COMMUNITY PROFILE REPORT

Susan G. Komen for the Cure® Sacramento Valley

2011

Disclaimer

The information in this Community Profile Report is based on the work of the Sacramento Valley 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

The Community Profile team was comprised of Donna Sanderson, Executive Director of the Sacramento Valley Affiliate; Silvia Ramirez, Grants, Education and Race Coordinator; Melen Vang, Volunteer and Education Coordinator; Amanda Robison, Intern; Ellen Schaefer, Group Works; and Christina Slee, MPH, public health consultant. Technical assistance was provided by California Cancer Registry epidemiologist Monica Brown, PhD., and Crystal Schiffbauer-Bowles, GIS Analyst and Volunteer. With assistance from the entire Community Profile team, this Community Profile report was authored by Ellen Schaefer, Group Works.

Thank you to the many professionals in the community who participated in the Breast Health Needs Assessment Meeting at the 2010 Grant Writing and Networking Conference. Thanks also to those professionals who made time to share their points of view on the 2009 Community Needs Assessment Online Discussion Board and in personal and telephone interviews. We are also grateful to the women who participated in the 2011 focus groups and phone interviews to share their breast health experiences. Special thanks to Barbara Clifford, California Health Collaborative, and Candy Simbalenko, St. Joseph's Foundation and Medical Center, for assisting with the focus groups and to Loraine Joy McBurney, Colusa Regional Medical Center, and Delores Vasquez, California Health Collaborative, for providing Spanish to English translation assistance in the focus groups.

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Executive Summary

Introduction

The Sacramento Valley Affiliate of Susan G. Komen for the Cure® was established in 1993 and serves 17 Northern California counties, including Sacramento, the Central Valley, and its surrounding counties. Along with more than 120 other Affiliates, it is part of the world's largest and most progressive grassroots network fighting to end breast cancer forever. Komen for the Cure's promise is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to discover the cures.

Working to meet this promise, the Komen Sacramento Valley Affiliate raises funds, of which 75 percent of net proceeds stays in the area to fund local health programs and 25 percent goes to research. In the past fourteen years, the Affiliate has put over $10 million dollars back into the community through local grants that support breast health education, breast cancer screening, and support for the medically underserved in the Affiliate service area. Because the California State Capital of Sacramento is in the center of its service area, the Affiliate has also played a leadership role in the Komen California Collaborative Public Policy Committee's breast health advocacy efforts.

In order to leverage limited resources for the greatest possible impact and benefit, the Affiliate is committed to identify the greatest breast health needs in the service area. This is accomplished through a community needs assessment process that includes a review of demographic and breast cancer statistics and outreach to local stakeholders for input on the greatest service gaps, barriers to care, and unmet needs related to breast health. The end result of this process is this Community Profile report that summarizes the community needs assessment findings and establishes direction for the Affiliate's education, outreach and advocacy efforts, and outlines priorities for awarding future grants.

Statistics and Demographic Review

The data for the Sacramento Valley Community Profile report were selected from a variety of sources. Data provided by Claritas Inc. (© 2009) and Thomas Reuters (© 2010) was used to report the demographic characteristics of counties in the Sacramento Valley region. Data relating specifically to breast cancer in the Sacramento Valley counties was provided by the California Cancer Registry (CCR). Data on the uninsured was obtained from a report by the UCLA Center for Health Policy Research.

The Sacramento Valley 17-county service area is remarkable in its diversity. Sacramento, the largest county, comprises 32 percent of the region's female population

and is one of the three counties in the region with a higher than average percentage of African Americans. San Joaquin and Stanislaus counties are populous agricultural counties with larger Hispanic populations. Solano County is distinctive for having the highest proportion of African Americans in the region. Placer and El Dorado Counties, east of Sacramento, are predominately white. The five western counties of Butte, Colusa, Sutter, Yolo, and Yuba combined comprise 14 percent of the service area population and have large rural areas. Colusa has the highest percentage Hispanics in the service area (48.5 percent). The six eastern counties of Amador, Nevada, Yuba, Tuolumne, Plumas, and Sierra combined comprise only 6 percent of the region's population. These counties are all very small, predominately rural and white. (© 2009, Claritas Inc., ©2010 Thomson Reuters (C/TR))

One area of grave concern in California that has an impact on accessing breast health care is the number of Californians without health insurance. The UCLA Center for Health Policy Research estimates that the uninsured in California increased from 19.5 percent in 2007 to 24.3 percent in 2009. Several counties had over 25 percent uninsured for all or part of the year in 2009, and a number of counties saw over 30 percent increases in the proportion of the population that was uninsured between 2007 and 2009. (UCLA Center for Health Policy Research (UCLA), 2009) This trend is particularly problematic given that the Cancer Detection Program: Every Woman Counts (CDP: EWC) safety net program was frozen for 11 months in 2010, leaving many uninsured women without access to coverage for screening or diagnosis.

Another primary area of concern from reviewing the statistical data is the increase in late stage diagnosis of breast cancer. Comparing age-adjusted incidence rates for breast cancer by stage of diagnosis from the California Cancer Registry, there is an increasing trend in those with a late stage (Stage III or IV) vs. early stage (Stage I or II) diagnosis. This trend is statistically significant for some counties for women age 20-49 and even more counties for women over age 50. As one example, in the Western Counties (Colusa, Yolo, Butte, Sutter, and Yuba combined), the average annual age-adjusted breast cancer incidence rate for women age 50 and over has increased from 29.0 per 100,000 in 2000-2002 to 55.5 per 100,000 in 2006-2008, an average percent change of 11.4 percent per year. (Public Health Institute/California Cancer Registry Data Services, California Department of Public Health, California Cancer Registry, Sacramento, CA: 2010. (PHI/CCR, 2010)

The demographics and breast cancer statistics led the Affiliate to identify the following targets for additional investigation: the significant increases in those who are uninsured in the region and the impact on breast health, the trend in late-stage breast cancer diagnosis and identification of obstacles in earlier diagnosis, the diverse population of the region and ways to provide outreach to them, and the large number of rural areas in the region and their unique needs.

Health Systems Analysis

To better understand the gaps, needs and barriers throughout the continuum of care for breast health in the Affiliate's 17-county region, several research steps were undertaken. To identify mammography screening facility availability throughout the 17-county service area, data on licensed mammography screening facilities was obtained from the California Department of Health Services, Radiologic Health Branch. Locations of screening facilities were mapped, along with age-adjusted incidence of breast cancer and rates of uninsured. To obtain input on the gaps, needs and barriers, three methods were used. In the summer of 2009, 60 professionals from all 17 counties were invited to participate in an online discussion board about breast health and about a third of them participated. In the summer of 2010, a survey was conducted of 42 professionals from 25 organizations representing past and prospective grantees who attended a Komen-sponsored Grant Writing Workshop. These research efforts were supplemented by in-person and telephone interviews with over a dozen professionals. Professionals included program directors, patient navigators, support group facilitators, health care providers, and other professionals informed about breast health.

The primary issues in breast health raised by key informants are the lack of awareness, gaps in coverage, and instability of funding for the Every Woman Counts (CDP: EWC) program which covers screening and diagnostic services for those with limited financial means. These issues affect the entire region and are not limited to any single target community. In the 2009 Community Profile, key informants were concerned about the service gap for women under 40 with symptoms not covered by CDP: EWC and the program's overall economic viability. In 2010, breast health advocates' worst fears were realized when all new enrollments into CDP: EWC were frozen and services for women 40-49 were shut off. In 2010, the Sacramento Valley Affiliate focused its energies in two directions: spearheading policy advocacy to reinstate funding for CDP: EWC and revising its grant program to try to fill in the coverage gaps. This was a challenge, given the magnitude of costs and that most grantees have focused on education and outreach in the past and needed to look for partners to cover screening and diagnostic services. It was determined unfair to conduct outreach in lower income communities to educate women about the need for screening when they have no way to offer coverage to pay for the recommended services. By the end of the year, the advocacy effort was successful and the CDP: EWC program was reinstated for eligible women over 40. Key priorities for the Affiliate will continue to be advocacy for sustainable funding for this vital support program and funding grants that help women obtain equal access to breast health education and early screening, diagnosis and treatment of breast cancer.

In addition to inability to pay, other barriers to obtaining breast health care raised by key informants include lack of education and awareness about the importance of early detection and availability of services, cultural barriers such as mistrust of health care system and language translation needs, navigation assistance to access care and financial support, and women in rural counties who feel more isolated with fewer facilities and resources. It is likely that a combination of these barriers contributes to

inconsistent screening and may be contributing factors to the increasing trend toward later stage breast cancer diagnosis.

Qualitative Data Overview

To gain a better understanding of the breast health needs and experiences of women in the service area, the team conducted qualitative research consisting of four focus groups in three counties: Butte, Colusa, and San Joaquin, supplemented by telephone interviews with six women in more rural areas of Butte and Plumas counties. A total of 39 women were included in the research, including survivors (14), those without a cancer diagnosis (25), Spanish-speaking Latina women (6), and African American women (11).

While limited in scope, the qualitative research findings were consistent with the issues raised by key informants. The women interviewed gave voice to many concerns and unmet needs related to breast health in their communities. The main themes centered on the key obstacles to early detection, diagnosis, and treatment: inability to pay and lack of insurance, challenge of finding financial assistance, lack of education and lack of consistent referrals for mammograms from doctors, feeling lost in trying to find services, and the rural area obstacles of fewer resources and greater distances to travel to obtain services. These barriers comprise the priority areas of need that the Sacramento Valley Affiliate hopes to focus on with its future advocacy, education, and grant programs.

Conclusions

After reviewing the statistics and research, identifying priority areas of need, and brainstorming action plan options, the Community Profile team agreed upon the following recommended Affiliate Action Plan.

Action Plan

Overall Goals:

- Increase early stage breast cancer diagnosis and treatment in order to reduce mortality rates through education, screening, and support services.
- Target areas of highest need and women who are most underserved.

PRIORITY 1: Expand support for programs that provide breast cancer screening and diagnostic services for the uninsured.

Objective 1: Continue public policy advocacy efforts by working with a coalition of stakeholders and legislators to ensure the continued funding of the Every Woman Counts: Cancer Detection Program beyond the current 2011 budget.

Objective 2: By March 2012, fund grantee(s) that otherwise would not be able to provide screening and diagnostic services to fill in gaps for the uninsured who need breast health services and are not covered by any government programs (i.e. *CDP: EWC, Family Pact, MediCal)*.

PRIORITY 2: Support education and outreach efforts to increase awareness of the importance of early breast cancer detection and treatment.

Objective 1: By March 2012, fund grantee(s) that support community outreach efforts that spread the word about the importance of early screening and detection.

Objective 2: By December 2011, update the Online Resource Guide on the Affiliate website to include links to breast cancer education materials in multiple languages.

Objective 3: By June 2012, recruit an advertising agency partner and invest $100,000 of the general education budget to develop public service announcements to be run four times a year to remind women of the importance of early detection.

Objective 4: By June 2012, host a second Circle of Promise Ambassador training to educate the African American community about the goals and promise of the program. Continue to educate and inform the African American community about the importance of early detection through the Circle of Promise by hosting a variety of events and partnering with local churches.

PRIORITY 3: Increase awareness of breast cancer programs and services available in the Affiliate service area, including the availability of *CDP: EWC* programs.

