



COMMUNITY PROFILE REPORT

Susan G. Komen for the Cure®
Southern Arizona



2009

Acknowledgements

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Well Woman HealthCheck Program -Graham
Well Woman HealthCheck Program -Pima

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Report Detail

Introduction

Affiliate History

A promise made by one is now a promise shared by millions. Our promise-turned-mission, to save lives and end breast cancer forever, is the driving passion of Susan G. Komen for the Cure. The impact of our work has led to nearly every major advancement in breast cancer research, initiated public policies that have broken down barriers and closed gaps for those needing services, provided quality care through our community outreach programs, and empowered individuals to be self advocates through grassroots education efforts.

Since our establishment in 1999, the Southern Arizona Affiliate has remained steadfast in our commitment to our service area, which includes the southern six counties stretching from Greenlee on the east to Yuma on the west. By funding international research and local programs that provide vital education, screening, and treatment to underserved women, and by igniting activism and empowerment through public policy and education initiatives, the affiliate acts with purpose and conviction driven by our commitment to save lives and end breast cancer forever. The local office serves as a community contact for all breast health needs and houses a resource library with education and support materials for survivors, co-survivors, and those seeking information on breast health.

Organizational Structure

We are fortunate to have an efficient, talented staff and a large, dedicated cadre of volunteers who help us deliver on the Komen Promise. Figure 1 illustrates the organizational structure for the Board of Directors, which is expressly designed to provide sound governance in all areas of operations. Through a rigorous strategic-planning process, the Board continually assesses how to best meet the most pressing needs identified by the CPR and fine-tunes staff and volunteer structures to ensure that we have the human talent capacity to do so. As a result, we have a dynamic, agile organization poised to respond to an ever-changing environment.

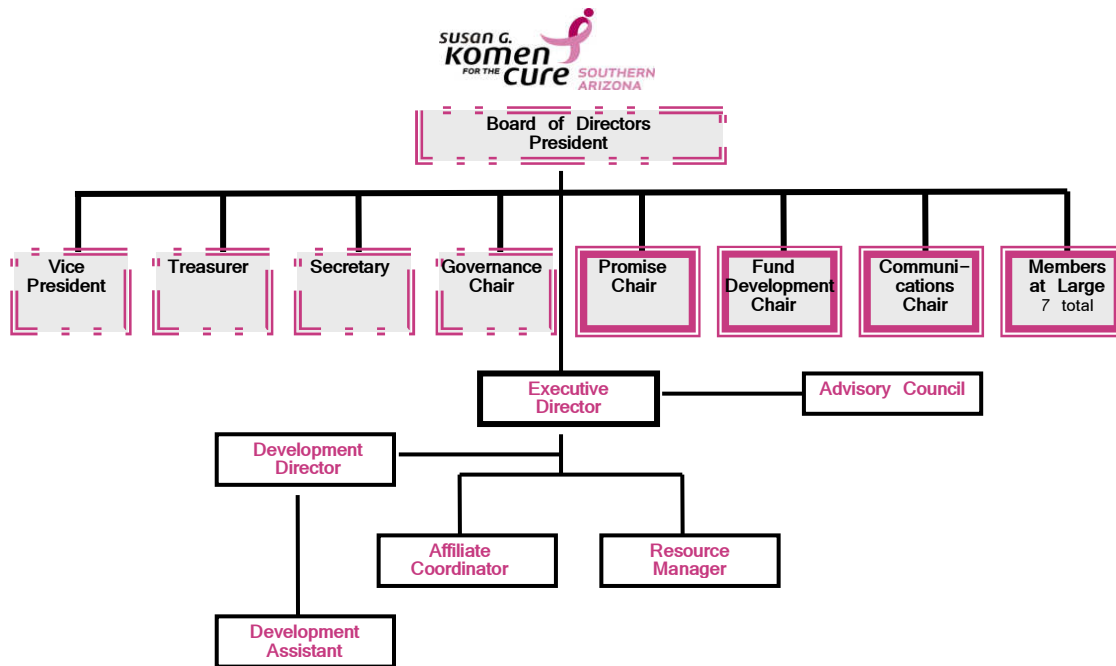


Figure 1. Organizational Chart for Southern Arizona Affiliate of Susan G. Komen for the Cure

Description of Service Area

The Southern Arizona service area consists of six counties: Cochise, Graham, Greenlee, Pima, Santa Cruz, and Yuma (Figure 2). Pima County leads in population size with approximately 930,000 people, followed by Yuma, Cochise, Santa Cruz, Graham, and Greenlee County, which has the lowest population (7,754). With the vast majority of mammography, treatment, and support services, Pima County acts as a hub for comprehensive breast health care within the service area. In comparison to other Arizona regions and the United States, Southern Arizona has a higher percent of women, Hispanics or Latinos, and people age 65 or older.

From its rugged canyons to deserts, from suburban areas to rural areas, Southern Arizona overflows with diversity and is a classic representation of Southwestern culture. With close proximity to the international Mexican border and reservation lands, Southern Arizona is home to indigenous peoples, refugees, and immigrants. Industrially, the region thrives on recreation and tourism, mining, agriculture, small businesses, nonprofit organizations, and university revenue.

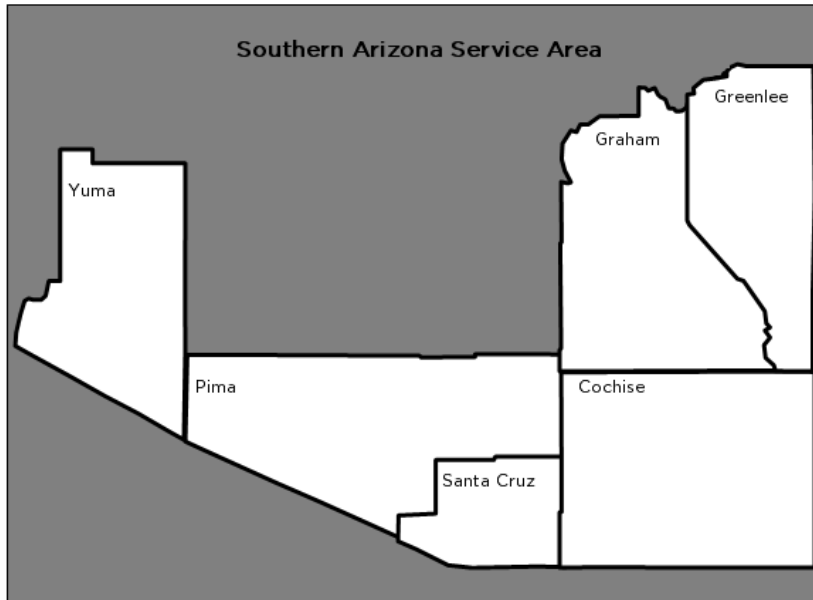


Figure 2. Southern Arizona Service Area

In addition, there are three large Native American Reservations within Southern Arizona. Two small tribes are located near Yuma. Table 1 describes the names, location, and size of each.

