

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



SOUTHWEST REGION

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ABOUT SUSAN G. KOMEN®

In 1980, Nancy G. Brinker promised her dying sister, Susan, that she would do everything in her power to end breast cancer forever. In 1982, that promise became a global movement. What started with \$200 and a shoebox full of potential donor names has now grown into the world's largest nonprofit source of funding for the fight against breast cancer - the Susan G. Komen® organization.

Komen funds more breast cancer research than any other nonprofit organization outside of the US government while also providing real-time help to those facing the disease. Since 1982, Komen and its local Affiliates have funded more than \$920 million in research and provided more than \$2 billion for breast cancer screening, education and treatment programs serving millions of people in more than 30 countries worldwide.

Our efforts have contributed to advancements in early detection and treatment that have reduced death rates from breast cancer by 37 percent (between 1990 and 2013).

The image is a composite. On the left, a grayscale photograph shows a woman with long hair hugging a young child from behind. The child is smiling. On the right, a black rectangular box contains text in white and pink. The text reads: "KOMEN'S BOLD GOAL IS TO REDUCE THE CURRENT NUMBER OF BREAST CANCER DEATHS BY 50% IN THE U.S. BY 2026". At the bottom right of the black box is a small Susan G. Komen logo.

A Bold Vision

Vision
A World Without Breast Cancer

Mission
To save lives by meeting the most critical needs of our communities and investing in breakthrough research to prevent and cure breast cancer.

KOMEN'S BOLD GOAL IS TO
REDUCE THE CURRENT NUMBER OF BREAST CANCER DEATHS BY
50%
IN THE U.S. BY 2026



COMMUNITY PROFILE INTRODUCTION

The Community Profile is a needs assessment completed by Susan G. Komen and its Affiliates to assess breast cancer burden within the US by identifying areas at highest risk of negative breast cancer outcomes. Through the Community Profile, populations most at-risk of dying from breast cancer can be identified. The Profile provides detailed information about these populations, including demographic and socioeconomic characteristics, as well as, needs and disparities that exist in availability, access and utilization of quality care. This assessment allows Komen to make data-driven decisions in the development of collaborative opportunities, grant funding priorities and implementation of evidence-based community health programs that will meet the most urgent needs and address the most common barriers to breast cancer care in order to make the biggest impact.

This report contains data for Komen's Southwest Region. This region includes the states of Arizona, California, Hawaii and Nevada.

As of August 2016, there were 10 Komen Affiliates¹ located in the Southwest Region:

- Komen Arizona
- Komen Central Valley
- Komen Hawaii
- Komen Inland Empire
- Komen Los Angeles
- Komen Nevada
- Komen Orange County
- Komen Sacramento Valley
- Komen San Diego
- Komen San Francisco

¹ While 12 Affiliates within the Southwest Region completed the 2015 Community Profile process, only 10 remain due to mergers and/or dissolution

ANALYSIS OF THE 2015 COMMUNITY PROFILE DATA

Purpose

From 2014-2016, Komen Affiliates completed Community Profiles of their local service areas while Komen Headquarters completed State Community Profiles.

While Komen Affiliates provide services at the community level, they are also grouped into seven regions that provide an opportunity for collaboration on a multi-state level. Although local and state data are included in the Affiliate and State Community Profile Reports, regional data about breast cancer outcomes, needs and disparities are not. In addition, there is a lack of information regarding common strategies that Affiliates are implementing to address Community Profile findings.

Therefore, the Evaluation and Outcomes team at Komen Headquarters conducted an analysis of the Affiliate and State Community Profiles in order to compile data and provide a broader perspective of the results found within the Komen Southwest Region. The data provided in this report are meant to aid Komen Headquarters and the Affiliates within the Southwest Region in identifying issues and barriers to care that are common in the region, and enable Affiliates to work together to address common goals, when appropriate.

Methods

The Evaluation and Outcomes team at Komen Headquarters reviewed data from the four State and 12 Affiliate Community Profile Reports² from the Komen Southwest Region and compiled the available data into this Komen Regional Community Profile Report.

Quantitative Data

To determine which communities (e.g., counties, cities) in the Southwest Region bear the greatest burden of breast cancer, data representing all communities from the State Community Profiles were compared to Healthy People 2020 breast cancer targets, the benchmark for each community. Healthy People 2020 (HP2020) is a major federal government initiative that provides specific health objectives for communities and for the country as a whole. HP2020 has several cancer-related objectives, including the targets used in this report: reducing the number of breast cancers that are found at a late-stage and reducing women's death rate from breast cancer.

For this report, late-stage breast cancer is defined as regional (Stage III) or distant stage (Stage IV) using the Surveillance, Epidemiology and End Results (SEER)

² While 12 Affiliates within the Southwest Region completed the 2015 Community Profile process, only 10 remain due to mergers and/or dissolution

Summary Stage definitions (Young et al., 2001). The breast cancer late-stage diagnosis rate is calculated as the number of women with regional (Stage III) or distant (Stage IV) breast cancer at the time of diagnosis in a particular geographic area divided by the number of women living in that area. Late-stage diagnosis rates are presented in terms of 100,000 women and have been adjusted for age. Late-stage diagnosis rates are important because medical experts agree that it's best for breast cancer to be detected early. Women whose breast cancers are found at an early stage (Stage I or Stage II) usually need less aggressive treatment and do better overall than those whose cancers are found at a later stage (US Preventive Services Task Force, 2016).

The breast cancer death rate shows the frequency of death from breast cancer among women living in a given area during a certain time period. The death rate is calculated as the number of women from a particular geographic area who died from breast cancer divided by the total number of women living in that area. Death rates are presented in terms of 100,000 women and have been adjusted for age.

The Evaluation and Outcomes team compiled breast cancer late-stage diagnosis and death rates and trends (changes over time) from the four State Community Profile Reports reflecting the Southwest Region. Communities that are predicted not to meet both the HP2020 breast cancer late-stage diagnosis rate and death rate benchmarks are referred to as "Highest Priority" communities, since they carry the highest burden of breast cancer within the region.

The Evaluation and Outcomes team also compiled key demographic and socioeconomic characteristics from the State Community Profile Reports including race, ethnicity, age, education level, poverty, unemployment, immigration (i.e., foreign born), use of English language (e.g., linguistically isolated), medically underserved, rural areas and uninsured. These population characteristics are known to impact health outcomes and may provide information on the types of services and interventions necessary to alleviate the burden of breast cancer in these areas (Adler and Rehkopf, 2008; American Cancer Society, 2015a; American Cancer Society, 2015c; Braveman, 2010; Danforth, 2013; Lurie and Dubowitz, 2007; Robert Wood Johnson Foundation, 2008).

The following sources were used for gathering the quantitative data:

- Death rate data: Centers for Disease Control and Prevention (CDC)- National Center for Health Statistics- Surveillance, Epidemiology and End Results (SEER)* Stat, 2006-2010
- Death trend data: National Cancer Institute (NCI) and CDC- State Cancer Profiles, 2006-2010

- Late-stage diagnosis and trends data: North American Association of Central Cancer Registries (NAACCR)-CINA Deluxe Analytic File, 2006-2010
- Race, ethnicity and age data: US Census Bureau- Population Estimates, 2011
- Education level, poverty, unemployment, immigration and use of English language data: US Census Bureau- American Community Survey, 2007-2011
- Rural population data: US Census Bureau- Census, 2010
- Medically underserved data: Health Resources and Services Administration, 2013
- Health insurance data: US Census Bureau- Small Area Health Insurance Estimates, 2011

Health System Analysis

The Evaluations and Outcomes team used a comprehensive internet search to identify and classify facilities offering breast cancer services including screening providers, diagnostic providers and treatment providers for each state.

The internet search included the following sites. For additional detail regarding the internet search please see Appendix A.