Objective 1: By March 2012, fund grantee(s) that provide education and navigation services to help guide women to available support services throughout the continuum of care. This may include educating key point people in clinics and medical offices where women are notified of breast health services they need but may not be able to afford.

Objective 2: By June 2012, schedule two collaborative meetings hosted by the Affiliate to support networking and collaboration among grantees, providers, and other breast health organizations in the 17-county service area to encourage leveraging of resources, the development of new partnerships, and sharing of best practices.

Objective 3: By December 2011, develop a comprehensive Online Resource Guide with information and links to breast cancer and breast health resources available in the 17-county service area. This resource will be accessible to all grantees, providers, and patients throughout the service area to increase access to care. It will also facilitate additional health system analysis to inform the community needs assessment process.

PRIORITY 4: Increase access to breast health education, screening and treatment in rural areas.

Objective 1: By March 2012, fund grantee(s) that are able to integrate community outreach, awareness, education, and navigation efforts with access to breast cancer screening, diagnosis and treatment in rural areas. This can be accomplished through mobile mammography, volunteers providing transportation, transportation vouchers, and navigation support services.

Objective 2: By June 2011, complete the application to add Glenn and Tehama counties to Komen's service area.

Objective 3: By October 2011, invite a board member from one of the rural counties in the service area to ensure that the needs of the many rural communities in the service area are represented on the Board.

Objective 4: By June 2012, expand the WeCare Peer Navigation program in four rural counties to recruit and train breast cancer survivors to act as peer support for women newly diagnosed with breast cancer.

Objective 5: By June 2012, establish a pilot Volunteer Train-the-Trainer Program in Stockton to train and educate key volunteers to conduct volunteer trainings in their county. If successful, expand to other parts of the service area.

Introduction

Affiliate History

The Sacramento Valley Affiliate of Susan G. Komen for the Cure was accepted as an Affiliate of the National Komen for the Cure in 1993. It was started with three volunteers and has grown to have five paid staff members, a full Board of Directors with eight volunteer board members, a 20-member Race Committee, over 300 Affiliate volunteers, and over 600 Race volunteers who work on the Affiliate's annual Komen Race for the Cure, always held the Saturday morning before Mother's Day.

Along with more than 120 other Affiliates, it is part of the world's largest and most progressive grassroots network fighting to end breast cancer forever. Komen for the Cure's promise is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to discover the cures.

Of the funds raised by the Affiliate, up to 75 percent of the net income remains in the community to support local programs that enhance breast health education, and breast cancer screening and support services for the medically underserved. At least 25 percent of the net income supports the Susan G. Komen for the Cure Award and Research Grant Program, which funds research grants at the national level.

In 1997 the Affiliate held its first Komen Sacramento Race for the Cure. It was a very successful, first-time event with 2,039 participants raising $239,000. The Race has been held annually since 1997. The 14th Annual Komen Sacramento Race for the Cure held at Cal Expo in Sacramento, California on May 8, 2010 had over 21,000 participants and raised $1.8 million dollars.

In 2007, the Affiliate passed the $1 million mark for grants awarded in one fiscal year. In the past 14 years, the Affiliate has put over $10 million dollars back into the community, supporting breast health programs throughout the Affiliate's 17-county service area.

Established in 2003, the Sacramento Valley Affiliate provides leadership for the California Collaborative, made up of seven statewide Affiliates, representing more than 100,000 California supporters with a demonstrated interest in the issues of breast cancer and breast health. Created as a vehicle to advance the Komen Promise by maximizing and leveraging resources through active statewide Affiliate participation, the Collaborative focuses on coordinating fundraising, education and public policy advocacy.

The Affiliate held its first annual California Lobby Day event in 2005. A favorite of each Lobby Day is lighting the State Capitol building PINK to raise public awareness of breast health.

Organizational Structure

The Sacramento Valley Affiliate has five paid staff positions and a Board of Directors that includes the Executive Director and eight volunteer board members *(See Figure 1).*

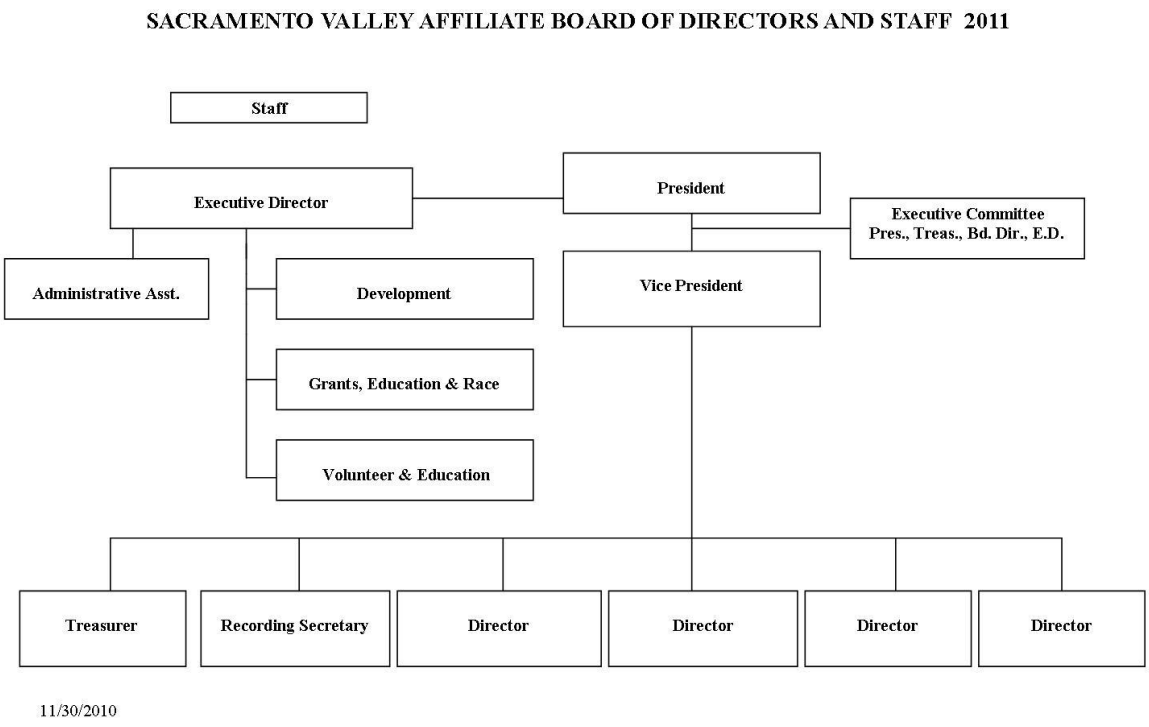

Figure 1: Sacramento Valley Affiliate organization chart.

Description of Service Area

The Sacramento Valley Affiliate covers a 17-county area in Northern California. The most populous county is Sacramento, seat of the state's capital, with 32 percent of the service area population. The service area also includes many suburban areas around Sacramento, agricultural communities in the Central Valley, and counties with smaller populations and more rural areas to the north and in the foothills of the Sierras to the east. Part of Solano County is shared with the San Francisco Bay Affiliate and parts of El Dorado, Nevada, and Placer are shared with the Northern Nevada Affiliate *(See Figure 2)*.

Figure 2. Map of Sacramento Valley Affiliate service area.

Purpose of Report

Susan G. Komen for the Cure's promise is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to discover the cures.

Working to meet this promise, the Sacramento Valley Affiliate raises funds that are divided between contributions to nationally-funded breast cancer research efforts and local grants to organizations that support education, screening, and support for the underserved in the 17-county service area.

In order to leverage limited resources for the greatest possible impact and benefit, the Affiliate is committed to identifying the greatest breast health needs in the service area. This is accomplished through a community needs assessment process that includes a review of demographic and breast cancer statistics and outreach to local stakeholders for input on the greatest service gaps, barriers to care, and unmet needs related to breast health.

The end result of this process is this Community Profile report that summarizes the community needs assessment findings and establishes direction for the Affiliate's education, outreach and advocacy efforts, and outlines priorities for awarding future grants.

Methodology

The data for the Sacramento Valley Community Profile report were selected from a variety of sources. Data provided by Claritas Inc. (© 2009) and Thomas Reuters (© 2010), were used to report the demographic characteristics of counties in the Sacramento Valley region.

Data relating specifically to breast cancer in the Sacramento Valley counties was provided by the California Cancer Registry (CCR). The CCR is California's statewide population-based cancer surveillance system that collects data on all cancers diagnosed in California. These data are commonly used by researchers, community agencies, and policy makers to develop programs that support cancer detection and treatment. To date the CCR has collected detailed information on more than 3.4 million cases of cancer among Californians diagnosed from 1988 forward. More than 162,000 new cases are added annually. (California Cancer Registry (CCR) website (http://www.ccrcal.org/), 2010)

Data from the CCR were provided for two different data presentations. First, the online California Cancer Registry Inquiry System was used to produce age-adjusted rates for breast cancer incidence. Incidence relates to the development of new breast cancer cases and is more meaningful for program planning purposes than prevalent breast cancer, which is an estimate of new and existing disease within a population at a specific point in time. Age-adjusted rates eliminate the differences in rates owing to age, thereby creating fair comparisons of rates in counties that have different age distributions. This is done by standardizing the crude rates to the US population from 2000.

The second type of data presentation provided by the CCR are the tables of early vs. late stage breast cancer by age group, namely women age 20-49 and women age 50+. In December 2009, the Every Woman Counts (CDP: EWC) Program—California's safety net program for breast and cervical screening—closed its enrollment to women under age 50. This policy decision has created an interest among health advocates and policy makers in early and late stage breast cancers and how trends by stage vary between women age 20-49 and women age 50+. Many community groups want to understand the breast cancer profile for younger women so that screening and diagnostic services can be made available to high-risk women in the absence of public programs like CDP: EWC. Epidemiologist Monica Brown, PhD, from the Public Health Institute/California Cancer Registry Data Services ran the analysis to create the figures presented in this report. She noted that these data can be more helpful to policy decisions than breast cancer mortality rates, which may be unstable due to small numbers.

Many of the counties in the Sacramento Valley are rural. To create stable rates in the breast cancer stage reports, Dr. Brown used several analytic tactics to overcome the problem of small numbers. First, she created an average annual breast cancer incidence rate based on two-year intervals: 2000-2002, 2003-2005, and 2006-2008. She also combined counties into groups based on the shared socio-demographic characteristics of the counties. The two groups include the northwestern valley counties (Colusa, Yolo, Butte, Sutter, and Yuba) and the eastern valley counties (Plumas, Sierra, Nevada, Amador, Calaveras, and Tuolumne). The northwestern valley counties represent a largely agricultural area with higher proportions of women who are working-age (i.e., under 50), Hispanic, and uninsured. The eastern valley counties, comparatively speaking, have less industry and larger proportions of white middle-class women over age 50.

Overview of the Affiliate Service Area

Demographics: 2009 Population and Ethnicity

The overall service area includes 2.25 million women. Sacramento has the largest portion of the service area with 32 percent of the women in the area. Home of the state capital, Sacramento is quite diverse: 52 percent White, 19 percent Hispanic, 14 percent Asian/Pacific Islander, 10 percent Black, and 5 percent Other. The next most populous counties in the service area are San Joaquin and Stanislaus, which are south of Sacramento in the Central Valley. These counties are notable for having large Hispanic populations, 36 percent and 38 percent respectively. More than 80 percent of women living in the eastern region of the Sacramento Valley, including El Dorado, Nevada, Tuolumne, Calaveras, Amador, Plumas, and Sierra, are white. The northwestern part of the region, including Yolo, Colusa, Sutter, and Yuba counties, is more than 20 percent Hispanic. Solano County has the highest proportion of African American and Asian/Pacific Islander women in the region at 14 percent and 15 percent, respectively. *(C/TR, 2009/2010) (See Table 1)*

Table 1
Women Living in the Sacramento Valley Region by Ethnicity, 2009.

