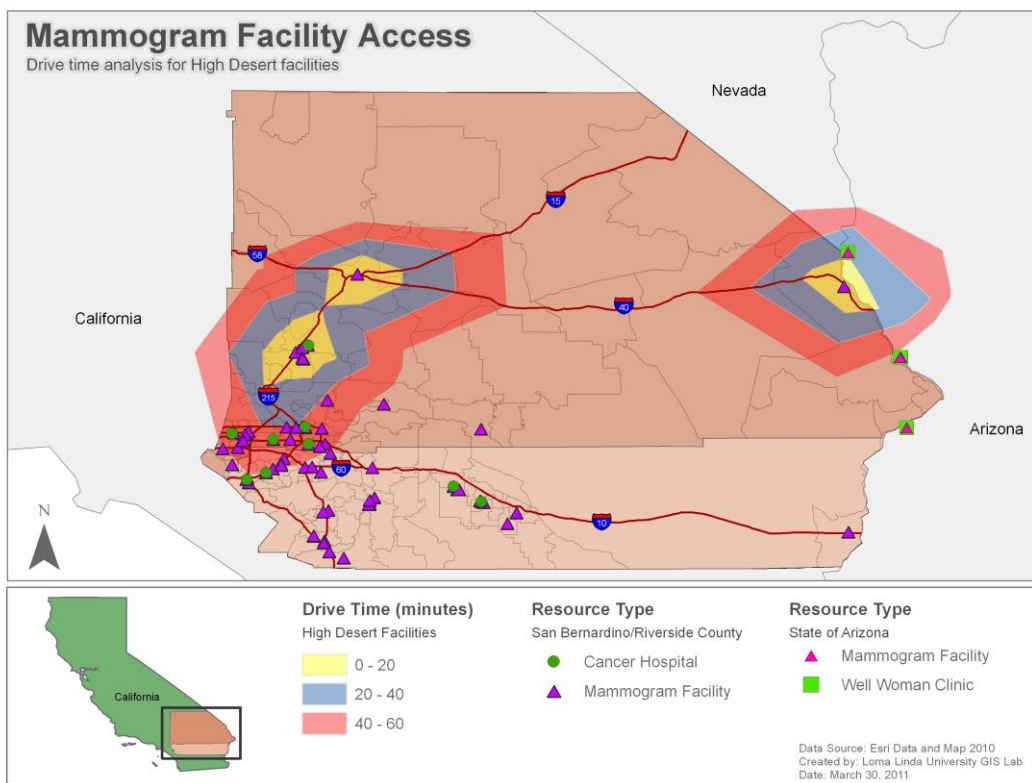


Figure 9. Access to Mammogram Facility by Drive Time  
Map provide by Loma Linda University, School of Public Health, Health Geoinformatics Program

## Insurance

It is estimated that 21.0% of High Desert women, and 17.2% of women 18-64, are uninsured.<sup>16</sup>

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### Mortality in High Desert

The breast cancer mortality rate per 100,000 females is 19.54 in the High Desert region. This is close to the mortality rate of 20.20 per 100,000 females in California. However, the overall rate masks some disparity in the cities that comprise the High Desert. Table 1 shows the mortality rate for each city, all but four of which are higher than 18.59—the mortality rate in the Inland Empire.<sup>17</sup> In 2009, 43 women died of breast cancer.

Table 1. Female Mortality Rate Per 100K in High Desert Cities

City	Mortality Rate Per 100K Females
Ludlow	28.57
Lytle Creek	27.79
Newberry Springs	24.97
Needles	24.93
Pinon Hills	24.67
Wrightwood	24.62
Apple Valley	24.32
Phelan	21.07
Hesperia	19.58
City	Mortality Rate Per 100K Females
Victorville	18.64
Barstow	18.03
Adelanto	11.99
Baker	11.07
Fort Irwin	5.55

Table 2. Female Incidence Rate Per 100K in High Desert Cities

City	Incidence Rate Per 100K Females
Lytle Creek	131.71
Ludlow	127.14
Wrightwood	119.52
Newberry Springs	119.22
Pinon Hills	117.58
Needles	116.50
Apple Valley	111.51
Phelan	105.26
Hesperia	95.67
Barstow	90.05
Victorville	89.59
Adelanto	64.73
Baker	60.65
Fort Irwin	35.84

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Graph developed by Health Assessment Resource Center, 2011.

### Incidence in High Desert

As shown in Table 2, nine of the fourteen cities that comprise the High Desert have incidence rates above the rate for the Inland Empire (90.4).<sup>18</sup>

### Stage of Diagnosis in High Desert

The incidence by stage for the High Desert is similar to that for the Inland Empire with 64.3% Stage 1, 27.9% Stage II, 3.4% Stage III, and 4.4% Stage IV.

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<sup>18</sup> 2009, Claritas Inc., © 2010 Thomson Reuters. All Rights Reserved

## Conclusions

Collectively, the incidence and mortality patterns throughout the High Desert reveal a failure to detect breast cancer early in the natural history of the disease. The pattern of lower risk of pre-invasive (*in situ* carcinoma) and invasive breast cancer, accompanied by higher risk of death from breast cancer are consistent with a failure to provide early detection and state-of-the-art treatment for this disease. Clearly, a greater proportion of the burden of a later breast cancer stage is experienced by Blacks/African American women in the High Desert. The National Cancer Institute defines "cancer health disparities" as "differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific populations groups in the United States." Disparities in health and services available are exemplified in the Inland Empire women and their families who have been touched by breast cancer. Therefore, the Affiliate has chosen the High Desert, and its respective communities, as a target community for the cancer health disparities throughout its region. The Affiliate has also identified the Black/African American population as a target community due to the disproportionate incidence rate of a later stage breast cancer diagnosis and mortality.

# Health Systems Analysis of Communities

## Overview of Continuum of Care

The continuum of care surrounding breast cancer is reliant on varying determinants. Factors influencing the quality and functionality of the continuum of care include: level of education, knowledgeable and competent medical provider/staff, screening, diagnostic services, treatment, support, follow-up care, knowledge of clinical trials, etc. It is imperative that each stage in the continuum of care is clearly defined for establishing a standard of care throughout the entire process. The analysis of the continuum of care phases is used to further understand the gaps, barriers, and issues present for women at each phase, and to assist in eliminating them.

## Methodology

### Asset Maps

The San Bernardino and Riverside County maps were created using the desktop version of ArcGIS 10 by Loma Linda University, School of Public Health, Health Geoinformatics Program. Geographic layers including boundaries, zip codes, and census tracts were imported from the 2000 census data. Demographic layers including total population were imported from the 2010 estimates of the 2000 census data. Feature layers including health clinics, public health facilities, cancer hospitals, mammogram centers, hospitals, Native American clinics, and casinos were received as an Excel file from Susan G. Komen for the Cure®, cross referenced for accuracy and updates, and imported and geocoded in ArcGIS. Demographic data used in the choropleth maps were calculated using the percent of females per census tract and normalized by the total population (males and females). Drive time distance estimates were calculated using ArcGIS Business Analysis, polygons were grouped and merged according to travel time, and the modified shapefile was imported into the project maps.

### Provider Surveys

Health Assessment Resource Center (HARC) collaborated with Susan G. Komen for the Cure® staff to design an English language questionnaire suitable for medical providers in Riverside and San Bernardino Counties. Susan G. Komen for the Cure® staff provided a list of providers. This initial list consisted of 57 names. Providers were encouraged to forward the survey link to others within their organization, and to other providers in Riverside and San Bernardino Counties. Additionally, Susan G. Komen staff provided the survey link to individual providers they met during meetings and outreach activities. A total of three reminder emails were sent to non-respondents encouraging them to complete the survey and distribute the link to other providers.

## Overview of Community Assets

Due to the immense service area, women and families in the outlying areas, as well as, urban areas face many challenges accessing healthcare, breast health education, screening and diagnostic services and if diagnosed with breast cancer, women face continuing gaps in services for after care, availability to clinical trials, as well as survivorship needs.

The health systems analysis clearly identified the need for the Komen Inland Empire Affiliate to increase awareness and education efforts across all age groups and all ethnicities, highlighting that early detection saves lives, while serving as a resource to access screening and diagnostic services throughout the service area. The Affiliate must make their 4 million constituents aware of Komen's Promise and how they are making a difference in the lives of those dealing with breast cancer.

The Inland Empire Affiliate's main office is located in the southwest corner of Riverside County (see map). Due to the immense service area (27,000 square miles), many different approaches must be taken to educate about available services and resources, including how to access care and navigate the healthcare system. The Affiliates efforts include launching strategically located resource centers, facility resource guides designed specifically for each geographical area, community liaisons, and community partnerships.