- Community Health Centers: <http://nachc.org/about-our-health-centers/find-a-health-center/>
- Title X: <http://www.hhs.gov/opa/title-x-family-planning/initiatives-and-resources/title-x-grantees-list/>
- Mammography Centers: <http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMQSA/mqsa.cfm>
- Hospitals: <https://data.medicare.gov/Hospital-Compare/Hospital-General-Information/v287-28n3>

The internet search consisted of locating the following types of facilities in the communities identified as having the greatest need (“Highest Priority” communities):

- Hospitals (e.g., public or private, for-profit or non-profit)
- Community health centers that provide care regardless of an individual’s ability to pay (e.g., Federally Qualified Health Centers (FQHCs) and FQHC look-alikes)
- Free and charitable clinics that utilize a volunteer staff model and restrict eligibility to individuals who are uninsured, underinsured and/or have limited to no access to primary health care
- Health departments (e.g., local county or city health department funded by a government entity)
- Title X providers that are usually family planning centers that also offer breast cancer screening services

- Facilities that provide breast cancer services, but do not fit under any of the other categories. (e.g., non-medical service providers)

Facilities were classified as screening if they provided clinical breast exams, screening mammograms and/or patient navigation into screening. Classification as a diagnostic service provider included locations that provide diagnostic mammography, ultrasound, biopsy, magnetic resonance imaging (MRI) scanning and/or patient navigation into diagnostic services. Classification as a treatment service provider included locations that provide chemotherapy, radiation therapy, surgery, reconstruction and/or patient navigation into treatment services. A facility may be classified under more than one classification depending on the breast cancer services provided.

The comprehensive internet search also included the identification of facilities that provide breast cancer services that are accredited by a national organization that monitors the facility to ensure that the quality of care being provided meets specific benchmarks. Each national organization's website was used to identify the accredited facilities in each state. For this report, the following national accreditations were used to measure the quality of care available:

- American College of Surgeons Commission on Cancer Certification (CoC) - <https://www.facs.org/quality-programs/cancer/coc>
- American College of Surgeons National Accreditation Program for Breast Centers (NAPBC) <https://www.facs.org/quality-programs/napbc>
- American College of Radiology Breast Imaging Centers of Excellence (BICOE)- <http://www.acr.org/Quality-Safety/Accreditation/BICOE>
- National Cancer Institute's designated Cancer Centers - <http://www.cancer.gov/research/nci-role/cancer-centers>

Each State Community Profile Report contains the number, type and location of facilities that provide breast cancer services along with the number of accredited facilities that are available. The Evaluations and Outcomes team extracted from the State Community Profile Reports the number, type and location of facilities that provide breast cancer services in the Southwest Region's "Highest Priority" communities. In addition, the number and type of accredited facilities in the Southwest Region's "Highest Priority" communities were extracted and used in this report.

The following icons are used in the health systems analysis and discussion section to represent the different types of breast cancer services available in the "Highest Priority" communities.



Screening



Diagnostic



Treatment

Qualitative Data

The Evaluations and Outcomes team analyzed qualitative data from 12 Komen Affiliates³³ in the Southwest Region, which was collected during 2014-2015. Data were gathered from health care providers, breast cancer survivors and community members who represented the target communities. These communities were selected by Affiliates. The methods used by Affiliates to collect an individual's attitude and beliefs about breast cancer care in the local community included:

- Surveys: open-ended questions to gather information in an online or paper format
- Focus groups: structured discussion used to obtain in-depth information from a group of people
- Key informant interviews: in-depth, structured discussions with people who are very familiar with the community
- Document review: review of published materials that used qualitative data collection methods

Using thematic analysis, the Evaluations and Outcomes team identified common themes from the qualitative data findings presented in the Affiliate Community Profile Reports. Themes were added, combined and revised as commonalities became more prevalent. The themes were tracked in a spreadsheet and were classified by Affiliates and community of interest. The most frequently cited themes are discussed in the qualitative data section of this report. A list of all themes and their corresponding definitions are located in Appendix B.

The following icons were used in the qualitative data analysis section to represent different data collection methods conducted by the Affiliates.



Survey



Focus Group



Key Informant Interview



Document Review

Mission Action Plan

Using the data collected during the Community Profile process, Komen Affiliates developed an action plan, referred to as the Mission Action Plan (MAP), to implement within a four-year time period to address the needs identified. Each Affiliate's MAP consists of problem statements, priorities and objectives. The problem statements

³³ While 12 Affiliates within the Southwest Region completed the 2015 Community Profile process, only 10 remain due to mergers and/or dissolution

summarize the issues revealed during the Community Profile process in the communities of interest. Priorities represented the goals that the Affiliates expected to achieve within five years. Objectives are the activities that an Affiliate is going to do to reach the priorities. There were 12 Affiliates⁴ in Komen's Southwest Region that completed a Mission Action Plan.

The Evaluations and Outcomes team used descriptive analysis to identify commonalities within the problem statements, priorities and objectives in each Affiliate's Mission Action Plans. The problem statements, priorities and objectives were first classified into descriptive categories. The categories were then analyzed to identify commonalities. Commonalities identified from the Southwest Region Affiliates' MAPs are presented in the conclusions section of this report.

Challenges and Limitations

The various methods used to gather data for the 2015 Community Profile process resulted in challenges that limit the generalizability of the data collected.

Recent data

At the time of quantitative data collection for the State and Affiliate Community Profile Reports, the most recent data available were used but, for breast cancer late-stage diagnosis and death rates, these data are still several years behind. The breast cancer late-stage diagnosis and death rates data available in 2013 when data were being collected were from 2010. For the US as a whole and for most states, breast cancer late-stage diagnosis and death rates do not often change rapidly. Rates in individual communities might change more rapidly. In particular, if a cancer control program has been implemented in 2011-2013, any impact of the program on late-stage diagnosis and death rates would not be reflected in this report.

As time passes, the data in this report will become more out-of-date. However, the trend data included in the report can help estimate current values. Also, the State Cancer Profiles Web site (<http://statecancerprofiles.cancer.gov/>) is updated annually with the latest cancer data for states and can be a valuable source of information about the latest breast cancer rates. However, it is unlikely that the data that is presented in this report will change significantly in the five years between Community Profile updates to result in changes to the "Highest Priority" communities.

The available breast cancer services (e.g., screening, diagnostic and treatment) and accredited facilities (e.g., CoC, BICOE, NAPBC, and NCI Cancer Centers) identified in the health system analysis section of this report were collected between September

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2014 – March 2015. Therefore, local facilities that provide breast cancer services (e.g., screening, diagnostics and treatment) may have changed since March 2015 and may be either over-represented or under-represented in the community.

Data Availability

For some communities, data might not be available or might be of varying quality. Cancer surveillance programs vary from state to state in their level of funding and this can impact the quality and completeness of the data in the cancer registries and the state programs for collecting death information. There are also differences in the legislative and administrative rules for the release of cancer statistics used for studies such as community needs assessments. These factors can result in missing data for some of the data categories in this report. Communities missing both death and late-stage diagnosis rate data were excluded from HP2020 priority classification. This does not mean that the community may not have high needs; it only means that sufficient data are not available to classify the community.

There are also many factors that impact breast cancer risk and survival for which quantitative data are not available. Some examples include family history, genetic markers like HER2 and BRCA, other medical conditions that can complicate treatment, and the level of family and community support available to the patient. Good quantitative data are not available on how factors such as these vary from place to place.