County	2009 Population	Share of Service Area	% White	% Black	% Am Indian	% Asian/Pac Islander	% Other	% Hispanic
Sacramento	724,920	32.2%	52.2%	9.7%	0.7%	13.6%	4.7%	19.1%
San Joaquin	346,200	15.4%	39.0%	7.4%	0.5%	13.5%	4.0%	35.6%
Stanislaus	266,715	11.8%	50.1%	2.6%	0.6%	4.9%	3.3%	38.4%
Solano	207,866	9.2%	43.5%	14.0%	0.5%	15.4%	5.2%	21.4%
Placer	175,588	7.8%	78.7%	1.5%	0.6%	5.6%	2.8%	10.9%
Butte	112,119	5.0%	79.8%	1.2%	1.4%	3.8%	2.6%	11.1%
Yolo	102,384	4.5%	53.8%	2.4%	0.7%	12.2%	4.1%	26.8%
El Dorado	90,452	4.0%	81.6%	0.9%	0.6%	3.5%	2.5%	10.9%
Nevada	48,247	2.1%	89.0%	0.4%	0.5%	1.1%	1.9%	7.1%
Sutter	47,294	2.1%	55.6%	2.2%	1.1%	11.8%	3.0%	26.2%
Yuba	36,399	1.6%	62.1%	2.7%	1.8%	7.7%	3.8%	21.8%
Tuolumne	27,634	1.2%	89.4%	0.5%	1.1%	0.9%	1.9%	6.2%
Calaveras	23,898	1.1%	85.3%	0.7%	1.1%	1.4%	2.2%	9.3%
Amador	18,171	0.8%	90.2%	0.3%	1.0%	1.0%	1.6%	6.0%
Colusa	10,994	0.5%	44.9%	0.9%	1.5%	2.0%	2.2%	48.5%
Plumas	10,466	0.5%	91.3%	0.6%	1.3%	0.6%	1.5%	4.7%
Sierra	1,547	0.1%	94.3%	0.1%	0.3%	0.2%	0.3%	4.7%
Total	2,250,894	100.0%	56.1%	6.3%	0.7%	10.2%	3.9%	22.8%

Uninsured

The number of Californians without health insurance has been increasing in recent years. The UCLA Center for Health Policy Research estimates the uninsured in California increased from 19.5 percent in 2007 to 24.3 percent in 2009. Figure 3 illustrates the proportion of the population living in the Sacramento Valley that was uninsured in all or part of 2007 and 2009. Due to the small size of some counties, Tuolumne County was included with Calaveras, Mariposa, Mono, Alpine, Inyo and Amador counties; Plumas County was included with Del Norte, Siskiyou, Lassen, Trinity, Modoc, and Sierra counties; and Colusa County was combined with Glen and Tehama counties. Plumas County and its surrounding area had the highest proportion of uninsured in 2009. However, five counties had a percent change in the proportion of the population that was uninsured in excess of 30 percent between 2007 and 2009; these include Sacramento (34.4 percent increase), Solano (36.2 percent increase), Placer (56.3 percent increase), El Dorado (36.9 percent increase), and Yuba (40.6 percent increase). (UCLA, 2009)

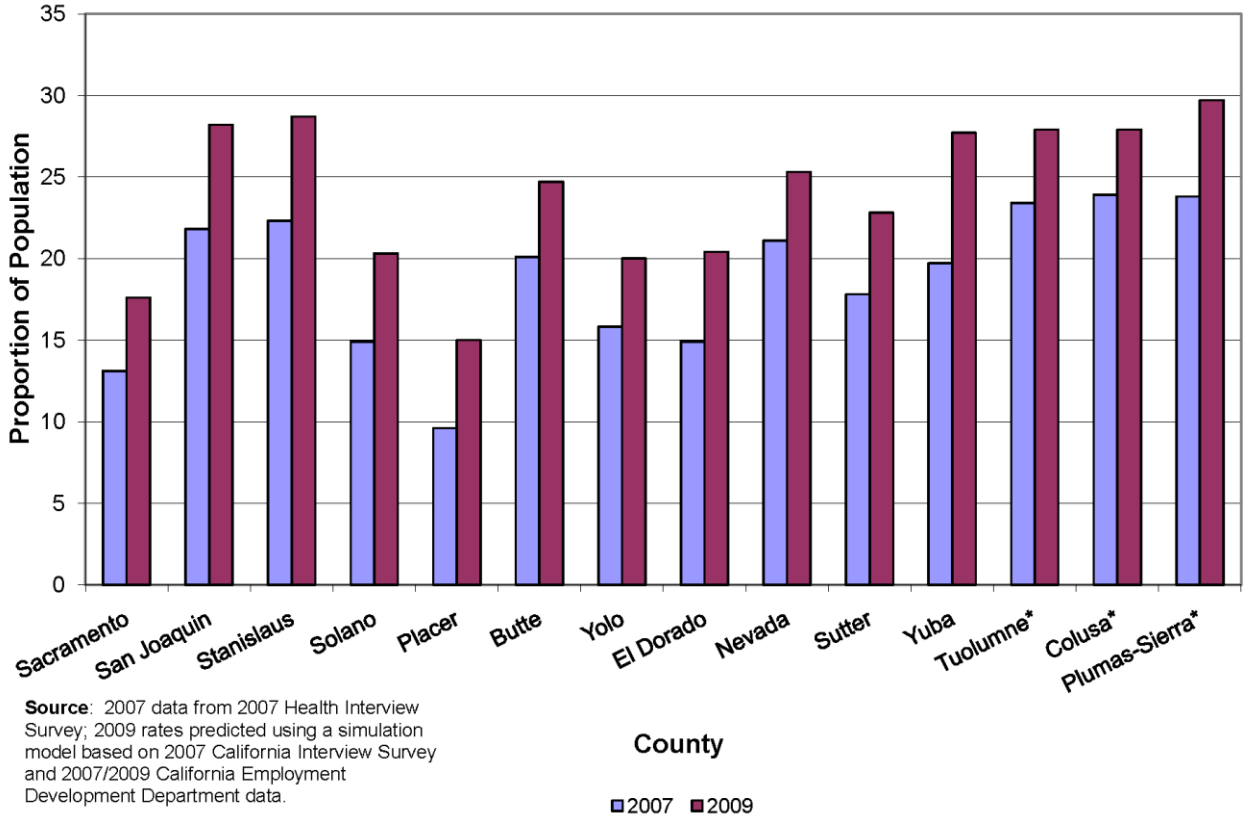

Figure 3. Percent uninsured all or part of year, Age 0-64, 2007 & 2009.

UCLA Center for Health Policy Research Fact Sheet, August 2010

Incidence of Breast Cancer by Age

The California state average incidence of breast cancer is 109.44 per 100,000 females. Figure 4 shows the incidence of breast cancer for women age 18-44, 45-64, and over age 65 and highlights the increasing incidence with age. The highest breast cancer incidence in the Affiliate's service area appears among women over age 65 who live in Nevada, Plumas, Butte, Tuolumne, and Yuba counties. (C/TR, 2009/2010)

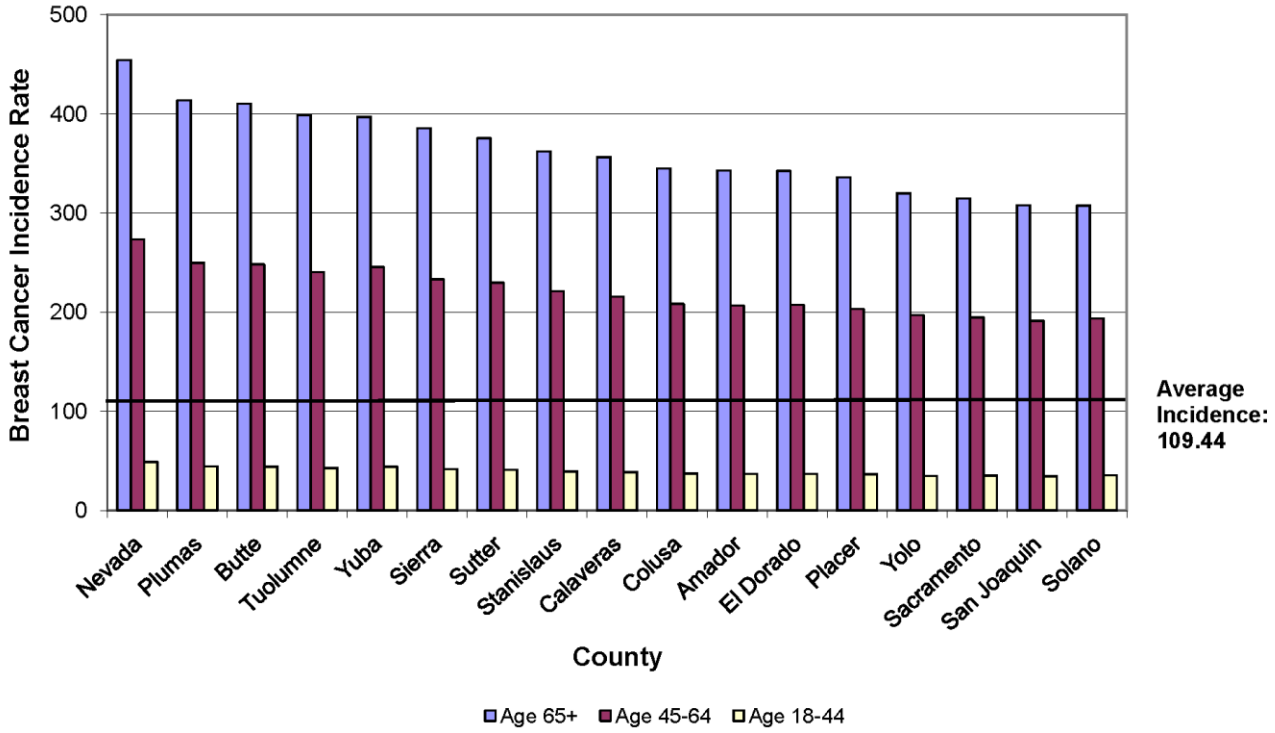

Figure 4. Incidence of Breast Cancer per 100,000 women by age and county, 2009.

Age Adjusted Incidence of Breast Cancer

Figure 5 shows age-adjusted breast cancer incidence by county. The nine counties with the highest age-adjusted invasive breast cancer incidence rates are Tuolumne, Nevada, Placer, Butte, El Dorado, Yolo and Amador-Calaveras. They all rise above the age-adjusted rate of 122.09 for the state of California (CCR, 2010).

Note that due to small numbers, some counties were combined, as indicated with an asterisk. Sierra and Yuba counties were combined; Tuolumne County was combined with Mariposa County; Amador and Calaveras counties were combined with Alpine County; Plumas County was combined with Lassen and Modoc counties; and Colusa County was combined with Glen and Tehama counties. To boost numbers and establish better stability in the incidence rates, data were combined for 2006-2008.