As part of the 2009 Community Profile Goals and Objectives, the Affiliate established the **Susan G. Komen for the Cure, Inland Empire Breast Health Resource Center**, located in Rancho Mirage, which currently serve Coachella Valley residents. The Breast Health Resource Center is located near the bottom, central portion of the service area (see map). Although the Affiliate has made great strides in expanding our outreach efforts through implementing the resource center in the desert, education and outreach to the remaining service areas remain a major challenge. Not only is distance a factor, but due to the population density in the southwestern area of both counties, traffic congestion contributes to the problem. Climate can also pose a barrier, for some of our service areas experience snow, high winds, and others, unbearable hot temperatures limiting travel. The map below (Figure 10) shows the location of resources and the total population.

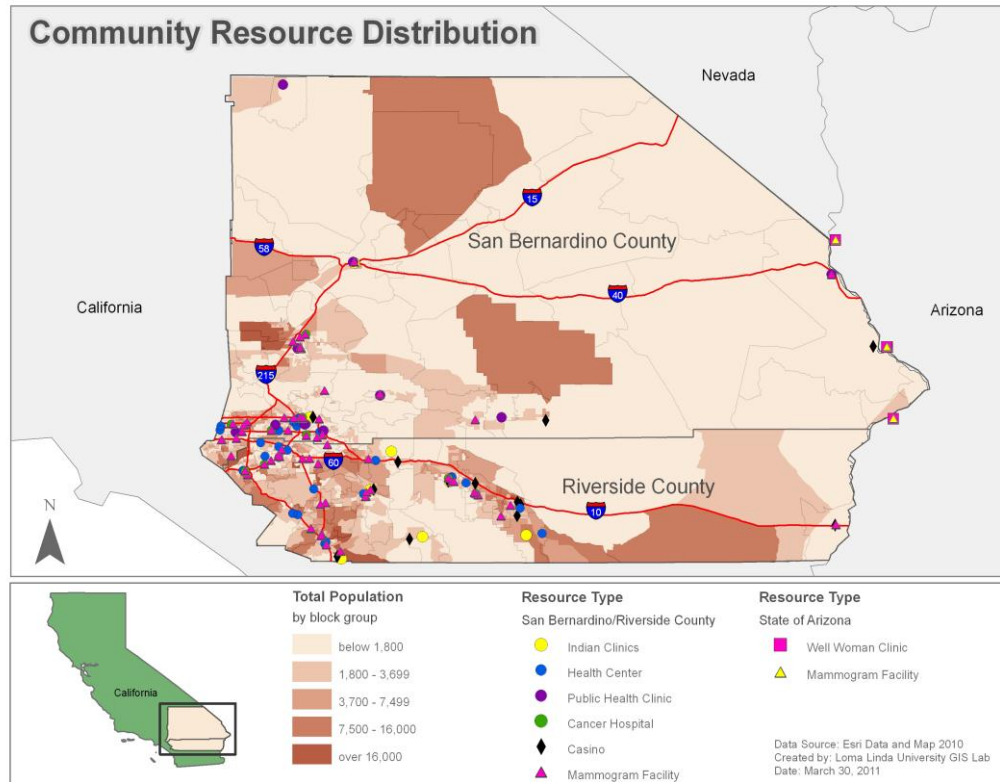


Figure 10. Resource Distribution by Total Population  
 Map provide by Loma Linda University, School of Public Health, Health Geoinformatics Program

### Existing Inland Empire Affiliate Partnerships

As the Affiliate continues to expand, we strive to identify potential partnerships and collaborations throughout the service area, and abroad, in order to enhance our ability to provide access to resources, as well as broaden our knowledge and leadership in the community. The following lists of partnerships are not inclusive, and are continually developing.

**Komen California Collaborative** - All seven Komen California Affiliates meet quarterly to address the needs of the independent service areas, as well as, programs and services where all can work together to strengthen the impact of breast cancer for women, men and families in the State of California.

**Bi-National Mexican Consultant** - Bi National Health Week has become one of the largest mobilization efforts in the Americas to improve the health and well-being of the underserved immigrants and the migrants of Mexican and Central American origin living in the United States, Canada, and Mexico. It encompasses an annual weeklong series of health promotion and health education activities that include workshops, insurance referrals, and medical screenings.

American Cancer Society - Goal: to ensure diverse audiences in community-based organizations and ethnic populations are provided with life saving information and knowledge of resources available

Access to Care Forum- Began August 2008-Spearheaded by the American Cancer Society, this collaboration between different healthcare and service organizations provided a program for the community to learn more and get involved in improving Access to Healthcare, thus making a difference in lives of individuals while making an impact on cancer. This will be an ongoing outreach.

Every Woman Counts - Cancer Detection Programs: Every Woman Counts (CDP: EWC) provides clinical breast exams, mammograms, pelvic exams and Pap tests to California's underserved women. These women are age 40 and older (cervical cancer screening is provided to women 25 and older), and have an income at or below 200% of the federal poverty. CDP: EWC is funded by a federal grant and state tobacco tax revenue.

Inland Agency Breast Health Coalition - EWC Providers, community members, nonprofit organizations committed to serving the uninsured women in the Inland Empire. Members' network and exchange resources to better serve the community.

Latino Outreach Committee - Committee works to ensure that community-based organizations and diverse populations are provided with life-saving information and resources and have access to programs that improve their quality of life.

Inland Empire Coalition for Health- Community and Business Leadership to improve the public's health of the Inland Empire. It is achieved by: 1) Taking a leadership role in building collaboration and advocacy on behalf of and with our community. 2) Promoting policies that further our Mission 3) Assessing community health and social needs 4) Building linkages and partnerships 5) Communication with policy makers 6) Communicating with the public.

Loma Linda University, School of Public Health - Student Interns working on their MPH or other areas of International Public Health that are interested in supporting the breast health projects of the Affiliate.

We Care - Education and Screening Mobile Outreach Program in the Coachella Valley serving all the desert cities.

San Bernardino American Newspaper - The oldest minority legally adjudicated newspaper in San Bernardino and the Inland Empire. Focuses outreach to the African American Community.

KOMEN-ON-THE-GO - Visited the following higher education institutions: The goals are to increase awareness for Komen, breast health and public policy issues related to breast cancer.

College of the Desert (COD) – Two-year college, and the number one source of transfer students to California State University, San Bernardino, COD offers a variety of vocational and technical programs, including nursing and health sciences.

University of California Riverside – Four-year university, located in Riverside, offers undergraduate and graduate degrees. UCR is preparing the first enrollment in the University of California Riverside, School of Medicine in the fall of 2012.

### **Inland Empire Affiliate Grant Recipients from 2011 and 2012 Funding Cycles**

Breast Cancer Solutions – Provides direct financial assistance, community referrals, and compassionate moral and mental health support.

Desert Cancer Foundation - Provides free breast cancer screening and diagnostic services to low income, uninsured/underinsured Coachella Valley residents who have been referred to the program due to a breast health issue.

Gilda's Club Desert Cities – Provides programs that address the physical and psychosocial health of breast cancer survivors by structuring support groups, workshops, and recreational activities targeted to evaluate the quality of survival of those diagnosed with breast cancer, and to minimize or stabilize adverse effects experienced cancer survivorship.

Inland Agency- The Pink Ribbon Place - The Pink Ribbon Place provides patient navigation and support services to uninsured/underinsured women and men under age 40 who are symptomatic, have had an abnormal mammogram, and/or are diagnosed with breast cancer residing in parts of Riverside and San Bernardino Counties not served by other programs.

Kids Konnected – Provides free, professional group support for children affected by a parent's breast cancer diagnosis or death.

Kommah Seray Inflammatory Breast Cancer Foundation – Provides educational gatherings to increase awareness and mammogram screening among African American females.

Loma Linda University Medical Center – Aims to improve clinical trial enrollment rate of underserved minority women in the Inland Empire in a culturally sensitive basis.

Loma Linda University School of Public Health – Provides culturally appropriate breast cancer clinical trial education to reinforce the importance of making an informed decision about participation in clinical trials and research studies.

Michelle's Place - Provides breast health resources, education, navigation, financial assistance and support to women and their families dealing with breast cancer, as well as free and low cost diagnostic breast health services to uninsured/underinsured women less than 40 years old who have a symptom of breast cancer.

