



COMMUNITY PROFILE REPORT

©2011 Salt Lake City Affiliate of Susan G. Komen for the Cure®



2011

DISCLAIMER	3
ACKNOWLEDGEMENTS	4
EXECUTIVE SUMMARY	5
INTRODUCTION.....	5
STATISTICS AND DEMOGRAPHIC REVIEW	5
HEALTH SYSTEMS ANALYSIS.....	7
QUALITATIVE DATA OVERVIEW	8
CONCLUSIONS	9
AFFILIATE ACTION PLAN.....	9
INTRODUCTION	11
AFFILIATE HISTORY	11
ORGANIZATIONAL STRUCTURE.....	11
DESCRIPTION OF SERVICE AREA	12
PURPOSE OF THE REPORT	13
BREAST CANCER IMPACT IN AFFILIATE SERVICE AREA	14
METHODOLOGY	14
OVERVIEW OF AFFILIATE SERVICE AREA.....	14
COMMUNITIES OF INTEREST	16
CONCLUSIONS	22
HEALTH SYSTEMS ANALYSIS OF TARGET COMMUNITIES	23
OVERVIEW OF CONTINUUM OF CARE.....	23
METHODOLOGY	25
OVERVIEW OF COMMUNITY ASSETS	26
LEGISLATIVE ISSUES IN TARGET COMMUNITIES	27
KEY FINDINGS.....	28
CONCLUSIONS	31
BREAST CANCER PERSPECTIVES IN THE TARGET COMMUNITIES	32
METHODOLOGY	32
KEY FINDINGS.....	32
CONCLUSIONS	34
CONCLUSIONS: WHAT WE LEARNED, WHAT WE WILL DO	35
REVIEW OF THE FINDINGS	35
CONCLUSIONS	36
AFFILIATE ACTION PLAN.....	37

Disclaimer

The information in this Community Profile Report is based on the work of the Salt Lake City Affiliate of Susan G. Komen for the Cure® in conjunction with key community partners. The findings of the report are based on a needs assessment public health model but are not necessarily scientific and are provided "as is" for general information only and without warranties of any kind. Susan G. Komen for the Cure and its Affiliates do not recommend, endorse or make any warranties or representations of any kind with regard to the accuracy, completeness, timeliness, quality, efficacy or non-infringement of any of the programs, projects, materials, products or other information included or the companies or organizations referred to in the report.

Acknowledgements

We would like to express our gratitude to the following individuals for their expertise and valuable time spent assisting in this effort.

Maritza Arce-Larreta
APRN-BC, MSN, RN
Clinical Coordinator
Utah Cancer Control Program

Lauren Anderson
Intern and Graduate Student
Public Health

Masha Boguslavsky
Comunidades Unidas

Susan Beck, Ph.D.
College of Nursing
University of Utah

Rena Clark
Survivor

Vicky Fuentes
Comunidades Unidas

Tate Jensen
Exodus Healthcare

Dianne Kane
Nursing Director of Oncology Services
Intermountain Health Care

Han Kim, Ph.D.
Assistant Director of Public Health
Westminster College

Anita Kinney, Ph.D., RN
Huntsman Cancer Institute

Kurt Micka
Executive Director
Utah Partners for Health

Lisa Nichols
Executive Director
Midtown Clinic Ogden

April Northstrom
Jigsaw Communications, Inc.

Jeff Partner, MA
Health Clinics of Utah

Kami Peterson
Public Health Nursing Manager
Salt Lake County Health Department

Candace Tatton
President
Young Survivor Sisters

Katie Wagley
BYU Graduate Student
Public Health

Nann Worrel
Executive Director
People's Health Clinic

Lori Wright
Deputy Director of Mountain Lands
Community Health Center

Executive Summary

Introduction

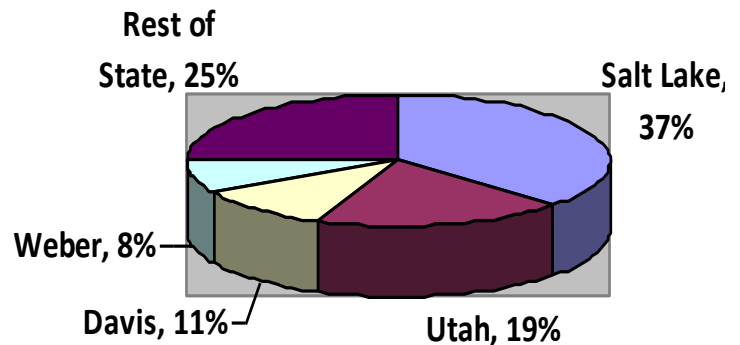
Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982, that promise became Susan G. Komen for the Cure® and launched the global breast cancer movement. Susan G. Komen for the Cure's promise is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to discover the cures. Today, Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists.

The Salt Lake City Salt Lake City Affiliate of Susan G. Komen for the Cure® was founded in 1997, the same year as the Affiliate's first Race for the Cure®. Our inaugural race involved 1,700 participants from across the state of Utah. Fifteen years later, our race has grown to more than 17,000 participants and in 2010, raised nearly \$650,000 for breast cancer awareness, research and advocacy.

Since 1997, Affiliate has been able to award nearly \$4 million to local programs for breast cancer screenings, treatment and education in the communities we serve. Up to 75 percent of the net income collected through the Race for the Cure® will stay in Utah. The additional 25 percent goes to fund groundbreaking breast cancer research, meritorious awards and educational and scientific conferences around the world directly through the national Komen for the Cure Grant Program. During 2010, the Salt Lake City Affiliate was able to award an estimated \$600,000 in grants to local groups to fund breast cancer screenings, treatment and education.

Statistics and Demographic Review

The population in Utah is approximately 2.8 million and according to the U.S. Census Bureau, more than 75 percent of residents live in Salt Lake, Utah, Weber or Davis counties. There are approximately 1,391,600 women living Utah. During 2010, 1,200 women in Utah were diagnosed with breast cancer and 250 women died from the disease. The breast cancer occurrence rate in Utah for 2010 was 101.68 per 100,000 and is lower than the national average reported at 122.54 per 100,000.

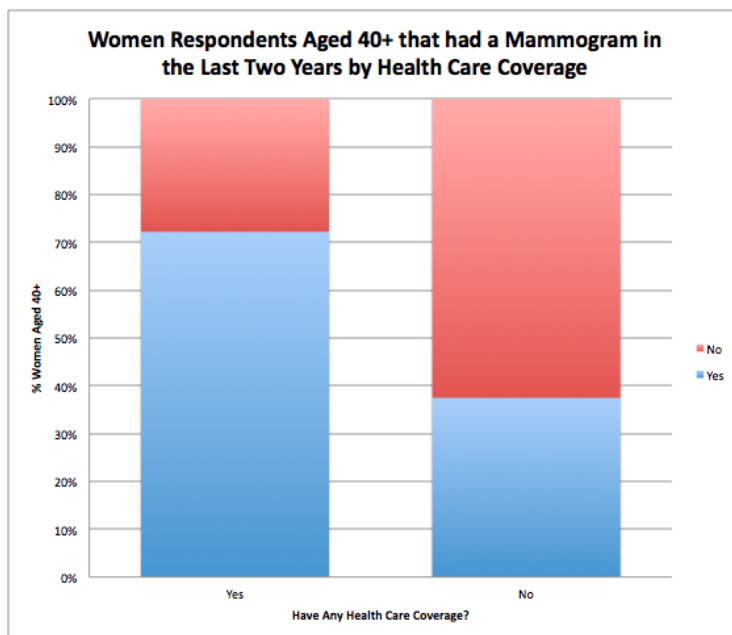


While not in the Affiliate's direct service area, examination of data shows Summit County has the highest incidence rate in Utah at 148.6 per 100,000, Wasatch County is second at 137.7 per 100,000 and Tooele County is at 118.7 per 100,000. While these

areas do have smaller overall populations, it is important to note that a large percentage of the population is affected by breast cancer.

Under the guidance of group of community advisors during 2010, the Affiliate systematically gathered data from a variety of sources that would provide evidence-based information about breast cancer and health disparities across the Wasatch Front. Using a host of federal, state and local resources, including interviews with key organizations who serve uninsured and underinsured populations facing breast cancer, were used to gather information.

Race/ethnicity, age specific incidences and mortality rates for breast cancer in Utah were calculated using estimates from the United State Census Bureau, the Kaiser Family Foundation, the Utah Cancer Registry and the Behavioral Risk Factor Surveillance System and the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program. Our analysis focused on breast cancer among females because the annual breast cancer rates among males are small and often untracked by data sources.



Through our data analysis, we discovered that Utah has one of the lowest mammography screening rates in the country with less than 68% of women aged 40 and over in the state reporting having had a mammogram within the last two years. Utah falls significantly below the national average of 76% and four of the five states that rank at the bottom are in the Mountain West area of the U.S. Upon further investigation, we found the largest gaps existed in women who have no health insurance with only 38% reporting having had a mammogram compared to 71% of women with insurance.

In 2009, there were 286,600 non-elderly uninsured adults in Utah of which 47% are women. So based on these numbers, we can estimate that there are 135,000 women in Utah that are without health insurance coverage which translates to 101,655 women in our current service area that fall into the uninsured category.

Based on this data, the Affiliate chose to focus our efforts on determining what barriers exist for women who are uninsured and how we as an Affiliate could address them.

Health Systems Analysis

Our findings show that Utah has a breast cancer incidence rate that is lower than the national average. There seems to be large gaps in health care delivery for women who do not have health care coverage. The higher rates of uninsured women living along the Wasatch Front suggests that there are areas that lack adequate breast health services, especially with regards to screenings and mammograms. In addition, there is a need to address the growing health care needs of the Hispanic population and for residents in Summit, Wasatch, and Tooele counties.

We created a map of “Assets” already working within the target communities. Some of these assets we already partner with and others are groups that we can explore for future collaboration.

