CONFRONTING THE CHALLENGE

PROTECTING THE FUTURE

THE NEBRASKA BREAST CANCER CONTROL PLAN

2011 – 2016

This plan is dedicated to Nebraska's breast cancer patients, caregivers and survivors.

Survivors and caregivers on the *Journey of Self-Healing and Inner Strength* release pink balloons in Kearney October 14, 2010.

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Every Woman Matters

Nebraska Office of Women's Health

Susan G. Komen for the Cure® Nebraska

Nebraska NECCCP Comprehensive Cancer Control Program

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Acknowledgements

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Introduction

Purpose of the Plan

The leadership for this planning process sought to provide a forum for major stakeholders to work in partnership to establish a common vision and mission. Their goal was to create a process and plan that would:

- decrease duplication of efforts
- utilize and build on strengths
- lead to pooled resources
- streamline processes and increase efficiencies
- identify gaps and needs
- improve the quality of services

Planning Process

The collaborating partners: the Nebraska Department of Health and Human Services (DHHS) *Every Woman Matters* Program, Nebraska Affiliate of Susan G. Komen for the Cure, the American Cancer Society, Nebraska Region, and the Nebraska Comprehensive Cancer Control Program, DHHS, provided contact names and email addresses for stakeholders they believed should be invited to join the planning process, or contacted those stakeholders directly.

An online participant invitation and survey was sent to over 170 individuals, asking if they would like to participate in a needs assessment survey, attend in-person planning sessions, and/or provide feedback on drafts of the plan as it was developed. Eighty-four individuals chose to participate in the process.

Along with representatives from the four collaborating partner organizations, responding participants represented county health departments, hospitals, health centers, collaborating businesses and service organizations, the University of Nebraska Medical Center (UNMC) and Creighton University, medical clinics and practitioners, breast cancer survivors, and the Nebraska Office of Health Disparities and Health Equity in the Nebraska Department of Health and Human Services.

Seventy people expressed interest in completing the needs assessment and were sent an online provider survey or invited to participate in a telephone interview by Enquire Research. The survey asked about Education, Screening, Follow-up after an abnormal screening, Treatment and Support. Participants chose which portions of the survey to answer based upon their expertise and interests. Fifty-two service providers completed the survey which is included in the Appendices.

Results of the survey are detailed in the Challenges and Issues section of this report. Enquire Research also conducted secondary research to compile statistics related to Nebraska breast cancer incidence and mortality, staging, mammography rates, access to care, and screening disparities.

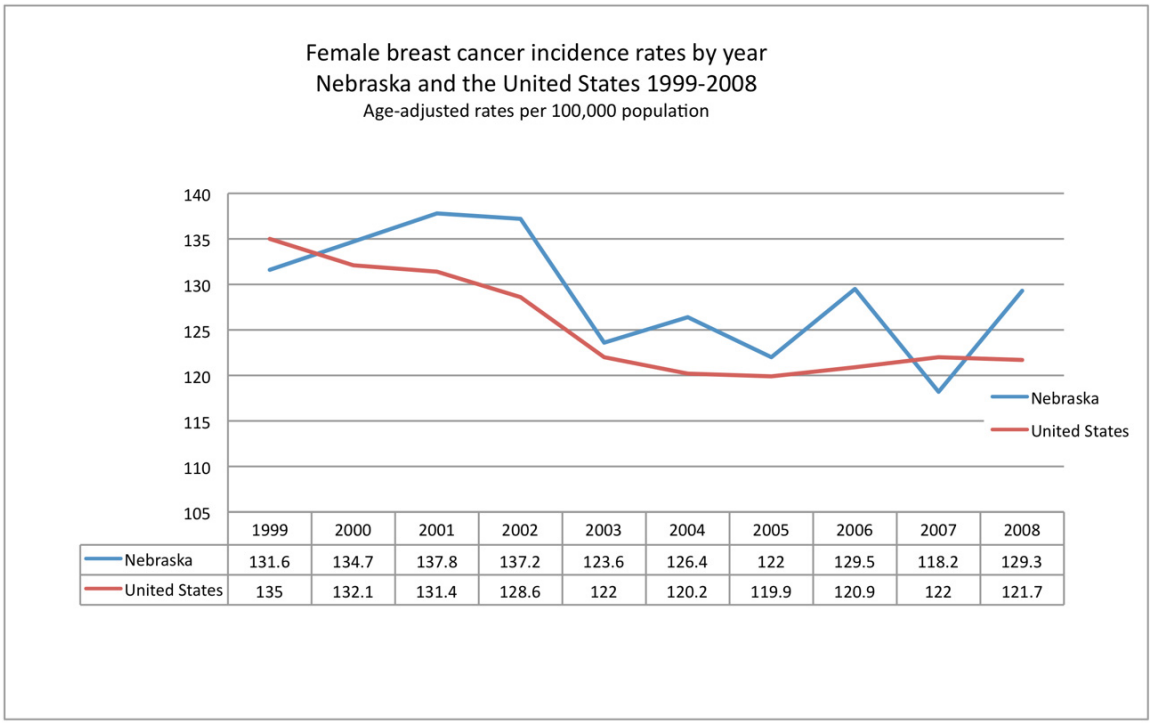
A planning task force met three times between August and October, 2010 to craft the plan. Day-long meetings were held August 20th and September 23rd and a half-day meeting was held on October 26th. Individuals who were not able to attend task force meetings provided feedback via email as drafts of the plan were developed and sent out for review.

Additionally, a draft of the plan was presented at a town hall meeting held in North Platte on October 14, 2010 that brought survivors and caregivers together as part of the state's annual cancer conference. Their feedback was incorporated into the plan at the final meeting of the planning task force. Additional survivor comments from the town hall meeting are included in the Appendices.

Breast Cancer in Nebraska

Incidence and Mortality

In 2008, statistics show that 129.3 women in Nebraska out of every 100,000 were diagnosed with invasive (malignant) breast cancer. The incidence rate for breast cancer in Nebraska was slightly greater in 2008 than for the US as a whole. Looking at the trend since 1999, the incidence has declined in both Nebraska and the US. Nebraska's incidence over time has tracked closely with national trends.

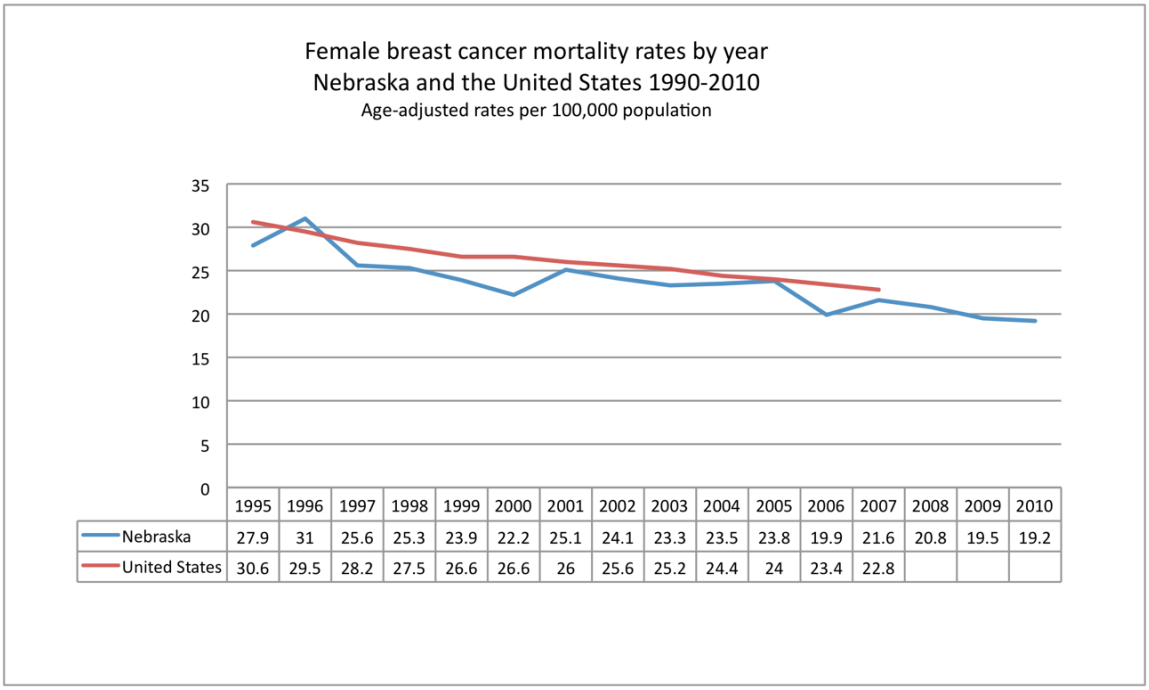


	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
Nebraska	131.6	134.7	137.8	137.2	123.6	126.4	122	129.5	118.2	129.3
United States	135	132.1	131.4	128.6	122	120.2	119.9	120.9	122	121.7

Source: Nebraska Cancer Registry and National Program of Cancer Registries (CDC)

In 2008, 46% of new breast cancer cases in Nebraska were women age 65 and older; 35% were women age 50-64; and 14% were women age 40-49. Women under age 40 comprised 5% of all new cases.