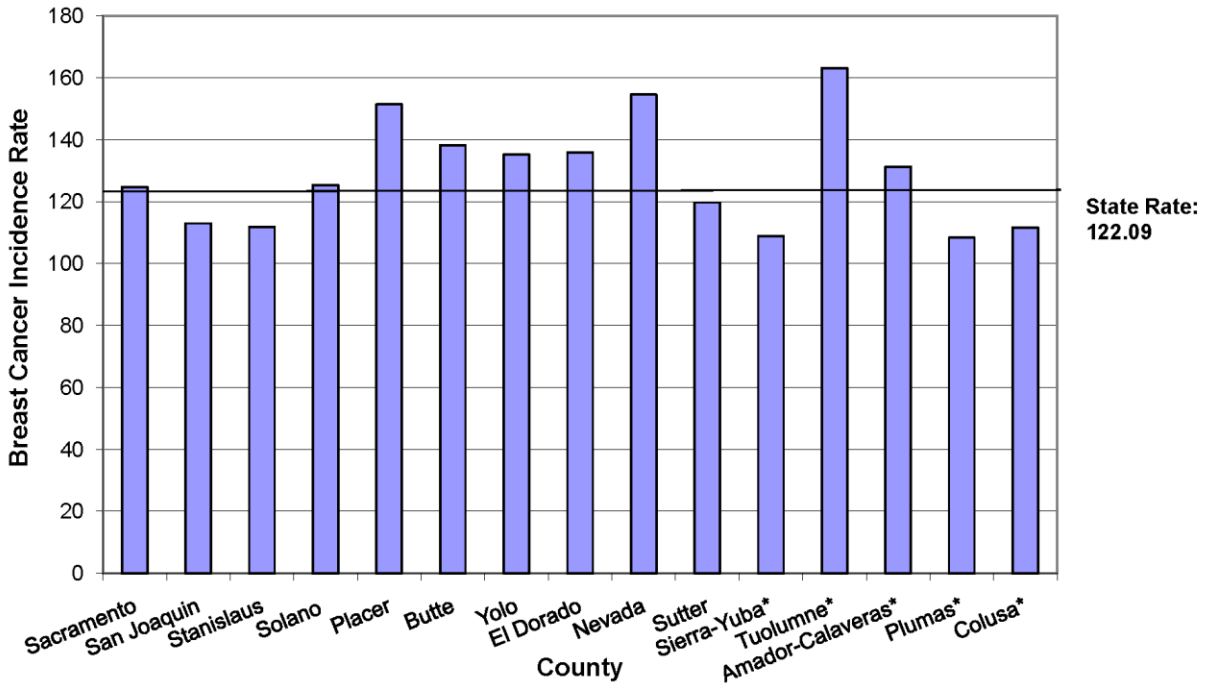

Figure 5. Age-adjusted invasive breast cancer incidence rate (per 100,000 women), 2006-2008.

California Cancer Registry Cancer Inquiry System, data accessed November 15, 2010. Based on June, 2010 quarterly extract released June 17, 2010.

Age Adjusted Incidence of Invasive Breast Cancer by Race/Ethnicity

Figure 6 reports age-adjusted breast cancer incidence by race/ethnicity for the most populous counties in the Sacramento Valley. This approach was chosen because the California Cancer Registry does not report breast cancer incidence by race/ethnicity when there are fewer than 15 deaths. Here, breast cancer incidence for African American and white women is comparable in Sacramento, Stanislaus, and Solano counties. In San Joaquin County, the invasive breast cancer incidence rate for African American women is higher than it is in Sacramento, Stanislaus, or Solano County (CCR 2010).

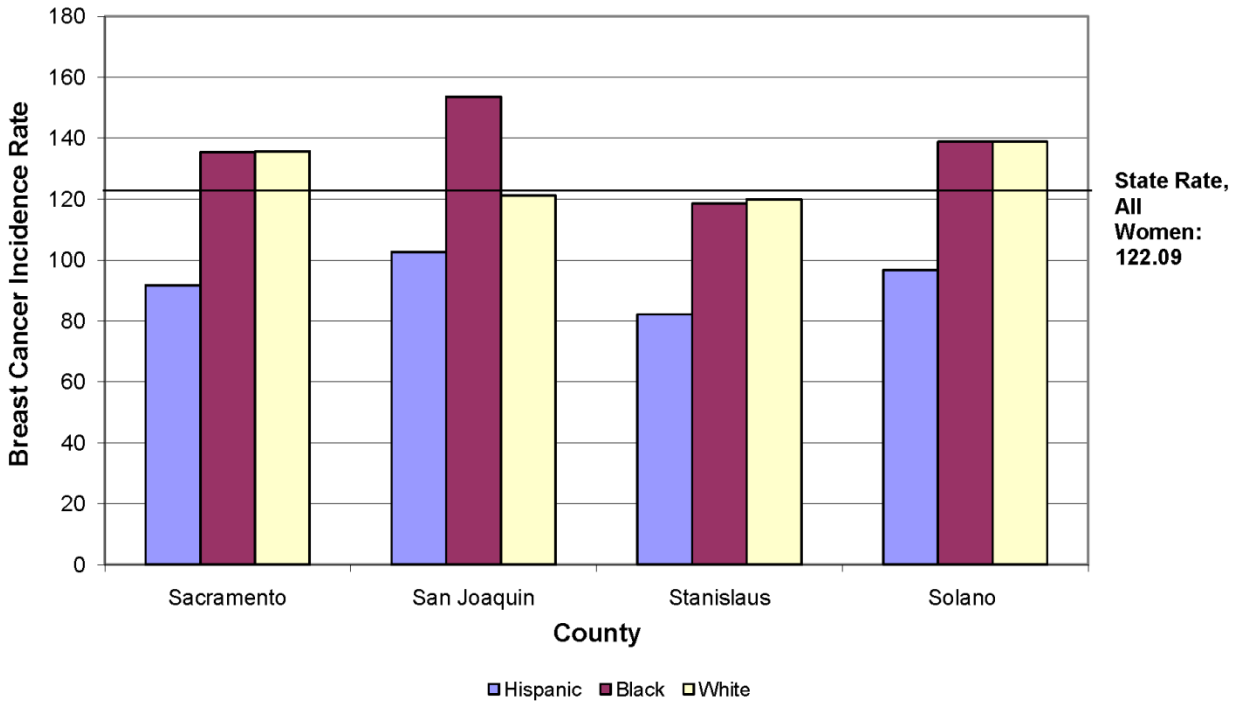

Figure 6. Age-adjusted invasive breast cancer incidence rate (per 100,000 women), by race/ethnicity, 2006-2008.

California Cancer Registry Cancer Inquiry System, data accessed November 15, 2010. Based on June, 2010 quarterly extract released June 17, 2010.

Age Adjusted Breast Cancer Mortality Rate

Figure 7 shows age-adjusted breast cancer mortality rates by county. Because rates are not calculated when there are fewer than 15 reported deaths for a county, we chose to include data for the period 2006-2008. Eleven counties exceeded the mortality rate for the state of 21.9 deaths per 100,000 women. The highest were the eastern counties of Nevada, Sierra/Yuba, and Tuolumne, followed closely by Solano, Placer, Butte, El Dorado, Stanislaus and San Joaquin. Breast cancer mortality in Sacramento County was close to the state rate (CCR 2010).

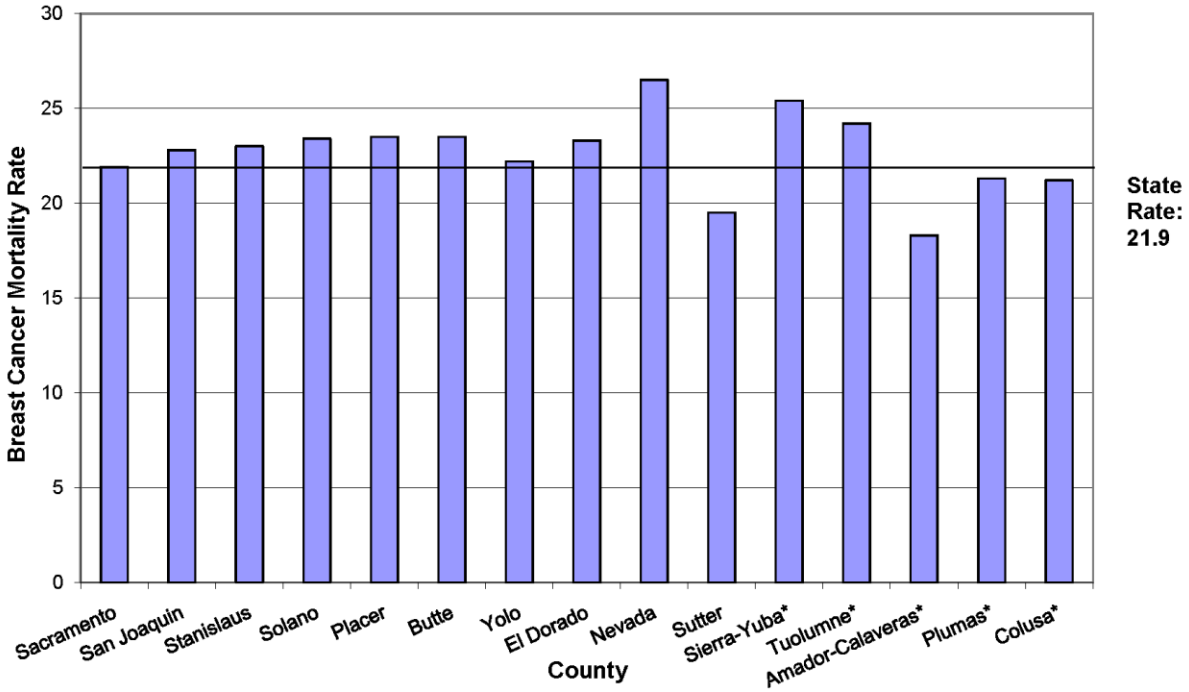

Figure 7. Age-adjusted breast cancer mortality rate (per 100,000 women), 2006-2008.

California Cancer Registry Cancer Inquiry System, data accessed November 15, 2010. Based on June, 2010 quarterly extract released June 17, 2010.

Age Adjusted Breast Cancer Incidence Rates by Breast Cancer Stage

In this year's report, age-adjusted incidence rates for breast cancer according to the stage of the cancer at diagnosis are presented. Because many of the counties in the Sacramento Valley are quite small, average annual incidence rates were calculated over a two-year period. Using an average creates stability in the rate that is lost when rates are calculated one year at a time. Additionally, these rates are age adjusted, which means that the results have been standardized to the 2000 US population, thereby washing away any difference in incidence that can be attributed to a particular county have a higher proportion of older or younger women.

In Tables 2 and 3, early stage represents stage I and II cancers, which are more amenable to treatment and frequently have a better prognosis than late stage cancers. Late stage cancers include those diagnosed as stage III and IV. These cancers have a poorer prognosis and are frequently characterized by metastases of the primary cancer to other organs. Table 2 is designed to show trends for both types of cancer for women age 20-49; highlighted rows indicate that the trend is significantly different from 0 or "no change" and that one would expect to find a result of this size less than 5 percent of the time. In San Joaquin, the incidence of early stage cancers has shown a statistically significant decrease since 2000. Conversely, there is a statistically significant increase in late stage cancers. This type of finding may indicate that women are presenting with advanced cancers because they didn't have their breast cancers detected at an earlier stage in the disease process.

