

COMMUNITY PROFILE REPORT

EXECUTIVE SUMMARY

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“ There is no one else like you.”

“Take care of yourself!”

*“ Most young women don’t worry
about breast cancer. ”*

*“ The fact is ALL women
are at risk. ”*

2011
2011



Executive Summary

introduction

Since its inception in 1999, the Susan G. Komen Southern Arizona Affiliate remains committed to its service area of six counties, four of which border Mexico and all of which spread over 31,193 square miles of the Sonoran desert. The Affiliate's priorities are:

- funding local programs that provide education about, screening for, and treatment of breast diseases for targeted communities,
- advocating for and supporting public policy education about funds available for breast cancer screening, specifically, the Center for Disease Control (CDC) National Breast and Cervical Cancer Early Detection Program (NBCCEDP),
- preserving the state's health insurance program, Arizona Health Care Cost Containment System (AHCCCS),
- serving as a local resource for those affected by breast cancer and in need of education and support.

As a result, the Southern Arizona Affiliate has positioned itself as a premier partnering agency in matters of breast cancer education, early detection, treatment, and public policy. The Community Grants Program funds local education, screening and treatment. Collaborative partners include health organizations such as the American Cancer Society and coalitions that help Komen break down cultural barriers. Efforts such as these and the pursuit of private funding help Komen realize its Promise: a world without breast cancer.

The Southern Arizona Affiliate's Community Profile Report (CPR) serves as a framework to guide the operations of the Affiliate. The 2011 CPR goals were:

- determine breast cancer screening, incidence, mortality, and survival rates,
- establish a network of conveners for focus groups in each county,
- determine breast health needs and assets in each county,
- explore potential for convening champions of breast cancer for early detection and treatment within each county,
- determine strategic objectives for the Affiliate Promise Committees.

The 2011 CPR provides an overview of the six counties in the service area; identifies existing gaps in services, education, and outreach; and directs public policy efforts. In addition, it highlights areas needing concentrated public relations and marketing efforts; and identifies areas requiring further study and exploration.

Key findings:

The CPR, written in conjunction with key community partners, sets the stage for ongoing inquiry into early detection rates, breast cancer incidence and mortality rates. Key findings are:

- Declining mammography rates are a major concern, since breast cancer can be favorably treated when diagnosed early. Yearly mammograms decreased from 60% to 50% nationally, and in Arizona to a low of 40% in 2009.
- Hispanic, African American and American Indian women are least likely to receive regular breast screenings. American Indians' two-year screening rates are as low as 17%.
- Low income white women, undocumented Hispanic women, and the underinsured/uninsured are also less likely to be screened.
- African American and American Indian women consistently have lower rates of survival throughout the one-to-five year range. African American women are most likely to be diagnosed later. American Indians, like African Americans, may be genetically predisposed towards poorer survival.
- White and American Indian women have an 89% five-year survival rate when diagnosed at Stage 1 breast cancer, nine percentage points lower than the national average of 98%. Hispanic women face an 86% five-year survival rate, while African American women have the lowest five-year survival rate for all stages, at 72%.
- The Affiliate recognizes the need for more accurate data collection in order to understand: poorer cancer prognoses in African American and American Indian women; and how actual breast cancer incidence, mortality and survival rates across the service area differs by race/ethnicity.

Sources: AHCCCS, Arizona Cancer Registry, San Antonio Breast Cancer Symposium, CDC

| 5 Year Survival Rates for Stage I Breast Cancer (2000-2007)* – Southern Arizona Affiliate Counties | |
|--|-------|
| RACE | |
| White | 89.4% |
| African American | 72.1% |
| Asian | 87.9% |
| Hispanic | 86.5% |
| American Indian | 89.3% |

* The national average is 98%
Source: ACR

statistics and demographic review

In order to create a comprehensive look at breast cancer in Southern Arizona, the CPR utilizes quantitative data from: the Arizona Department of Health Services (ADHS); the Arizona Cancer Registry (ACR); Arizona Health Survey (St. Luke's Health Initiatives, 2010); the Arizona State University Center for Health Information and Research; the CDC; the Survey, Epidemiology and End Result (SEER) cancer database; and the US Census Bureau (American Community Survey and Population Estimates Program).