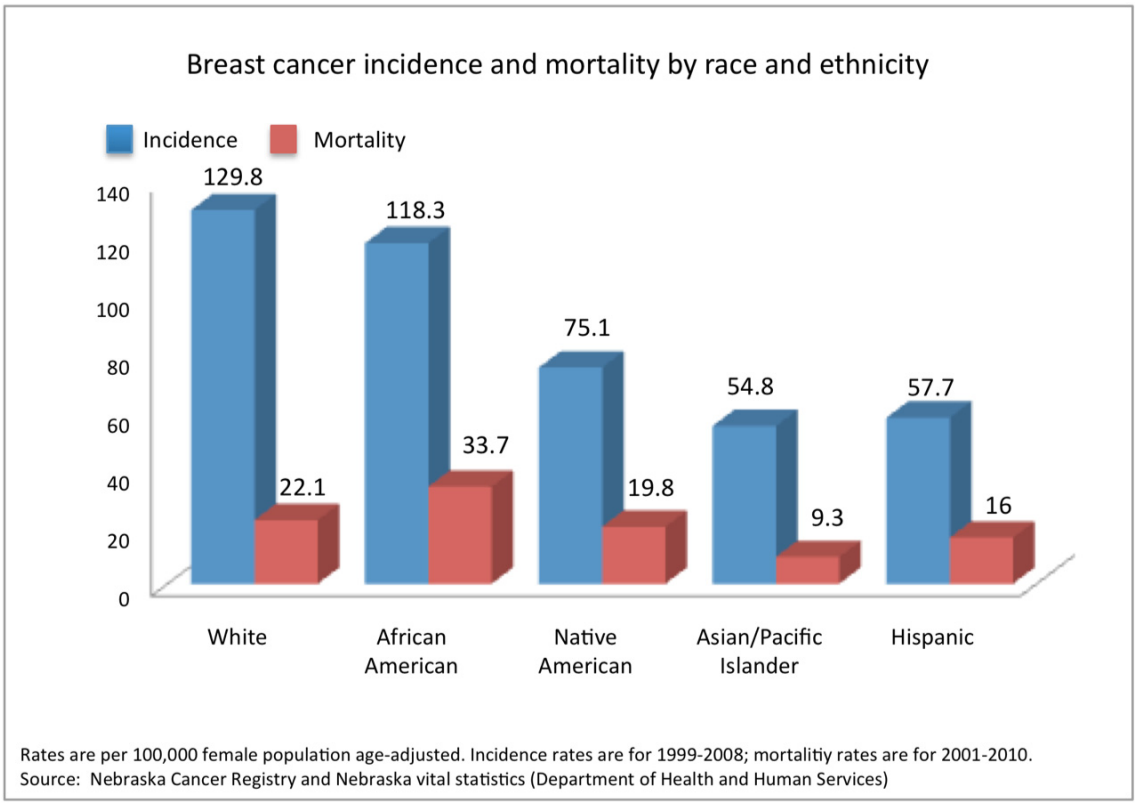
The breast cancer mortality rate is lower in Nebraska compared to the US. Nationally, mortality has declined steadily from 30.6 deaths per 100,000 women in 1995 to 22.8 deaths per 100,000 in 2007. Mortality rates for Nebraska have also declined from 27.9 in 1995 to 19.2 in 2010.



	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Nebraska	27.9	31	25.6	25.3	23.9	22.2	25.1	24.1	23.3	23.5	23.8	19.9	21.6	20.8	19.5	19.2
United States	30.6	29.5	28.2	27.5	26.6	26.6	26	25.6	25.2	24.4	24	23.4	22.8			

Source: Nebraska Cancer Registry and National Program of Cancer Registries (CDC)

Whites have the highest incidence rate for breast cancer, but African Americans bear the highest burden with a mortality rate of 33.7. Nationally, we see the same patterns in incidence and mortality.

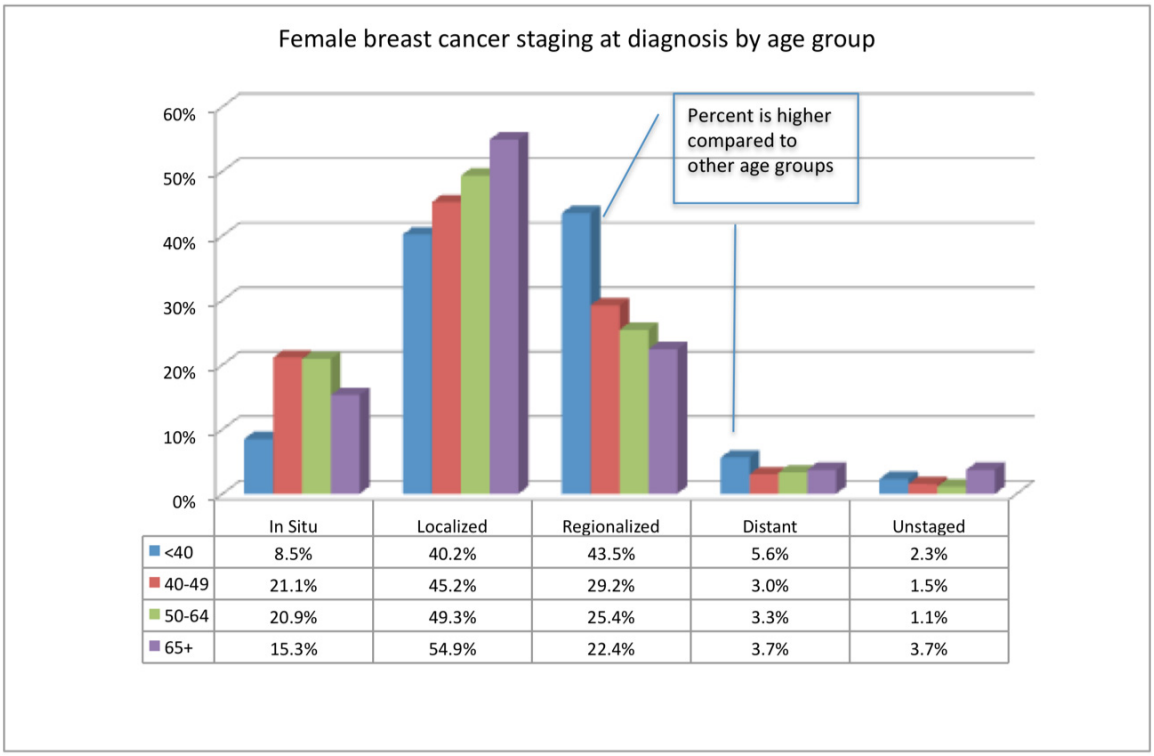


Looking at the data in five-year intervals, the mortality rate for white women declined from 23.8 in 2001-2005 to 20.2 in 2006-2010 (significant at the 95% confidence level). The mortality rate for African-American women declined from 38.8 to 28.4 in the same time period. This drop is not statistically significant given the small number of breast cancer deaths among African American women (51 in 2001-2005 and 41 in 2006-2010). However, the decline is encouraging and rates over the next few years should be monitored closely to see if this trend continues.

The number of Hispanic women and women of other races is too small to glean any meaningful information over a five year time period.

Staging

The Nebraska Cancer Registry tracks the stage at diagnosis. Women under age 40 are more likely to have regional or distant malignancies at diagnosis compared to women in other age groups. Population sizes for staging breakdown by race and ethnicity are too small to report.

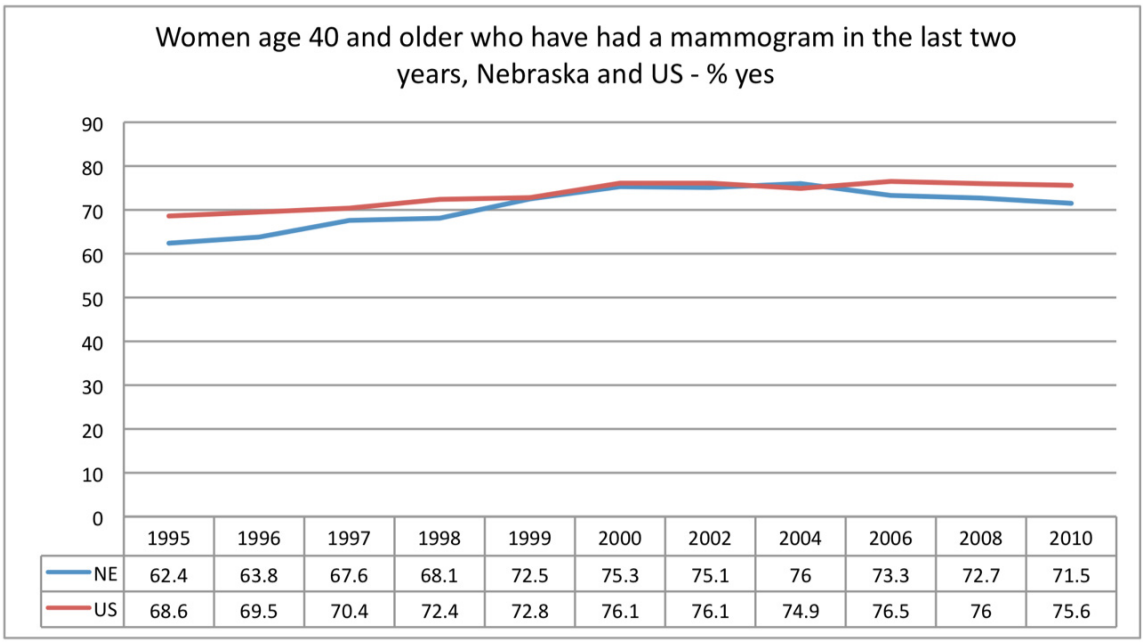


	In Situ	Localized	Regionalized	Distant	Unstaged
<40	8.5%	40.2%	43.5%	5.6%	2.3%
40-49	21.1%	45.2%	29.2%	3.0%	1.5%
50-64	20.9%	49.3%	25.4%	3.3%	1.1%
65+	15.3%	54.9%	22.4%	3.7%	3.7%