Table 1
Native American Reservations in Southern Arizona
(N = 5)

Name	Location	Area in Square Miles	2000 Population
Cocopah	Yuma	9.4	1,025
Pascua Yaqui	Tucson	1.4 in Tucson 1,152 Trust lands	3,315
San Carlos Apache	San Carlos	2,853.1	9,385
Tohono O'odham	West of Tucson	4,446.3	10,787
Ft. Yuma Quechan	Yuma	68.1	36

Source: Inter Tribal Council of Arizona, Inc., 2009

Purpose of Report

The Southern Arizona Affiliate's Community Profile Report becomes the driving force behind our activities, funded programs, outreach initiatives, and public policy efforts. Input from local breast health providers, community agencies, survivors, and breast health advocates within each county allowed us to reach the core of the community and conduct a comprehensive community needs assessment. This report attempts to identify existent breast

health and breast cancer services within the communities, as well as gaps in services within those same communities.

The CPR is an indispensable tool that allows the organization to:

- Affect change and positively impact breast health and breast cancer needs
- Drive the organization's mission elements of the strategic plan developed by the Board of Directors
- Provide operational focus, consistent with our promise/mission
- Establish local grant application and review processes
- Determine educational and outreach priorities
- Set priorities for public policy initiatives
- Identify and establish opportunities for partnerships with all types of community groups and agencies.

Demographic and Breast Cancer Statistics

Data Source and Methodology Overview

Arizona state and county demographic estimates were obtained from Thomson Reuters © 2007. In order to better understand the six counties of the Southern Arizona service area, it was necessary to obtain additional data from the Arizona Cancer Registry (2005), and Arizona Department of Health Services Vital Statistics (2007). The Community Health Status Indicators (2008) developed by the US Department of Health and Human Services and profiles produced by the Arizona Department of Commerce (2007) provided additional information on the health and economic status of each county. Information on the Native American tribes and reservations within the service area was obtained from the Inter Tribal Council of Arizona, Inc. website.

Overview of Key Demographic and Breast Cancer Statistics at State and County Level

The number of individuals 65 years of age and older, a higher percentage of women, and a large Hispanic group in comparison to the rest of Arizona and the U.S. population, characterize the population in Southern Arizona, as determined by estimates from Thomson Reuters © 2007. Southern Arizona has a higher prevalence and incidence rate of breast cancer (128.6 per 100,000), compared to Arizona (102.9 per 100,000) and the United States (117.6 per 100,000). Older age is unlikely the major contributing factor to these high breast cancer rates. Based on 2005 data from the Arizona Cancer Registry the higher rates are observable in some minorities, such as Hispanic. Stage I breast cancer is more common in Southern Arizona than the average of the whole state and the U.S., but there are not many differences in stages III and IV breast cancer incidence rates between Southern Arizona and the average of Arizona. For example, Pima has the highest breast cancer incidence rate but also highest percent of women who have had mammograms in our service area (Thomson Reuters © 2007; Arizona Department of Health Services Vital Statistics, 2007). Use of mammography seems lowest in Graham, followed by Santa Cruz, Greenlee, and Yuma, based on actual data from Arizona Department of Health Services Vital Statistics (2007). Actual data from Arizona Cancer Registry (2005) indicate that higher stages of breast cancer at diagnosis are common in blacks, which is similar to the state and national profile. Due to the large population size, Pima has the majority of the estimated prevalence and incidence breast cancer cases (Thomson Reuters © 2007). Similarly, the number of deaths from breast cancer is also the highest in Pima. Importantly, there are an observed higher

number of breast cancer deaths in young Hispanic women, based on the actual 2007 mortality data (Arizona Cancer Registry 2005).

In Southern Arizona, the percent of females is slightly higher (50.8%) than males, especially in Pima (51.1%) and Santa Cruz (52.5%). This is consistent with the pattern of Arizona females (50.1%) and the whole U.S. female population (50.7%). The Southern Arizona population contains a higher percentage of people 65 or older (15.1%), in comparison to 12.9 percent in Arizona, and 12.6 percent in the U.S. Yuma (17.4%) and Cochise (16.3%) have the largest percentages of people 65 or older. Southern Arizona is serving a large Hispanic population (37%) vs. Arizona (29.6%) and the U.S. (15.1%). The females in minorities are younger than females in the non-Hispanic white population. For example, the percentage of females over 65 is 23.4 percent for non-Hispanic whites, but only 7.8 percent for Hispanics. On the other end of the age spectrum, 19.4 percent of non-Hispanic white females are younger than 20 years, whereas the percentage for the same age group of Hispanics is 38.1 percent. These population statistics are estimates from Thomson Reuters © 2007 data.

In Southern Arizona, data published by the Arizona Department of Commerce (2007) indicate Santa Cruz (20.1%) has the highest percentage of families below the poverty level, Graham (18.6%) the second highest, and Yuma (15.7%) the third highest.

In women aged 18-64 in Southern Arizona, Santa Cruz (42.6%) has the highest percentage of uninsured, Graham (37.5%) the second highest, and Cochise (31.3%) the third highest, as described in data from the Arizona Department of Health Services Vital Statistics (2007).

The breast cancer prevalence rate based on estimates of Thomson Reuters © 2007 data is higher in Southern Arizona (518.2 per 100,000) vs. Arizona (385.6) and U.S. (440.7). Pima County had the highest prevalence rate (518.2) among all counties in Southern Arizona. The average age at diagnosis is 60 for Southern Arizona, which is older than the Arizona average of 59.4 years and the national average of 59.0 years. However, the average age of those living with breast cancer is younger in Santa Cruz (58.5) and Greenlee (58.6) than other counties, partially due to the low percentage of older people in these two counties. These prevalence and incidence rates are based upon estimates from Thomson Reuters © 2007 data.

The estimated incidence rate is higher in Southern Arizona for both women (128.6 per 100,000) and men (0.99 per 100,000), in comparison to Arizona (102.9 Female, 0.76 Male) and the U.S. (117.6 Female, 0.88 Male). This is mainly driven by the higher incidence rate in Pima (138.06 Female, 1.05 Male) and

Cochise (125.02 Female, 1.01 Male) with the large population sizes in Pima and Cochise (Thomson Reuters © 2007).

Based on 2005 data from Arizona Cancer Registry, the age-adjusted incidence rate in Arizona females was 99.7 per 100,000, whereas it was 106.2 for Pima and Graham 106.0, suggesting that older age could not completely explain the higher incidence rate in Pima, since these counties do not have a high percentage of people age 65 and older, as estimated in the Thomson Reuters © 2007 data.

Based on 2005 data from Arizona Cancer Registry, age-adjusted incidence rates for female breast cancers were usually higher for minorities, but not for non-Hispanic whites. However, these results should be interpreted with caution because of the small number of incidence cases in some minority groups.

Arizona Cancer Registry (2005) data indicate Southern Arizona has a slightly higher percent of stage I breast cancer (65.5%) than Arizona (65.1%) and the whole U.S. (64.3%). Yuma has the highest percentage breast cancer incident cases at stage I (66.1%). Similar to the pattern for U.S. and Arizona, blacks are more likely to present with later stages of breast cancer and have a higher percent diagnosed at stage IV.

Pima has the highest percentage of women age 40 or older who had mammograms in the past 12 months (60.6%), whereas Graham has the lowest rate (56.8%), as described in data from Arizona Cancer Registry (2005).

Data from the Arizona Cancer Registry indicate the number of deaths from breast cancer is highest in Pima County. Arizona has had relatively lower breast cancer mortality rates for both men and women, whereas Southern Arizona has a slightly higher rate than Arizona, but is still lower than the national average for women, but higher for men. There are a higher number of deaths in the young Hispanic population.