In the western counties, a statistically significant trend appears for late stage cancers (CCR, 2010). This may be due to higher proportions of uninsured families. As shown earlier in Figure 3, the western counties of Colusa, Yuba, Sutter, and Butte have higher proportions of uninsured women. These factors may indicate barriers to access that prevented women from seeking screening or diagnostic services earlier in their care.

Table 2

Average Annual Age-adjusted Breast Cancer Incidence Rates per 100,000 by Breast Cancer Stage, Women Age 20-49, 2000-2008

	2000-2002	2003-2005	2006-2008	Average Percent Change
Sacramento				
Early Stage	54.1	53.3	51.5	-0.8
Late Stage	10.3	9.9	11.5	1.9
San Joaquin				
Early Stage	47.9	46.5	45.4	-0.9
Late Stage	7.7	10.5	13.6	9.9
Stanislaus				
Early Stage	44.8	52.5	36.3	-3.4
Late Stage	7.3	12.4	15.5	13.4
Solano				
Early Stage	55.3	52.2	50.9	-1.4
Late Stage	11.7	12.2	18.4	7.8
Placer				
Early Stage	55.7	61.7	55.2	-0.2
Late Stage	6.7	13.3	19.6	19.6
El Dorado				
Early Stage	59.1	58.3	50.2	-2.7
Late Stage	11.5	10.0	14.6	4.1
Eastern Counties*				
Early Stage	50.0	51.4	51.7	0.6
Late Stage	7.7	12.6	11.9	7.5
Western Counties**				
Early Stage	62.1	49.3	52.5	-2.5
Late Stage	9.4	10.8	12.7	5.1

Public Health Institute/California Cancer Registry Data Services (in situ cases excluded)

*Includes Plumas, Sierra, Nevada, Amador, Calaveras, and Tuolumne counties
**Includes Colusa, Yolo, Butte, Sutter, and Yuba counties
Note: Shaded rows indicate a statistically significant change ($p < .05$)

Table 3 reflects average annual age-adjusted incidence rates by breast cancer stage for older women, age 50 and older. Here, statistically significant trends for late-stage breast cancer appear for all counties except San Joaquin and the eastern counties.

Table 3

Average Annual Age-adjusted Breast Cancer Incidence Rates per 100,000 by Breast Cancer Stage, Women Age 50+, 2000-2008

	2000-2002	2003-2005	2006-2008	Average Percent Change
Sacramento				
Early Stage	365.1	295.9	262.0	-5.4
Late Stage	35.2	43.5	54.0	7.4
San Joaquin				
Early Stage	315.5	266.6	247.1	-4.0
Late Stage	27.0	39.9	43.4	8.2
Stanislaus				
Early Stage	321.3	263.0	246.5	-4.3
Late Stage	25.0	36.3	51.7	12.9
Solano				
Early Stage	341.9	292.6	276.5	-3.5
Late Stage	34.7	43.5	55.1	8.0
Placer				
Early Stage	378.3	329.6	340.4	-1.7
Late Stage	33.6	44.8	60.2	10.2
El Dorado				
Early Stage	367.1	327.7	309.7	-2.8
Late Stage	42.5	50.4	61.9	6.5
Eastern Counties*				
Early Stage	374.7	303.7	319.1	-2.6
Late Stage	29.7	46.4	52.0	9.8
Western Counties**				
Early Stage	358.8	268.1	278.7	-4.1
Late Stage	29.0	39.8	55.5	11.4

Public Health Institute/California Cancer Registry Data Services (in situ cases excluded)

*Includes Plumas, Sierra, Nevada, Amador, Calaveras, and Tuolumne counties
**Includes Colusa, Yolo, Butte, Sutter, and Yuba counties
Note: Shaded rows indicate a statistically significant change

Communities of Interest

As noted earlier, the Sacramento Valley region is quite diverse and the data summarized in the previous section indicates reasons to be concerned about each of the seventeen counties in the Sacramento Valley Affiliate's service area.

Sacramento is an important county due to its large size, comprising 32 percent of the region's female population and a similar proportion of breast cancer cases and deaths in the service area. It is one of the three counties in the region with a higher than average percent of African American women.

San Joaquin and Stanislaus counties are the second and third most populous counties in the region. Both are agricultural counties with high rates of uninsured and larger Hispanic populations. Both counties have seen significant increases in the rate of late-stage cancer diagnoses. San Joaquin also has the third highest percentage of African American women in the region and the greatest disparity between breast cancer incidence of its African American and white women.

Solano County is distinctive for having the highest proportion of African American population in the region. It also has an increasing trend in those uninsured and one of the highest rates of late stage breast cancer diagnosis.

Placer and El Dorado Counties, east of Sacramento, both have above average incidence of breast cancer, above average rates of late stage breast cancer diagnosis, and significant increases in those who are uninsured.

The five western counties of Butte, Colusa, Sutter, Yolo, and Yuba are also of note. Combined, these counties comprise only 14 percent of the region population, but are of concern because all five counties show a significant increase in late stage breast cancer diagnosis. Butte and Yolo have higher age adjusted breast cancer incidence than the state average. Colusa and Yuba have high rates of uninsured. Colusa also has the highest percentage of Hispanic population in the region.

The six eastern counties of Amador, Nevada, Calaveras, Tuolumne, Plumas, and Sierra combined comprise only 6 percent of the region's population, but are also of concern. These counties are all very small, predominately rural and white. Four of these counties, Amador, Calaveras, Nevada, and Tuolumne, have the highest age-adjusted incidences of breast cancer in the region. Three of the counties, Nevada, Tuolumne, and Sierra, have among the highest mortality rates in the region.

Conclusions

The demographics and breast cancer findings indicate several areas of interest for additional investigation.

- The significant increases in those who are uninsured in the region are a primary concern. This is particularly problematic given that the Every Woman Counts safety net program was frozen in 2010, leaving many uninsured women without access to screening, diagnosis or treatment.

- The increasing trend in late-stage breast cancer diagnosis is also worrisome. This may be due to a variety of barriers, including lack of insurance, cultural barriers of the diverse population to accessing mainstream healthcare, reduced access to breast health services in rural communities, or simply lack of awareness of the importance of early detection and treatment.

- The diverse population of the region and multiple counties with large populations of African American, Hispanic and other ethnicities also presents a challenge. Many groups may have difficulty accessing information and continuity of care in culturally accessible ways.

- The large number of rural counties in the region have many people who may not have access to as many breast health services as those in the urban capital core areas of the region.

Overview of Continuum of Care

The diagram below outlines the breast health continuum of care. It begins with screening. Those with abnormal findings are then referred for diagnostic service to determine if it is breast cancer and needs treatment. Once diagnosed, breast cancer patients may undergo a variety of treatment options. Follow-up care is also important for both breast cancer survivors and those without a cancer diagnosis who need to be re-screened on an ongoing basis. Also important are navigation support and support services to facilitate progression through the steps.

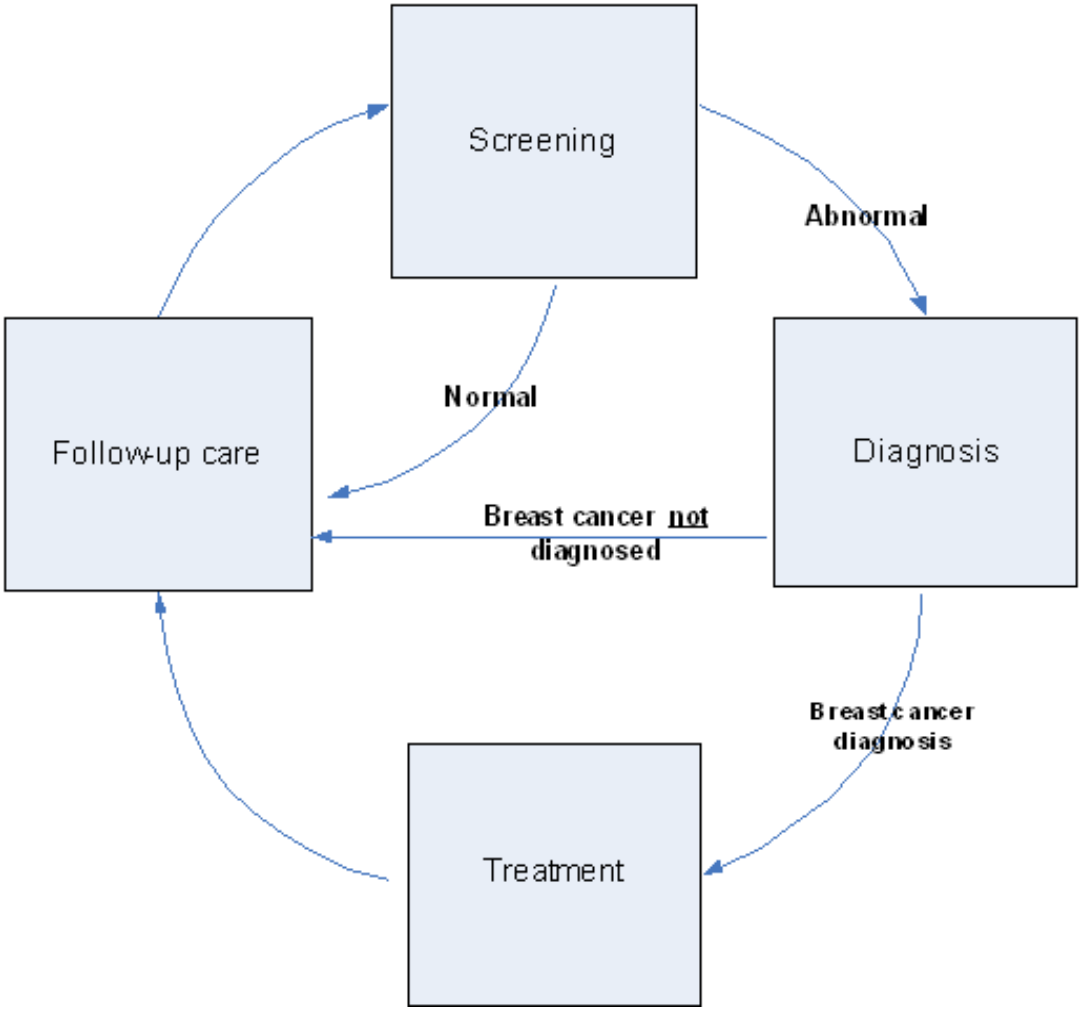

Figure 8: Continuum of care.

Methodology

This section describes the research steps taken to better understand the gaps, needs and barriers throughout the continuum of care for breast health in the Affiliate's 17-county region.

1. A key interest of the community profile team was to identify mammography screening facility availability throughout the 17-county service area. Data on licensed mammography screening facilities was obtained from the California Department of Health Services, Radiologic Health Branch.

2. To get a better picture of the region, the CP team engaged a volunteer familiar with GIS to map out the 17 counties with three key variables: age adjusted incidence of breast cancer, the proportion of country residents without health insurance, and the location of screening facilities.

3. On August 27, 2010, the Sacramento Valley Affiliate of Susan G Komen for the Cure hosted a Grant Writing Workshop for organizations in the community working on breast health. While the primary purpose of the meeting was to review grant guidelines and educate prospective grantees about grant writing, Komen also used the opportunity to gather input from these professionals on community needs for the Community Profile. Forty two people attended the workshop from 25 organizations, including both past and prospective grantees. Community Needs Assessment Surveys were passed out to all attendees; 37 attendees (88 percent) completed the anonymous survey. It should be noted that this feedback, while useful to gather qualitative input from the community about needs in the community, is not a statistically representative sample and was limited to past grantees and grantee prospects who attended the workshop.