Source: Nebraska Cancer Registry, includes cases diagnosed during 2004 – 2008

Mammography Rates

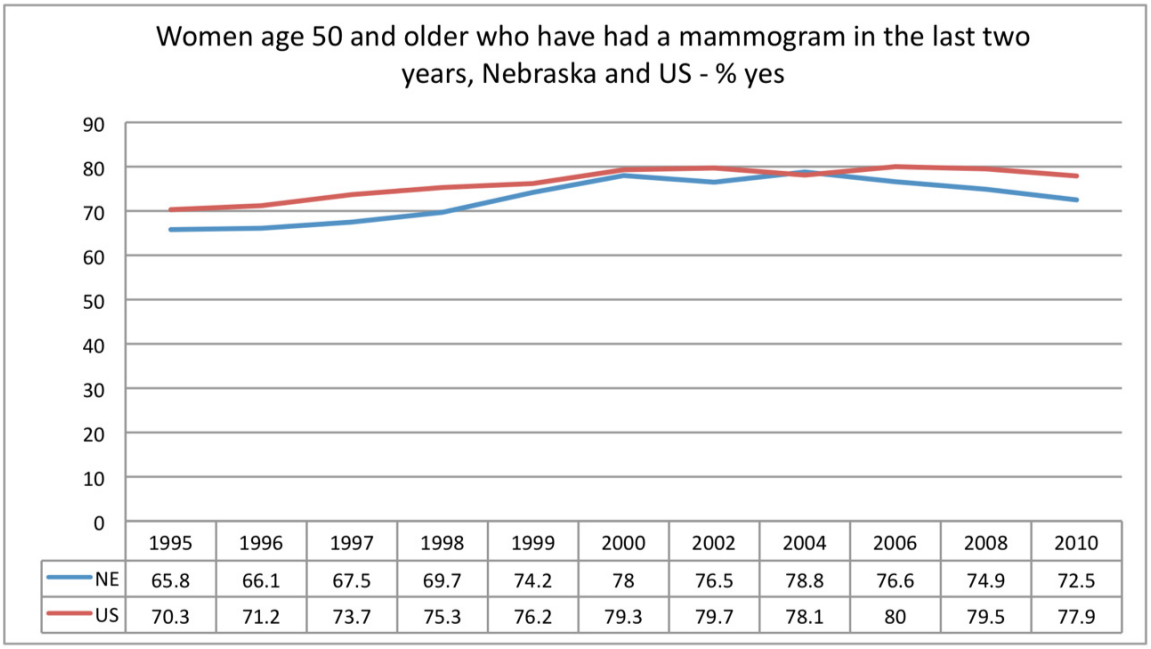
The percentage of Nebraska women age 40 and older reporting a mammogram in the last 2 years grew from 62.4% in 1995 to 71.5% in 2010. The highest point was in 2004, when 76% reported having a mammogram. The screening rate in Nebraska in 2010 is below the national rate.



	1995	1996	1997	1998	1999	2000	2002	2004	2006	2008	2010
NE	62.4	63.8	67.6	68.1	72.5	75.3	75.1	76	73.3	72.7	71.5
US	68.6	69.5	70.4	72.4	72.8	76.1	76.1	74.9	76.5	76	75.6

Source: Behavioral Risk Factor Surveillance System (CDC)

The percentage of Nebraska women age 50 and older reporting a mammogram in the last 2 years grew from 65.8% in 1995 to 78.8% in 2004. It has dropped to 72.5% in 2010. Fewer women age 50 and over are being screened in Nebraska compared to the national rate.



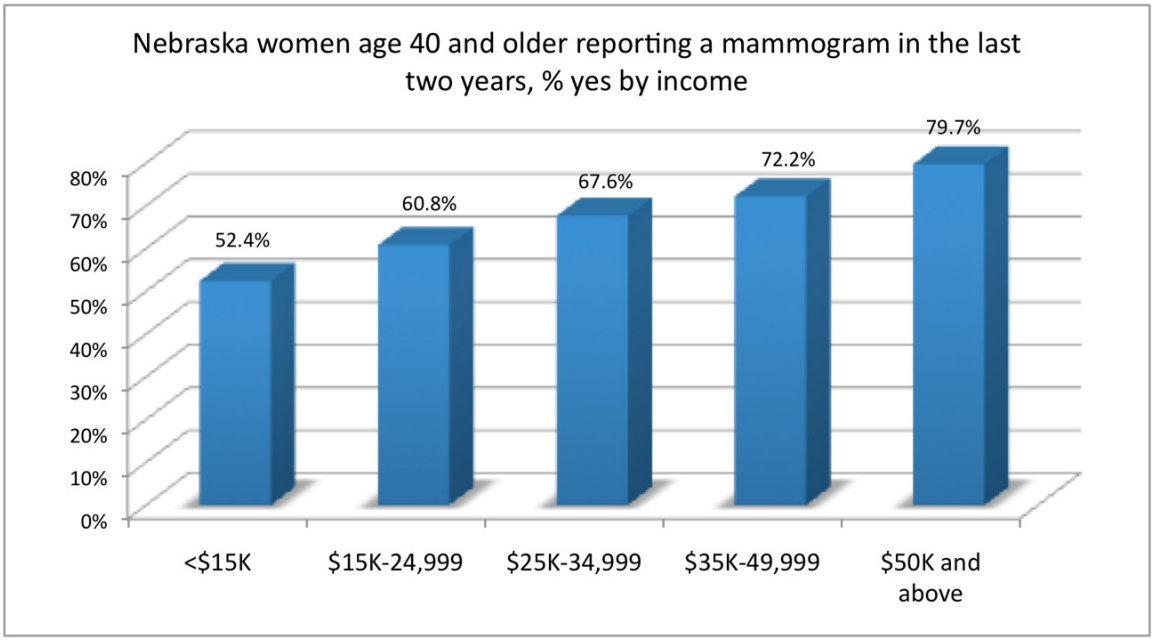
	1995	1996	1997	1998	1999	2000	2002	2004	2006	2008	2010
NE	65.8	66.1	67.5	69.7	74.2	78	76.5	78.8	76.6	74.9	72.5
US	70.3	71.2	73.7	75.3	76.2	79.3	79.7	78.1	80	79.5	77.9

Source: Behavioral Risk Factor Surveillance System (CDC)

Screening Disparities

Income

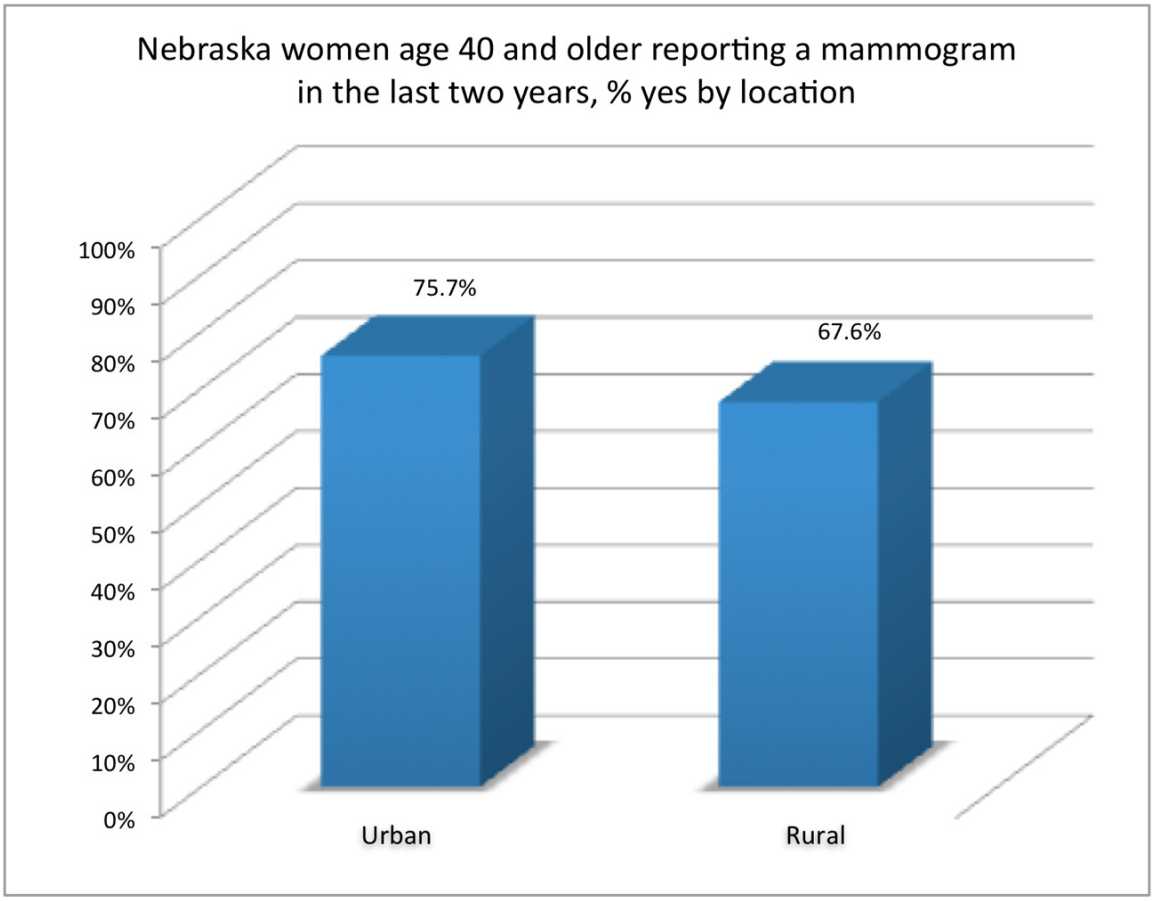
The higher a woman's income, the more likely she is to report having a mammogram in the last 2 years. Nearly eighty percent of women with incomes of $35,000 and over report a recent screening according to the annual Behavioral Risk Factor Surveillance Survey, which includes questions about mammography in even number years. Just over 60% of women with incomes under $35,000 report being screened (aggregated category not shown).