Breast cancer statistics involve, among other things, incidence, mortality and survival rates of various ethnicities based on stage of diagnosis. The SEER database provides the most comprehensive data nationwide; however, Arizona does not report to SEER but rather to the ACR. At best, the ACR database is a few years behind, and, at times, incomplete due to inaccuracies and inconsistencies in filling out ACR documents and death certificates, and inconsistencies in rural county reporting.

The Southern Arizona Affiliate includes Pima, Yuma, Cochise, Santa Cruz, Greenlee and Graham counties which account for a population of about 1.4 million. Pima County has 72% of the population and Yuma county borders California. The remaining counties are smaller and some are rural, making it difficult to ensure that demographic data is accurate and stable. Pima County has almost 1 million residents of which 73.9% are white alone, and 32.8% are of Hispanic or Latino origin. Blacks are 3.4% of the population. The median household income is \$45,888 and 29% of the people over the age of 25 do not have a high school diploma. Over 15% live below the federal poverty level.

The remaining five counties are similar to Pima but a few distinctions exist: some counties have a five to ten percent higher high school graduation rate, more retirees over the age of 65 live in Yuma, Graham is 15.5% American Indian, and Santa Cruz is 79.9% Hispanic or people of Latino origin.

The Hispanic, African and Native American, low income white women, undocumented Hispanic women, and the underinsured/uninsured require Komen's resources. Though the six counties share these demographics, disparities exist between rural communities and urban centers. Graham and Greenlee County, both of which are rural, have few, if any, FDA approved mammography facilities and no existing Komen grantees. Pima County includes the city of Tucson; the University of Arizona; the Arizona Cancer Center; and many providers, hospitals, laboratories and mammography facilities. Komen's challenge is to meet the needs of the wide-spread rural communities, including parts of Pima County, while at the same time enlisting the expertise of personnel in Tucson to help support the entire service area.

Across the service area are women insured by the state's Medicaid program: Arizona Health Care Cost Containment System (AHCCCS). These women have lower mammography rates when compared to the same racial/ethnic group of women in self-reported mammogram data by county. Many women are part of the "working poor" and are not covered by AHCCCS or any other health insurance. These numbers are certain to grow as the state deals with budget constraints and cuts to AHCCCS.



“Because I was only 23 when I got my first diagnosis, I could not qualify for any free mammogram programs because they only took people after 40. Financial help was a huge stressor for me because I fell in the gap the second time and I had to fight my way through the system to get treatment. Having a physical job I lost so much income too.” - **Survivor**

analysis of the health care system

The Affiliate conducted three separate surveys: a Health Systems Analysis, a Direct Care Provider Survey (oncology) and a Direct Care Provider Survey (primary care and gynecological). Four provider and healthcare worker focus groups were also performed, including physicians, nurses, healthcare staff, Well Women Health Check (part of the CDC's National Breast and Cervical Cancer Early Detection Program {NBCCEDP}) staff/directors, and promotoras, the latter of which are trained healthcare facilitators and providers without degrees in medicine.

The Health Systems Analysis determined assets as well as gaps and barriers existing within the Affiliate service area. Using the online survey tool SurveyMonkey, surveys were sent to approximately 20 healthcare facilities in early 2011, including county health departments, community health agencies and local Komen grant recipients. The Direct Care Provider Survey for oncologists provided perspective on breast care, treatment, barriers faced, and whether or not providers collaborated to provide treatment. In early 2011, surveys were sent to approximately 25 oncology providers; the Affiliate received 11 completed surveys, representing Arizona Oncology, University of Arizona Cancer Center, US Oncology, Ars Nova Internal Medicine and Arizona Community Physicians. The Direct Care Provider Survey for primary care physicians and gynecologists provided perspective on breast care, screening, diagnosis, and follow up treatment. In early 2011, surveys sent to approximately 40 individual providers resulted in 19 completed surveys being returned, representing two organizations: University Medical Center and El Rio Community Health Center.