4. An Online Discussion Board was conducted from July 15 to July 24, 2009. Over 60 professionals from all 17 counties were invited, and over one third of them participated. Participants included current and former grantees, program directors, patient navigators, support group facilitators, providers, breast cancer survivors, and other professionals informed about breast health.

5. Many of the participants in both the Online Discussion Board and Grant Workshop Survey indicated there is a need for a better list of resources in the community. In recognition of this need, the Sacramento Valley Affiliate is currently engaging an intern to spearhead the effort of collecting this information and creating a comprehensive database of breast health resources in the region that can ultimately be accessed and maintained online from the Affiliate website. This information will also be used to create additional asset maps to aid in the ongoing assessment of unmet needs in the service area.

Overview of Community Assets

Mammography Screening Facilities

As shown in Figures 11 and 12, mammography screening facilities are concentrated in the more populous counties of Sacramento, San Joaquin, Stanislaus, Solano and Placer. Several of the smaller counties do not have any screening facilities or have only one or two. Also notable is that more than half the machines in the service area are digital mammography machines (California Department of Health Services, Radiologic Branch, 2009).

Table 4
Licensed Mammography Screening Facilities & Machines by County, 2009

COUNTY	# of Screening Facilities	# of Digital Machines	# of Film Machines	Total # of Screening Machines	Female* Population
Sacramento	27	20	24	44	724,920
San Joaquin	12	14	2	16	346,200
Stanislaus	9	11	3	14	266,715
Solano	9	5	8	13	207,866
Placer	10	13	7	20	175,588
Butte	6	3	5	8	112,119
Yolo	5	4	2	6	102,384
El Dorado	3	3	0	3	90,452
Nevada	2	2	0	2	48,247
Sutter	3	2	2	4	47,294
Yuba	1	0	1	1	36,399
Tuolumne	3	1	3	4	27,634
Calaveras	2	0	2	2	23,898
Amador	0	0	0	0	18,171
Colusa	1	0	1	1	10,994
Plumas	3	0	3	3	10,466
Sierra	0	0	0	0	1,547
TOTAL	96	78	63	141	2,250,894

California Department of Health Services, Radiologic Branch, Sacramento, California, April 2009.

Many of the more rural counties also have either higher than average incidence of breast cancer, higher than average rates of uninsured, or both *(See Figure 9).*

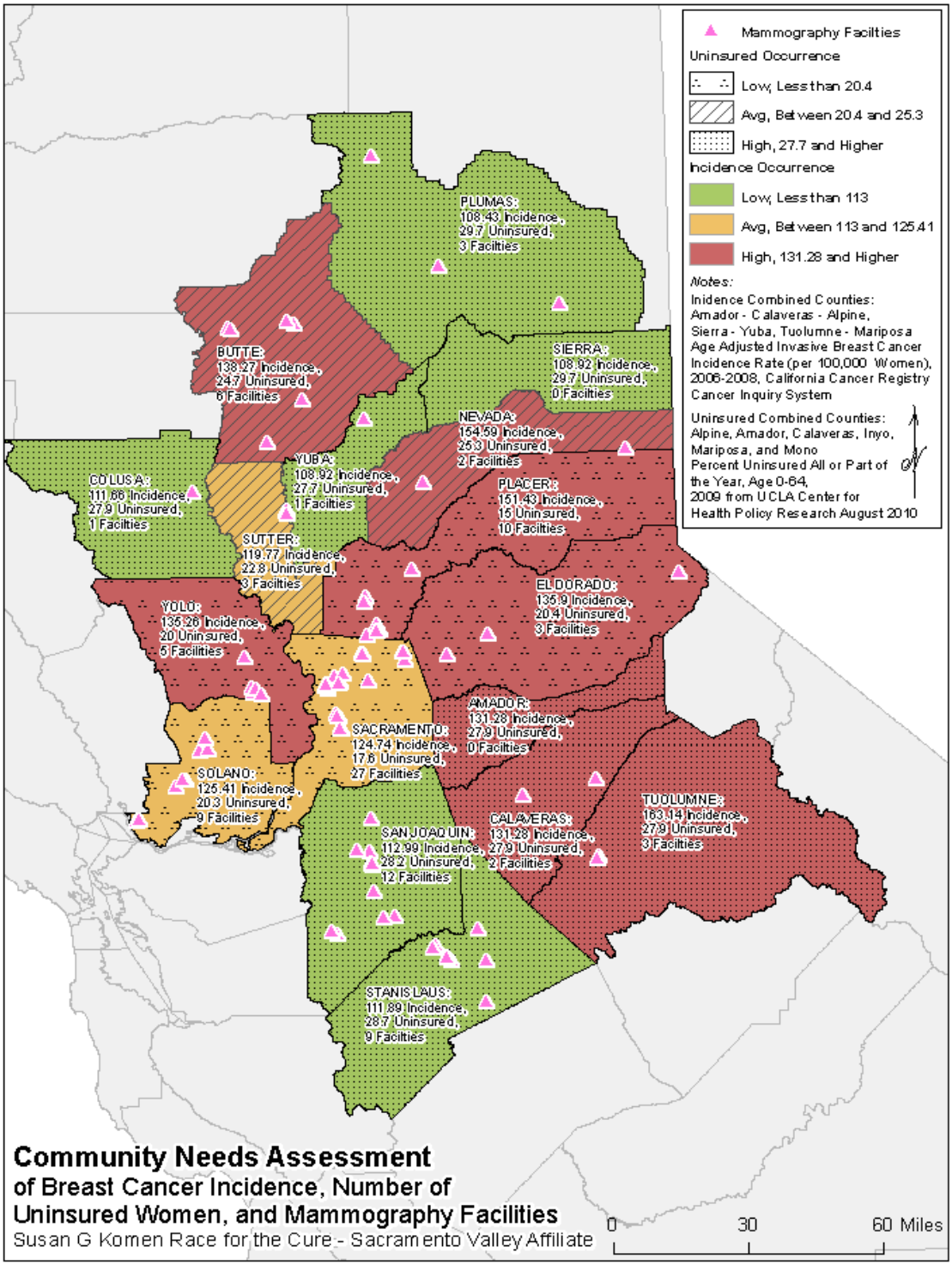

Figure 9. Breast cancer incidence, uninsured and mammography facilities.

Current Grantees and Future Partnerships

Granting efforts by the Affiliate have focused in the past on education and outreach in underserved communities due to ethnic or geographic barriers, promoting screening and early detection leading to early treatment and better outcomes, and navigation services to help ensure women access to services throughout the continuum of care and ensure they do not fall through the cracks. Current grantees skew towards education and outreach services and in the more populous counties, although some also provide services in rural areas. In 2010, the Sacramento Valley Affiliate was able to fund 17 grantee programs, which are listed on the Komen Web site at http://www.komensacramento.org/grants/current-grant-recipients/. The Affiliate continues to seek out potential grantees that provide services in any of the 17 counties to expand the Affiliate's impact throughout the service area.

The Breast and Cervical Cancer Early Detection Program

The National Breast and Cervical Cancer Early Detection Program is administered through the Centers for Disease Control. This program was developed as a result of the Breast and Cervical Cancer Mortality Prevention Act passed by Congress in 1990. One stated goal is to lower the mortality rate from breast and cervical cancer by providing access to early screening. The AB 478, Breast Cancer Act of 1993, authorized the State of California to participate in the NBCCEDP and established the Cancer Detection Program: Every Woman Counts (CDP: EWC). It provides free breast cancer screening (clinical breast exam and mammography) and diagnostics for women age 40 and over who are low-income (up to 200 percent of the federal poverty level) and uninsured or if a woman is unable to make her co-pay (underinsured).

The CDP: EWC Regional Contractors in the Sacramento Valley service area include four Cancer Partnerships operated through the California Health Collaborative. The California Health Collaborative is one of the Affiliate grantees.

The Affiliate's 2009 Community Profile noted that a primary barrier to care in the region was the increasing number of women without insurance to cover even basic screening services and the limitations of the CDP: EWC program in meeting all those needs. One problematic gap noted by many key informants was coverage for uninsured women under 40, particularly high risk or symptomatic women with nowhere to turn to pay for a mammogram and diagnosis. The Affiliate made addressing gaps in coverage one of its priorities in 2009. Many at that time expressed concerns about CDP: EWC's future viability, given the economic downturn.

In December, 2009, many of breast health advocates' worst fears were realized when, due to an unprecedented fiscal challenge resulting from an increased demand for breast cancer screening services and declining tobacco tax revenues, all new enrollment into

the CDP: CDP: EWC program was frozen as of Jan 1, 2010, and services for women 40-49 were shut off, increasing the number of women with nowhere to turn for help.

This became the most significant issue for the Sacramento Affiliate in 2010. The Affiliate took action in two ways to address the issue. First, the Affiliate revised the grant Requests for Application to include funds for screening and diagnosis for the uninsured. This presented a challenge for grantees that have focused on education and outreach in the past and now needed to seek out partners to deliver these services. Secondly, the Affiliate spearheaded an advocacy group to lobby for reinstatement of the CDP: EWC program, which was ultimately successful.

Legislative Issues

The Sacramento Affiliate was among the first seven Affiliates to participate in a Public Policy pilot project conducted by the National Komen organization. The leaders of the Affiliate realized that advocacy was a very important component to making a difference in the health and lives of people who are living with cancer and those who have not yet been diagnosed.

With this in mind, the Affiliate has taken a lead role in establishing a statewide collaborative of the seven Komen Affiliates in California. The Collaborative has been very active in working with legislators to keep the issue of breast cancer at the forefront and to offer our services as a resource.

In 2010 the Public Policy Committee of the California Collaborative (part of Susan G. Komen for the Cure Advocacy Alliance) played a vital role in organizing a lobbying campaign to reverse the state's December 2009 freeze on the vitally important Every Woman Counts Program. They organized a Capital Lobby Day in February 2010 and formally requested an Independent Audit of the program. They mobilized a grassroots effort, prepared statement papers and press releases, made social media posts on a regular basis and promoted a letter writing campaign. The Collaborative successfully sought out statewide coalition partners to bolster our efforts including: American Cancer Society, California Primary Care Association, American Congress of Obstetricians and Gynecologists, Community Health Councils and the California Radiological Society. The Sacramento Affiliate, on behalf of the Collaborative, planned a rally on February 8, 2010, on the Capitol steps. All seven Affiliates (San Francisco, Sacramento, Central Valley, Inland Empire, Los Angeles, Orange County and San Diego) had representatives meeting with their service area legislators to educate them about the crisis created by the CDP: EWC program changes.

These collaborative lobbying efforts were successful and on December 1, 2010, the California Department of Public Health (CDPH) breast cancer detection program announced it was reopening enrollment to women age 40 and older for breast cancer screening and diagnostic services to qualifying low-income women.

Key Informant Findings

While the demographic and statistical data reviewed in the first part of the Community Profile tell part of the breast cancer story, the professionals out in the field had much to add to fill in the human side of the region's breast health profile.

In both the 2009 Online Discussion Board and the 2010 Grant Workshop Survey, most breast health advocates agreed that the greatest unmet breast health need in the region continues to be the large and increasing number of uninsured women who are unable to get screened, diagnosed and treated in a timely fashion. Many women, and even providers, are unaware of services available and need guidance to access assistance programs. In addition to learning about the services available, many women need assistance enrolling in the program and navigating the health care system. Several informants suggested increased efforts to spread the word and provide more patient navigation support to link needy women to CDP: EWC.