Source: Behavioral Risk Factor Surveillance System (CDC)

Rural vs. Urban

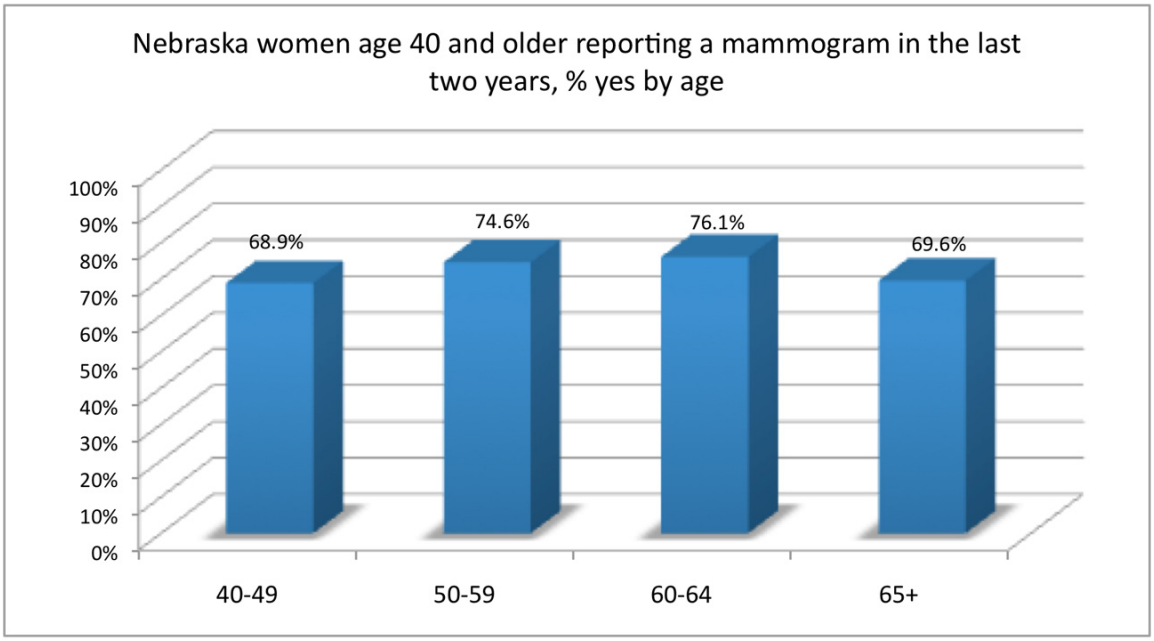
Women who live in the rural areas of the state are less likely to report having a mammogram than those who live in urban counties. In 2010, 76% of urban women over 40 reported having a mammogram compared to 68% of rural women. Nebraska's urban counties are defined as Cass, Douglas, Lancaster, and Sarpy counties. All other counties are considered rural.



Source: *Behavioral Risk Factor Surveillance System (CDC)*

Age

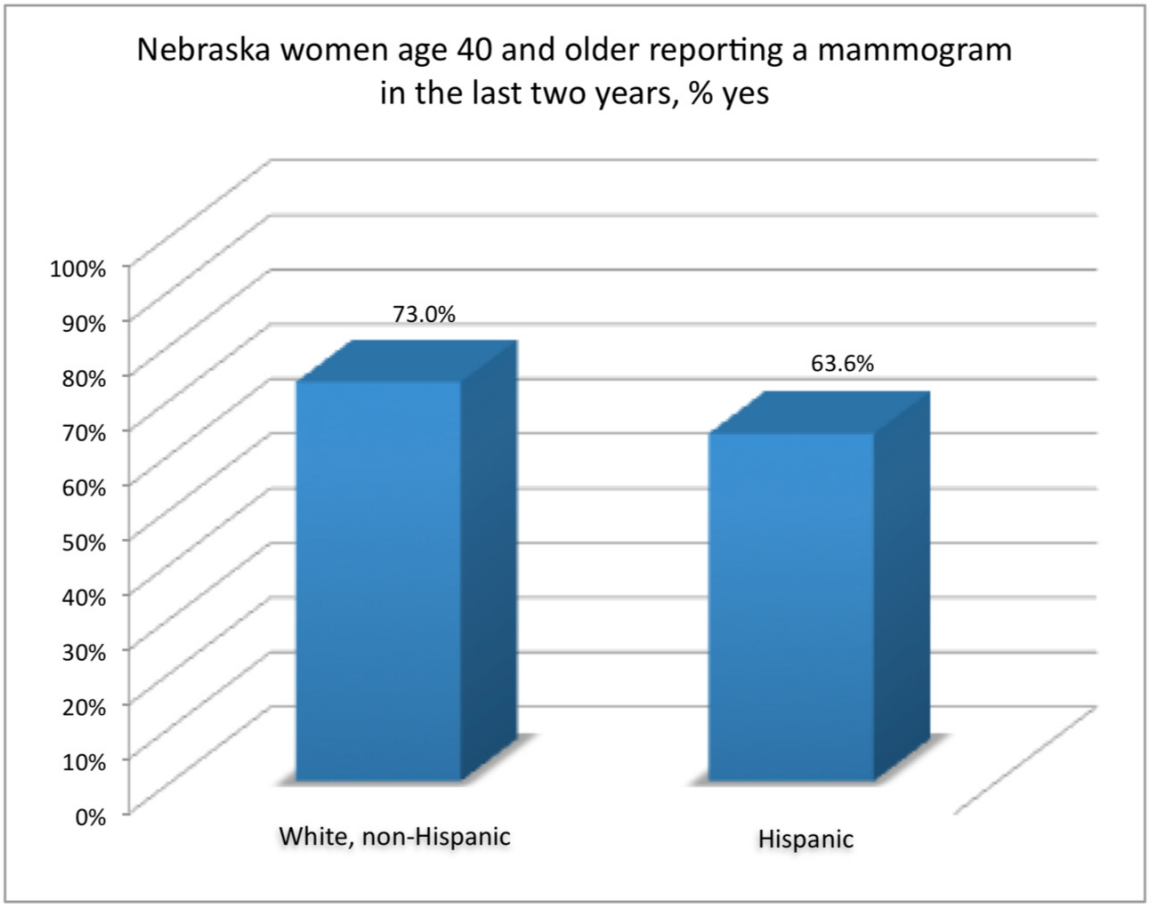
Fewer women age 40-49 reported being screened in the last 2 years compared to women age 50 and older. Women age 65 and older are less likely to be screened compared to women age 60-64, despite the fact that Medicare pays 80% of the cost of screening.



Source: Behavioral Risk Factor Surveillance System (CDC)

Race and Ethnicity

There are also ethnic disparities in mammography screening. The Behavioral Risk Factor Surveillance System reports screening rates every 2 years and the percentage of non-white respondents is small, reflecting the state's small minority population. By combining several years of data (2006-2010) disparities between Hispanic and white, non-Hispanic women are evident. Almost three-fourths of white women age 40 and older report having a mammogram in the last 2 years compared to less than 2/3 of Hispanic women. The number of African American, Asian, and Native American women in the survey sample is too small to make meaningful statistical comparisons even if data from multiple years are combined.



Source: Behavioral Risk Factor Surveillance System (CDC)

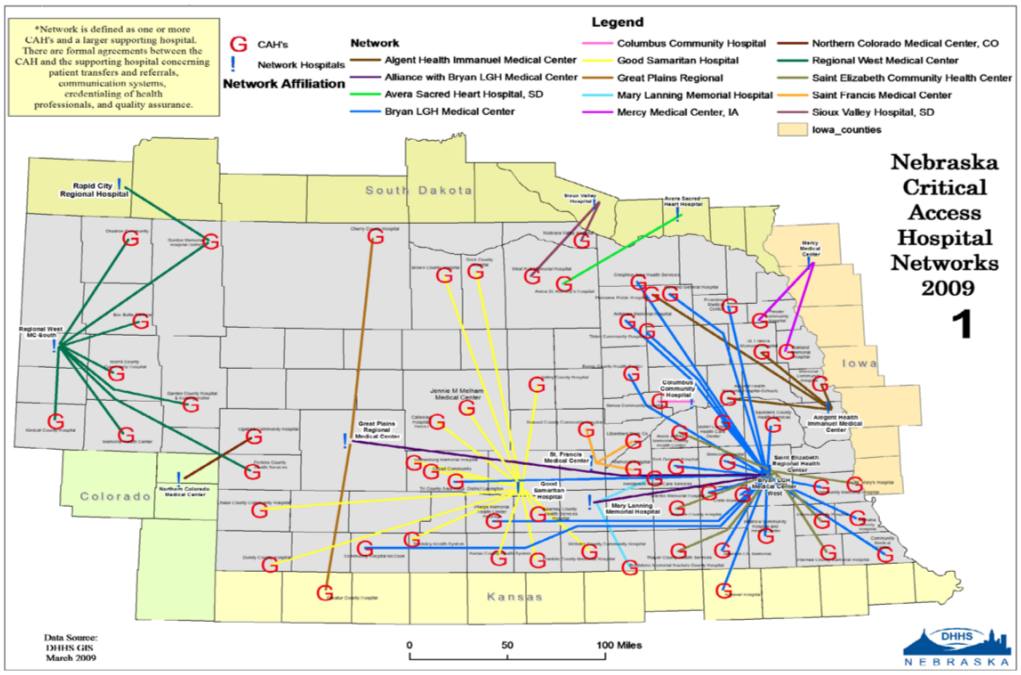
Access to Care

Uninsured and underinsured women have less access to health care than women with adequate health insurance coverage.

- Approximately 15.7% of Nebraska women age 18-64 do not have health insurance.
- Uninsured rates are higher among minority population groups.
- 49% of Hispanics do not have health insurance compared to 13% of non-Hispanic white women.
- Differences in health insurance coverage rates for some ethnic/racial groups in Nebraska are larger than national rates for the same groups.

