



# COMMUNITY PROFILE REPORT

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2011

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## **Acknowledgements**

We would like to extend our heartfelt thank you to the community members who assisted with the 2011 Community Profile Report.

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## **Executive Summary**

### **Introduction**

Founded in 1993, the Phoenix Affiliate of Susan G. Komen for the Cure® has evolved from a Race-centric, special events organization, to a well-rounded, breast health agency with a strong community grants program. The expansion of Affiliate operations to enhance Affiliate-sponsored, promise-related activity has yielded a tremendous Community Outreach Ambassadors program; funded a new Affiliate-based Communities of Color initiative; ignited advocacy and public policy activism surrounding federal funding for breast cancer screening and the preservation of the state's health insurance program, Arizona Health Care Cost Containment System (AHCCCS); and positioned the Affiliate as a premier partnering agency in matters of education, early detection, public policy and private funding.

The first Komen Phoenix Race for the Cure in 1993 drew 1,500 participants and raised \$65,000. The Affiliate's most recent Race raised nearly \$2 million with more than 30,000 participants. Since our inception, the Affiliate has raised more than \$18 million for groundbreaking national breast cancer research programs and local community grants that fund education, screening and treatment programs. Of those funds, 75 percent remain in the community and 25 percent fund the national Susan G. Komen for the Cure Research Grants Program. The Komen Phoenix Affiliate is the largest private grantor of breast cancer funding in Arizona.

The basis for everything we do is a promise that Nancy G. Brinker made to her sister, Susan G. Komen, nearly 30 years ago. Today, more than 120 Komen Affiliates throughout the world abide by this promise: to save lives and end breast cancer forever by empowering people, ensuring quality of care for all and energizing science to find the cures. Fulfilling this promise is about much more than a pink ribbon and hosting a successful Race for the Cure each year – it's about empowering our fellow Arizonans to conquer breast cancer by making an impact through advocacy, education, outreach and support activities.

The biennial Community Profile Report is just one example of how we collaborate with community partners to carry out our vision. Designed to give our community a comprehensive look at the state of breast cancer throughout central and northern Arizona, the report is meant to be not only educational and informative, but also inspirational and motivating. While it demonstrates the things that are going well in our state, it also clearly outlines the areas in which our state needs to improve. The Affiliate will use this report to set our strategic goals and direction for the future, and we encourage other organizations and agencies to do the same.

### **Statistics and Demographic Review**

In order to create a comprehensive look at breast cancer in central and northern Arizona, the Affiliate utilized quantitative data from multiple sources. To determine the Breast Cancer Impact in the Affiliate Service Area, we drew data from the Arizona Department of Health Services (breast cancer incidence, mortality and stage of diagnosis data) from several consecutive years to provide for sufficient numbers to generate relatively stable and reliable rates. Supplementary data was also included from sources such as the Arizona Health Survey (St. Luke's Health Initiatives, 2010), the ASU Center for Health Information and Research, and the U.S. Census Bureau (American Community Survey and the Population Estimates Program).

Compared to other states in the nation, Arizona has low rates of breast cancer incidence and mortality. Indeed, Arizona's incidence rate of 106.7 cases per 100,000 persons for the period 2003 through 2007 was the lowest in the nation for that time period. Arizona's breast cancer mortality rate of 21.3 per 100,000 persons for that time period was second lowest only to Hawaii (Louisiana's rate was highest at 28.3 deaths per 100,000 persons). However, Arizona's death rate still exceeds the *Healthy People 2020* target death rate of 20.6 deaths per 100,000 population.

In Arizona, incidence rates are highest among Yavapai County residents (117.5 per 100,000), followed by Maricopa (109.7 per 100,000) and Mohave County residents (101.7 per 100,000). Rates of new cases also vary by race/ethnicity, with White women having the highest rates (100.1 per 100,000), and Native American women having the lowest rates (51.4 per 100,000). However, these rates must be viewed with caution as race-specific variation between counties may be due to small numbers rather than actual differences in incidence.

The rate of early diagnosis also varies by race/ethnicity. African American/Black and Native American women residing in Phoenix Affiliate counties are less likely to be diagnosed early in the course of the disease. For women diagnosed at the "local" stage (confined to the breast), five-year survival is highest among White, Asian and Native American women and lowest for Hispanic and African American/Black women. For women diagnosed at the "regional" stage (spread to regional lymph nodes), African American/Black and Native American women have consistently lower rates of survival throughout the one- to five-year survival range. The national tendency for mortality rates to be highest among African American/Black women is also found in Arizona.

Self-reported mammogram data by county reveals that screening rates are lowest in Apache (70.1%) and Navajo (70.8%) counties, and highest in Maricopa (84.4%) and Yavapai (82.9%) counties. Statewide mammogram rates for women 40 years and older reveals that Native Hawaiian/Pacific Islander women were the most likely to have had a mammogram in the past two years (85.6%), followed by White women (76.4%). Asian women were the least likely to have had a mammogram in the past two years (59.6%). Again, these rates must be viewed with caution as race-specific variation may be due to small numbers rather than actual differences.

### **Analysis of the Health Care System**

To obtain a thorough analysis of local services, the Affiliate conducted two separate surveys: a Health Systems Analysis and a Direct Care Provider Survey. The Health Systems Analysis was used primarily to determine where gaps and barriers exist within the Affiliate service area. Using the online survey tool SurveyMonkey™, surveys were sent to approximately 30 healthcare organizations in early 2011, including county health departments, community health agencies and local Komen grant recipients. The Affiliate received 19 completed surveys.

The purpose of the Direct Care Provider Survey was to obtain the provider (primarily oncologist) perspective on breast care, including what treatments they provide, what barriers they face, and whether or not they collaborate to provide treatment. In early 2011, surveys were sent to approximately 25 individual providers via SurveyMonkey™ and the Affiliate received seven completed surveys representing four organizations.

The Affiliate created asset maps to demonstrate where services are the most populous, as well as where they might be lacking. The Community Profile features two of these maps, one showing FDA-approved mammography centers and another showing Well Woman HealthCheck Program (a state-wide program that provides free cancer screenings for women who qualify) providers. In addition to these community assets, the Affiliate is engaged in a variety of community and collaborative partnerships designed to fill in gaps in service and empower Arizonans to conquer breast cancer. The Affiliate's Community Grants Program funds local education, screening and treatment programs that are selected based on their ability to meet the Affiliate's service priorities. Collaborative partners include, among others, health organizations such as the American Cancer Society and coalitions that help Komen break down cultural barriers.

In general, the perception is that Arizona's current system is average in meeting breast health needs. However, while there are sufficient services for many groups, there are still particular demographics that fall through the cracks. The primary barrier mentioned by nearly every respondent was 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 HealthCheck 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 mentioned frequently was a lack of education and awareness about available resources. While some programs have established a continuum of care model that appears to be working, others rely on Komen funds to provide vital services that otherwise would not be available. However, with such a large population to serve and large pockets in the service area where no Komen treatment funding exists, the number of women that can be treated is diminished.

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

- Programs that target the Hispanic population
- The far eastern and western sections of Maricopa County, which do not have any Komen-funded screening programs
- Women identified as least likely to get regular breast screenings are:
  - Hispanic, African American/Black, and Native American women;
  - refugees;
  - low income White women;
  - undocumented Hispanic women; and
  - the underinsured or uninsured.

## **Overview of Community Perspectives on Breast Cancer**

To determine the breast cancer perspective 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 759 individuals within the Komen Phoenix database with a goal of reaching individuals in each county. The Affiliate received 87 surveys back; some were complete, others were incomplete. Participants included 18 African American women, one Asian woman, nine Hispanic women, one Native American male, 43 White females and five White males. The surveys were sent via the online survey tool SurveyMonkey™.

Survivor surveys were sent to 227 survivors, some of whom were part of the Komen Phoenix survivor database and others who had been identified by local grant recipients. The Affiliate received 27 surveys back. The participants included 26 White women and one Hispanic woman. 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, there were common issues reflected frequently among all groups. These themes include:

- Lack of health insurance and a need for more financial assistance programs
- Lack of education regarding breast health
- A need for more support resources and education about available resources
- Fear of treatment, side effects and reoccurrence

The most common themes from the survivor surveys include:

- The need for more financial assistance programs
- Training for medical providers regarding both sensitivity issues and awareness of local resources
- More support groups and information on accessing wigs and prosthesis
- A hub within the community with access to various resources and information
- Increased services in rural areas
- Issues survivors face include the fear of reoccurrence and health insurance and the ability to afford follow-up care

Twenty-two women reported to have had health insurance at the time of diagnosis (all private). However, only 13 reported that it covered the total cost of care. Three women reported they had no health insurance and relied on the Well Woman HealthCheck Program or paid for services themselves. A lack of health insurance and inadequate health insurance were identified as the top barriers to access to care. When asked what issues they have faced for which there were no services, the top response was emotional followed by sexual, financial and physical.

## **Conclusions**

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

To determine the following priorities, the Affiliate assembled a Community Profile committee to review the demographic data, the analysis of the health care system and the community perspectives on breast cancer to uncover gaps in the system and other common themes. While the results are listed below, in order of priority, it's important to note that each of these objectives must be addressed by our community in order to create a comprehensive and successful breast health system in Arizona.

This report defines medically underserved as Hispanic, African American/Black, and Native American women; refugees; low income White women; undocumented Hispanic women and underinsured and uninsured populations. Priority focus is being placed on Hispanic, African American/Black, and Native American women and the underinsured and uninsured populations.

**Priority One: Enhance education and outreach of breast-self awareness message to increase early detection by**

- Creating messages that focus on breast health and the importance of early detection targeted to the Native American and African American/Black populations who have demonstrated disparities as far as later staged breast cancer presentation, lower five-year survival rates and lower breast cancer screening rates.
- Creating a centralized breast health and breast cancer resource centers in rural areas that include information on a range of subjects, from breast self-awareness to breast cancer resources and available services for breast cancer survivors.
- Presenting information to health care providers to increase their knowledge of the Well Woman HealthCheck Program (WWHP) and its eligibility criteria to ensure those who are eligible enroll; of the health care system, community resources and available services; of the fears patients have and how to address those fears in a sensitive manner.
- Creating programs that target the Hispanic population.

**Priority Two: Improve access to direct care and the continuum of care by**

As an organization, Komen wants to ensure quality care for all by eliminating and breaking down barriers to people's access to care.

- Improving uninsured people's ability to get into the health care system.
- Eliminating cost barriers to screening and treatment services.
- Eliminating transportation barriers.
- Supporting patient navigation and Promotora programs to assist patients through the screening, diagnostic, treatment and post-treatment support process for those defined as medically underserved.
- Increasing access to screening by encouraging the use of mobile mammography units.
- Creating collaborative partnerships with multiple agencies that maximize financial and human resources to extend the reach of community programs and serve more individuals.
- Creating a forum to advance public policy issues on a State level.
- Creating programs that target the Hispanic population to increase screening utilization and access to treatment.

