

susan g. komen.  **COMMUNITY**
PROFILE REPORT 2015



SUSAN G. KOMEN®
NORTHERN NEVADA

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Executive Summary

Introduction to the Community Profile Report

Susan G. Komen® Northern Nevada was founded in 1999 by a group of women dedicated to providing access to breast cancer screening and treatment programs in northern Nevada, while raising awareness of how early detection can prevent breast cancer deaths.

Thanks to the generosity of the local community and the success of the Northern Nevada Susan G. Komen Race for the Cure®, the Affiliate has invested nearly \$3.5 million in life-saving breast health programs in Northern Nevada and the Lake Tahoe community since its founding, and has contributed nearly \$1 million to the Susan G. Komen Research Programs.

The Susan G. Komen Northern Nevada Race for the Cure® is the Affiliate's signature annual fundraising event. In addition to the Race, there are many fundraising opportunities each year including third party events and private donations.

Seventy-five percent of net proceeds generated by the Affiliate is committed to mission work including local breast cancer programs. The remaining 25 percent is pooled with contributions from the entire Affiliate network and from Komen Headquarters Research Programs to fund a portfolio of lifesaving research in all areas of breast cancer including risk reduction, basic biology, treatment and survivorship.

During the period from 2000 to 2015, the Affiliate awarded 151 community health grants totaling \$3.34 million. These grants primarily funded screening and treatment support services. Screening programs provided access to mammography both in northern Nevada's urban and rural communities via a mobile mammography van. Treatment support programs provided financial assistance to rural residents traveling into urban areas for breast cancer medical care, as well as basic assistance to low-income patients during breast cancer treatment.

Between 2012 and 2015, the Affiliate focused its funding priority on breast cancer screening services for the uninsured as a result of the dramatic shortage of funding in Nevada's National Breast and Cervical Cancer Early Detection Program — Women's Health Connection.

Komen Northern Nevada is a non-profit organization that is governed and powered by an active working Board of Directors who give their time and talent to promote the Komen mission to the communities in the service area. Komen Northern Nevada employs a full-time executive director.

The Affiliate's service area includes all of Northern Nevada and a region of central eastern California whose residents frequently access cancer care at Reno/Sparks hospitals (Figure 1).

The Affiliate's service area is home to 25 percent of the state's population; half of whom live in the urban areas of Reno/Sparks and Carson City. The remaining Nevada residents served by the Affiliate live in a scarcely populated rural and frontier region that covers 65,500 square miles.

KOMEN NORTHERN NEVADA SERVICE AREA

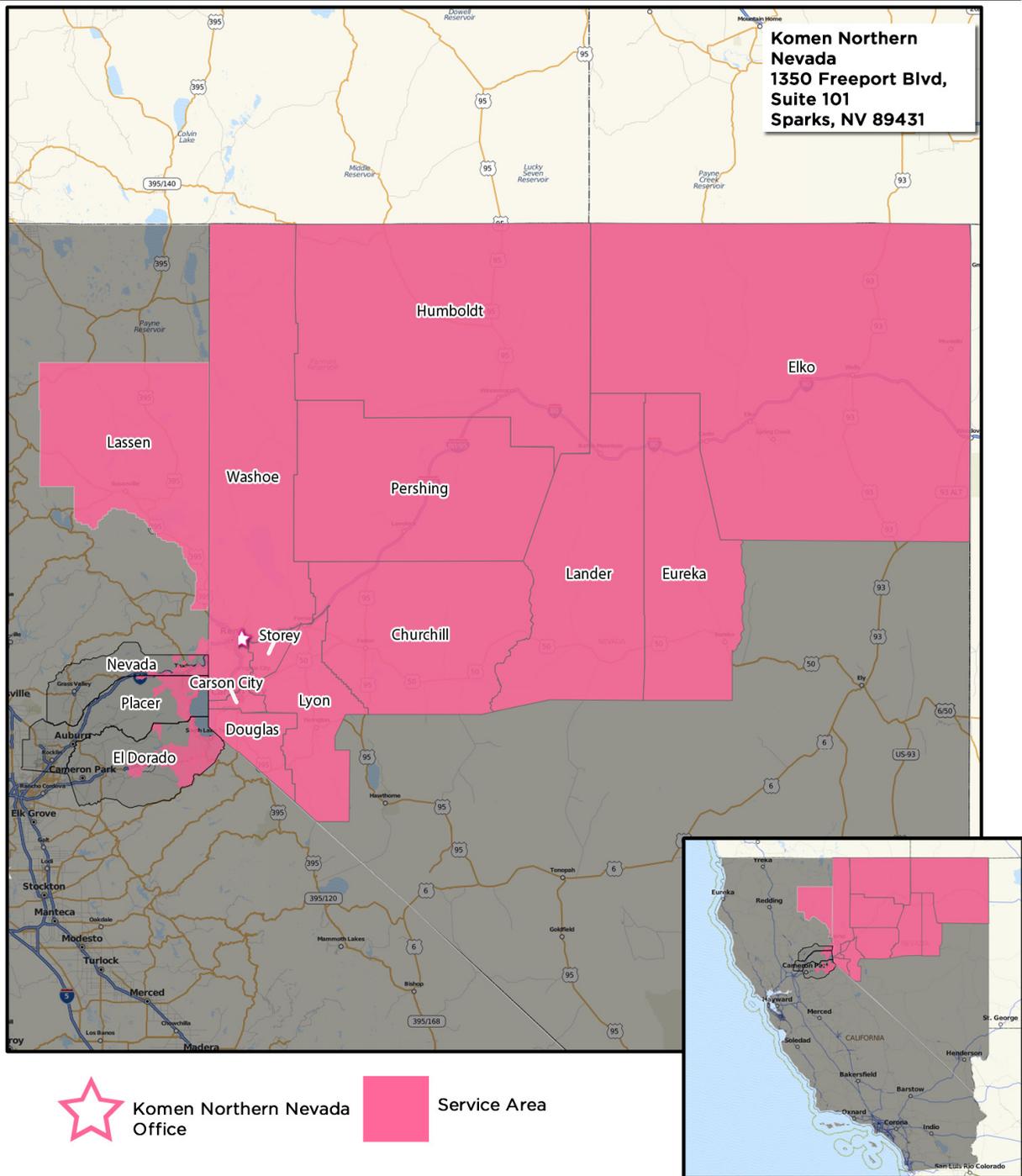


Figure 1. Susan G. Komen Northern Nevada service area

In order to fulfill its mission, Komen Northern Nevada conducts a quantitative and qualitative needs assessment every five years. The findings from this needs assessment are reported in the Community Profile, which informs the Affiliate of resources and needs in its service area and guides funding priorities. Furthermore, the findings identify the regions, communities and

populations where directing efforts will have the most impact. Thus, the Community Profile serves as a document to ensure that the Affiliate's efforts are targeted and non-duplicative.

Elko, Humboldt, Lander and Eureka Counties as well as Susanville, California and the Lake Tahoe communities were added to the service area after the 2009 Community Profile recognized a need for breast health services in these rural areas. The entire state of Nevada was serviced by the Northern and Southern Komen Affiliates for the first time during the 2011 grant cycle.

This document is designed to help the Affiliate in the following ways:

- Establish and align community outreach, grantmaking and public policy activities.
- Identify clear grantmaking priorities that aim to educate and raise breast cancer awareness.
- Build and strengthen relationships with sponsors by clearly communicating the breast health and breast cancer needs of the community.

Through the development of the Community Profile, community strengths are assessed to develop partnerships and collaborations. Through interviews, focus groups and surveys, the Community Profile also includes the voices of individuals living and working in areas of highest need. The Affiliate will make this document accessible to all stakeholders including, but not limited to, health care systems, legislators, constituents, and funders.

Overall this Community Profile report will help Komen Northern Nevada be strategic in its direction towards marketing, outreach programs and by creating synergy between mission-related, strategic plans and operational activities.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

The quantitative data report combines evidence from many credible sources and identifies the highest priority areas for evidence-based breast cancer programs. It includes data tables, maps, preliminary data interpretation, and identification of priority areas.

The Affiliate's service area is comprised of the northern half of Nevada and a portion of north eastern California, primarily the Lake Tahoe community. It includes 11 Nevada counties (Carson City, Churchill, Douglas, Elko, Eureka, Humboldt, Lander, Lyon, Pershing, Storey and Washoe), all of Lassen County, CA and specific zip codes in the following California counties — El Dorado Nevada, and Placer County. Much of the service area is a vast rural and frontier region where the population is often medically underserved and must travel long distances to access health care services, particularly cancer care. Data presented in the quantitative data report are reported at the county, state and federal level. Therefore, data for the California zip codes served by Komen Northern Nevada are not available in this report.

To determine priority areas, each county's estimated time to reach the HP2020 target for late-stage diagnosis and death rates were compared and then each county was categorized into seven potential priority levels. One county in the Komen Northern Nevada service area is in the highest priority category: Humboldt County, NV. Humboldt County was not selected as a target community because of its very small population.

Two counties in the Komen Northern Nevada service area are in the high priority category: Washoe County, NV and Carson City, NV. Reno/Sparks Metropolitan Area (Washoe County) and Carson City account for half the population in the service area. Because of the high priority for intervention and the concentration of individuals impacted, Reno/Sparks Metropolitan Area (Washoe County) and Carson City were selected as target communities.

Reno/Sparks Metropolitan Area (Washoe County)

Healthy People 2020 reports that that Washoe County will require 10 years to meet the HP2020 breast cancer death rate target and 13 years or longer to meet breast cancer late-stage diagnosis rate target. Washoe County has an incidence rate of 120.1 per 100,000 women which is higher than the State of Nevada rate (111.8) and has an increasing trend of 5.1 percent each year.

Washoe County's late-stage diagnosis rate of 43.2 per 100,000 women is increasing 7.9 percent a year and is higher than the State of Nevada (39.5). The rising incidence rate may indicate that more women are being diagnosed with breast cancer because more women are being screened. Unfortunately, the data suggests more individuals diagnosed with breast cancer are diagnosed at a late-stage.

Many factors can contribute to disparities in access to the breast health continuum of care including lack of insurance, low income and cultural and language differences. Washoe County has a relatively large Hispanic/Latina population (22.3 percent) and a high poverty level with 31.9 percent of Washoe County residents having an income below 250 percent of the poverty level. The county's uninsured percentage for ages 40-64 (20.5 percent) is higher than the US (16.6 percent). Additionally, 9.3 percent of the population is unemployed which is higher than the US (8.7 percent). These factors along with the fact that three-quarters of Washoe County residents live in the Reno/Sparks Metropolitan Area, make the county a logical focus of further efforts.

Carson City

Carson City is a target community because of its high priority ranking regarding HP2020 targets and its relatively large population, accounting for roughly 7.0 percent of the women in the service area. While the breast cancer death rate for Carson City is decreasing annually (-1.8 percent), the county has a relatively low percentage of women receiving screening (64.1 percent) and has an increasing annual late-stage incidence rate (10.2 percent). The data suggests that women may not be receiving regular screening services, and therefore more of those who are diagnosed with breast cancer are diagnosed at a late-stage.

Factors that may be contributing to an increase in late-stage diagnoses include residents with limited financial resources and health care coverage, and potential cultural and language barriers. Carson City has a high percentage of residents that are unemployed (11.5 percent) and 32.2 percent of employed residents with an annual income less than 250 percent of the poverty level. In addition, while only 3.7 percent of the population is linguistically isolated, Carson City has a substantially larger Hispanic/Latina female population (21.5 percent) than the US (16.2 percent). Among the Hispanic/Latina community, breast cancer is the most common cancer. The Affiliate has identified low-income and uninsured residents as the highest priority population in Carson City.

Health Systems and Public Policy Analysis

The Reno/Sparks Metropolitan Area has health care providers for all steps in the Continuum of Care: breast cancer screening, diagnosis, treatment, follow-up, and survivor support. It is served by three hospitals: Renown Health, Saint Mary's Regional Medical Center and Northern Nevada Medical Center. Both Renown and Saint Mary's have comprehensive cancer treatment centers. The American College of Radiology recognizes both as Centers of Excellence for their breast imaging services and both have American College of Surgeons Accredited Breast Centers.

There are 37 screening, 11 diagnostic and 4 treatment facilities in the Reno/Sparks area. Both Renown and Saint Mary's provide survivorship support.

Medically underserved populations in this community are served primarily by federally qualified health centers (Community Health Alliance and Northern Nevada HOPES), a medical discount program (Access to Healthcare) and charities.

Carson City has six screening, four diagnostic, and three treatment facilities. In addition, of the facilities in this community, Carson Tahoe Regional Medical Center is an American College of Surgeons Accredited Cancer Center.

A mobile mammography unit (Nevada Health Centers Mammovan) visits both target communities. It is accredited by the American College of Radiology.

Access to breast health care services is constrained by financial resources in the Affiliate's target communities but generally not by the availability of health care providers. Komen Northern Nevada has long standing relationships with providers and charities that provide breast health education and screening, and breast cancer services to underserved populations in both target communities. The Affiliate seeks partnerships with all providers who address the needs of the underserved, financially disadvantaged and hard-to-reach populations.

Target community strengths: Comprehensive breast health and breast cancer services are available in Reno/Sparks Metropolitan Area (Washoe County) and Carson City.

Target community weaknesses: Individuals with low-incomes have difficulty navigating the complex network of insurance and assistance programs that are available to provide them with breast health services.

The greatest need for breast health support in the target communities continues to be women who are uninsured, despite the Affordable Care Act (ACA), and underinsured women who are unable to bear the financial burden of out-of-pocket breast health care expenses. Poverty continues to be the greatest barrier to accessing life-saving breast cancer education, screening, and treatment for many residents in Northern Nevada.

Where the Affiliate's funding priority used to be funding breast cancer screening because of Women Health Connection's limited funding, the hope is that ACA will reduce the need for free screening services and that Komen resources can shift to diagnosis and treatment services.

The Affiliate continues to monitor the changing landscape of federal funding and health care regulation and is concerned about Women's Health Connection funding cuts. Continued federal funding of the program as well as the hope that the state will recognize the critical need for additional state contribution is the Affiliate's highest public policy priority. The Affiliate will continue to work with its Breast Cancer Collaborative partners in advocating for state funding.