Source: Behavioral Risk Factor Surveillance Survey (CDC)

Nebraska is served by 65 critical access hospitals (CAH) that are part of 14 networks connected to larger health systems in metropolitan areas. Almost three quarters of the 51 CAH responding to a 2006 survey conducted by the Nebraska Office of Rural Health offer mammography screening.



Population Trends

It is important to consider demographic trends in Nebraska when planning for future needs. Between 2000 and 2010 in Nebraska:

- The percentage of population that is white and not Hispanic decreased from 87.3% to 82.1% of total population.
- The Hispanic population increased from 5.5% to 9.2%.
- All other minorities (non-Hispanic) increased from 7.1% to 8.7%.

These trends indicate an increasing need for communications and services that are culturally appropriate in order to reach a growing population of women who are less likely to have access to care.

Source: US Census Bureau (www.census.gov)

Every Woman Matters Program

The Nebraska Every Woman Matters (EWM) Program is part of the National Breast and Cervical Cancer Detection Program. Women between the ages of 40 and 64 are eligible for screening services if they are uninsured or underinsured with an income at or below 225% of poverty guidelines. Medicare pays for screening for women age 65 and older. Women age 18 to 39 are eligible for diagnostic services if they meet the income qualifications.

Women needing further treatment are referred to Medicaid if they meet the eligibility requirements. The EWM Foundation provides up to $2000 for treatment costs.

The EWM program also includes screening for cervical cancer and the WISEWOMAN Program (Well -integrated Screening and Evaluation for Women Across the Nation), which includes wellness checks for diabetes and heart disease risk factors.

EWM screened almost 14,000 women in 2007 and 2008. 800 clinical sites participate in the program, including an estimated 95% of primary care providers.

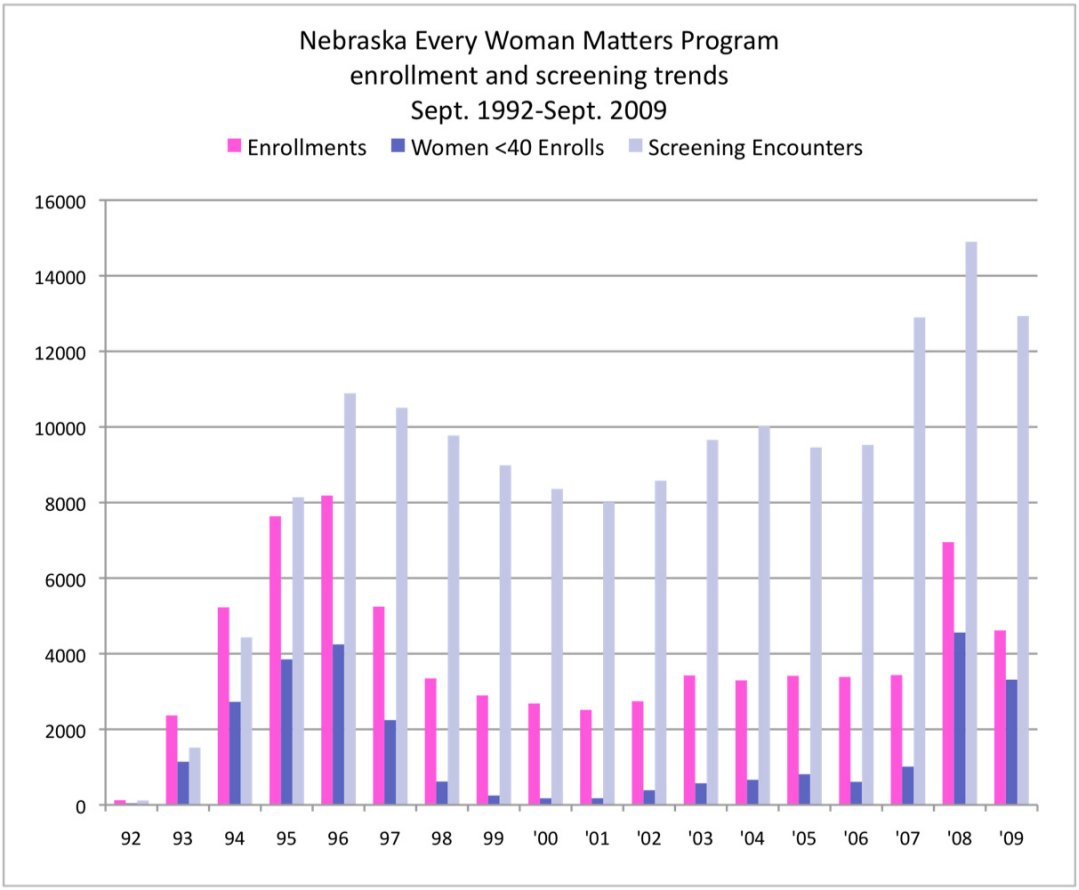
A snapshot of women in the EWM program in 2009 shows that:

- 95% have family incomes that are less than 200% of the federal poverty level.
- 77% have no insurance coverage (22% unknown).
- 41% report a high school diploma as the highest level of education completed.
- 19% did not finish high school.

In contrast, according to the 2008 American Community Survey (US Census), a high school diploma or equivalency is the highest level of education for 26% of Nebraskans and 8% did not finish high school.

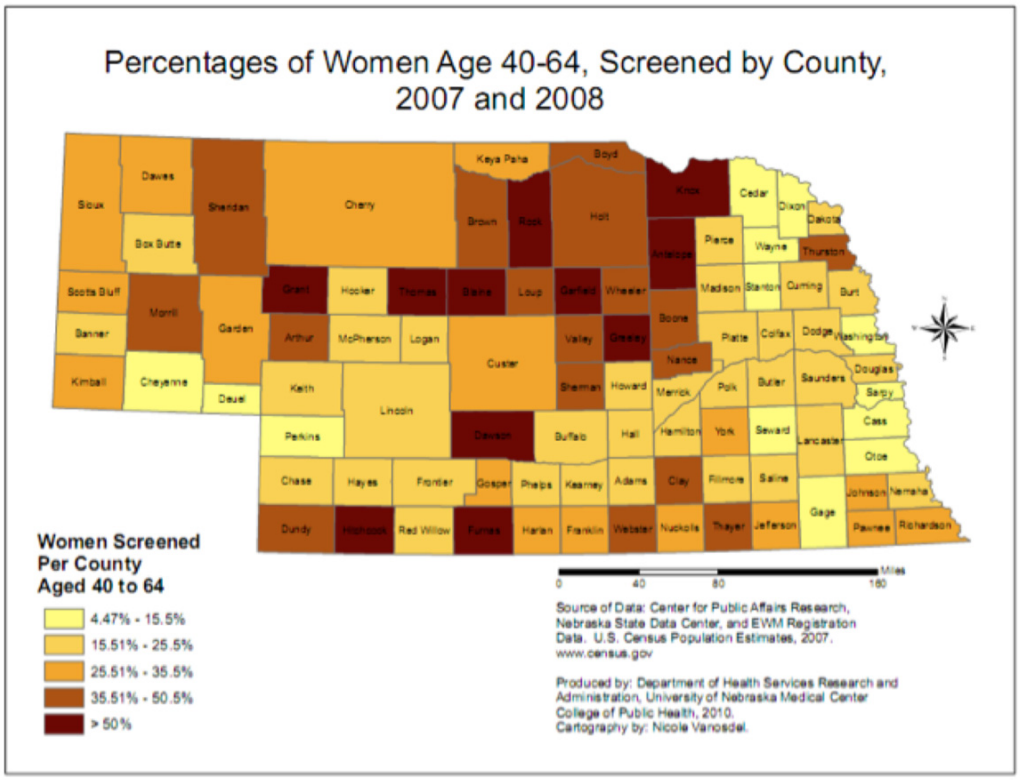
Enrollment and Screening Trends

- 1997- *Policy Change* - Only women 40 and older could come in for screening. Current participants under age 40 were grand-mothered in.
- 2001- **New Services** - Medicaid Treatment Act - Anyone diagnosed through the program with breast or cervical cancer or pre-cancer could go to Medicaid for treatment if they were a citizen, a Nebraska resident and had no insurance. Women enrolled specifically to get treatment resources, particularly younger women for diagnostic services.
- 2002- **New Services** - Women age 40 and up could now receive cardiovascular and diabetes screening. (WISEWOMAN Program)
- 2006- **New Services** - Colorectal program serves women age 50 and up.
- 2008- Initiated direct mailing to all clients for comprehensive service reminder.
- 2009- *New Policy* - LB403[1] All enrollees must have legal residence in the US.
- 2010- Mammography screening is declining. Reasons may include LB403 policy and confusion over screening guidelines.