Qualitative Data

Qualitative methods (e.g., surveys, focus groups, key informant interviews) that were used during the Affiliate Community Profile process gathered information regarding an individual's attitude and beliefs about breast cancer care in their local community. The qualitative data used in this report have some specific limitations that were unable to be controlled for because the methods implemented and data collected were completed by 12 different Affiliates⁵. These limitations include, but are not limited to:

- Small sample sizes limit the ability of the data to accurately represent everyone in the community
- Data collected by the Affiliates were not always from communities that were classified as "Highest Priority" in this report
- Bias of the facilitator and/or interviewer in which they give preference to their own view over others and recall information that favors their view only
- Response bias in which participants provide answers they believe the facilitator or interviewer wants to hear, even if untrue

⁵ While 12 Affiliates within the Southwest Region completed the 2015 Community Profile process, only 10 remain due to mergers and/or dissolution

- Poor wording of questions may have resulted in inaccurate, or unrelated responses that do not match the intent of the question
- Sampling bias in which attitudes and beliefs of those that participated in the different qualitative methods may be different than those that did not (e.g., those that participated may have less barriers than those that did not participate)

These limitations may result in the qualitative data in this report not being representative of the geographic areas that are not predicted to meet HP2020 targets for death and late-stage diagnosis rates, and may only represent the perspectives of those that participated in the surveys, focus groups and key informant interviews

DISCUSSION

In order to better understand the breast cancer issues and barriers to care that are common across the Southwest Region and enable Affiliates within the region to work together to address common goals, Komen Headquarters Evaluation and Outcomes team compiled available quantitative, health systems and qualitative data within the Southwest Region. This section details the findings of this regional analysis.

Quantitative Data Analysis

Breast cancer late-stage diagnosis and death rates and trends were analyzed across the Southwest Region in order to assess the burden of breast cancer within the region. These data were then compared to Healthy People 2020 targets for breast cancer to identify the areas of greatest need within the region. Table 1 shows both late-stage diagnosis and death rates and trends for the states within Komen's Southwest Region.

Table 1. Female breast cancer late-stage diagnosis and death rates and trends- Komen Southwest Region

Population Group	Female Population (Annual Average)	Late-Stage Diagnosis and Trends			Death Rates and Trends		
		# of New Late-stage Cases (Annual Average)	Age-adjusted Late-stage Diagnosis Rate /100,000	Late-stage Trend (Annual Percentage Change)	# of Deaths (Annual Average)	Age-adjusted Death Rate /100,000	Death Trend (Annual Percent Change)
US (states with available data)	145,332,861	70,218	43.7	-1.2%	40,736	22.6	-1.9%
Arizona	3,138,990	1,294	38.2	0.0%	733	20.6	-2.0%
California	18,413,837	8,287	43.5	-1.7%	4,251	21.9	-2.1%
Hawaii	665,806	294	38.3	3.5%	133	16.4	-1.8%
Nevada	1,273,022	527	39.5	2.3%	306	23.0	-1.5%

NA - data not available.

Late-stage diagnosis data are for years 2006-2010 except for Nevada which are 2005-2009.

Death data are for years 2006-2010.

Rates are cases/deaths per 100,000.

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

Source of late-stage diagnosis rates and trend data: NAACCR - CINA Deluxe Analytic File.

Source of death rate data: CDC - NCHS mortality data in SEER*Stat.

Source of death trend data: NCI/CDC State Cancer Profiles.

Comparison to Healthy People 2020 Targets

Healthy People 2020 (HP2020) is a major federal government initiative that provides specific health objectives for communities and for the country as a whole. HP2020 targets for breast cancer late-stage diagnosis and death rates were used as a benchmark to determine which communities (e.g., county, city) in the Southwest Region have the highest breast cancer needs. In 2014, the HP2020 target for late-stage diagnosis rate was 41.0 per 100,000 females and the target for breast cancer death rate was 20.6 per 100,000 females.

Breast cancer late-stage diagnosis and death rates and trends (changes over time) were used to calculate whether each community in the Southwest Region would meet the HP2020 target, assuming that the trend seen in years 2006 to 2010 continue for 2011 and beyond. A negative trend means that the rates are predicted to decrease each year; while a positive trend indicates that rates are increasing each year. For breast cancer late-stage diagnosis and death rate, a negative trend is desired.

Communities are classified as follows:

- Communities that are not likely to achieve either of the HP2020 targets for late-stage diagnosis or death rates are considered to have the highest needs.
- Communities that have already achieved both targets are considered to have the lowest needs.
- Other communities are classified based on the number of years needed to achieve the two targets.

Table 2 shows how communities are assigned to priority categories. There has not been any indication that either one of the two HP2020 targets is more important than the other. Therefore, the report considers them equally important.

Table 2. Priority classification based on the projected time to achieve HP2020 breast cancer targets

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

If the time to achieve the HP2020 target cannot be calculated for one of the HP2020 indicators (i.e., late-stage diagnosis rate or death rate), then the community is classified based on the other indicator. If both indicators are missing, then the community is classified as “unknown”. This doesn’t mean that the community may not have high needs; it only means that sufficient data are not available to classify the community.

Table 3 represents communities in the Komen Southwest Region that have been designated “Highest Priority”. Communities designated as “Highest Priority” mean that they are not likely to meet the Healthy People 2020 targets for breast cancer late-stage diagnosis or deaths. In addition, key demographic and socioeconomic characteristics have been provided in Table 3 that may assist in identifying who in these communities may be most in need of help. For this report, demographic and socioeconomic characteristics are considered influential factors when the percentage is substantially higher than the state. Substantially higher is defined as three percentage points higher for a factor less than 10.0 percent and five percentage points higher for a factor equal to or greater than 10.0 percent. Detailed information regarding key population characteristics of each of the “Highest Priority” communities can be located in Appendix C.

Demographic characteristics include populations that have been found to less favorable breast cancer outcomes:

- Black/African-American women: Breast cancer is the most common cancer among Black/African-American women. In 2013, breast cancer deaths were 39 percent higher in Black/African-American women than in white women (Howlader et al., 2016). Although breast cancer survival in Black/African-

American women has increased over time, survival rates remain lower than among white women.

- Hispanic/Latina women: Breast cancer is the leading cause of cancer death in Hispanic/Latina women (American Cancer Society, 2015b).
- Asian and Pacific Islander (API) women: Breast cancer incidence among Asian-American, Native Hawaiian and Pacific Islander women have increased since 2005 (American Cancer Society, 2016). Breast cancer is the second leading cause of cancer death in Asian-American, Native Hawaiian and Pacific Islander women (American Cancer Society, 2016).
- American Indian and Alaska Native (AIAN) women: The last two decades have seen large increases in both incidence and death rates for American Indian and Alaska Native women (American Cancer Society, 2015a). Among AIAN women, those who live in Alaska and the Southern Plains have the highest death rates and women who live in the Southwest have the lowest mortality rates (White et al., 2014).
- Older women (65 and older): The risk of breast cancer increases as an individual becomes older. Most breast cancers and breast cancer deaths occur in women aged 50 and older (American Cancer Society, 2015a)

Socioeconomic characteristics include factors that have been identified as barriers that may prevent individuals from being able to access care, afford care and/or understand the care that their doctor recommends. For example, uninsured individuals that have an annual income below 200 percent Federal Poverty Level may not have the financial resources to pay for diagnostic services if they have an abnormal mammogram. Immigrants that do not speak English fluently may experience cultural and language barriers when receiving care. Individuals that reside in rural and/or medically underserved areas may have to travel outside of their community to access care which requires transportation resources as well as longer periods of time off work.