Trends:

The percentage of insured increased from 2005 to 2007, but is still below the average from 5 and 10 years ago. Since 1999, there have been some decreases in the percentage of women age 50 or above who have had mammograms; similar, but less linear, decreases in using mammograms also were observed in women age 40 and above, according to data from Arizona Department of Health Services Vital Statistics (2007). In Arizona, data from the Arizona Cancer Registry (2005) indicate a trend of decreasing breast cancer incidence rate, but the breast cancer mortality rate has been relatively stable in the past few years. Although the mortality rate is stable, with increases in

population size, the number of deaths due to breast cancer has shown an increasing trend upward in the past 5 years.

County/Counties of Interest: What the Data Shows

Table 2

Demographic Characteristics of Counties in Service Area

	Southern Arizona Counties					
	Cochise	Graham	Greenlee	Pima	Santa Cruz	Yuma
Population	133,501	32,999	7,754	969,679	42,981	191,746
% Females	50.0%	47.9%	50.8%	51.1%	52.5%	50.3%
% Age 65+	16.3%	13.0%	11.7%	14.8%	11.3%	17.4%
% Female Minorities						
Black	3.7%	1.5%	0.5%	2.8%	0.2%	1.7%
Hispanic	31.1%	28.3%	47.2%	32.3%	81.9%	56.0%
NA	1.0%	15.8%	1.4%	2.7%	0.3%	1.2%
Asian	1.8%	0.6%	0.2%	2.4%	0.5%	1.0%
Other	2.1%	0.8%	0.9%	1.8%	0.3%	0.9%
% Poverty	13.1%	18.6%	8.0%	10.5%	20.1%	15.7%
% Uninsured						
All females	22.3%	26.7%	19.1%	22.0%	29.9%	21.2%
Females 18-64	31.3%	37.5%	25.8%	30.2%	42.6%	29.4%
BC Prevalence Rate (Female)	470.7	423.8	405.1	518.2	395.0	342.7
Age in prevalence cases (oldest)	60.2	59.8	58.6	59.9	58.5	61.1
BC incidence rate (Female)						
0-17	0.03	0.03	0.03	0.03	0.03	0.02
18-44	35.52	37.30	35.36	40.41	36.72	27.38
45-64	207.68	215.12	203.84	237.11	214.65	160.55
65+	341.38	358.69	334.20	397.34	350.53	274.44
BC incidence rate (Male)	1.01	0.76	0.84	1.05	0.77	0.78
2005 age-adjusted BC incidence rate						
White (non-Hispanic)	100.9	110.1	101.8	111.0	105.1	111.5
Black	130.8			118.7		49.9
Hispanic	52.4	163.0	57.5	77.4	70.3	35.5
NA	275.2			38.7		
Asian				86.1		
Stage for white						
I	66.0%	65.9%	65.3%	65.9%	65.2%	66.7%
II	26.5%	26.5%	27.3%	26.5%	27.4%	25.6%
III	3.3%	3.3%	3.3%	3.3%	3.3%	3.3%
IV	4.3%	4.3%	4.2%	4.3%	4.2%	4.4%
Stage for black						
I	54.0%	55.0%	50.6%	54.8%	54.2%	55.1%
II	32.1%	31.2%	35.3%	31.3%	31.9%	31.1%
III	6.0%	5.8%	6.5%	5.8%	5.9%	5.8%
IV	8.0%	8.0%	7.6%	8.1%	8.0%	8.1%
Stage for other						
I	64.8%	63.9%	64.1%	62.7%	63.7%	62.8%
II	28.0%	28.7%	28.4%	29.8%	28.9%	29.7%
III	3.1%	3.2%	3.3%	3.3%	3.2%	3.3%
IV	4.1%	4.2%	4.2%	4.2%	4.1%	4.2%
%Mammogram <=12 months	61.9	56.8	61.1	63.6	60.5	60.6
Mammograms >12 months	3.9	3.4	3.1	3.8	3.4	4.0

BC death estimated #						
White	16.8	3.4	0.7	105.1	3.1	14.4
Black	0.5	0.0	0.0	3.2	0.0	0.3
Other	2.1	0.4	0.1	8.8	0.4	1.1
BC mortality rate						
Female	27.41	24.15	20.69	23.64	15.63	17.41
Male	0.03	0.02	0.20	0.24	0.01	0.46
BC mortality rate						
White	32.15	31.58	25.21	28.70	18.07	22.57
Black	20.67	22.9	10.55	24.01	22.12	24.38
Other	8.59	7.64	8.68	7.58	7.61	6.62
MD per 100,000 pop	74	65	48	239	57	100
Actual number (2000)	98	23	4	2,292	25	90
High School Graduate or higher	79.5	75	82.5	83.4	60.7	65.8
Bachelor's degree or higher	18.8	11.8	12.2	26.7	15.2	11.8
Population enrolled in AHCCS 2007	19.4	23.1	14.2	17.70	29.5	23.4

Sources: Thomson Reuters© 2007; Arizona Department of Health Services Vital Statistics, 2007; Community Health Status Indicators, 2008

As data were analyzed and reviewed, it became apparent that no specific counties stood out as targets. Table 2 presents a summary of key variables for each county. The following paragraphs will describe each county in more detail and their specific needs.

Cochise and Greenlee counties are rural. Cochise County has a high prevalence of breast cancer and a high number of uninsured females. The mortality rate for breast cancer in both of these counties is higher than the other counties, as estimated by Thomson Reuters© 2007.

Graham County has the highest percentage of Native American population, relative to its population size, a high rate of poverty and uninsured females, and a high rate of women enrolled in the state Medicaid (AHCCCS) program, based upon estimates from Thomson Reuters© 2007. It has a high rate of breast cancer among non-Hispanic white women, and the lowest rate of mammography screening. The number of people with a high school education or higher is lowest in the service area (US Census Data, 2000).

Pima County has the largest population and the highest incidence and prevalence of breast cancer and mortality due to breast cancer based upon estimates from Thomson Reuters© 2007. Although the actual number of African-Americans in Pima County is not high, Pima County has a high percentage of black minorities, compared to the percentages in other counties. Pima County has the highest percentage of females, highest rate of mammogram screening (63.6%), lowest percent at the poverty level, and highest percent of high school and college graduates, according to estimates from Thomson Reuters© 2007.

Santa Cruz County has the highest percentage of females and the highest population of Hispanics, according to estimates from Thomson Reuters© 2007. These same statistics estimate that it has the highest rate of people living in poverty and the highest percentage of females who are uninsured. It has the highest percentage of enrollees in AHCCCS. The mammogram screening rate is low, based upon data from Arizona Department of Health Services Vital Statistics (2007).

Yuma County has the highest percentage of population over the age of 65, relative to population size, based upon estimates from Thomson Reuters© 2007. The second largest percentage of Hispanics live in Yuma County. There is a high rate of poverty, and a high number of individuals enrolled in AHCCCS. The prevalence rate for breast cancer is the lowest, and the percentage of stage I cancer is the highest, based upon estimates from Thomson Reuters© 2007.