Source: Every Woman Matters Program, Nebraska Department of Health and Human Services, Office of Women's Health 2010

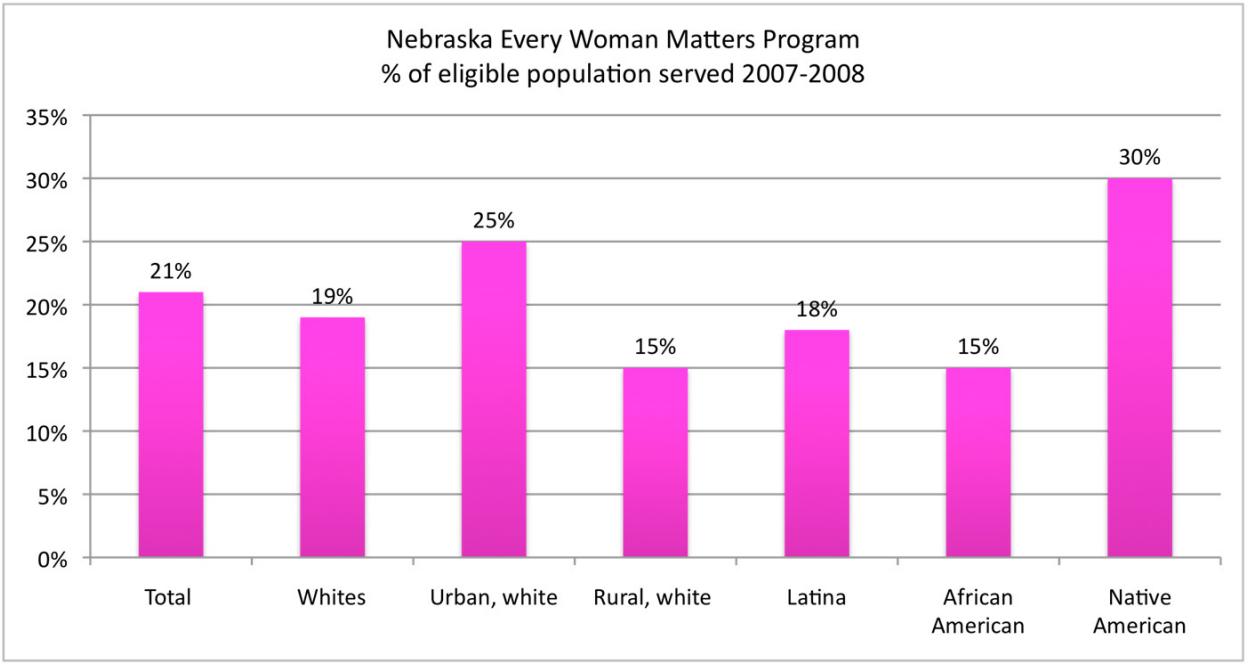
1 Neb. Rev. Stat. §§ 4-108, 111-112 requires that an individual seeking public benefits in Nebraska must have proof of legal US residence.



Source: Every Woman Matters Program, Nebraska Department of Health and Human Services, Office of Women's Health 2010
Screening rates are based on the estimated population eligible for EWM services.

Screening Rates

- In 2007 and 2008, EWM screened an estimated 21% of the population of eligible women age 40-64.
- Nationally, an estimated 15% of women eligible under the National Breast and Cervical Cancer Detection Program are screened.
- The estimate of the population of women eligible for services is based on the number of women age 40-64 with incomes at or below 225% of the federal poverty level.
- The estimated number of women eligible for the Nebraska EWM program is 66,091.
- The map shows estimated screening rates by county, based on the estimate of the eligible population and actual numbers screened in 2007 and 2008.



Eligible population is women age 40-64 meeting income guidelines.
Source: Every Woman Matters Program, Nebraska Department of Health and Human Services, Office of Women's Health 2010. The percentage screened is based on estimates of the size of the population eligible for EWM services.

The chart above shows the percentage of the eligible population served by EWM in 2007 and 2008 broken down by race. Screening percentages are based on the EWM program estimate of the size of the eligible population. The program reached 21% of all eligible women across the state. Thirty percent of all eligible Native American women received services compared to 15% of rural, white women. Eighteen percent of all eligible Latinas received services.

Most in Need

The EWM program has designated the following populations as most in need of screening services:

- White women in Douglas, Sarpy, and Lancaster Counties
- African American women age 50-64 in Douglas, Sarpy, and Lancaster Counties
- Latina women in Dakota and Sarpy Counties age 50-64
- Asian women age 40-64 in Douglas and Sarpy Counties
- Native American women in Knox, Sarpy, and Sheridan Counties
- Rural white women in Arthur, Butler, Cass, Dakota, Dixon, Hayes, Otoe, Perkins, Washington and Wayne Counties

"Most in need" designation is based on estimated screening rates and the size of the eligible population.

Challenges and Issues

Note: Existing programs and services discussed in this section do not represent a complete list.

At the beginning of the planning process Enquire Research invited potential participants to complete an online Provider Survey or participate in a telephone interview. The survey was divided into five parts and participants chose which portions of the survey to answer based on their expertise and interests. The following reflects the input gained from the fifty-two survey respondents.

Education

Survey respondents identified the following needs in the area of education:

- Materials and strategies that are culturally appropriate for different ethnicities, generations, and geography. These might incorporate targeted messages that dispel some of the cultural myths about screening and reduce the stigma of needing help.

- Simple materials emphasizing pictures instead of words.

- Agreement among providers and programs on a single screening standard. Respondents reported that women are confused about how frequently screening should be done and this may be a factor in the reduced number of screenings reported by the EWM program in 2010.

- Messages that emphasize the importance of mammography.

- Messages informing women age 65 and older that Medicare pays for routine screenings.

- A single, easy-to-access source of information about screening guidelines and options for screening, follow-up, treatment, transportation, and support in the caller's community. This might be in the form of one number that women can call to get answers to their questions.

- Programs to educate physicians, their clinical and office staff, and other health professionals about resources, eligibility requirements for EWM assistance, and evidence-based practices to increase patient screening (and re-screening).

- Expand educational outreach by working with churches, schools, and other community groups and programs.

- Use one-on-one outreach through promotoras to educate minority women about the importance of screening. Promotoras are trusted community leaders who are trained to provide information, reassurance, and support.

Quotes from Provider Survey Respondents:

"We are very rural and it is hard to reach some populations without having a champion within the community to pave the way for education and screening. Sometimes it is a matter of knowing how and where to find women in a group setting for educational outreach."

"Our materials are not adapted to the specific issues of Latina, African American, American Indian, Sudanese, and groups that are low English proficiency. For example, it is very inappropriate to speak of certain topics among certain groups because of issues around modesty."

Federal guidelines limit the amount that the Every Woman Matters program at DHHS can spend on education. A minimum of 60% must be spent on direct services, leaving 40% for administration, education, and other activities. The result has been fewer statewide campaigns about breast health and screening.

Screening

Respondents identified the following barriers that must be addressed to reduce screening disparities.

Attitudes about health and prior experiences influence the likelihood of being screened.

- Some cultures do not attach importance to screening or other preventative health behaviors.
- Distrust of providers can be based on a personal experience, a group experience,[1] or cultural differences.
- Fear, pain, and modesty are also barriers to screening.

Women who do not have a medical home or who visit their physician infrequently are less likely to get screened.

- The majority of referrals to Every Woman Matters come from family physicians.

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[1] The example given was the Tuskegee experiment, a syphilis study, which generated mistrust among African Americans. See www.tuskegee.edu.

- 37% of Hispanic women in Nebraska do not have a regular physician, compared to 28% of all minorities combined and 10% of white, not Hispanic women (Kaiser Family Foundation, *Putting Women's Health Care Disparities on the Map,* July 2009)

Some women, particularly those who are limited English-speaking, are not familiar with the health care system and need assistance understanding how to find a provider, make an appointment, and rules regarding assistance.

The Every Woman Matters program (EWM) does not serve all women who cannot afford mammography.

- Neb. Rev. Stat. §§ 4-108, 111-112 (LB403 enacted in 2009) restricts services to those women who are in the United States legally, which has resulted in fewer Latinas being served.
- EWM does not provide routine screening for women age 18-39, even those with higher risk factors.

Women who have health insurance may face high deductibles and/or co-payments.

Lack of transportation is a barrier for both urban and rural women. Finding childcare and getting time off from work are also barriers.

Quotes from Provider Survey Respondents:

"What outreach workers hear: 'Once is enough'; 'It's not broke, so why do it?' 'They might find something.'"

"Uninsured and underinsured need financial assistance, which the EWM program provides, but some women have never heard of it. All hospitals in the area are contractors, but we need more dissemination of information."

"We need a program to offset financial costs for women who do not qualify for EWM!

"I knew that I was supposed to get screened (I am a nurse), but family finances were tight. One year we had some other medical expenses and we met the deductible so I thought it would be a good time to get screened." - Breast cancer survivor

"Women that are BRCA positive, under age 40 and uninsured are in need of screening assistance, as are undocumented individuals who are primarily Hispanic."

Many state and community entities and programs are working to increase screening rates and reduce disparities.

Rescreening programs

- Every Woman Matters has developed a recall process that has improved re-screening rates. The process includes mail reminders and follow-up phone calls. EWM is currently focusing on increasing rescreening rates among current clients rather than growing their client base, but this policy could change.
- The Nebraska Affiliate of Susan G. Komen For the Cure continues to provide financial support for the EWM program. Susan G. Komen grants also provide screening for high-risk women under age 40.
- The Nebraska Chapter of the American Cancer Society is currently considering a state plan for helping physicians provide screening reminders to patients.

Navigation programs

- Patient and lay navigator programs have been shown to increase screening rates. Navigation assistance is important not only for screening but during follow-up after an abnormal screening and treatment. The complexity of the health care system, including payment issues, may be difficult to understand, particularly for immigrant women and non-English speakers. Several organizations in Nebraska currently provide patient navigators.

Physician engagement

- The Every Woman Matters program is developing a provider toolbox that will include materials for increasing provider-patient engagement. The toolbox is being created for the WISEWOMAN program initially, but will be expanded in the future to include engagement tools for colon cancer and breast cancer screening.

Evidence- based practices

- The Centers for Disease Control and Prevention provides information and guidance on using evidence-based strategies to increase breast cancer screening. Specific strategies are included in the Appendices.
- The Office of Health Disparities and Health Equity in the Nebraska Department of Health and Human Services is creating a database of evidence-based practices that are culturally adapted to meet the specific needs of racial ethnic minority groups and rural women and urban women who live in poverty.

Follow-up after Abnormal Screening

Attitudes

Some women may place a lower importance on follow-up. Children, work, and other demands may have a higher priority. Participants spoke about rural women who would literally "give their lives to save the farm."

Finances
Financial issues can also delay or prevent follow-up. Every Woman Matters pays for follow-up diagnostics. However, there are concerns about the complexity of eligibility requirements and the required paperwork being a barrier. Some hospitals provide follow-up regardless of the ability to pay.

For women with insurance, follow-up procedures may be subject to co-payments and deductibles that might stretch beyond the family budget.