Quinn's Community Outreach Corporation - Southern California Witness/Esperanza y Vida Projects- Address the critical need for culturally relevant, community-based breast cancer education/awareness, outreach and support to uninsured, underinsured, and low income African American and Latina women and men of all ages residing in the Inland Empire.

Redland's Community Hospital – Provides education, navigation assistance, and free diagnostics, as well as follow-up through the Women's Health Imaging Center and Community-Based Outreach Programs.

San Antonio Community Hospital - Offers the Women Caring for Women (WCW) outreach program, specifically designed to remove traditional barriers by bridging the existing gap in services to low-income and uninsured /underinsured women.

St. Bernadine Medical Center Foundation - Breast Cancer Patient Navigation program will improve patients' access to information, offer support programs, and language translation services.

St. Mary Hospital Foundation - Provides screening, diagnostic, patient navigation services, assistance with transportation, lymphedema garments, wigs, and special needs to women at-risk, under age 40, low-income, uninsured, and women without access to state-funded cancer detection programs. St. Mary Hospital also offers a mobile clinic providing primary healthcare to for low-income, uninsured adults and children.

SSG/PALS for Health – Provides patient educators to promote breast cancer screening in a culturally and linguistically appropriate manner, to empower underserved women to advocate for language assistance and quality breast health care for themselves, as well as provide face-to-face, trained interpretation services.

The Foundation for Community and Family Health - provides breast cancer diagnostic services for eligible symptomatic women age 49 and younger in Corona, Norco, and surrounding Western Riverside communities.

## **Partnerships and Grant Opportunities**

Our partnership in the desert community of Rancho Mirage resulted in the **Susan G. Komen for the Cure, Inland Empire Breast Cancer Resource Center**, enabling the Affiliate to increase outreach efforts to the women in the low desert cities. The Affiliate encourages collaboration among organizations, businesses, agencies, etc. We consistently seek out potential partnerships and collaboration opportunities throughout the service area.

Grant Opportunities for 2012-2013 and 2013-2014 are released as Request for Applications (RFA) beginning in the fall of 2011 and fall of 2012. Grant funding priorities are based on the goals and objectives to address community needs in the Community Profile Report. Please visit our website at [www.komenie.org](http://www.komenie.org) to review current funding opportunities.

### ***Promising Practices and Evidence-Based Programs***

Southern California Witness/Esperanza y Vida Projects are the result of ethnic breast cancer research for African American and Latina women through the University of Arkansas Little Rock Center for medical science in Little Rock, Arkansas, the Roswell Park Center Institute in Roswell, New York and Mount Sinai School of Medicine in Harlem, New York. This program is critical for the African American and Latina community of Inland Empire and impacts breast cancer mortality programs by promoting early detection.

Faith Based Programs---The Affiliate has supported “Pink Sunday” programs in some targeted African American Churches, however, by re-igniting this type of outreach on a larger scale could serve as grassroots approach to increase awareness about Komen IE and breast health throughout the service area.

Patient Navigator Programs---Several Komen Grantees offer various types of patient navigator programs. These programs can be very effective in streamlining the patient through screening services as well as the healthcare maze once diagnosed.

## **Public Policy Perspectives**

The Inland Empire Affiliate Board of Directors, staff, and volunteers are committed to engage and involve public officials on a state and national level on breast health and breast cancer issues that impact the health and well-being of women, men and their families throughout the Inland Empire.

The Inland Empire Affiliate participated in Lobby Day in Sacramento in January 2011 with all 7 Affiliates to discuss critical breast health issues for the uninsured

/underinsured women and the Every Woman Counts program. Currently only 19% of the 1.2 million eligible women receive services through this program. The EWC program in the IE has even fewer women utilizing the program/services 10% (San Bernardino) and 11% (Riverside). This truly indicates the need for early detection education in our service area

National Lobby Day Washington, D.C. - Inland Empire Affiliate has participated in National Lobby Day in April 2011 and will attend National Lobby Day 2012 to assist in influencing policy decisions throughout California and the nation.

## Key Informant Findings

### Medical Providers

In order to gain a more in-depth understanding of medical providers throughout the service area, the Affiliate obtained provider surveys. This data will allow the Affiliate to understand the community’s needs and barriers to breast health resources from a provider’s perspective, as well as obtain information about the medical provider and staff educational needs surrounding the breast health continuum of care within the service area.

Respondents were asked, “In general, how knowledgeable is your staff about the guidelines for breast cancer screening?” As shown in 11, 60% indicated their staff is “very knowledgeable,” 23.3% reported their staff is “somewhat knowledgeable,” 16.7% reported their staff is “a little knowledgeable;” no-one indicated their staff is “not at all knowledgeable.”

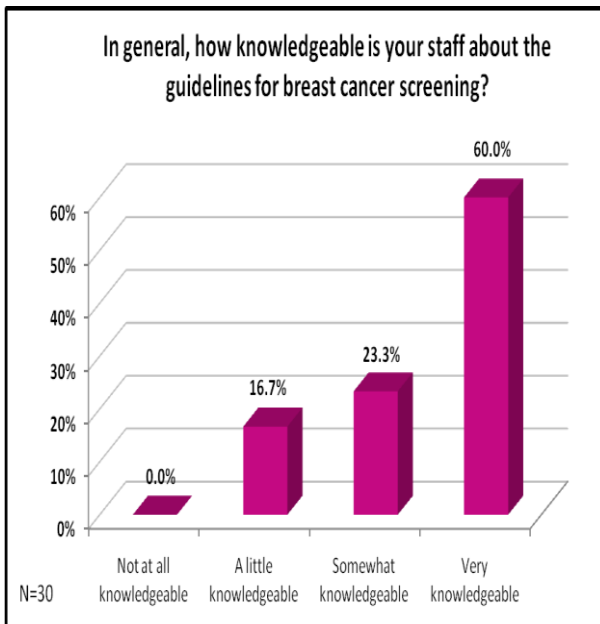


Figure 11. Knowledge of Staff about Guidelines for Screening Health Assessment Resource Center, 2011.

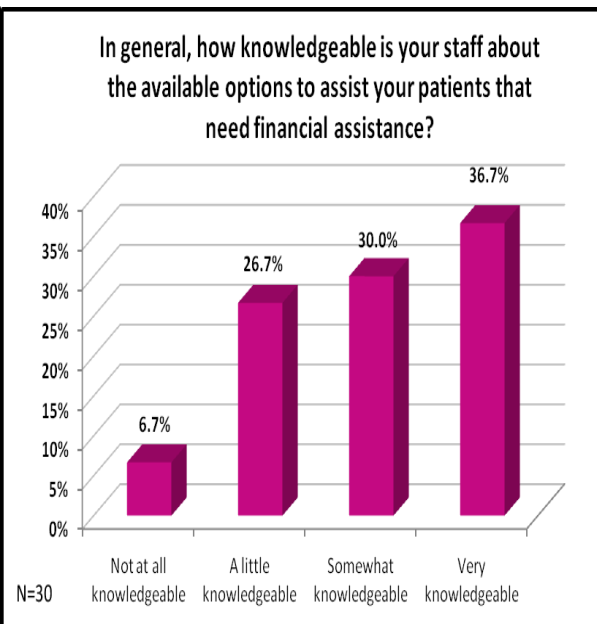


Figure 12. Knowledge of Staff Regarding Financial Assistance for Patients

Respondents were asked, “In general, how knowledgeable is your staff about the available options to assist your patients that need financial assistance?” These data are shown in 12. Knowledge in this area is less, with one-third indicating their staff is either “not at all” or “a little” knowledgeable. The largest proportion (36.7%) is still described as “very knowledgeable.”

**Barriers to Screening**

Respondents indicated the extent to which ten factors created a barrier for the women that their organization serves in terms of seeking or obtaining breast health screenings. Response options were “Large barrier,” “Somewhat of a barrier,” “Not much of a barrier,” and “Not at all a barrier.” These were coded 4, 3, 2, and 1, respectively so that a large number represents a large barrier. Shown in Table 3, these barriers range from a low of 1.78 for “the belief that mammograms increase the chances of developing breast cancer” to a high of 3.17 for “lack of transportation to services.” A total percent is not provided as providers could select more than one answer. The top barriers, in order, were transportation, low income/poverty, uninsured/underinsured, and patients that “fall through the cracks” because they are don’t qualify for federal programs but they are unable to pay. These were rated 3.33 or higher on the 4-point scale.