In general, respondents note that Southern Arizona's current system is average in meeting breast health needs. However, while sufficient services exist for many groups, particular demographics fall through the cracks.

The primary barrier mentioned by nearly every respondent was access to insurance. Eligibility requirements for the Arizona Health Care Cost Containment System (AHCCCS), the state's Medicaid program, and ongoing reductions in services increasingly limit access to care for those who are uninsured or underinsured. Additional legislative issues include:

- Arizona is an Option 1 (most restrictive) state under the Breast and Cervical Cancer Prevention and Treatment Act of 2000, which means that women who were diagnosed at a non-Well Woman Health Check Program (WWHP) facility are not eligible for funds that have been earmarked for treatment.
- Additional funding to supplement the WWHP funds is needed in order to increase the number of women able to be screened.

Another challenge was lack of education and awareness about available resources such as WWHP. While some successful programs have established a continuum of care model, others rely on Komen funds to provide services otherwise not available.

Additional needs identified by health care providers and the Affiliate include:

- Graham and Greenlee counties have sparse populations and few breast health providers.
- Women identified as least likely to get regular breast screenings are: Hispanic, African American, and American Indian women, low income White women, undocumented Hispanic women, and underinsured or uninsured.

"I think Inflammatory Breast Cancer needs to receive more media attention so women are told that there is NO lump and mammograms can miss it. Most women I have talked to were not aware of IBC or knew what it was." - Survivor



community perspectives on breast cancer

To determine breast cancer perspectives in target communities, the Affiliate reached out to both breast cancer survivors and the general public via electronic surveys and focus groups.

Surveys for the general public were sent to 250 individuals within the Komen Southern Arizona database with a goal of reaching individuals in each county. The Affiliate received 41 surveys back; some were complete, others were incomplete. Participants included one African American woman, one Asian woman, ten Hispanic women, 25 White females and three White males. The surveys were sent via the online survey tool SurveyMonkey.

Survivor surveys were sent to 450 survivors, some of whom were part of the Komen Southern Arizona survivor database and others who had been identified by local grant recipients. The Affiliate received 189 surveys back. The participants included 135 White women, three Asian women, three American Indian women, one African American woman and 52 Hispanic women. These surveys were also sent via the online survey tool SurveyMonkey.

While the most common themes from both the electronic surveys and the focus groups vary slightly between survivors, non-survivors and different ethnic groups, common issues appear frequently in all groups. These themes include:

- lack of health insurance and the high costs of medication and co-pays,
- lack of information about early detection and information about access in their areas,
- need for familial resources such as support groups for co-survivors and children,
- fear of treatment, side-effects and recurrence,
- uncertainty about how immigration status will affect breast cancer treatment.

The most common themes from the survivor surveys include:

- need for more financial assistance such as daycare and housing subsidies,
- training for medical providers regarding WWHP and other financial opportunities,
- more support groups and information on accessing wigs and prosthesis,
- awareness in the healthcare community about the emotional impact on survivors,
- increased services in rural areas and transportation assistance,
- uncertainty about how immigration status will affect breast cancer treatment.

One hundred sixty three female survivors reported having private health insurance at the time of diagnosis (all private); only 145 reported that it covered total costs. Eleven women reported having no health insurance and relied on the WWHP or paid for services themselves.

Barriers to accessing care were a lack of or inadequate health insurance and transportation, and fear of treatment or side-effects. When asked what issues they have faced for which there are no services, the top response was emotional, followed by sexual, financial and physical.