Additionally, the Affiliate and the Collaborative have identified women in hard-to-reach populations (including undocumented immigrants) as a particularly vulnerable population. Federal regulations exclude these members of the community from receiving many programs that provide life-saving breast health services.

And finally, the Affiliate recognizes the need for resources directed specifically at individuals with metastatic breast cancer (MBC). Though psychosocial support services are available to women in breast cancer treatment and post treatment, no support groups exist specifically for the special needs of individuals with MBC.

Qualitative Data: Ensuring Community Input

Qualitative data were collected to help the Affiliate answer the following questions about breast cancer health care needs in the target communities of the service area.

1. What barriers prevent women from being screened for breast cancer?
2. What barriers prevent women from receiving diagnostic services after receiving an abnormal screening result?
3. What barriers prevent women from receiving treatment after a breast cancer diagnosis?

Two surveys were used to collect information regarding the questions of barriers: 1) an online survey emailed to breast cancer survivors and 2) a paper breast cancer screening survey distributed through the Nevada Health Centers' Mammovan during its visits to the target communities.

The Affiliate was also able to obtain the results of a focus group conducted by the Nevada Cancer Coalition during the summer of 2014 in Carson City and Minden. Participants were questioned about barriers to screening and the perceived efficacy of proposed interventions.

Additionally, a series of Northern Nevada Breast Cancer Collaborative meetings provided focus group data. The Collaborative is comprised of stake holders in the continuum of care: survivors, patient navigators, nurses, foundation administrators, physicians, support group facilitators, and representatives from Women's Health Connection.

Qualitative data identified the same primary concerns as the quantitative data report regarding breast cancer in the target communities. The populations at greatest risk of facing barriers to

breast cancer screening, diagnosis and treatment are the uninsured, underinsured and poor. A lack of education about breast cancer risk factors and the importance of regular screening compounds the likelihood that the target population will neglect screening.

Mission Action Plan

Komen Northern Nevada's primary goal is to reduce late-stage breast cancer diagnoses and breast cancer deaths in its service area. The Affiliate's highest priority is to achieve this goal by providing breast health resources to individuals who would otherwise not have access to them. The Affiliate has identified uninsured and underinsured individuals receiving breast health services in the Reno/Sparks Metropolitan Area and in Carson City as target communities. Both communities have a high-priority designation for receiving interventions.

The health system and public policy analysis indicates that though the Affordable Care Act has increased the number of individuals who are covered by health insurance in Nevada, individuals with limited incomes continue to face financial barriers to basic breast health services whether they are covered by health insurance or not. Existing assistance programs present a labyrinth of eligibility hurdles for an individual.

Thus, the Affiliate has chosen to focus on the most vulnerable individuals in the community who are impacted by breast cancer – those who are not able to surmount the financial barriers to breast cancer screening, diagnosis and treatment without assistance.

Furthermore, qualitative analysis indicates that particularly among vulnerable communities, having health insurance is not enough. Breast health education plays a critical role in the continuum of care. A woman must know *what* health services are beneficial to access as well as *how* to access them.

In addition, the Affiliate recognizes that the health systems in its target communities do not offer services that target the special needs of individuals with metastatic breast cancer. The Affiliate aims to explore opportunities and partnerships to develop resources for the metastatic community.

The Affiliate has created the following action plan to guide its operations during the planning period (2015-19).

Need Statement: Washoe County and Carson City have higher than average breast cancer late-stage diagnosis rates.

Priority 1: In order to reduce the number of late-stage diagnoses in Reno/Sparks Metropolitan Area (Washoe County) and Carson City, programs that provide access to screening and diagnostic services will be a funding priority.

Objectives

- Beginning with the FY2016 Community Grant Request for Application, a funding priority will be programs that provide screening and diagnostic services to uninsured individuals in Reno/Sparks Metropolitan Area (Washoe County) and Carson City.

- Beginning with the FY2017 Community Grant Request for Application, a funding priority will be programs that provide funding for diagnostic services for underinsured individuals in Reno/Sparks Metropolitan Area (Washoe County) and Carson City.

Need Statement: Reno/Sparks Metropolitan Area (Washoe County) and Carson City screening rates are below Healthy People 2020 target levels (81 percent).

Priority 2: Increase number of insured women in target communities who use their breast cancer screening benefits and the number of uninsured women who access free breast cancer screening services.

Objectives

- Beginning in FY16, support health literacy campaigns that aim to increase use of breast cancer screening benefits by newly insured residents of target communities through Affiliate’s community breast health education activities and in collaboration with grantees.
- Beginning in FY16, improve awareness of the availability of free breast cancer screening programs for uninsured individuals in target communities through Affiliate’s community breast health education activities and in collaboration with grantees.
- Beginning in FY17, develop partnerships with at least one new community organization annually in each target community to increase the distribution of Komen’s breast self-awareness messages.

Need Statement: Washoe County and Carson City have a high percentage of low-income, uninsured residents who are unable to afford breast cancer treatment.

Priority 3: Reduce the burden of a breast cancer treatment for individuals seeking treatment in Reno/Sparks Metropolitan Area and Carson City.

Objectives

- Beginning with the FY2016 Community Grant Request for Application, a funding priority will be programs that provide financial assistance to breast cancer survivors from Washoe County and Carson City during breast cancer treatment.

Need Statement: The target communities provide limited services specifically addressing the needs of individuals with metastatic breast cancer.

Priority 4: Explore opportunities to collaborate with community partners to develop or support resources that specifically address the needs to individuals with metastatic breast cancer.

Objectives

- Beginning in FY2016, develop a better understanding of the specific needs faced by the metastatic breast cancer community and identify one or more services that it would be desirable to develop in the community.
- Beginning with the FY2017 Community Grant Request for Application, include a call for applications that propose pilot programs to address the specific needs of the metastatic breast cancer community.

Disclaimer: Comprehensive data for the Executive Summary can be found in the 2015 Susan G. Komen® Northern Nevada Community Profile Report.

Introduction

Affiliate History

Susan G. Komen® Northern Nevada was founded in 1999 by a group of women dedicated to providing access to breast cancer screening and treatment programs in northern Nevada, while raising awareness of how early detection can prevent breast cancer deaths.

Thanks to the generosity of the local community and the success of the Susan G. Komen Northern Nevada Race for the Cure®, the Affiliate has invested nearly \$3.5 million in life-saving breast health programs in northern Nevada and the Sierra since its founding in 1999, and has contributed nearly \$1 million to the Susan G. Komen Research Program.

The Komen Northern Nevada Race for the Cure® is the Affiliate's signature annual fundraising event that supports Komen's mission and grantmaking. In addition to the Race, there are many fundraising opportunities each year including third party events and private donations.

Seventy-five percent of net proceeds generated by the Komen Northern Nevada are granted to lifesaving local breast cancer programs. The remaining 25.0 percent is pooled with contributions from the entire Affiliate network and from Komen Headquarters Research Programs to fund a portfolio of lifesaving research in all areas of breast cancer, from risk reduction to basic biology to treatment and to survivorship.

During the period from 2000 to 2015, the Affiliate awarded 151 community health grants totaling \$3.34 million. These grants primarily funded screening and treatment support services. Screening programs provided access to mammography both in northern Nevada's urban rural communities via a mobile mammography van. Treatment support programs provided financial assistance to rural residents traveling into urban areas for breast cancer medical care, as well as basic financial assistance to any patient in need during breast cancer treatment.

Between 2012-2015, the Affiliate focused its funding priority on breast cancer screening services for the uninsured as a result of the dramatic shortage of funding in Nevada's National Breast and Cervical Cancer Early Detection Program (NBCCEDP) — Women's Health Connection.

The Affiliate has been an active member of the Breast Cancer Collaborative that was lead by the Nevada Cancer Coalition as an outgrowth of Nevada's Comprehensive Cancer Plan.

Affiliate Organizational Structure

Komen Northern Nevada is a non-profit organization that is governed and powered by an active working Board of Directors who give their time and talent to promote the Komen mission to the communities in the service area. Komen Northern Nevada employs a full-time executive director.

Affiliate Service Area

The Affiliate's service area includes all of northern Nevada and a region of central eastern California whose residents frequently access cancer care in Reno/Sparks (Figure 1.1).

Nevada: Carson City, Churchill, Douglas, Elko, Eureka, Humboldt, Lander, Lyon, Pershing, Storey and Washoe counties.

California: Lassen County and portions of Nevada, Placer and El Dorado Counties that surround Lake Tahoe.

Elko, Humboldt, Lander and Eureka Counties as well as Susanville, California, and the Lake Tahoe communities were added after the 2009 Community Profile recognized a need for breast health services in these rural areas. The entire state of Nevada was first serviced by the Northern and Southern Komen Affiliates for the first time during the 2011 grant cycle.

The Affiliate's service area is home to 25.0 percent of the state's population; half of whom live in the urban areas of Reno/Sparks and Carson City. The remaining Nevada residents served by the Affiliate live in the scarcely populated rural and frontier region that covers 65,500 square miles.

KOMEN NORTHERN NEVADA SERVICE AREA

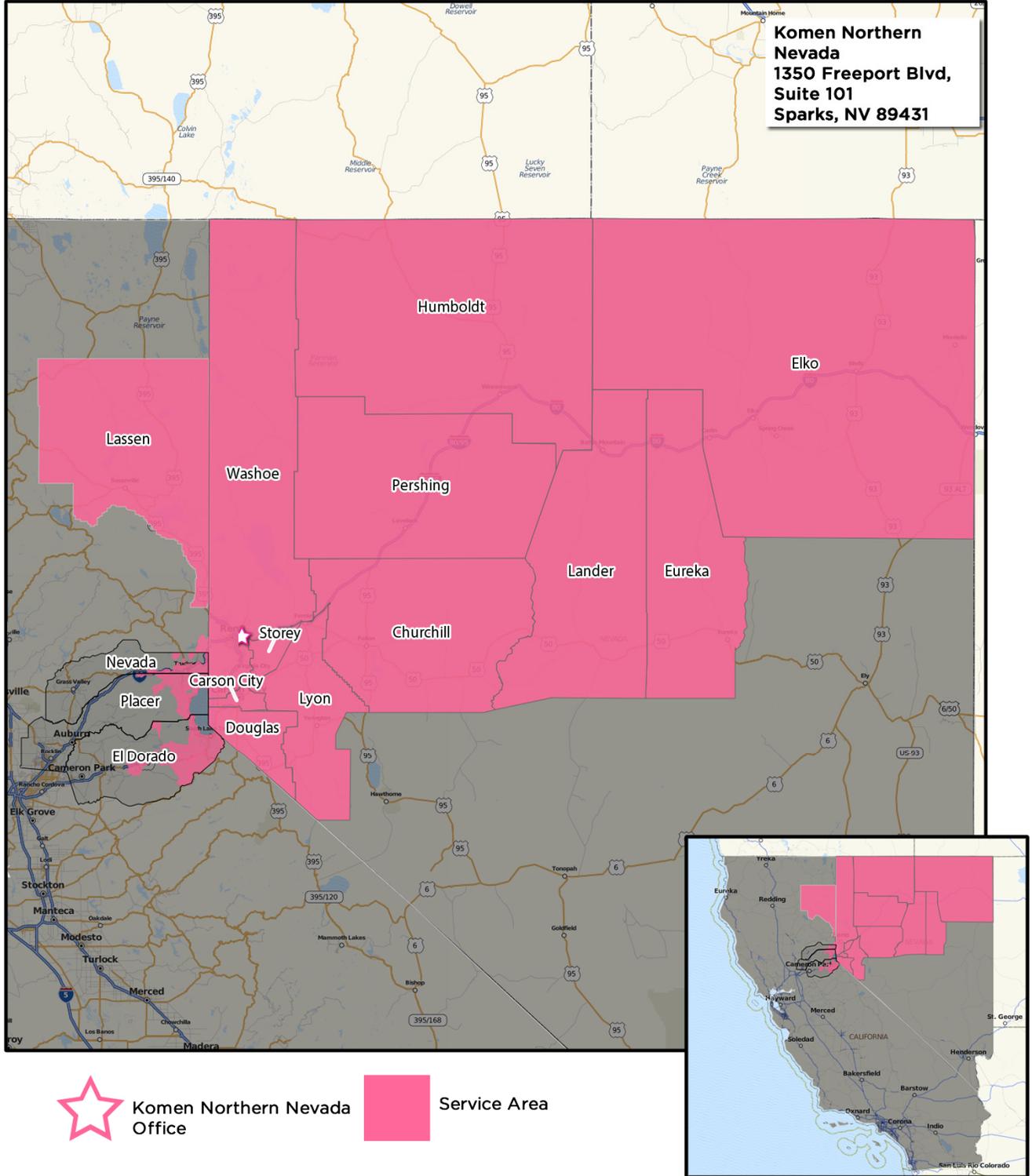


Figure 1.1. Susan G. Komen Northern Nevada service area

Purpose of the Community Profile Report

In order to fulfill its mission, Komen Northern Nevada conducts a quantitative and qualitative needs assessment every five years. The findings from this needs assessment are reported in the Community Profile, which informs the Affiliate of assets and gaps in its service area, and guides funding priorities. Furthermore, the findings identify the regions, communities and populations where directing efforts will have the most impact. Thus, the Community Profile serves as a document to ensure that the Affiliate's efforts are targeted and non-duplicative.

This document is designed to help the Affiliate in the following ways:

- Establish and align community outreach, grantmaking and public policy activities
- Identify clear grantmaking priorities that aim to educate and raise breast cancer awareness
- Build and strengthen relationships with sponsors by clearly communicating the breast health and breast cancer needs of the community

Through the development of the Community Profile, community strengths are assessed to develop partnerships and collaborations. Through interviews, focus groups and surveys, the Community Profile also includes the voices of individuals living and working in areas of highest need. The Affiliate will make this document accessible to all stakeholders including, but not limited to, health care systems, legislators, constituents, and funders. Overall this Community Profile Report will help Komen Northern Nevada to be strategic in its direction towards marketing, outreach programs and by creating synergy between mission-related, strategic plans and operational activities.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Quantitative Data Report

Introduction

The purpose of the quantitative data report for Susan G. Komen® Northern Nevada is to combine evidence from many credible sources and use the data to identify the highest priority areas for evidence-based breast cancer programs.

