

Susan G. Komen for the Cure®

Boise, Idaho Affiliate



2011

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# **Executive Summary**

#### Introduction

Susan G. Komen for the Cure® was born in a promise. Ambassador Nancy Brinker, founding chair of Susan G. Komen for the Cure, promised her dying sister Susan G. Komen, that she would do everything in her power to end breast cancer. That promise became Susan G. Komen for the Cure, which has grown to be the world's largest and most progressive grassroots network of survivors and activists fighting to end breast cancer forever.

Komen's promise *is to save lives* and *end breast cancer forever* by *empowering people*, *ensuring quality care for all and energizing science to find the cures*. To fulfill this promise, the Boise Affiliate of Susan G. Komen for the Cure<sup>®</sup> *empowers* one full time Executive Director, two three-quarter time employees, plus over 400 volunteers every year to assist with Boise's Race for the Cure<sup>®</sup> and other fundraising events.

The Komen Boise Affiliate's achievements are seen in *ensuring quality of care*. The Affiliate has played a critical role in supporting the 19 county service area grantees

with funding for breast health education, screening and treatment programs. Exceptional programs positively impact breast health for women who otherwise could not afford it. The Affiliate service area in Southwest and Central Idaho consists of the following counties: Ada, Adams, Blaine, Boise, Camas, Canyon, Cassia, Elmore, Gem, Gooding, Idaho, Jerome, Lincoln, Minidoka, Owyhee, Payette, Twin Falls, Valley, and Washington (see Figure 1).

The Affiliate has had a remarkable impact growing from granting \$175,800 in 1999 to over \$525,000 in 2010. Since its inception in 1999, the Affiliate has invested over \$4 million dollars in community grants and *energized the sciences* through research programs. Seventy-five percent of the net proceeds stay in the Boise Affiliate's 19 county service area and twenty-five percent supports the national Susan G. Komen for the Cure Research Grant Program which reinforce ground breaking



Figure 1. Affiliate Service area

breast cancer research and scientific programs around the world.

The purpose of this community profile project was to collect, compile and correlate qualitative and quantitative data within the Affiliate service area to gain better knowledge and understanding of the gaps and barriers that can inhibit women from receiving breast cancer screening and treatment. Data collected would additionally provide the Boise Affiliate a chance to review access and availability of services in the

region. Collectively an evaluation of all that information would allow the Affiliate to engage in strategic planning and allocate resources appropriately toward assisting breast cancer agencies in reducing the breast cancer burden in all areas of the continuum of care for women in the service area.

#### **Statistics and Demographic Review**

The Affiliate was provided estimate data from Thomson Reuters<sup>©</sup> 2009. After a thorough review of the data pack, the Affiliate partnered with the Cancer Data Registry of Idaho (CDRI) to obtain access to additional data. Breast cancer data was also acquired from the Idaho Behavioral Risk Factor Surveillance System (BRFSS) and demographic data for the state of Idaho was obtained from the Idaho Department of Labor and the U.S. Census Bureau. Data was compiled and put into correlation charts to compare breast cancer and demographic data for the region. The Core Committee analyzed the correlation charts to determine the 2011 Community Profile focus area.

Compared to the rest of the state of Idaho, the Affiliate service area counties rank the same in breast cancer mortality with a rate of 21.1, but the service area counties have slightly lower screening rates for women 40 and older who have had a mammogram and clinical breast exam (CBE) in the past two years with 58.9% compared to Idaho's average of 63.2%. It appears the Affiliate's service area counties also have a slightly higher average in late stage incidence (44.3), versus the rest of Idaho (43.7).

Table 1.
Boise Affiliate Mortality, Screening and Diagnosis by County

Geographic Area	Mortality Rate	% of Mammograms and CBE	Late Stage Breast Cancer Incidence Rate
State of Idaho	21.1	63.2%	43.7
Komen Boise Affiliate Counties (19)	21.1	58.9%	44.3
Ada	20.0	70.1%	45.5
Adams	16.7	61.7%	76.9
Blaine	16.4	70.8%	35.1
Boise	18.1	66.8%	31.5
Camas	41.9	*ND	237.2
Canyon	21.6	60.1%	42.4
Cassia	10.1	46.7%	30.2
Elmore	18.5	68.0%	49.8
Gem	17.8	49.7%	26.4
Gooding	22.2	51.8%	48.3
Idaho	29.8	56.9%	36.6
Jerome	31.1	62.6%	58.5
Lincoln	8.8	44.3%	10.8
Minidoka	16.6	53.0%	35.3
Owyhee	30.4	60.3%	32.7
Payette	25.4	62.4%	52.2
Twin Falls	26.3	61.8%	49.6
Valley	11.3	69.7%	46.0
Washington	26.3	44.1%	31.3

Mortality & Incidence Source: Cancer Data Registry of Idaho.

Additional research and analysis revealed that rural counties in the Affiliate service area were most affected by breast cancer. The six Affiliate counties that ranked highest in categories of mortality, late stage incidence and early stage incidence, were among the most rural and remote counties in Idaho. For example Owyhee County shows one of the highest mortality rates at 30.4. Payette County was noted for its top six ranking in the same three categories. These repeated themes indicate that early screening may not occur and breast cancer diagnosis happens only after breast cancer has progressed to advanced stages. These factors can contribute to higher mortality rates.

A literature review was conducted to determine characteristics that affect rates of screening. Results of the literature review show that some factors that contribute to lack of screening are limited income, education and health insurance (Lauver, Settersten, Kane & Henriques, 2003, p. 2724). Further, research conducted by Chris Johnson, MPH, an Epidemiologist with the Cancer Data Registry of Idaho, revealed that the female with the highest need for screening is one whom is aged 40-49, is uninsured and is a non-college graduate (2010). Data analysis showed that Idaho County has the highest percent of uninsured females of all ages with 26.7% uninsured. Owyhee and Adams counties are a close second with 23.5% and 22.6% uninsured respectively (Local Area Unemployment Statistics Program, July 2010). While data from the U.S. Census Bureau did not show percentages of women in Idaho aged 40-49, the female population in Idaho is approximately 49.8% (757,442) of the total population (U.S. Census Bureau, 2009). The Affiliate service area female population is around 430,302, approximately 57% of the total Idaho female population (U.S. Census Bureau, 2009). The focus area was chosen based on the following eight categories:

- Unemployment
- Median household income
- Uninsured females
- Mortality rates
- Low rates of early stage incidence
- High rates of late stage incidence
- Invasive prevalence rates
- Low rates of mammography and clinical breast exam in the past two years

The Core Committee devised a system, recognizing its limitations, for determining the counties with the highest combination of the eight categories. The top six counties for each category were listed and given a star for each time the county appeared in the category. Further, a ranking system was devised where points were assigned to symbolize a ranking position. For example, if a county was number one in unemployment, it was given six points, the number two county was given five points, and this method continued down to the number six county being awarded one point. Total stars for each county were summed and points were tabulated. From these two systems, a list of the top seven counties was compiled. Analysis showed that four of the top seven counties were located in Idaho's Southwest District Health Department III (SWDH) region. The health district is comprised of six counties:

Adams

- Canyon
- Gem
- Owyhee
- Payette
- Washington

Table 2, represents each SWDH county with a top six rankings for startling statistics in social, demographic and breast cancer categories. The top ranked counties were used to determine an area of focus.

Table 2.
Southwest District Health Counties and Categories in Top 6

County	Categories
Adams	High Unemployment, Low Median Household Income, High Uninsured, High Late Stage Incidence, High Invasive Prevalence
Gem	High Unemployment, Low Early Stage Incidence, High Invasive Prevalence, Low Mammogram & CBE 40+
Owyhee	Household Income, High Uninsured, High Mortality, Low Early Stage Incidence
	Low Median Household Income, High Mortality, Low Early Stage Incidence, High Invasive Prevalence, Low Mammography & CBE 40+
Canyon	Not rank in the top 6 categories
Payette	Not rank in the top 6 categories

#### Sources:

Unemployment: Idaho Department of Labor, July 2010 Median Household Income: Thomson Reuters<sup>©</sup> 2009 Uninsured Females: U.S. Census Bureau 2000 Mortality: Cancer Data Registry of Idaho 2007

Early & Late Stage Incidence: Cancer Data Registry of Idaho 2007

Invasive Prevalence: Cancer Data Registry of Idaho 2007

Mammography & CBE ≥ 40: Idaho BRFSS 2008

Table 3.