As part of our investigation process, we interviewed eight health providers and Affiliate partners along the Wasatch Front. All of the interviewees work with the uninsured and low-income population that we were most interested in investigating. We chose these particular interviewees because we believed they would be able to provide valuable first-hand knowledge of the needs of the communities they serve. We also felt they would be able to identify partners and agencies that could partner with the Affiliate to improve the experiences of women within the continuum of care. The Affiliate chose to include information from Summit County because recent research revealed that this community has a higher than average incidence rate. Further research is needed to reveal whether or not they should be permanently included in our service area.

The most commonly cited limitation to providing adequate breast cancer service were resources, including lack of funding for screening and follow-up care once a cancer is diagnosed. Lack of accessibility for screening and of specialists for follow-up care was also noted. One participant summed up the problem “There is always more need than there are resources”. One participant identified that younger women may be at particular risk as they often do not qualify for existing programs.

The Breast Cancer Control Program in the State of Utah provides free mammograms to women who qualify through state and local health departments. These clinics provide services to the uninsured and underinsured populations who are aged 50-64 and who have an income of up to 250 percent of the federal poverty level. There are also nonprofit health clinics that provide free screenings, primary care and a mobile clinic that travels to a variety of locations each week to provide clinical breast exams and referrals for discount mammography.

There is a gap for women aged 40-49 that are recommended for screening, but are not provided for with state and federal money. Women under 40 are also at risk. It is often difficult for younger women to get a diagnostic mammogram to explore an abnormal change in their breast, if they don't have insurance. Some of these issues have been addressed through our grants program, but we have a desire to improve and expand our services for those affected by breast cancer.

As a result of our investigation, we found that a lack of health care coverage and decreased ability to pay for health care services was identified as the number one reason that mammography rates are so low in Utah.

Qualitative Data Overview

In order to further define barriers to breast health care, the Affiliate independently conducted two community discussions. One was specific to breast cancer survivors and the other was geared toward a general audience. We asked questions that addressed education and awareness, screening, treatment, and follow-up care. Because our target was women without health insurance, we asked our state's cancer control program and a clinic that offers free screenings to women in the area to help recruit women for these discussions. We had ten survivors and two co-survivors that participated in the first group and a combination of five survivors and eight women from the general public participate in the second group.

None of the women in either group identified risk factors outside of family history and there was significant confusion regarding screening recommendations. Both groups indicated that until there was a personal connection, they really didn't pay attention to awareness campaigns and the messaging didn't connect. A lack of information on available resources to women for free or discounted services was also identified as an issue. Many of the women stated that their primary care doctors either didn't offer referrals for screening or made it seem like it wasn't a priority and the lack of insurance to pay for screenings was also a strong contributing factor.

For the survivors, once they were diagnosed and approved for Medicaid, they stated that treatment went very smoothly. Providers made necessary appointments and spent quality time reviewing options and what the process of treatment would entail. Two of the women acknowledged some difficulty in receiving diagnostic testing, and one woman in the group said she had experienced complications from her cancer treatment that Medicaid would not cover. All of the women in this group found a lump or other abnormality in their breast and went in for diagnostic testing. Another issue that arose surrounded follow-up care. Medicaid does not pay for genetic testing and certain medications recommended by doctors, and the expense is too great for them to pay out of pocket.

When asked about how breast cancer has impacted their lives financially, emotionally and physically, most of them focused on their emotional support system. For many, the men in their lives either left, disconnected or somehow felt powerless to help. They all agreed that this diagnosis helped them "learn who your friends are", and that they had developed strength they didn't know they had. "It kicked my butt, so I kicked it back." They understood the need to learn how to ask for help. One participant indicated that she had no support from family or friends and she also mentioned more problems with complications, communication difficulties with providers, and a sense of feeling

overwhelmed and alone. Physical and financial problems were mentioned, but only briefly.

Conclusions

It is clear there is still a considerable amount that can be done to improve the experiences of women in the service area. Breast health education, awareness and access to screening are priorities. Further research into the difficulties mentioned in regard to diagnosis and follow-up care may lead us to see whether it is appropriate to advocate for these services to be covered through Medicaid.

There are current services that can be bolstered, as well as opportunities to expand our impact by engaging community groups, businesses, churches and media. We can influence outcomes in the lives of women by collaborating and encouraging these assets to take a more active role in supporting our goal of providing not only for those women without health care coverage, but for all women. A lack of education about breast cancer risks and the benefits of early detection is not confined to any one group and we believe that knowledge is power.

Affiliate Action Plan

Based on the information gathered in this process we have determined that we will expand our current service area to include, Summit, Wasatch and Tooele counties within the current fiscal year. To address the issues identified in this report, the Affiliate will focus on the following priority areas and plan to take the actions listed.

Priority #1

- Increase the rate of mammography screening for women of all ethnic backgrounds aged 40 and over who are uninsured or underinsured throughout the current and expanded service area.

Objectives

- Reach out to at least two mammography providers by the end of 2011 that we have not previously been involved with outside of Salt Lake County to expand our impact in other areas.
- Meet with current screening grantees and encourage them to engage primary health care providers in their partner clinics to reinforce the need for referrals for screening.
- By the end of FY'12, reach out to two non-profit groups, including screening providers and other strategic partners, located in each of the three counties in the expanded service area to encourage application for funding of programs where appropriate.

Priority #2

- Continue to educate and inform women of all backgrounds about the risk factors for breast cancer, prevention, and reinforce the benefits of early detection through screening, as well as available resources.

Objectives

- Meet with all current grantees by the end of 2011 to reinforce current messaging and encourage development of innovative ways to connect with women.
- By the end of this fiscal year, target two organizations with media connections including English and Spanish language and encourage collaboration and application for funding where appropriate.

Priority #3

- Enrich the lives of breast cancer survivors by providing support services for survivors and their families/co-survivors.

Objectives

- Meet with grantees currently offering support services by the end of 2011, to discuss potential expansion and increased awareness of their programs.
- Reach out to three new organizations outside of Salt Lake County to develop support services and encourage application for funding where appropriate.

As an Affiliate we are excited about the progress that has been made in the service area to this point, but we are even more optimistic moving forward about the opportunities we see to make an even greater impact in the lives of women and their families

Introduction

Affiliate History

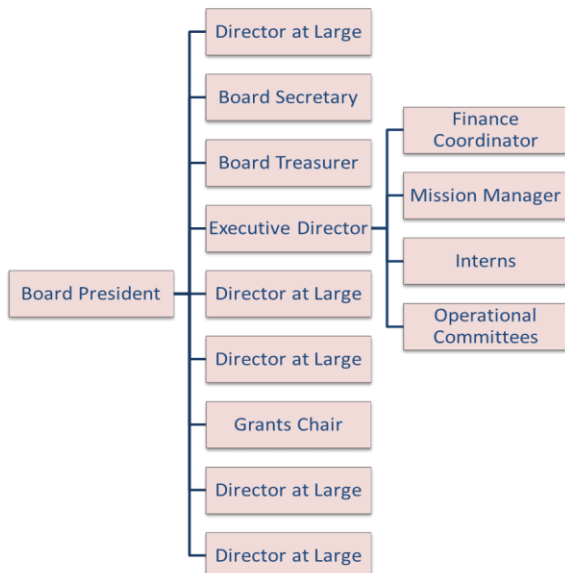
Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982, that promise became Susan G. Komen for the Cure® and launched the global breast cancer movement. Susan G. Komen for the Cure's promise is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to discover the cures. Today, Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists.

The Salt Lake City Affiliate of Susan G. Komen for the Cure® was founded in 1997, the same year as the Affiliate's first Race for the Cure®. Our inaugural race involved 1,700 participants from across the state of Utah. Fifteen years later, our race has grown to more than 17,000 participants and in 2010 raised nearly \$650,000 for breast cancer awareness, research and advocacy.

Since 1997, the Salt Lake City Affiliate has been able to award over \$4 million to local programs for breast cancer screenings, treatment and education in the communities we serve. Up to 75 percent of the net income collected through the Race for the Cure® as well as other events and partnerships support efforts in Utah. The additional 25 percent goes to fund groundbreaking breast cancer research, meritorious awards and educational and scientific conferences around the world directly through the national Komen for the Cure Grant Program. During 2010, the Salt Lake City Affiliate was able to award an estimated \$600,000 in grants to local groups for breast cancer screenings, treatment and education.