Demographic and Breast Cancer Findings

Based upon the above analysis, it was determined that additional information be sought from all six counties in the service area. Pima, Graham, and Cochise were chosen because of their high rates of breast cancer; Graham County because of its low rate of mammogram screening; and Greenlee, Santa Cruz, and Yuma were chosen because of the high rates of poverty and higher numbers of uninsured and/or enrolled in AHCCCS. It became apparent that there were no specific target counties, and that each county would be included in further review of programs and services and the exploratory data collection.

Programs and Services



Data Source and Methodology Overview

The Southern Arizona Affiliate's assessment of programs and services was utilized to identify mammography and treatment services, support services, and other resources within each county of the service area. The data were collected using the following sources: the Medline Plus Go Local website (<http://www.nlm.nih.gov/medlineplus/golocal/index.html>); the Arizona Cancer Control Program Resource Directory and the American Cancer Society, In My Community, website (http://www.cancer.org/docroot/com/com_0.asp); and the U.S. Food and Drug Administration's website for certified mammography facilities (<http://www.fda.gov/cdrh/mammography/certified.html>). Key informants in each county were interviewed in person or by telephone to add, verify, or correct the data collected.

Asset mapping was used to determine the distribution of services and demonstrates the topography and rural nature of the counties (Figure 3). The asset map highlights the location of each county in the service area, and the location of hospitals, Indian Health Services, mammography facilities, and Komen Grantees. The asset map also confirmed statements by providers and survivors regarding rural areas and lack of services.

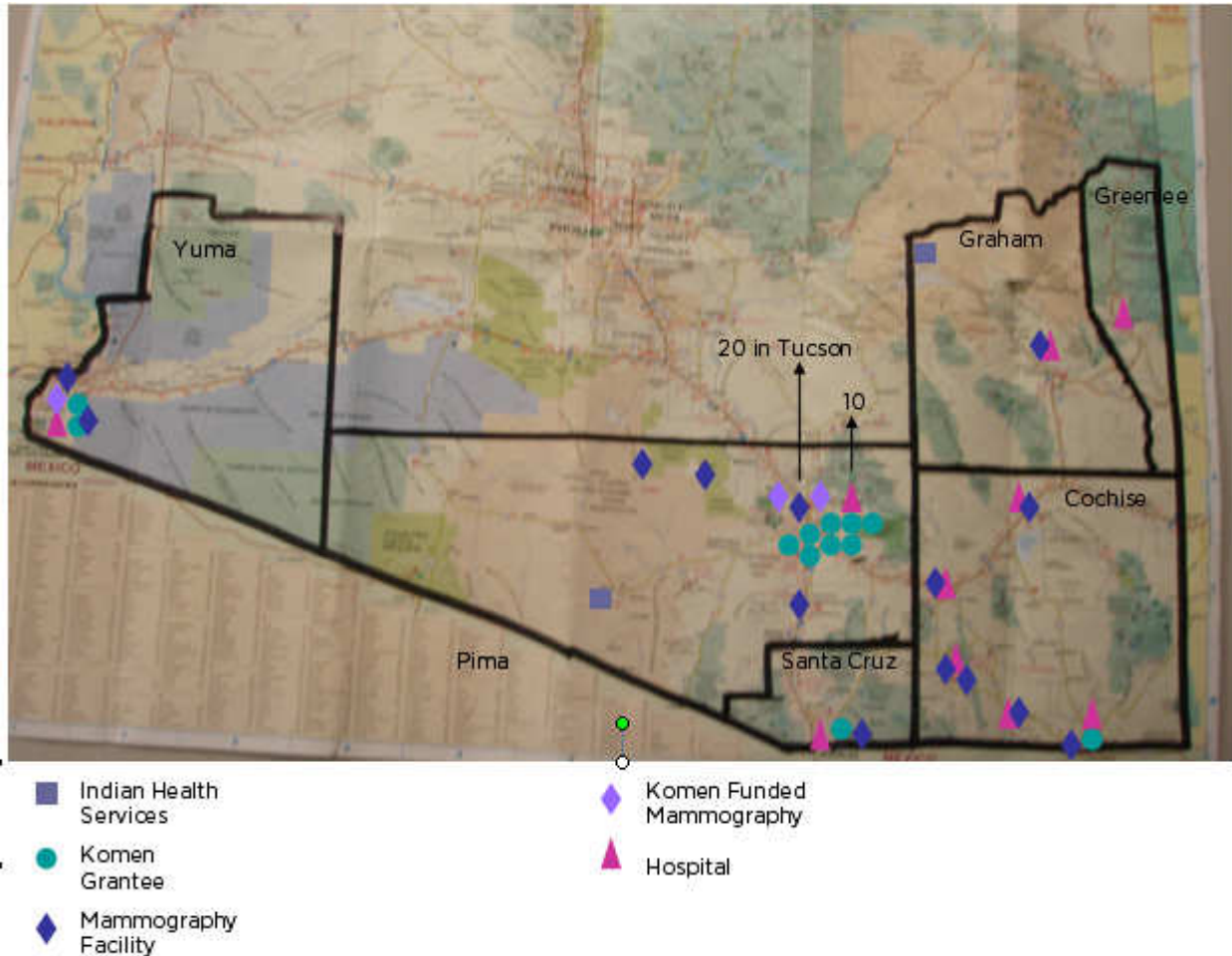


Figure 3. Asset Map

Programs and Services Overview

Within the Southern Arizona service area, the majority of mammography and treatment services are located in Pima County, due to its population size. Since other counties within the service area have limited resources, this creates barriers in accessing care for many Southern Arizona women. As geographic boundaries and transportation become key factors, those greatly affected include women in rural areas, those with no means of transportation or transportation programs, and limited financial resources. Transportation and financial issues also create barriers in accessing care to those living in Pima County. The crisis created by limited access to care not only restricts screening and early detection, but also limits treatment and survivorship.

Service Area Resources

In each county there are exceptional organizations, community health clinics, support services, and breast health education programs. All six counties have at least one hospital and one FDA-certified mammography facility. Cochise and Pima counties have the most health facilities, and Pima has a higher rate of physicians. Cochise, Graham, Pima, and Yuma have oncology services to treat breast cancer. Greenlee County has few health services and those in Cochise are clustered in the western section of the county (Arizona Department of Commerce, 2007). Greenlee County has the lowest number of physicians in the state, but is smallest in population size for Southern Arizona (Arizona Department of Commerce, 2007). In Santa Cruz County, the number of physicians for the population is low at 57 per 100,000 (Arizona Department of Commerce, 2007).

Appendix A lists the health services and programs by county. Appendix B lists mammography services by county.

American Cancer Society

By providing programs such as Reach to Recovery, Look Good Feel Better, and Road to Recovery, the American Cancer Society has impacted the lives of countless individuals within the Southern Arizona service area. Its presence, resources, and services complement the Southern Arizona Affiliate's mission to end breast cancer forever. In addition, the American Cancer Society serves some county areas as the information line for the state's Well Woman HealthCheck Program and entry point into the program.



Partnerships and Grant Opportunities

Southern Arizona, and more specifically Tucson, is noted for a high number of non-profits per capita, based on its metro area size. Although this can present challenges in fundraising, it also presents opportunities for partnership and collaboration, both key factors in increasing our ability to address and meet the needs of those in our community.