**Priority Three: Improve quality of life through survivorship support programs by**

Breast cancer survivorship begins on the day of diagnosis.

- Supporting services that address the emotional, sexual, financial, physical and other impacts that occur after a breast cancer diagnosis.
- Creating a centralized location for information on available services after diagnosis, during treatment and after treatment including resources for wigs, prosthesis, lymphedema treatment and support groups.
- Increasing availability of financial assistance.
- Creating programs that educate survivors on the reduction of risk for breast cancer in an effort to reduce the fear of reoccurrence.

### **Affiliate Action Plan**

These priorities will help set the direction of the Affiliate until the next Community Profile is issued in 2013. By the end of July 2011, the Affiliate's Board of Directors will utilize the findings in this report to determine long- and short-term strategic and operational goals addressing the priorities listed above. In addition, the Affiliate will create funding guidelines for the annual Community Grants Program that coincide with these priorities and organizations will be awarded grants based on their ability to fulfill the community's most pressing needs.

## **Introduction**

### **Affiliate History**

Founded in 1993, the Phoenix Affiliate of Susan G. Komen for the Cure® has evolved from a Race-centric, special events organization, to a well-rounded, breast health agency with a strong community grants program. The expansion of Affiliate operations to enhance Affiliate-sponsored, promise-related activity has yielded a tremendous Community Outreach Ambassadors program; funded a new Affiliate-based Communities of Color initiative; ignited advocacy and public policy activism surrounding federal funding for breast cancer screening and the preservation of the state's health insurance program, Arizona Health Care Cost Containment System (AHCCCS); and positioned the Affiliate as a premier partnering agency in matters of education, early detection, public policy and private funding.

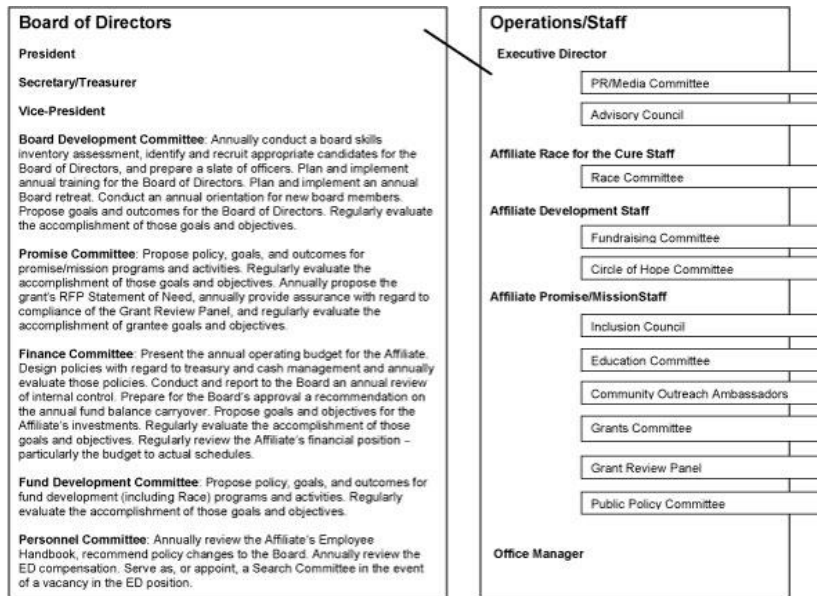
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### **Organizational Structure**

The Phoenix Affiliate is comprised of eight employees. Day-to-day operation is the responsibility of the executive director, and its governance is provided by a volunteer board of directors who receive no compensation for their services. Figure 1 below shows the Affiliate's organizational structure.

Figure 1.  
*Organizational Structure of the Komen Phoenix Affiliate*



Board Committees (left side) are exclusive to elected members of the Board of Directors (and applicable ex officio staff). All Board members serve on a Board Committee. Operations' Committees (right side) may involve hundreds of volunteers in support of our Affiliate's programs. Board members may, from time to time, also volunteer on an Operations' Committee. In doing so, however, they act as an individual volunteer, not as a representative or member of the Board of Directors. Board members volunteering on Operations' Committees understand that their role is to support the work of that specific committee under the direction of the appropriate Affiliate staff – unrelated to their role as Board members.

## Purpose of Community Profile Report

The purpose of the Community Profile is to create a usable resource that outlines the state of breast cancer in Arizona in general, and the nine counties served by its Phoenix Affiliate. By providing an in-depth study based on actual data, surveys and key informants, this document is a critical tool for statewide strategic planning and collaboration. The Profile, which is updated every two years, will be one of the central documents for educating stakeholders, the public and government leaders who are working to reduce death rates from breast cancer and increase early detection. With public funding growing more limited and the need increasing across economic levels, the Affiliate must collaborate with its community partners to ensure not only that gaps in services are eliminated, but also that services are not duplicated. As seen below, the Affiliate encompasses a large and diverse service area in which different populations have different needs and challenges.

## Description of Service Area

Arizona is the fifth largest land mass state in the country with a total population of 6,595,778 according to the U.S. Census most current figures. Komen Phoenix is one of two Affiliates in Arizona responsible for carrying out the Komen Promise on a local level. The Phoenix Affiliate service area covers nine central and northern Arizona counties, which include Apache, Coconino, Gila, La Paz, Maricopa, Mohave, Navajo, Pinal, and Yavapai. The Southern Arizona Affiliate, located in Tucson, provides services to the six southern Arizona counties which are Cochise, Graham, Greenlee, Pima, Santa Cruz, and Yuma.

Demographic data are provided below for the nine Komen Phoenix Affiliate service area counties. The total population for these counties is 5,160,231 (U.S. Census estimate, July 1, 2009), or 78% of the statewide population estimate of 6,595,778.

Table 1.  
*Population by county by race (U.S. Census estimate, July 1, 2009)*

	Total	White alone	Black alone	Native American or Alaska Native alone	Asian alone	Native Hawaiian/Pacific Islander	Two or more races	Hispanic or Latino origin*
Apache	70,591	23.8%	1.7%	72.5%	0.5%	0.2%	1.3%	6.0%
Coconino	129,849	64.8%	1.5%	30.3%	1.2%	0.1%	2.0%	12.5%
Gila	52,199	82.0%	0.7%	15.1%	0.8%	0.1%	0.4%	16.9%
La Paz	20,012	78.6%	1.1%	13.8%	0.5%	0.1%	2.0%	23.9%
Maricopa	4,023,132	87.3%	5.2%	2.2%	3.2%	0.2%	1.8%	30.5%
Mojave	194,825	92.8%	1.4%	2.6%	1.2%	0.1%	1.8%	13.7%
Navajo	112,975	50.4%	1.4%	46.1%	0.4%	0.1%	1.5%	9.7%
Pinal	340,962	85.7%	4.6%	6.1%	1.7%	0.1%	1.8%	29.8%
Yavapai	215,686	94.8%	1.0%	1.7%	0.8%	0.1%	1.6%	12.6%

\* In the 2000 Census, individuals were asked to designate themselves and household members as one or more races (e.g., “White” or “Native American”). Separately, “Hispanic or Latino” was included as an option for ethnicity. Therefore, the race categories sum to 100%, and the “Hispanic or Latino” category separately includes individuals who consider themselves “Hispanic or Latino”.

Table 2.  
*Selected demographic characteristics – Phoenix Affiliate Service Area  
U.S. Census Bureau, American Community Survey, 2005 – 2009*

	Population	Individuals living below the federal poverty level	Median household income	People 25+ years of age without high school diploma	Health insurance coverage for women 40+ years*
Apache	70,591	36.7%	\$28,378	30.4%	90.5 ± 21.4%
Coconino	129,849	17.4%	\$48,259	13.9%	95.7 ± 14.4%
Gila	52,199	19.3%	\$36,930	15.5%	93.1 ± 18.2%
La Paz	20,012	19.7%	\$31,640	25.3%	87.5 ± 34.6%
Maricopa	4,023,132	13.3%	\$55,223	15.7%	89.0 ± 2.6%
Mojave	194,825	15.4%	\$40,157	17.6%	87.1 ± 10.6%
Navajo	112,975	24.6%	\$38,197	21.3%	90.9 ± 17.1%
Pinal	340,962	13.9%	\$49,301	18.3%	90.6 ± 10.0%
Yavapai	215,686	12.7%	\$43,965	11.3%	90.2 ± 8.5%

\* Source: Arizona Health Survey, St. Luke’s Health Initiatives, 2010

The extremes in geography throughout central and northern Arizona, coupled with many sparsely populated areas, play a critical role in access to healthcare and present challenges for the Affiliate. Maricopa County, home to greater Phoenix, is the largest and most populated of the state’s fifteen counties. However, within the Affiliate’s wide service area, pockets of population are scattered and, at times, unreachable, especially, in the far northern counties. Travel from

county to county can be daunting, especially in the winter. Distance and transportation to breast cancer service providers has been and continues to be a major challenge, especially for Native Americans residing on and off the reservations in Navajo and Apache counties.

According to the Arizona Department of Health Services Cancer Registry, the following statistics apply to Arizona:

- Breast cancer is the second leading cause of death and most commonly diagnosed cancer in women, with approximately 111 new cases per 100,000 women per year.
- Since 2000, breast cancer incidence and mortality rates have slowly decreased.
- During 2007, 3,799 women were diagnosed and 715 women died from breast cancer.
- Most breast cancer cases are diagnosed in women between 55-74 years of age.
- White women have the highest incidence rates, but African American/Black women have the highest mortality rates compared to other racial and ethnic groups.

### **Capacity to Serve**

With a service area that encompasses a large metropolitan area and outlying rural areas, the Affiliate strives to fulfill many roles. In the current year, we have funded 28 agencies that deliver breast health and breast cancer programs; staffed an office that responds to community needs and requests; provided breast health and breast cancer information at over 180 community events through our Community Outreach Ambassador program; and participated in eight key community partnerships that expand our reach into our service area.

In particular, the Affiliate places an emphasis on filling the gaps for the medically underserved, including the uninsured and underinsured. All nine counties within the Affiliate's service area contain some of the Health Resources and Services Administration (HRSA) designated 43 Medically Underserved Areas and Populations (MUA/MUP), which have:

- Difficulty obtaining transportation to receive necessary care. Specifically, necessary specialty care may require extensive travel.
- Fewer choices for health insurance coverage because the HMO penetration rate in rural areas is lower than in urban areas. Employer-sponsored insurance is less widely available in rural areas due to the proliferation of small businesses that are unlikely to offer employee health insurance.

Arizona's Well Woman HealthCheck Program (WWHP), a state-wide program that provides free cancer screening to women that qualify, enhances the Affiliate's capacity to serve the community by providing free clinical breast exams, mammograms, pelvic exams and Pap tests. According to the Arizona Department of Health Services (ADHS), there are over 100,000 women in Arizona who are eligible for the WWHP. (See page 22 for more data on the WWHP.)

Eligible participants include all women aged 40-64 who are also between 100-250 percent of the federal poverty level (FPL). Using multiple funding sources, the WWHP program was able to screen approximately 10 percent of the eligible population, compared to 14 percent of the eligible population at a national average level. The program has received level funding from the CDC the last few years and has maximized the number of women that can be screened for breast cancer.