Table 3. Barriers to Screening

<b>Barriers to Screening</b>	<b>Frequency</b>	<b>Range</b>	<b>Mean</b>
Lack of transportation to services	18	1-4	3.17
Low income/ poverty	18	1-4	3.67
Uninsured or underinsured	18	1-4	3.61
Don't qualify for state or federal programs, but they are unable to pay, so they "fall through the cracks."	18	1-4	3.33
Don't think they need one/ no family history	18	1-4	2.94
Language barriers	18	1-4	2.83
Low literacy of population	18	1-4	2.82
Confusion created by new Task Force recommendations	18	2-4	2.72
Concerned about their immigration status	18	1-4	2.72
Belief that mammograms increase chances of developing breast cancer	18	1-4	1.78

Health Assessment Resource Center, 2011.

**Barriers to Treatment**

Respondents indicated the extent to which nine factors create a barrier for their organization in terms of providing treatment for the women it serves. Response options were “Large barrier,” “Somewhat of a barrier,” “Not much of a barrier,” and “Not at all a barrier.” These were coded 4, 3, 2, and 1, respectively so that a large number represents a large barrier. Shown in Table 4, these barriers range from a low of 2.10 for “reimbursement is not timely” to a high of 3.36 for “patients are uninsured or underinsured.” The other top barriers are “patients lack transportation”

and “services are not covered by insurance.” A total percent is not provided as providers could select more than one answer.

Table 4. Barriers to Treatment

Barriers to Treatment	Frequency	Range	Mean
Patients are uninsured or underinsured	11	1-4	3.36
Patients lack transportation	11	1-4	2.64
Services are not covered by insurance	10	1-4	2.60
Patients cannot get HMO authorization	11	1-4	2.55
Patients do not understand what is covered by their insurance plan	11	1-4	2.36
Patients need “off hour” appointments like evenings and weekends	10	1-3	2.20
We lack the funds to provide services to those who need it	10	1-4	2.20
Language barriers	11	1-4	2.18
Reimbursement is not timely	10	1-3	2.10

Health Assessment Resource Center, 2011.

### Follow-up Care

Of the 28 valid responses, 16 (57.1%) respondents indicated that their organization provides follow-up care; 12 (42.9%) do not provide follow-up care after breast cancer treatment.

### Barriers to Follow-up Care

Respondents indicated the extent to which ten factors create a barrier for their organization in terms of providing follow-up care for the women it serves. Response options, as previously described, were “Large barrier,” “Somewhat of a barrier,” “Not much of a barrier,” and “Not at all a barrier.” These were coded 4, 3, 2, and 1, respectively so that a large number represents a large barrier. Shown in Table 5, these barriers range from a low of 1.87 for “reimbursement is not timely” to a high of 3.40 for “patients are uninsured or underinsured.” The other top barriers are “patients lack transportation” and “patients don’t qualify for state or federal programs, but are unable to pay, so they fall through the cracks.”

Table 5. Barriers to Follow-up Care

Barriers to Follow-up Care	Frequency	Range	Mean
Patients are uninsured or underinsured	15	1-4	3.40
Patients lack transportation	14	1-4	3.00
Patients don't qualify for state or federal programs, but are unable to pay, so they "fall through the cracks."	15	1-4	3.07
Providers lack the funds to provide services to those who need it	14	1-4	2.71
Patients cannot get HMO authorization	15	1-4	2.60
Services are not covered by insurance	14	1-4	2.50
Language barriers	15	1-4	2.33
Patients do not understand what is covered by their insurance plan	14	1-3	2.21
Patients need "off hour" appointments like evenings and weekends	15	1-3	2.20
Reimbursement is not timely	15	1-4	1.87

Health Assessment Resource Center, 2011.

### Services Provided During and/or After Treatment

Respondents were presented with a list of 12 services and indicated if they provide each during treatment, after treatment, or if they do not provide it at any time to their clients/patients. Table 6 is ordered in decreasing order in terms of services not provided. Providers are least likely to offer alternative therapies, palliative/end-of-life care, pain management, long-term treatment, reconstruction, durable medical goods, lymphedema therapy, and managing side-effects. These are all not provided by the majority of providers who answered these series of questions.

Table 6. Services Provided During/ After Treatment

Services Provided During/ After Treatment	DO NOT PROVIDE	Provide During Treatment	Provide After Treatment
Alternative Therapies (e.g., acupuncture, massage, herbal remedies)	64.3	17.9	14.3
Palliative/End-of-life care	60.7	21.4	14.3
Pain Management	60.7	28.6	17.9
Long-term treatment	57.1	25.0	17.9
Reconstruction	57.1	21.4	17.9
Durable medical goods (e.g., specialized mastectomy clothing, pressure bandages, prostheses)	53.6	32.1	28.6
Lymphedema Therapy	53.6	28.6	21.4
Managing side-effects	53.6	35.7	17.9
Individual Counseling	42.9	46.4	35.7
Nutritional counseling/ classes	39.3	50.0	39.3
Group Counseling	35.7	50.0	39.3
Support Groups	35.7	53.6	46.4

Health Assessment Resource Center, 2011.

### Clinical Trials

The majority (71.4%) of respondents indicated that their staff is “not at all” or “a little knowledgeable” of breast cancer clinical trials available in their area. All valid data are shown in Figure 13.

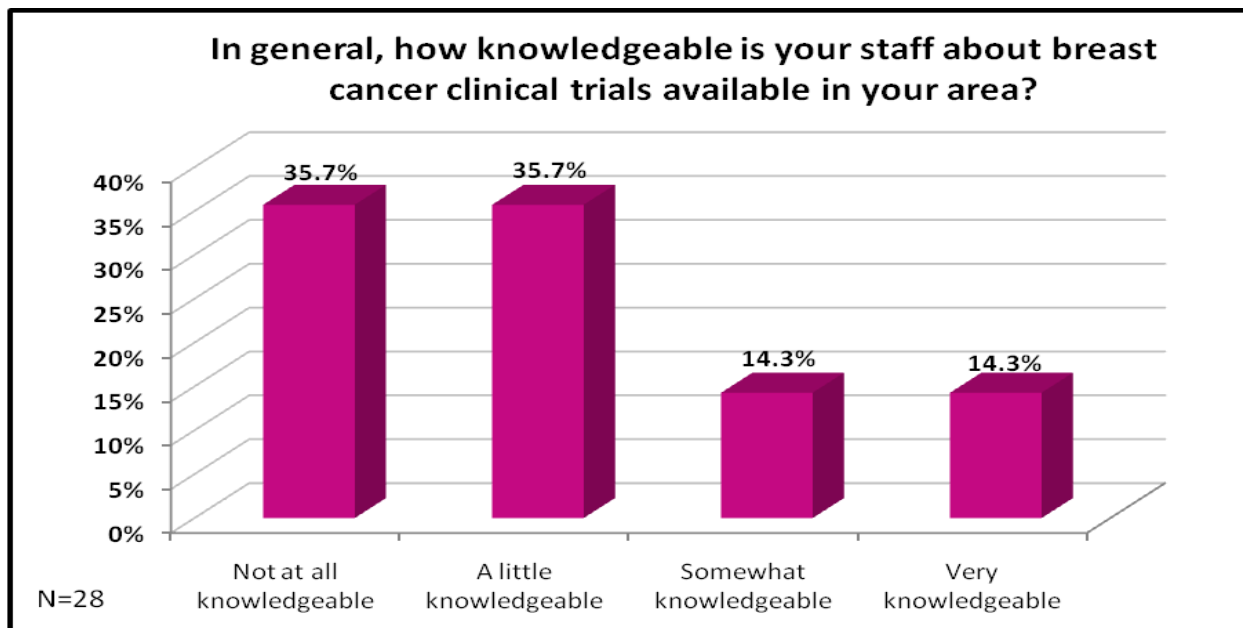


Figure 13. Knowledge of Staff Regarding Clinical Trials  
Health Assessment Resource Center, 2011

The map below (Figure 14) displays the available mammography centers and cancer hospitals located in the Affiliate’s service area and the drive time. Note the large gaps in facility locations.