The Southern Arizona Affiliate has recognized the value and impact effective partnership collaborations have in maximizing resources and allowing programs, services, and messages to have the greatest reach possible. Our most successful collaborative initiative is demonstrated as an outcome of our community grants program. In 2004, the local affiliate was presented with a series of cases of women who were diagnosed outside of the Well Woman HealthCheck Program, leaving them ineligible for any treatment-assistance funds. No other low-cost treatment programs were in existence at the time. Through its local grants programs, the affiliate called on all hospitals, oncology groups, health clinics, and other providers to come together. The purpose was to (a) leverage the strengths and resources each agency was noted for, and (b) share the cost and create a collaborative program where dollars could be stretched to effectively treat these women who had fallen through the cracks. We are in the fourth year of funding the service area's most competitive and vital treatment collaborative.

Building on that success, grant workshops were structured to allow a venue and forum for interested applicants to share proposed ideas and meet with other agencies with similar ideas/proposals. These ensure elimination of duplication in services and that programs are built in partnership to broaden the reach of these services. Other collaborative programs formed or in discussion for design by outside agencies are transportation programs, promotora (see Promising Practices)/patient navigator programs, and resource centers in rural areas.

Collaboration and partnership also has been a cornerstone of the Board's strategic plan and internal affiliate operations, education, outreach, and marketing. As each community profile targets and identifies the populations and areas with the greatest need, non-profit organizations that serve these populations and businesses and have established relationships in these areas are targeted for new Komen partnership initiatives and outreach programs. Some of the existing relationships, program outreach, and open doors established and conducted with partnering agencies have been (1) Community Food Bank, (2) Dex Media, (3) Sierra Vista Cancer Center, (4) Arizona Cancer Center, (5) American Cancer Society, as well as faith-based

communities and even laundromats, a common gathering place in some communities and a place to disseminate information.

The affiliate's largest collaborative effort currently under development involves creating a better understanding of support programs, streamlining grant funding, targeting breast health education and outreach, and influencing public policy in partnership with the American Cancer Society and the Arizona Cancer Center. New partnerships up for discussion have involved local women and children's shelters and correctional facilities.

Grantees

Our current grantees play a large role in screening, diagnosis, and treatment of breast cancer, as well as in outreach and education. They also assist in addressing the affiliate's priorities. The following paragraphs briefly describe each grantee program and the services it provides.

- **Arizona Department of Health Services' *Treatment Assistance Program Grant*** -- provides breast cancer treatment services to women in all six counties who do not qualify for the Breast and Cervical Cancer Treatment Program.
- **Arizona Orthopaedic Research Center's *AORC Lymphedema Treatment Program*** -- reaches breast cancer survivors in Southern Arizona who are underinsured or uninsured, to improve the knowledge of primary care providers in treatment options, and to provide education to all breast cancer survivors in strategies to prevent lymphedema.
- **Chiricahua Community Health Centers' *Women's Outreach*** -- reaches the economically disadvantaged and isolated women in rural areas of Cochise County through the use of promotoras, case managers, outreach teams, and two technical mobile units.
- **El Rio Community Health Center's *El Rio Breast Cancer Awareness Project*** -- educates medically underserved Latina women living in transitional facilities, as well as those living on Tucson's south side, about breast cancer risk reduction and provides breast health awareness information.
- **Foundation of Yuma Regional Medical Center's *Yuma Coalition for Awareness Breast Cancer Screening Program*** -- provides low-cost mammogram screenings and breast health education to women ages

35-49 who are uninsured and underinsured, fall 250 percent below the federal poverty guidelines, and live in Yuma County.

- **Mariposa Community Health Center's *Juntos Contra El Cancer*** -- educates community members about cancer prevention and education in Santa Cruz County using a promotora-based outreach, referral, and support program.
- **Pima County Health Department's *Bridging the Gap*** -- complements the Well Woman HealthCheck program in Pima County by funding breast cancer screening, diagnostics, and, in some cases, treatment for uninsured/underinsured women ages 40-49 residing in rural Pima County.
- **Regional Center of Border Health's *Between Friends/Entre Amigas Community Outreach Program*** -- provides culturally sensitive breast health education; promotes healthy lifestyles, early breast cancer detection, and treatment; and seeks to improve access to breast health screenings and treatment services to economically disadvantaged and medically underserved women in Yuma County.
- **St. Elizabeth's Health Center's *Covering Treatment for Uninsured Breast Cancer Patients Outside the Well Woman Program*** -- provides treatment for men and women in the six counties who do not qualify for Well Woman HealthCheck or public assistance.
- **Tucson Medical Center's *TMC Breast Health and Education Program*** -- provides digital mammography services to low-income uninsured women above the age of 40. In addition, a full continuum of services from education to screening, diagnostics, treatment, and a patient navigator program is provided.
- **University of Arizona's *Mujer A Mujer: Una Platica Sobre Cancer de Seno/Woman to Woman: Let's Talk About Breast Cancer*** -- produces a culturally and linguistically competent breast cancer education program in partnership with Latina breast cancer survivors to be disseminated, via DVDs and the internet, throughout community networks in Southern Arizona.
- **University Medical Center's *Education and Screening Regarding BRAC1/2 Mutations and Associated Cancer Risks to the Underserved Urban, Rural and Latina Population at High Risk for Hereditary Breast Cancer in Southern Arizona Via Tele-Genetic Counseling*** -- designed to develop a model for genetic counseling and provide testing for

BRAC1/2 mutation status for the underserved Latina population of Southern Arizona.

Promising Practices and Evidence-Based Programs

Promotora de Salud

The promotora program has proven to be an effective approach in reaching medically underserved women in Southern Arizona. A promotora is a community-based individual trained by healthcare professionals to spread breast health messages and to empower women in their community to become advocates of their own health. Promotoras educate women in the community about breast health awareness, risk reduction of breast cancer, the importance of screening and early detection, and the proper way to perform a breast self-examination. The promotora also may serve as a patient advocate. By collaborating with programs and community health centers that provide free or low-cost services and acting as an information resource, the promotora is able to help alleviate barriers to accessing care for medically underserved women.

Coalition Model

Founded in 2005, the Yuma Coalition for Awareness has developed a well-organized, effective, and efficient process to provide services without overlap. The coalition meets monthly to identify needs and gaps in services, to determine priorities, and to determine which provider will assume leadership. Through this collaboration, funding has been maximized to assure a wider array of services for the underserved members of the community.

Public Policy Perspectives

National Breast and Cervical Cancer Early Detection Program

Established in 1993 as part of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), the Well Woman HealthCheck Program (WWHP) serves low-income, uninsured, and underinsured women up to 250 percent of the federal poverty level and those with no other health insurance, including Medicare. Women who qualify for the program are eligible to receive free mammograms, diagnostic testing, and breast health education. WWHP is administered by the Arizona Department of Health Services and can be accessed in each of the six counties in the Southern Arizona Affiliate service area. The two funding sources for the WWHP are the Centers for Medicare and Medicaid Services and the State of Arizona. However, the WWHP receives no funding for cancer treatment, which means countless women who do not qualify for the program face substantial difficulties when accessing treatment care. Women who are program-eligible and require treatment are referred to Arizona Health Care Cost Containment System

(AHCCCS), Arizona's Medicaid program, whereas those who are not eligible for AHCCCS are referred to charitable providers within the community.