Table 3. Healthy People 2020 “Highest Priority” communities in the Komen Southwest Region

State	Community	Affiliate	Late-Stage Diagnosis Rate per 100,000 (trend)	Death Rate per 100,000 (trend)	Key Population Characteristics
Healthy People 2020 Target			41.0*	20.6*	
United States (states with available data)			43.7 (-1.2%)	22.6 (-1.9%)	
Arizona	Graham County	Komen Arizona	44.2 (+8.2%)	31.8 (+1.4%)	%AIAN, poverty, rural
Arizona	Santa Cruz County	Komen Arizona	22.6 (+7.8%)**	22.2 (NA)	%Hispanic/Latina, education, poverty, employment, foreign, language, rural, insurance, medically underserved
California	Amador County	Komen Sacramento Valley	40.6 (+8.9%)**	22.8 (+0.5%)	Older, employment, rural, medically underserved
California	Colusa County	Komen Sacramento Valley	33.7 (+32.9%)**	SN	%Hispanic/Latina, education, employment, language, rural
California	Humboldt County	Not Currently Served By A Komen Affiliate	38.8 (+2.9%)**	26.8 (-1.1%)	%AIAN, rural, medically underserved
California	Mariposa County	Not Currently Served By A Komen Affiliate	40.9 (+23.4%)**	SN	Older, employment, rural, medically underserved
California	San Bernardino County	Komen Inland Empire	42.6 (+1.7%)	25.1 (-1.2%)	%Hispanic/Latina
California	Yuba County	Komen Sacramento Valley	45.3 (+0.3%)	22.5 (-0.4%)	Poverty, employment, rural
Hawai'i	Honolulu County	Komen Hawai'i	39.2 (+4.3%)**	15.6 (NA)	%API
Hawai'i	Maui County	Komen Hawai'i	35.6 (+8.8%)**	17.2 (NA)	Rural
Nevada	Humboldt County	Komen Nevada	44.0 (+3.8%)	SN	%AIAN, rural
Nevada	Nye County	Komen Nevada	41.3 (+2.7%)	24.4(NA)	Older, poverty, employment, rural

*Target as of the writing of this report.

** While this community currently meets the HP2020 target, because the trend is increasing it should be treated the same as a community that will not meet the HP2020 target.

NA - data not available.

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

Late-stage diagnosis data are for years 2006-2010 except for Nevada which are 2005-2009.

Death data are for years 2006-2010.

Rates are cases/deaths per 100,000.

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

Source of late-stage diagnosis rate and trend data: NAACCR - CINA Deluxe Analytic File.

Source of death rate data: CDC - NCHS mortality data in SEER*Stat.

Source of death trend data: NCI/CDC State Cancer Profil

In the Komen Southwest Region, there are 12 communities that are considered “Highest Priority” based on the prediction of meeting HP2020 breast cancer late-stage diagnosis and/or death rates. There are two “Highest Priority” communities in the Southwest Region that are not within a local Komen Affiliate service area, they include Humboldt County, CA and Mariposa County, CA.

When viewing the region as a whole, 10 of the 12 communities have a substantially higher percentage of individuals residing in rural areas, which are listed in Table 4. In addition, six of the 12 communities have a high percentage of residents that are unemployed. These factors have been linked to barriers associated with accessing quality and timely care.

Table 4. HP2020 “Highest Priority” communities in the Southwest Region with a substantially higher percentage individuals living in rural areas

Komen Affiliate	Community	Key Demographic/ Socioeconomic factors
Komen Arizona	Graham County, AZ	%AIAN, poverty, rural
	Santa Cruz County, AZ	%Hispanic/Latina, education, poverty, employment, foreign, language, rural, insurance, medically underserved
Komen Hawai'i	Maui County, HI	Rural
Komen Inland Empire	Yuba County, CA	Poverty, employment, rural
Komen Nevada	Humboldt County, NV	%AIAN, rural
	Nye County, NV	Older, poverty, employment, rural
Komen Sacramento Valley	Amador County, CA	Older, employment, rural, medically underserved
	Colusa County, CA	%Hispanic/Latina, education, employment, language, rural
Not Currently Served by a Komen Affiliate	Humboldt County, CA	%AIAN, rural, medically underserved
	Mariposa County, CA	Older, employment, rural, medically underserved

Within the Komen Southwest Region, there were four “Highest Priority” communities considered medically underserved; these include Santa Cruz County, AZ, Amador County, AZ, Humboldt County, CA and Mariposa County, CA. According to the US Department of Health and Human Services, areas are designated as medically underserved when they have too few primary care providers to serve the area. Other commonalities included a high percentage of individuals with incomes below poverty level (four communities) and a substantially older female population (three communities).

Breast cancer is the leading cause of death in Hispanic/Latina women (American Cancer Society, 2015b). In the Komen Southwest Region, three of the “Highest Priority” communities had a substantially larger Hispanic/Latina female population than its respective state as a whole:

Komen Arizona



- Santa Cruz County, AZ

Komen Inland Empire

- San Bernardino County, CA

Komen Sacramento Valley

- Colusa County, CA

In the past two decades, there has been an increase in death rates for American Indian and Alaska Native women (American Cancer Society, 2015a). Women who live in the Alaska and the Southern Plains have the highest death rates (White et al., 2014). In the Komen Southwest Region, three of the “Highest Priority” communities had a substantially larger American Indian and Alaska Native female population than its respective state as a whole:

Komen Arizona

- Graham County, AZ

Komen Nevada

- Humboldt County, NV

Not Currently Served by a Komen Affiliate

- Humboldt County, CA

Figure 1 shows each community within Komen’s Southwest Region prioritized according to their priority classification based on HP2020. Communities that are classified as “Highest Priority” are those that are predicted not meet the HP2020 benchmarks for late-stage diagnosis rates and/or death rates. When both of the indicators used to establish a priority for a community are not available, the priority is shown as “undetermined” on the map.

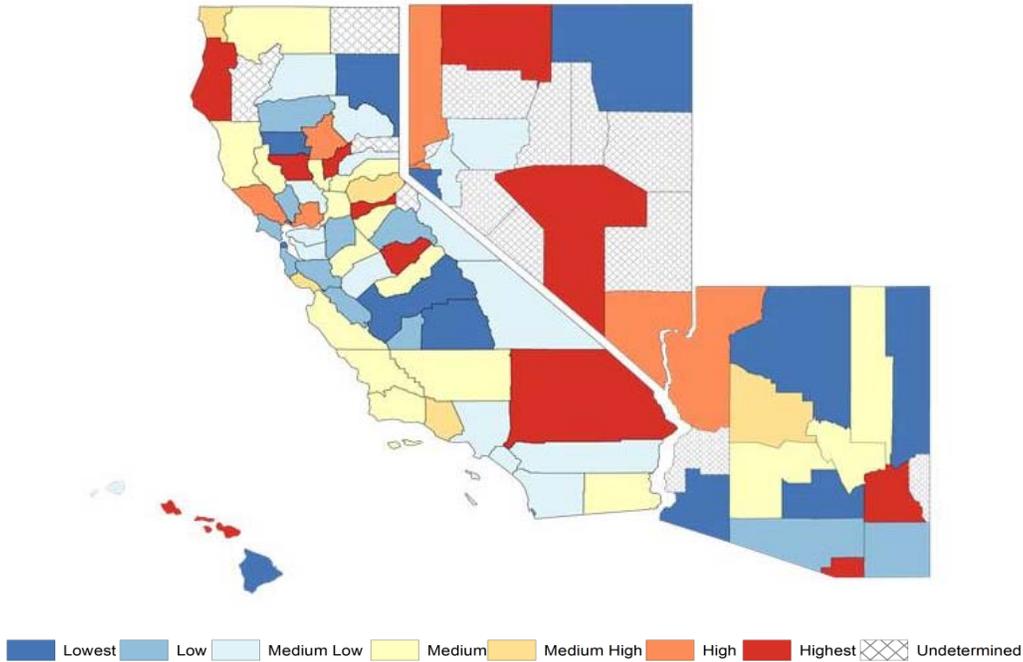


Figure 1. Healthy People 2020 priority classifications- Komen Southwest Region

Health Systems Analysis

An inventory of breast cancer programs and services in the Komen Southwest Region was collected by Komen Headquarters Evaluation and Outcomes team through a comprehensive internet search (Appendix A) to identify the following types of health care facilities or community organizations that may provide breast cancer related services: hospitals, community health centers, free clinics, health departments, Title X providers, and additional facilities that provide breast cancer services (e.g., non-medical service providers).



In Komen’s Southwest Region, there are 2,671 facilities that provide screening services (i.e. clinical breast exam, screening mammography and/or patient navigation into screening services). Of those facilities that provide screening services, 198 are located in a “Highest Priority” community.