Percentage of women (age 40+) who had not had mammogram and clinical breast exam in past 2 years

Idaho District Area	% of females age 40+ who had not had a mammogram or CBE in the past 2 years
Idaho (statewide)	36.8%
Public Health District	
District 1	39.4%
District 2	39.2%
District 3	42.7%
District 4	26.8%
District 5	40.9%
District 6	39.0%
District 7	42.0%

Source: Idaho Behavioral Risk Factor Surveillance System, 2008

The Idaho Behavioral Risk Factor Surveillance System reported that Health District III, has the highest percentage of women who have not had a mammogram or clinical breast exam in the last two years (Table 3). The analysis and assessment of the statistical and demographic data directed the Affiliate to focus on the SWDH III area as target communities for mission initiative work for the 2011 Community Profile.

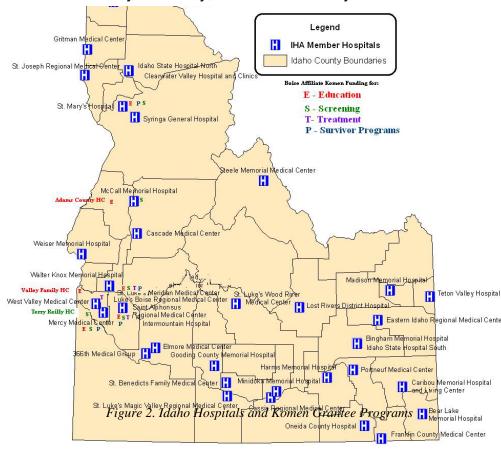
#### **Health Systems Analysis**

A health system analysis was also conducted to review breast health and breast cancer services in the Boise Affiliate service area. An Idaho hospital map (Figure 2) was received by the Idaho Hospital Association showing critical care services offered. Boise Affiliate grants in the SWDH III area were overlaid to show funded programs in education, screening and treatment. Review of the map revealed limited services in almost all of the SWDH counties. It is apparent by the map that a barrier exists to accessing screening and treatment in Canyon County, where there is only one fixed site

offering breast care services.

In order for the Affiliate to gain perspectives from experts involved in providing education, diagnosis and treatment of breast cancer, eleven key informant interviews conducted. were Informants were chosen based on their involvement in breast health services offered in the SWDH area and included personnel from the following:

Southwest
 District
 Health
 Department,



- St. Alphonsus Medical Center Nampa,
- Women's Health Check

The Affiliate also compared the Idaho hospital map to an Idaho road atlas map showing major highways and road ways. Road atlas maps showed that there is only one major interstate running East/West in Idaho. This comparison plus data provided from key informant interviews showed the Affiliate that women living in Owyhee,

Washington, and Adams counties travel approximately two hours to receive screening and/or treatment.

Southwest District III screening rates show 42.7 percent of the target population has not received clinical breast exams and/or mammograms in the past two years. Stronger partnerships with mobile units and encouraging transportation grants for screening and/or treatment will help women access breast care services in their communities.

#### **Qualitative Data Overview**

The Core Committee used a variety of methods to receive multiple perspectives on breast health services in the SWDH area. The Affiliate conducted focus groups, key informant interviews, surveyed patients in the waiting room of a non-profit clinic in Canyon County and surveyed breast cancer survivors via an online survey. One focus group was conducted in Canyon County, the county with the largest population in the SWDH area. The other focus group took place in Payette County, a county that emerged as an area of high concern in regard to breast cancer mortality, early stage incidence and late stage incidence.

Common themes from focus groups and key informants revealed that fear of diagnosis, fear of pain during a mammogram, and lack of finances (including lack of insurance) were issues that deter women from obtaining preventive care. The lack of a medical/provider home also inhibits women from obtaining the correct information about preventive health care screenings such as mammograms. The top needs identified included better marketing and advertisement of programs and increased financial assistance that would encourage more women to seek screening mammograms.

Respondents to the breast cancer survivor survey emphasized the importance of obtaining direct and detailed information from physicians regarding diagnosis and/or treatment. Relaying the message of the significance for physicians to recommend and educate patients about the importance of breast health screening will reduce fear and create trusting relationships between doctor and patient. Survivors also revealed the need for peer-to-peer support groups or consultation with another survivor prior to treatment.

The interviews, surveys and focus groups allowed the Affiliate to create priorities for the 2011-2012 grant cycle. The Affiliate plans to increase fundraising efforts, build relationships with grantees and partners, and increase education and awareness endeavors.

#### Conclusions

Review of the data, programs and services provided the Affiliate insight into removing existing barriers to services, decreasing mortality rates and increasing screening rates. Asset maps and key informant interviews indicate that many women 40 and older live in underserved areas with little available resources. The information shows themes of common factors that contribute to the gaps and barriers in breast health. Based on the evaluation of the 2011 Community Profile findings, the Affiliate chose the following themes to set the Affiliate priorities:

1) Addressing quality of and access to the full continuum of care

- 2) Education and Breast Cancer Awareness
- 3) Mission and Grant initiatives

The following priorities were selected for the Boise Affiliate:

**Priority 1:** Ensuring quality of care for all women by improving access to the full continuum of care.

Desired Outcome: Improving access to quality care in the SWDH area and to women with low and middle income levels, including but not limited to uninsured and underinsured.

**Priority 2**: Develop new methods of delivering educational messages.

Desired Outcome: To eliminate and reduce barriers that hinder one's access to care and increase the number of women receiving breast cancer screenings.

**Priority 3**: Strengthen Grants programs that use evidence-based approaches to building programs that result in positive changes in reduction of morality, early screening and/or reduce rates of late stage diagnosis.

Desired Outcome: To give priority to grant programs that result in increase screening numbers and show measureable impact.

#### Introduction

#### **Affiliate History**

Ambassador Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982, that promise became Susan G. Komen for the Cure<sup>®</sup> which launched a global breast cancer movement. Today, Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists. The Boise Affiliate is one of 127 affiliates working toward fulfilling Ambassador Brinker's promise.

The Boise Affiliate of Susan G. Komen for the Cure<sup>®</sup> is a tax-exempt 501(c) (3) organization that works to better the lives of those facing breast cancer in our communities. Since its inception in 1999, the Komen Boise Affiliate will have invested almost four million dollars in local breast health and breast cancer awareness projects in the 19 county service area. The 19 counties within the service area include: Ada, Adams, Blaine, Boise, Camas, Canyon, Cassia, Elmore, Gem, Gooding, Idaho, Jerome, Lincoln, Minidoka, Owyhee, Payette, Twin Falls, Valley, and Washington.

The Affiliate's main fundraising event is the Susan G. Komen Race for the Cure<sup>®</sup> part of the largest series of 5K run/fitness walks in the world. In 1999, Boise joined the national effort and held its first Race for the Cure. With over 6,500 participants attending this race; it was the largest ever for a Komen first year race. Since that time, the Boise race has grown to over 16,000 participants.

The Komen Boise Race for the Cure<sup>®</sup> is more than a race for runners or fitness walkers. It is an opportunity for people of all ages and abilities to honor and support loved ones who have lost the battle with breast cancer, are winning the battle now, and to help raise funds to fight the disease. Boise Race for the Cure® funds a variety of community-based breast health education, screening and treatment projects for the medically underserved. In 2010, \$525,000 was granted to twenty-seven breast health and breast cancer projects and programs in southwest Idaho.

#### **Organizational Structure**

The organizational structure in Figure 1 below represents the Affiliate's three staff members and current office volunteers. The Affiliate staff consists of one full time Executive Director, two three-quarter time employees and two half-time interns. Oversight of Affiliate is the responsibility of the Board of Directors. Primary Board responsibilities include oversight of the Director. establishing direction of the organization's strategic plan, fiscal oversight, and guidance and support of policies and procedures. Board positions include President, Vice President. Grants Committee Chair. Treasurer, Secretary, Board

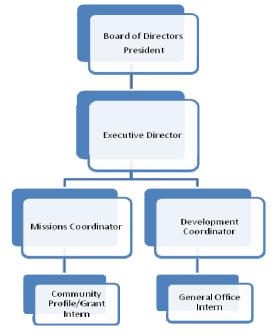


Figure 3. 2011 Boise Affiliate's Organizational Structure

Development Chair, and two Board- at- Large positions. Positions are filled based on recruitment and election process.

#### **Description of Service Area**

The Affiliate service area is comprised of 19 counties in Idaho. The counties served are primarily located in southwest and central Idaho. The service area includes Ada, Adams, Blaine, Boise, Camas, Canyon, Cassia, Elmore, Gem, Gooding, Idaho, Jerome, Lincoln, Minidoka, Owyhee, Payette, Twin Falls, Valley, and Washington. Figure 4 shows the Boise service area in purple.