Organizational Structure

The Salt Lake City Affiliate of Susan G. Komen for the Cure® is governed by a



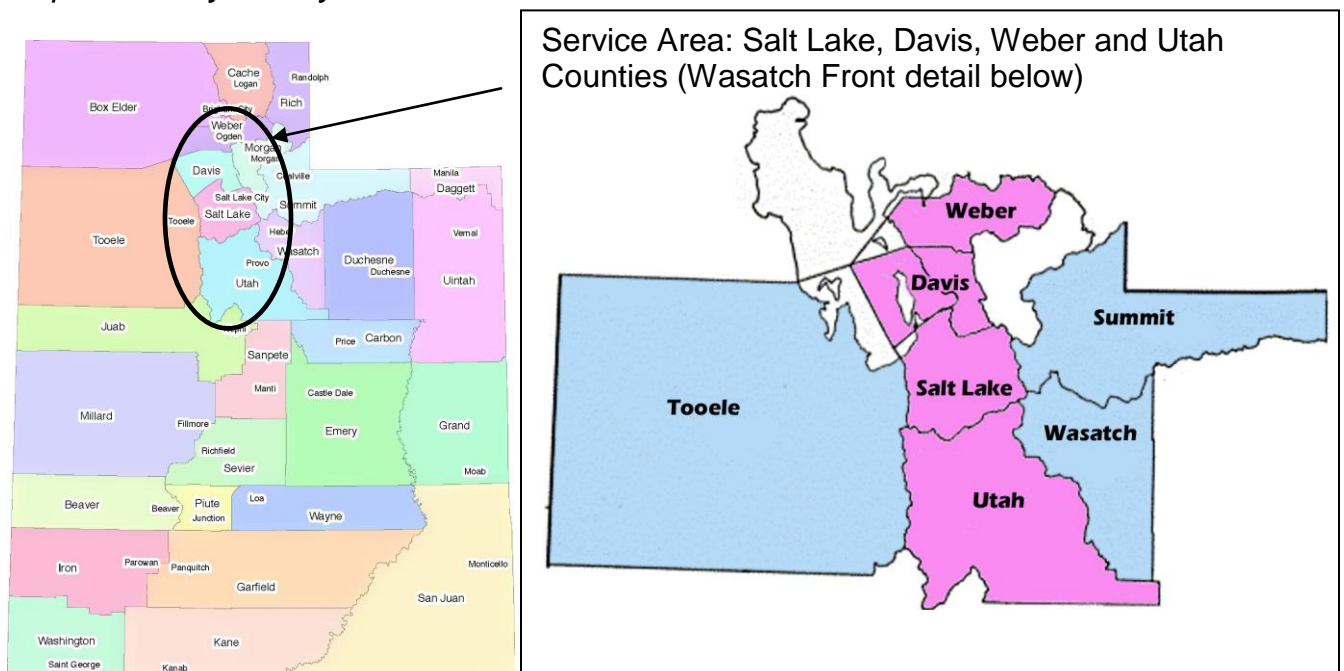
dedicated, nine-member board of directors, comprised of working professionals, volunteers and community members. As of 2011, the Affiliate operates with two full-time and one part-time staff members, including an executive director, a mission manager and a finance coordinator. The organization also operates utilizing interns and with a 45-member Race committee who volunteer approximately 675 hours per year to plan and execute the Affiliate's largest fundraising event.

Description of Service Area

The State of Utah has twenty-nine counties and nearly 2.8 million residents. The Salt Lake City Affiliate currently serves the four most populous counties in Utah: Salt Lake County, Utah County, Weber County and Davis County, where more than 75 percent of residents live and work. This area of northern Utah is commonly referred to as the Wasatch Front. Salt Lake County has the largest population with 1.04 million residents comprising 37.2 percent of the state's population in 2009 and is home to the capitol city, Salt Lake City. Salt Lake City is considered an urban community with considerable outlying suburban areas.

According to the 2010 U.S. Census, 81.2 percent of Utah residents are Caucasian, 12.3 percent Hispanic or Latino, 2.9 percent Asian/Pacific Islander, 1.4 percent American Indian/Alaska Native, and 1.4 percent African American/Black. Since 2000, there has been a 5.5 percent increase in Utah's Hispanic population. There are approximately 1,391,600 women living in Utah.

Figure 1.
Map of Utah by County



Purpose of the Report

The promise of Susan G. Komen for the Cure® is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to discover the cures. To meet this promise, the Salt Lake City Affiliate relies on the information gathered in a Community Profile Report to guide our efforts.

The purpose of this report is to identify the issues that are important to our service area and broaden the diversity in our Affiliate's work so we are able to make good decisions about how to best apply our resources, and to make the greatest impact through our grants program. This process also allows us to identify existing assets within the service area that can help us build partnerships and collaboration in order to address the needs of those we serve. This report is compiled by a team of community members who volunteer their time and efforts to help build our strategic direction. We also rely on the feedback from community members, breast cancer advocates and survivors through surveys and interviews.

The information collected for this report guides inclusion efforts in Utah's breast cancer community, informs public policy efforts, determines outreach and education needs and informs the Affiliate's fundraising efforts. This report is also designed to be used by members of the community who are interested in the Affiliate's service delivery, grant programs and opportunities to expand build collaborative partnerships.

Breast Cancer Impact in Affiliate Service Area

Methodology

During 2010, under the guidance of group of community advisors, the Affiliate systematically gathered data from a variety of sources that provided evidence-based information about breast cancer and health care disparities across the Wasatch Front. Using a host of federal, state and local resources, including interviews with key organizations who serve uninsured and underinsured populations facing breast cancer, were used to gather information.

Race/ethnicity, age specific incidences and mortality rates for breast cancer in Utah were calculated using estimates from the United State Census Bureau, the Kaiser Family Foundation, the Utah Cancer Registry and the Behavioral Risk Factor Surveillance System and the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program.

Our analysis focused on breast cancer among females because the annual breast cancer rates among males are small and often untracked by data sources.

Overview of Affiliate Service Area

Demographics

The population in Utah is approximately 2.8 million and according to the U.S. Census Bureau, more than 75 percent of residents live in Salt Lake, Utah, Weber or Davis counties. There are approximately 1,391,600 women living Utah.

Table 1.

Populations by County for Wasatch Front (U.S. Census Bureau, 2010)

County	Population Count	Percentage
Salt Lake	1,042,125	37%
Utah	531,442	19%
Davis	307,656	11%
Weber	227,259	8%
TOTAL	2,108,482	75%

Poverty and Income Levels in Utah

Utah's poverty rate increased from 9.6 percent in 2008 to 11.5 percent in 2009 (U.S. Census Bureau, 2010). While Utah's overall poverty rate grew at nearly double the national rate between 2008 and 2009, it is still below the national average of 14.5 percent.

Rates of Uninsured Individuals in Utah

In 2009, there were 286,600 non-elderly uninsured adults in Utah of which 47% are women. So based on these numbers, we can estimate that there are 135,000 women in Utah that are without health insurance coverage which translates to 101,655 women in our service area that fall into the uninsured category.

Ethnicity and Racial Diversity in Utah

According to the 2010 U.S. Census, 81.2 percent of Utah residents are Caucasian, 12.3 percent Hispanic or Latino, 2.9 percent Asian/Pacific Islander, 1.4 percent American Indian/Alaska Native, and 1.4 percent African American/Black. Since 2000, there has been a 5.5 percent increase in Utah's Hispanic population.

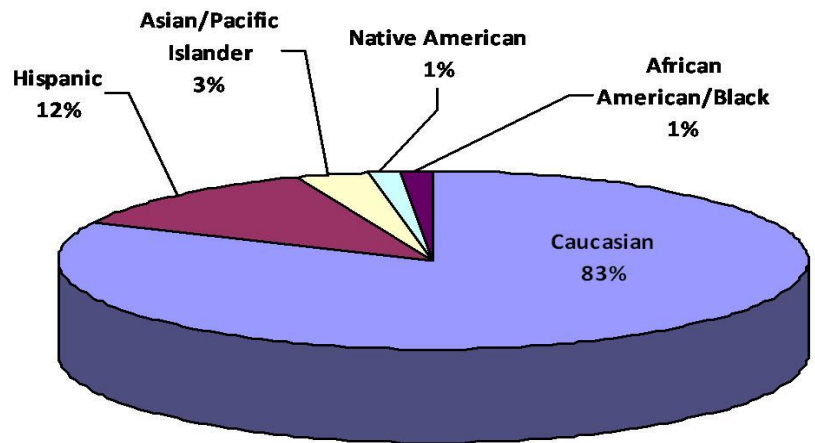


Figure 2. *Ethnic Diversity in Utah, 2010*

One of the limitations to our investigation is the small percentage of the Utah breast cancer population that report race other than Caucasian. Ethnic identification was reported as “other” for more than 80 percent of women over 40 that had a mammogram within the last two years (Horner, 2009).

Prevalence and Incidences of Breast Cancer

During 2010, 1,200 women in Utah were diagnosed with breast cancer and 250 women died from the disease. The breast cancer occurrence rate in Utah for 2010 was 101.68 per 100,000 and is lower than the national average reported at 122.54 per 100,000. Utah County has the lowest rate in the service area with 87.7 reported in 2007 and Davis County reports the highest rate at 106.8 per 100,000. Salt Lake County reports 104.72 and Weber County is at 92.9 per 100,000.

According to the U.S. Census Bureau's 2010 Annual Social and Economic Supplement, 9.7 percent of households or 271,600 Utah residents are living at or below the poverty level (U.S. Census Bureau, 2010). In Utah, approximately 10 percent of adult women do not have health insurance and 12.5 percent of women in Utah are living below the poverty level. These numbers are nearly identical for the Affiliate's service area along the Wasatch Front (Governor's Office of Planning & Budget).

Communities of Interest

The following table shows incidence rates and mortality rates in each county of the service area. While not in the Affiliate's direct service area, examination of data shows Summit County has the highest incidence rate in Utah at 148.6 per 100,000, Wasatch County is second at 137.7 per 100,000 and Tooele County is at 118.7 per 100,000. While these areas do have smaller overall populations, it is important to note that a large percentage of the population is affected by breast cancer. During the next year, the Affiliate will work to gather information about these communities and find ways to incorporate them into the service area (see Table 2).

Age-Adjusted Breast Cancer Incidence and Mortality Rates by County in Utah from 2003-2007 Includes All Races, All Ages per 100,000

	Average Annual Incidence Rate	Average Annual Count	Average Annual Death Rate	Average Deaths per Year
Total U.S.	120.6		24.0	41,021
State of Utah	108.1	1,103	22.8	234
Summit	148.6	20	43.3	4
Wasatch	137.7	10	N/A	N/A
Tooele	118.7	21	19.8	3
Salt Lake	113.6	465	23.8	96
Davis	106.8	109	23.3	23
Weber	101.4	99	20.9	21
Utah	101.8	141	22.2	31

Table 2.

Age-Adjusted Breast Cancer Incidence Rates

There are 363,894 women aged 40-64 who live in the state of Utah, 274,274, aged 40-64, live along the Wasatch Front (Governor's Office of Planning & Budget). During 2007, the highest rates of breast cancer diagnosis in the Affiliate's current service area were in Davis and Salt Lake counties (Kim, 2011).