In Komen’s Southwest Region, there are 1,124 facilities that provide diagnostic services (i.e. diagnostic mammography, ultrasound, biopsy, magnetic resonance imaging (MRI) scanning and/or patient navigation into diagnostic services). Of those facilities that provide diagnostic services, 93 are located in a “Highest Priority” community.



In Komen’s Southwest Region, there are 280 facilities that provide treatment services (i.e. chemotherapy, radiation, surgery, reconstruction and/or patient navigation into treatment services). Of those facilities that provide treatment services, 24 are located in a “Highest Priority” community.

A facility may be classified under more than one classification depending on the services provided. Appendix D provides the total number of screening, diagnostic and treatment facilities for the Southwest Region’s “Highest Priority” communities and states.

These numbers, however, do not tell the whole story about the availability of services for individuals that are residing in a “Highest Priority” community. An individual residing in a “Highest Priority” community may only have only one or two of the services available within a short distance from their residence and may have to travel a greater distance within the community, or to another community, to receive additional care. A lack of local services increases the likelihood that an individual will have difficulty accessing initial screening services and follow-up care after an abnormal screening. This, in turn, may contribute to breast cancer being diagnosed at a later stage when treatment options are limited, and prognosis is poor, or may result in delays in treatment after diagnosis, which contribute to poorer outcomes.

In the Komen Southwest Region, one HP2020 “Highest Priority” community has in-community screening services, but do not have any facilities that provide diagnostic and treatment services and is not currently served by a Komen Affiliate:

- Mariposa County, CA

In the Komen Southwest Region, three HP2020 “Highest Priority” communities have in-community screening and diagnostic services, but do not have any facilities that provide treatment services:

Komen Nevada

- Nye County, NV

Komen Sacramento Valley

- Amador County, CA
- Colusa County, CA

The remaining communities have breast cancer screening, diagnostics and treatment services available locally.

Although these communities may have services, this doesn’t account for quality of care that may be provided at these facilities. The Institute of Medicine defines quality of care as “providing patients with appropriate services in a technically competent manner, with good communication, shared decision-making and cultural sensitivity”

(Hewitt and Simone, 1999). Hospitals and medical centers that provide quality care tend to have up-to-date facilities and equipment, follow current breast cancer screening, diagnostic and treatment guidelines, and have doctors with appropriate credentials and experience in treating breast cancer. Overall, quality of care is about the process of care, outcomes of care, and patient satisfaction levels from a particular program and/or organization.

Komen Headquarters Evaluation and Outcomes team collected data on the number of facilities in the Southwest Region that were accredited by standard quality programs for breast cancer care in the United States. The specific breast cancer related accreditations considered for this report include American College of Radiology Breast Imaging Centers of Excellence, American College of Surgeons Accreditation Program for Breast Centers, American College of Surgeons Commission on Cancer Certification and the National Cancer Institute's designated Cancer Centers.

While screening, diagnostic and treatment services are available through facilities located in HP2020 "Highest Priority" communities, the services provided may not follow recommended guidelines and lack care coordination to diagnostic and treatment services. This may result in the individual having to coordinate their own care within a complex health care system. Confusion and frustration of navigating a complex health care system may lead to individuals forgoing care, not being aware that additional tests are needed, or taking longer to be diagnosed leading to potential delays in beginning recommended breast cancer treatment. Additionally, patients may not be made aware of breast cancer clinical trials that they may be eligible to participate in, and planning and coordination of care may be "siloed" (e.g., each medical provider focused on one isolated part of care and not how that care functions within a larger treatment plan).

American College of Radiology Breast Imaging Centers of Excellence (BICOE)

<http://www.acr.org/Quality-Safety/Accreditation/BICOE>

The American College of Radiology (ACR) BICOE "designation is awarded to breast imaging centers that achieve excellence" in providing effective, safe and quality breast imaging care to patients (American College of Radiology, n.d.).

In order for a facility to receive designation as a BICOE, the facility must meet quality breast imaging screening and diagnostic performance measures for mammography, stereotactic breast biopsy, breast ultrasound and breast MRI.

In the US, there are 8,283 facilities that provide breast cancer screening and diagnostic services; of those facilities, 1,343 (16.2%) are accredited as an ACR BICOE facility.

In Komen’s Southwest Region, there are 1,124 facilities that provide breast cancer screening and diagnostic services; of those facilities, 138 (12.3%) are accredited as an ACR BICOE facility.

Within the Southwest Region’s HP2020 “Highest Priority” communities, there are 90 facilities that provide breast cancer screening and diagnostic services; of those facilities, five (5.6%) are accredited as an ACR BICOE facility. Individuals that reside in communities that have accredited screening and diagnostic facilities have access to services that meet quality breast imaging performance measures. However, in the Southwest Region, there are 85 facilities located in nine HP2020 “Highest Priority” communities that are not accredited and the services provided to individuals seeking care may not meet quality breast imaging performance measure (Table 5).



In the Southwest Region, the five ACR BICOE accredited facilities are located in the following two communities:

Komen Hawai’i

- Honolulu County, HI

Komen Inland Empire

- San Bernardino County, CA

Table 5. HP2020 “Highest Priority” communities in the Southwest Region without ACR BICOE accredited facilities

Komen Affiliate	Community	Key demographic/socioeconomic factors
Komen Arizona	Graham County, AZ	%AIAN, poverty, rural
	Santa Cruz, AZ	%Hispanic/Latina, education, poverty, employment, foreign, language, rural, insurance, medically underserved
Komen Hawai’i	Maui County, HI	Rural
Komen Nevada	Nye County, NV	Older, poverty, employment, rural
Komen Sacramento Valley	Amador County, CA	Older, employment, rural, medically underserved
	Colusa County, CA	%Hispanic/Latina, education, employment, language, rural
	Yuba County, CA	Poverty, employment, rural
Not Currently Served by a Komen Affiliate	Humboldt County, CA	%AIAN, rural, medically underserved
	Humboldt County, NV	%AIAN, rural

American College of Surgeons National Accreditation Program for Breast Centers (NAPBC)

<https://www.facs.org/quality-programs/napbc>

The American College of Surgeons' (ACS) NAPBC is focused on improving quality of care and outcomes for patients with diseases of the breast (American College of Surgeons, 2014b). The NAPBC utilizes evidence-based standards, patient and provider education, and encourages leaders from major disciplines to work together to diagnose and treat breast disease.

In order to be an ACS NAPBC programs, the breast center must demonstrate a multidisciplinary, integrated and comprehensive model for providing breast care services and meet high-quality breast cancer care performance measures. NAPBC facilities must meet performance standards in providing screening, diagnostic and treatment services, employing medical providers with specialized knowledge and skills in diseases of the breast, participation in clinical trials, and implementation of education, support and survivorship programs.

In the US, there are 2,925 facilities that provide breast cancer screening, diagnostic and treatment services; of those facilities, 541 (18.5%) are accredited as an ACS NAPBC facility. In Komen's Southwest Region, there are 275 facilities that provide breast cancer screening, diagnostic and treatment services; of those facilities, 38 (13.8%) are accredited as an ACS NAPBC facility.

Within the Southwest Region's "Highest Priority" communities there are 24 facilities that provide treatment services; of those facilities, two (9.1%) are accredited as an ACS NAPBC facility. Individuals that reside in communities that have NAPBC facilities have access to services that meet high-quality breast cancer care performance measures. However, in the Southwest Region, there are 20 facilities located in nine HP2020 "Highest Priority" communities that are not accredited and the services





provided to individuals seeking care may not meet high-quality breast cancer care performance measures (Table 6).