This year, due to recent budget cuts, the WWHP had to return 60 percent of its state budget, which impacted the program tremendously. The end result of the decreased budget will mean that at least 1,000 women will not receive screening and about 20 women will go undiagnosed with cancer. Currently, under the Breast and Cervical Cancer Prevention and Treatment Act of 2000, Arizona has the most restrictive guidelines for qualification, naming it as an Option 1 state. Being an Option 1 state means that a woman is only considered screened under the program if NBCCEDP pays for all or a portion of her screening cost. Ultimately, under Option 1, a woman may be denied services simply because she was not screened or diagnosed by a participating NBCCEDP provider. Currently, in Pima County there are only three NBCCEDP providers for the entire county: St. Elizabeth's Health Center, Pima County Health Department, and El Pueblo Clinic. The other five service area counties each have only one provider: Greenlee County Health Department, Graham County Health Department, Mariposa Community Health Center, Chiricahua Community Health Center, and Yuma County Health Department. In total there are eight NBCCEDP providers for the entire Southern Arizona service area. Therefore, a need exists for increased screening and treatment funds and a change in legislation to allow more equitable access to the program.

The affiliate has a collaborative working relationship with the state NBCCEDP Director and ADHS. For the past three years the affiliate has funded a treatment assistance program through the ADHS. The State of Arizona NBCCEDP Director is Virginia Warren, Community Services Office Chief for the Arizona Department of Health Services (ADHS). Changes in legislation to improve access to the WWHP and appropriated AHCCCS funds for breast cancer treatment have been the target of the Southern Arizona Affiliate's public policy and advocacy plan for the past two years. These changes cannot happen overnight and require relationship building and education surrounding the WWHP issue. Fortunately, the affiliate has had positive interaction with national and state level representatives. Congressional Representatives Raul Grijalva and Gabrielle Giffords have both been supportive, as has Senator Jon Kyl's office; the Governor's Office of Children, Youth and Families; and Representative Amanda Aguirre. Better relationships are needed and will continue to be built with state representatives in all six Southern Arizona counties. The Board of Directors and local Komen affiliate have established long-term and short-term goals to address the issues surrounding public policy efforts. These goals can be found in the affiliate action plan.

Programs and Service Findings

Based upon analysis of the asset map, program and services overview, current partnerships and grantees, and the public policy perspectives, several areas of concern were revealed. The rural nature of several counties contributes to an inequitable distribution of breast health services. Many residents experience high levels of poverty and lack of insurance. Since all but two of the counties border on Mexico, Hispanics comprise a high percent of the residents and often have immigration issues that limit their access to care. Indian reservations lie within three of the counties and have Indian Health Service hospitals; little is known, however, about the breast health needs of the Native American women. The affiliate has ongoing relationships with national and state representatives, but will continue to cultivate and strengthen these relationships to better advocate for changes that will increase access to the WWHP regardless of location of diagnosis.

Exploratory Data



Data Sources and Methodology Overview

To better understand the issues and gaps in services in the Southern Arizona Affiliate service area, the community profile assessment drew upon information from grantees, providers, and survivors in Cochise, Graham, Greenlee, Pima, Santa Cruz, and Yuma counties.

Eighteen surveys were completed by current and past grantees, hospitals, NBCCEDP clinics, and cancer treatment providers. The survey included a mixture of closed and open-ended questions and was implemented using the online survey tool, Survey Monkey. The survey addressed issues and themes identified during analysis of the preliminary statistical data and the mapping exercise. It was determined that organizations in the entire service area would be surveyed, in order to better understand the issues surrounding breast health care for women and to identify gaps in services to women in all six counties. The questions were structured to elicit information about the importance of breast cancer as a health issue, the financing of breast health care, who provides breast health care, the referral sources, what breast health education services and materials are available, the need for non-English language services and materials, and ideas about ways to improve breast health services within their communities.

Three key informant interviews were completed in selected counties to further understand the issues and gaps. These interviews were conducted in person and by telephone and ranged from 45-60 minutes. Two people using a scripted questionnaire conducted the interviews. The key informants included providers and program directors from established providers within the selected counties of Greenlee, Pima, and Yuma.

One focus group was completed in Santa Cruz County. A bi-lingual group facilitator conducted the focus group in the offices of the Mariposa Community Health Center in Nogales, Arizona. The facilitator was familiar to the participants and the response was excellent. The forty-six participants were all Latina survivors. Forty-six women participated in the group and the session was conducted entirely in Spanish. The script for the focus group included 10 questions to solicit their assessment of experiences (a) with breast health care providers, (b) during their treatment, (c) with follow-up services, (d) with barriers met when seeking a mammogram, (e) with lack of services in their community, and (f) their suggestions for improving services. The conversation was tape recorded and then translated into English for analysis and separation into themes.

Thirty surveys were completed by survivors across the service area. The surveys included both closed and open-ended questions using the online survey tool, Survey Monkey, as well as telephone interviews. The results from the telephone surveys were entered into Survey Monkey for analysis. The survey questionnaire solicited demographic data and information on the survivors' experiences with screening, diagnosis, and treatment of their breast cancer. Other questions elicited information about the barriers encountered, survivorship issues, and suggestions for improving services and support.

Exploratory Data Overview

Grantees

Survey results indicated that seven current grantees work with women who live in Cochise, Pima, Santa Cruz, and Yuma counties. The Arizona Department of Health Services and St. Elizabeth's Health Clinic have treatment grants that are available to women in all six counties. Currently there are no grantees in Graham or Greenlee counties. Chiricahua Community Health Centers provide services to uninsured and underinsured women living in the rural areas of Cochise County. The Pima County Health Department, El Rio Community Health Center, and St. Elizabeth's Health Center provide services to underinsured and uninsured women. St. Elizabeth's Health Center provides treatment to uninsured women. Mariposa Community Health Center offers promotora services to Latina women in Santa Cruz County. The

Regional Center for Border Health and the Foundation of Yuma County Health Department offer screening and diagnostic services within Yuma County.

Provider-Education and Services: Barriers and Identified Needs

The results of the provider surveys indicate several barriers to providing breast health services. The barriers and obstacles to providing education, screening, diagnosis, treatment, and follow-up care, along with recommendations for removing the barriers, are:

General Issues

- Lack of financial resources: women are underinsured or uninsured
- Poor or no transportation for screening, diagnosis, or treatment
- Lack of treatment services, especially in rural areas and small communities
- Insufficient or a lack of screening mammography services, especially in rural areas and small communities
- No funds for treatment
- Immigration issues

One respondent provided a picture of the changing economic scene in Southern Arizona: “Lots of changes are happening in our county due to massive layoffs of mine employees, shift in priorities and health care.”

Another respondent pointed out that “Our program doesn’t screen undocumented women because we cannot provide treatment services--we would be able to screen if there were funds for treatment available to them.”

Provider Specific Issues

- Lack of knowledge about proper method to conduct breast clinical exams
- Lack of knowledge about current breast health clinical guidelines
- Lack of knowledge on risks, identification, and treatment of lymphedema
- Incidence of aggressive breast cancer in young Hispanic women
- Need for more breast cancer specialists outside Pima and Yuma counties

As one respondent stated: “We need more breast surgeons in Cochise County.” Another noted that: “We need more provider education opportunities here in Greenlee County that offer CEUs and CMEs.”

Cultural Issues

- Need for Spanish language services and educational materials
- Need for low-literacy materials

- Cultural sensitivity for specific populations: Lesbian, Bisexual, and Transgender, and Native Americans

One provider stated that: “We need more Spanish language materials.”