The service area also encompasses two of the most populated areas in Idaho; Ada County which has a population of 384,656 and Canyon County with a population of 186,615 (U.S. Census Bureau, 2009).

## Purpose of the Report

The purpose of the Community Profile is to collect, compile and correlate data for an assessment of the Affiliate service area gaining a better knowledge and understanding of the gaps and barriers that inhibit one from receiving a mammogram.



Figure 4. Boise Affiliate 19 county service area.

The profile is completed every two years in order to update the data and develop new initiatives that will reduce the burden of breast cancer in southwest and central Idaho. Data is obtained from national organizations, the local cancer data registry, local health care providers and survivors in the following categories:

- Breast cancer statistics: prevalence, mortality, screening rates, and incidence rates
- Preventive health care behaviors: knowledge of, and gaps and barriers to
- Breast health services and programs: education, screening, and treatment

# **Breast Cancer Impact in Affiliate Service Area**

#### Methodology

Quantitative data was collected, analyzed, and interpreted from the various public sources and contributing groups which are listed below. The Core Committee validated demographic data by comparing multiple sources of data. Breast cancer data was analyzed by comparing data from each county in correlation charts. Conclusions of social determinants were drawn from the correlation charts and the top six counties of need were identified.

#### 2009 U.S. Census Bureau- American Community Survey

The American Community Survey is an ongoing survey collected by the U.S. Census Bureau that gathers data for the purpose of giving communities current information needed to plan investments and services. Surveys cover topics such as age, sex, race, family and relationships, income and benefits, health insurance, education, disabilities, veteran status, where citizens work, transportation to work, geographic location, and how individuals pay for some essential services. Data is available in one-year, three-year and five-year sets.

#### Behavioral Risk Factor Surveillance System (BRFSS) 2008

The Behavioral Risk Factor Surveillance System (BRFSS) is an ongoing national health survey of adults that collects information on health risk behaviors, preventive health practices and health care access. Each state annually conducts its BRFSS survey via telephone.

#### **Cancer Data Registry of Idaho**

The Cancer Data Registry of Idaho (CDRI) is a population based cancer registry that collects incidence and survival data on all cancer patients residing in the state of Idaho or are diagnosed and/or treated for cancer in Idaho. The data included in this report is over a five-year period from 2003-2007.

#### **Local Area Unemployment Statistics Program (LAUS)**

The Local Area Unemployment Statistics program (LAUS) is a federal and state venture that counts the number of people working by where they reside and reports estimates of total employment and unemployment monthly.

### Thomson Reuters<sup>©</sup> 2009

Komen selected Thomson Reuters<sup>©</sup> 2009 to provide estimates (not actual data) of demographic and breast cancer statistics for the 2011 Community Profile. Thomson Reuters<sup>©</sup> created breast cancer estimates in order to provide the Affiliate Network with statistics at the county and zip code level where actual rates do not exist either because they are suppressed or because of limitations in data availability. The estimates were developed using Surveillance, Epidemiology and End Results (SEER) data from 1998 to 2004.

#### **Overview of the Affiliate Service Area**

The Boise Affiliate service area encompasses 19 of Idaho's 44 counties in southwest and central Idaho (see Figure 4). In 2008, BRFSS survey data ranked Idaho at 46<sup>th</sup> out of 51 (including District of Columbia) for percent of females age 40 and over who had not had a mammogram in the last 2 years. The Core Committee also obtained breast cancer information from the Cancer Data Registry of Idaho to determine which Idaho counties carry more breast health burden.

**Mortality:** Mortality is a measure of the number of deaths in a given population, over a space of time. The mortality rates below are expressed as deaths per 100,000 people. Breast cancer deaths in the state of Idaho versus the Boise Affiliate are the same (see Table 4).

Table 4. Breast Cancer Mortality, Idaho Females 2004-2008

Geographic Area	Breast Cancer Deaths	Rate
State of Idaho	809	21.1
Komen Boise Affiliate Counties		
(19)	447	21.1
Ada	172	20.0
Adams	2	16.7
Blaine	10	16.4
Boise	3	18.1
Camas	1	41.9
Canyon	86	21.6
Cassia	6	10.1
Elmore	10	18.5
Gem	10	17.8
Gooding	9	22.2
Idaho	16	29.8
Jerome	16	31.1
Lincoln	1	8.8
Minidoka	9	16.6
Owyhee	9	30.4
Payette	15	25.4
Twin Falls	57	26.3
Valley	3	11.3
Washington	12	26.3

Source: Cancer Data Registry of Idaho

Rates are per 100,000 and age-adjusted to the 2000 US Std Population (19 age groups - Census P25-1130) standard.

**Early Stage Incidence:** Early stage diagnosis means that women are detected with breast cancer in the early stages of the disease. Incidence is the number of new cases of a disease in a population over a period of time. High rates of early stage incidence indicate females are receiving screening. In interpreting this data, the Core Committee chose to highlight areas with low early stage incidence for communities of interest. The Affiliate's rates of early stage incidence are 4.5 percent higher than the rest of the state

of Idaho, indicating that perhaps Komen grants for screening mammography are being utilized by women who need them. *Table 5* shows data for Idaho Females early state incidence rate by county.

Table 5.
Early Stage Breast Cancer Incidence, Idaho Females 2003-2007

Geographic Area	In Situ and Localized Cases	Rate
State of Idaho	3,395	93.8
Komen Boise Affiliate Counties	1,961	98.3
Ada	923	112.3#
Adams	12	96.7
Blaine	53	90.2
Boise	20	99.9
Camas	2	64.4
Canyon	313	85.4
Cassia	30	54.3#
Elmore	53	94.6
Gem	37	75.9
Gooding	45	106.9
Idaho	48	88.5
Jerome	49	104.1
Lincoln	10	90.3
Minidoka	45	87.7
Owyhee	18	62.8
Payette	50	83.8
Twin Falls	199	99.6
Valley	25	97.7
Washington	29	82.6

Source: Cancer Data Registry of Idaho

# The rate ratio indicates that the rate is significantly different than the rate for State of Idaho (p<0.05). Rates are expressed per 100,000

**Invasive Prevalence:** Invasive breast cancer is cancer that has broken through normal breast tissue and invades surrounding areas. Prevalence is the number of total cases of a disease in a population over a period of time. Greatest invasive prevalence of the 19-county Boise Affiliate is in Adams and Camas counties (see Table 6).

Table 6. *Invasive Prevalence* 

County	Estimated Count	County Female Population Percent
Ada	2,434	1.3%
Adams	38	2.2%
Blaine	166	1.5%
Boise	47	1.3%
Camas	12	2.2%
Canyon	842	0.9%
Cassia	121	1.1%

Elmore	170	1.3%
Gem	125	1.5%
Gooding	112	1.7%
Idaho	122	1.6%
Jerome	135	1.3%
Lincoln	23	1.0%
Minidoka	131	1.4%
Owyhee	55	1.0%
Payette	151	1.3%
Twin Falls	524	1.4%
Valley	84	2.0%
Washington	80	1.6%

Source: Cancer Data Registry of Idaho

**Screening:** Women aged 40 and above who reported having a mammogram and clinical breast exam (CBE) in the past two years are highest in the most populace (Ada) and affluent (Blaine) Boise Affiliate counties. Ada County has a population of 393,642, a population density of 371 people per square mile. Blaine County has the highest median household income (\$66,740) of all Boise Affiliate counties. The lowest screening rates reported were in Canyon and Adams counties as seen in *Table 7*.

Table 7.

Percent of women 40 and older who received a clinical breast exam and mammogram in the past two years, 2008

County	Percent of Females 40 + Who Have Received a Mammogram or Clinical Breast Exam
Ada	70.1%
Adams	61.7%
Blaine	70.8%
Boise	66.8%
Camas	ND
Canyon	60.1%
Cassia	46.7%
Elmore	68.0%
Gem	49.7%
Gooding	51.8%
Idaho	56.9%
Jerome	62.6%
Lincoln	44.3%
Minidoka	53.0%
Owyhee	60.3%
Payette	62.4%
Twin Falls	61.8%
Valley	69.7%
Washington	44.1%

Source BRFSS 2008, ND=No Data

Late Stage Breast Cancer Incidence: Late stage diagnosis means that women are

detected with breast cancer in the late stages of the disease, probably stage 3 or stage 4. Incidence is the number of new cases of a disease in a population over a period of time. Late stage incidence for the Affiliate service area is slightly higher than that of the rest of the state as shown in *Table 8*.

Table 8.