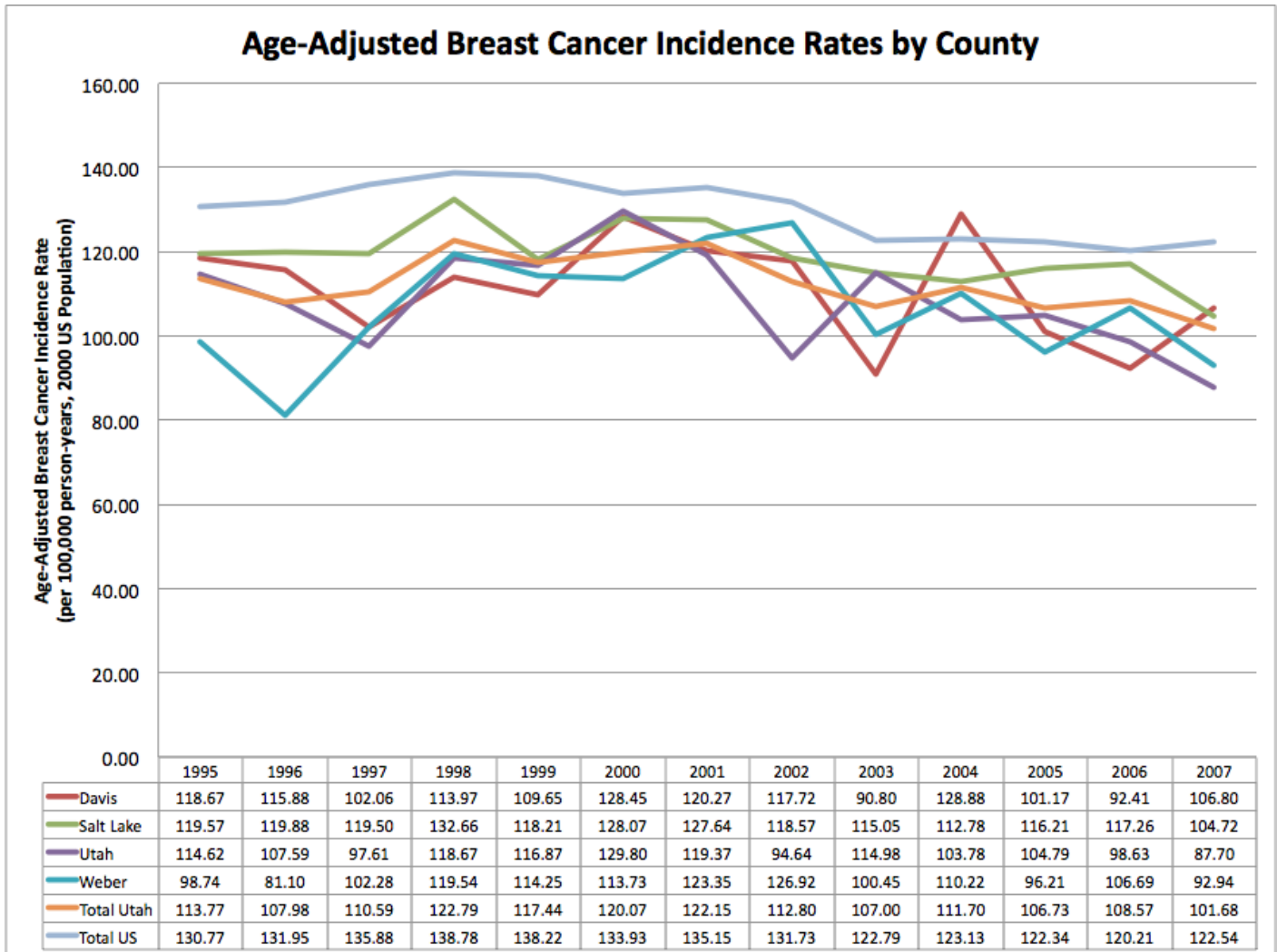


Table 3.

Mortality Rates for Breast Cancer in Utah

Approximately 250 women died from breast cancer in Utah during 2010. Utah's mortality rate increased from 19.76 to 22.04 per 100,000 during 2007-2009. This is close to the national average reported in 2007 of 22.84 per 100,000. Weber County reported the lowest mortality rate at 13.09 and Davis County the highest at 23.58 per 100,000. Salt Lake County reported 19.67 and Utah County's rate reported at 19.94 per 100,000 (Kim, 2011).

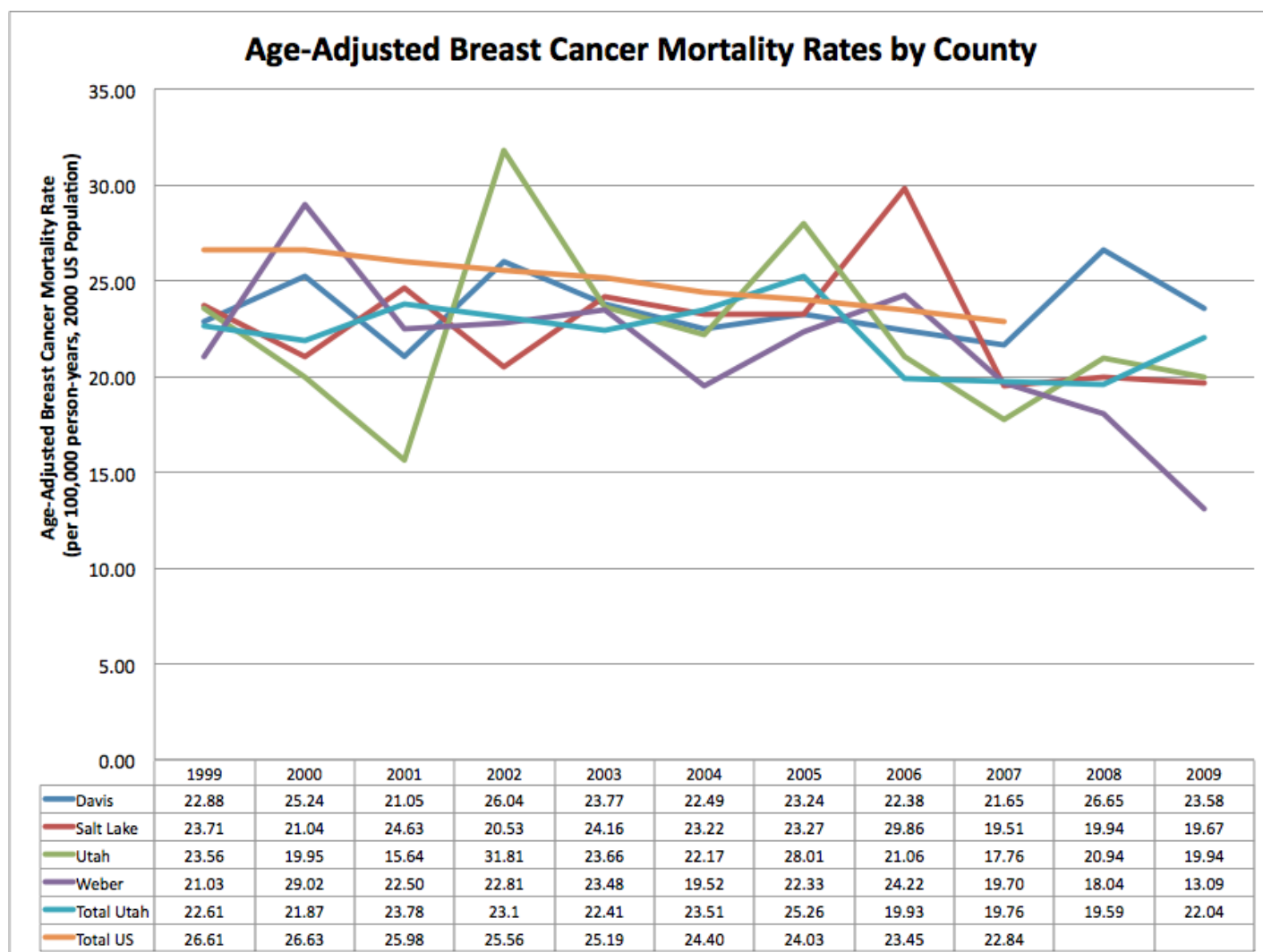


Table 4.

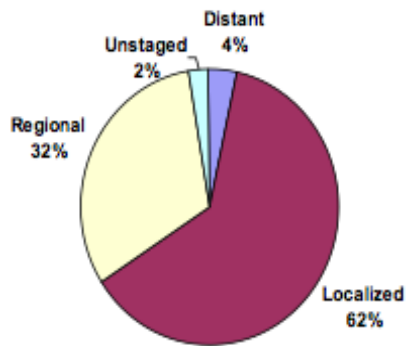
Stage at Diagnosis

An early stage diagnosis for breast cancer is usually detected by regular screenings and mammograms. *Localized* breast cancer is cancer that is confined to the breast. *Regional* cancer is found in the breast and where cancer cells are detected in the lymph nodes. *Distant*, also called metastatic, is cancer that has spread to another part of the body. The most common areas for cancer to spread are the brain, bone, liver and lungs. *Unstaged* is cancer that has been diagnosed but not staged yet so the full extent of the cancer is unknown (see Figure 3).

Figure 3. *Female Breast Cancer: Stage of Disease at Diagnosis, 2000*

Female Breast Cancer: Stage of Disease at Diagnosis

Residents of Utah, 1991-2000



Stage at Diagnosis	Utah	
	Count	Percent
Localized	5489	61.95%
Regional	2836	32.01%
Distant	324	3.66%
Unstaged	212	2.39%

Most importantly, early stage diagnosis is linked to a better prognosis and recovery. If breast cancer is detected early enough the survival rate is 98 percent - compared to regional at 84 percent and 23 percent for distant. Late stage diagnosis (stages 3 and 4) is a key indicator in community breast cancer health. Figure 3 highlights the stage of disease at diagnosis for Utah breast cancer patients. Based on this information we know that 38 percent of diagnoses occur at later stages. From this we see that there are opportunities to improve detection and increase healthy outcomes.