## Breast Cancer Impact and Statistics in the Affiliate Service Area

### Data Source and Methodology Overview

As compared to the 2009 Community Profile, which used a combination of synthetic estimates and actual Arizona data, the 2011 Community Profile draws exclusively from actual Arizona data. The Arizona Department of Health Services provided breast cancer incidence, mortality and stage of diagnosis data. In many cases, these data were drawn from several consecutive years to provide for sufficient numbers to generate relatively stable and reliable rates. Supplementary data was also included from sources such as the Arizona Health Survey (St. Luke’s Health Initiatives, 2010), the ASU Center for Health Information and Research, and the U.S. Census Bureau (American Community Survey and the Population Estimates Program).

### Breast Cancer in Arizona

Compared to other states in the nation, Arizona has low rates of breast cancer incidence and mortality. Indeed, Arizona’s incidence rate of 106.7 cases per 100,000 persons for the period 2003 through 2007 was the lowest in the nation for that time period. Connecticut had the highest rate at 134.5 per 100,000 persons. Arizona’s breast cancer mortality rate of 21.3 per 100,000 persons for that time period was second lowest only to Hawaii (Louisiana’s rate was highest at 28.3 deaths per 100,000 persons). However, Arizona’s death rate still exceeds the *Healthy People 2020* target death rate of 20.6 deaths per 100,000 population.

While Arizona’s incidence and mortality rates are below the national rates, there are still specific populations within Maricopa County and other counties within the services area where the data reflects disparities, as will be discussed further in this report.

### Incidence and Mortality

In Arizona, breast cancer incidence and mortality vary by county and by race/ethnicity. Table 5 provides breast cancer incidence data for the nine Phoenix Affiliate counties:

Table 5.

*Age-adjusted breast cancer incidence rates by race/ethnicity  
2003 – 2007, Arizona Cancer Registry, Arizona Department of Health Services*

County	All	White	Black	Native American	Hispanic	Asian American or Pacific Islander
Apache	61.5	100.1	--	51.4	--	--
Coconino	53.9	124.6	114.3	44.3	80.6	77.2
Gila	94.6	106.2	--	56.9	33.2	--
La Paz	39.9	43.0	--	60.8	--	--
Maricopa	109.7	117.1	97.9	53.5	67.3	67.7
Mohave	101.7	106.3	49.9	29.2	52.3	89.2
Navajo	87.9	111.4	33.2	48.8	99.1	84.7
Pinal	95.8	109.1	110.1	13.3	55.5	58.9
Yavapai	117.5	119.5	73.6	69.4	91.7	36.9
<b>Arizona</b>	<b>106.7</b>	<b>115.8</b>	<b>95.2</b>	<b>48.7</b>	<b>67.9</b>	<b>65.1</b>

Incidence rates are highest among Yavapai County residents, followed by Maricopa and Mohave County residents. Rates of new cases also vary by race/ethnicity, with White women having the highest rates, and Native American women having the lowest rates. However, these rates must be viewed with caution as race-specific variation between counties may be due to small numbers rather than actual differences in incidence.

Table 6 below provides statewide mortality rates by race/ethnicity. As can be clearly seen, the national tendency for mortality rates to be highest among African American/Black women is also found in Arizona.

Table 6.  
*Breast cancer mortality rates by race – Arizona*  
*Per 100,000 females, age-adjusted to 2000 standard*

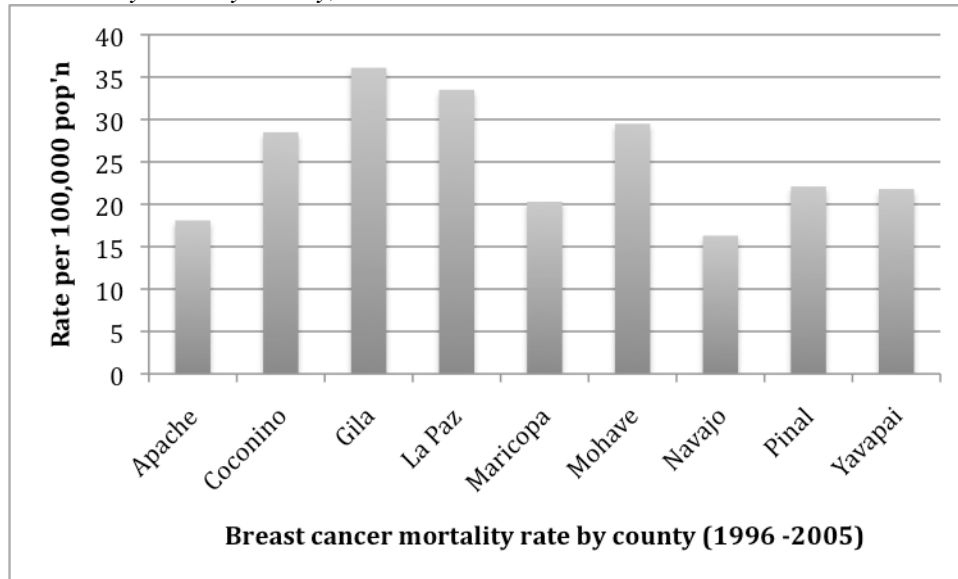
<b>Year</b>	<b>All</b>	<b>White</b>	<b>Black</b>	<b>Native American</b>	<b>Hispanic</b>	<b>API</b>
2009	19.2	19.8	30.7	11.6	16.4	11.6
2008	19.8	20.6	38.0	11.6	15.1	7.1
2007	20.1	20.5	23.9	16.2	16.9	11.3
2006	21.6	21.4	25.7	6.9	14.0	7.5
2005	20.7	22.3	35.7	14.9	19.8	17.3

As will be seen below, this is in part due to the fact that African American/Black women are most likely among all racial/ethnic groups to be diagnosed later in disease. However, Native American women are also likely to be diagnosed later in disease but have relatively low mortality rates. This suggests there are other factors affecting breast cancer mortality related to race/ethnicity.

Breast cancer mortality data by county is provided in Chart 2 below. As can be seen, rates vary significantly between counties.

Chart 2.

Breast cancer mortality rates by county, 1996-2005



Source: Health Resources and Services Administration, age-adjusted breast cancer mortality rate 100,000 population; 1996 – 2005.

### Stage of diagnosis

Early diagnosis is a critical factor in breast cancer survival. Table 7 below provides five-year survival rates by stage of diagnosis. As can be seen, the five-year survival rate is 98 percent for individuals diagnosed early in the disease course, i.e., localized.

Table 7.

Stage of diagnosis and 5-year survival rates

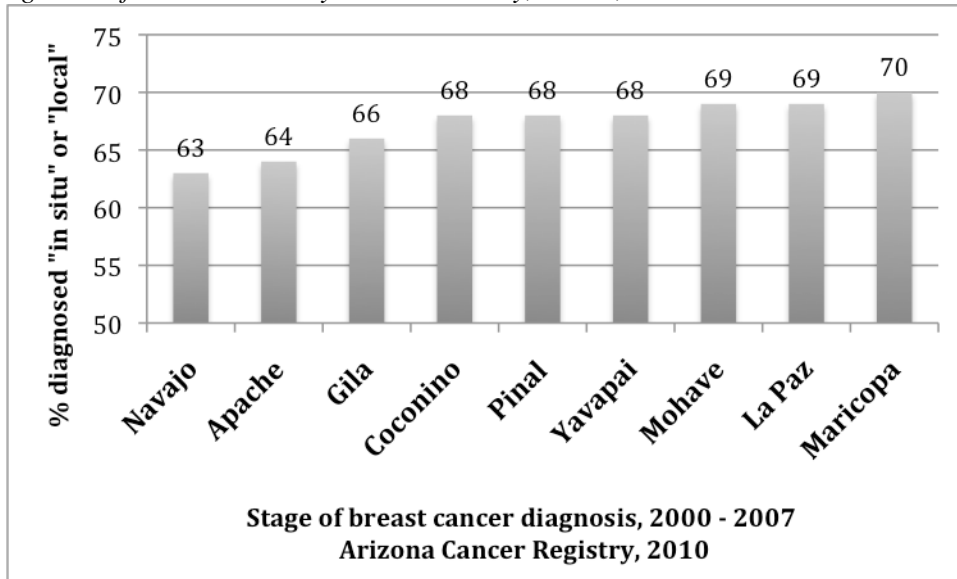
Stage at Diagnosis	Stage	5-year
	Distribution (%)	Relative Survival (%)
Localized (confined to primary site)	60	98.0
Regional (spread to regional lymphnodes)	33	83.6
Distant (cancer has metastasized)	5	23.4
Unknown (unstaged)	2	57.9

Source: Surveillance, Epidemiology and End Results (SEER) Program (1999 – 2006), NIH, NCI

Data from the Arizona Department of Health Services suggests that the majority of breast cancer diagnoses among residents of the Phoenix Affiliate counties are “localized” – either “in situ” or “local”. Chart 3 below provides the percentage of “localized” diagnoses by county of residence.

Chart 3.

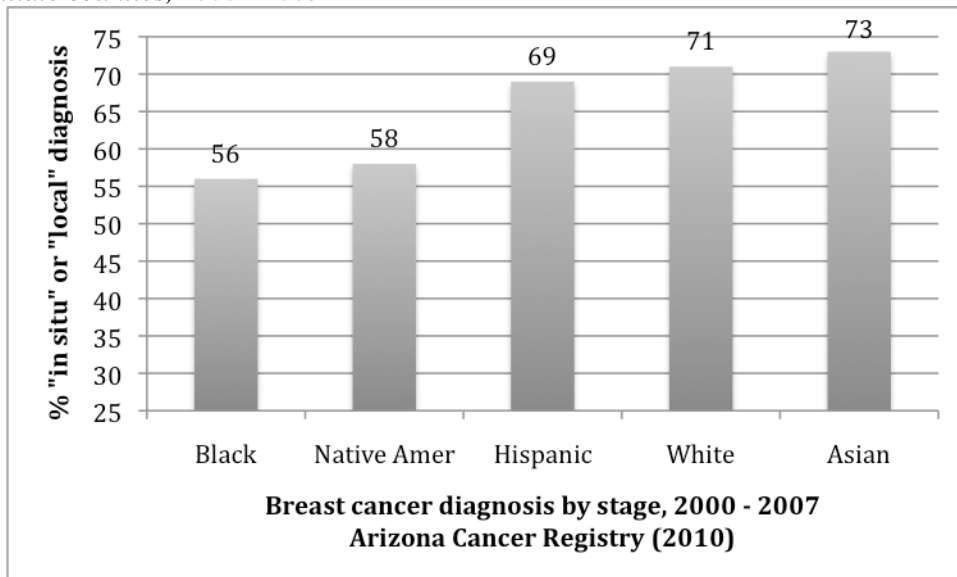
*Localized diagnoses of breast cancer by Arizona County, ADHS, 2010*



The rate of early diagnosis also varies by race/ethnicity. Chart 4 below indicates that African American/Black and Native American women residing in Komen Phoenix Affiliate counties are less likely to be diagnosed early in the course of the disease.