Late Stage Breast Cancer Incidence, Idaho Females 2003-2007

Geographic Area	Regional and Distant Stage Cases	Rate
State of Idaho	1,578	43.7
Komen Boise Affiliate Counties (19)	884	44.3
Ada	383	45.5
Adams	8	76.9
Blaine	20	35.1
Boise	7	31.5
Camas	7	237.2#
Canyon	156	42.4
Cassia	18	30.2
Elmore	28	49.8
Gem	13	26.4
Gooding	18	48.3
Idaho	19	36.6
Jerome	29	58.5
Lincoln	1	10.8
Minidoka	19	35.3
Owyhee	10	32.7
Payette	28	52.2
Twin Falls	97	49.6
Valley	12	46.0
Washington	11	31.3

Source: Cancer Data Registry of Idaho

# The rate ratio indicates that the rate is significantly different than the rate for State of Idaho (p<0.05). Rates are expressed per 100,000

Late Stage Incidence: A map of late stage incidence overlaid with mammography facilities and mobile mammography sites reveals that the majority of mammography facilities are located in Ada and Canyon counties, where late stage incidence rates are 35.4 – 46.0 per 100,000 people. In Adams County, late stage incidence rates are among the highest in the Boise Affiliate area with 52.3 – 237.2 per 100,000 (see Figure 5), this directly relates with the facts there are no mammography facilities and no mobile unit visits to this area.

# Komen Boise Affiliate Late Stage Female Breast Cancer Incidence, 2003-2007

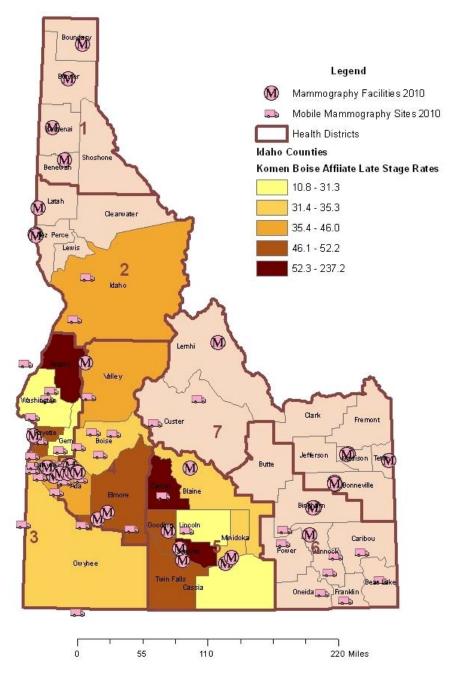


Figure 5. Late Stage Female Breast Cancer Incidence 2003-2007 for Boise Affiliate's 19 county service area, showing mobile mammography and fixed facility mammography sites

Source: CDRI

*Insurance:* Table 9 shows counties with highest rates of uninsured females which include Idaho, Owyhee and Adams.

Table 9. *Uninsured Females* 

		2009 Total County	Uninsured Females	
County	County Seat (City)	Female Population	Population	%
Ada	Boise	188,481	1,931	19.7%
Adams	Council	1,724	208	22.6%
Blaine	Hailey	10,717	78	16.6%
Boise	Idaho City	3,648	145	17.9%
Camas	Fairfield	543	ND	ND
Canyon	Caldwell	93,307	2,501	16.3%
Cassia	Burley	10,632	1,371	17.1%
Elmore	Mountain Home	13,257	157	16.8%
Gem	Emmett	8,218	1,073	13.6%
Gooding	Gooding	6,782	412	14.6%
Idaho	Grangeville	7,421	341	26.7%
Jerome	Jerome	10,205	152	17.2%
Lincoln	Shoshone	2,229	218	15.4%
Minidoka	Rupert	9,420	925	16.4%
Owyhee	Murphy	5,274	174	23.5%
Payette	Payette	11,549	778	15.0%
Twin Falls	Twin Falls	37,648	97	18.3%
Valley	Cascade	4,188	172	13.1%
Washington	Weiser	5,059	58	14.4%

Source: LAUS 2010

**Ethnicity:** Idaho's race demographic is largely White, approximately 94.4%. Hispanic or Latino is the second leading ethnic background in Idaho (10.7%).

Table 10.

Race in Idaho versus the United States

Ethnicity	ldaho	United States
White	94.4%	79.6%
Black or African American	1.0 %	12.9%
American Indian or Alaska Native	1.6%	1.0%
Asian	1.2%	4.6%
Native Hawaiian and Other Pacific Islander	0.1%	0.2%
Hispanic or Latino	10.7%	15.8&

Source: U.S. Census Bureau 2009

**Education:** Less than half of BRFSS respondents obtained an education level of 12<sup>th</sup> grade or GED (see Table 11). A woman without a college degree is less likely to regularly receive screening. College graduates for the Boise Affiliate service area is only at 25.8 percent.

Table 11. Education

	Idaho (statewide)	19 county service area
Number of respondents	2287	1035
Education Attainment		
K-11	53.2%	53.4%
12th grade or GED	41.3%	41.9%
Some college	35.5%	33.1%
College graduate+	29.8%	25.8%

Source: BRFSS 2008

#### **Communities of Interest**

The Core Committee analyzed breast cancer specific data including: mortality, early stage incidence, late stage incidence, invasive prevalence and screening among women 40 and older. Initially, Camas County presented as an area of high interest with a high rate of mortality (41.9), late stage incidence (237.2) and invasive prevalence (2.2 percent). The Core Committee determined, with expert advice from the Cancer Data Registry of Idaho, that Camas County's high rates are a result of its rural status and small population (total female population of 543 people). Camas County lacks free standing health care facilities and largely utilizes health care services from the Blaine County and Twin Falls County areas. Due to these issues, the Affiliate chose to focus its efforts in areas with larger population bases.

It was important to the Core Committee to find the top counties for breast cancer related data as well as additional categories that have been proven in expert literature to affect screening rates. Additional data came from the categories:

- Unemployment
- Median household income
- Uninsured females

The top six counties for all data sources were charted and a list of the top counties with the highest combination of factors overall was compiled. This compilation revealed seven top counties of concern:

- Adams
- Washington
- Idaho
- Camas
- Owyhee
- Gem
- Twin Falls

Examination of the top counties in all categories revealed that four of the counties, Adams, Washington, Owyhee and Gem, were contained in the Southwest District

Health III (SWDH) area. The majority of the SWDH counties (75%) have low median household incomes; 75 percent also have low early stage incidence rates. In addition, 50 percent have low rates of mammography and clinical breast exams (CBE) for women 40 years and older. The complete list of factors among the top four counties is seen in *Table 12*.

Table 12. Top Counties with Combined Socio-Economic Factors

County	Top Points and Socio-Economic Categories
Adams	High Unemployment, Low Median Income, High Uninsured, High Late Stage Incidence, High Invasive Prevalence
Washington	Low Median Household Income, High Mortality, Low Early Stage Incidence, High Invasive Prevalence, Low Mammography and CBE over 40
Owyhee	Low Household Income, Uninsured, High Mortality, Low Early Stage Incidence
Gem	Unemployment, Low Early Stage Incidence, Invasive Prevalence, Low Mammography and CBE over 40

#### Sources:

Unemployment: Idaho Department of Labor, July 2010 Median Household Income: Thomson Reuters<sup>©</sup> 2009 Uninsured Females: U.S. Census Bureau 2000 Mortality: Cancer Data Registry of Idaho 2007

Early Stage Incidence: Cancer Data Registry of Idaho 2007 Late Stage Incidence: Cancer Data Registry of Idaho 2007 Invasive Prevalence: Cancer Data Registry of Idaho 2007

Mammography & CBE ≥ 40: Idaho BRFSS 2008

The Southwest District Health III area contains two additional counties Payette and Canyon that the core committee decided to include as part of targeted mission initiatives due to the following. While Payette County's rates were not among the top three in any category, low rates of early stage incidence can indicate lack of screening. Additionally, it appears women in Payette are receiving later stage cancer diagnoses as indicated by high late stage incidence, see *Figure 5*. The Core Committee also recognized that Payette County, a small farming community, was an area of concern based on the breast cancer-related categories mortality, early and late stage incidence, referring to data in *Table 16*. Canyon County is the second most populace county in Idaho and also is the only county in the SWDH area with a facility offering the full continuum of care. Yet this county has the highest number of uninsured females (*Table 9*) in the service area.

#### **Conclusions**

After analyzing the breast cancer-specific data the Southwest District Health III area continually showed poor statistics in mortality, early stage incidence, late stage incidence, invasive prevalence and screening among women 40 and older data. The Southwest District Health III area comprised of six counties Adams, Gem, Owyhee, Payette, Washington and Canyon County was chosen to be a focus for the 2011

Community Profile. Below details each SWDH county and the breast cancer related data and the rank associated with the categories.