The data provided in the report are used to identify priorities within the Affiliate's service area based on estimates of how long it would take an area to achieve Healthy People 2020 objectives for breast cancer late-stage diagnosis and death rates (<http://www.healthypeople.gov/2020/default.aspx>).

The following is a summary of the Komen Northern Nevada's Quantitative Data Report. For a full report please contact the Affiliate.

Breast Cancer Statistics

Incidence rates

The breast cancer incidence rate shows the frequency of new cases of breast cancer among women living in an area during a certain time period (Table 2.1). Incidence rates may be calculated for all women or for specific groups of women (e.g. for Asian/Pacific Islander women living in the area).

The female breast cancer incidence rate is calculated as the number of females in an area who were diagnosed with breast cancer divided by the total number of females living in that area.

Incidence rates are usually expressed in terms of 100,000 people. For example, suppose there are 50,000 females living in an area and 60 of them are diagnosed with breast cancer during a certain time period. Sixty out of 50,000 is the same as 120 out of 100,000. So the female breast cancer incidence rate would be reported as 120 per 100,000 for that time period.

When comparing breast cancer rates for an area where many older people live to rates for an area where younger people live, it's hard to know whether the differences are due to age or whether other factors might also be involved. To account for age, breast cancer rates are usually adjusted to a common standard age distribution. Using age-adjusted rates makes it possible to spot differences in breast cancer rates caused by factors other than differences in age between groups of women.

To show trends (changes over time) in cancer incidence, data for the annual percent change in the incidence rate over a five-year period were included in the report. The annual percent change is the average year-to-year change of the incidence rate. It may be either a positive or negative number.

- A negative value means that the rates are getting lower.

- A positive value means that the rates are getting higher.
- A positive value (rates getting higher) may seem undesirable—and it generally is. However, it's important to remember that an increase in breast cancer incidence could also mean that more breast cancers are being found because more women are getting mammograms. So higher rates don't necessarily mean that there has been an increase in the occurrence of breast cancer.

Death rates

The breast cancer death rate shows the frequency of death from breast cancer among women living in a given area during a certain time period (Table 2.1). Like incidence rates, death rates may be calculated for all women or for specific groups of women (e.g. Black/African-American women).

The death rate is calculated as the number of women from a particular geographic area who died from breast cancer divided by the total number of women living in that area. Death rates are shown in terms of 100,000 women and adjusted for age.

Data are included for the annual percent change in the death rate over a five-year period.

The meanings of these data are the same as for incidence rates, with one exception. Changes in screening don't affect death rates in the way that they affect incidence rates. So a negative value, which means that death rates are getting lower, is always desirable. A positive value, which means that death rates are getting higher, is always undesirable.

Late-stage incidence rates

For this report, late-stage breast cancer is defined as regional or distant stage using the Surveillance, Epidemiology and End Results (SEER) Summary Stage definitions (<http://seer.cancer.gov/tools/ssm/>). State and national reporting usually uses the SEER Summary Stage. It provides a consistent set of definitions of stages for historical comparisons.

The late-stage breast cancer incidence rate is calculated as the number of women with regional or distant breast cancer in a particular geographic area divided by the number of women living in that area (Table 2.1). Late-stage incidence rates are shown in terms of 100,000 women and adjusted for age.

Table 2.1. Female breast cancer incidence rates and trends, death rates and trends, and late-stage rates and trends

Population Group	Incidence Rates and Trends				Death Rates and Trends			Late-stage Rates and Trends		
	Female Population (Annual Average)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of Deaths (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)
US	154,540,194	198,602	122.1	-0.2%	40,736	22.6	-1.9%	70,218	43.7	-1.2%
HP2020	-	-	-	-	-	20.6*	-	-	41.0*	-
California	18,413,837	23,266	122.0	-0.6%	4,251	21.9	-2.1%	8,287	43.5	-1.7%
Nevada	1,300,998	1,487	111.8	1.5%	306	23.0	-1.5%	527	39.5	2.3%
El Dorado County Zip Codes– CA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Lassen County – CA	12,505	14	93.8	3.9%	SN	SN	SN	4	30.8	-18.6%
Nevada County Zip Codes– CA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Placer County Zip Codes – CA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Carson City - NV	26,637	48	139.9	1.5%	9	23.4	-1.8%	16	49.4	10.2%
Churchill County - NV	12,448	14	100.3	-5.3%	SN	SN	SN	6	42.5	-1.5%
Douglas County - NV	23,500	34	103.4	3.4%	5	14.0	-4.8%	10	29.0	-6.9%
Elko County - NV	22,973	19	98.3	2.0%	4	20.5	NA	6	28.6	-0.7%
Eureka County - NV	846	SN	SN	SN	SN	SN	SN	SN	SN	SN
Humboldt County - NV	7,630	9	126.4	30.5%	SN	SN	SN	3	44.0	3.8%
Lander County - NV	2,707	SN	SN	SN	SN	SN	SN	SN	SN	SN
Lyon County - NV	25,534	31	105.5	-7.2%	8	26.3	-3.1%	12	39.8	-16.9%
Pershing County - NV	2,456	4	130.8	47.8%	SN	SN	SN	SN	SN	SN
Storey County - NV	1,968	SN	SN	SN	SN	SN	SN	SN	SN	SN
Washoe County - NV	204,120	259	120.1	5.1%	52	23.7	-1.4%	93	43.2	7.9%

* Target as of the writing of this report.

NA – data not available.

SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period).

Data are for years 2006-2010 except for the incidence and late-stage data for Nevada counties which are from 2005-2009.

Rates are in cases or deaths per 100,000.

Age-adjusted rates are adjusted to the 2000 US standard population.

Source of incidence and late-stage data: NAACCR – CINA Deluxe Analytic File.

Source of death rate data: CDC – NCHS death data in SEER*Stat.

Source of death trend data: NCI/CDC State Cancer Profiles.

Incidence rates and trends summary

The breast cancer incidence rate in the State of California was similar to that observed in the US as a whole and the incidence trend was slightly lower than the US as a whole. The breast cancer incidence rate in the State of Nevada was significantly lower than that observed in the US as a whole and the incidence trend was higher than the US as a whole.

The following county had an incidence rate significantly lower than the State of California as a whole:

- Lassen County, CA

The following municipality had an incidence rate **significantly higher** than the State of Nevada as a whole:

- Carson City, NV

The rest of the counties had incidence rates and trends that were not significantly different than their respective state as a whole or did not have enough data available.

It's important to remember that an increase in breast cancer incidence could also mean that more breast cancers are being found because more women are getting mammograms.

Death rates and trends summary

The breast cancer death rate in the State of California was similar to that observed in the US as a whole and the death rate trend was slightly lower than the US as a whole. The breast cancer death rate in the State of Nevada was similar to that observed in the US as a whole and the death rate trend was slightly higher than the US as a whole.

Significantly more favorable trends in breast cancer death rates were observed in the following county:

- Douglas County

The rest of the counties had death rates and trends that were not significantly different than their respective state as a whole or did not have enough data available.

Late-stage incidence rates and trends summary

The breast cancer late-stage incidence rate in the State of California was similar to that observed in the US as a whole and the late-stage incidence trend was lower than the US as a whole. The breast cancer late-stage incidence rate in the State of Nevada was significantly lower than that observed in the US as a whole and the late-stage incidence trend was higher than the US as a whole.

None of the counties had late-stage incidence rates and trends that were not significantly different than their respective state as a whole or did not have enough data available.

Mammography Screening

Getting regular screening mammograms (and treatment if diagnosed) lowers the risk of dying from breast cancer. Screening mammography can find breast cancer early, when the chances of survival are highest. Table 2.2 shows some screening recommendations among major organizations for women at average risk.

Table 2.2. Breast cancer screening recommendations for women at average risk*

American Cancer Society	National Comprehensive Cancer Network	US Preventive Services Task Force
<p>Informed decision-making with a health care provider at age 40</p> <p>Mammography every year starting at age 45</p> <p>Mammography every other year beginning at age 55</p>	<p>Mammography every year starting at age 40</p>	<p>Informed decision-making with a health care provider ages 40-49</p> <p>Mammography every 2 years ages 50-74</p>

*As of October 2015

Because having regular mammograms lowers the chances of dying from breast cancer, it's important to know whether women are having mammograms when they should. This information can be used to identify groups of women who should be screened who need help in meeting the current recommendations for screening mammography. The Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factors Surveillance System (BRFSS) collected the data on mammograms that are used in this report. The data come from interviews with women age 50 to 74 from across the United States. During the interviews, each woman was asked how long it has been since she has had a mammogram. The proportions in Table 2.3 are based on the number of women age 50 to 74 who reported in 2012 having had a mammogram in the last two years.

The data have been weighted to account for differences between the women who were interviewed and all the women in the area. For example, if 20.0 percent of the women interviewed are Hispanic/Latina, but only 10.0 percent of the total women in the area are Hispanic/Latina, weighting is used to account for this difference.

The report uses the mammography screening proportion to show whether the women in an area are getting screening mammograms when they should. Mammography screening proportion is calculated from two pieces of information:

- The number of women living in an area that the BRFSS determines should have mammograms (i.e. women age 50 to 74).
- The number of these women who actually had a mammogram during the past two years.

The number of women who had a mammogram is divided by the number who should have had one. For example, if there are 500 women in an area that should have had mammograms and 250 of those women actually had a mammogram in the past two years, the mammography screening proportion is 50.0 percent.

Because the screening proportions come from samples of women in an area and are not exact, Table 2.3 includes confidence intervals. A confidence interval is a range of values that gives an idea of how uncertain a value may be. It's shown as two numbers—a lower value and a higher

one. It is very unlikely that the true rate is less than the lower value or more than the higher value.

For example, if screening proportion was reported as 50.0 percent, with a confidence interval of 35.0 to 65.0 percent, the real rate might not be exactly 50.0 percent, but it's very unlikely that it's less than 35.0 or more than 65.0 percent.

In general, screening proportions at the county level have fairly wide confidence intervals. The confidence interval should always be considered before concluding that the screening proportion in one county is higher or lower than that in another county.

Table 2.3. Proportion of women ages 50-74 with screening mammography in the last two years, self-report

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
US	174,796	133,399	77.5%	77.2%-77.7%
California	4,347	3,512	81.8%	80.3%-83.2%
Nevada	1,716	1,229	73.1%	70.3%-75.8%
El Dorado County Zip Codes- CA	NA	NA	NA	NA
Lassen County - CA	12	12	100%	64.9%-100%
Nevada County Zip Codes - CA	NA	NA	NA	NA
Placer County Zip Codes - CA	NA	NA	NA	NA
Carson City - NV	105	65	64.1%	52.4%-74.4%
Churchill County - NV	45	29	64.8%	45.9%-80.1%
Douglas County - NV	93	74	83.0%	71.9%-90.3%
Elko County - NV	59	34	59.0%	41.6%-74.3%
Eureka County - NV	SN	SN	SN	SN
Humboldt County - NV	19	12	68.4%	38.1%-88.4%
Lander County - NV	SN	SN	SN	SN
Lyon County - NV	96	67	70.2%	57.3%-80.5%
Pershing County - NV	SN	SN	SN	SN
Storey County - NV	SN	SN	SN	SN
Washoe County - NV	532	387	74.0%	68.9%-78.6%

NA- data not available.

SN – data suppressed due to small numbers (fewer than 10 samples).

Data are for 2012.

Source: CDC – Behavioral Risk Factor Surveillance System (BRFSS).

Breast cancer screening proportions summary

The breast cancer screening proportion in the State of California was significantly higher than that observed in the US as a whole. The breast cancer screening proportion in the State of Nevada was **significantly lower** than that observed in the US as a whole.

None of the counties had screening proportions that were not significantly different than their respective state as a whole or did not have data available.

Population Characteristics

The report includes basic information about the women in each area (demographic measures) and about factors like education, income, and unemployment (socioeconomic measures) in the areas where they live (Tables 2.4 and 2.5). Demographic and socioeconomic data can be used to identify which groups of women are most in need of help and to figure out the best ways to help them.

It is important to note that the report uses the race and ethnicity categories used by the US Census Bureau, and that race and ethnicity are separate and independent categories. This means that everyone is classified as both a member of one of the four race groups as well as either Hispanic/Latina or Non-Hispanic/Latina.

The demographic and socioeconomic data in this report are the most recent data available for US counties. All the data are shown as percentages. However, the percentages weren't all calculated in the same way.

- The race, ethnicity, and age data are based on the total female population in the area (e.g. the percent of females over the age of 40).
- The socioeconomic data are based on all the people in the area, not just women.
- Income, education and unemployment data don't include children. They're based on people age 15 and older for income and unemployment and age 25 and older for education.
- The data on the use of English, called "linguistic isolation", are based on the total number of households in the area. The Census Bureau defines a linguistically isolated household as one in which all the adults have difficulty with English.