Access to Mammograms, Health Screenings and Treatment

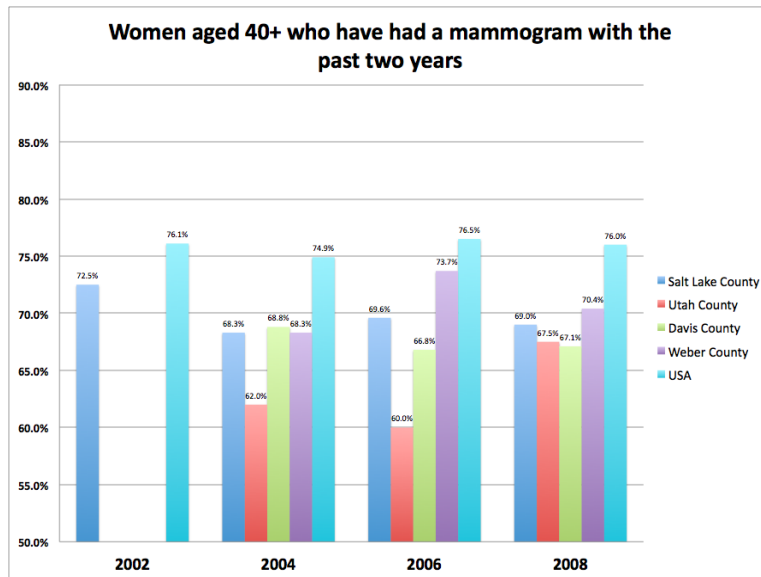
Mammography is currently the most effective screening tool to find breast cancer. Mammography can detect cancers at an early stage, when they are too small to be felt, but are most responsive to treatment (Susan G. Komen for the Cure).

In 2008, Utah ranked number 44 out of 51 (including the District of Columbia) for the number of clinical breast exams performed. The State ranked 49 out of 51 for women over 40 who received mammograms. Alaska (50) and Wyoming (51) fell into the next two positions respectively. Four of the five states in the bottom are in the Mountain West area of the United States, including Wyoming, (51), Utah (49), Nevada (48) and Idaho (47). For women over 50, Utah ranked number 47 out of 51, with Wyoming, Mississippi, Nevada and Oklahoma ranking in the last four places. There is concern that this

decrease in screening mammography may lead to an increase in breast cancer mortality because fewer cancers will be found early when they are most treatable.

Table 5.

Women Aged 40+ Who Had a Mammogram Within the Past Two Years, 2008



The 2008 Behavioral Risk Factor Surveillance System (BRFSS) conducted by the Center for Disease Control and Prevention (CDC), revealed that women are not getting screened for breast cancer as recommended. The survey results showed that an average of less than 68 percent of women over the age of 40 in our service area had a mammogram within the past two years, compared to the national average of 76 percent (Horner, 2009).

In Utah, the county with the highest reported number of mammogram procedures for women over 40, within the past two years was Weber County at 70.4 percent. Salt Lake County was second at 69 percent, and Davis County had the lowest reported percentage at 67.1 percent. Something intriguing arose from this data. Utah County's mammography rate for women over 40 jumped from a reported 60 percent in 2006 to 67.5 percent in 2008. We would like to explore this increase in participation and determine how to duplicate the efforts elsewhere (Kim, 2011).

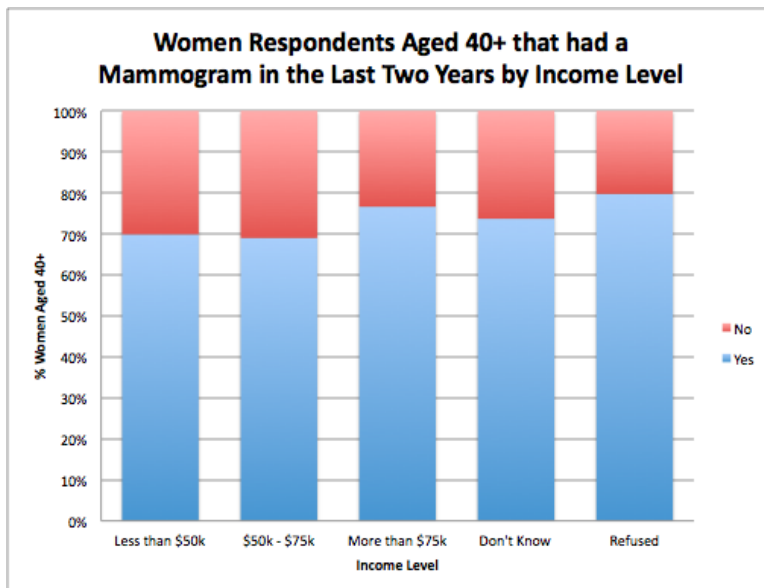
For women over 50, the survey results showed that only 73.1 percent of women had a mammogram within the past two years. This was an increase from results for women over 40, but still below the national average of 79.5 percent for the age group. Upon further examination of income levels, education and ethnicity, the most severe gap in these differences was health care coverage. Of the respondents that were 40 years or older, roughly 71 percent who had health care coverage reported they had received a mammogram in the last two years compared to approximately 38 percent of those without health care coverage.

Utah County reported a significant increase in mammography rates from 62.7 percent in 2006 to 77.3 percent in 2008 which is the highest percentage in the state. Weber County was at 73.2 percent which is actually down from 78.9 percent in 2006. Davis County remained steady at 69 percent and Salt Lake County reported in 2008 at 72.9 percent down from 76.3 percent in 2006. In the U.S., 79.5 percent of women had a mammogram.

Our investigation looked at education levels and found differences that indicate education levels can influence whether or not women seek mammogram procedures. Women over 40 who have less than high school education reported at approximately 62 percent. Women who are high school graduates and have some college experience both reported at 68 percent and college graduates reported the highest at about 73 percent.

Table 6.

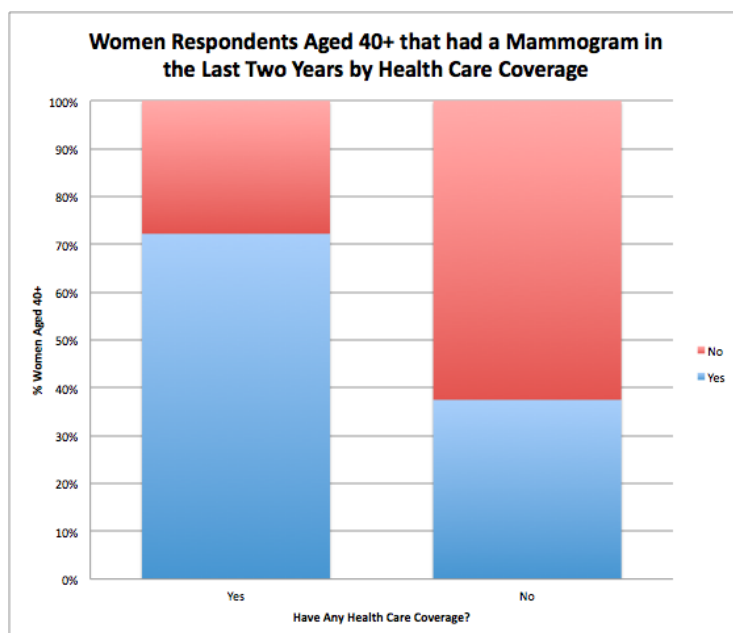
Women Respondents Aged 40+ Who Had a Mammogram Within the Past Two Years by Income Level, 2008



When comparing income levels, the rates for mammogram screenings varied only slightly. Seventy percent of women over 40 with an income less than \$50,000 reported that they had received a mammogram within the past two years. Seventy-five percent of women over 40 with an income over \$75,000 reported that they had received a mammogram within the past two years (Kim, 2011).

Table 7.

Women Respondents Aged 40+ Who had a Mammogram Within the Past Two Years by Health Care Coverage, 2008



One area of investigation that showed significant differences among respondents was health care coverage. Women aged over 40 years of age, with health care coverage reported having had a mammogram within the last two years at about 71 percent. Women over 40 years of age without health care coverage reported having had a mammogram within the last two years at about 38 percent.

The women in this age range benefit the most from regular mammography screenings. We know that roughly 101,655 adult women in our service area are uninsured, but not all of these women are between 40 and 64, but we see there is a need for services to address this group. The five year survival rate for breast cancer patients is 98 percent when it is detected early and confined to the breast compared to 84 percent for regionalized and 23 percent for distant stage (Horner, 2009) (Kim, 2011).

Conclusions

Our findings show that Utah has a breast cancer incidence rate that is lower than the national average. There seems to be large gaps in health care delivery for women who do not have health care coverage. The Utah Department of Health reports certain areas within the Affiliate's service area have a much larger percentage uninsured women. The higher rates of uninsured women living along the Wasatch Front suggests that there are areas that lack adequate breast health services, especially with regards to screenings and mammograms. In addition, there is a need to address the growing health care needs of the Hispanic population and for residents in Summit and Wasatch counties

Health Systems Analysis of Target Communities

Overview of Continuum of Care

The Breast Cancer Continuum of Care represents the journey of a breast cancer patient through the health care system. As a provider of resources and support for breast cancer health, the Affiliate looks for gaps and deficiencies along the continuum. After identifying barriers and key issues for women along their breast cancer journey, we seek opportunities to improve the patient's experience and advance better outcomes in the communities that we serve.

It is important to understand why women do not enter or continue along the continuum, especially for those who are part of our underserved or target communities. Once we can identify which factors are important in our target communities, we can address them through education programs, partnerships, grant making, and advocacy.