#### **Adams County**

Adams County emerged as a top three county in five categories (see *Table 13*). From our analysis, we inferred that the county's high rank in the lower socioeconomic categories impacts whether or not a woman in Adams County receives a regular screening mammogram. Adams County has a population of 3,518.

Table 13. Adams County Combined Categories

Rank	Category	Rate
3	Unemployment	11.6%
2	Median Household Income	\$36,459
3	Uninsured Females	22.6%
2	Late Stage Incidence	76.9
1	Invasive Prevalence	2.2%
NR	Mortality	16.7%

NR – Not ranked in the top six

#### Gem County

Gem County has a total population of 16,462. It appears the county has low rates of early diagnosis as shown by its early stage incidence rate. Further, it ranks fourth for the least percentage of women aged 40 and older who have had a mammogram and clinical breast exam (CBE) in the past two years, approximately 50.3% of the women in this county have <u>not</u> received a mammogram and CBE in the past two years (see Table 14).

Table 14. Gem County Combined Categories

Rank	Category	Rate
5	Unemployment	10.5%
4	Early Stage Incidence	75.9
5	Invasive Prevalence	1.5%
4	Mammography + CBE ≥ 40	49.7%
NR	Mortality	17.8%

NR – Not ranked in the top six

# **Owyhee County**

Owyhee County is the least populated county in the SWDH area with 10,880 residents, or one person per square mile. Owyhee County ranked in the top three in the following categories: median household income, uninsured females, mortality and early stage incidence. Further, its number two ranking in uninsured and early stage incidence (see Table 15), may indicate that a lack of insurance hinders women from obtaining mammography screening.

Table 15. Owyhee County Combined Categories

Rank	Category	Rate
3	Median Household Income	\$37,036
2	Uninsured Females	23.5%
3	Mortality	30.4
2	Early Stage Incidence	62.8

### **Payette County**

Payette County came forward as a high area of concern to the Core Committee and Epidemiologist with CDRI, due to its mortality rates as well as early and late stage incidence rates (see Table 16). The low rates of early stage incidence and higher rates of late stage incidence demonstrate that emphasis on screening mammography may not be present in this community.

Table 16. Payette County Combined Categories

Rank	Category	Rate
6	Mortality	25.4
6	Early Stage Incidence	83.8
4	Late Stage Incidence	52.2

#### **Washington County**

Washington County has a population of 10,228. This county is ranked number one for lowest rates of women aged 40 and older receiving a mammogram and clinical breast exam (CBE) in the past two years. Approximately 55.9 percent have <u>not</u> received a mammogram and CBE in the past two years. In addition, median household income for this county is low, which may indicate why women do not receive screening early enough in this county (see *Table 17*).

Table 17. Washington County Combined Categories

Rank	Category	Rate
5	Median Household Income	\$39,064
5	Mortality	26.3
5	Early Stage Incidence	82.6
4	Invasive Prevalence	76.9
1	Mammography + CBE ≥ 40	44.1%

#### **Canyon County**

Canyon County is the most populated county in the target group with 186,615 people and an unemployment rate of 11.1 percent (see Table 18). Canyon County also has the highest number of residents of Hispanic or Latino origin than anywhere else in Idaho, around 41,055 people (U.S. Census Bureau, 2009).

Table 18. Canyon County Unemployment rate

Rank	Category	Rate
4	Unemployment	11.1%
	Mortality	21.6%

**Screening:** Additional analysis from BRFSS also showed that the counties in the Southwest Health District III area as a group have the highest percentage of women 40 years and older who have <u>not</u> had a mammogram and clinical breast exam (CBE) in the past two years (*see Table 19*).

Table 19. Screening Chart; percent of females 40 and older without a mammogram or clinical breast exam in the last 2 years.

Health District	Service County(s)	Percent Females ≥ 40 w/o Mammogram and CBE in last 2 years
1	N/A	39.4%
II	Idaho*	39.2%
III	Adams*, Canyon, Gem, Owyhee*, Payette, Washington	42.7%
IV	Ada, Boise, Elmore, Valley Blaine, Camas, Cassia,	26.8%
V	Gooding, Jerome, Lincoln, Minidoka*, Twin Falls	40.9%
VI	N/A	39.0%
VII	N/A	42.0%

Source: BRFSS 2008

\* 2009 Community Profile Target Area N/A – Not in the Komen Boise Affiliate Area

**Hispanic Population:** Table 20 shows the Hispanic population in the Southwest District Health III counties. The SWDH area comprises approximately 43 percent of the Hispanic population in the 19 county Boise Affiliate area.

Table 20. Hispanic Population for Southwest District Health III Area

County	Total Population (All Races)	Percent Hispanic Population
Adams	3,520	3.0%
Canyon	186,615	22.0%
Gem	16,437	8.0%
Owyhee	11,223	26.0%
Payette	23,099	15.0%
Washington	10,119	17.0%
Total SWDH	251,013	20.1%
Boise Affiliate	876,115	13.5%

Source: U.S. Census Bureau 2009

The median household income for the total Boise Affiliate is \$49,947 with 7.6 percent of families at or below poverty level. Federal poverty thresholds for January

2009 ranged from \$10,830 for one person in the family unit to \$37,010 for families of eight. A family of four has a poverty threshold of \$22,050. The SWDH median household income is \$40,406 with 11.02 percent living at or below poverty level (U.S. Census Bureau, 2009). The total female population of this area is about 125,131 or 29 percent of the total Boise Affiliate female population (U.S. Census Bureau, 2009).

Reviewing the combined data of unemployment, household income levels, uninsured status, breast cancer incidence and prevalence, the Core Committee determined the Southwest District Health III area should be the focus of the 2011 community profile.

# **Health Systems Analysis of Target Communities**

#### **Overview of Continuum of Care**

For the analysis of the existing health systems in Southwest Idaho, the Boise Affiliate defined the continuum of care as the full spectrum of services offered from education through screening, diagnostics, and follow-up care for all individuals. *Figure 6* illustrates the four phases that make up the continuum of care. Phase 1 includes educational presentations, Clinical Breast Exams (CBE's) and screening mammograms. Phase 2 is comprised of the additional testing necessary to determine breast cancer diagnosis. Phase 3 includes a variety of treatments prescribed following a breast cancer diagnosis such as surgery, chemotherapy, and/or radiation treatments. In the final phase, Phase 4, the patient continues to use the health care system for general health and preventive care.

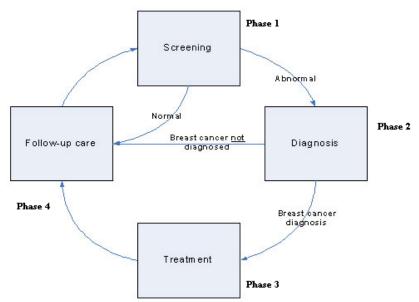


Figure 6. Health systems continuum of care

Each county was analyzed to determine if access, e.g. the availability of fixed-site facilities and mobile screening vans, had an impact on the continuum of care. Further analysis was done in order to gain a better understanding of the gaps in services and geographic barriers that relate to mortality, prevalence, incidence, and screening rates.

It is evident from the breast cancer data that access to services has a direct impact on each phase of the continuum of care.

For instance, in Phase 1, there are limited screening services available in the SWDH area. The data in this area shows higher mortality rates and low screening rates; 42.7% of women 40 and older had <u>not</u> received a mammogram and CBE in the last two years (Idaho BRFSS, 2008) and there is a combined average mortality rate of 22.93% (Idaho Cancer Data Registry, 2008). Throughout the Affiliate's service area there was a direct correlation between low screening rates and high mortality rates in relation to lack of fixed sites.

A patient may have to travel long distances (2-3 hours) to receive care when there is a lack of cancer treatment centers in their county, therefore, patients have difficulty assessing the services identified in Phase 2 and Phase 3. The Boise Affiliate funds The American Cancer Society of Idaho grant program that offers funds for travel to treatment; however, in general, few resources are actually allocated to assist patients in transportation issues.

The most commonly reported deterrents to the continuum of care identified through survivors and medical provider surveys were lack of insurance, finances, and lack of awareness of breast health screening programs. Key informant interviews also revealed there are meager advertising and marketing budgets for screening programs in areas without fixed sites and few grantee programs. In areas where fixed sites are not available, the client relies on doctor referral to a facility and/or mobile mammography van schedules which can be cancelled due to few reservations.

Grantee programs are trying to address some of the common deterrents to breast cancer health care access. Most of Komen Boise grantee programs in Adams and Payette counties are breast health educational projects only. Other grantees in Idaho, Canyon, and Owyhee counties conduct educational projects as well as clinical breast exam screening with a voucher program for patients to receive free or reduced screening mammograms at one of Ada County's fixed site facilities.