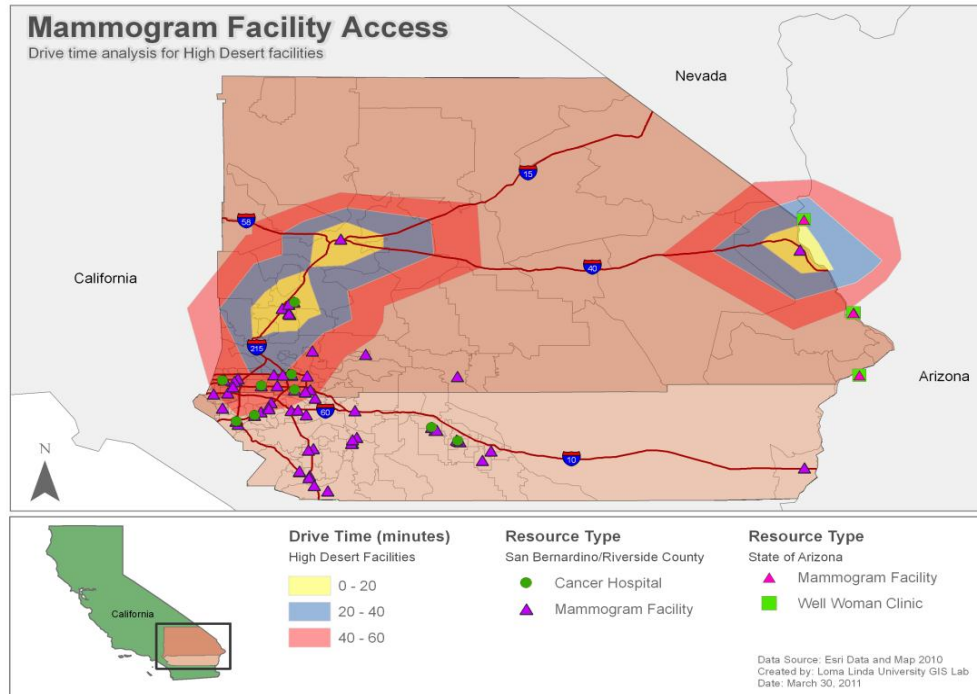


Figure 14. Mammography Facility Access and Drive Time  
Map provide by Loma Linda University, School of Public Health, Health Geoinformatics Program

### Healthcare Services for Breast Health in the Inland Empire

Hospitals---41 includes 3 County Hospitals  
Mammography Facilities---71  
Community and Public Health Clinics---49  
Indian Health Clinics---8

### Arizona Border

Community and Public Health Clinics---3  
Mammography Facilities---3

## Conclusions

Analysis of programs and services revealed an inequitable geographic distribution of breast cancer services in the Inland Empire. Although the majority of the population resides in the southwest area of both counties, the outlying areas have minimal resources. Additionally, findings in the Health Systems Analysis of Target Communities demonstrate a deeper understanding of the impact of breast cancer throughout Riverside and San Bernardino Counties. The lack of facilities and resources in target communities, such as the High Desert, are a hindrance in making strides to reach more constituents throughout the service area. It is also important to note the quality/level of knowledge among medical providers and staff surrounding breast health screening, assistance programs and resources, services provided, clinical trials, and barriers affecting patients, in relation to the continuum of care as an entire process. It has been identified by providers that barriers to screening and treatment include

uninsured/underinsured, lack of transportation, unable to obtain HMO authorization, and patients “fall through the cracks”.

In 2009, it was estimated that 36.6% of women over the age of 40 did not have a mammogram in the last 12 months<sup>19</sup>. To our knowledge, only one breast cancer program exists for uninsured/underinsured women age 40 to 64, the Cancer Detection Program: EWC (Every Woman Counts) helps underserved women receive free breast cancer screening and diagnostic services through diagnosis as well as cervical cancer prevention for women who qualify. Surveys indicate that barriers to accessing screening and treatment include lack of transportation, uninsured/underinsured, low income/poverty, “fallen through the cracks”, job loss, and unable obtain HMO authorization. Feedback from women and clinics estimates there are not enough providers especially in the outlying areas and the above mentioned data demonstrates that uninsured women are not accessing the Every Woman Counts program.

The Affiliate has made important strides in building partnerships and expanding the Komen promise in the service area since the previous Community Profile, particularly with the Breast Health Resource Center in Rancho Mirage. The Breast Health Resource Center is approximately 80 miles from the Affiliate’s main office, and several hours from other service areas, leaving many areas without breast health education and outreach services.

The Komen Grantees play a key role in education and outreach. Efforts by the Affiliate to have the grantees “network” has helped with improving access to resources for women throughout the service area. The Affiliate encourages the expansion of programs into underserved areas throughout both Riverside and San Bernardino Counties, and looks to fund programs which meet our Affiliate’s priority needs in those areas.

Through advocacy involvement, the Affiliate has received requests from Assembly members and Senators on a State level, as well as Congressional Members and Senators on a Federal level, that they support our efforts and want their “local” offices to participate in Komen activities. The Affiliate continues to make its presence known with local legislators, and engages in grass-roots lobbying efforts.

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<sup>19</sup> Thomson’s PULSE Healthcare Survey 2009.

# **Breast Cancer Perspectives in the Communities**

## **Methodology**

### **Community Survey**

Health Assessment Resource Center (HARC) collaborated with Susan G. Komen for the Cure® staff to design an English language questionnaire suitable for community at large in Riverside and San Bernardino Counties. The Inland Empire Affiliate of Susan G. Komen for the Cure® distributed surveys designed for the community (not including breast cancer survivors) of San Bernardino and Riverside Counties. The purpose of the survey was to obtain information regarding the knowledge, beliefs, and behaviors surrounding breast health and breast cancer. The survey also obtained information regarding the community's awareness and perception of the Inland Empire Affiliate of Susan G. Komen for the Cure®.

Affiliate volunteers distributed surveys at local Sam's Club Stores in San Bernardino, Riverside, and Palm Desert, as well as in the High Desert which included Phelan, Victorville, Apple Valley, and Hesperia at Calvary Chapel of Phelan (church) and upon meeting individuals throughout the High Desert communities. Additionally, Affiliate volunteers distributed surveys at health fairs, the College of the Desert in Palm Desert, and the University of California Riverside in Riverside.

### **Survivor Online Survey**

Health Assessment Resource Center (HARC) collaborated with Susan G. Komen for the Cure® staff to design an English language questionnaire suitable for online administration to breast cancer survivors in Riverside and San Bernardino Counties. Questions were developed to assess survivors' experience along the "continuum of care—from screening, through treatment, and follow-up care." The questionnaire began with questions regarding screening and diagnosis, including participation in the "Every Woman Counts" program. Respondents indicated the barriers they encountered their sources of information after diagnosis, and their access to and use of a breast health coordinator/patient navigator. Treatment questions focused on their interaction with their surgeon and oncologist and barriers they encountered; several questions assessed their participation in clinical trials. Questions related to follow-up care included visits to their oncologist and/or primary care physician and barriers encountered in receiving the care they require. Standard demographic items were also included.

An email was originally sent to 776 breast cancer survivors whose contact information (email only) was provided by the Susan G. Komen Inland Empire Affiliate. Additionally, the Affiliate sent an e-mail to grant recipients to send to breast cancer survivors within their system. The survey was online and

anonymous. A total of three reminder emails were sent encouraging individuals to complete the survey. Additionally, email recipients were encouraged to provide the survey link to other breast cancer survivors they knew in Riverside and San Bernardino Counties.

### **Survivor Focus Group**

Focus group discussions consist of eight to twelve interacting individuals having some common interest or characteristic, brought together with a moderator to gain information about a specific issue. The shared characteristic for this group of individuals is that they are breast cancer survivors.

Effective focus group moderators create a permissive and supportive environment that encourages different perceptions and points of view, without pressuring participants to reach consensus. Focus group interviews are a very popular and effective means of exploratory, qualitative research. Their primary purpose is to generate ideas, not numbers. Although this qualitative information is subjective, the rich description of the topics under discussion is extremely useful. For example, this qualitative information supplements the quantitative, “fixed response” rating information obtained by administration of the online survey administered to breast cancer survivors.

A focus group discussion of approximately 90 minutes was conducted in April, 2011 with six breast cancer survivors in a conference room at the Hilton Hotel in Rancho Cucamonga. The Hilton Hotel had generously donated both the room and refreshments. No one-way mirrors were installed, so all participants were visible to one another. Food and beverages were served at the discussion, but no incentives were provided.

The discussion guide for the focus group was developed collaboratively by HARC and Susan G. Komen for the Cure® staff. Topics included barriers to screening, education/outreach regarding breast health and breast cancer, positive and negative aspects of treatment, the main challenges they face as survivors, and services and policies in the area that are effective, ineffective, and services that are currently needed.

The session was audio-taped with the participants’ permission, and the primary raw data for analysis is the typed transcripts of the recording, filling 49 single spaced pages. The transcript summarized in this report was content analyzed to extract themes, which are supported by direct quotations from the transcript. Direct quotations appear in the results section as indented text. It is important to note that approximately 90% of respondents reported being of Caucasian ethnicity. Efforts to obtain a more equally distributed group of ethnicities throughout the Affiliate’s service area is to be completed for the 2013 Community Profile.