For example, language barriers may discourage some women to seek adequate health care resources and therefore, they fail to enter or maintain treatment along the continuum. To address this barrier, Affiliates may consider implementing bilingual programs or collaborating with organizations that serve women who speak a language other than English.

The Stages in the Continuum of Care

Stage 1: Screening

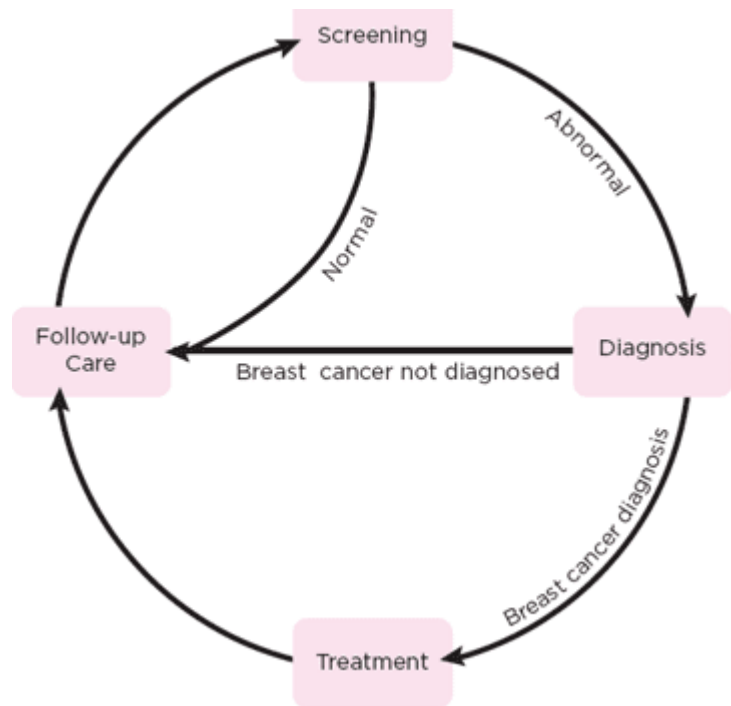
Breast cancer screening is the first step in the continuum. Komen's screening recommendations are:

- Ask your doctor which screening tests are right for you if you are at a higher risk;
- 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; and
- Know what is normal for you and report any changes to your health care provider right away.

Figure 4.

Continuum of Care Model

Source: Komen National Continuum of Care Model



Stage 2: 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. An abnormal test may indicate the need for further testing. It is important that women receive timely follow-up tests after an abnormal mammogram or clinical breast exam.

Typically, the health care provider will begin with less invasive tests like a diagnostic mammogram or ultrasound. If these tests cannot rule out cancer, he or she may recommend a biopsy. If further testing reveals that the abnormality is not cancer, the patient will need to continue to follow screening recommendations. If testing reveals a diagnosis of breast cancer, they will then need to enter the treatment stage of the continuum.

Stage 3: Treatment

A breast cancer diagnosis leads to the treatment stage on the continuum. Health care providers work with the patient to determine a course of treatment. The best treatment plans are typically determined when the patient and provider work together and may involve one of the following or a combination:

- Surgery
- Radiation therapy
- Chemotherapy
- Hormonal therapy
- Targeted therapy

Stage 4: Follow-up Care

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

Men and Breast Cancer

Breast cancer in men is rare, but it does occur. Approximately one in 100 cases of breast cancer occurs in the male population. The survival rate of men is comparable to that of women depending on the stage of disease at the time of diagnosis. However, men are usually diagnosed at a later stage because they are less likely to report any symptoms. Treatment of breast cancer in males is the same as treatment for female patients and usually includes a combination of surgery, radiation and chemotherapy and/or hormone therapy.

Since the rate of breast cancer in males is much lower than that of females, Komen and this Community Profile Report focus on the efforts to treat females with breast cancer. However, efforts are continually being made to improve access and support for male breast cancer patients.

Methodology

Based on the data collected that revealed large disparities in mammography rates for the uninsured, the Affiliate chose to focus on women who fall into this category. As part of this process, we mapped out what we call “Assets” already working in the community that serve our target population. Asset mapping is a useful tool in creating a visual representation of services and providers within a community. This mapping exercise aids in the process of looking for possible solutions to gaps in the current continuum of care. Through this exercise, we can see the needs and issues of a target community, effective program models, and current and future collaborative partnerships. Asset mapping helps direct our granting program by assessing what the Affiliate is doing well and what areas need strengthening.



Figure 5.
Assets and Partners Along the Wasatch Front

The Affiliate interviewed eight health system providers and partners along the Wasatch Front. All of the interviewees work with the uninsured and low-income population that we were most interested in investigating. We chose these particular interviewees because we believed they would be able to provide valuable first-hand knowledge of the needs of the communities they serve. We also felt they would be able to identify valuable partners who would reinforce our efforts to improve the experiences of women within the continuum of care.

We also chose to include information from Summit County because recent research revealed that this community has a higher than average incidence rate. Further research is needed to reveal whether or not they should be permanently included in our service area. Below is a map of partners that assist women who are uninsured as well as a map of our current grantees.

Overview of Community Assets

The Breast Cancer Control Program in the State of Utah provides free mammograms to women who qualify through state and local health departments. These clinics provide services to the uninsured and underinsured populations who are aged 50-64 and who have an income of up to 250 percent of the federal poverty level. If a woman is diagnosed with breast cancer through this program, they usually also qualify for Medicaid that will provide for their treatment.

There is a gap for women aged 40-49 that are recommended for screening, but are not provided for with state and federal money. Women under 40 are also at risk. It is often difficult for younger women who don't have insurance to receive a mammogram to explore an abnormal change in their breast. Some of these issues have been addressed through our grants program, but we have a desire to improve and expand our services for those affected by breast cancer. The Salt Lake City Affiliate grants program allows us to partner with local nonprofit groups that assist different communities throughout the service area.

There are nonprofit health clinics that provide primary care and a mobile clinic that travels to a variety of locations each week to provide clinical breast exams and referrals for discount mammography. These programs specifically target low-income and immigrant populations that otherwise would not have access. There are a few organizations that will provide or coordinate free screenings and diagnostic services to women who may not qualify for the state run screening program. Some of these programs specifically target younger women with a strong family history or a genetic mutation that makes them more susceptible to breast cancer.

At least one organization provides free clinical breast exams at multiple events within Salt Lake County and give vouchers for free screening or diagnostic mammograms. If a woman is diagnosed through this program, they will assist with application for Medicaid as well as offer treatment through their Charity Care services.

There are also groups that provide access to home health and palliative care for women with breast cancer whose medical coverage will not pay, and at least one organization that provides daily travel for women from rural areas to Utah County for treatment.

A variety of groups provide education to the Latina, LBT, and immigrant communities by attending health fairs, holding workshops, support groups for survivors and their families and peer networking programs. They provide culturally appropriate information on breast cancer and available resources as well as educating providers on how best to serve these populations. At least one also helps with non-medical expenses for women with breast cancer.

Utah also has several programs specifically aimed at enriching the lives of breast cancer survivors. They provide classes, retreats, and support groups to address the physical, emotional and financial impacts of this disease.

Services outside of Salt Lake County are more limited in scope and this provides an opportunity to impact the lives of women in other parts of the service area.

Through our efforts, the Affiliate has identified potential future partnerships including: the Multicultural Health Department within the State Health Department, the People's Health Clinic in Summit County, St. Benedict's Foundation in Ogden, the local chapter of the American Cancer Society, the local chapter of the United Way, the Junior League, and Jewish Family Services.

Legislative Issues in Target Communities

Budget shortfalls have dramatically affected Utah during the 2010-2011 fiscal year. Unfortunately, some of the more vital services provided by the Utah Breast and Cervical Cancer Early Detection Program were targeted in committee for cuts in the FY2011 and FY2012 budgets. There is a potential risk to eliminate \$1.5 million in care for women who have no other access to health care by decreasing program eligibility from 250 percent of federal poverty level to 133 percent. This proposed cut affects more than half of the women in Utah who are currently eligible for services.

The decision to cut these programs would not save the state money in the long run, but would create a higher cost both financially and in the lives of women in the state because cancer would likely be discovered at a later stage. When breast cancer is detected and treated in early stages, it is two thirds the cost of treating late stage diagnosed cancers. Taking away the early detection option can lead to later stage diagnosis and these women are then forced to find treatment where they can, or simply spend down their resources and end up receiving Medicaid anyway. And the unlucky ones will show up in the emergency rooms with terminal cancers that will cost the state hundreds of thousands of dollars in the end.

The Salt Lake City Affiliate, along with the Susan G. Komen for the Cure® Advocacy Alliance in Dallas, TX, was involved in contacting legislators to inform them of concerns

over this issue. The Advocacy Alliance is the nonpartisan voice of the 2.5 million breast cancer survivors and the people who love them. Their mission is to translate Susan G. Komen for the Cure's promise to save lives and end breast cancer forever into action at all levels of government. We teamed up with Michael Siler from the American Cancer Society to coordinate our efforts and made sure our message was delivered. These recent efforts by the Affiliate are only the beginning of advocacy opportunities to bring awareness to health care issues that impact women in Utah.

Key Findings

Eight interviews were conducted with key stakeholders providing services to seven Northern and Central Utah counties: Salt Lake, Weber, Davis, Tooele, Utah County, Summit and Wasatch. All service providers served uninsured, underinsured, and undocumented members of the community. Some also provided service to individuals with insurance and/or private pay. All participants provided primary care services including education, screening and detection. No specialty or cancer treatment providers were interviewed due to our focus on screening. Two of the participants represented programs funded by Komen. Interviews were completed in January and February 2011.