"More timely access to healthcare professionals [is needed] once diagnosed." - Survivor

conclusions

While the purpose of the Community Profile is to provide an overview of the state of breast cancer in Southern Arizona for healthcare professionals, administrators, legislators, policymakers, and the general public, it is also the basis upon which the Affiliate sets its priorities for the coming years.

Data Collection

A need exists to refine collection and reporting of breast cancer data in Arizona. The Arizona Cancer Registry (ACR) is understaffed and coping with budget constraints. Providers in Arizona may not always accurately and consistently fill out forms in a timely fashion sent to them by the ACR. Much of Southern Arizona is rural and home to populations with cultural barriers that prevent accurate and timely submission of incidence and mortality rates of breast cancer. Without complete ACR data regarding breast cancer incidence, mortality and survival rates for stage of diagnoses and ethnicity, it is difficult to ascertain positive or negative outcomes from various grant programs and services. Additionally, in order to understand breast cancer data from the ACR, age distribution in Arizona compared to the national data must be calculated.

Barriers to Healthcare

Populations of people in Arizona may know of breast health facilities and programs, but are unable to access care due to lack of transportation or the rural nature of communities. The primary barrier to adequate breast healthcare mentioned by nearly every survey or focus group respondent was no insurance and insured co-pays so high that healthcare becomes too costly. Changing AHCCCS eligibility requirements and ongoing reductions in services increasingly limit access to care for the uninsured/underinsured.

Legislative Issues

Additional legislative issues needed to be addressed, including changing Arizona's restrictive Option 1 of accessing the Breast and Cervical Cancer Prevention and Treatment Act of 2000, under which women who are diagnosed at a non-WWHP facility are not eligible for treatment funds from WWHP. This finding indicates the need to educate both the target populations for this service as well as the provider community, including primary care providers and urgent care centers who provide treatment.

Where the Gaps Exist

An insufficient level of education and awareness prevails about available breast cancer resources and the importance of early detection. Data exists showing that yearly mammography screening rates in Arizona have dropped from 65% to 40% in 2009.* While some health centers have established a successful Continuum of Care model, others rely on Komen funds to provide vital services otherwise not available. With such a vast rural population, gaps exist where no Komen treatment funding exists, reducing the number of women accessing early detection, diagnosis and treatment. Healthcare providers request programs and facilities targeting Hispanics, African Americans, American Indians, and Asian populations. For example, Graham and Greenlee counties were not well represented in the Community Profile as they have no Komen grants and only one FDA-approved mammography facility.

priorities

To determine priorities, the Affiliate assembled a Community Profile committee to review demographic data, the analysis of the healthcare system, and community perspectives on breast cancer, in order to uncover gaps in the system and other common themes. The results listed below must be addressed by our community in order to create a comprehensive and successful breast health system.

Priority One: Enhance education and outreach of breast self-awareness messages to increase early detection by as much as 10% in all service areas.

- develop messages focusing on importance of early detection
- create a focused campaign for African American, American Indian and Hispanic women to increase mammography rates and avoidance of late stage diagnoses

- inform private sector, non-Well Women HealthCheck Program (WWHP) providers about referring women eligible for WWHP to an appropriate facility; a breast cancer diagnosis made in a non-WWHP facility will make them ineligible for treatment through WWHP.
- develop education for providers about community resources and available services for mammography, diagnosis and treatment.

Priority Two: Increase access to direct care and continuum of care.

- increase capacity of breast cancer provider community to improve accessibility and “seamless “system of care for breast cancer treatment in service area
- work together to eliminate cost barriers to screening and treatment services
- improve and support patient navigation and promotora** programs to assist patients, beginning at initial diagnosis and continuing through treatment and survivorship
- assist providers in learning how to help patients with fears in a sensitive manner.

Priority Three: Develop a set of education messages and set of policy objectives aimed to improve overall observation, data collection and reporting for the state of Arizona.