Key Informants

Discussions with key informants provided further affirmation of these barriers. The overwhelming themes were lack of financial resources to provide preventive education and screening, and diagnosis and treatment services. As the economy rapidly changes and resources become more scarce, the challenges faced by breast health providers become even greater as they compete with the priorities of other conditions and diseases for the allocation of health care dollars. This has implications for both grant funding and public policy priorities. A second concern is the lack of specific breast health services ranging from no local mammography services to a lack of breast cancer treatment providers in specific communities and counties. Transportation, therefore, becomes a significant issue. The informants unanimously expressed concerns about the funding cuts to the Well Woman HealthCheck programs. These respondents verified the need for awareness and education for younger women, the impact of poverty in their communities, and the need for treatment funding.

Survivorship

A group of survivors demonstrated their courage and commitment to breast health issues by participating in a focus group and openly sharing their feelings and experiences. Their own words best describe the continuum of breast health care in their community, Nogales, which lies on the southern border of the United States with Mexico. Most of the participants had been served by the Mariposa Community Health Center and had received services under a Southern Arizona Susan G. Komen for the Cure grant.

Many survivors completing the survey questionnaire shared their experiences and provided firsthand knowledge of the state of breast health care from their perspectives as members of their communities. Each county was represented in the responses. A majority of the respondents were Hispanic (16) compared to Caucasian (14). The mean age of the Hispanic respondents was 47.1 and Caucasian was 55.6. The majority were married and half (50%) had insurance at the time of their diagnosis. Of those with insurance, it paid for more than half to all of their treatment. Those without insurance financed their treatment with cash (3), payment program (2), AHCCCS (3), or Well Woman HealthCheck (5). Nineteen were under five years of survivorship and an oncologist is providing their follow-up care, and twenty-seven have not had a

recurrence. Sixty percent had a family history of breast cancer; three had both a mother and sister with history of breast cancer.

Survivorship Issues

- Lack of or no insurance for treatment, which had an impact on the treatment decisions and choices
- Lack of surgeon choices due to insurance coverage
- Lack of continuum of care services or patient navigation at time of diagnosis

As one respondent said, “My insurance was cut off, and with no other way to pay for my treatments, I went to the VA Medical Center, which was not a good place for me. I was the first woman they had given radiation to in 8 years!”

Another said, “It was difficult to find a doctor that would start treatment without receiving money in advance.”

“I feel there are adequate services; it was just knowing where to go to get the information that was lacking.”

- Side effects of treatment
- Lymphedema
- Lack of support services, including educational materials, support groups, and alternative therapies for survivors

These respondents experienced a variety of side effects associated with surgery, chemotherapy, and radiation therapy. One woman discontinued treatment due to the severity of the side effects. Lymphedema was described most often as a debilitating side effect, and they noted a dearth of health professionals to treat it. Several survivors expressed a need for affordable complementary therapies after treatment.

As succinctly stated by a respondent, “Train physicians to recognize and deal with lymphedema.”

“Provide economical access to complementary therapies: healing touch, Reiki, massage. The charges are too high. They should be made available at cancer centers free of charge.”

The survivors delineated the need for the following services and support before, during, and after treatment:

- Educational materials in several languages, primarily Spanish in Southern Arizona

- Support groups during and after treatment
- Improved communications with health care professionals
- Exercise places or gyms
- Economical access to complementary therapies
- Affordable survivor retreats
- Navigation or continuum of care services at the time of diagnosis
- Lymphedema support and treatment

“Provide more distribution of breast cancer materials and early screening so women are aware that they need to have annual mammograms.”

“Everyone knows that chemotherapy has physical effects; it is true that the extent in each individual is different. However a mindful follow-up and a ‘rehab’ program that becomes the next step after therapy would not help patients, but it may produce some excellent epidemiological data about the after effects and better ways to help survivorship.”

“Sometimes the information is not available until after treatment.”

Conclusions Based on Exploratory Data

It is evident that there is a need for increased access to care across all the counties. This includes funding for services ranging from screening mammograms to treatment of breast cancer. Providers, grantees, and survivors identified a need for transportation in all areas, but there is a greater need in rural and outlying areas.

Outreach and education continues to be a need for all populations and for specific at-risk groups, including Native Americans, Hispanics, and Lesbian, Bisexual, and Transgender women. Providers and survivors talked about the need for educating health care professionals on screening guidelines for breast cancer, for identifying and treating lymphedema, and the correct method for conducting a clinical breast exam.

According to survivors, their concerns and issues extend from diagnosis to post-treatment needs, including those arising long after their treatment had ended. Several described the need for a system to provide information and navigation during the continuum of care from diagnosis to after care. They noted that services usually were available, but they were unaware of how and when to access a particular service. Lymphedema was a dominant concern for several survivors; a lack of lymphedema specialists outside the communities of Tucson, Benson, and Yuma was noted. Several survivors desired having access to affordable complementary therapies.

Conclusions

Selection of Target Areas for Southern Arizona

Preliminary service area analysis based on breast cancer and demographic statistics revealed that all six counties were target areas for the Southern Arizona Affiliate. Cochise has a high prevalence and incidence and mortality rate of breast cancer. Graham County has the highest percent of Native Americans, high rates of poverty and uninsured females, and the lowest rate of mammography screening. Greenlee County has the fewest health care services in the service area. Pima County has the highest prevalence and incidence rates for breast cancer together with the highest mortality rate. Santa Cruz County has the highest percent of Hispanics and highest rate of women living below the poverty level and uninsured. It has a low mammogram-screening rate. Yuma County has the highest rate of population over the age of 65 and a high rate of poverty. All six counties were identified as target areas due to disparities in services and high poverty levels.

Analysis of program services revealed an uneven distribution of breast cancer services in Southern Arizona. The majority of services were clustered in Cochise and Pima County, specifically Tucson. Tucson has the highest number of hospitals, mammography facilities, and oncology practices. Graham, Greenlee, and Santa Cruz counties have the fewest facilities—on average one hospital, one mammography facility, and limited oncology practices. Greenlee County has the fewest resources. The Arizona Legislature has included a cut in funding to rural hospitals; this would have an immediate effect and could lead to some rural hospitals closing.

The data collected from grantees and survivors validated many of the problems and barriers identified by the providers in each county. The surveys and interviews confirmed that access to care was a concern across all the counties. Both providers and grantees expressed increasing concern about access to care as state funding is cut and reduced for WWHP programs in all the counties. The findings showed that transportation for screening, diagnosis, and treatment is a barrier within all the counties, especially for those with limited health care resources and facilities. The findings from the exploratory data demonstrated a need for education on a variety of breast health and breast cancer topics, including, but not limited to, performing a clinical breast exam, breast cancer screening guidelines, and identifying and managing lymphedema. Several respondents indicated a continuing need for culturally sensitive and appropriate education and care.

Putting the Data Together

Breast cancer statistics determined that all six counties are target areas for the Southern Arizona 2009 Community Profile Report. Therefore, the purpose of the follow-up data collection was to better understand from the program and services, as well as community perspective, what is contributing to the barriers to health care.

The provider and service review included all six counties to better understand the gaps in services. The analysis demonstrated an inequitable distribution of services within each county, ranging from a plethora of services in Pima County to a dearth of services in Greenlee County. Each county has at least one hospital and one mammography facility. However, in the larger counties, there are vast rural areas with no health care services, thus forming a barrier to preventive care and screening. The lack of oncology practices in some counties requires patients to travel long distances for treatment.