Table 2.4. Population characteristics – demographics

Population Group	White	Black /African-American	AIAN	API	Non-Hispanic /Latina	Hispanic /Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
US	78.8 %	14.1 %	1.4 %	5.8 %	83.8 %	16.2 %	48.3 %	34.5 %	14.8 %
California	75.1 %	7.3 %	2.0 %	15.6 %	62.5 %	37.5 %	45.5 %	31.5 %	13.1 %
Nevada	78.6 %	9.6 %	1.9 %	10.0 %	73.4 %	26.6 %	46.2 %	32.4 %	13.3 %
El Dorado County Zip Codes - CA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Lassen County - CA	90.2 %	2.3 %	5.3 %	2.2 %	88.7 %	11.3 %	51.8 %	38.2 %	14.8 %
Nevada County Zip Codes- CA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Placer County Zip Codes - CA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Carson City - NV	92.5 %	1.5 %	3.1 %	2.9 %	78.5 %	21.5 %	54.4 %	41.2 %	19.5 %
Churchill County - NV	86.6 %	2.6 %	6.2 %	4.6 %	87.8 %	12.2 %	50.3 %	37.1 %	16.3 %
Douglas County - NV	94.1 %	0.8 %	2.5 %	2.6 %	88.8 %	11.2 %	61.3 %	47.7 %	21.2 %
Elko County - NV	90.5 %	1.1 %	6.9 %	1.5 %	76.9 %	23.1 %	41.8 %	27.9 %	8.9 %
Eureka County - NV	95.6 %	0.8 %	2.5 %	1.2 %	88.7 %	11.3 %	50.7 %	35.4 %	13.3 %
Humboldt County - NV	92.2 %	1.1 %	5.3 %	1.4 %	75.6 %	24.4 %	45.1 %	31.0 %	10.6 %
Lander County - NV	92.2 %	1.5 %	5.7 %	0.6 %	78.3 %	21.7 %	45.9 %	31.9 %	12.0 %
Lyon County - NV	92.1 %	1.6 %	3.7 %	2.5 %	84.8 %	15.2 %	53.0 %	39.8 %	17.2 %
Pershing County - NV	91.2 %	1.6 %	5.9 %	1.3 %	78.9 %	21.1 %	53.4 %	39.6 %	18.2 %
Storey County - NV	94.1 %	1.5 %	1.7 %	2.7 %	94.2 %	5.8 %	66.9 %	53.1 %	18.6 %
Washoe County - NV	87.4 %	3.0 %	2.4 %	7.3 %	77.7 %	22.3 %	47.5 %	33.8 %	13.5 %

NA - data not available.

Data are for 2011.

Data are in the percentage of women in the population.

Source: US Census Bureau – Population Estimates

Table 2.5. Population characteristics – socioeconomics

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistic-ally Isolated	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age: 40-64)
US	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
California	19.2 %	14.4 %	35.6 %	10.1 %	27.2 %	10.3 %	5.0 %	16.7 %	20.2 %
Nevada	15.8 %	12.9 %	34.7 %	10.4 %	19.2 %	6.7 %	5.8 %	3.0 %	21.1 %
El Dorado County Zip Codes - CA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Lassen County - CA	20.2 %	14.6 %	31.5 %	10.0 %	7.0 %	0.9 %	70.5 %	18.1 %	14.1 %
Nevada County Zip Codes - CA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Placer County Zip Codes-CA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Carson City - NV	12.9 %	14.4 %	32.5 %	15.7 %	11.5 %	3.7 %	4.8 %	0.0 %	20.5 %
Churchill County - NV	11.6 %	10.5 %	33.4 %	9.6 %	6.1 %	2.1 %	34.7 %	0.0 %	19.4 %
Douglas County - NV	8.0 %	9.8 %	25.4 %	10.5 %	6.5 %	0.8 %	31.6 %	0.0 %	16.1 %
Elko County - NV	15.3 %	8.6 %	24.6 %	4.8 %	10.5 %	2.9 %	37.9 %	5.9 %	18.5 %
Eureka County - NV	11.8 %	15.3 %	29.5 %	4.3 %	3.3 %	1.5 %	100.0 %	100.0 %	14.9 %
Humboldt County - NV	18.4 %	13.5 %	27.0 %	10.2 %	13.7 %	4.6 %	37.9 %	0.0 %	18.7 %
Lander County - NV	22.4 %	12.3 %	23.8 %	10.7 %	6.8 %	3.7 %	39.0 %	100.0 %	15.6 %
Lyon County - NV	14.8 %	13.6 %	38.0 %	16.7 %	7.1 %	1.2 %	36.9 %	100.0 %	22.4 %
Pershing County - NV	19.4 %	11.9 %	37.5 %	11.1 %	12.8 %	1.6 %	100.0 %	0.0 %	23.1 %
Storey County - NV	8.4 %	6.4 %	25.8 %	18.3 %	5.6 %	0.5 %	92.6 %	100.0 %	19.0 %
Washoe County - NV	13.5 %	12.9 %	31.9 %	9.3 %	15.1 %	4.6 %	4.3 %	0.0 %	20.5 %

NA- data not available.

Data are in the percentage of people (men and women) in the population.

Source of health insurance data: US Census Bureau – Small Area Health Insurance Estimates (SAHIE) for 2011.

Source of rural population data: US Census Bureau – Census 2010.

Source of medically underserved data: Health Resources and Services Administration (HRSA) for 2013.

Source of other data: US Census Bureau – American Community Survey (ACS) for 2007-2011.

Population characteristics summary

California

Proportionately, the State of California has a slightly smaller White female population than the US as a whole, a substantially smaller Black/African-American female population, a substantially larger Asian and Pacific Islander (API) female population, a slightly larger American Indian and Alaska Native (AIAN) female population, and a substantially larger Hispanic/Latina female population. The state’s female population is slightly younger than that of the US as a whole. The state’s education level is slightly lower than and income level is slightly lower than those of the US as a whole. The state's unemployment level is slightly larger than that of the US as a whole. The state has a substantially larger percentage of people who are foreign born and a substantially larger percentage of people who are linguistically isolated. There are a substantially smaller percentage of people living in rural areas, a slightly larger

percentage of people without health insurance, and a substantially smaller percentage of people living in medically underserved areas.

The following county has a substantially larger AIAN female population percentage than that of the State of California as a whole:

- Lassen County, CA

Nevada

Proportionately, the State of Nevada has a slightly smaller White female population than the US as a whole, a slightly smaller Black/African-American female population, a substantially larger Asian and Pacific Islander (API) female population, a slightly larger American Indian and Alaska Native (AIAN) female population, and a substantially larger Hispanic/Latina female population. The state's female population is slightly younger than that of the US as a whole. The state's education level is slightly lower than and income level is about the same as those of the US as a whole. The state's unemployment level is slightly larger than that of the US as a whole. The state has a substantially larger percentage of people who are foreign born and a slightly larger percentage of people who are linguistically isolated. There are a substantially smaller percentage of people living in rural areas, a slightly larger percentage of people without health insurance, and a substantially smaller percentage of people living in medically underserved areas.

The following counties have substantially larger AIAN female population percentages than that of the State of Nevada as a whole:

- Churchill County, NV
- Elko County, NV
- Humboldt County, NV
- Lander County, NV
- Pershing County, NV

The following municipality and counties have substantially older female population percentages than that of the State of Nevada as a whole:

- Carson City, NV
- Douglas County, NV
- Storey County, NV

The following county has a substantially lower education level than that of the State of Nevada as a whole:

- Lander County, NV

The following municipality and counties have substantially lower employment levels than that of the State of Nevada as a whole:

- Carson City, NV
- Lyon County, NV
- Storey County, NV

Priority Areas

Healthy People 2020 forecasts

Healthy People 2020 (HP2020) is a major federal government initiative that provides specific health objectives for communities and for the country as a whole. Many national health organizations use HP2020 targets to monitor progress in reducing the burden of disease and improve the health of the nation. Likewise, Komen believes it is important to refer to HP2020 to see how areas across the country are progressing towards reducing the burden of breast cancer.

HP2020 has several cancer-related objectives, including:

- Reducing women's death rate from breast cancer (Target as of the writing of this report: 20.6 cases per 100,000 women).
- Reducing the number of breast cancers that are found at a late-stage (Target as of the writing of this report: 41.0 cases per 100,000 women).

To see how well counties in the Komen Northern Nevada service area are progressing toward these targets, the report uses the following information:

- County breast cancer death rate and late-stage diagnosis data for years 2006 to 2010.
- Estimates for the trend (annual percent change) in county breast cancer death rates and late-stage diagnoses for years 2006 to 2010.
- Both the data and the HP2020 target are age-adjusted.

These data are used to estimate how many years it will take for each county to meet the HP2020 objectives. Because the target date for meeting the objective is 2020, and 2008 (the middle of the 2006-2010 period) was used as a starting point, a county has 12 years to meet the target.

Death rate and late-stage diagnosis data and trends are used to calculate whether an area will meet the HP2020 target, assuming that the trend seen in years 2006 to 2010 continues for 2011 and beyond.

Identification of priority areas

The purpose of this report is to combine evidence from many credible sources and use the data to identify the highest priority areas for breast cancer programs (i.e. the areas of greatest need).

Classification of priority areas are based on the time needed to achieve HP2020 targets in each area. These time projections depend on both the starting point and the trends in death rates and late-stage incidence.

Late-stage incidence reflects both the overall breast cancer incidence rate in the population and the mammography screening coverage. The breast cancer death rate reflects the access to care and the quality of care in the health care delivery area, as well as cancer stage at diagnosis.

There has not been any indication that either one of the two HP2020 targets is more important than the other. Therefore, the report considers them equally important.

Counties are classified as follows (Table 2.6):

- Counties that are not likely to achieve either of the HP2020 targets are considered to have the highest needs.
- Counties that have already achieved both targets are considered to have the lowest needs.
- Other counties are classified based on the number of years needed to achieve the two targets.

Table 2.6. Needs/priority classification based on the projected time to achieve HP2020 breast cancer targets

		Time to Achieve Late-stage Incidence Reduction Target				
		13 years or longer	7-12 yrs.	0 – 6 yrs.	Currently meets target	Unknown
Time to Achieve Death Rate Reduction Target	13 years or longer	Highest	High	Medium High	Medium	Highest
	7-12 yrs.	High	Medium High	Medium	Medium Low	Medium High
	0 – 6 yrs.	Medium High	Medium	Medium Low	Low	Medium Low
	Currently meets target	Medium	Medium Low	Low	Lowest	Lowest
	Unknown	Highest	Medium High	Medium Low	Lowest	Unknown

If the time to achieve a target cannot be calculated for one of the HP2020 indicators, then the county is classified based on the other indicator. If both indicators are missing, then the county is not classified. This doesn't mean that the county may not have high needs; it only means that sufficient data are not available to classify the county.

Affiliate Service Area Healthy People 2020 Forecasts and Priority Areas

The results presented in Table 2.7 help identify which counties have the greatest needs when it comes to meeting the HP2020 breast cancer targets.

- For counties in the “13 years or longer” category, current trends would need to change to achieve the target.
- Some counties may currently meet the target but their rates are increasing and they could fail to meet the target if the trend is not reversed.

Trends can change for a number of reasons, including:

- Improved screening programs could lead to breast cancers being diagnosed earlier, resulting in a decrease in both late-stage incidence rates and death rates.
- Improved socioeconomic conditions, such as reductions in poverty and linguistic isolation could lead to more timely treatment of breast cancer, causing a decrease in death rates.

The data in this table should be considered together with other information on factors that affect breast cancer death rates such as screening percentages and key breast cancer death determinants such as poverty and linguistic isolation.

Table 2.7. Intervention priorities for Komen Northern Nevada service area with predicted time to achieve the HP2020 breast cancer targets and key population characteristics

County	Priority	Predicted Time to Achieve Death Rate Target	Predicted Time to Achieve Late-stage Incidence Target	Key Population Characteristics
Humboldt County - NV	Highest	SN	13 years or longer	%AIAN, rural
Carson City - NV	High	8 years	13 years or longer	Older, employment
Washoe County - NV	High	10 years	13 years or longer	
Churchill County - NV	Medium Low	SN	3 years	%AIAN, rural
Lyon County - NV	Medium Low	8 years	Currently meets target	Employment, rural, medically underserved
Lassen County - CA	Lowest	SN	Currently meets target	%AIAN, rural
Douglas County - NV	Lowest	Currently meets target	Currently meets target	Older, rural
Elko County - NV	Lowest	NA	Currently meets target	%AIAN, rural
El Dorado County Zip Codes - CA	Undetermined	NA	NA	
Nevada County Zip Codes- CA	Undetermined	NA	NA	
Placer County Zip Codes - CA	Undetermined	NA	NA	
Eureka County - NV	Undetermined	SN	SN	Rural, medically underserved
Lander County - NV	Undetermined	SN	SN	%AIAN, education, rural, medically underserved
Pershing County - NV	Undetermined	SN	SN	%AIAN, rural
Storey County - NV	Undetermined	SN	SN	Older, employment, rural, medically underserved

NA – data not available.

SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period).

Map of Intervention Priority Areas

Figure 2.1 shows a map of the intervention priorities for the counties in the Affiliate service area. When both of the indicators used to establish a priority for a county are not available, the priority is shown as “undetermined” on the map.