The most commonly cited limitation to providing service were resources, including lack of funding for screening and follow-up care once a cancer is diagnosed. Lack of accessibility for screening and of specialists for follow-up care was also noted. One participant summed up the problem "There is always more need than there are resources ". One participant identified that younger women may be at particular risk as they often do not qualify for existing programs.

All of the providers partnered with other agencies and community resources. These included governmental organizations (state and local health departments); schools including a university and a school district, non-governmental organizations (e.g. Junior League, Komen, Jewish Family Services, United Way, Alliance Community Services), and health care organizations and providers, both private and nonprofit. Only one business (American Express) was mentioned.

When asked about why mammography screening rates are so low in Utah, participants felt that lack of resources including insurance was the predominant reason. One explained "the number one reason in my community is ability to pay; their priority is to make ends meet." Other reasons included lack of awareness of need for screening and what resources are available for screening. The recent controversy about screening guidelines nationally contributed to confusion about when mammography was recommended. There are misconceptions about risk factors, especially family history. Other contributing factors included primary care providers failing to recommend mammograms, fears by women including pain and possible diagnosis of cancers. There is also a need for more culturally relevant educational programs, particularly in the growing immigrant and refugee populations.

Numerous resources were identified to make women aware of the need for mammography screening. These varied by setting and included media outreach, brochures, mobile clinics, the state health department cancer prevention and control program (which, it was noted, has suffered from recent budget cuts). One clinic is implementing a system to prompt providers to recommend mammography screening. In Summit County, no outreach programs were identified.

Participants reported variable success with reaching uninsured and undocumented women. One reported “The resources reach some, but more is always needed”. In some settings, outreach is limited to those who come to the clinic for services. Of note was the success of the Utah Cancer Control Program in reaching Hispanic women, although they identified a need to also reach higher numbers of uninsured Caucasian women.

Participants identified varying program components that worked well for promoting screening. The most consistent was when providers recommended mammography to women in their practice. Using local resources such as the health department screening program or the IMC voucher program (only for diagnostic mammography) also contribute to success.

When asked about gaps, participants identified specific populations including Pacific Islanders, Hispanics, uninsured and undocumented women and low-income Caucasian women. There is a need to increase focus on prevention, both in terms of funding for preventive services, as well as consistent practice among primary care providers. One identified that implementing consistent documentation of mammography with electronic medical records will facilitate provider monitoring of screening. Similar gaps exist for treatment. An additional gap in regards to screening is timely appointments to aid clients in compliance with screening recommendation.

Specific ideas to address the current gaps included: (also including gaps in treatment):

1. Regular communication between clinics and health department.
2. Maximize use of word-of-mouth awareness campaign using community-based mentors or promoters. Marketing in community venues like restaurants, markets and Laundromats. Other potential venues include libraries, the Department of Workforce services, and the Department of Child and Family Services offices.
3. Provide screening information in flu shot or blood pressure clinics.
4. Increase convenience of access to screening facilities.
5. Increase in funding to existing successful programs to expand screening coverage for all in the recommended population. Be sure to include younger population (40-50 years).
6. Use women’s group clubs, senior centers, church groups.

7. Increase reminders from providers. We need doctors to reinforce recommendations of screening guidelines and remind women of the benefits of early detection, and make referrals if necessary.
8. Involve medical professionals in media efforts to address confusion regarding recommendations for mammography. Keep important issues in the public dialog by creating public service announcements (PSA).
9. Improve efforts to reduce cultural disparities; e.g. Pacific Islander women generally will not speak about health issues when men are around and do not want to go to a clinic because it could mean a visit to the hospital and eventually death.
10. Increase frequency of no-cost screening events at least two times per year.

Recommendations for partnering included many current Komen partners. Additional suggestions included the Peoples Health Clinic (in Summit County), the Multicultural Health Department at the Utah Department of Health, Health Insight, St Benedicts Foundation and insurance providers.

Community assets currently providing screening are governmental programs through health departments, Intermountain Health Care programs (IHC voucher program), and services through the University of Utah. Three interviewees stated that they had no screening services available directly in their communities, or that services available were only for diagnostic mammograms, not screening mammograms. Three participants stated that the resources reached the uninsured/undocumented women. Two participants felt the resources were not effective.

One individual stated: “diagnostic services reach patients, but there are currently no screening services.” One missed population highlighted was the undocumented women. Undocumented women need to be a county resident to be eligible for voucher program screenings. The Utah Cancer Control Program voucher system only reaches women over 50 years of age.

Several programs were mentioned as working well in the community including Intermountain Health Care voucher program, Utah Partners for Health, and Hispanic programs. Annual screening events were mentioned as successful, and there is great interest in holding these events more often to accommodate all those who have interest in screenings.

Referrals for treatment once a cancer is diagnosed routinely go to two sources, the Utah Cancer Control Program and Intermountain Healthcare. Most of the women without health insurance qualify for Medicaid and are able to receive treatment for their cancer. One of responses also mentioned a non-profit that helps to coordinate specialty care for individuals without health coverage in Utah County only. Another response mentioned referrals to the Huntsman Cancer Institute.

All of the responses indicate that once a treatment referral is made, their program mission does not provide follow-up care and that they know of very few resources outside of those already mentioned. Gaps indicated include provider awareness of follow-up care services; Medicaid program covers the cost of cancer treatment, but not any other health issues a woman might experience; and Spanish speaking support groups outside of Salt Lake County.

Recommendations to address gaps include getting key players in a room to discuss gaps, resources and collaboration. Suggested partners include, Utah Cancer Action Network, Intermountain Healthcare, Health Access Project, Utah Partners for Health, Comunidades Unidas, Utah Health Policy Project, Community Health Connect, Community Health Centers, Huntsman Cancer Institute, St. Marks Hospital, and the United Way of Utah.

Conclusions

While there are a variety of services currently available to the uninsured or underinsured, many programs are limited by a lack of funding, by rules about qualification such as age, immigration status and financial means, and difficulty for the patient to navigate the health care system. Many of the women who could benefit most from breast health services are not aware that affordable or free services exist. Transportation is also a concern for low-income women who must find a way to travel across town to receive a screening exam.

Furthermore, basic education about women's health and breast cancer is complicated by health care barriers including language, culture, or perceptions of traditional health care settings. The number one reason women reported about their failure to receive regular screenings was lack of insurance or the inability to pay for screening services. This coincides with our previous data from the BRFSS (Horner, 2009). The underserved and uninsured populations have a variety of competing priorities and mammography often falls low on their list of priorities.

Through this exercise we have identified the breast health issues most prevalent among women in Utah. We have also discovered services outside of Salt Lake County are more limited in scope. This creates an opportunity to utilize current and future partnerships that will help the Affiliate address these barriers and increase the Affiliate's impact in the communities that need us most.

Breast Cancer Perspectives in the Target Communities

Methodology

The information collected through our Health Systems Analysis uncovered a variety of issues in receiving breast health and breast cancer services among women without health care coverage. To gather more information from impacted women, we decided to hold two community discussions at a local library. One group was specific to breast cancer survivors and one was for a general audience of women aged 30 and above. Since our target was uninsured women, we asked our state's cancer control program and a breast health clinic that offers free mammograms to uninsured women in Utah to help us recruit for these discussions. We offered a \$15 gift card for participating. The session was recorded on a voice only recorder and we had two people taking notes of significant information. For privacy, we collected only first names and made no connection of those names to any of the comments recorded. The questions we asked addressed education, screening, diagnosis, treatment and follow-up care. We were somewhat limited in our information because we were only able to talk to women within Salt Lake County. Each discussion lasted one hour. We compiled the notes and identified not only consistent issues, but also what worked well.

Key Findings

Twelve women participated in the survivor group. Two of the women were caregivers who came in support of their loved one. One obstacle that came to light was that before their diagnosis, breast cancer was something they knew very little about. "I didn't pay attention to any of it until I was diagnosed." Most of the women thought that 50 was the recommended age to begin screening mammograms, not 40. One of the women mentioned that breast cancer ran in her family, but thought she didn't have to start checking until age 35. "Three months before my 35th birthday, I found out." One mentioned that her doctor didn't treat screenings as a priority and one was told that unless her mother or sister had it, other family history was irrelevant. None of the participants identified risk factors outside of family history, or understood the prevalence, and survivability rates of breast cancer.

Two of the women had gone for screening mammograms when they had insurance, but when life circumstances got in the way, such as losing insurance or other priorities needing attention, screenings were neglected. All of the women in the group found lumps or other issues with their breast then sought diagnostic testing.

Two of the women in particular had issues with diagnosis. One was told because of the size of her lump, it was probably a cyst, and ended up waiting three weeks for a mammogram and ultrasound, and then she had to wait two weeks for a biopsy. Another mentioned that because the PCN health plan she was enrolled in wouldn't pay for a biopsy, she had to wait almost two months to get a donated biopsy. Once she was diagnosed, she qualified for Medicaid and from there, treatment went much more smoothly.

All of the women mentioned how smoothly the treatment portion of their care was once they were approved for Medicaid. Most providers made all necessary appointments for them and the doctors spent quality time explaining the choices and processes. One of the participants has had some complications from treatment and mentioned that there were difficulties surrounding payment from Medicaid to treat these issues. The Utah Cancer Control Program was mentioned several times as providing excellent care and follow-up.

One other hurdle mentioned was payment for medications like Femara and Zometa that their doctors recommended. The medications are too expensive for them to pay out of pocket and Medicaid will not cover them. Another subject discussed was the expense of genetic testing, and that Medicaid will not cover the test.

When asked about how breast cancer has impacted their lives financially, emotionally and physically, most of them focused on their emotional support system. For many, the men in their lives either left, disconnected or somehow felt powerless to help. They all agreed that this diagnosis helped them “learn who your friends are”, and that they had developed strength they didn’t know they had and learned how to ask for help. “It kicked my butt, so I kicked it back.” One of the participants indicated that she had no support from family or friends and she also mentioned more problems with complications, communication difficulties with providers, and a sense of feeling overwhelmed and alone. Physical and financial problems were mentioned, but only briefly.