#### Methodology

Idaho's hospitals were plotted on a map (Figure 7) to show which counties have access to care. Grantee programs that offer education. screening. and/or treatment programs were added to the map for the SWDH and Ada County Ada County is areas. southwest Idaho's main hospital and full continuum of care medical services are predominantly clustered in this area. Data from the Cancer Data Registry of

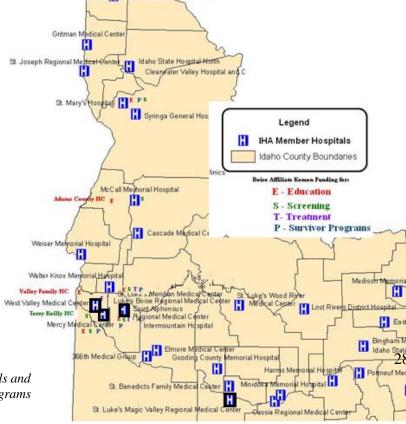


Figure 7. Idaho Hospitals and Komen Grantee Programs

Idaho identified critical care only hospitals in the in the target area which do not offer the full continuum of care. The full continuum of care hospitals in Figure 7, highlighted in black, are also primarily located in the Ada County area.

#### **Key Informants**

Eleven key informant interviews were conducted in the Southwest District Health III area. Interviewees included breast health experts from Southwest District Health Department, breast care personnel from St. Alphonsus Medical Center in Nampa, and program administrators with the Women's Health Check at the Idaho State Department of Health and Welfare.

Furthermore, five medical providers completed an online survey sent to all Boise Affiliate grantees from the target area. Limitations to qualitative data collection included:

- Unable to interview mobile mammography Directors to verify number of women served via mobile units
- Rural terrain and limited providers in SWDH area limited the number of key informant interview
- Few medical providers' responded to the survey, as well as limited questions regarding the continuum of care for this group

#### **Overview of Community Assets**

# Mammography Screening Locations, 2010 Mammogram Within Previous 2 Years, Women Aged 50+ Aggregated BRFSS Data 2006-2008

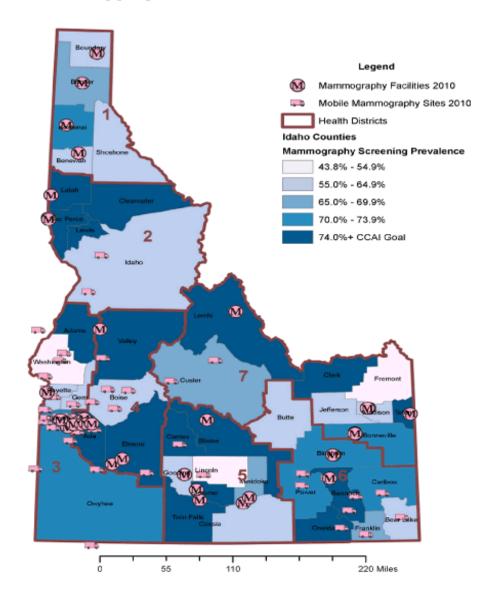


Figure 8. Asset Map: Mammography Screening Sites and Mobile stops Source: Cancer Data Registry of Idaho

The Boise Affiliate service area has 17 fixed mammography facilities. Of the 17 sites, only three provide the full continuum of care to breast cancer patients. None of these sites are located in the Southwest District Health III area. However mobile mammography does travel to each county (more specific data not received). The only fixed site that offers screening and diagnostic mammograms within the SWDH area is St. Alphonsus Medical Center – Nampa located in Canyon County. Women residing in

Payette, Gem, Washington and Adams counties must travel to Nampa or Boise for mammogram services or schedule an appointment with a mobile mammography unit. Mobile mammography vans visit Washington, Payette, Gem, Canyon, and Idaho counties. Mobile mammography visits Owyhee County, but rural terrain, a small population of 11,000 (U.S. Census), and limited interstates, roads, and isolated towns create additional access to care issues as shown on *Figure 9*. The average driving time for women to receive screening mammography services is approximately two hours and average travel time for treatment is approximately three hours.



Figure 9. Idaho Road Map

Source: Geology.com/cities-map/idaho

#### **Komen Partnerships**

In 2010 the Affiliate partnered with five community grantees, locations shown in *Figure 7*, to improve education and screening efforts in SWDH counties. Education programs are offered in Adams County at the Adams County Health Center and in Payette County at Valley Family Health Care. The Affiliate's grantee, Terry Reilly Health Services offers reduced cost or free screenings with a voucher in Owyhee and Canyon counties. Southwest District Health Department is a grantee program that also offers education and vouchers for screening mammograms in all six counties. In

Canyon County, the only Affiliate grantee offering both education and screening services is St. Alphonsus Regional Medical Center-Nampa.

# National Breast and Cervical Cancer Control Early Detection Program – Women's Health Check Program

Idaho's National Breast and Cervical Cancer Control Early Detection Program (NBCCCEDP) is referred to as the Women's Health Check Program (WHC). Women who financially qualify and do not have other resources such as insurance, Medicare or are Medicaid recipients can still receive free screening and diagnostics under the WHC guidelines.

The Affiliate previously had a limited relationship with the WHC program. Recently, however, a new relationship has developed between the Affiliate and WHC to create collaborative educational and outreach programs. The Affiliate will continue to foster relationships with independent groups such as the Comprehensive Cancer Alliance of Idaho, WHC, American Cancer Society and the Idaho Hospital Association. These groups show support of fighting breast cancer through lobbying, outreach programs and other preventive health programs. The Affiliate also will continue to build stronger partnerships with area hospitals to support effective breast health programs.

#### Idaho Legislature

Idaho's legislature decreased funds for programs such as Medicare and Medicaid while balancing the state budget. These measures will potentially decrease the number of constituents who have access to breast health services.

The Affiliate's Executive Director and board members participate in statewide and national lobbying efforts, including Komen lobby days. The agenda of lobby day's annual meeting with Idaho's legislature is to advocate for increased funding and support of breast cancer research initiatives in Idaho. Komen Boise Affiliate will continue to work on these year round efforts.

#### **Key Informant Interview Findings**

Eleven key informant interviews were conducted throughout the Southwest District Health III area. Interviewees included breast health experts from Southwest District Health Department, breast care personnel from St. Alphonsus Medical Center-Nampa, and program administrators with the Women's Health Check at the Idaho State Department of Health and Welfare. Key findings in regard to a woman receiving all four phases of care according to the continuum are detailed below.

#### **Southwest District Health (SWDH)**

The SWDH public health department employs case workers that follow the patient from screening through diagnostics and, if need be, treatment and follow up. SWDH is an Affiliate grantee that provides Clinical Breast Exam (CBE) screening and mammography to women through a voucher process. Services are offered at free standing facilities located in Ada and Canyon counties. A Southwest District Health patient could potentially live two or more hours away from the facility. Without a public transportation system available in the Nampa or Caldwell area, most clients must rely on personal transportation to get to the clinics.

When asked to describe SWDH patients, key informants reported that almost fifty percent of patients are ages 20-29, ten percent are between ages 40-49, and most are Hispanic females. Additionally, there is also a sixty percent zero-pay rate on all services provided, with the remainder of patients partially paying and approximately seventeen percent with having insurance or type of Medicare. Regardless of insurance status, SWDH examines and refers patients for screenings and diagnostic mammograms. Patients may be insured, uninsured and undocumented citizens; however their referral program has limited providers who will take an undocumented citizen.

When asked how patients learn about services all informants reported that 'word of mouth' was most effective with their populations. The SWDH facilities are not primary care clinics and are mainly utilized for their reproductive services. Initially breast health screenings are incorporated into reproductive screenings, but little to no advertising is specifically done for breast health services outside of the clinic.

#### St. Alphonsus Regional Medical Center-Nampa

St. Alphonsus Regional Medical Center-Nampa (SARMC-Nampa) offers breast cancer screening and diagnostic services but not treatment services. Women who are diagnosed with breast cancer are referred to a hospital in Boise (Ada County) for treatment. SARMAC-Nampa offers several resources to women in the Canyon County area including free rides to a screening clinic via the W.I.S.E. van. SARMC-Nampa also accepts all patients, regardless of their ability to pay or documentation status. The self-pay rate for services is around 25 percent and the charity care financial support is higher than it ever has been. It was reported by key informants at SARMC-Nampa that in the Canyon County community, a majority of their patients are migrant farm workers and Hispanic, with over three-quarters of their patients are Hispanic that utilize They do provide Spanish breast health material and mammography services. interpreters and they believe their marketing efforts are targeted to this population with newspaper and local magazine ads. Key informants at St. Alphonsus-Nampa report that some area physicians will assist the migrant population to provide treatment services at low cost or pro bono to undocumented women. Even so, when asked to describe the women that are most difficult to reach to inform about breast health services, the key informants described a woman with no insurance, women with fear of the mammogram procedure, and busy-active women.