In the Southwest Region, the two ACS NAPBC accredited facilities are located in the following communities:

Komen Hawai'i

- Honolulu County, HI

Komen Inland Empire

- San Bernardino County, CA

Table 6. HP2020 “Highest Priority” communities in the Southwest Region without an ACS NAPBC accredited facility

Komen Affiliate	Community	Key demographic/socioeconomic factors
Komen Arizona	Graham County, AZ	%AIAN, poverty, rural
	Santa Cruz, AZ	%Hispanic/Latina, education, poverty, employment, foreign, language, rural, insurance, medically underserved
Komen Hawai'i	Maui County, HI	Rural
Komen Nevada	Nye County, NV	Older, poverty, employment, rural
	Humboldt County, NV	%AIAN, rural
Komen Sacramento Valley	Amador County, CA	Older, employment, rural, medically underserved
	Colusa County, CA	%Hispanic/Latina, education, employment, language, rural
	Yuba County, CA	Poverty, employment, rural
Not Currently Served by a Komen Affiliate	Humboldt County, CA	%AIAN, rural, medically underserved

American College of Surgeons Commission on Cancer (CoC)

<https://www.facs.org/quality-programs/cancer/coc>

The American College of Surgeons (ACS) CoC “recognizes cancer care programs for their commitment to providing comprehensive, high-quality and multidisciplinary patient centered care” (American College of Surgeons, 2014a).

Throughout the cancer continuum of care accredited programs are at the forefront of improving survival and quality of life for those diagnosed with cancer by setting care standards, research, prevention, education and monitoring to ensure comprehensive quality care is being provided (American College of Surgeons, 2014a).

The benefits of having an ACS CoC accredited facility in the local community include (American College of Surgeons, 2014a):

- Dedicated resources to ensure quality treatment and supportive care services are provided
- Community-based cancer prevention and screening events
- Guarantee that patients have access to treatment recommended by Health and Medicine Division (formerly the Institute of Medicine), National Cancer Comprehensive Network and American Society of Clinical Oncology
- Patients' care is coordinated through a multidisciplinary oncology team
- Patients are informed about clinical trials
- Patients are provided a standard of care verified by a national organization
- Patients have access to quality cancer care that is close to home



In the US, there are 2,997 facilities that provide breast cancer treatment services; of those facilities, 1,422 (47.5%) are accredited as an ACS CoC facility.

In Komen's Southwest Region, there are 280 facilities that provide breast cancer treatment services; of those facilities, 129 (46.1%) are accredited as an ACS CoC facility.

Within the Southwest Region's "Highest Priority" communities, there are 24 facilities that provide breast cancer treatment services; of those facilities, 15 (62.5%) are accredited as an ACS CoC facility. Individuals that reside in communities with ACS CoC accredited facilities have access to comprehensive, quality breast cancer treatment close to home. However, in the Southwest Region, there are seven facilities located in four HP2020 "Highest Priority" communities that are not accredited and the service provided to individual seeking care may not meet ACS cancer care standards.

In the Southwest Region, the 15 ACS CoC accredited facilities are located in the following four communities:

Komen Hawai'i

- Honolulu County, HI

Komen Sacramento Valley

- Yuba County, CA

Komen Inland Empire

- San Bernardino County, CA

Not Currently Served by a Komen Affiliate

- Humboldt County, CA

The following HP2020 "Highest Priority" communities have facilities that offer breast cancer treatment services; however, none of the facilities located within the community are ACS CoC accredited:

Komen Arizona

- Graham County, AZ
- Santa Cruz, AZ

Komen Hawai'i

- Maui County, HI

Komen Nevada

- Humboldt County, NV

National Cancer Institute Designated Cancer Centers

<http://www.cancer.gov/research/nci-role/cancer-centers>

A National Cancer Institute (NCI) designated Cancer Center is an institution dedicated to researching the development of more effective approaches to the prevention, diagnosis, and treatment of cancer (National Cancer Institute, 2012). A NCI-designated Cancer Center conducts cancer research that is multidisciplinary and incorporates collaboration between institutions and university medical centers. This collaboration also provides training for scientists, physicians, and other professionals interested in specialized training or board certification in cancer-related disciplines. NCI-designated Cancer Centers also provide clinical programs that offer the most current forms of treatment for various types of



cancers and typically incorporate access to clinical trials of experimental treatments.

There are 69 NCI-designated Cancer Centers in the United States with 12 centers located in Komen’s Southwest Region. Of those 12 facilities located in the Southwest Region, one of the NCI-designated Cancer Centers is located Honolulu, HI, a “Highest Priority” community. The other 11 NCI-designated Cancer Centers in the Komen Southwest Region are located in communities that are not considered “Highest Priority”.

In summary, each of the 12 HP2020 “Highest Priority” communities in the Southwest Region has facilities that offer screening services. In the Southwest Region, one HP2020 “Highest Priority” community only has access to in-community screening services; three “Highest Priority” communities have in-community screening and diagnostic services; and eight “Highest Priority” communities have in-community access to screening, diagnostic and treatment services. While services may be available within the community, the number of available facilities may be too few to service the population in need, facilities may not accept an individual’s health insurance plan, individuals can become “lost in the system” after an abnormal screening mammogram and/or the care received does not meet any quality-based standards. In the Southwest Region, there are eight HP2020 “Highest Priority” communities that do not have any quality-based accredited breast cancer services (Table 7).

Table 7. HP2020 “Highest Priority” communities in the Southwest Region without accredited screening, diagnostic and treatment services

Komen Affiliate	Community	Key demographic/socioeconomic factors
Komen Arizona	Graham County, AZ	%AIAN, poverty, rural
	Santa Cruz, AZ	%Hispanic/Latina, education, poverty, employment, foreign, language, rural, insurance, medically underserved
Komen Hawai’i	Maui County, HI	Rural
Komen Nevada	Nye County, NV	Older, poverty, employment, rural
	Humboldt County, NV	%AIAN, rural
Komen Sacramento Valley	Amador County, CA	Older, employment, rural, medically underserved
	Colusa County, CA	%Hispanic/Latina, education, employment, language, rural
	Yuba County, CA	Poverty, employment, rural

Qualitative Data Analysis

In order to gain a better understanding of the key barriers to breast cancer care in the local communities, Komen Headquarters Evaluation and Outcomes team analyzed qualitative data collected by Komen Affiliates. This analysis includes the review of qualitative data reports for all Affiliates within the Southwest Region and

the coding of central themes that were cited most frequently by survey, interview and focus group participants and published qualitative documents (Figure 2).

During 2014-2015, Affiliates conducted qualitative data collection in communities of interest (e.g., HP2020 “Highest Priority” communities and/or non-“Highest Priority” communities) within their service area to “hear” from local health care providers and/or community members the challenges local residents have in accessing breast cancer care; as well as potential solutions that may assist individuals in receiving physician recommended breast cancer screening, diagnostic and treatment services.

In the Southwest Region, 11 of the 12 Komen Affiliates⁶ collected qualitative data from 38 communities of interest during the Community Profile process. Of the 38 communities of interest, nine are designated as a HP2020 “Highest Priority” community. The common barriers to breast cancer care identified were cited by interview, focus groups and survey participants with varying demographics and socioeconomic factors and in published qualitative literature in each Affiliate’s qualitative data report; but may not have been a barrier in each community of interest. Therefore, the qualitative data collected may not be representative of the specific HP2020 “Highest Priority” communities, but only the perspective of those that participated in the qualitative data collection process.

 530 Surveys	 244 Focus Groups
 209 Interviews	 38 Document Review

Figure 2. Komen Southwest Region qualitative data collection methods and number of participants/documents

Community members who provided feedback during the qualitative data collection process along with the review of the documents frequently cited the following five barriers that may prevent an individual from getting breast cancer services in the Komen Southwest Region:

1. Financial Barriers

- Lack of funds to receive adequate breast cancer care
- Unemployment
- Lack of pay due to time off work for appointments

“It was devastating financially. Even though we were in a good place and we had insurance, insurance only pays for so much. And then there were out-of-pocket expenses.” - Survivor

⁶ While 12 Affiliates within the Southwest Region completed the 2015 Community Profile process, only 10 remain due to mergers and/or dissolution

2. Breast Cancer Education

- Need for culturally appropriate education and outreach
- Lack of awareness and confusion regarding breast cancer screening guidelines
- Lack of breast cancer education including personal risk of breast cancer

"Misconceptions still persist about not being diagnosed since there is no family history, either you get breast cancer because you do or do not breast feed, injuries to the breast cause breast cancer, "you will get breast cancer from the radiation in the mammogram screenings;" "mammograms flatten your breast;" "I'm too old to have it;" "breast size affects your cancer risk..." - Key Informant

3. Transportation

- Lack of available public transportation methods, ride-sharing or personal vehicle
- Time, frequency and/or availability of public transportation or ride-sharing was not in alignment with appointments
- Lack of resources (e.g., time off work, money to pay for gas/public transportation, childcare/adult care) to be able to travel the distance required to receive care

4. Availability of Services

- Lack of available facilities and/or providers that provide breast cancer screening, diagnostic and treatment services
- Facilities and/or provider have limited hours and/or days opened.