Chart 4.

*Percentage of breast cancer cases with localized diagnosis  
Phoenix Affiliate counties, 2000 - 2007*



### Survival Data

One- to five-year breast cancer survival rates are calculable through data from the Arizona Cancer Registry. These data are provided by race/ethnicity for the Affiliate counties in Tables 8 - 13 below. As can be seen, for each racial/ethnic group, survival improves with earlier diagnosis.

Table 8. Survival Rates among <b>White Women</b> by Stage of Diagnosis (2000 – 2007) – Phoenix Affiliate Counties				
	All	Local	Regional	Distant
<b>Case Count</b>	<b>14,607</b>	<b>8,411</b>	<b>4,488</b>	<b>542</b>
1 YR	97.0%	100.0%	98.3%	59.5%
3 YR	90.0%	97.0%	88.4%	36.2%
5 YR	81.0%	91.8%	76.9%	19.9%

Table 9. Survival Rates among <b>Black Women</b> by Stage of Diagnosis (2000 – 2007) – Phoenix Affiliate Counties				
	All	Local	Regional	Distant
<b>Case Count</b>	<b>397</b>	<b>167</b>	<b>162</b>	<b>27</b>
1 YR	93.5%	98.2%	96.7%	60.1%
3 YR	72.3%	89.1%	73.1%	*
5 YR	58.5%	78.6%	53.7%	*

Table 10. Survival Rates among <b>Asian Women</b> by Stage of Diagnosis (2000 – 2007) – Phoenix Affiliate Counties				
	All	Local	Regional	Distant
<b>Case Count</b>	<b>214</b>	<b>130</b>	<b>66</b>	<b>5</b>
1 YR	95.4%	96.8%	99.4%	*
3 YR	89.1%	94.3%	85.7%	*
5 YR	86.2%	93.1%	76.7%	*

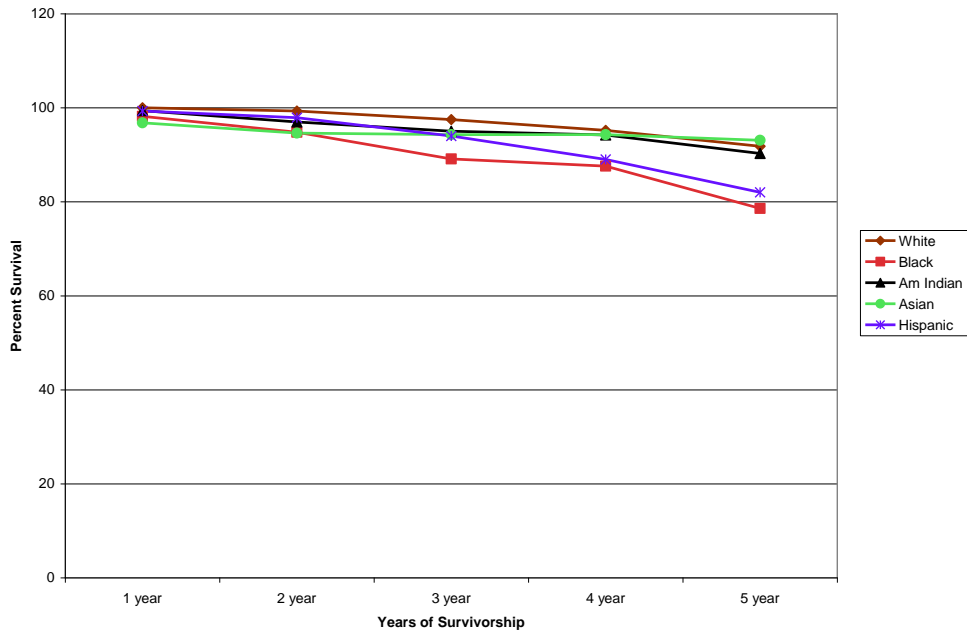
Table 11. Survival Rates among <b>Native American Women</b> by Stage of Diagnosis (2000 – 2007) – Phoenix Affiliate Counties				
	All	Local	Regional	Distant
<b>Case Count</b>	<b>279</b>	<b>121</b>	<b>113</b>	<b>19</b>
1 YR	94.5%	99.4%	99.3%	52.0%
3 YR	79.9%	95.0%	78.5%	*
5 YR	63.6%	90.3%	56.0%	*

Table 12. Survival Rates among <b>Hispanic Women</b> by Stage of Diagnosis (2000 – 2007) – Phoenix Affiliate Counties				
	All	Local	Regional	Distant
<b>Case Count</b>	<b>1,157</b>	<b>538</b>	<b>447</b>	<b>70</b>
1 YR	95.5%	99.3%	97.3%	63.4%
3 YR	84.2%	94.0%	84.9%	34.4%
5 YR	70.4%	82.0%	70.6%	*

\* Cells with less than 10 cases are suppressed because of an unstable error rate.

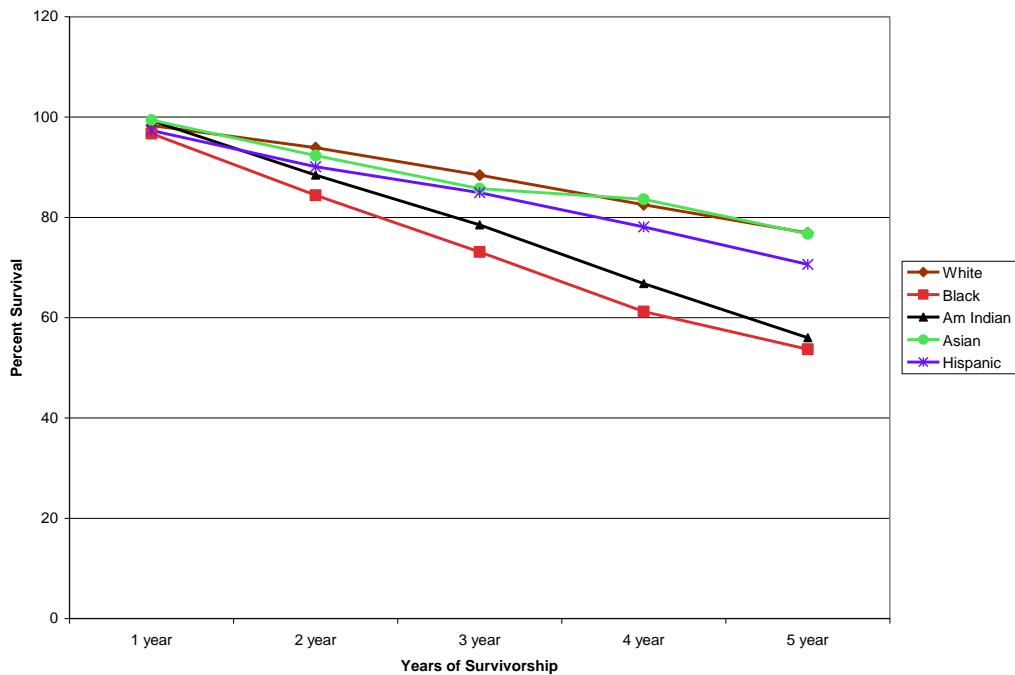
While data from these tables indicate the value of early diagnosis for all racial/ethnic groups, survival rates for each stage of diagnosis vary by race/ethnicity. Charts 5 and 6 below show this variation for women by “local” and “regional” stage of diagnosis.

Chart 5.  
*Survival rates by race/ethnicity, “local” stage of diagnosis*  
*Phoenix Affiliate counties, 2000 - 2007*



For women diagnosed at the “local” stage, five-year survival is highest among White, Asian and Native American women and lowest for Hispanic and African American/Black women.

Chart 6.  
*Survival rates by race/ethnicity – “regional” stage of diagnosis*  
*Phoenix Affiliate counties, 2000 - 2007*



For women diagnosed at the “regional” stage, African American/Black and Native American women have consistently lower rates of survival throughout the one- to five-year survival range. This would suggest that there are factors post-diagnosis that differentially influence survival. These could include access to care and treatment, genetics, and/or cultural perceptions, among other causes.

### Screening

There are several sources of data to describe the pattern of mammogram utilization among various populations. Table 13 below provides self-reported mammogram data by county. As can be seen, rates are lowest in Apache and Navajo counties, and highest in Maricopa and Yavapai counties. Table 14 offers statewide mammogram rates for women 40 years and older.

Table 13.

*History of mammogram by county of residence*

County of Residence	Mammogram within the past two years (age 50+)	Confidence interval
Apache	70.1%	60.6 – 79.6%
Coconino	77.4%	71.2 – 83.6%
Gila	78.7%	70.0 – 87.4%
La Paz	Insufficient data	
Maricopa	84.4%	82.0 – 86.8%
Mohave	74.3%	69.1 - 79.6%
Navajo	70.8%	64.6 - 76.9%
Pinal	79.5%	74.6 - 84.3%
Yavapai	82.9%	78.9 – 86.9%
<b>Arizona</b>	77.4%	

Source: CDC. Behavioral Risk Factor Surveillance System, 2000 – 2006

Table 14.

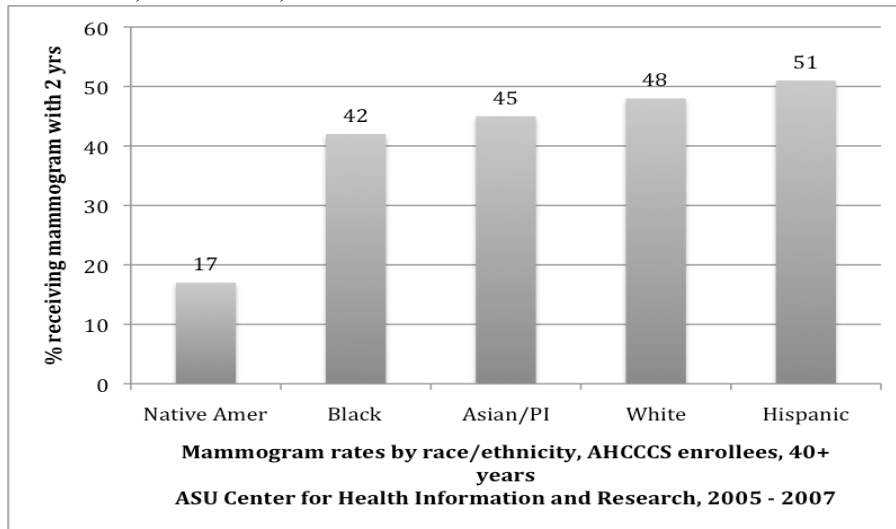
*Mammogram within the past two years, Arizona women 40+ years of age*

	Weighted %	Total Sampled
White	76.4	5,604
Black	70.9	91
Native American	75.1	256
Asian	59.6	44
Hispanic	71.4	497
Native Hawaiian/PI	85.6	25
Multi-race	64.3	33
Other	71.0	836
Total	75.4	7,295

Source: ADHS. Behavioral Risk Factor Surveillance System, 2004, 2006, 2008

Race-specific data is also available on mammogram rates among enrollees in the Arizona Health Care Cost Containment System (AHCCCS), Arizona’s Medicaid agency. The chart below provides mammogram rates among women 40 years of age and older (enrolled in AHCCCS for at least two consecutive years).