#### **Women's Health Check**

The Women's Health Check Program (WHC) offers qualified women over the age of 50, access to services for a clinical breast exam and/or mammograms. Additionally, women aged 30-49 who have symptoms and/or are suspicious of breast cancer can be enrolled into the WHC program if breast cancer symptoms have been confirmed by a health care provider and their income meets the financial criteria of at or below 200% of federal poverty guidelines.

The interview revealed there is little advertising or promotion of the WHC program because every available dollar goes to services. The program relies on state coordinating contractors to inform providers and/or word of mouth advertising. There

are nine state coordinating contractors throughout the state of Idaho and over 400 health care providers that accept listed procedures at Medicare rates.

For the SWDH area, WHC enrolled 726 women for free mammograms in 2009. A woman with insurance coverage may be accepted into the program if for example, the woman has a high deductible or only catastrophic insurance coverage. However, enrollment into the program is at the health care provider's discretion. This federally funded program declares that undocumented U.S. women do not qualify for this program.

#### Conclusion

Fixed mammography sites are concentrated in the Ada County area as shown on *Figure 8*. The fixed mammography facilities are Saint Alphonsus Hospital and St. Luke's Health System, both located in Ada County, specifically in Boise. Both hospitals offer breast cancer screening services in the greater Boise metro area, including the cities of Meridian, Eagle, Caldwell, and Nampa. The Idaho Hospital and Komen Grantee Program figure, *Figure 7, also* shows a similar illustration with five Affiliate grantees who offer education, screening vouchers and treatment programs, but are predominantly found around the larger populated counties within the Southwest District Health III.

Both figures show the lack of continuum of care and the lack of coverage in most Idaho's counties. Screening rates in the Southwest District area show that 42.7% of women 40 and older have not received clinical breast exams and/or mammograms in the past two years, in part due to fragmentation of services and lack of access.

Few services offered in rural and low population areas create access issues for women in the Southwest District Health III area. The Affiliate needs to communicate with area grantees about transportation programs, mobile mammography dates, and create networking opportunities for clinics and facilities to collaborate on effective breast health and care programs. These efforts could assist in bringing greater services to residents in the SWDH area.

# **Breast Cancer Perspectives in the Target Communities**

The intention of the breast cancer perspectives research was to gain a community voice and learn what community members believed to be barriers to access within their communities.

# Methodology

In an effort to gain multiple perspectives from various sources and achieve triangulation, the Core Committee utilized four methods to determine breast cancer perspectives in the Southwest District Health III area:

- 1) Focus Groups
- 2) Breast Cancer Survivor Online Surveys
- 3) Patient Surveys
- 4) Key Informant Questionnaires

#### **Focus Groups**

Women were selected for focus group interviews by contacting outreach workers and hospital directors to identify women in the SWDH community who may be interested in participating. As a result, two focus groups were coordinated; one in Canyon County and one in Payette County. A script with specific questions was developed to obtain information from participants to understand their knowledge, attitudes and beliefs about breast cancer, to learn about breast cancer resources in their communities, and solicit their recommendations on how to reach women in their community. The Affiliate Mission Coordinator, joined by a graduate intern, conducted both focus groups to ensure the validity of the responses. Each focus group was voice recorded and transcribed following the interview. Results were analyzed for themes and comparison between the two focus groups.

#### Focus Group 1

Participants for Focus Group 1 were recruited by an outreach coordinator in the Payette county area. Hispanic women were invited from towns in Payette and Canyon county; Fruitland, Payette, and Parma. There were seven participants, five of which had health insurance and two that did not. Three of the women spoke both English and Spanish, one spoke Spanish only and the remainder spoke English only. Two of the women in the group have obtained a grade school-level of education, two have graduated from high school, one obtained a GED and two others went to college but did not graduate with a degree.

#### **Focus Group 2**

Participants for Focus Group 2 were recruited by St. Alphonsus Regional Medical Center-Nampa. Key women from the community were selected and invited to a focus group luncheon. There were 10 total participants; most participants fell in the age range of 40-60. All 10 participants currently have health insurance, and all ten have completed college, with two having completed either a graduate degree or other professional certification beyond a four-year degree.

#### **Breast Cancer Survivor Surveys**

A breast cancer survivor survey was created to determine current breast cancer education, screening, diagnosis, treatment and support programs available in the Affiliate service area from a survivor's perspective. An Affiliate monthly newsletter invited survivors to take an online survey via Survey Monkey. There were 150 respondents to the breast cancer survey. Of the 150 respondents, 28 came from the Southwest Health District III area. Each of the six counties was represented at least once in survey responses. Sixty percent of survivors who answered the survey were between the ages of 40-59, another 15% are in the 30-39 age range.

#### **Patient Surveys**

The Core Committee felt it was important to speak with women receiving care in a non-profit clinic serving low socioeconomic populations in the Canyon County area. Permission was granted from clinic administration for the Affiliate to set up a table in the clinic's waiting area and survey patients. Komen educational brochures and pamphlets were available at the table in English and Spanish. Komen giveaways such as

backpacks, magnets and wristbands were also given to surveyed patients. Patients were asked three questions:

- 1) At what age should a woman get a screening mammogram?
- 2) Reasons women <u>don't</u> receive mammograms.
- 3) Where can you get a Clinical Breast Exam or mammogram in your area?

Due to the clinic's high population of Spanish-speaking patients, a volunteer interpreter joined a graduate intern at the clinic to survey patients. Reponses were collected from 32 patients, two of which were male, the remainders were female. Patient ages ranged from 19 to 79, with the majority living in Canyon County (26) but other counties were represented as well: Payette (2) and Ada (3). One patient chose not to respond to this demographic data. Anecdotal evidence also suggests that among the population who read and spoke English, low literacy rates exist, as demonstrated by surveyed patients asking data collection assistants how to spell words such as 'hospital' and 'white' as well as pronunciation of words such as 'ethnic'.

#### **Key Informant Interviews**

Eleven key informant interviews were conducted with breast care experts and administrators at the following entities located in or serving the SWDH area:

- 1. Southwest District Health Family and Reproductive Health Clinic
- 2. St. Alphonsus Regional Medical Center-Nampa
- 3. Idaho Women's Health Check

After each key informant interview or focus group was completed, the recorded dialogue was reviewed, listened to and transcribed. The transcript was coded for themes and charted in an Excel spreadsheet. Key themes from the interviews and focus groups were reported to the Core Committee for discussion.

Breast cancer survivor survey results were tabulated by Survey Monkey and given to the Affiliate for further analysis.

#### **Review of Qualitative Findings**

Notable themes identified by key informant interviews, patient surveys, breast cancer survivor surveys and focus groups included:

- Financial Barriers
- Fear
- Lack of Education and Awareness
- Lack of Medical Home
- Trust

#### **Financial Barriers**

Key informants identified low incomes, high unemployment rates, lack of insurance, underinsurance, and high-deductible insurance plans as reasons for women not receiving preventive care. Additionally, one key informant indicated that the Southwest District Health III area has race barriers that contribute to financial barriers: "Health District III has a larger overall Hispanic population than any other health district. It was reported by one of the key informants that Hispanics (in their area) have higher poverty levels and higher uninsured rates than any other population" (Key informant

interview, January 6, 2011). Focus group participants revealed that many women are not aware of screening programs that offer free or reduced cost mammograms to women who are uninsured or underinsured. The participants also contemplated those women who do know that they can receive a free mammogram or have insurance to cover a mammogram, may worry that if they are diagnosed with breast cancer, they will not be able to afford treatment.

Patients surveyed at a local non-profit clinic agree that financial barriers or lack of insurance contribute to women not receiving screening for breast cancer. In fact, lack of insurance and financial barriers ranked number one for the question pertaining to reasons women don't receive mammograms.

#### Fear

Fear emerged as a top concern among all key informants interviewed as well as among focus groups and patients surveyed. Focus group participants reported specifically that fear of pain associated with mammography was a deterrent from receiving screening. Also, a Latina woman pointed out that many women of her culture believe medical tests may cause cancer, saying "the squishing of the breast and bruising will cause cancer" (Focus group, January 27, 2011). A clinic outreach worker agreed, noting that, "The biggest issue we hear in the clinic is that x-rays will cause cancer" (Focus group, January 27, 2011). One patient surveyed at a non-profit clinic explained, "they {women} don't get screened because they're scared it's {breast cancer} real" (Onsite survey and interviews, January 20, 2011).