Transportation
Transportation, particularly for rural women and Latinas, is a major issue. Medical services are limited in many areas of Western Nebraska and women travel several hundred miles for services. Regional West Breast Health Center in Scottsbluff and other Panhandle providers have developed protocols for same-day services. A woman may receive an initial screening, diagnostic views, a breast ultrasound, and sometimes a biopsy in the same day.

Quotes from Provider Survey Respondents:

"Transportation is a huge issue in our district. Someone undergoing treatments has a very difficult time accessing transportation to their treatment center."

"When doing some educational programs in Dawson County one thing we noticed was that the women walked and brought their children to the programs. If they drove a car then they would have to borrow their husband's car."

"Patients trust and build a rapport with individuals they have a relationship with or an individual that may have gone the "extra mile" for them in another situation. Patients are more likely to identify the true barrier to non-compliance to a trusted provider or volunteer."

Engaging the healthcare team including doctors, PA-Cs, APRNs, nursing staff, radiology technicians, social workers, case managers and breast cancer survivors to emphasize its importance may be one way to increase the likelihood of follow-up.

Treatment

Respondents identified unmet treatment needs as follows:

- Low income, uninsured and underinsured, and women who are Hispanic or another ethnic minority have unmet needs accessing treatment.
- These groups, plus rural women, need transportation for treatment.
- Unmet needs in financing, getting information about treatment options, and having access to treatment options (including clinical trials), can affect all women.

Clinical trials

- The Nebraska Cancer Research Center in Lincoln monitors clinical trials available to Nebraska residents. The Cancer Research Center has nurses at the state's 13 Cancer Centers that screen patients for trials.
- Sometimes, opportunities depend on having a physician in the local area who is a "champion" and very active in finding clinical trials for his or her patients. According to the Research Center, urban and rural residents participate in trials equally.
- The Nebraska Commission on Cancer plans to revise its Program Standards in 2012 to include increased requirements for the enrollment of patients in clinical trials.

Financial assistance

- American Cancer Society (ACS) outreach workers visit Cancer Centers and provider offices to engage patients in discussions about financial help, but these discussions are sometimes hard to initiate because people do not want to talk about their finances.
- Patients are reluctant to ask for financial help. Some fear that if they disclose financial problems they will not receive treatment.
- Hospitals provide some counseling about financial assistance.

Transportation

- ACS offers transportation services in some communities and gas cards are available to anyone in Nebraska. Patients who travel 50 miles or more quality for $100 and those who travel less than 50 miles qualify for $50 if there is no Road to Recovery transportation serving their area.
- The Visiting Nurse Association provides transportation services through a program that is funded by Susan G. Komen for the Cure. Hospitals also might have assistance available for transportation.
- Women often do not know that they do not have to go to the facility that their doctor recommends for chemo if there is a facility closer to home that is chemo-certified.

Research

- Researchers in Nebraska are involved in many projects including hereditary breast-ovarian cancer syndromes (HBOC) and treatment of triple-negative breast cancers. These types and other hereditary breast cancers have a poor prognosis and are more often found among African-American women. (Creighton University)

Quotes from Provider Survey Respondents:

"Resources and navigation should be offered to those with insurance. If you have no insurance and enroll in EWM you are eligible for Medicaid treatment. If you have insurance you can still be left with difficulty making ends meet."

"Some hospitals in the area do not know about clinical trials or are not good about giving women information."

Standards for Accredited Cancer Programs in Nebraska

In 2012, the Commission on Cancer program standards for accredited state Cancer Centers will be revised to be more focused on outcomes of treatment, screening and prevention activities. Accredited programs will need to address the following new patient-centered standards:

1. Navigation
2. Survivorship plan
3. Psychosocial distress management
4. Genetic counseling
5. Palliative care

Support Services

Women of all ages, ethnicities and geography need support services including:

- Support for basic needs
- Help understanding bills and treatment
- Personal needs (wigs, prostheses)
- Support for families and caregivers
- Post-treatment support
- Symptom management for treatment-related issues, especially for older, lower-income women who are geographically isolated
- Emotional support

Barriers
Respondents report that many women rely on family and friends for support. Often, family and friends don't know what services are available and how to find them.

Some women find it difficult to ask for help. Others are so overwhelmed with the physical and emotional aspects of diagnosis and treatment that they may not think about supportive services. HIPPA restrictions regarding the release of medical records make it difficult for support groups to reach out to women who might need their services.

Provider role

Physicians, hospitals and other providers are logical conduits for information. Women may be more open to support services with a referral or recommendation from their provider. Even something as simple as a single card with contact information for support programs that is provided during a doctor or treatment visit might make it easier for women to seek support.

Current program examples

There are many programs that provide breast cancer support services to women in Nebraska communities. Respondents identified the following programs in the survey:

- The American Cancer Society (ACS) *Reach to Recovery* program pairs a survivor with a peer to provide information and support.
- *Susan G. Komen for the Cure* offers a helpline providing professional support services to patients and families.
- *A Time to Heal* is a 12-week support program staffed by professionals and offered in 13 communities.
- *Look Good, Feel Better* – another ACS program.
- *Live Strong at the Y* – a post-treatment exercise program designed for wellness.
- Support services in rural areas have been provided using telehealth technology to connect participants in distant locations.
- The American Cancer Society (ACS) works with health systems across the state to increase patient referrals to ACS for services. ACS has a Patient Services number that patients can call to access a wide range of support services, including financial assistance, transportation, housing assistance, and programs that support patients during recovery. Patients who call the *ACS Patient Services Center* are assigned a navigator who helps them identify financial and other resources in their community.
- *Tackle Cancer* is a Kearney, Nebraska program that raises money for expenses not covered by insurance.
- Chadron Hospital has started a program called *Circle of Light* with funds from Susan G. Komen for the Cure to help women diagnosed with breast cancer get financial assistance while going through treatment.

Quotes from Provider Survey Respondents:

"As a cancer survivor there needs to be more (personal) follow-up after treatment/surgery. It probably depends on doctors and/or oncology departments. I didn't have chemo or radiation, so after mastectomy, other than oncology visits, there was no follow-up for personal items, and I was still too stunned to even think about that option."

"A lot of the programs (such as housekeeping) are only available within a certain mile radius of Lincoln and not available to women in this district who really need the help."

Nebraska Breast Cancer Control Plan 2011-2016

Mission

To promote breast cancer education, screening, follow-up, treatment, support services and research, and to increase the number of Nebraskans who access those services.

Vision

Everyone in Nebraska has access to excellent breast health services and care and the state's breast cancer mortality rates are the lowest in the nation.

Guiding Principles

We are a partnership of Nebraska healthcare providers, funding sources, service organizations and consumers who are collaborative, respectful, inventive, and patient-centered. We share resources, a deep sense of commitment, and responsibility for taking action.

Goals

- By 2016, **reduce** Nebraska's breast cancer mortality rate from 19.2 per 100,000 women to 18.

- By 2016, reduce disparities among demographic groups. Specifically:
    - **Reduce** the breast cancer mortality rate for African-American women from 28.4 per 100,000 women to 18.
    - **Increase** the screening rates for women with incomes below $35,000/yr from 61% to 70%.
    - **Increase** the screening rates for rural women from 68% to 76%.

Achievement of goals will be measured by data supplied by the Cancer Registry and through the Behavioral Risk Factor Survey.

Objectives and Strategies

"*Educating at a young age is important*" – Town Hall Meeting Participant, October 14, 2010

1. **Increase consumer access to current and culturally-appropriate information and education.**
    a. Collect and review multi-lingual materials from Susan G. Komen for the Cure, American Cancer Society, National Cancer Institute, Centers for Disease Control.
    b. Form a group to monitor and evaluate new evidence. Meet yearly.

c. Identify what messages are available, what are needed and how to get messages out to all populations; use focus groups as needed with targeted populations.
d. Educate consumers about Medicare and insurance coverage.
e. Distribute newly evaluated and approved materials.
f. Promote materials at Nebraska's Annual Cancer Conference.
g. Put information about materials on affiliate websites to link to Komen and other sources.
h. Consider developing an event model to increase educational reach and garner publicity.

"Are you really your own best advocate when going through the process? It seems to me that personal advocates would be useful." – Town Hall Meeting Participant, October 14, 2010

2. **Build on successful models to create comprehensive, community-based navigation systems that increase access to education, screening and follow-up services.**
    a. Assess need and review/explore best practices and models already in Nebraska for community health navigation systems.
    b. Review Massachusetts, New Jersey, New York and Colorado curriculum for navigators (already tested).
    c. Define navigation and develop core concepts and standards.
    d. Publish and distribute standards.
    e. Assess capacity and training needs of organizations to carry out community health navigation.
    f. Assess areas of greatest need for tailored health navigation systems including vulnerable populations.
    g. Develop system for individuals to access/request navigation.
    h. Identify comprehensive tools and resources for navigators.
    i. Identify an organization to address male breast cancer as a partner and supporter.

"Radiology departments must be convinced somehow that their efforts to personalize their reminders will pay off with increased screenings." – Town Hall Meeting Participant, October 14, 2010

3. **Increase delivery of screening services and improve follow-up by healthcare providers.**
    a. Review screening disparities information to identify priority targets.
    b. Query state for existing data and information from annual mammography reporting forms.

c. Review provider and client evidence-based strategies or promising practices; identify potential strategies for priority targets and possible organizational partners.
d. Survey providers to identify those interested in increasing service numbers; identify local screening champions.
e. Conduct focus groups to learn more about reaching targets.
f. Identify and pursue funding to support implementation of evidence-based interventions.
g. Develop/adapt evidence based interventions and provide tools as needed.
h. Follow-up with providers to ascertain success and refine/modify approach.