Chart 7.  
Mammogram rates for AHCCCS enrollees, 2005 – 2007  
Phoenix Affiliate counties, ASU CHIR, 2010



As can be seen from the data provided above, mammography utilization varies by race/ethnicity for both the general population and for those women enrolled in AHCCCS.

The Arizona Department of Health Services Well Woman HealthCheck Program (WWHP) offers free breast and cervical cancer screenings to uninsured or underinsured women 40 years and older with a household income less than 250 percent of the Federal Poverty Level. Services include annual clinical breast exams, mammograms, pelvic exams and Pap tests. The table below provides service data by county and race for 2009.

Table 15.  
WWHP mammograms by race and county, 2009, ADHS

	White*		Black		Native American		Asian		Pacific Islander		Other	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Apache	69	99%	--	--	--	--	1	1%	--	--	--	--
Coconino	296	86%	1	0%	33	10%	8	2%	1	0%	5	1%
Gila	--	--	--	--	--	--	--	--	--	--	--	--
La Paz	17	100%	--	--	--	--	--	--	--	--	--	--
Maricopa	1,420	85%	68	4%	88	5%	61	4%	2	0%	21	1%
Mohave	323	98%	1	0%	4	1%	1	0%	1	0%	1	0%
Navajo	183	96%	2	1%	1	0%	2	1%	--	--	2	1%
Pinal	335	97%	6	2%	1	0%	2	1%	--	--	2	--
Yavapai	264	96%	1	0%	3	1%	5	2%	1	0%	--	--
<b>Total</b>	<b>2,907</b>	<b>90%</b>	<b>79</b>	<b>2%</b>	<b>130</b>	<b>5%</b>	<b>80</b>	<b>2%</b>	<b>5</b>	<b>0%</b>	<b>31</b>	<b>1%</b>

\* White race category includes Hispanic individuals

In the table above, Hispanics were included in the “White” category. Table 16 breaks these individuals into Hispanic and non-Hispanic categories. As can be seen, Hispanic individuals did constitute a sizable percentage of recipients of mammograms through the WWHP. For instance, 65% of mammogram recipients in Maricopa County considered themselves Hispanic Whites.

Table 16.  
*WWHP mammogram users as a percent of all users  
 by ethnicity, 2009, ADHS*

	Hispanic White	Non-Hispanic White
Apache	27%	72%
Coconino	38%	49%
Gila	--	--
La Paz	65%	35%
Maricopa	65%	21%
Mohave	27%	71%
Navajo	31%	65%
Pinal	76%	21%
Yavapai	25%	72%

**Conclusion**

Compared to other states in the nation, Arizona has low rates of breast cancer incidence and mortality. However, the state’s death rate still exceeds the *Healthy People 2020* target death rate of 20.6 deaths per 100,000 population.

Incidence rates are highest among Yavapai County residents (117.5 per 100,000), followed by Maricopa (109.7 per 100,000) and Mohave County residents (101.7 per 100,000). Rates of new cases vary by race/ethnicity, with White women having the highest rates (100.1 per 100,000), and Native American women having the lowest rates (51.4 per 100,000).

The rate of early diagnosis also varies by race/ethnicity. African American/Black and Native American women residing in Phoenix Affiliate counties are less likely to be diagnosed early in the course of the disease. The national tendency for mortality rates to be highest among African American/Black women is also found in Arizona. Self-reported mammogram data by county reveals that screening rates are lowest in Apache (70.1%) and Navajo (70.8%) counties, and highest in Maricopa (84.4%) and Yavapai (82.9%) counties.

While breast cancer incidence in Arizona is low compared to other states, there are still wide discrepancies in incidence, screening and mortality among different demographics. The following section will examine the health system in central and northern Arizona, with hopes of discovering the reasons behind some of these discrepancies.

## **Analysis of the Health Care System**

This section provides an analysis of breast health services within the Affiliate’s service area from the perspective of community health organizations and direct service providers. In order to have a better understanding of the system’s strengths and weaknesses, it is first necessary to understand the continuum of care specific to the health care system (i.e. county health departments, hospitals, physicians).

### **Continuum of Care Model**

The Breast Cancer Continuum of Care represents one’s movement through the healthcare system to screen for breast cancer, and if necessary diagnose and treat breast cancer. The Continuum of Care has four stages: Screening, Diagnosis, Treatment and Follow-up Care. It is important to understand why women do not enter or continue the continuum, especially those who are part of “high need” or target communities.

#### **Screening**

Breast cancer screening is the first step in the continuum and includes knowing which screening tests are right for you. Have a mammogram every year starting at age 40 if you are at average risk, have a clinical breast exam at least every three years starting at age 20 and every year starting at age 40. Know what is normal for you and report any changes to your healthcare provider right away.

#### **Diagnosis**

For most women who have a mammogram or clinical breast exam, the results will be normal. For some women, the results may be abnormal and it is important that women receive timely follow-up tests after an abnormal mammogram or clinical breast exam. Follow-up diagnostic care may include a diagnostic mammogram, ultrasound or biopsy. If further testing reveals that the abnormality is not cancer, the woman will need to continue to follow screening recommendations. For those that have a diagnosis of breast cancer, they will then need to enter the treatment stage of the continuum.

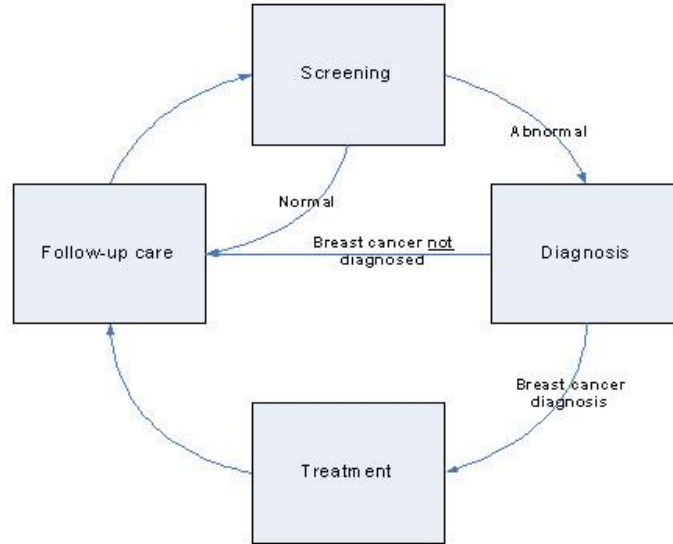
#### **Treatment**

A breast cancer diagnosis will lead to the treatment stage of the continuum. The best treatment plans are typically determined when the patient and healthcare provider work together. Treatment may involve one of the following or a combination of surgery, radiation therapy, chemotherapy, hormonal therapy and/or targeted therapy.

#### **Follow-up Care**

Follow-up care includes regular screening as recommended by a health care provider following normal or abnormal results. Women with normal screenings need support to continue and maintain proper screening practices. For those diagnosed with cancer, follow up care ensures their needs are met post treatment in order to address quality of life issues. Some survivors receive care related to side-effect management, long-term treatment, reconstruction and end-of-life care.

Figure 2.  
Breast cancer continuum of care



## Methodology

To obtain a thorough analysis of local services, the Affiliate conducted several separate surveys: a Health Systems Analysis, a Direct Care Provider Survey and surveys of the general public including breast cancer survivors. While this section primarily encompasses data from the two health care provider surveys, it also draws on responses from the survivor surveys. The Health Systems Analysis was used primarily to determine where gaps and barriers exist within the Affiliate service area. Using the online survey tool SurveyMonkey™, surveys were sent to approximately 30 healthcare organizations in early 2011, including county health departments, community health agencies and local Komen grant recipients. The Affiliate received 19 completed surveys from the following organizations:

- Apache County Health District
- Arizona Association of Community Health Services
- Banner Good Samaritan - Laura Dreier Breast Center
- Flagstaff Medical Center
- Golden Gate Community Center
- HOPI (Office of Prevention and Education)
- Maricopa County Department of Public Health
- Maricopa Health Foundation
- Mohave County Health Department
- Pinal County Health Services District
- Raul H. Castro Institute
- Regional Center for Border Health
- St. Joseph's Hospital and Medical Center
- Sun Life Center for Women and Children
- Sun Life Family Health Center
- The Nurses Office

- Yavapai County Community Health Services

The purpose of the Direct Care Provider Survey was to obtain the provider (primarily oncologist) perspective on breast care, including what treatments they provide, what barriers they face, and whether or not they collaborate to provide treatment. In early 2011, surveys were sent to approximately 25 individual providers via SurveyMonkey™ and the Affiliate received seven completed surveys representing four organizations:

- Arizona Oncology
- Arizona Oncology Services
- Mayo Clinic
- St. Joseph’s Hospital and Medical Center

### **Findings from Interviews with Health Care Providers**

The surveys the Affiliate received from local health care providers help identify where perceived gaps, barriers and needs exist in the system.

The following themes were prevalent throughout the Health Systems Analysis and Direct Care Provider Surveys:

- AHCCCS cuts and eligibility limit access to care
- Inadequate services for the underinsured and uninsured
- Low screening rates among ethnic minorities and low-income women
- More services and resources needed for rural communities
- Literacy and language barriers

The majority of respondents in both surveys describe the current health care system in Arizona as average. However, while there are adequate services available for some populations, many women fall through the cracks – for example, uninsured women who are not diagnosed through the WWHP are then ineligible for most treatment services. In addition, AHCCCS cuts and eligibility requirements limit access to care for many women. While Komen funds are said to be beneficial, several respondents mentioned that they are inadequate to cover the entire need. **The women identified as least likely to get regular breast screenings are:**

- **Hispanic, African American/Black, and Native American women;**
- **refugees;**
- **low income White women;**
- **undocumented Hispanic women; and**
- **the underinsured or uninsured.**

When asked what programs would help improve the current system, responses included: a national health care system, patient navigator programs, transportation programs, mobile mammography, increased outreach and education, and programs that offer services at a reduced rate (sliding scale).

While collaboration is repeatedly mentioned as a key to overcoming barriers in the health system, respondents site several challenges to collaborating. These include: a lack of resources to cover services and personnel, a lack of time, a hesitancy to collaborate, dealing with other high-

priority health care issues, and a lack of awareness about what others are doing in the community. In fact, two county health departments that responded to the survey admitted to not knowing what services were available in their own community.

When asked how breast cancer organizations could better collaborate, proposed solutions included establishing cancer coalitions, increasing knowledge of other programs, holding quarterly meetings with partners, networking with organizations in different counties and creating a five-year strategy that includes action items and realistic goals.