Komen Northern Nevada Affiliate Counties

Priority Areas

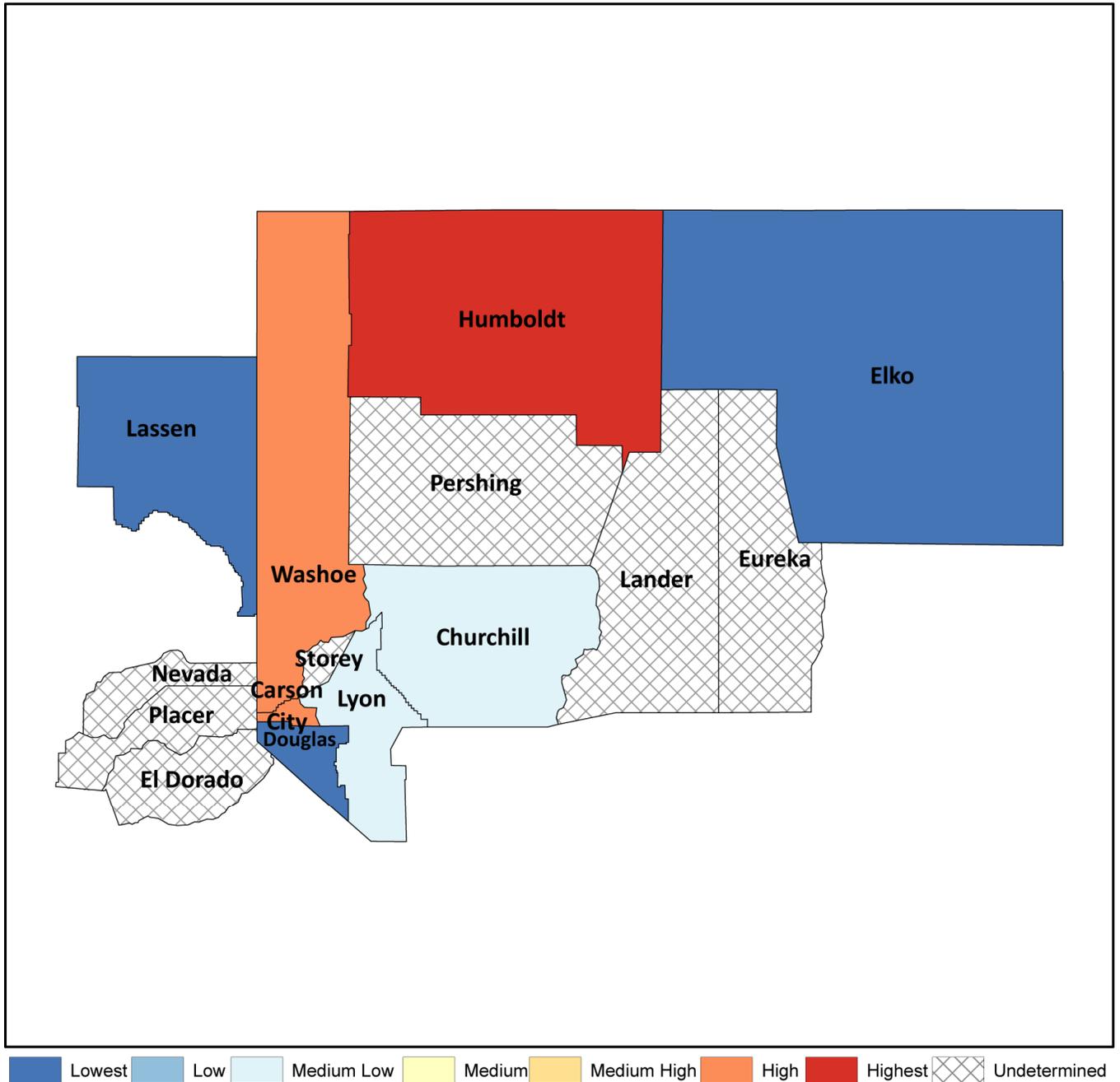


Figure 2.1. Intervention priorities

Data Limitations

The following data limitations need to be considered when utilizing the data of the Quantitative Data Report:

- The most recent data available were used but, for cancer incidence and deaths, these data are still several years behind.
- For some areas, data might not be available or might be of varying quality.

- Areas with small populations might not have enough breast cancer cases or breast cancer deaths each year to support the generation of reliable statistics.
- There are often several sources of cancer statistics for a given population and geographic area; therefore, other sources of cancer data may result in minor differences in the values even in the same time period.
- Data on cancer rates for specific racial and ethnic subgroups such as Somali, Hmong, or Ethiopian are not generally available.
- The various types of breast cancer data in this report are inter-dependent.
- There are many factors that impact breast cancer risk and survival for which quantitative data are not available. Some examples include family history, genetic markers like HER2 and BRCA, other medical conditions that can complicate treatment, and the level of family and community support available to the patient.
- The calculation of the years needed to meet the HP2020 objectives assume that the current trends will continue until 2020. However, the trends can change for a number of reasons.
- Not all breast cancer cases have a stage indication.

Quantitative Data Report Conclusions

Highest priority areas

One county in the Komen Northern Nevada service area is in the highest priority category. Humboldt County, NV is not likely to meet the late-stage incidence rate HP2020 target. Humboldt County, NV has a relatively large American Indian and Alaska Native population.

High priority areas

Two counties in the Komen Northern Nevada service area are in the high priority category. Both of the two, Carson City, NV and Washoe County, NV, are not likely to meet the late-stage incidence rate HP2020 target.

The age-adjusted incidence rates in Carson City (139.9 per 100,000) are significantly higher than the state as a whole (111.8 per 100,000). Carson City has an older population and high unemployment.

Selection of Target Communities

Nevada has a high unemployment level (10.4 percent versus 8.7 percent of the US), a high rate of uninsured residents (21.1 percent versus 16.6 percent of the US), and a poverty level that is higher than the national rate (34.7 percent of Nevada, versus 33.3 percent of the US have incomes below 250 percent of federal determined poverty level). Many Nevada residents are poor and struggle to access health services. Komen Northern Nevada is focusing on the low-income, uninsured and underserved individuals seeking breast health services in the following target communities:

1. Reno/Sparks Metropolitan Area (Washoe County)
2. Carson City

Reno/Sparks Metropolitan Area (Washoe County)

Fifty-four percent of the women living in the Affiliate's service area reside in Washoe County. The Affiliate has identified Washoe County as a target community because it has the largest target population in the service area and because of its classification as a high intervention priority ranking; the Healthy People 2020 reports that that Nevada will require 10 years to meet the HP2020 death rate target and 13 years or longer to meet the late-stage target (Table 2.7). Washoe County has an incidence rate of 120.1 per 100,000 women which is higher than the State of Nevada rate (111.8) and has an increasing trend of 5.1 percent each year (Table 2.1). Washoe County's late-stage diagnosis rate of 43.2 per 100,000 women is increasing 7.9 percent a year and is higher than the State of Nevada (39.5). The rising incidence rate may indicate that more women are being diagnosed with breast cancer because more women are being screened. Unfortunately, the data suggests that more individuals diagnosed with breast cancer are diagnosed at a late-stage.

Many factors can contribute to disparities in access to the breast health continuum of care including lack of insurance, low income and cultural and language differences (Komen, 2014). Washoe County has a relatively large Hispanic/Latina population (22.3 percent) and a high poverty level with 31.9 percent of Washoe County residents having an income below 250 percent of the poverty level (Table 2.5). The county's uninsured percentage for ages 40-64 (20.5 percent) is higher than the US (16.6 percent) (Table 2.5). Additionally, 9.3 percent of the population is unemployed which is higher than the US (8.7 percent). These factors along with the fact that three-quarters of Washoe County residents live in the Reno/Sparks Metropolitan area make the county a logical focus of further efforts. Furthermore, many residents of Nevada's rural counties who need breast cancer services travel to the Reno/Sparks Metropolitan Area for them because cancer care is largely unavailable in rural Nevada.

Carson City

Carson City is a target community because of its high priority ranking regarding HP2020 targets and its relatively large population, accounting for roughly 7.0 percent of the women in the service area. While the breast cancer death rate for Carson City is decreasing annually (-1.8 percent), the county has a relatively low percentage of women receiving screening (64.1 percent) and has an increasing annual late-stage incidence rate (10.2 percent) (Tables 2.1 and 2.3). The data suggests that women may not be receiving regular screening services, and that more women who are diagnosed with breast cancer are diagnosed at a late-stage.

Factors that may be contributing to higher than average late stage diagnosis rates include limited financial resources and health care coverage, and potential cultural and language barriers (Komen, 2014). Carson City has a high percentage of residents that are unemployed (11.5 percent) and 32.2 percent of employed residents with an annual income less than 250 percent of the poverty level. In addition, while only 3.7 percent of the population is linguistically isolated, Carson City has a substantially larger Hispanic/Latina female population (21.5 percent) than the US (16.2 percent) (Table 2.4). Among the Hispanic/Latina community, breast cancer is the most common cancer (Komen, 2014). The Affiliate has identified the poor and uninsured individuals as the highest priority population in Carson City.

Health Systems and Public Policy Analysis

Health Systems Analysis Data Sources

The following sources were used to build a list of breast health service providers in the Komen Northern Nevada service area:

- Grant e-Management System, Susan G. Komen Northern Nevada
- Nevada Cancer Coalition (<http://nevadacancercoalition.org/>)
- US Food and Drug Administration Mammography Facilities Listing (<http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMQSA/mqsa.cfm>)
- Centers for Medicare & Medicaid (<https://data.medicare.gov>)
- American College of Surgeons Commission on Cancer (http://datalinks.facs.org/cpm/CPMApprovedHospitals_Search.htm)
- American College of Radiology Centers of Excellence (<http://www.acr.org/Quality-Safety/Accreditation/Accredited-Facility-Search>)
- American College of Surgeons National Accreditation Program for Breast Centers (NAPBC) (<http://napbc-breast.org/resources/find.html>)
- National Cancer Institute Designated Cancer Centers (<http://www.cancer.gov/researchandfunding/extramural/cancercenters/find-a-cancer-center>)

The Affiliate engaged graduate students from the University of Nevada, Reno's Masters of Public Health program to collect information about breast health service providers in the service area. Students made every effort to contact each service provider listed to verify information.

Health Systems Overview

Breast Cancer Continuum of Care Model

The Breast Cancer Continuum of Care (CoC) is a model that shows how a woman typically moves through the health care system for breast cancer care (Figure 3.1). Komen Northern Nevada uses the Continuum of Care model to frame the Health System and Public Policy Analysis from which the Affiliate identifies what breast health services are available and what barriers to access exist at each step in the continuum.

A woman would ideally move through the CoC quickly and seamlessly, receiving timely, quality care in order to have the best outcomes. Education should play an important role throughout the entire CoC.

While a woman may enter the CoC at any point, ideally, a woman would enter the CoC by getting screened for breast cancer – with a clinical breast exam or a screening mammogram. If the screening test results are normal, she would loop back into follow-up care, where she would get another screening exam at the recommended interval. Education encourages women to get screened and reinforces the need to continue to get screened

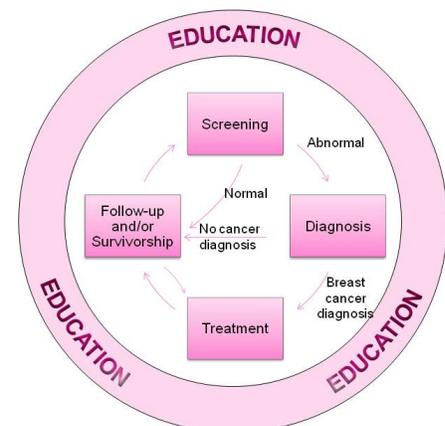


Figure 3.1. Breast Cancer Continuum of Care (CoC)

routinely thereafter.

When screening results are abnormal, the individual needs to progress to diagnosis to determine if the abnormal finding is breast cancer. Diagnostic tests may include additional mammograms, breast ultrasounds or biopsies. When diagnostic tests are negative (or benign), the woman advances to the follow-up step, and returns for screening at the recommended interval. The recommended intervals may range from 3 to 6 months for some women to 12 months for most women. Education emphasizes importance of keeping follow-up appointments, proactively getting test results, and understanding them. Education can empower a woman and help manage anxiety and fear.

If breast cancer is diagnosed, the individual proceeds to treatment. Education informs patients about treatment options, helps explain how pathology reports determine treatment options, prepares her for side effects and how to manage them, and helps her formulate questions for her providers.

For some breast cancer patients, treatment may last a few months and for others it may last years. While the CoC model shows that follow up and survivorship come after treatment ends, they actually may occur at the same time. For individuals with metastatic breast cancer, treatment may never end. Follow up education can include how to navigate insurance issues, locate financial assistance, manage ongoing symptoms such as pain, fatigue, sexual issues, bone health, etc. Education can teach how to make healthy lifestyle choices, how to manage side effects, and the importance of follow-up appointments and communication with their providers. Most women will return to screening at a recommended interval after treatment ends, or for some, during treatment (such as those taking long term hormone therapy).

Delays in moving from one step in the Continuum to another can all contribute to poorer outcomes. There are also many reasons why a woman does not enter or continue in the breast cancer CoC. These barriers can include lack of transportation, an overburdened health system, language barriers, fear, and lack of information - or the wrong information (myths and misconceptions). Education can address some of these barriers and help a woman progress through the CoC more quickly.

The Continuum of Care model frames the analysis of what services are available in the service area and what barriers to access exist at each step.

Assessment of health system in target communities

Reno/Sparks Metropolitan Area and Carson City

The Reno/Sparks Metropolitan Area has health care providers for all steps in the Continuum of Care: breast cancer screening, diagnosis, treatment, follow-up, and survivor support. It is served by three hospitals: Renown Health, Saint Mary's Regional Medical Center and Northern Nevada Medical Center. Both Renown and Saint Mary's have comprehensive cancer treatment centers. The American College of Radiology recognizes both as Centers of Excellence for their breast imaging services and both have American College of Surgeons Accredited Breast Centers.

There are 37 screening, 11 diagnostic and 4 treatment facilities in the Reno/Sparks area. Both Renown and Saint Mary's provide survivorship support.

Medically underserved populations in this community are served primarily by federally qualified health centers (Community Health Alliance and Northern Nevada HOPES), a medical discount program (Access to Healthcare) and charities.

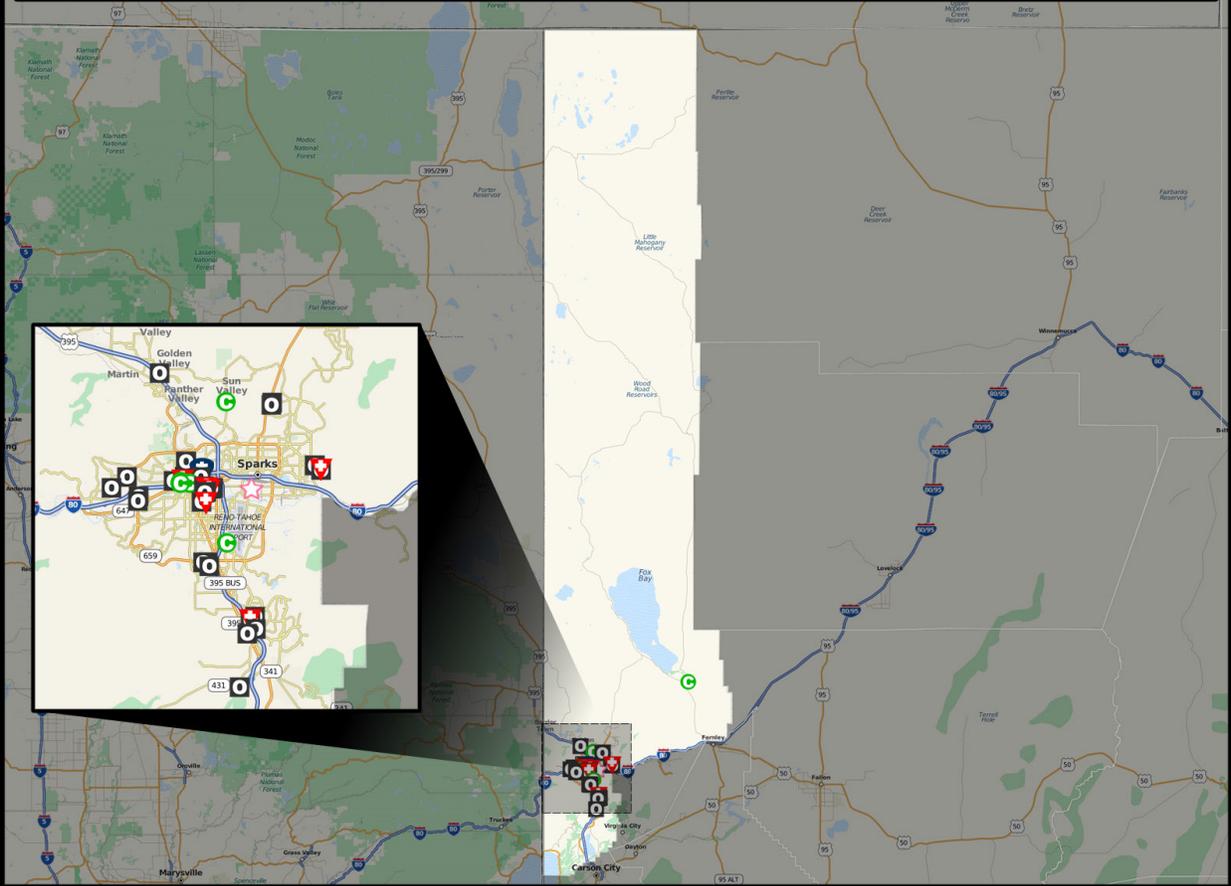
Carson City has six screening, four diagnostic, and four treatment facilities and a provider of support services. In addition, of the facilities in this community, Carson Tahoe Regional Medical Center is an American College of Surgeons Accredited Cancer Center.