5. Cultural/Language

- Lack of available providers that resemble the patient or can relate to the patients concerns
- Lack of culturally appropriate breast cancer programming and outreach

Other barriers that were mentioned less frequently were fear of breast cancer diagnosis, lack of insurance other health priorities that take precedence and lack of social support. For a list of all qualitative data themes identified with corresponding definitions please see Appendix B.

CONCLUSIONS

The Komen Southwest Region consists of four states and twelve Affiliates⁷. Within the Komen Southwest Region, one state (Nevada) has late-stage diagnosis and death rates higher than the US as a whole. While the Komen Southwest Region states may have better breast cancer outcomes than the US as a whole, communities within each state may face disparate outcomes.

Healthy People 2020 breast cancer death and late-stage diagnosis rate targets were set as the standard that all communities in the Komen Southwest Region must strive to achieve to reduce overall breast cancer deaths. Communities that are predicted not to be able to meet the standard by 2020 are classified as “Highest Priority” and indicate that the communities is of greater need for target breast cancer programs than other areas within the region. Within the Komen Southwest Region, there are 12 communities that are considered “Highest Priority” and all are located in a local Komen Affiliate service area.

Within the 12 HP2020 “Highest Priority” communities there are 198 screening facilities, 93 diagnostic and 24 treatment facilities. In two of the 12 “Highest Priority” communities there are five American College of Radiology BICOE accredited sites. There are 22 facilities that provide screening, diagnostic and treatment services in the HP2020 “Highest Priority” communities; however only two “Highest Priority” communities have facilities that are recognized as meeting the American College of Surgeons NAPBC performance measures. When reviewing the accreditations for quality treatment in Komen’s Southwest region, there are 15 American College of Surgeon CoC facilities in four of the 12 “Highest Priority” communities. In addition there is one NCI designated Cancer Center located in Honolulu, HI, a “Highest Priority” community.

While the 12 HP2020 “Highest Priority” communities are located in several states, there are demographic and socioeconomic commonalities between the communities that link them to potentially sharing the same barriers to accessing care. In the Komen Southwest Region, 10 of the 12 “Highest Priority” communities have a substantially higher percentage of individuals residing in rural areas. The communities that do not have facilities that are accredited by the American College of Radiology, American College of Surgeons or the National Cancer Institute tend to be rural and classified as medically underserved by the US Department of Health and Human Services.

⁷ While 12 Affiliates within the Southwest Region completed the 2015 Community Profile process, only 10 remain due to mergers and/or dissolution

Linked to the HP2020 “Highest Priority” communities being rural is the lack of available breast cancer services located within the community, which was also voiced as a barrier to receiving care by the community members that participated in the qualitative data process. While all the “Highest Priority” communities had at least one local screening facility, there were several communities that have no local facilities that provide breast cancer diagnostic and/or treatment services. This requires an individual to navigate between health care systems and have resources to travel to other communities to receive care. Additional barriers to access cited by residents included facilities and/or providers have limited hours and/or days opened and there is a lack of accredited breast cancer services.

Quantitative data showed that six of the 12 communities have a substantially larger percentage of individuals that are unemployed. This was also highlighted by “Highest Priority” residents who participated in focus groups, interviews and surveys. Financial barriers were the most frequently cited concern by residents. These financial barriers included lack of funds to receive adequate breast cancer care, unemployment and potential lack of pay due to time off work for breast cancer appointments.

Other frequently cited barriers to breast cancer care cited by community members were transportation, fear (e.g., pain from the procedure, immigration status and health care system distrust), lack of insurance coverage (e.g., uninsured or underinsured) and confusion regarding personal risk of breast cancer and screening recommendations.

Collaboration between Komen Arizona, Komen Sacramento Valley, Komen Inland Empire, Komen Hawai’i and Komen Nevada may be able to address these common barriers and concerns.

To address these identified barriers in accessing breast cancer care, Komen Southwest Region Affiliates have identified priorities within their local service area that share commonalities with all Affiliates in the region. These are the most common priorities that the Affiliates located in the Southwest Region intend to focus on to reduce breast cancer late-stage diagnosis and deaths over the next five years:

- Support programs that reduce or eliminate barriers that have been identified as interfering with an individual being able to access breast cancer screening, diagnostic and treatment services. Client-oriented programs to reduce barriers include, but are not limited to free or low-cost breast cancer services, transportation assistance, mobile mammography, extended clinic hours/locations and interpreter services.
- Support patient navigation programs. Patient navigation is a process by which a trained individual- patient navigator- guides patients through and around barriers in the complex breast cancer care system. The primary focus

of a patient navigator is on the individual patient, with responsibilities centered on coordinating and improving access to timely diagnostic and treatment services tailored to individual needs. Patient navigators offer interventions that may vary from patient to patient along the continuum of care and include a combination of informational, emotional, and practical support (i.e., breast cancer education, counseling, care coordination, health system navigation, and access to transportation, language services and financial resources).

- Develop community and organizational partnerships to address concerns raised by the community members regarding lack of patient navigation and transportation services available in the region.
- Provide and/or support breast cancer education programs in local communities that provide accurate, evidence-based information.

In the Southwest Region, Affiliates identified Black/African-American women, Hispanic/Latina women, Women over 65, Asian and Pacific Islander women and medically underserved women may have a greater challenge in overcoming barriers to care. The local Affiliates intend to focus efforts to reduce the breast cancer disparities that these individuals may be experiencing.

In conclusion, community members who participated in focus groups, interviews and surveys from the HP2020 “Highest Priority” communities identified these top five barriers to receiving breast cancer care: financial barriers, lack of appropriate breast education, transportation barriers, availability of services and cultural/language barriers. These results align with some of the HP2020 socioeconomic data showing a majority of the “Highest Priority” communities are classified as rural and have a higher percentage of persons who are unemployed.

Komen Affiliates are a local breast cancer resource for “Highest Priority” communities within a service area. The local Komen Affiliate is a breast cancer resource for each “Highest Priority” community that can assist with addressing the identified barriers to care, convene stakeholders to develop solutions to increase access of available breast cancer services, and provide “real-time” assistance to areas of greatest need through funding of local community grants. Collaboration across service areas and state borders provide an opportunity for the Komen Southwest Region to share resources and best-practices, provide consistent messaging and address similar barriers to care, all in an effort to reduce the number of breast cancer deaths by 50.0 percent by 2026.

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APPENDICES

Appendix A. Health System Analysis Internet Search

The Evaluations and Outcomes team developed a tracking template for the Health Systems Analysis section to capture resources in target communities. The following sites were used to capture data.

Community Health Centers (CHC's) <http://nachc.org/about-our-health-centers/find-a-health-center/>

The team used the “Download Health Centers and Look-Alikes Report by State (PDF)”. Select the state you are working on and click “Generate Report”. Behavioral, Dental, Teen, Children’s, Shelters, Nursing homes, Jails, Schools and Administrative facilities were not be included in the information collected.

Title X <http://www.hhs.gov/opa/title-x-family-planning/initiatives-and-resources/title-x-grantees-list/>

The team used the facilities in the Title X list on the page. If the facility found matches the name and address information from CHC, the team retained the CHC. Behavioral, Dental, Teen and Children’s facilities should not be included in the information collected. The records are all listed by states that are applicable.