One respondent, HOPI Cancer Support Services, cited a continuum of care that appears to be effective in meeting the needs of their patient population:

*“The program works with two major health care sites: Tuba City Indian Medical Center, which provides follow up to final diagnosis, and the Hopi Health Care Center, which refers all women to the HOPI Cancer Support Services for mammograms. They will only complete a CBE. Through our program we refer patients to Tuba City Indian Medical Center for follow up. All treatment is then referred to the Flagstaff Cancer Center, Tucson Cancer Center, or Phoenix Mayo Clinic for treatment services. The HOPI Cancer Support Services Case Manager ensures that women receive a complete follow up through final diagnosis. She will also work with the provider at each clinical site to develop a plan for the client. Those who are going through treatment are also followed to ensure that they complete their treatment. The HOPI Cancer Support Services also has another program called the Hopi Cancer Assistance Fund Program whose coordinator will then work with the case manager to find additional help as requested by the client and/or family and make a referral. The case manager is always involved throughout the full process until the client no longer needs help. As far as the two health care facilities that the program works with, our program is suitable to them as it provides all the navigation and case management for clients so that no one falls between the cracks.*

*“If our program was not available, women in our area would either have to go into Flagstaff, which is 98 miles one way, to get a breast screening and pay for it out of pocket or with insurance or women would only be screened if there was an abnormal finding during the clinical breast exam. Therefore, our program has been successful in screening women for breast cancer in our area.”*

### **Overview of Community Assets**

This section gives a comprehensive look at all of the breast cancer services – including education, screening and treatment – available in the Affiliate service area. Community assets include both Komen programs and partnerships and services not affiliated with Komen.

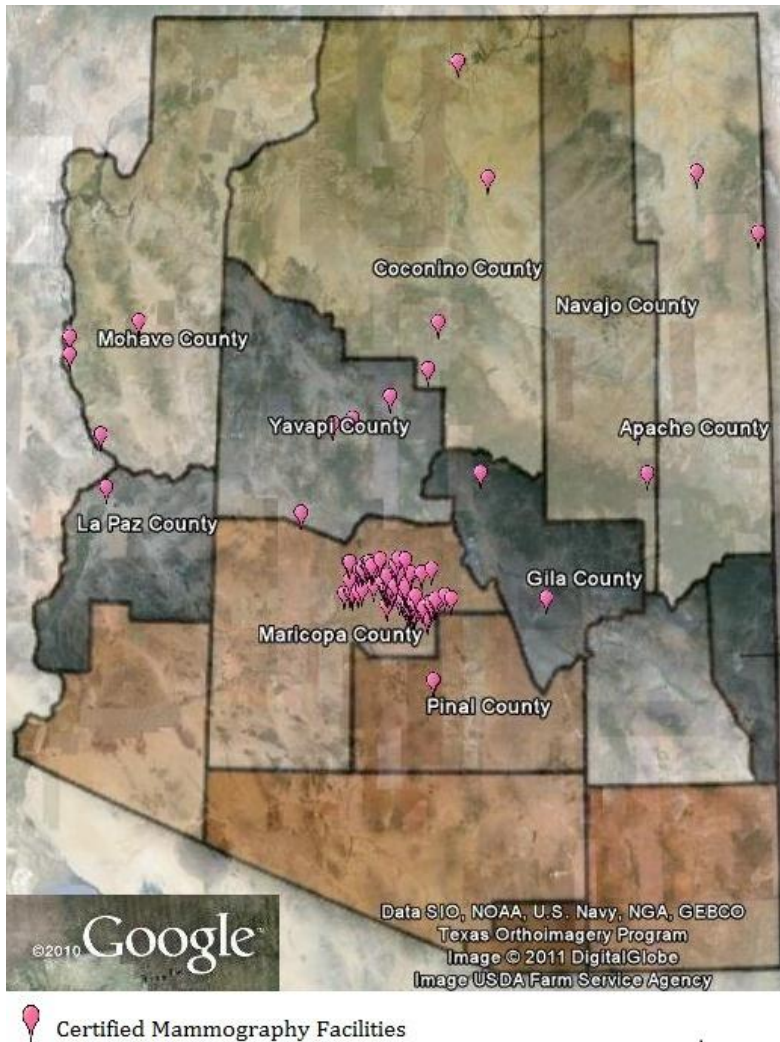
### **Asset Maps**

The asset maps below were created using Google Earth software to show the locations of providers throughout the Affiliate’s central and northern Arizona service area. Providers include FDA approved mammography centers (Figure 3) and Well Woman HealthCheck Program providers (Figure 4). The resulting asset maps help demonstrate where services are the most populous, as well as where they may be lacking.

Note that the electronic version of the asset map (available at [www.komenphoenix.org](http://www.komenphoenix.org)) contains more locations than may be visible in the static images below. For example, one pinpoint on the map may actually represent multiple locations in close proximity. It is also worth noting that the map does not include a population overlay.

Figure 3.

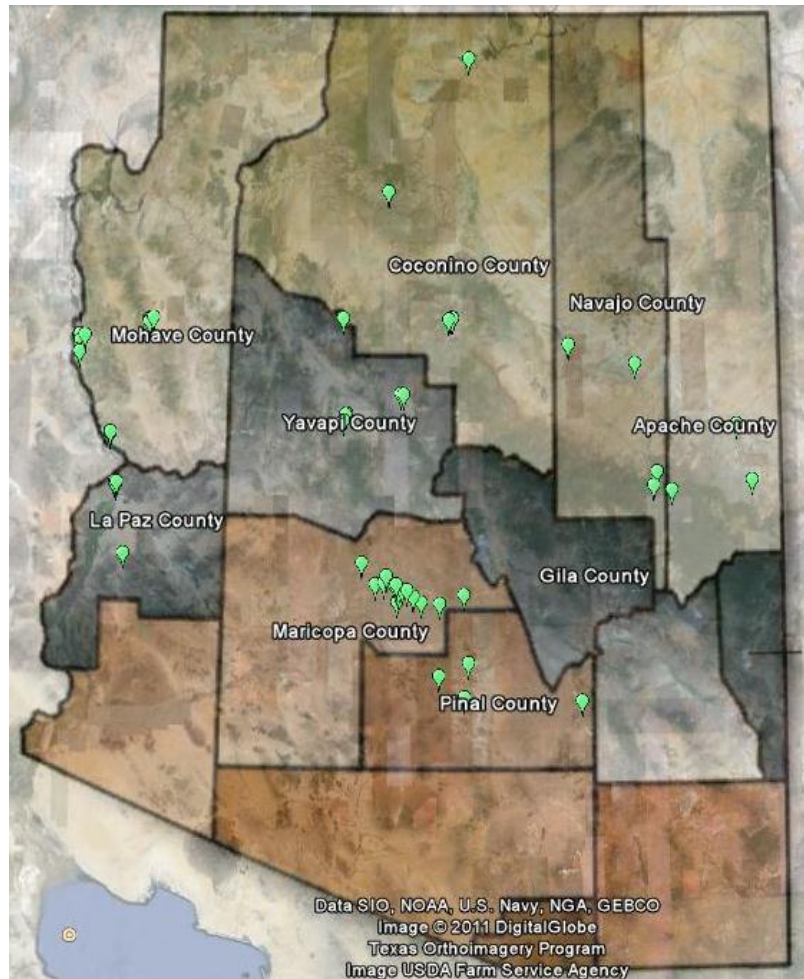
*Asset map featuring FDA approved mammography centers in the Komen Phoenix Affiliate Service area*



**Susan G. Komen for the Cure - Phoenix Affiliate**

Figure 4.

Asset map featuring Well Woman HealthCheck providers in the Komen Phoenix Affiliate service area



 Well Woman HealthCheck Program Providers

Susan G. Komen for the Cure - Phoenix Affiliate

### **Komen Phoenix Affiliate Community Assets**

While state-funded programs help meet some of the need in Arizona, there are still significant service gaps. The Affiliate attempts to fill these gaps by forming partnerships with organizations throughout the state where the need is greatest. While these partnerships take many forms, most fall into one of two categories: community partnerships with Komen-funded grant recipients and collaborative partnerships in which we join forces with other organizations to empower Arizonans in their progress toward a world without breast cancer.

### **Community Partnerships/Community Grants Program**

The Affiliate's network of grant recipients provides a variety of programs addressing the education, screening and treatment needs in the service area. These programs are the conduit for

assuring the Affiliate's priorities are implemented. They are the Affiliate's eyes and ears in the community, ensuring we reach as many people as possible, particularly in outlying areas. The programs, funded through the Community Grants Program, help to fill gaps for populations that would otherwise not have services; in particular, women and men who fall between the cracks of criteria set by government programs.

The Affiliate's contribution to direct service providers in the nine central and northern Arizona counties has helped eliminate barriers and challenges for diagnosis and treatment. Its grantees, both current and past, remain an integral resource for all community breast cancer health care efforts.

- **Education Grants** – The Affiliate's education grants fund programs that target various populations to articulate the importance of early detection and screening and dispel cultural fears in familiar settings such as homes, churches and community facilities. Most programs are led by health educators of the specific population, such as Promotoras. There are grant-funded programs that provide breast cancer education to the Native American population within the Ak-Chin, Hopi, Navajo, and Yavapai Nation tribes. Underserved Hispanic women are reached through collaboration with the Raul H. Castro Institute and the Cartwright School District in Maricopa County. Asian and Pacific Islander women receive information about breast health and mammography resources in Maricopa County. An audiovisual educational curriculum using breast health materials was created for Somali refugee women and delivered through partnerships with three refugee organizations. Despite the fact that both Maricopa (30.5 percent) and Pinal (29.8 percent) counties show the highest percentage of Hispanics within the Phoenix Affiliate service area (Table 1 of this report), the Affiliate has limited knowledge of the breast cancer needs of this population. While the Affiliate has been successful in funding a handful of grants that reach, or specifically serve, this population, the Affiliate itself has done very little to learn more about Hispanics in these counties. The Affiliate has not had the staffing for the intensive outreach efforts required for an inclusion initiative to this population. **Therefore, programs that target the Hispanic population are seen as a need.**
- **Screening Grants** - Screening grant programs typically seek to increase screening rates of underserved populations, including women who are underinsured or uninsured. Many of the organizations utilize a mobile mammography unit to reach medically underserved areas, which also helps alleviate cost and transportation barriers. They may also provide an education component regarding the importance of early detection and screening, usually using the Promotora model. There are eight organizations that provide low- or no-cost screening mammograms in central, northern and southern Maricopa County. There are two Komen-funded screening programs in Pinal County, and one Komen-funded screening program in each of these counties: Yavapai, Apache and Navajo. The Hopi Tribe also receives Komen funding for a screening program. **The far eastern and western sections of Maricopa County do not have any Komen-funded screening programs.**

- **Treatment Grants** – These grants fund breast cancer treatment services, including diagnostic follow-up, biopsies, surgery, radiation, chemotherapy and other treatments as appropriate. These treatment services may be for needs that are not covered by either the Well Woman HealthCheck Program or AHCCCS. Several programs provide transportation to appointments and services and lodging as needed. Other programs provide comprehensive lymphedema treatment and garments or post-mastectomy prostheses. Komen-funded grants to provide breast cancer treatment that includes surgery, chemotherapy, radiation and other modalities are provided to seven organizations in Maricopa County, one in Pinal County, one in Coconino County and one in Navajo County. One organization in Coconino County receives funds to provide lymphedema management. **With such a large population to serve and large pockets in the service area where no Komen treatment funding exists, the number of women that can be treated is diminished.**

### **Collaborative Partnerships**

Overcoming physical and/or cultural obstacles can only be successfully achieved with a network of health care and advocacy partnerships and coalitions. The Affiliate has many collaborative partnerships – some long-standing and other just beginning – with like-minded community organizations.