## **African American Women Focus Group**

Focus group discussions consist of eight to twelve interacting individuals having some common interest or characteristic, brought together with a moderator to gain information about a specific issue. The shared characteristic for this group of individuals is that they are African American women between the ages of 28 and 60; all but two are 40 years of age or older.

Effective focus group moderators create a permissive and supportive environment that encourages different perceptions and points of view, without pressuring participants to reach consensus. Focus group interviews are a very popular and effective means of exploratory, qualitative research. Their primary purpose is to generate ideas, not numbers. Although this qualitative information is subjective, the rich description of the topics under discussion is extremely useful.

A focus group discussion of approximately 90 minutes was conducted in April, 2011 with ten African American women at a hair salon in Rialto, California. No one-way mirrors were installed, so all participants were visible to one another. Food and beverages were served at the discussion, but no incentives were provided.

The discussion guide for the focus group was developed collaboratively by HARC and Susan G. Komen for the Cure® staff. Topics included barriers to screening, education/outreach regarding breast health and breast cancer in the African American community, and the available services in their area and the services they felt were needed for their community.

The session was audio-taped with the participants' permission, and the primary raw data for analysis is the typed transcripts of the recording, filling 45 single spaced pages. The transcript summarized in this report was content analyzed to extract themes, which are supported by direct quotations from the transcript. Direct quotations appear in the results section as indented text.

## **Review of Quantitative Findings**

### **Community Survey**

The analysis of the Community Survey indicated that there were a total of 327 respondents, of which 1 in 5 were male. Approximately 36.9% of respondents identified as Hispanic, 33.4% White, 11.1% Black/African American, and 9.9% Asian/Pacific Islander. Respondents ranged from 13 to 83 years of age, and 75.3% did not possess an educational degree. Analyzing the survey data reveals the general community's knowledge, beliefs, and behaviors surrounding breast

health and breast cancer, as well as access to breast health information, and resources for breast health needs.

Education and Resources

According to community surveys, the community looks to obtain information about breast health primarily (57.5%) from medical professionals. 5.5% indicated they “do not have a source of information about breast cancer. (Table 7)

Table 7. Sources of Information about Breast Health

Sources of Information	Frequency	Percent
Medical Professionals	188	57.5
Friends and Family	123	37.6
Internet	105	32.1
Worksite Program	16	4.9
Other	16	4.9

Health Assessment Resource Center, 2011.

It was disappointing to learn that when respondents were asked if they had heard of Stage 0 breast cancer only 24.4% had heard of Stage 0 breast cancer, and 75.6% had not. In situ (non-invasive Stage 0) breast cancer occurs at much lower rates than invasive breast cancer. Approximately 85% of these cases will be ductal carcinoma in situ (DCIS). The increase in the number of DCIS cases is the result of mammography screening that has facilitated the detection of these early breast cancers (ACS Cancer Facts and Figures 2010). Additionally, it was unfortunate that 57.8% of respondents indicated that they were not aware of the Cancer Detection Program: EWC (Every Woman Counts) helps underserved women receive free breast cancer screening and diagnostic services through diagnosis as well as cervical cancer prevention for women who qualify. Respondents were also asked about myths and cultural beliefs surrounding breast cancer. Surprisingly, 85.8% of respondents believe that 80 percent of women diagnosed with breast cancer have a family history of the disease, when in actuality only an estimated 20% of women diagnosed with breast cancer have a family history of the disease.

**Survivor Online Survey**

The Survivor Online Survey provided information from the breast cancer survivor perspective, identifying the needs that are not being met for those that have been diagnosed.

Education and Resources

Over 78% of survivors indicated that they “agreed” there needs to be more breast health awareness in their community. Noting this that education and resources are needed, suggests a need to analyze what current education efforts and resources are available, thus allowing the Affiliate

and the community to implement needed services in underserved locations.

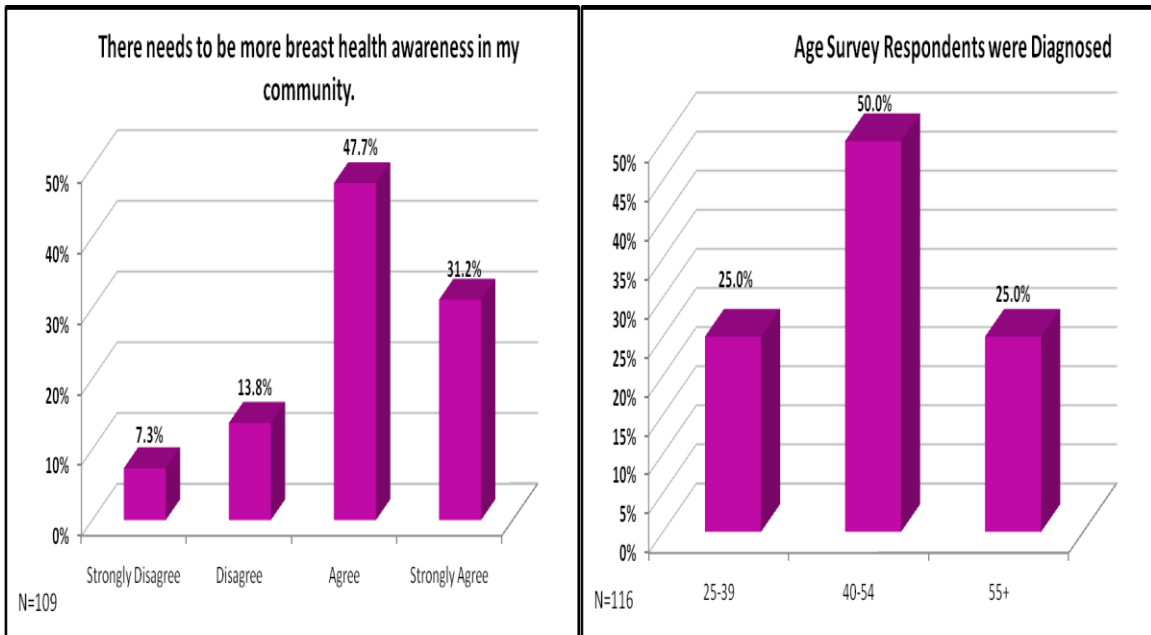


Figure 15. Breast Health Awareness Health Assessment Resource Center, 2011.

Figure 16. Respondent Age at Diagnosis

**Screening and Diagnosis**

The age of diagnosis for survey respondents ranged from 28 to 73. Of those that specified, 75% were diagnosed at 40 years of age or older. The distribution of age at diagnosis for respondents is presented in Figure 16.

Of those that specified, 14.7% were diagnosed at Stage 0, the largest proportion, 41.4%, was diagnosed at Stage I, followed by 31.0% diagnosed at Stage II. More than 12% were diagnosed at Stage III or Stage IV.

Table 8. Stage Diagnosed

Stage Diagnosed	Frequency	Percent
Stage 0	17	14.7
Stage I	48	41.4
Stage II	36	31.0
Stage III	10	8.6
Stage IV	5	4.3
<b>Total</b>	<b>116</b>	<b>100.0</b>

Health Assessment Resource Center, 2011.

Prior to treatment, 35.9% of respondents had access to a breast health “coordinator” or “navigator”, whereas 64.1% did not receive this service.

Of those with access, 61.9% used this coordinator/navigator during their journey.

Survivors indicated that the most problematic phase along the continuum of care was the diagnosis. However, note that follow-up care is more problematic than screening, and more than half of going through treatment.

Table 9. Most Problematic Along Continuum of Care

Sources of Information	Percent
Screening	14.1
Diagnosis	37.0
Treatment	30.4
Follow-up Care	18.5
<b>Total</b>	<b>100.0</b>

Health Assessment Resource Center, 2011

### Sources of Information after Diagnosis

Respondents indicated which sources of information they used after their diagnosis. Almost all (92.0%) rely on medical professionals, 62.4% rely on friends and family, and 59.2% look for information on the Internet. Sadly, 5.5% of respondents indicated they “did not have a source of information about breast cancer.”

Table 10. Sources of Information about Breast Health

Sources of Information	Frequency	Percent
Medical Professionals	115	92.0
Friends and Family	78	62.4
Internet	74	59.2
Medical Books	38	30.4
Medical Journals and Articles	25	20.0
Support Group	22	17.6
Non-Medical Books and Magazines	16	12.8
Worksite Program	3	2.4
Other	12	9.6

Health Assessment Resource Center, 2011.