Survivors painted a picture of further need for support and care as survivors. They noted a lack of access to affordable complementary therapies. These therapies may be available, but the cost is prohibitive. Survivors described the need for a way to navigate the continuum of care from diagnosis to treatment to survivorship. Several indicated that physicians and other health care providers lack knowledge and skills regarding clinical breast exams, screening guidelines, and risks for and treatment of lymphedema. Both survivors and providers pointed out a need for education and training in providing culturally sensitive and appropriate care to Hispanic, Native American, and Bisexual, Lesbian, and Transgender populations.

Affiliate Priorities

The members of the Southern Arizona Community Profile Committee met to review the findings and determine and draft priorities based on key findings. The membership of the committee included a member of the Southern Arizona Affiliate Board of Directors, the Chair of the Affiliate Education Committee, the Chair of the Affiliate Grant Committee, the Education and Outreach Intern, a representative of an agency in Mariposa County, and the Medical Director of Pima County Public Health Department, as well as the Executive Director and Community Resource Manager of the affiliate. As a team, each participant stated her priorities based upon the established problems/themes derived from the findings. A brainstorming process was used to assure that all the significant findings were discussed. Following the brainstorming process, participants indicated their significant priorities. Out

of this process, three top priorities emerged. In a separate meeting and utilizing the goals and priorities developed by the Affiliate Board of Directors at a strategic-planning retreat, the final goals and objectives were established.

Affiliate Action Plan

Historically, the Board of Directors' strategic plan has been based on the prioritized needs developed by the Community Profile Report. This CPR was completed after the Board of Directors met to establish the affiliate's new strategic plan; however, many of these issues were somewhat known as a result of the affiliate's close work with the community. Although some aspects of the profile's key findings were not specifically addressed in the strategic plan, they will be incorporated into the next strategic- and goal-planning cycle, and the operational committees will use this profile as they move forward with their outreach plans.

The following will list the current affiliate strategic goals, listing long-term and short-term objectives.

Strategic Categories

Fundraising Objective

Long Term: Increase income by 10 % in 3 yrs. (\$1.5 million based on actual from 2008)

Diversify funding stream with at least 50 percent coming from non-Race sources (keeping Race income sustainable) in 5 yrs. - 10% each yr.

Short Term: Update and implement funds diversification plan, which takes into account the most likely areas for increasing revenue streams - 1 yr.

Public Policy Objective

Long Term: Continue to work toward a change in state law surrounding access to screening and treatment funds (Option 1 to Option 3 in WWHP) - 3 to 5 yrs.

Short Term: Develop a Public Policy/Advocacy Plan - 1 yr.

Defend existing funding levels for breast health programs - 1 to 3 yrs.

Branding/PR Objective

Long Term: Effectively brand Komen Southern Arizona throughout our service area - 3 to 5 yrs.

Short Term: Create a marketing plan for Komen Southern Arizona - 1 yr.

Expand current PR/Marketing campaign - 1 yr.

Promise Activity- Education/Outreach/Grants Objective

Long Term: Establish a real and visible presence in each major community in our 6 Arizona counties - 3 to 5 yrs.

Short Term: Create an outreach plan, based on the Community Profile Report, that will identify the top education and funding opportunities/activities within our service area -1 to 3 yrs.

People Objective

- Long Term: Diversify Board and volunteer network within 3 to 5 yrs. to create a culture of inclusion that will engage leaders within the key constituencies that we serve.
Increase the human talent capacity of our affiliate to support the strategic plan, relative to budget allowances - 3 to 5 yrs.
- Short Term: Develop and begin to implement a Governance Plan - 1 to 3 yrs.
Create and implement a network plan to develop relationships with groups, agencies, and individuals that will facilitate our understanding of the populations that we serve and their engagement in the cause - 1 to 3 years

The specific and measureable tactics and steps to achieve these objectives have been developed by the appropriate staff and committee members and have become the operational and dynamic element of the strategic plan.

The following section will address the community profile priorities and highlight the specific affiliate strategic goal by which each priority is supported.

Priority 1: Increase access to care by expanding funding levels for screening, diagnostic, and treatment services for women in all locations; addressing transportation issues; and encouraging medical providers to establish practices in rural areas.

- Strategic Category: Public Policy
 - Change in state legislation (Option 1 to Option 3 -WWHP)
- Strategic Category: Promise Activity
 - Cultivating grant applications

Priority 2: Establish a real and visible presence for education and outreach in each of the six counties, with a focus on the general population and special populations and health professionals.

- Strategic Goal: Promise Activity
 - Create an outreach plan for education and fundraising
- Strategic Category: Branding/PR
 - Effectively brand Komen Southern Arizona

Priority 3: Address survivorship issues by supporting funding for complementary therapies, navigator programs, and lymphedema management.

- Strategic Goal: Public Policy
 - Defend funding for breast health programs
- Strategic Goal: Promise Activity
 - Cultivating grant applications

The Community Profile Report will be used to update the Board of Directors and Committee goals to ensure that each priority is addressed in the next fiscal year.

APPENDIX A

HEALTH CARE SERVICES BY COUNTY

Cochise County

Benson Hospital
Chiricahua Community Health Center *
Cochise County Health Department
Cochise Oncology
Cooper Queen Community Hospital
Dr. Mark E. McCarthy Oncology and Hematology
Fort Huachuca
Northern Cochise Community Hospital
Sierra Vista Cancer Center
Sierra Vista Regional Health Center
Southeast Arizona Medical Center

Graham County

Arizona Oncology Associates
Canyonlands Community Health Care
Graham County Health Department
Mt. Graham Regional Medical Center
Safford Community Health Clinic

Greenlee County

Clifton Community Health Center
Duncan Health Clinic
Greenlee County Health Department-WWHP

Pima County

Arizona Cancer Center*
Arizona Orthopaedic Research Center *
Davis Monthan Air Force Base
El Rio Health Center *
Pima County Health Department *
St. Elizabeth's Health Center*
Sunstone Cancer Support Centers
Tucson Breast Center
Tucson Medical Center *
United Community Health Center- Green Valley

University Medical Center
University Physicians Healthcare
Wingspan
YWCA

Santa Cruz County

Arizona Oncology Associates
Carondelet Holy Cross Hospital
Mariposa Community Health Center*

Yuma County

Regional Center for Border Health*
Sunset Community Health Center
Sunset Women's Medical Group
Sunstone Cancer Support Centers
Western Arizona Health Education Center
Yuma County Health Department
Yuma Regional Medical Center *

* Denotes a Southern Arizona Affiliate Grantee

APPENDIX B

NUMBER OF CERTIFIED MAMMOGRAPHY CENTERS BY COMMUNITY AND COUNTY

County	City or Town	Number of Facilities
Cochise	Benson	1
	Bisbee	1
	Douglas	1
	Ft.	1
	Huachuca	
	Sierra Vista	2
Graham	Safford	1
Greenlee	Morenci	1
Pima	Green	2
	Valley	
	Oro Valley	1
	Tucson	24
Santa	Nogales	2
Cruz		
Yuma	Yuma	2

Source: U.S. Food and Drug Administration. Certified Mammography Sites. (2008)

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