"Regardless of all the other barriers, not having programs that will support with funds to cover the cost is one of the biggest barriers for most women. Women will find someone to translate for them or drive them to their appointment, but who are they going to find to pay for their exams?"

"Some women search for months to find a place to get mammograms or wait for October when more screening activities occur."

Key informants were asked to describe the impact of the 2010 CDP: EWC hold on services. They made the following observations:

- Huge gap in coverage, lack of funding for breast health services for uninsured
- Confusion about coverage at all levels: patients, clinics, providers
- Clinics and providers refusing services to CDP: EWC recipients
- Women getting billed for services CDP: EWC doesn't cover
- Increase in calls from women with nowhere to turn for help
- Women with lumps delaying diagnosis and treatment
- Cancellation of outreach events and mobile mammovan trips
- Decrease in screening activity with likely decrease in awareness, "out of sight, out of mind"
- Women diagnosed through the program that are under 50 left without follow-up care

Even reinstated, the CDP: EWC program has a number of limitations, including the following:

1) Those who do not qualify for CDP: EWC
    a. Women under age 40.
    b. Women age 40 or older under or uninsured who have a gross income of greater than 200 percent Federal Poverty Level (covered on a case by case basis only).

c. Men are not covered by CDP: EWC

2) Women who were provided breast cancer screening and diagnostic services they could not afford and it was found out after the fact that she qualified for CDP: EWC (lack of reliable retroactivity for CDP: EWC)
3) Women erroneously enrolled into CDP: EWC by providers (most often due to age) whose claims are denied by CDP: EWC and have, therefore, incurred bills for services they thought were free.
4) CDP: EWC does not cover men
5) Lack of evidence based, targeted education and outreach regarding the program (a very small percentage - 20 percent - of women in California who are eligible for the program actually access the program)
6) Lack of 'inreach' (encouraging of individualized routine breast cancer screening and pointing out programs for which a woman may qualify to cover the cost if they are not eligible for Medicare, MediCal, CMSP, etc.) by clinicians/staff who work in the clinical setting with large numbers of women eligible for FamilyPACT (Planning, Access, Care and Treatment) and CDP: EWC.

Other concerns raised by key informants are the wide range of ethnic groups in the region with multiple cultural barriers to accessing healthcare services and women in rural counties with additional difficulties accessing care.

When asked about groups of women who are most underserved, key informants indicated the following groups as being underserved:

Uninsured.

- Uninsured, under-insured
- Unemployed, newly unemployed
- Particularly high-risk/symptomatic/women with an abnormal screening/women diagnosed with breast cancer
- Symptomatic women under 40 not covered by CDP: EWC
- Low income minorities
- Homeless women

Cultural/ethnic groups.

- African American
- Asian American (including Cambodian, Chinese, Hmong, Indo-Fijian, Khmu, Laotian, Mien, Sri Lankan, Vietnamese)
- Filipino American
- Latina
- Migrant farm workers, non-citizens fearful of being reported
- Native American
- Russian
- Women with barriers involving language, modesty, myths, fears

"In general, low income, uninsured, underserved women have trouble finding transportation, child care, and clinics that are open after work hours. Certain

counties within the Gold Country region are very ethnically diverse, and language has also been a barrier for many women in these communities. Also, there needs to be more culturally competent programs that will assist the women in receiving breast health services. Many new immigrant women may not understand western medicine and rely more on Eastern medicine or holistic methods. They may not know or understand that routine screening is a primary form of prevention for many diseases."

Women in rural counties.

- Fewer facilities, resources more scattered; not concentrated in one center
- More isolation, less assistance
- Longer distances

"My hotline callers from these areas report difficulties in travelling to more populated locations where the screening technology is more readily available. When involved in treatment, this becomes less of a logistics problem, however. It seems as though it's the unavailability which leads to the reluctance of women to seek screening, especially if it's for a baseline mammogram."

In the 2010 Grant Workshop Survey, key informants were asked what services have the greatest need in the community. Given limited resources, the top priorities suggested included:

- Services for the uninsured
- Advocacy for public funding of services for the uninsured
- Rural outreach/mobile mammography
- Navigation services
- Early screening promotion
- Cultural outreach

Below are some quotes from the Grant Workshop survey that capture the reasoning behind these suggested priorities.

"I chose Advocacy because until there is true health care reform or until health insurance reforms are fully rolled out in 2014, public funding is crucial in addressing the financial disparities for low income and medically underserved individuals."

"At this time education about breast health and screening is important. However, the lack of funds to do the screening makes the education less meaningful, and women get frustrated that they know the importance of screening but cannot access it. Because of this, due to the hold on CDP, any efforts at raising funds to actually cover screening as well as diagnostics is of extreme importance."

"I consider high-risk uninsured women to be highest priority because they are very susceptible to breast cancer due to not being able to get treated. Advocacy

for public funding is important to get funding for the uninsured. Outreach of mobile mammography is third priority because it provides people in rural areas or who don't have transportation with a means of cancer screening."

"Rural communities have higher incidence and mortality rates due to lack of access to screening and education. Mobile mammography and outreach in these areas is a must. Advocacy and public policy are the ways to ensure access to services for those who are most vulnerable. A breast cancer diagnosis can be quite confusing with so many options for treatment - a navigator is key for mental and emotional support. "

Additional Rural Counties - Glenn and Tehama Counties

The Sacramento Valley Affiliate has a proposal pending approval to expand its 17-county service area to add two new rural counties to the service area; Glenn and Tehama. Several providers have contacted Komen to make it aware that this area is severely underserved with breast health services and education. These two counties closely border the town of Chico and although Chico itself falls within Butte County, most of the people living in Tehama and Glenn go to Chico for medical attention. Over the years, a current grantee in Chico, the California Health Collaborative, has received several requests from women living in these two underserved counties for additional breast health education and services. Both of these counties also house a large population of immigrant and low-income families, making breast health services even less accessible. Expanding the service area to include these two counties is one of the objectives in the Action Plan at the end of this report.

Conclusions

The barriers to breast health in the community and key issues raised in the key informant research exploration can be summarized in the following key problem areas:

1. Lack of insurance and inability to pay. Concern for continuity of CDP: EWC funding and gaps in coverage.

2. Fears, lack of knowledge about the importance of early detection and treatment, and confusion over conflicting reports about screening recommendations.

3. Lack of awareness of services and resources and challenges in navigating the system. Confusion about coverage among patients, clinics, and providers is not uncommon.

4. Cultural/language barriers to obtaining breast health care.

5. Remote areas with fewer services and transportation challenges.

Breast Cancer Perspectives in the Target Communities

Methodology

To gain a better understanding of the breast health needs and experiences of women in the service area, the team conducted focus groups in three counties: Butte, Colusa, and San Joaquin. Telephone interviews were conducted with several women in more rural areas of Butte and Plumas counties who lived too far to attend the focus groups.

In San Joaquin County, a breast cancer support group for primarily African American women associated with the St. Joseph's medical center allowed us to conduct a focus group as part of their regular support group meeting. This group included both survivors and supporters without a breast cancer diagnosis.

In the three northern counties of the service area, the California Health Collaborative recruited women to participate from their database of screening event attendees and those who had been provided ancillary or navigation breast health services. Focus groups participants were provided lunch and a $25 cash incentive to participate.

A total of 39 women were included in the qualitative research: 16 from Butte County, 14 from San Joaquin County, six from Colusa County, and three from Plumas County. They included both survivors (14) and those without a cancer diagnosis (25). The San Joaquin support group had 11 African American, two Latina, and one white woman. The northern county groups and interviews included 6 Spanish–speaking Latina women and 19 English-speaking white women.

The Community Profile team acknowledges that the research undertaken was limited and views it as a first step in an ongoing research effort. Additional qualitative research is strongly encouraged, both to include women who are not served by current grantees and those who represent other counties served by the Affiliate. Survey research should also be considered to quantify findings, although it is difficult to justify investing research dollars to measure unmet needs when resources are needed for service delivery.

While limited in scope, the findings from the research were consistent with the issues raised by key informants. The women interviewed gave voice to many concerns and unmet needs related to breast health in the community and helped improve our understanding of the toll the economy and lack of consistent information has had on the breast health needs of our community.

Review of Qualitative Findings

The stories heard from women in this qualitative research effort can be summarized in four broad themes relating to the major obstacles to obtaining early breast cancer screening and treatment:

- Inability to pay
- Uncertainty about need for mammograms
- Feeling lost
- Less access in rural areas

Inability to Pay

Nearly all the women interviewed talked about the inability to pay being the primary barrier to breast health care. In each group a chart of the primary barriers to regular screening was created based on women's comments and some variation of "no money" or "no insurance" was at the top of the list in each group. Many women described examples of the poor economy including slowed construction, mill layoffs, bank layoffs, small businesses shutting down, failed stores, and "more and more people without health insurance."

We heard multiple stories of women who did not get mammograms due to lack of insurance or inability to pay. We also heard from women who had abnormal findings from a mammogram but could not afford diagnostic services and did not know about or did not qualify for aid programs.

"I never did mammograms. I had no insurance and couldn't afford them. My doctor found my lump when I was in to get a pap smear."

"I had a questionable mammogram and they recommended an ultrasound, but I had no insurance so I didn't get it."

"I used to go get a mammogram every year, but then I lost my insurance and quit going."

"I know it's important, but I'm not going to get a mammogram because I don't have the money."

Some described that when times are hard you focus on feeding your family and paying bills first and there is no time or money for screening. Women tend to wait for major problems rather than be proactive about screening and preventive health care, unknowingly putting themselves at greater risk for later stage diagnoses and less favorable outcomes.

Uncertainty about Need for Mammograms

Some women are confused about whether mammograms are necessary and if so, how often and at what age. Some have vague recollections about reading in the media or hearing about changes in recommendations and are uncertain whether mammograms are still necessary. Many women said their doctors are not actively recommending mammograms. One woman said she had to advocate with her doctor to give her a referral for a mammogram.

"You hear conflicting things about whether it's important. I didn't go because I never felt a lump and my doctor said his wife doesn't even get them."

"You hear so many different things and you wonder, 'Is it or isn't it important?'"

There are multiple practical barriers to obtaining screening mammograms: cost, inconvenience, discomfort, time, transportation, and childcare challenges. There are also emotional barriers such as embarrassment and fear. Given all these barriers, if women are uncertain that mammograms are an effective and important early screening procedure, they are less likely to overcome the other obstacles and make the effort to get screened in a timely manner on an ongoing basis.

When asked how breast health could be improved in their communities, many women said that there needs to be more wide-spread education about the importance of early screening, detection and treatment. They suggested more outreach to women and also to doctors to encourage them to recommend mammograms to their female patients.

"Doctors should be more encouraging. My doctor was lackadaisical about them."

A few of the Latina women in the Colusa group also suggested that education classes targeted to Latina families would be useful because some of their husbands are uncomfortable permitting their wives to bare their breasts in front of others without being educated about the need for early screening and detection.

Women in the support group identified additional cultural barriers in the African American community, noting that there is sometimes a general lack of trust of medical providers, and some indicated that they believe only white women can survive breast cancer because they never see any other ethnicities in advertisements about breast health. These additional cultural barriers indicate the need for culturally appropriate education and outreach in this community. A few women in the group suggested mobile mammography vans coming to places they trust such as local churches.