Some focus group participants reported that fear, however, may be generational. One participant, aged 22, said, "The pain [of mammography] is worth it for younger women, I'll take bruises over cancer," (Focus group, January 27, 2011).

#### **Lack of Education and Awareness**

Key informants reported there is often a lack of understanding about the importance of prevention. One key informant noted that medical organizations do not always promote prevention and breast health messages as well as they could, "I think we can work harder to identify areas that we can provide more education to our overall hospital patients on breast health and educate our physicians on having those {screening and prevention} talks with patients" (Key informant interview, January 6, 2011).

In addition, focus group participants explain that many women put off going to the doctor. One noted, "We've been that {caregivers to everyone else} for so long that we don't know how to care for ourselves" (Focus group interview, January 13, 2011). One focus group participant said "I really think I might have been one of those women who put it on the back burner" (Focus group interview, January 13, 2011). However, due to exposure to breast cancer information through community events, she has come to be informed about the importance of screening mammograms and will receive one next year when she turns 40. Four other women over 40 who had not scheduled an initial screening mammogram, but were expressing their urgency to get one scheduled soon.

Breast cancer survivor surveys revealed that many survivors wish they had better education and information to help them through the treatment process. Furthermore, survivors indicated there are not enough support groups and patient navigators offered

through treatment facilities and note having a support group for all stages (during and after treatment) would have improved their experience. One survivor explained, "Knowledge once you're told you have breast cancer to be given material or someone to talk to that has gone through cancer. And to know it can be a curable disease and not a death wish".

Breast cancer survivor surveys as well as key informant interviews showed a lack of marketing education programs and services. One key informant described the extent of the organization's marketing tactics as displaying posters in clinics. Another key informant explained that one of the areas eliminated from their program as a result of statewide budget cuts was marketing efforts.

#### **Lack of Medical Home**

Focus group participants indicated they were exposed to screening practices often because their primary care provider recommended screenings. One key informant noted lack of referrals for screening as a major barrier for women receiving a mammogram. Further, participants from Focus Group 2 explained that they receive the majority of their care from various non-profit clinics, and they typically do not receive medical care from the same provider each time. However, women from this focus group agreed that if they had a primary care provider who had access to their medical and family health history, they would receive better care. They also admitted that if their PCP referred them to a screening mammogram, they would be sure to schedule an appointment and get one.

Participants from Focus Group 2 explained that their own primary care provider is confused about mammogram screening guidelines and as a result, she, the patient is confused. This can lead to unwillingness of patients to receive care from the provider(s) and stray from their medical home.

#### **Trust**

Key informants noted that trust in the health care community and trust in screening programs is essential for women to receive care. Focus group participants also explained that trust in their doctor is very important.

One key informant explained that the northern part of the state has very successful screening outcomes due to the trust the citizens have in their public health department. Further, cultural barriers such as a general distrust of government leads to patient wariness in accepting aid from programs such as Women's Health Check.

#### Conclusions

Information obtained from focus groups and patient surveys validated the barriers identified by key informants. These barriers are also consistent with the literature. In key informant interviews, focus groups and patient surveys alike, barriers included the fear of both pain during screening and a potential breast cancer diagnosis along with financial constraints discouraged women from receiving screening. Lack of medical homes for screening referral and distrust in medical facilities or government programs are also contributing factors. Lastly, survivors emphasized the importance of support groups, better information about the treatment process, and education to assist patients through the treatment process.

Breast cancer perspectives in the Southwest Health District III area revealed areas of improvement in order to reduce breast care service gaps. Increased funding for screening will be necessary to reach uninsured, underinsured and high-deductible health plan patients. Educational programs aimed at reducing fear and increasing awareness will be important to improving outcomes in the SWDH area. Lastly, improving partnerships with healthcare providers and facilities can help eliminate trust issues and lack of medical home.

# Conclusions: What We Learned, What We Will Do

#### **Review of the Findings**

Analysis of breast cancer-related data and barriers to screening, such as median household income, unemployment and lack of insurance, revealed that the Southwest District Health III (SWDH) area carries the highest burden for the 19 county Affiliate area. The data for the Southwest District Health III area revealed the following information:

#### Socioeconomic

- Median Household income is approximately \$9000 less than the rest of Affiliate.
   The median household income for the SWDH area is \$40,406, while the rest of the Affiliate area is \$49,947 (BRFSS, 2008).
- Median Unemployment: SWDH area is slightly higher than the Affiliate area with 9.3 percent compared to 9.1 percent, respectively" (LAUS, 2010).

#### **Demographic**

- Female population of the Southwest Health District III area is 125,131, about 29 percent of the total Affiliate female population (U.S. Census Bureau, 2009).
- Also, SWDH comprises approximately 43 percent of all Hispanics in the 19 county Affiliate areas.

#### **Breast Cancer Data**

- SWDH III shows the highest percentage of any other health district in the state of Idaho at 42.7% of women 40 years and older that have <u>not</u> had a mammogram. and clinical breast exam (CBE) in the past two years (BRFSS, 2008).
- Mortality Average Rate per 100,000 for SWDH area is 23.03.
- Early stage Incidence rate per 100,000 for SWDH area is 81.2.
- Late Stage incidence rate per 100,000 for SWDH area is 43.65.

# Health Systems analysis showed the following:

- Only fixed site offering screening and diagnostic mammograms within the priority area is St. Alphonsus Regional Medical Center-Nampa located in Canyon County.
- Travel time to get to screening and/or treatment services in the SWDH III counties can be as long as 2-3 hours.

# Focus groups and key informant interviews revealed the following key themes to screening and breast cancer treatment barriers:

- Financial barriers
- Fear
- Lack of education and awareness of breast health screening programs
- Lack of medical home and trust in programs
- Care facilities and providers
- Lack of awareness.
- Meager advertising and marketing for screening programs in these areas.

#### **Conclusions**

"We must find some way to reduce fears and let women know there is a way to get a mammogram." This statement is just one of many that encouraged the Core Committee to set goals and outcomes that will help reduce the burden of breast cancer in Idaho.

Review of the data, programs and services provided the Affiliate insight in removing existing barriers to services, decreasing mortality rates and increasing screening rates. Asset maps and key informant interviews indicate that many women 40 and older live in underserved areas with little available resources. The information shows gaps and barrier themes in breast health services. Based on the evaluation of the 2011 Community Profile findings, the Affiliate chose the following themes to set the Affiliate priorities:

- 1) Addressing quality and access the full continuum of care
- 2) Education and Breast Cancer Awareness
- 3) Mission and Grant initiatives

#### **Action Plan**

**Priority 1**: Ensuring quality of care for all women by improving access to the full continuum of care.

Desired Outcome: Improving access to quality care in the SWDH area and to women with low and middle income levels, including but not limited to uninsured and underinsured.

- By March 2012, require grant programs to make collaborative partnerships to fulfill the continuum of care cycle for patients.
- By March 2012, partner with mobile mammography units and request an increase in mobile mammography unit visits to target areas.
- For 2012-2013 Grant applications, make transportation assistance grants (travel assistance to screenings and/or treatment) a priority.
- During the 2012-2013 grant cycle, promote mechanisms and tools for grantees to use to ensure quality of continuum of care services.

**Priority 2:** Develop new methods of delivering educational messages.

Desired Outcome: To eliminate and reduce barriers that hinder one's access to care and increase the number of women receiving breast cancer screenings.

- By July 2012, develop and disseminate educational awareness campaign highlighting messages about the importance of breast health; messages must also be culturally relevant, target women ages 30-50, decrease fear, and also encourage early screenings.
- During 2011-2012, create a grassroots outreach program that can be used by grantee programs and rural agencies.
- By year end 2012, list and collaborate with primary care physicians and hospitals to increase annual breast cancer screenings and reinforce the message about screening; providing doctors' and providers' offices with complimentary Komen breast health materials.

**Priority 3**: Strengthen grant programs that use evidence-based approaches to building programs that result in positive changes in early screening and/or reduce rates of late stage diagnosis.

Desired Outcome: To give priority to grant programs that result in increase screening numbers that show measureable impact.

- By March 2012, strengthen outcome/data evaluation methods for grantee reporting
- For the 2012-2014 grant cycles, continually cultivate new grantee applications and/or programs.
- By March 2013, increase Grantees participations in Breast Health education events in their community and additionally report activities to the Affiliate.
- Continually assist Grantees and other health care agencies with marketing and fundraising opportunities in the target areas.

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