- The **American Cancer Society** and the Southern Arizona and Phoenix Affiliates have partnered on various state public policy issues including Affordable Oral Chemotherapy Treatment and preserving statewide funding for the Well Woman HealthCheck Program. The Phoenix Affiliate partners with ACS for State Lobby Day. Our newest collaborative efforts, which are currently under development, involve creating a better understanding of support programs, streamlining community grant funding, targeting breast health education and outreach, and continuing to influence public policy.
- **Arizona Alliance for Chronic Care** is a united voice dedicated to improving the lives of the chronic care community of Arizona. The Alliance will raise the visibility of broad issues and their potential solutions between the chronic care community and elected officials, government agencies, business groups and mass media.
- The Affiliate is a participating member of the **Arizona Cancer Control Program's** Early Detection and Screening committee. The committee seeks to promote, increase and optimize the appropriate utilization of high quality cancer screening and follow-up care in an effort to detect and treat cancer at its earliest possible state.
- The Affiliate partners with the **Arizona Department of Health Services** and its Well Woman HealthCheck Program to stay informed of issues relating to funding of the program and required changes.
- **Buddy Check 12** is a community outreach program designed to raise awareness about breast health through monthly email or telephone reminders to women to assess

their breasts so that they can identify any changes. This is a partnership with 12 News, Fry's Food Stores and John C. Lincoln Hospitals.

- **Coalition of Blacks against Breast Cancer (CBBC)** is a community partnership that brings together Black women (and men) in order to better understand the needs of Black breast cancer survivors, to create a place to share information and to increase education and screening in the Black community.
- **Communities of Color Leadership Council** is an initiative of the Affiliate to convene leaders from various communities to create Komen messaging on breast health and breast cancer that is culturally relevant to various communities of color; create a council that will serve in an advisory role to develop culturally sensitive solutions to disparities in specific communities; and assist in creating partnerships with Komen and leaders in the communities of color to strengthen Komen's presence and acceptance in these communities. Organizations that are part of the leadership council include Maricopa County Public Health Hard to Reach Populations, Mexican Consulate, Native Health, Asian Pacific Community in Action, Refugee Community representative, and City of Phoenix.
- **Fry's Food Stores** have numerous in-store efforts designed to create awareness and promote Komen's breast self-awareness messages.
- **KPNX 12 News** (NBC Affiliate) has continually aired stories related to breast health and breast cancer issues.
- In efforts to harness strengths of the local Susan G. Komen for the Cure Affiliates, the Phoenix Affiliate and the **Southern Arizona Affiliate**, located in Tucson, are working together to deliver life-saving, breast self-awareness and access to care messages to growing and underserved populations in our state. Each affiliate maintains strong working relationships with non-profit, business and media entities as well as public officials in our respective areas, and by working together in education, outreach and public policy, Komen will speak with one united, powerful voice.
- To better understand and meet the breast health and breast cancer needs of the Hispanic people of Arizona, the Affiliate has begun a collaboration and partnership with **Valle del Sol**, a non-profit community-based organization whose mission is to inspire positive change by investing in human services to strengthen families with tools and skills for self-sufficiency and by building the next generation of Latino and diverse leaders. Through Valle del Sol's Hispanic Leadership Institute, the organizations will work together to engage Hispanic leaders and Hispanic-serving organizations in key activities that will address community needs.

#### **Additional Community Assets (Non-Komen Related)**

Through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), the Centers for Disease Control (CDC) provides low-income, uninsured, and underserved women

access to timely breast and cervical cancer screening and diagnostic services. An estimated 8- 11 percent of U.S. women of screening age are eligible to receive NBCCEDP services.

To improve access to screening, Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990, which guided the CDC in creating the NBCCEDP to provide screening services for breast and cervical cancer. The program helps low-income, uninsured, and underinsured women gain access to breast and cervical cancer screening and diagnostic services, including clinical breast examinations, mammograms, Pap tests, pelvic examinations, diagnostic testing and referrals to treatment.

In Arizona, this program is administered through the Arizona Department of Health Services and called the Well Women HealthCheck Program (WWHP). Eligible women have no insurance, have insurance that does not cover these preventive services, or have insurance that has a high deductible (as determined by the Well Woman HealthCheck Program).

In 2000, Congress passed the Breast and Cervical Cancer Prevention and Treatment Act (BCCPT), which gives states the option to offer women in the NBCCEDP access to treatment through Medicaid. To date, all 50 states and the District of Columbia have approved this Medicaid option. Under the legislation, states were given the choice of three options to administer the funds.

**OPTION ONE (most restrictive)** - Women are considered eligible only if their clinical services were provided all or in part by the state's NBCCEDP-funded breast and cervical cancer early detection program.

**OPTION TWO (medium)** - Women are also considered eligible even if their particular clinical service was not provided by the state's NBCCEDP funded breast and cervical cancer early detection program, but the service was within the scope of a grant, sub-grant or contract under that state program.

**Option Three (least restrictive)** - Women are considered eligible if they are screened by any provider.

In Arizona, the Medicaid program is Arizona Health Care Cost Containment System (AHCCCS). The funds for breast cancer treatment are administered through AHCCCS. In implementing the Treatment program, the state of Arizona selected the most restrictive Option 1 of the three options available. The results of this determination have produced a challenge and barrier to care hence, treatment cannot be paid for with these funds if the patient's abnormal screening was not diagnosed by a Well Women HealthCheck provider.

### **Legislative Issues Affecting Target Communities and Komen's Role**

The Phoenix Affiliate's role in addressing local legislative issues is multifaceted. The Affiliate has made public policy a priority, calling attention to the disparity that disqualifies many women from receiving lifesaving treatment. **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 HealthCheck Program (WWHP) facility are not eligible for funds that have been earmarked for treatment.** This disparity leaves many women with a diagnosis, but with few, if any, options for treatment and survival. On the other hand, women in Option 3 (least restrictive) states can receive treatment services regardless of where they were diagnosed. Through the Komen Advocacy Alliance, the Affiliate is calling attention to this disparity and seeking change from state leaders.

As stated in the Capacity to Serve section of this report, approximately 10 percent of the eligible population can be screened through the WWHP as compared to 14 percent of the eligible population as a national average. **Additional funding to supplement the WWHP funds is needed in order to increase the number of women able to be screened.**

The following response from a participant in the Health Systems Analysis Survey to a question about laws or policies that make it difficult for women to get breast health services summarizes additional frustration: *“Insurance riders that keep women who have cancer from having adequate coverage. Laws that are keeping health care reform from occurring. Policies that drive prevention and screening, yet have no funding for adequate diagnosis and treatment.”*

### **Conclusion**

In general, the perception is that Arizona’s current system is average in meeting breast health needs. However, while there are sufficient services for many groups, there are still particular demographics that fall through the cracks. The primary barrier mentioned by nearly every respondent was insurance. Eligibility requirements for 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 HealthCheck 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 mentioned frequently was a lack of education and awareness about available resources. Some programs, such as the Hopi program, have established a continuum of care model that appears to be working. Others are able to use Komen funds to provide vital services that otherwise would not be available. With such a large population to serve and large pockets in the service area where no Komen treatment funding exists, the number of women that can be treated is diminished.

The greatest need was identified as:

- Programs that target the Hispanic population
- The far eastern and western sections of Maricopa County, which do not have any Komen-funded screening programs
- Women identified as least likely to get regular breast screenings are:
  - Hispanic, African American/Black, and Native American women;

- refugees;
- low income White women;
- undocumented Hispanic women; and
- the underinsured or uninsured.

The following section, Community Perspectives on Breast Cancer, will look at how individuals, including many from the underserved groups listed above, navigate the breast cancer continuum of care in Arizona and the challenges they face.

## **Community Perspectives on Breast Cancer**

Covering nine counties, the Komen Phoenix service area is broad and diverse. Not only does it encompass nearly 80 percent of the state's population, it also includes a wide range of ethnicities with very diverse lifestyles and experiences. This section attempts to summarize the community's experiences with breast cancer, including the similarities and differences among different populations.

### **Methodology**

To determine the breast cancer perspective 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 759 individuals within the Komen Phoenix database, with a goal of reaching individuals in each county. The Affiliate received 87 surveys back; some were complete, others were incomplete. Participants included 18 African American/Black women, one Asian woman, nine Hispanic women, one Native American male, 43 White females and five White males. The surveys were sent via the online survey tool SurveyMonkey™.

Survivor surveys were sent to 227 survivors, some of whom were part of the Komen Phoenix survivor database and others who had been identified by local grant recipients. The Affiliate received 27 surveys back. The participants included 26 White women and one Hispanic woman. These surveys were also sent via the online survey tool SurveyMonkey™.

The Affiliate also partnered with community organizations to gather input from focus groups with Asian men and women. Facilitated by the Asian Pacific Community in Action in 2009, these included Chinese, Vietnamese and Filipino men and women. The participants were recruited via newspapers ads and were offered an incentive of \$35 cash.

### **Review of Qualitative Findings**

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

- Lack of health insurance and a need for more financial assistance programs
- Lack of education regarding breast health
- A need for more support resources and education about available resources
- Fear of treatment, side effects and recurrence

### **Public Surveys**

The most common themes among the general public surveys include:

- Lack of health insurance and inadequate health insurance as the top two barriers facing cancer patients, followed by fear of side effects and fear of treatment
- Breast health concerns among minority women
- More education regarding breast cancer and breast health among women and men
- Sedentary lifestyle/physical activity

**Additional Findings by Ethnicity:****African American/Black** (Based on 18 Responses; all female)

Every participant responded that she felt she knew how to check for changes in the look and feel of the breast and all but one stated that she knew where to access breast health information (examples included Channel 12, Komen, hospitals, doctors and the Internet). Only 13 of the women reported receiving an annual mammogram, one responded every two years, one responded more than every two years and three skipped the question. Only two of the respondents reported not to be concerned about their breast health.

**Asian** (Based on one response; female)

The Affiliate received only one survey from an Asian woman, who reported to know where to access breast health information and how to check for changes in the look and feel of her breast. Despite being concerned about her breast health, the respondent has never had a mammogram due to an inability to pay for services.

Focus groups consisting of both Asian men and women found that individuals receive care in their native country or in the United States, depending on their health insurance coverage; that they tend to embrace screening and prevention methods, but that a lack of health insurance, inadequate health insurance and federal immigration law limit access to care and services. Regarding cancer, most see screening methods as something positive and necessary, along with other prevention methods such as a healthy diet, rest, positive attitude and stress relief.