Feeling Lost

Many of the women in this research effort who had experienced symptoms or a breast cancer diagnosis described feeling lost and confused about how to make decisions and access services needed for the next step in their continuum of care.

"Not easy to find out about services, didn't know where to go, where to find doctors, how to get payment, fill out forms. I was in shock and not able to think."

This was especially true for women without financial means. Several women told stories about delaying care because they did not have the means to pay and no one told them about the availability of support programs. They were frustrated that even professionals in medical and public assistance positions were unfamiliar with any programs to help them. Some were disappointed to learn they didn't qualify for a particular program because they didn't meet the age criteria, they'd had a hysterectomy, or that their husband was employed even though there was no insurance or enough money to pay for services.

The patchwork of programs with different names, acronyms, and requirements is confusing to many people. Even women who had received aid were uncertain which program it was that helped them. Many need assistance in completing the enrollment process. One woman said she had found something about Every Woman Counts online and called a 1-800 number for an information packet but was so overwhelmed by the complexity of the packet she was sent that she didn't even attempt to pursue it. The fact that enrollment was closed for most of last year and the age limit changed has added to the general confusion. Even among women who speak English, a "translator" is often needed to help them navigate the process of enrolling and accessing the program.

Women interviewed who did find their way to assistance and had benefited from navigation services or financial assistance were extremely grateful and wished that support was more widely available and that programs like Every Woman Counts and others were more well-known.

"There needs to be more navigation assistance to help you find your way. So many are lost and need education about what to do and where to go."

When asked how to get the word out about breast health services for the uninsured, they suggested a range of locations, starting with education of people in medical offices where women are first seen.

"Need to educate doctors and nurses and people in medical offices about programs; they should know about services available to help those without insurance."

They also suggested making posters and pamphlets available with very simple messaging in government offices where women go for assistance and in the places they frequent in the community. Below is a list of suggestions made in the focus groups for locations for education outreach:

Medical

- Clinics
- Doctor offices
- Imaging centers
- Hospitals
- Health Fairs
- Mental health facilities

Government

- Social services departments, social workers
- Welfare departments
- Medi-Cal departments
- Public county health departments
- County Medically Indigent Services Program (CMISP)

Community

- Post office (all the Spanish-speaking women in Colusa focus group go to the post office every day)
- Grocery store
- Laundromat
- Workplace bulletin boards
- Schools, colleges
- Farmer's Markets
- Low income housing
- Beauty salons, gyms
- Libraries
- Churches (African American group)

Advertising

- TV, Radio, Newspaper
- Social Media

Less Access in Rural Areas

Women in the more rural areas described numerous instances of less access to care. Some people live several hours from services and depend on family or friends for transportation. One woman explained that the "machine in town broke down so I put off mammograms for 3 years rather than drive to Chico." One uninsured woman said the mammogram she got in her area was not adequate and had to drive over an hour away to get a second mammogram that she also paid cash for without being counseled about available assistance. Another described how the distance to a support group is too far for her to go in the winter due to weather and darkness.

"If I was in Chico there's all kind of support, but not out here in Plumas."

Conclusions

Input from key informants and women in this qualitative research were consistent in identifying the following four key areas of need in the Sacramento Valley Affiliate Service Area:

- Priority Need #1: Lack of insurance and inability to pay continues to be the greatest unmet need in the service area
- Priority Need #2: Lack of education about the importance of early detection
- Priority Need #3: Lack of awareness about screening, treatment, and support options, including availability of financial support programs for the uninsured
- Priority Need #4: Less access to services in rural areas

Conclusions: What We Learned, What We Will Do

Conclusions

The Community Profile team reviewed the statistics and qualitative research and identified the following overall goals and top four priority needs.

Overall Goals:

- Increase early stage diagnosis and treatment in order to reduce mortality rates through education, screening, and support services.
- Target areas of highest need and women who are most underserved.

The Affiliate feels it can have the greatest positive impact on mortality in the service area by focusing on ensuring that all women have information and access to early screening and diagnosis thereby facilitating early treatment and reducing mortality.

Priority Need #1: Lack of insurance and inability to pay continues to be the greatest unmet need in the service area.

The current economic situation has exacerbated the already significant problem of uninsured families in the state, and many key informants feel that finding ways to help those who are uninsured or underinsured obtain access to screening and early diagnosis and treatment is the most urgent need in the service area.

California's experience with losing the CDP: EWC program for a year dramatized the need for this support program for the uninsured. It highlighted the importance of Komen's advocacy role at the policy level to make sure that support for these services is sustained on an ongoing basis. While the Affiliate attempted to fund grants to fill in gaps in 2010, it is not feasible for a local Affiliate to raise the funds necessary to meet the needs of the uninsured on its own. With the state capital in its service area it is especially vital for the Affiliate to make public policy advocacy a priority.

Even when funded, there are limitations and gaps in the CDP: EWC program. Many key informants expressed concern for uninsured women under the age of 40 who have symptoms, but do not qualify for coverage. These women are at greater risk for delaying diagnosis and life-saving treatment.

Priority Need #2: Lack of education about the importance of early detection.

Many key informants expressed surprise that women continue to be uninformed about the importance of early detection. Many feel that this need for education crosses all demographics and must continue to be an ongoing priority for Komen. All women deserve to know about the importance of early detection and treatment to achieve better health outcomes.

The reports in the media about the changes in screening recommendations have created confusion. Some women are less certain that mammograms are important. Some informants say that doctors are not referring women for routine screening and don't actively encourage women to seek mammograms. As a well-known and reputable non-profit, Komen must continue providing education about the latest developments in breast health guidelines and help women make sense of them.

For some women, there are additional cultural barriers to obtaining screening and treatment. Some of the barriers (in addition to inability to pay) raised by key informants include language barriers, lack of cultural competency of providers, mistrust of the medical community, and new immigrants who may rely more on Eastern medicine and holistic health practices and don't understand the role of routine screening as a preventive tool. Many past and current grantees have developed community outreach programs targeted to specific ethnic groups to help overcome these barriers and facilitate education and access to breast health care.

Priority Need #3: Lack of awareness about screening, treatment, and support options, including availability of financial support programs for the uninsured.

Many key informants also claim that often women are not aware of the programs and services that are available to them. There is a continual need for community outreach and education to make sure that women are informed about the options available to them to increase access to care.

Also important is that not all providers are familiar with assistance programs and the details about how to access them. More education and outreach with providers is needed to increase awareness, access, and use of the programs.

Priority Need #4: Less access to services in rural areas.

Many parts of the Affiliate service area are rural, with less convenient access to screening facilities and other sources of health care information, services, and support. Some areas would benefit from periodic visits from a mobile mammography unit combined with community outreach that educates women about the importance of screening and spreads the word about service options.

Action Plan

After reviewing the statistics and research, identifying priority areas of need, and brainstorming action plan options, the Community Profile team agreed upon the following Affiliate Action Plan.

Overall Goals:

- Increase early stage breast cancer diagnosis and treatment in order to reduce mortality rates through education, screening, and support services.
- Target areas of highest need and women who are most underserved.

PRIORITY 1: Expand support for programs that provide breast cancer screening and diagnostic services for the uninsured.

Objective 1: Continue public policy advocacy efforts by working with a coalition of stakeholders and legislators to ensure the continued funding of the Every Woman Counts: Cancer Detection Program beyond the current 2011 budget.

- By November 2011, through the Public Policy Committee, hold a Lobby Day to keep funding for breast cancer screening in the news and encourage support.

Objective 2: By March 2012, fund grantee(s) that otherwise would not be able to provide screening and diagnostic services to fill in gaps for the uninsured who need breast health services and are not covered by any government programs (i.e. *CDP: EWC, Family Pact, MediCal, etc.)*.

- Currently known coverage gaps include
    - Uninsured women, under 40 who are at high risk for breast cancer or have symptoms.
    - Age 40 or older, underinsured or uninsured who have a gross income of greater than 200 percent Federal Poverty Level.
    - Women erroneously enrolled into CDP: EWC by providers (most often due to age) whose claims are denied by CDP: EWC and have, therefore, incurred bills for services they thought were free.
    - Women who were provided breast cancer screening and diagnostic services they could not afford and it was found out after the fact that they qualified for CDP: EWC.
    - Men with breast cancer symptoms.
- Grantees that provide access to these gap services are encouraged to reach out to local medical providers to make sure they are aware of available resources and can refer women appropriately and avoid women falling between the cracks.

PRIORITY 2: Support education and outreach efforts to increase awareness of the importance of early breast cancer detection and treatment.

Objective 1: By March 2012, fund grantee(s) that support community outreach efforts that spread the word about the importance of early screening and detection.

- Grantees are encouraged to customize outreach efforts to the demographics of their communities, including provision of culturally appropriate translated materials for ethnic/cultural groups where needed.
- Grantees are encouraged to help educate health care providers in their communities about the need for early breast cancer detection and promote referrals for mammogram screening.
- Outreach efforts may include participation in health fairs, community events, high school and college programs, and distribution of education materials in community locations that women frequent, such as clinics, doctors offices, churches, laundromats, post offices, and social service offices.

Objective 2: By December 2011, update the Online Resource Guide on the Affiliate website to include links to breast cancer education materials in multiple-languages.

Objective 3: By June 2012, recruit an advertising agency partner and invest $100,000 of the general education budget to develop public service announcements to be run four times a year to remind women of the importance of early detection.

Objective 4: By June 2012, host a second Circle of Promise Ambassador training to educate the African American community about the goals and promise of the program. Continue to educate and inform the African American community about the importance of early detection through the Circle of Promise by hosting a variety of events and partnering with local churches.

PRIORITY 3: Increase awareness of breast cancer programs and services available in the Affiliate service area, including the availability of *CDP: EWC* programs.

Objective 1: By March 2012, fund grantee(s) that provide education and navigation services to help guide women to available support services throughout the continuum of care. This may include educating key point people in clinics and medical offices where women are notified of breast health services they need but may not be able to afford.

Objective 2: By June 2012, schedule two collaborative meetings hosted by the Affiliate to support networking and collaboration among grantees, providers, and other breast health organizations in the 17-county service area to encourage leveraging of resources, the development of new partnerships, and sharing of best practices.

Objective 3: By December 2011, develop a comprehensive Online Resource Guide with information and links to breast cancer and breast health resources available in the 17-county service area. This resource will be accessible to all grantees, providers, and patients throughout the service area to increase access to care. It will also facilitate additional health system analysis to inform the community needs assessment process.

PRIORITY 4: Increase access to breast health education, screening and treatment in rural areas.

Objective 1: By March 2012, fund grantee(s) that are able to integrate community outreach, awareness, education, and navigation efforts with access to breast cancer screening, diagnosis and treatment in rural areas. This can be accomplished through mobile mammography, volunteers providing transportation, transportation vouchers, and navigation support services.

Objective 2: By June 2011, complete the application to add Glenn and Tehama counties to Komen's service area.

Objective 3: By October 2011, invite a board member from one of the rural counties in the service area to ensure that the needs of the many rural communities in the service area are represented on the Board.

Objective 4: By June 2012, expand the WeCare Peer Navigation program in four rural counties to recruit and train breast cancer survivors to act as peer support for women newly diagnosed with breast cancer.

Objective 5: By June 2012, establish a pilot Volunteer Train-the-Trainer Program in Stockton to train and educate key volunteers to conduct volunteer trainings in their county. If successful, expand to other parts of the service area.

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