A mobile mammography unit (Nevada Health Centers Mammovan) visits both target communities. It is accredited by the American College of Radiology.

Access to breast health care services is constrained by financial resources in the Affiliate's target communities but generally not by the availability of health care providers. Komen Northern Nevada has long standing relationships with providers and charities that provide breast health education and screening, and breast cancer services to underserved populations in both target communities. The Affiliate seeks partnerships with all providers who address the needs of the underserved, financially disadvantaged and hard to reach populations.

Reno/Sparks Metropolitan Area (Washoe County)

 Hospital	 Community Health Center	 Other
 Free Clinic	 Department of Health	 Affiliate Office



Statistics

Total Locations in Region: 48

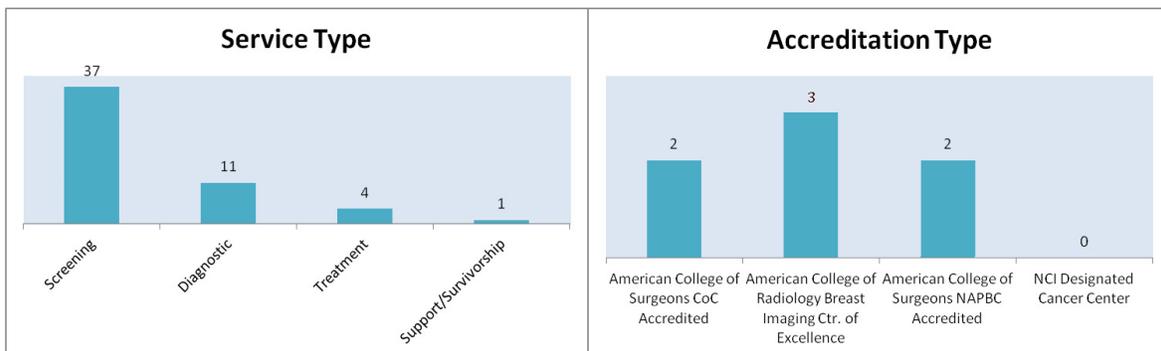


Figure 3.2. Breast cancer services available in Reno/Sparks Metropolitan Area

Carson City



Hospital



Community Health Center



Other



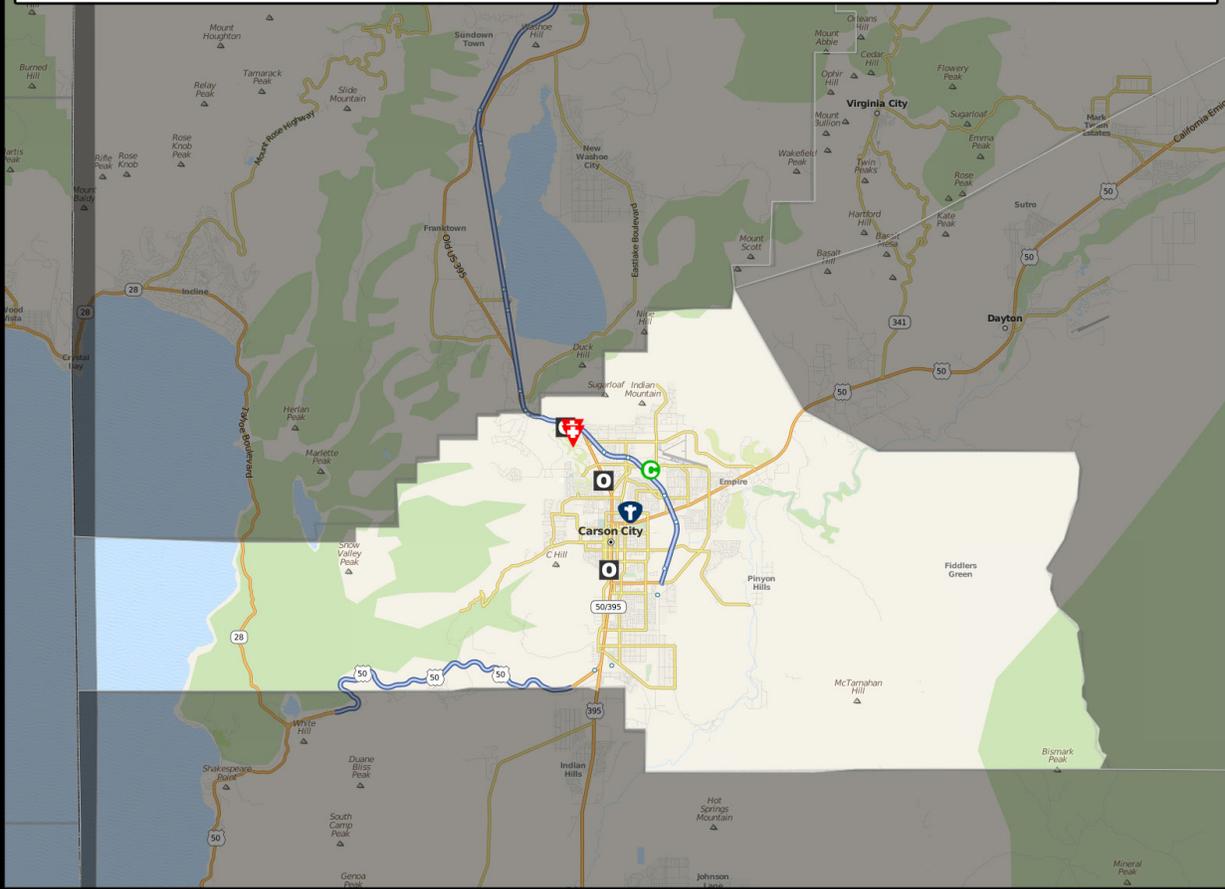
Free Clinic



Department of Health



Affiliate Office



Statistics

Total Locations in Region: 8

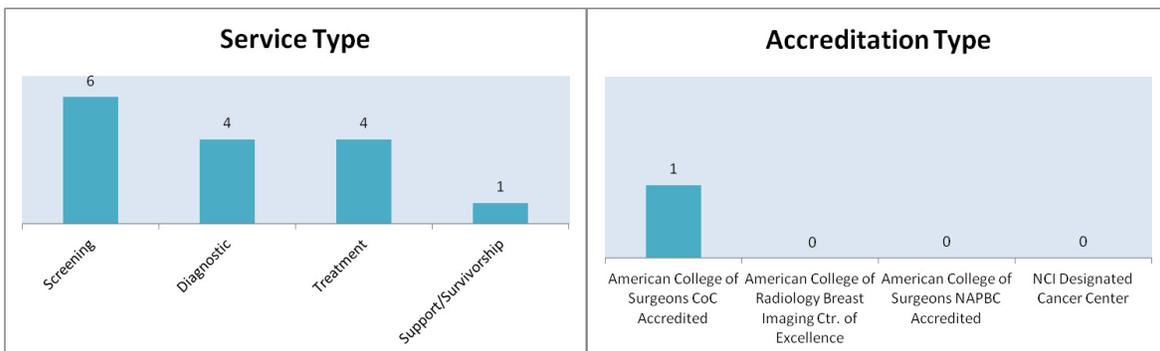


Figure 3.3. Breast cancer services available in Carson City

Public Policy Overview

This public policy overview includes information about the following programs that provide services to underserved populations in the service area.

- **Women’s Health Connection** (Nevada’s National Breast and Cervical Cancer Early Detection Program)
- **Nevada Medicaid**
- **Affordable Care Act insurance exchange - Nevada Health Link** (Nevada’s health insurance exchange created by the Affordable Care Act)
- **Access to Healthcare Network**

Each of these programs provides services to the underserved in the Affiliate service area. Note that all four of these programs are interrelated and eligibility is dependent on income and resident status. An individual may enter the financial assistance system through any one of these programs and, ideally, will be directed to the most appropriate service for which the applicant is eligible.

In addition to these assistance programs, a number of private foundations provide assistance recognizing that even women who are eligible for government assistance are faced with the daunting financial burdens associated with surviving breast cancer.

Women’s Health Connection (WHC)

The Women’s Health Connection (WHC) is a federally funded program through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) of the Centers for Disease Control and Prevention (CDC). WHC provides free breast and cervical cancer screening and diagnostic services to low-income, uninsured, and underinsured women ages 40 to 64 (Figure 3.4).

Women’s Health Connection Eligibility

Women 40 years of age or older who do not have health insurance, Medicaid, Medicare Part B, HMO coverage; or whose health insurance coverage does not pay for preventative services; and who meet the program’s income guidelines are eligible for enrollment in Nevada Women’s Health Connection. (Nevada Division of Public and Behavioral Health).

Covered Services

For women **40 to 49 years of age**, the program pays for a clinic office visit at a contracted clinic including the following services:

- Annual pelvic exam
- Annual clinical breast exam (the hands-on breast exam performed by a clinician)
- Pap test in accordance with established screening schedules and guidelines

For women **50 years of age and older**, the program pays for a clinic office visit at a contracted clinic including the following services:

- Annual pelvic exam
- Annual clinical breast exam (the hands-on breast exam performed by a clinician)
- Pap test in accordance with established screening schedules and guidelines
- Annual mammogram

Figure 3.4. Women’s Health Connection eligibility

In the case of women who are diagnosed with breast cancer through the WHC program there are federal mandates in place that govern the amount of time that may lapse between diagnosis and the initiation of treatment. This helps ensure women are “fast-tracked” into Medicaid and are able to begin treatment as soon as possible. However, while coverage can be expedited and urgent cases moved higher up the list, the challenge at this point in the Continuum of Care is to identify a Primary Care Provider (PCP) who has space in their panel for a Medicaid patient to establish care and is able to refer her for treatment. Medicaid enrollers may be able to help prioritize such cases on an individual basis. Women who are diagnosed with breast cancer outside of the WHC program and who are eligible for Medicaid may be at greater risk for delays in receiving treatment but are prioritized in the same way.

Women who experience difficulties enrolling in Medicaid in a timely way may also seek help from the Governor’s Office of Consumer Health Assistance (GOVCHA). GOVCHA advocates for access to health care resources, helps appeal insurance denials, provides care resource information and provides assistance to the uninsured.

Approximately 70.0 percent of WHC clients are ineligible for Nevada Medicaid or health insurance policies through Nevada Health Link (Nevada’s health insurance exchange established by the Affordable Care Act).

Access to Healthcare Network

Access to Healthcare Network (AHN) is a 501c3 organization established in 2007. Its mission is to increase access to primary and specialty health care services for low and moderate income Nevada residents through shared responsibility and community-wide partnerships. The shared responsibility model means everyone contributes something to the cost of health care (providers and patients). Health care is offered at heavily discounted rates and may be subsidized with grant or donated funds for those experiencing the greatest financial hardship. Community-wide partnerships mean that no single provider assumes a greater burden of providing exceptionally low cost services than any other. AHN is a medical discount program rather than health insurance. The success of the program depends on provider sign up and additional support from organizations such as Susan G. Komen Northern Nevada. AHN provides an alternative for economically disadvantaged individuals who are not eligible for Nevada Medicaid or for Women’s Health Connection because their income falls above those programs’ eligibility thresholds.

Nevada Medicaid

Medicaid is a government funded health insurance program for individuals receiving public assistance payments and individuals and families with low income. The program provides a broad range of medical and related services to assist individuals to attain or retain an optimal level of health care. The Nevada Division of Welfare and Supportive Services (DWSS) determines eligibility for Medicaid which is a state-administered, federal grant-in-aid program.

Nevada expanded Medicaid coverage under the Affordable Care Act. Prior to 2014, an individual or household was eligible for Medicaid if their income was 87.0 percent or less of the federal poverty level (FPL). The threshold level was raised to 138 percent in 2014. The federal government will fund the full cost of expanded Medicaid coverage for the first three years and at least 90.0 percent of the cost in future years.

According to the Kaiser Family Foundation, there were 621,000 uninsured Nevadans in 2012 and the number eligible for Medicaid coverage was estimated by the Urban Institute to be 265,000. By June 2014, 159,093 individuals who had applied for insurance coverage through Nevada Health Link had been referred to Medicaid, and 107,643 of them were eligible. In 2013 Nevada had one of the lowest Medicaid coverage rates in the nation at only 11.0 percent compared to the national average of 20.0 percent.

Of significance to the breast cancer community, the Affordable Care Act for the first time makes Medicaid coverage available to childless adults between the ages of 19 and 65.