Mammography Centers

<http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMQSA/mqsa.cfm>

This site provides a listing by zip code or state, of all mammography facilities certified by the FDA or Certifying State as meeting baseline quality standards for equipment, personnel and practices under the Mammography Quality Standards Act of 1992 (MQSA) and subsequent Mammography Quality Standards Reauthorization Act (MQSRA) amendments. To legally perform mammography, a facility must be FDA certified. This list of Food and Drug Administration (FDA) Certified Mammography Facilities is updated weekly according to the website. The team searched by state and list accordingly.

Hospitals <https://data.medicare.gov/Hospital-Compare/Hospital-General-Information/v287-28n3>

This site is a list of all hospitals that have been registered with Medicare. The team did not include psychiatric and children’s hospitals. The team verified what services are offered across the Continuum of Care by visiting the hospital’s website.

Appendix B. Southwest Region Qualitative Data Themes

Availability of Services – Lack of health services in community, limited number of health professionals in community.

Awareness/Education – Lack of awareness of available services, lack of awareness of screening guidelines and confusion of screening guidelines.

Cultural/Language – Lack of interpreter services, lack of physicians who resemble patient’s culture, lack of programs that are culturally appropriate.

Financial Barriers- Lack of funds necessary to pay for the breast cancer services during the continuum of care.

Fear –Pain and discomfort during screening, diagnosis and treatment, legal or immigration status concerns if treatment is obtained, denial of diagnosis, afraid of breast cancer stigma.

Insurance – Lack of insurance, lack of adequate insurance coverage (underinsured).

Lack of Awareness of Resources – Lack of awareness of available resources that may or may not be free or reduced cost including screening, diagnostic, treatment and support services as well as Komen Affiliate activities.

Lack of Childcare/Adult Care – Lack of assistance to watch or take care of children or other adult family members during appointment.

Lack of Social Support –Lack of counseling, family support, difficulty shopping, cooking and caring for family, lack of emotional support or psychological services.

Navigation – Lack of direction by health system, lack of appointment verification or scheduling, lack of connectivity through continuum of care.

Other Health Priorities – Health concerns that are immediate including weight management, asthma, diabetes etc.

Pride/Modesty – Lack of female physicians in community and unwillingness to be seen by male physician, unwillingness to accept cancer diagnosis, unwillingness to ask for help.

Quality of Care – Lack of accredited health services in community, patients distrust in the health system due to experiences, lack of provider education and expertise, lack of facility technology, poor provider-patient interaction.

Transportation – Lack of personal transportation available, inadequate public transportation, access to public transportation, distance to services, availability of ride-share opportunities, and public transportation limited hours.

Time -Amount of time it takes for screening, diagnosis and appointments, lack of time off work, school or away from family, work conflicts.

Appendix C. Population characteristics, Southwest Region Healthy People 2020 “Highest Priority” communities

Population Group	Black/ African- American (females)	AIAN (females)	API (females)	Hispanic/ Latina (females)	Age 65 Plus (females)	Less than HS Education (females and males)	Income Below 100% Poverty (females and males)	Income Below 250% Poverty (Age: 40-64) (females and males)	Un- employed (females and males)	Foreign Born (females and males)	Linguis- tically Isolated (females and males)	In Rural Areas (females and males)	In Medically Under- served Areas (females and males)	No Health Insurance (Age: 40-64) (females and males)
US	14.1 %	1.4 %	5.8 %	16.2 %	14.8 %	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
Arizona	4.8 %	5.6 %	3.7 %	29.7 %	15.4 %	14.8 %	16.2 %	36.8 %	8.9 %	13.9 %	5.6 %	10.2 %	17.7 %	18.2 %
Graham County	1.5 %	16.5 %	0.9 %	28.6 %	13.4 %	17.4 %	21.6 %	45.1 %	10.1 %	4.8 %	3.1 %	46.4 %	0.0 %	15.8 %
Santa Cruz County	0.8 %	1.3 %	0.8 %	83.6 %	14.5 %	28.8 %	26.2 %	56.9 %	13.2 %	32.7 %	24.2 %	26.9 %	100.0 %	27.1 %
California	7.3 %	2.0 %	15.6 %	37.5 %	13.1 %	19.2 %	14.4 %	35.6 %	10.1 %	27.2 %	10.3 %	5.0 %	16.7 %	20.2 %
Amador County	1.1 %	2.4 %	1.9 %	9.9 %	24.4 %	12.7 %	10.0 %	27.7 %	15.2 %	5.8 %	0.8 %	60.4 %	27.4 %	14.7 %
Colusa County	1.4 %	3.3 %	2.4 %	54.4 %	12.9 %	29.5 %	14.4 %	43.0 %	13.8 %	24.2 %	13.4 %	31.7 %	0.0 %	24.2 %
Humboldt County	1.8 %	7.5 %	3.4 %	9.9 %	15.0 %	9.8 %	18.4 %	41.1 %	9.7 %	5.6 %	1.5 %	29.8 %	27.1 %	18.9 %
Mariposa County	1.4 %	3.9 %	1.7 %	9.6 %	22.0 %	11.3 %	14.4 %	36.9 %	13.2 %	4.8 %	1.7 %	100.0%	90.1 %	16.5 %
San Bernardino County	10.6 %	2.4 %	8.1 %	49.6 %	10.2 %	22.2 %	16.0 %	41.0 %	12.9 %	21.4 %	8.2 %	4.7 %	11.4 %	23.2 %
Yuba County	4.8 %	4.0 %	8.7 %	25.6 %	11.1 %	21.7 %	20.3 %	47.4 %	17.0 %	11.7 %	6.3 %	26.2 %	12.7 %	18.3 %
Hawaii'	2.4 %	0.5 %	74.2 %	8.7 %	16.5 %	9.9 %	10.2 %	29.0 %	6.4 %	17.8 %	6.1 %	8.1 %	6.7 %	8.1 %
Honolulu County	2.9 %	0.4 %	78.1 %	7.9 %	16.8 %	9.7 %	9.3 %	26.6 %	5.5 %	19.6 %	7.6 %	0.9 %	8.7 %	7.0 %
Maui County	1.2 %	0.6 %	64.8 %	9.8 %	14.6 %	10.8 %	9.2 %	30.7 %	8.2 %	15.7 %	3.4 %	14.6 %	4.7 %	10.0 %
Nevada	9.6 %	1.9 %	10.0 %	26.6 %	13.3 %	15.8 %	12.9 %	34.7 %	10.4 %	19.2 %	6.7 %	5.8 %	3.0 %	21.1 %
Humboldt County	1.1 %	5.3 %	1.4 %	24.4 %	10.6 %	18.4 %	13.5 %	27.0 %	10.2 %	13.7 %	4.6 %	37.9 %	0.0 %	18.7 %
Nye County	2.7 %	2.3 %	2.9 %	13.4 %	24.2 %	19.4 %	20.5 %	42.0 %	15.6 %	8.5 %	2.5 %	35.3 %	0.0 %	21.5 %

*The data in red represent at least a 3.0 (if <10.0%) or 5.0% (if ≥ 10.0%) percentage point difference than the state average.

Source of race, ethnicity and age data: Source: US Census Bureau - Population Estimates, 2011.

Source of health insurance data: US Census Bureau - Small Area Health Insurance Estimates (SAHIE), 2011.

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

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

Source of other data: US Census Bureau - American Community Survey (ACS), 2007-2011.

Appendix D. Breast cancer services available within HP2020 “Highest Priority” communities and the state, Komen Southwest Region*



	“Highest Priority”	State	“Highest Priority”	State	“Highest Priority”	State
Arizona	8	343	2	156	2	31
California	104	2,118	50	859	10	214
Hawaii	77	110	34	40	10	14
Nevada	9	100	7	69	2	21

* Data represents information gathered through an internet search in 2014. Therefore not all services in a community may be represented.