AFFILIATE ACTION PLAN

Action Area 1: Organize a Promise Collaborative serving all three priority areas in the service area, including the Phoenix Affiliate, the Arizona Department of Health Services and a statewide “Common Cause Campaign” to ensure:

- improved surveillance and reporting of breast cancer incidence and mortality rates,
- development of statewide training system for WWHP contractors and organizations,
- development of resources leveraged for renewed outreach, education and enrollment for early detection.

Action Area 2: Refine rural outreach plan to mobilize assets within and across service area.

- convene formal and informal leader to develop Komen Councils within each county
- identify and prioritize goals for increasing breast cancer survivorship through focusing on early detection, access to treatment and support for survivors within each county

Action Area 3: Refine Request For Award (RFA) and grants management program to ensure:

- a balance in RFA goals and evaluation of goals attainment,
- current and historic grantees energize and produce early detection campaigns.
- development of a set of comprehensive outcomes-based results that guide refinement of the grant-making program
- grant programs target outreach and early detection in African American and American Indian communities in service area
- grants ensure an actual change in knowledge, skills and behaviors to improve early detection.

* Source: CDC, BRFSS Survey Data, 2009

** A promotora is a lay, bilingual healthcare worker, usually a member of the community they serve.

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, public policy initiatives which have broken down barriers and closed gaps for those needing services, and quality care through our community outreach programs. It has also empowered individuals to be self advocates through grass roots education efforts.

Since establishment in 1999, the Southern Arizona Affiliate has remained true in its commitment to its service area which includes the southern six counties stretching from Greenlee on the eastern border to Yuma on the western border. By funding international research, local programs that provide vital education, screening and treatment to underserved women, and motivating activism and empowerment through our public policy and education initiatives, the Affiliate acts with purpose and conviction in its commitment to saving lives and ending breast cancer forever. Our 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.

To meet our promise, the Southern Arizona Affiliate relies on the Community Profile process to provide the framework and guide the organization. The Community Profile provides an overview of the six counties in our service area identifying existing and gaps in services, education and outreach needs, as well as directing public policy efforts. In addition, the Community Profile will pinpoint areas to concentrate public relations and marketing efforts. This Profile also identifies areas for further study and exploration, specifically American Indian and young Hispanic women's breast health needs and services.

references

1. Arizona Cancer Registry
2. U.S. Cancer Statistics Working Group. United States Cancer Statistics: 1999–2007 Incidence and Mortality Web-based Report. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2010. Available at: [HYPERLINK www.cdc.gov/uscs](http://www.cdc.gov/uscs).
3. Edwards BK, Ward E, Kohler BA, et al. Annual report to the nation on the status of cancer, 1975--2006, featuring colorectal cancer trends and impact of interventions (risk factors, screening, and treatment) to reduce future rates. *Cancer* 2010; 116:544-73.
4. Berry DA, Cronin KA, Plevritis SK, et al. Cancer Intervention and Surveillance Modeling Network (CISNET) collaborators. Effect of screening and adjuvant therapy on mortality from breast cancer. *N Engl J Med* 2005 Oct 27; 353:1784-92.
5. CDC. Health, United States, 2009: with special feature on medical technology. Hyattsville, MD: US Department of Health and Human Services, CDC, National Center for Health Statistics; 2010.
6. Miller JW, King JB, Ryerson AB, Ehemann CR, White MC. Mammography use from 2000 to 2006: state-level trends with corresponding breast cancer incidence rates. *Am J Roentgenol* 2009;192:352-60.
7. US Department of Health and Human Services. Healthy People 2020. Washington DC, U.S. Department of Health and Human Services; 2010. Available at: <http://www.healthypeople.gov/2020/about/default.aspx>
8. LC Richardson, MD, SH Rim, MPH, M Plescia, MD, Div of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, CDC. *MMWR* July 6, 2010; 59: 6-9.

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Breast cancer knows
no boundaries –
be they age, gender,
socio-economic status
or geographic location