## Review of Qualitative Findings

### Survivor Focus Group

#### Education and Resources

Social and cultural myths are frequent among those uneducated about breast health and breast cancer. For example, the Young Survivor Coalition (YSC) participants noted that misinformation and fear cause

problems for them with individuals who may think they are being supportive upon hearing about a breast cancer diagnosis:

“I have a friend, and she's still a friend after saying this to me, and she didn't come right out and say I caused it, but she is very into holistic medicine and is on all the alternative websites, and she believes that mammograms cause breast cancer...”

“I had a friend that's a nurse and she said, "Well, that's what happens sometimes when you go looking for things...you find them." And I'm like, "Yeah."

“I had a co-worker that when she found out that I had breast cancer you know, of course she came and hugged me and you know said, "You're going to be okay and blah, blah, blah," and you know, all the good stuff everyone tells you, and um two months later she was diagnosed with breast cancer. And she went around the office saying, "Don't hug [HER NAME], it's contagious."

### Screening and Diagnosis

Survivor survey respondents were presented with a brief description of Cancer Detection Program: EWC (Every Woman Counts) helps underserved women receive free breast cancer screening and diagnostic services through diagnosis as well as cervical cancer prevention for women who qualify. Surprisingly, 53.2% of the survivors were not aware of the program. Only four respondents indicated they participated in the program.

“...I presented to my doctor with symptoms and he didn't want to screen me and I saw the P.A. first and she didn't want to screen me and they both were like, "Oh, you're too young for breast cancer, you're fine. It's this, it's that," you know, all these other things instead of addressing that yeah, it was possible and then that's actually what happened. And I think if I hadn't pushed so much myself I wouldn't have gotten diagnosed as early as I did. It could've been a totally different story because I think in that medical office and even when I did my ultrasound the tech was like, "Oh, you're fine, you're so young there's not going to be anything there," so there was a misconception in that medical community.”

### Treatment

Respondents were presented with a brief description of the Breast and Cervical Cancer Treatment Program and asked if they had been aware of the program prior to reading the description. More than 82% of the respondents had never heard of this program.

“It's tough too you know when you're sitting there... like for example, I call it the... the chemo lounge, but the infusion room, and you're sitting in there and there's all these recliners in there and you see someone come in and have the nurse come over and say, "No treatment today, you're white blood counts aren't good enough," and they'd say, "Well, what can I do? Can I take the shot that she got?" "And no, your insurance doesn't cover it." And like you're seeing people get turned away and it's really, really hard. It's really hard. I remember one time I leaned over and I said, "Look, can I buy her a shot? Please, can I buy her a shot?" And she goes, "[NAME], it's twenty seven hundred dollars." I'm like, "Oh..."

### Follow-up Care

Survivor Focus Group Respondents often spoke about the lack of quality follow-up care for survivors. The resounding theme was follow-up care post-treatment, including a need for support and understanding from medical practitioners about breast cancer survivorship needs.

“Because like you were saying, during chemo you're on a plan, you're got a plan, you've got treatments, surgery, follow-ups, and then now it's kind of like we all need kind of our own plan and path, and without it you know, we kind of feel lost and then the fear starts coming back, what if, what if? So I know for me personally, that's kind of my struggle is just finding the happy balance between not stressing because I put sugar in my tea or I didn't put sugar in my tea, or I'm eating non-organic strawberries or beating myself up because I had In and Out Burger.”

**“You fought so hard to live, so you want to live.”**

“I think when you're in treatment it's like [NAME] was saying, you have your plan, you have all these doctors around you, you have all these people rallying around you, supporting you; they're your cheerleaders and you have a plan. I've got to do chemo and then I've got to go for my check-up next week and then if everything looks good I'll get my next chemo, and you have all these things in place and you're focused and then you're also not feeling well so you're kind of just sick and it's to be expected, and then when you're done with all your treatment and surgeries and you're kind of like kicked out of the nest type feeling.”

“You know what else would really, really help? Like for ongoing screening needs and follow-ups and what-have-you, is to have doctors that are not oncologists understand your situation. Like for example, when I go for my annual gynecology visit she asks me every year, “When was your last mammogram?” And I always tell her, “I don’t have mammograms anymore; I have no mamms to gram.” ... It’s embarrassing. I don’t like to fight about it or argue or have to explain myself because then I lose confidence in my doctor. So it would be really great if follow-up care and follow-up screening and everything else that needs to be done is done by someone who understands what we’ve been through.”

“Education, I don’t know. I have said since the very beginning after treatment that I can’t just see a general practice doctor anymore. They don’t understand all of the complications, all of the lasting side effects of treatment, all of the... even all the scar tissue and everything else. I almost feel like we need to have... I don’t know, something else, a doctor with special training for us.”

## **African American Focus Group**

### *Education and Resources*

Although focus group participants were unable to name any programs or grants that Komen provides in the Inland Empire, they said that, to them, Komen means “helping women that have been through breast cancer,” “a fundraiser to get money to find a cure for cancer,” and a “support organization with different programs under her name.” Participants also mentioned that it’s a foundation that provides support for women without insurance:

“And I’m not for sure but isn’t Susan G. Komen also a foundation to help women who don’t have insurance? They can help them find a way to get medical attention and mammograms and all that.”

“I really don’t get a lot of questions like “Are you doing this?” When you’re there, they’ll do your breast examination and they’ll talk to you for that second, but there’s no information given to me about what you need to do, this is what you need to check, how often, it’s just something you talk about amongst women. I go every year or I go every two years and it’s just something that I do for myself. And that’s just talking to other women; I don’t get that information from my provider. And maybe because I have never went to them and said, “Oh, I need this information” but nobody comes, there’s no program to say okay, there’s a breast cancer awareness class; I just don’t get that information.”

“You have a lot of women that if they're told no, they're going to leave and that's it.”

Participants noted that the information might be “out there,” but not in a manner that is easily accessible to African American women. Moreover, mammograms are generally only discussed once a year with health care providers. Women were very passionate about ensuring that breast health and breast cancer messages are ubiquitous and directed at all women and girls, perhaps even starting as young as elementary school or at least when a girl starts menstruation. They discussed how easy it was to get information about birth control, even how easy it was to obtain condoms, because of the multitude of teen pregnancy programs and birth control classes taught in school. They believe breast health should be as visible.

“It shouldn't just be talked about when you're getting your pap smear. You are saying that they may talk about it during that instant and I can tell you the same thing. So they need to talk about it more. “Are you doing your monthly breast exam?” There are a lot of things that can serve as a trigger to remind women.”

“And maybe they should find out ways to send out information when you have captive audiences—like in salons and her program where she was teaching. There are so many little areas where you could send out information.”

“Specifically for the African American community, where would you recommend that this education be done?”

“I would say high schools and college campuses because I don't think that sending it in the mail [would work], because honestly, a lot of us don't like going to the doctor. So if you send it in the mail you're going to say, “Oh, okay, a mammogram.” You're not going to go get a mammogram—you're just not going to.”

“So if you target universities, churches, like they said, high schools, just wherever you would do like a drive—wherever you could just constantly give them the information—where it's always in their face, they would be more willing to get screened.”

Focus group participants were asked what existing services, programs, or policies in the area are effective at delivering breast health services. Unfortunately, they could not name a single program they felt was effective.

“None.”

“None.”

“Really?”

“None.”

“Put together some kind of free directory...”

“Right.”

“Right.”

“They can hand it out whether it's for Fontana, Rialto, San Bernardino, or Highland. Have all these clinics with whatever it is [they offer]—...”

The repetitiveness of this information from multiple sources, and the ability to talk to someone about what is presented, are especially important because oftentimes there is little communication between mothers and daughters. This seems to be a shared experience for the women in the focus group discussion.

“Because even as mothers, some of us have a lack of knowledge.”

“Because we weren't taught. And so we can't teach our own because we don't know.”

### Barriers to Access

The lack of awareness, knowledge, and education were also named as contributors to the higher breast cancer mortality rates for African American women. Additionally, focus group participants noted barriers posed by illiteracy and lack of transportation.

Although breast cancer continues to impact people from all backgrounds, there are significant differences when we look at mortality rates, the rate at which people die, among racial groups. Starting in 2001-2005, African American women had a 37% higher mortality rate than all other ethnicities. This may be due, in part, to the fact that African American women are more likely to be diagnosed with breast cancer at a later stage.

“Lack of education.”

“Lack of education.”

“That’s the key right there...”

“Education.”