Affordable Care Act

As a result of the Affordable Care Act (ACA), individuals with incomes between 138 and 400 percent of FPL may be eligible for subsidized health insurance. Nevada residents can compare private qualified insurance plans and purchase them through Nevada Health Link. Subsidized plans are available only to those who are not eligible for other coverage, such as Medicaid/CHIP, Medicare, or employer coverage, and who are citizens or lawfully present immigrants. Citizens and lawfully present immigrants with incomes above 400 percent of FPL can purchase unsubsidized coverage through the Nevada Health Link or directly from a private insurer. However, unless a qualifying event occurs, individuals can only purchase health insurance through the exchange during the annual open enrollment period. Individuals can apply for Medicaid coverage at any time through Nevada Health Link and do not need to wait for the open enrollment period.

Thirteen percent of uninsured Nevada residents are undocumented immigrants and are therefore ineligible for financial assistance under the ACA and are barred from purchasing coverage through the marketplace. This group is likely to remain uninsured, though they will still have a need for health care services. Hispanics/Latinos made up 17.8 percent of enrollment in private, qualified health plans through Nevada Health Link and 43.0 percent of uninsured Nevadans.

One component of the ACA is that it provides new options for breast cancer patients who have been denied insurance coverage due to pre-existing conditions. Insurance companies are now restricted from charging higher costs because of pre-existing conditions, including breast cancer. Preventive care, such as screening services and mammograms are now free for women with no out-of-pocket costs under most insurance plans due to ACA provisions.

The Affordable Health Care Act benefits the overall climate of health care and specific components within the ACA positively affect breast cancer screening, diagnosis, and treatment to patients. The ACA has the potential to extend coverage to the 621,000 uninsured Nevadans under its expanded coverage provisions.

As a result of provision in the Act, more people should be covered by insurance policies, and those policies will cover preventive care and regular breast cancer screenings. As a result, the limited funding that is available via Women's Health Connection should be under less demand, and will likely be shifted more and more to populations who are ineligible for Medicaid or subsidized policies through Nevada Health Link.

It is important to note that political pressures create an uncertain climate concerning the ACA, so federal regulations in effect today may not be in effect or enforced in the future. Furthermore, there is an inherent contradiction between ACA mandates and WHC funding. ACA nominally created a federal mandate that all individuals have health insurance while WHC distributes federal funds to pay screening costs for uninsured individuals. The very real possibility exists that the federal government will cut the one program that seeks to provide assistance to a group of people (uninsured) who by law should no longer exist.

Table 4.1. Summary of eligibility criteria for breast health assistance programs

		Annual income thresholds		
		1	2	3
Family size	FPL	138% FPL	250% FPL	400% FPL
1	\$11,770	\$16,243	\$29,425	\$47,080
2	\$15,930	\$21,983	\$39,825	\$63,720
3	\$20,090	\$27,724	\$50,225	\$80,360
4	\$24,250	\$33,465	\$60,625	\$97,000
5	\$28,410	\$39,206	\$71,025	\$113,640
6	\$32,570	\$44,947	\$81,425	\$130,280

FPL – 2016 Federal Poverty Level

1	Medicaid in Nevada
2	Women’s Health Connection, ACA insurance plans with subsidized out of pocket expenses, Access to Healthcare Medical Discount Program
3	ACA insurance plans with subsidized insurance premiums

Additional eligibility requirements

Nevada Medicaid

- Nevada resident
- US national, citizen, permanent resident, or legal alien

Women’s Health Connection

- Nevada resident
- Women 40 years of age or older
- Do not have health insurance, Medicaid, Medicare Part B, HMO coverage; or whose health insurance coverage does not pay for preventative services

Health insurance subsidies through ACA

- US resident
- US citizen or legal resident
- Not incarcerated
- Not eligible for Medicaid

Access to Healthcare

- Nevada resident
- Do not have medical insurance

State Comprehensive Cancer Control Coalition

The State of Nevada Comprehensive Cancer Plan 2011-2015 outlines the state's goals and objectives for reducing the cancer burden and improving the quality of life in Nevada. The Nevada State Health Division developed the plan and funded the creation of the Nevada Cancer Coalition for the purpose of implementing the plan's objectives in collaboration with other entities in the state that share an anti-cancer mission. Funding for both the Cancer Plan and the Coalition are provided by a grant from the Centers for Disease Control and Prevention. CDC provides funding to every state for similar programs.

The Coalition works with service providers, medical professionals, governmental agencies, nonprofit organizations as well as citizens. Susan G. Komen Northern Nevada has been an active participant in the Northern Nevada Breast Cancer Collaborative which met regularly during 2013-14 to identify unmet community breast health needs and to develop joint strategies for address them. Much of the collaborative's work aligns with the Affiliate's goals to identify community needs, gaps in services, barriers to services and develop plans to reach the objectives outlined in the Cancer Plan.

The Plan outlines the following broad goals:

1. Reduce the risk of developing cancer
2. Increase early detection and appropriate screening for cancer
3. Increase consumer awareness and provider education on the access of appropriate and effective cancer treatment and care
4. Address quality of life issues for health care consumers affected by cancer

Objectives specific to breast cancer include improving screening percentages and reducing disparities.

One noteworthy outcome of the State Comprehensive Cancer Control Plan with regards to breast cancer is the formation of the Breast Cancer Collaborative. The Collaborative pulls together all the key service providers in the continuum of care in bimonthly meetings. Both Susan G. Komen Affiliates in Nevada have been active participants in the Collaborative since it was formed.

Affiliate's Public Policy Activities and Priorities

Susan G. Komen Northern Nevada considers advocating on behalf of underserved individuals in its service area a cornerstone of its work. Through community collaborations and partnerships with those concerned with cancer control, the Affiliate has a voice that is well-informed and meaningful in public policy issues at the local level.

National Breast and Cervical Cancer Early Detection Program/ Women's Health Connection Funding

In common with its partners at the Nevada Cancer Coalition, the Affiliate considers increased and sustained funding for Women's Health Connection (NBCCEDP) an urgent priority and is working with the Coalition to prepare for the 2015 Nevada Legislative session with the goal of

securing increased funding. Nevada is one of only six states that currently provides no funding for the NBCCEDP program. In nine states (including neighboring California) state appropriations are 100 percent or more than the CDC award and the remaining states provide funding of at least 33.0 percent. In addition, Nevada remains the only state that not only provides no state funding, but also has implemented a waiting list system which limits access and furthermore the program does not cover routine mammograms for women age 40-49. These combined factors create barriers to breast cancer screening. The Affiliate believes it is critical to ensure that all eligible women receive these lifesaving services.

The American Cancer Society estimates that 25,000 women in Nevada will continue to lack access to breast cancer screening in spite of the implementation of a state health exchange and expanded Medicaid coverage. According to the *Cancer in Nevada* report, screenings performed through WHC have been responsible for detecting an increasing number of *in situ* and invasive breast cancers. Approximately 4.0 percent of the new cases of breast cancer in Nevada are detected every year through the WHC program. The Bureau of Child, Family and Community Wellness, Nevada State Health Division, reports that for the fiscal years 2009 to 2011 only one in nine women who were eligible for the program were actually screened because of limited funding.

Not only is no in-state funding made available for this program but there is no provision for undocumented women who are screened as positive to receive treatment. The *Cancer in Nevada* report states “This is an important issue given that Nevada has the highest proportion of undocumented residents in the country (9.0 percent, approximately 230,000 population in 2008), and for undocumented women treatment may be very difficult to obtain in Nevada.” Susan G. Komen Northern Nevada will continue its efforts highlight the need for increased funding for the WHC program.

Oral Chemo Parity

Together with Komen Southern Nevada and organizations including Aim at Melanoma, American Cancer Society Cancer Action Network, Association of Community Cancer Centers, Leukemia & Lymphoma Society, Nevada Cancer Coalition, Nevada Oncology Society, Nevada Public Health Association, Nevada State Medical Association and the Oncology Nursing Society, Komen Northern Nevada supported SB266 which was signed into law in the 2013 Nevada legislative session and will take effect on January 1, 2015. SB266 provides for Oral Chemo Parity which will help eliminate insurance policies’ practice of charging grossly higher out-of-pocket costs for oral chemotherapy drugs than the equivalent IV chemotherapy drugs. The law limits the patient’s cost for orally administered anticancer treatments to \$100 per prescription. While the bill does not require insurers to pay for cancer treatment, it does make chemotherapy more accessible for cancer patients living in the rural/frontier counties of the state who experience geographical or economic barriers to receiving IV chemo treatment in a metropolitan area some distance away.

Other Public Policy Activities

Nevada is Covered in Pink Day

Wherever opportunities exist to advocate for better health care for women in Northern Nevada, including access to breast cancer screenings, affordable breast cancer treatment and discussion of ways to eliminate disparities and eradicate breast cancer as a life-threatening disease, the Affiliate will continue to play an active role. In 2011 and 2013, the Affiliate

partnered with Komen Southern Nevada to host a “Nevada is Covered in Pink” event at the Nevada Legislature and invited lawmakers to join a discussion about better care for better outcomes for Nevada’s women. The Komen Nevada Affiliates are proud to partner to ensure that breast health screening, treatment and education programs continue to be available to women throughout the state.

Breast Density Notification

The 2013 Nevada Legislative Session unanimously passed AB147 which requires the notification of patients regarding breast density. Specifically, for those women whose mammography screenings determine they have a degree of dense breast tissue, the mammography service provider must inform the patient with the following notification: “Because your mammogram demonstrates that you have dense breast tissue, which could hide small abnormalities, you might benefit from supplementary screening tests, depending on your individual risk factors. A report of your mammography results, which contains information about your breast density, has been sent to your physician’s office. You should contact your physician if you have any questions or concerns about this notice.”

Health Systems and Public Policy Analysis Findings

The greatest need for breast health support in the target communities continues to be women who are uninsured, despite the Affordable Care Act, and underinsured women who are unable to bear the financial burden of out-of-pocket expenses. Services are available, but the primary barrier to access continues to be financial. Poverty is the greatest barrier to accessing life-saving breast cancer education, screening, and treatment in Northern Nevada.

The Breast Cancer Collaborative, particularly in Northern Nevada, has developed into a strong group of breast health providers and organizations in the service area. Where the priority used to be funding screening because of limited funding from Women Health Connection, the hope is that ACA will reduce screening barriers and funding from non-governmental sources, such as Komen, can be shifted to treatment.

The Affiliate continues to monitor the changing landscape of federal funding and health care regulation and is concerned about Women’s Health Connection funding cuts. Continued federal funding of the program, as well as the hope that the state will recognize the critical need for additional state contribution, is the Affiliate’s highest public policy priority. The Affiliate will continue to work with its Breast Cancer Collaborative partners in advocating for state funding.

Additionally, the Affiliate and the Collaborative have identified women in hard-to-reach populations (including undocumented immigrants) as a particularly vulnerable population. Federal regulations exclude these members of the community from receiving many programs that provide life-saving breast health services.

Qualitative Data: Ensuring Community Input

As part of the Community Profile process, the Affiliate collected qualitative data to answer the following questions about breast cancer health care needs in the target communities of the service area.

1. What barriers prevent women from being screened for breast cancer?
2. What barriers prevent women from receiving diagnostic services after receiving an abnormal screening result?
3. What barriers prevent women from receiving treatment after a breast cancer diagnosis?

Qualitative Data Sources and Methodology Overview

Two surveys were used to collect information regarding the questions of barriers: 1) an online survey emailed to breast cancer survivors; and 2) a paper breast cancer screening survey distributed through the Nevada Health Centers' Mammovan during its visits to the target communities.

The Affiliate was also able to obtain the results of a focus group conducted by the Nevada Cancer Coalition during the summer of 2014 in Carson City and Minden. Participants were questioned about barriers to screening and the perceived efficacy of proposed interventions.

Additionally, a series of Northern Nevada Breast Cancer Collaborative meetings provided focus group data. The Collaborative is comprised of stake holders in the continuum of care: survivors, patient navigators, nurses, foundation administrators, physicians, support group facilitators, and representatives from Women's Health Connection.

Breast cancer survivor survey

The Breast Cancer Survivor Survey was distributed to women who identified themselves as breast cancer survivors through the Susan G. Komen Northern Nevada database, either as Race for the Cure registrants or database constituents. The survey included questions about barriers to screening, diagnosis and treatment services within the target communities (Washoe County and Carson City). The survey was conducted during the summer of 2014.

A frequency analysis (a breakdown of how survey participants answered questions) was conducted on each of the 17 questions investigating the two or three most common or frequent themes that occurred among each question asked. There were 71 total responses, with 67 respondents completing the entire survey. Unanswered questions were taken into consideration in the analysis.

A frequency analysis was conducted on common or repeating themes that occurred within the respondents' typed answers. Data were collected and analyzed by a Master of Public Health graduate student during a summer internship program under the supervision of her graduate advisor.

Breast cancer screening survey

The Breast Cancer Screening Survey collected beliefs and ideas about barriers to breast cancer screening mammography. Patients who presented at the Mammovan for breast screening were asked by the medical staff to complete a survey. A \$5.00 Walmart gift card was given to each person who completed the survey. The survey was conducted during the summer of 2014.

A frequency analysis was conducted on common or repeating themes that occurred within each of the respondent's written answers. The answers from each of the surveys were entered into an Excel spreadsheet for analysis. The analysis used the number of reoccurring themes in each question as the denominator, and used the classification of "Other" or "None" to account for the remaining responses where coded themes were not identified when needed. The themes are identified when respondents use the same words or idea that conveys the same meaning in their answers. Some themes can be fairly broad in nature, but are addressing the same basic idea. Data were collected and analyzed by a Master of Public Health graduate student during a summer internship program under the supervision of her graduate advisor.

Focus group on screening barriers

The Nevada Cancer Coalition conducted a focus group meeting comprised of women recruited from health clinics, hospitals, community centers and senior centers in Carson City.

Participants were a less biased sample because they were not recruited while receiving a screening mammogram nor were they identified as breast cancer survivors. In this way, the sample was more representative of the general population. The majority of participants had a low annual income that qualified them as part of the Affiliate's target population within Carson City. Data were collected and analyzed by a Master of Public Health graduate student during a summer internship program under the supervision of her graduate advisor during the summer of 2013. Focus group transcripts were coded for common themes and analyzed for theme occurrence.