The second group was a mix of five breast cancer survivors and eight women from the general public. When asked about what they knew about cancer, one of the survivors said that before her diagnosis she believed that “cancer means death.” None of the women knew all the correct screening guidelines and another said she only knew that if you got cancer, you would have to have chemo and you would lose your hair. One of the women said she knew that toxins in the environment can cause cancer, but really didn’t know how or what.

When asked where they go for breast health information, many said, “the internet” or friends and family. But, the general comment was that they wouldn’t start looking for information until they or someone they know was diagnosed. Most said it would take some sort of personal connection to get them interested in seeking information.

The reasons that might keep a woman from seeking breast health care or screening, was a lack of insurance, a fear of mammograms hurting as well as a sense of, “I really don’t want to know.” Another reason is the idea that I eat and live healthy and have no family history, so I am not at risk. Many mentioned a lack of information not only about breast cancer, but also about available resources as well. None of them knew where to go for free or discounted breast health services. They discussed that they perceive a considerable amount of misinformation and confusion surrounding breast cancer.

Comments about how health providers could encourage women to seek breast health services included handing out written guidelines and a resource card to take home after having a specific conversation about recommendations and offering a referral. Reminder cards mailed were also mentioned as a help.

We asked, “How can Komen and/or our community partners get the word out?” Many of the women mentioned that the message gets through when there is some form of personal connection. Sometimes it is a friend or family member being diagnosed that will trigger the awareness. We were told that creating a “picture” will help to make the message relatable. One idea was using survivors as “ambassadors” for education. They suggested using media to create a visual shock similar to the ads to educate people on the dangers of smoking, and incorporating famous or recognizable names who are survivors or family members of some that have passed. Also mentioned was incorporating messages into “fun” events and providing more information on prevention.

Conclusions

It is clear there is work to be done in all areas of awareness and education of breast health and breast cancer to the overall community, as well as providing information on available resources to women without health insurance. Treatment seems to run smoothly once patients are diagnosed and approved for Medicaid, but gaining access to diagnostic services can still be a hindrance. Follow-up care to provide medications, and treat complications surrounding treatment are areas that advocacy may be able to assist in. The impact on the lives of women with breast cancer are as varied as the women themselves, but one thing that appeared very clearly as a result of these discussions is that a person’s support system of friends and family are vital to the overall experience of these women as they navigate through the continuum of care.

Conclusions: What We Learned, What We Will Do

Review of the Findings

Utah has a population of about 2.8 million residents. More than 75 percent of the population lives in the four counties, Salt Lake, Utah, Davis and Weber that make up the Wasatch Front and comprise the Affiliate's current service area. The majority of the population is Caucasian (81.2 percent), but we have a fast growing Hispanic population that is up from 6.8 in 2000 to percent 12.3 percent in 2010. Asians make up 2.1 percent, American Indians/Alaska natives 1.4 percent, Blacks represent 1.4 percent and Pacific Islanders are the smallest group calculated at .8 percent. Women represent 49.7 percent of the overall population. The state has a lower percentage than the national average of residents that live at or below the federal poverty level.

Over 1,200 women were diagnosed in Utah and 250 women died of breast cancer in 2010. While Utah has a breast cancer incidence rate that is lower than the national average, the mortality rate is very close to being on par with the national average. We wanted to examine why that might be and one of the first things we discovered was that the screening rates for women in Utah are much lower than the national average and for women over 40 years of age. Utah is ranked number 49 out of 51 states and the District of Columbia with only Alaska and Wyoming ranked below.

There are many reasons why a woman may not receive mammography screening as recommended. We looked at income levels, education level and race, but there was not a significant difference in these categories. Women over the age of 40 with health care coverage reported having had a mammogram within the past two years at about 71 percent. Those women in the same age group without health care coverage reported having had a mammogram in the past two years at only 38 percent.

According to data compiled by Kaiser Family Foundation (Hoffman, Damico, & Garfield, 2011), the Affiliate estimates that there are about 101,655 uninsured non-elderly adult women in our service area or roughly 9.7 percent of the population. The poverty rate in Utah is lower than the national average, but 86 percent of those that are uninsured live within 250 percent or under the federal poverty level.

Many of the programs and groups that provide health care for residents who are uninsured, underinsured and/or who have a decreased ability to pay are in the Salt Lake City area. Outside of the health department, there are not many other resources in other parts of the service area. Unfortunately, we also found that the programs that do exist often suffer by not being fully funded, as well as limitations because of the rules of eligibility and accessibility. The need for services is greater than the resources available.

We interviewed eight health system providers and partners along the Wasatch Front. All of the interviewees work with the uninsured and low-income population that we were most interested in. Through this effort, we were able to discover screening programs

that work well in the service area as well as issues and gaps that exist. As a result of these interviews, we found that a lack of health care coverage and decreased ability to pay for health care services was identified as the number one reason that mammography rates are so low in Utah.

While programs exist that provide free and low cost mammograms to women who qualify, as mentioned before, they tend to lack adequate funding, not every woman that needs the services are aware of them or qualify due to age, citizenship, or they do not take advantage of them due to cultural and language barriers within our growing immigrant and refugee population or because of transportation issues. There are also still education and awareness issues that exist in particular as to family history, confusion over guidelines and overall risk of breast cancer. The women in this group also have a variety of competing economic, family and health priorities that overshadow proper health care maintenance.

Our providers indicated that one of the most successful ways to increase screening is for the providers to recommend it. Unfortunately, this message only gets delivered to the women who seek treatment within a clinic setting. They also identified other ways to clarify and spread the message of the need for screening within the harder to reach communities such as partnering with existing community groups, flu shot and blood pressure clinics, governmental agencies like the Department of Workforce Services and the Utah Division of Human Services.

The community discussions confirmed issues indicated by health providers surrounding awareness and education of breast health, breast cancer and available resources for women without health insurance in the state of Utah. They also uncovered the need for better awareness of current support services for breast cancer survivors and their families as well as potentially more of these services outside of Salt Lake County.

Conclusions

While progress has been made in many areas, there is still a considerable amount that can be done to improve the experiences of women in the service area in regards to breast health education, awareness and screening. We know that there are women who are not getting the proper care or recommended screenings due to a lack of resources, education and awareness. There are current services that can be bolstered, as well as opportunities to expand our impact by engaging community groups, businesses, churches and media. We can influence outcomes in the lives of women by collaborating and encouraging these assets to take a more active role in supporting our goal of providing not only for those women without health care coverage, but for all women. A lack of education about breast cancer risks and the benefit of early detection are not confined to any one group and we believe that knowledge is power.

We have some long term partnerships with grantees and sponsors that can be broadened to reach communities that we have not been able to reach previously.

Affiliate Action Plan

Based on the information gathered in this process we have determined that we will expand our current service area to include, Summit, Wasatch and Tooele counties within the current fiscal year. To address the issues identified in this report, the Affiliate will focus on the following priority areas and plan to take the actions listed.

Priority #1

- Increase the rate of mammography screening for women of all ethnic backgrounds aged 40 and over who are uninsured or underinsured throughout the current and expanded service area.

Objectives

- Reach out to at least two mammography providers by the end of 2011 that we have not previously been involved with outside of Salt Lake County to expand our impact in other areas.
- Meet with current screening grantees and encourage them to engage primary health care providers in their partner clinics to reinforce the need for referrals for screening.
- By the end of FY'12, reach out to two non-profit groups, including screening providers and other strategic partners, located in each of the three counties in the expanded service area to encourage application for funding of programs where appropriate.

Priority #2

- Continue to educate and inform women of all backgrounds about the risk factors for breast cancer, prevention, and reinforce the benefits of early detection through screening, as well as available resources.

Objectives

- Meet with all current grantees by the end of 2011 to reinforce current messaging and encourage development of innovative ways to connect with women.
- By the end of this fiscal year, target two organizations with media connections including English and Spanish language and encourage collaboration and application for funding where appropriate.

Priority #3

- Enrich the lives of breast cancer survivors by providing support services for survivors and their families/co-survivors.

Objectives

- Meet with grantees currently offering support services by the end of 2011, to discuss potential expansion and increased awareness of their programs.
- Reach out to three new organizations outside of Salt Lake County to develop support services and encourage application for funding where appropriate.

As an Affiliate we are excited about the progress that has been made in the service area to this point, but we are even more optimistic moving forward about the opportunities we see to make an even greater impact in the lives of women and their families.

References

- Centers for Disease Control and Prevention. (2009). *Behavioral Risk Factor Surveillance System*. Retrieved from Office of Surveillance, Epidemiology, and Laboratory Services: <http://www.cdc.gov/brfss/questionnaires/questionnaires.htm>
- Governor's Office of Planning & Budgets. (2009). *Governor's Office of Planning & Budgets Demographics*. Retrieved 2011, from www.governor.utah.gov/dea/demographics.html.
- Hoffman, C., Damico, A., & Garfield, R. (2011). *Research Brief: Insurance Coverage and Access to Care in Primary Care Shortage Areas*. Kaiser Family Foundation.
- Horner, M. R. (2009). *SEER Cancer Statistics Review*. Bethesda: National Cancer Institute.
- Kim, H. (2011). *Overview of Breast Cancer in Davis, Salt Lake, Utah and Weber Counties in Utah*. Westminster College.
- Susan G. Komen for the Cure. (n.d.). *Susan G. Komen Breast Cancer Mammography Facts*. Retrieved from <http://www5.komen.org/BreastCancer/Mammography.html>
- U.S. Census Bureau. (2010). *2010 Annual Social and Economic Supplement*. Retrieved from http://www.census.gov/hhes/www/cpstables/032010/pov/new46_100125_01.htm.
- U.S. Census Bureau. (2010). *U.S. Census Bureau's American Fact Finder*.