“It’s getting in these areas and educating. Making all ages feel comfortable with the education and making them feel comfortable with going and getting started and having a place for them to go whether or not they have insurance.”

“If you don’t have transportation, if you can’t write, it is hard to get all those things. And when I worked with girls, it took them months to get me all of those things. “

### Screening and Diagnosis

African American women mentioned the fear that some women have about “knowing” and the possibility of losing a breast:

“And I think too a lot of women, black women, all women I’m going to say, they’re afraid if they do find out that they have breast cancer, and I hear this from a lot of women that went through breast cancer also, they’re afraid that if the doctor tells them they’re going to have to remove their breast, they’re afraid of that. You know, the fear is if they’re not married, will I get a man? Will somebody marry me because I had to have my breast removed? And you know, they feel that it’ll make them less than a woman.”

In addition to the fear of knowing, and of losing a breast, participants noted that a lot of women lack insurance and that the expense of health care prevents them from seeking services.

### Recommendations

The women liked the idea of having an advocate or ambassador in their community for women of color. To them, being an advocate for breast cancer means:

“Going out in the community and actually being hands on in the churches and in the schools. It is someone who can be consistent in getting the information out on a regular basis. Being accessible for phone calls, emails, whatever it is...being able to go and have talks like this.”

## Conclusions

The analysis of the quantitative and qualitative data in the Breast Cancer Perspectives in the Communities section has revealed several important key findings. The utilization of focus groups and surveys provided a variety of vital information surrounding the held beliefs, behaviors, knowledge, and needs throughout the service area. It is interesting to note the similarities and differences between the responses of breast cancer survivors, medical providers, and the general community.

Analyzed qualitative data indicate the need for increased programs and services. An overall theme identified an increased need for breast health education and outreach services, utilizing a community ambassador/advocate, to include faith-based gatherings such as churches, as well as improve breast health education in schools. Moreover, a request for a resource guide to assist throughout the breast health continuum of care was established. Knowledge surrounding who and what the Susan G. Komen for the Cure® does, has been identified as limited within communities, particularly the African American community.

Furthermore, barriers to access the continuum of care were identified, and clearly align with the data from other sections in the 2011 Community Profile. The distribution of services is not conveniently located throughout the Affiliate's service area, especially rural areas. It is clear that many do not possess the knowledge, skills, or resources to navigate the healthcare system to obtain the services they need. The need for programs and services which can meet the need of those who do not qualify for programs such as the Every Woman Counts program and Breast and Cervical Cancer Treatment Program (BCCTP). Transportation and financial deficiencies are also identified as burdens to accessing care.

Data has clearly indicated that there is an increased need for education and resources throughout the service area. However, it is important to note that the desired source of information is primarily from medical providers and their staff. There is a need for medical provider and staff education surrounding guidelines for the continuum of care, available patient resources and assistance programs, and clinical trials, as well as assistance in removing barriers to access to care for their patients, as discussed in the Health Systems Analysis of Communities. Through increasing education to the medical community, as well as assisting in removing barriers to access for their patients, we would be making strides in diffusing education and resources into the service area. Additionally, efforts to improve breast health education and outreach services throughout the service area are necessary through establishing a presence in target communities.

## Conclusions: What We Learned, What We Will Do

### Review of the Findings and Conclusions

The Inland Empire Affiliate of Susan G. Komen for the Cure® consists of a service area spanning more than 27,000 sq. miles, bordering Nevada and Arizona, with a population well over 4 million people. Over 10% of the Inland Empire population has an income below the federal poverty level, more than 25% of adults in the IE did not complete high school, and more than 9% are unemployed. Therefore it is not surprising to learn that approximately 20% of females in the Inland Empire are uninsured.

High breast cancer prevalence, incidence, and mortality rates throughout the Inland Empire identify the Black/African American community, as well as communities within the High Desert as target communities in need of breast health programs, services, and resources. Black/African American females have a higher incidence rate of Stage III and Stage IV breast cancer than any other ethnicity. Stage III and Stage IV breast cancer diagnoses have a higher mortality rate than that of Stage I and Stage II breast cancer diagnoses. The High Desert cities indicate breast cancer prevalence, incidence, and mortality rates per 100,000 at more than 30% than the Inland Empire's prevalence, incidence, and mortality rates.

The asset maps have indicated the distribution of resources is not equally drawn throughout the service area, thus leaving gaps in the service area of uninsured/underserved populations, including those of target communities. It is imperative that we focus on improving service to these areas.

The analysis of surveys has provided us with unique information surrounding the needs of the community. Additionally, breast health education and outreach efforts are in great need throughout the entire service area.

**A newly identified education target audience includes the medical provider and their staff.**

The continuum of care has been identified as the all encompassing, or umbrella, of needs throughout the service area. Increased education, screening, diagnostics, treatment, and follow-up care all are imperative to improving the breast health of the community. However, the barriers to access these programs and services are a hindrance for many. Barriers to access include: lack of transportation, uninsured/underinsured, "falling through the cracks", knowledge and skills, low-income/poverty, unable to obtain HMO authorization, etc. It is with great effort that the Affiliate must take action to remove barriers to access, and improve the continuum of care throughout the Inland Empire.

After careful consideration, the Affiliate has established the following 2011 and 2012 Goals and Objectives/Action Plan to guide its' efforts and ensure quality, efficiency, and effectiveness.

### **Inland Empire Affiliate Goals & Objectives / Action Plan**

Goal 1: Increase education and outreach efforts throughout the Inland Empire.

Objective 1: Breast health: By March 31, 2013, we will have expanded education and outreach efforts to include faith-based organizations, college campuses, special events, and other venues as determined by completion of internal quarterly reports.

Objective 2: Advocacy and public policy: By March 31, 2013, we will have met with local legislatures to inform them about Community Profile data, breast health issues and policy, as well as increase our grass-roots lobbying campaigns, as demonstrated by completion of internal quarterly reports.

Objective 3: Komen: By March 31<sup>st</sup>, 2013, we will have launched a Mission Communications campaign to increase knowledge about Susan G. Komen for the Cure® and the Inland Empire Affiliate of Susan G. Komen for the Cure®, as demonstrated by completion of internal quarterly reports.

Goal 2: Increase knowledge and awareness of clinical trials.

Objective 1: Partner with clinical trials providers: By March 31<sup>st</sup>, 2013, we will have networked and provided outreach to clinical trials providers within the service area, as demonstrated by completion of internal quarterly reports.

Objective 2: Medical Providers: By March 31<sup>st</sup>, 2013, we will have partnered with a medical facility and have conducted a minimum of two professional clinical trials education seminars and one public clinical trials education seminar, as demonstrated by completion of internal annual reports.

Objective 3: Pilot a consortium for clinical trials discussions: By March 31<sup>st</sup>, 2013, we will have implemented a consortium to engage medical providers and clinical trial providers to discuss current clinical trials retention and recruitment options throughout the service area to enhance clinical trials enrollment, as demonstrated by completion of internal quarterly reports.

Goal 3: Improve the continuum of care for those diagnosed with breast cancer, as well as include enhancing programs and services available for co-survivors.

Objective 1: Increase the Affiliate's knowledge of the continuum of care within the service area: By March 31<sup>st</sup>, 2013, we will have designed, distributed, and collected English and Spanish language surveys from low-income, ethnically diverse populations within the service area to increase our knowledge of the continuum of care within those communities, as demonstrated by the 2013 Community Profile Report.

Objective 2: Increase knowledge and access to resources: By March 31<sup>st</sup>, 2013, we will have planned a continuum of care resource guide for the community, as demonstrated by internal quarterly reports.

Objective 3: Increase co-survivorship support: By March 31<sup>st</sup>, 2013, we will have increased activities to enhance the role of co-survivors, including resources and support for the co-survivors needs during their love one's journey.

### **Future Considerations**

The Inland Empire Affiliate would like to make special mention of areas of potential focus for the following 2013 Community Profile. These areas may include:

- Young survivors
- Native Americans
- Asian Americans
- Women with disabilities
- Women who partner with women
- Senior women
- Palliative Care/End of Life Care
- Pain Management
- Rehabilitation and breast cancer as a "chronic disease"
- Physical therapy
- Lymphedema support
- Psychosocial support
- Collaboration/partnering efforts with:
  - o In-home care
  - o Meals to breast cancer families
  - o Cleaning for a Reason
  - o Fresh and Easy
  - o 215
  - o Community organizations/special service groups
- Collaboration with border Affiliates (Arizona and Nevada) to identify current breast health outreach programs and determine if new strategies for outreach and reducing barriers to access of services are needed