Northern Nevada Breast Cancer Collaborative document review of meeting minutes

The Nevada Comprehensive Cancer Control Program produced *The State of Nevada Comprehensive Cancer Plan 2011-15* with the Nevada Cancer Coalition through funding from the Centers for Disease Control and Prevention. The Nevada State Health Division created the Nevada Cancer Coalition to develop and support strategies to meet the goals expressed in the Cancer Control Plan through the work of government and non-government members of the health care community. Nevada Cancer Coalition (NCC) initiated a series of roundtable meetings in July of 2013 to discuss the state of breast cancer in Nevada and strategies the community could use to achieve goals set in the Plan. The attendees of the roundtable included representatives from the major health care providers and stakeholders in Reno/Sparks, Carson City and Las Vegas. The group was split into Northern Nevada and Southern Nevada working groups. The northern working group has continued to meet in an effort to identify strategies for reducing the burden of breast cancer in Northern Nevada. Collaborative meeting data used as part of the qualitative data collection are from meetings that occurred from October 2013 through November 2014. The analysis of meeting minutes are derived from selected data that addresses the following questions: what are the primary barriers to screening, diagnostic services and treatment; and what community breast cancers needs have the greatest impact on breast cancer outcomes?

Qualitative Data Overview

With the exception of the focus group held in Carson City, the qualitative data collected is not segregated by target community. The Breast Cancer Collaborative included representatives from both Washoe County and Carson City. Survivor survey data were not segregated, nor was data collected from the Mammovan.

Breast cancer survivor survey

The results of the frequency analysis demonstrated that of the 71 women who responded, almost all the women (96.0 percent) had knowledge of the recommendation for annual clinical breast exams and a large percentage (83.0 percent) of the women followed those recommendations. The same percentage of women (96.0 percent) had knowledge of the recommendation for annual mammograms, but a smaller percentage of women (72.0 percent) followed the recommendations and had an annual mammogram prior to diagnosis. Additionally, 44.0 percent of the women who responded reported that they visited the doctor after feeling a lump themselves. This is in contrast to the 33.0 percent of women who reported it was discovered on a mammogram.

When asked about identifying obstacles to access to health care during the respondents' experiences with diagnosis and treatment, more than 80.0 percent of respondents answered "none." Obstacles that were identified were in the areas of cost, health insurance coverage or lack of coverage, no insurance, and provider complaints around lack of knowledge of resources or lack of compassion. In addition, 28.0 percent of women who responded needed financial assistance. Areas of financial need that occurred most frequently were living expenses and insurance co-pays. Out of the women who responded, 38.0 percent cited provider support as the most useful and empowering service they received during their breast cancer experience. The next areas of empowering support identified were family support (29.0 percent) and group therapy (17.0 percent).

After their experience with breast cancer, the percentage of respondents who have annual mammograms remained at 72.0 percent, and the percentage of women who have annual clinical breast exams remained at 83.0 percent. Cost and health insurance were identified most frequently as obstacles to needed services. The number of respondents who have health insurance currently is 94.0 percent.

There were 592 surveys sent via email with a Survey Monkey link, and 71 recipients (12.0 percent) completed the survey. All respondents were female, and all except one identified herself as White. The average age of the women at the time they responded to the survey was 58 with an age range of 34-86. The average age at diagnosis of the respondents was 50 with an age range of 32-77.

Breast cancer screening survey

Barriers to seeking mammography services included: cost (20.0 percent), difficulty traveling to services (16.0 percent), and lack of insurance (13.5 percent). When asked what could be done to improve access to breast cancer screening services, responses included: increasing detection and prevention education (23.0 percent) and maintaining the Mammovan services (35.0 percent). Thirteen percent (13.0 percent) of respondents indicated that advertising Mammovan schedules and increasing awareness about the Mammovan and screening services

was important. Forty percent (40.0 percent) of respondents stated that the Mammovan makes it easier for women to access mammography screening.

Focus group on screening barriers

The following themes were identified as the dominant reasons women choose not to get screened for breast cancer: fear (15.9 percent), lack of education about breast cancer screening (15.9 percent), lack of insurance or the cost of insurance (10.3 percent), and lack of transportation to screening center (16.8 percent). The overwhelmingly dominant selected intervention strategy that participants felt was most effective was reminder post cards (53.4 percent). Participants indicated that once educated about the importance of breast cancer screening, women would be more likely to follow through with screening if and when they were able to successfully schedule appointments, especially if cost and transportation burdens were reduced.

Northern Nevada Breast Cancer Collaborative document review of meeting minutes

Collaborative meetings were consistently attended by 15-20 members, most of whom represented health care providers in the region from both Reno/Sparks and Carson City. The Collaborative mapped the breast cancer continuum of care in Nevada and identified barriers to screening, diagnosis and treatment. The two dominant concerns were the need for patient navigation and financial assistance at all steps in the continuum. The Collaborative also identified health system weaknesses that need legislative action to rectify: the modernization of the Nevada Cancer Registry and the lack of state funding for the Women's Health Connection. Patient navigator services were identified as a high priority; the lack of a centralized health security net exacerbates the need for navigation services. Additionally, the collaborative recognizes that undocumented residents remain a population who are largely ineligible for financial assistance except from a limited number of private foundations.

Qualitative Data Findings

Qualitative Data Limitations

Breast cancer survivor survey limitations

The results of the survivor survey present a number of challenges in extracting meaningful data about the target communities. Ninety percent of respondents reported no challenges with insurance coverage at the time of their diagnosis and treatment with breast cancer. These data indicate that the respondents are not representative of the target population: uninsured, underinsured and the poor. Additionally, only one percent identified themselves as Hispanic, an underrepresentation of the population in Northern Nevada.

The survey had a low response rate of only 12.0 percent. However, it should be noted that this survey was not incentivized which could have helped raise the response rate. In addition, this was a convenience sample and not generalizable to overall population. The email database that was used to send out the survey was a database that contained email contacts for constituents or prior Susan G. Komen Race for the Cure participants. It is unknown if all contacts were able to respond to the survey or living at the time of the survey.

It should be noted that respondents were not representative of the target population, though they did identify the same barriers revealed by other qualitative data collection methods.

Breast cancer screening survey limitations

The sample includes only respondents who have successfully gained access to screening services on the Mammovan. The sample does not include individuals who have not overcome all barriers to screening.

Focus group on screening barriers limitations

The sample size of the focus group was 32, and recruiting venues were limited. However, the sample of participants was more inclusive than the two previously described surveys. Additional themes were identified therein, education and transportation.

Additional attempts to collect qualitative data were unsuccessful. Patient focus group events were scheduled both in Reno at the Community Health Alliance (Wells Avenue facility) and in Carson City at the Nevada Health Centers (Sierra Nevada Health Center, Research Way location). Both English and Spanish sessions were scheduled at both locations and included incentives. The Affiliate received no responses for any of the sessions, and therefore all sessions were cancelled.

A provider focus group session was scheduled to take place in Reno. It was cancelled as it became clear that the invitation list substantially coincided with Northern Nevada Breast Cancer Collaborative, and a separate event would be redundant and a duplication of that group's ongoing meetings. Documentation of the collaborative's work was provided by Nevada Cancer Coalition for inclusion in this report.

Northern Nevada Breast Cancer Collaborative document review of meeting minutes

The Collaborative met five times during 2013-14. Not all members were present at each meeting which potentially could have resulted in a single individual's thoughts not being represented on all topics the group discussed. However, each organization was normally represented at each meeting.

Conclusions

The following conclusions were made by the Affiliate as a result of the qualitative data collection and analysis.

1. What barriers prevent women from being screened for breast cancer?

- The cost of mammography is the primary barrier to breast cancer screening.
- A large percentage of the population recognizes need for regular breast cancer screening.
- Screening percentages could likely improve by culturally sensitive education and outreach to patients about the need for screening.
- Screening percentages could likely improve as primary care providers are educated about financial assistance programs available to patients.
- Some women without financial resources to pay for diagnosis and treatment choose not to be screened, even when assistance programs will pay for screening.
- Many women in Northern Nevada are geographically isolated from mammography services.

- Some of these women are able to access mammography approximately once a year when the Mammovan visits their area.
- Written and mailed reminders are an effective method to prompt regular screening.
- Undocumented immigrants are not eligible for many breast cancer screening financial assistance programs.
- Women between 40 and 49 cannot get screening mammograms through Women's Health Connection (WHC) funding unless they are symptomatic.
- Women's Health Connection primarily serves southern residents (80.0 percent to Clark County, 12.0 percent to Washoe County, 8.0 percent to remaining counties).

2. What barriers prevent women from receiving diagnostic services after receiving an abnormal screening result?

- If a screening mammogram that is not paid for by Women's Health Connection or Nevada Medicaid results in an abnormal finding, the patient faces barriers to enrolling in WHC or Nevada Medicaid, even if she is eligible for those assistance programs.
- If a woman is eligible for WHC or Nevada Medicaid, the best outcomes (fastest treatment) occur when the abnormal screening results and breast cancer diagnosis are paid for by those assistance programs.
- Fewer assistance programs exist to for diagnostic services than screening services, especially when abnormal mammography results are acquired outside of Women's Health Connection or Nevada Medicaid programs.
- Complex diagnostic procedures are more expensive than standard diagnostic procedures, and fewer providers are available to perform those procedures.

3. What barriers prevent women from receiving treatment after a breast cancer diagnosis?

- Unless a woman is eligible for Nevada Medicaid, almost no assistance programs are available to fund breast cancer treatment.
- Financial assistance is available to qualified women to help pay for treatment support (e.g. transportation costs, mortgage payment, copay/coinsurance obligations, groceries) through local cancer foundations.
- Some treatment support assistance programs limit eligibility to US citizens and immigrants with legal residence status who live in Northern Nevada.

Qualitative data reported herein identify the same primary concerns as the quantitative data report regarding breast cancer in the target communities. The populations at greatest risk of facing barriers to breast cancer screening, diagnosis and treatment are women with low-incomes and who lack adequate health insurance. A lack of education about breast cancer risk factors and the importance of regular screening reduces the likelihood that the target population will get screened. Additionally, even within the urban and suburban target communities, transportation remains a barrier to breast health services.

Mission Action Plan

Breast Health and Breast Cancer Findings of the Target Communities

Komen Northern Nevada's primary goal is to reduce late-stage breast cancer diagnoses and breast cancer deaths in its service area. The Affiliate's highest priority is to achieve this goal by providing breast health resources to individuals who would otherwise not have access to them. The Affiliate has identified uninsured and underinsured individuals receiving breast health services in the Reno/Sparks metropolitan area and in Carson City as target communities. Both communities have a high-priority designation for receiving interventions.

The health system and public policy analysis indicates that though the Affordable Care Act has increased the number of individuals who are covered by health insurance in Nevada, individuals with limited incomes continue to face financial barriers to basic breast health services whether they are covered by health insurance or not. Existing assistance programs present a labyrinth of eligibility hurdles for an individual.

As the health system analysis reveals Komen Northern Nevada aims to be the safety net of last resort to ensure that the most vulnerable among in the local community have somewhere to turn when they don't meet prescribed eligibility requirements of other public and private assistance programs.

Furthermore, qualitative analysis indicates that particularly among vulnerable communities, having health insurance is not enough. Breast health education plays a critical role in the continuum of care. A woman must know *what* health services are beneficial to access as well as *how* to access them.

In addition, the Affiliate recognizes that the health systems in its target communities do not offer services that target the special needs of individuals with metastatic breast cancer. The Affiliate aims to explore opportunities and partnerships to develop resources for the metastatic community.

Mission Action Plan

The Affiliate has created the following action plan to guide its operations during the planning period (2015-19).

Need Statement: Washoe County and Carson City have higher than average late-stage breast cancer diagnosis rates.

Priority 1: In order to reduce the number of late-stage diagnoses in Reno/Sparks Metropolitan Area (Washoe County) and Carson City, programs that provide access to screening and diagnostic services will be a funding priority.

Objectives

- Beginning with the FY2016 Community Grant Request for Application, a funding priority will be programs that provide screening and diagnostic

services to uninsured individuals in Reno/Sparks Metropolitan Area (Washoe County) and Carson City.

- Beginning with the FY2017 Community Grant Request for Application, a funding priority will be programs that provide funding for diagnostic services for underinsured individuals in Reno/Sparks Metropolitan Area (Washoe County) and Carson City.

Need Statement: Washoe County and Carson City have breast cancer screening rates below the Healthy People 2020 target levels (81 percent).

Priority 2: Increase number of insured women in target communities who use their breast cancer screening benefits and the number of uninsured women who access free breast cancer screening services.

Objectives

- Beginning in FY16, support health literacy campaigns that aim to increase use of breast cancer screening benefits by newly insured residents of target communities through Affiliate's community breast health education activities and in collaboration with grantees.
- Beginning in FY16, improve awareness of the availability of free breast cancer screening programs for uninsured individuals in target communities through Affiliate's community breast health education activities and in collaboration with grantees.
- Beginning in FY17, develop partnerships with at least one new community organization annually in each target community to increase the distribution of Komen's breast self-awareness messages.

Need Statement: Washoe County and Carson City have a high percentage of low-income, uninsured residents who are unable to afford breast cancer treatment.

Priority 3: Reduce the burden of a breast cancer treatment for individuals seeking treatment in Reno/Sparks Metropolitan Area and Carson City.

Objectives

- Beginning with the FY2016 Community Grant Request for Application, a funding priority will be programs that provide financial assistance to breast cancer survivors from Washoe County and Carson City during breast cancer treatment.

Need Statement: The target communities provide limited services specifically addressing the needs of individuals with metastatic breast cancer.

Priority 4: Explore opportunities to collaborate with community partners to develop or support resources that specifically address the needs to individuals with metastatic breast cancer.

Objectives

- Beginning in FY2016, develop a better understanding of the specific needs faced by the metastatic breast cancer community and identify one or more services that it would be desirable to develop in the community.
- Beginning with the FY2017 Community Grant Request for Application, include a call for applications that propose pilot programs to address the specific needs of the metastatic breast cancer community.

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