**Hispanic** (Based on nine responses; all female)

Eight of the nine Hispanic women stated that they know where to access breast health information (examples included the Internet, Virginia G. Piper Cancer Center and doctors). Seven respondents believe they know how to check for changes in the look and feel of their breast. Four women reported to have a mammogram annually, followed by longer than every two years and every two years. Reasons given for not having a mammogram included: age (under 40) and a lack of familiarity with the mammogram process. Three of the women reported to not be concerned about their breast health.

**Native American** (Based on one response; male)

The Affiliate received one response from a Native American male. He reported to know where to access breast health information but has no knowledge of how to check for changes in the look and feel of his breast. He reported that he is not concerned about his breast health and does not believe breast cancer is a problem for men. In addition, he reported to have never discussed his breast health with a medical provider or to have had a breast exam performed by a medical provider.

**White** (Based on 48 responses; 43 females and five males)

The majority of respondents (41) stated they know where to access breast health information (examples included Komen, Mayo Clinic, the Internet, doctors, hospitals and Ironwood Cancer Center). Nearly all (47) believe they know how to look for changes in the look and feel of their breast. Forty-one reported to have had a mammogram; 33 reported to have a mammogram annually followed by longer than two years and every two years. The reasons given for not having a mammogram included: Age (under 40) and Gender (male). While three out of five

males reported to not be concerned with their breast health and did not believe that breast cancer was a health problem for men, no female reported that she was not concerned about her breast health.

### **Survivor Surveys**

The most common themes from the 27 survivor surveys received include:

- The need for more financial assistance programs
- Training for medical providers regarding both sensitivity issues and awareness of local resources
- More support groups and information on accessing wigs and prosthesis
- A hub within the community with access to various resources and information
- Increased services in rural areas
- Issues survivors face
  - The fear of reoccurrence (#1 answer)
  - Health insurance and the ability to afford follow-up care

### **Health History**

The majority of survivors reported to be in good health followed by excellent and fair. Sixteen reported they exercise on a daily basis for at least 30 minutes. In regards to chronic diseases and conditions; there was one diagnosis of diabetes, three diagnoses of obesity, three diagnoses of heart disease, eight diagnoses of high cholesterol and nine diagnoses of hypertension. Nineteen survivors reported to have been pregnant at one time; 15 out of 19 reported pregnancies were before age 35. Twenty-two reported to have used oral contraceptives for birth control; 19 out of 22 stated they had stopped taking oral contraceptives for more than 10 years before being diagnosed with breast cancer. Ten reported that their menstrual cycle began before age 12. Out of these 10 women, five reported to have completed menopause before 55, one reported to have completed menopause after age 55 and four reported to not yet be in menopause. Sixteen women reported they have never had hormone replacement therapy. Only 13 women reported a family history of breast cancer.

### **Diagnosis and Treatment**

The majority of women reported they discovered their tumor, followed by a mammogram and clinical breast exam. The number one method of treatment was surgery (22 women) followed by radiation therapy, chemotherapy, hormone therapy and targeted therapy. Other treatments included Savi and a bone marrow transplant. Eighteen women reported to have had lymph nodes removed.

### **Health Insurance and Access to Care**

Twenty-two women reported to have had health insurance at the time of diagnosis (all private). However, only 13 reported that it covered the total cost of care. Three women reported they had no health insurance and relied on the Well Woman HealthCheck Program or paid for services themselves. A lack of health insurance and inadequate health insurance were identified as barriers to access to care. When asked what issues they have faced for which there were no services, the top response was emotional followed by sexual, financial and physical.

### **Additional Survivor Findings by County:**

#### **Coconino** (Based on one response):

- Diagnosed at age 50-59 with stage III breast cancer; 11-19yrs of survivorship
- Reported to not have to travel outside of the county to access treatment services.

#### **Gila County** (Based on two responses)

- Both women were diagnosed at age 50-59, but at different stages (I and II). They both have 6-10yrs of survivorship.
- One reported to have traveled outside of the county to access services

#### **Pinal** (Based on seven responses)

- Four reported to be diagnosed at age 50-59 and three reported to be diagnosed at age 40-49
- Four were diagnosed at stage I and three at stage II.
- Three reported to have traveled outside of the county access services

#### **Yavapai** (Based on four responses)

- Two reported to be diagnosed at age 31-39 and two reported to be diagnosed at age 40-49
- One diagnosis at stage I, two diagnoses at stage II and one diagnosis at stage III
- One reported to have traveled outside of the county to access services

#### **Maricopa** (Based on 10 responses)

- Three reported to be diagnosed at age 31-39, two at age 40-49 and five at age 50-59
- Three were diagnosed at stage 0, one at stage I, four at stage II, and one at stage III
- No one reported to have traveled outside out the county access services

### **Miscellaneous comments (direct quotes):**

#### **General Public:**

*“I wish there were more free mammograms programs out there accessible for women. So many women cannot afford it or know where to even begin because they don't think it can happen to them.”*

*“More publicity needs to be placed on PREVENTION, as opposed to detection. Obviously detection is important, but women need to be educated on prevention, so that the detection piece never has to come into it.”*

*“There needs to be a central place for all information...my mother went several years before I accidentally happened upon a place that provides custom fit bras for her that is covered by Medicare.”*

**Survivors:**

*“I want to see more grants available here and want the area to know that Komen has grants for this area. More publicity showing what Komen is doing in this area. It is making a difference.”  
(Yavapai County)*

*“I had to travel one hour each way for my radiation treatments and support group. Would like more services in East Valley. Hopefully the opening of MD Anderson Cancer Center at Banner Gateway this year will make services more available for Pinal County.”*

*“Well woman program is great, emphasis on 50 and over is really 40 and over, the over 50 brochures kept me from getting treatment earlier; I was 48 and did not think I qualified.”*

**Conclusion**

While responses vary among women and men of different demographic groups, many common themes emerged as well. Among the general public surveys, the most common barriers facing cancer patients were listed as a lack of health insurance and inadequate health insurance, followed by the fear of side effects and the fear of treatment. Respondents want more education regarding breast cancer and breast health among both women and men. And while breast health concerns were noted among minority women, many also stated that they lead a relatively sedentary lifestyle with little physical activity.

Similarly, the most common theme from the 27 survivor surveys received was the need for more financial assistance programs. Survivors want training for medical providers regarding both sensitivity issues and awareness of local resources. They also want more information and resources, including more support groups and information on accessing wigs and prosthesis; hubs within the community with access to various resources and information; and increased services in rural areas. The most common issues that survivors face were listed as the fear of reoccurrence (most common answer) and issues with health insurance and the ability to afford follow-up care.

Such perspectives from women and men in our community are crucial to developing relevant Affiliate priorities, which are outlined in the following section.

## Conclusions

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

To determine the following priorities, the Affiliate assembled a Community Profile committee to review the demographic data, the analysis of the health care system and the community perspectives on breast cancer to uncover gaps in the system and other common themes. While the results are listed below, in order of priority, it's important to note that each of these objectives must be addressed by our community in order to create a comprehensive and successful breast health system in Arizona.

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This report defines medically underserved as Hispanic, African American/Black, and Native American women; refugees; low income White women; undocumented Hispanic women and underinsured and uninsured populations. Priority focus is being placed on Hispanic, African American/Black, and Native American women and the underinsured and uninsured populations.

### **Priority One: Enhance education and outreach of breast-self awareness message to increase early detection by**

- Creating messages that focus on breast health and the importance of early detection targeted to the Native American and African American/Black populations who have demonstrated disparities as far as later staged breast cancer presentation, lower five-year survival rates and lower breast cancer screening rates.
- Creating a centralized breast health and breast cancer resource centers in rural areas that include information on a range of subjects, from breast self-awareness to breast cancer resources and available services for breast cancer survivors.
- Presenting information to health care providers to increase their knowledge of the Well Woman HealthCheck Program (WWHP) and its eligibility criteria to ensure those who are eligible enroll; of the health care system, community resources and available services; of the fears patients have and how to address those fears in a sensitive manner.
- Creating programs that target the Hispanic population.

### **Priority Two: Improve access to direct care and the continuum of care by**

As an organization, Komen wants to ensure quality care for all by eliminating and breaking down barriers to people's access to care.

- Improving uninsured people's ability to get into the health care system.
- Eliminating cost barriers to screening and treatment services.

- Eliminating transportation barriers.
- Supporting patient navigation and Promotora programs to assist patients through the screening, diagnostic, treatment and post-treatment support process for those defined as medically underserved.
- Increasing access to screening by encouraging the use of mobile mammography units.
- Creating collaborative partnerships with multiple agencies that maximize financial and human resources to extend the reach of community programs and serve more individuals.
- Creating a forum to advance public policy issues on a State level.
- Creating programs that target the Hispanic population to increase screening utilization and access to treatment.

**Priority Three: Improve quality of life through survivorship support programs by**

Breast cancer survivorship begins on the day of diagnosis.

- Supporting services that address the emotional, sexual, financial, physical and other impacts that occur after a breast cancer diagnosis.
- Creating a centralized location for information on available services after diagnosis, during treatment and after treatment including resources for wigs, prosthesis, lymphedema treatment and support groups.
- Increasing availability of financial assistance.
- Creating programs that educate survivors on the reduction of risk for breast cancer in an effort to reduce the fear of reoccurrence.

**Affiliate Action Plan**

These priorities will help set the direction of the Affiliate until the next Community Profile is issued in 2013. By the end of July 2011, the Affiliate’s Board of Directors will utilize the findings in this report to determine long- and short-term strategic and operational goals addressing the priorities listed above. In addition, the Affiliate will create funding guidelines for the annual Community Grants Program that coincide with these priorities and organizations will be awarded grants based on their ability to fulfill the community’s most pressing needs.

## Definitions

**AHCCCS** - Arizona Health Care Cost Containment System

**BCCPT** - Breast and Cervical Cancer Prevention and Treatment

**Incidence** - The number of new cases during a period of time (e.g. the number of people newly diagnosed with breast cancer in the year).

**Incidence Rate** - Calculated by dividing the number of new cases during a given period of time by the number of people known to be at risk.

**Mortality Rate** - Calculated by dividing the number of people who have died of a particular cancer during a given period of time by the total population at risk.

**NBCCEDP** - National Breast and Cervical Cancer Early Detection Program

**Rate** - Indicates the frequency of a given event (e.g., 100 births per 1,000 adults). It is a way of knowing the proportion of a population, possessing a particular variable, in order to compare areas or groups of different sizes.

**Patient Navigator** - A professional healthcare worker often in a medical facility that assists patients through the healthcare system of the organization; usually bi-lingual.

**Prevalence** - The number of existing cases at a point in time (e.g. the number of people living with breast cancer at this moment).

**Promotora** - A lay healthcare worker usually a member of the community they serve and bi-lingual.

**WWHP** - Well Women HealthCheck Program

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