"It is absolutely necessary to prepare and educate the relatives for them to understand and be able to help a loved one. Many family members do not know what to do." – Town Hall Meeting Participant, October 14, 2010

4. **Improve access to supportive services including transportation, financial assistance, emotional support, and education.**
    a. Identify resources currently in the American Cancer Society (ACS) database for its website directory (and 800-227-2345 number) that allows local searching for reduced or free of charge supportive services by zip code.
    b. Create and distribute a survey tool to collect more information on available resources from the state planning contact list.
    c. Write a mini-grant to fund telehealth conferences to promote ACS number and web directory.
    d. Incorporate information about more supportive services into the Personal Health Manager packet for patients that is packaged by the ACS and distributed to Cancer Centers.
    e. Develop a system to keep supportive services information current.
    f. Host two telehealth conferences on supportive services: one geared toward providers and one geared toward patients.
    g. Identify meetings and conferences where the ACS website should be displayed and promoted.
    h. Enlist the cooperation of other organizations and community leaders to promote the ACS website directory and information number to providers and the general public. Conduct webinars or other informational presentations as needed.
    i. Hold a supportive services breakout session at the Nebraska Cancer Coalition Summit with panel discussions and website demonstration.
    j. Identify churches and faith-based organizations that could be enlisted to promote and provide facilities to house support groups.

k. Coordinate with service providers to do co-marketing or sharing of available supportive services to clinics.

"With the projected deficit budget for the state of Nebraska, what guarantee do we have for funding? We need this info to move forward and a guarantee that all women and men will be treated in the same fashion." – Town Hall Meeting Participant, October 14, 2010

5. Advocate for policies and funding that increase access to services.

a. Develop advocacy partnerships.
b. Develop a group to become informed about the impact of health care reform on breast cancer.
c. Seek funding to expand local coalitions to focus on breast cancer screening.
d. Maintain state funding for Every Woman Matters.
e. Assure that policies do not deny services to vulnerable populations.
f. Promote the elimination of insurance barriers to clinical trials.
g. Encourage insurance coverage for mental health support/counseling services for breast cancer patients.
h. Encourage workplace policies to allow women time for screening and treatment – meeting the National Cancer gold standard.
i. Explore issue of Medicaid funding for genetic testing.

"Prepare the client so she can help herself and adopt a positive attitude." – Town Hall Meeting Participant, October 14, 2010

6. Promote healthy lifestyle behaviors that can decrease the risk of reoccurrence and death from breast cancer.

a. Identify and promote programs that assist patients to stop smoking or using other tobacco products.
b. Promote regular physical activity among survivors according to ACSM guidelines.
c. Develop and promote opportunities to modify nutritional intake and maintain energy balance.
d. Identify and promote ways for cancer survivors to manage stress related to cancer and daily life.
e. Promote adequate quality and quantity of sleep among survivors.
f. Identify and promote programs that assist patients who abuse alcohol or other substances.

Recommendations for Implementation

This plan should be considered to be a living document: one that is always changing as more is learned, resources grow, and situations change. The objectives and strategies reflect the best thinking of the planning group at the time of development. As task forces continue to meet and further develop components of the plan, the document will continue to evolve.

Each task force working on an objective should set measurable goals and/or milestones and determine appropriate measures and timelines for measurement. Baseline measures need to be taken as soon as possible where appropriate.

State planning leadership should consider the value of adding awareness questions to the Behavioral Risk Factor Survey that would help to assess the effectiveness of awareness and education efforts.

Research data collected during the planning phase should be used to inform funding applications and partnership proposals.

Task forces working on objectives should meet at least quarterly to refine and revise their plans. The full stakeholder group should reconvene annually to assess the progress of each task force and review/adjust the plan.

Progress toward achievement of goals should be measured at the end of five years. Periodic measures, if conducted, should be used at the annual full group meetings to help assess impact and inform decisions about plan changes.

Appendices

Appendix A: Provider Survey
Appendix B: Evidence-based Strategies
Appendix C: Additional Strategies Suggested by Planning Participants
Appendix D: Survivor Comments from Town Hall Meeting

Appendix A: Provider Survey
July 26, 2010

Thank you! Your participation in this part of the process is very important!

This survey covers the following areas: Education, Screening, Follow-up, Treatment, and Support.
Please answer as many questions as you can, based on your role and your experience. You may skip entire sections or questions within a section.

Background Information

Your name:

Your organization:

Your role or job title:

B1. What types of services do you/does your organization provide? Please place an "x" in front of all that apply.

__ Education
__ Screening
__ Follow-up
__ Treatment
__ Support
__ Financial assistance to individuals
__ Transportation
__ Other _____
__ None

B2. What geographic area do you serve? Choose one only.

__ Nebraska
__ Region _____
__ County or multiple counties _____
__ City or urban area _____
__ Other _____
__ None

B3. Do you work with or focus on any specific sub-populations? Please check all that apply.

__ African American
__ American Indian
__ Spanish-speaking
__ Asian
__ Other ethnicities _____
__ Low income
__ Uninsured
__ Underinsured
__ Rural
__ Urban
__ Other _____
__ No focus, we serve all women
__ None, not a provider

About this Survey

This survey is divided into 5 sections which are listed below. **You do not have to respond to questions in all 5 sections.** Choose those sections that are relevant to your role or expertise and check "yes". Check "no" for the sections you want to skip. The survey will automatically take you to those sections that you checked "yes" and will skip the other sections. If you want to do all the questions in the survey, please check "yes" for all the sections.

	Yes	**No**
Education	___	___
Screening	___	___
Follow-up	___	___
Treatment	___	___
Support	___	___

Note: On the web survey, you will see only those sections where you checked "yes" above.

When answering the survey questions please think about your experience in the geographic area that you serve, the kinds of clients you work with, and your knowledge of other programs and services targeting similar women in your service area.

Education

Please think about ***Breast Cancer Education*** as you answer the questions in this section.

E1. What populations in the areas you serve are not being adequately reached? (urban/rural, specific neighborhoods or areas, age, race, ethnicity, income, other)

E2. What resources are needed to adequately deliver key messages?

E3. What suggestions do you have for improving breast cancer education in your geographic area?

E4. What programs/approaches are working well that can be duplicated?

Screening

Now, please think about ***Breast Cancer Screening*** for the questions in this section.

SCR1. What populations in the areas you serve are not being adequately served? (urban/rural, specific neighborhoods or areas, age, race, ethnicity, income, other)

SCR2. What services are they not receiving?

SCR3. What are the barriers to screening?

SCR4. How can these barriers be reduced?

SCR5. What programs/approaches are working well that can be duplicated?

Follow-up

Please think about ***Follow-up after an abnormal screening*** when answering the questions in this section.

F1. What populations in the areas you serve are not receiving sufficient follow-up after an abnormal screening? (urban/rural, specific neighborhoods or areas, age, race, ethnicity, income, other)

F2. What are the barriers to appropriate follow-up? (transportation, child care, attitudes, other.) Please be specific.

F3. What programs/approaches for increasing follow-up effectiveness are working well that can be duplicated?

Treatment

Now, please think about ***Breast Cancer Treatment*** for the questions in this section.

T1. Are there any unmet needs in the following areas?

	YES	NO
Access to treatment		
Transportation services		
Financial assistance for treatment		
Access to information regarding treatment options (this includes clinical trials)		
Access to treatment options (are there differences in access to treatment options among women with the same cancer type and staging?)		
Other: _____		

T2. If yes to any of the above, what populations are not adequately being served? (geography, age, race, ethnicity, income, etc.). Please make sure you identify which services they are not receiving.

T3. What strategies could be implemented to help meet these needs?

T4. What programs/approaches are you aware of that are working well and can be duplicated?

Support

The last group of questions is about ***Breast Cancer Support***.

S1. What support services are inadequate or not being provided?

S2. What populations are not adequately being served? (geography, age, race, ethnicity, income, etc.)

S3. What programs/approaches are you aware of that are working well and can be duplicated?

S4. What suggestions do you have for improving breast cancer support in your area?

(Everyone will answer these questions)

Overall

Thinking about breast cancer education, screening, follow-up, treatment, and support:

O1. In your opinion, what are the three most important needs across all five services? Please list in order of importance. If a need is specific to a population, please include that as well.

O2. Based on your experience, is there any unnecessary duplication of services in any of five areas listed above? If yes, please explain.

O3. What opportunities for collaboration do you see that would increase the efficiency and reach of services that are provided?

O4. What are the barriers to collaboration in your community?

Thank you for your input! Please use the space below for any other comments or information that you think are important to the process of developing a Breast Cancer Control Plan for Nebraska.

Appendix B: Evidence-based Strategies

The Guide to Community Preventive Services (www.thecommunityguide.org) is a resource that summarizes intervention programs that have demonstrated effectiveness in producing results. The following tables summarize the evidence-based practices to increase screening rates for breast cancer with providers and clients.

Provider-Oriented – Breast Cancer	
Aim to increase recommendation and delivery of screening for breast cancers by healthcare providers.	
Provider assessment and feedback	Recommended
Provider incentives	Insufficient evidence
Provider reminder and recall systems	Recommended

Client-Oriented – Breast Cancer	
Interventions that either provide education to increase cancer screening or make it easier for clients to be screened	
Client reminders	Recommended
Client incentives	Insufficient evidence
Small media	Recommended
Mass media	Insufficient evidence
Group education	Insufficient evidence
One-on-one education	Recommended
Reducing structural barriers	Recommended
Reducing out-of-pocket costs	Recommended

Appendix C: Additional Strategies Suggested by Planning Participants 9/23/2010

Improve screening/follow-up systems

Find funding and support for Cancer Screening days especially in rural areas, or other areas where taking the time to go for several screenings is prohibitive. Bring the screenings to those who need it.

Many communities do health screenings on a regular basis (i.e.: cholesterol tests). Can there be a way to incorporate breast education or screenings in the similar manner for a minimal cost whether by donation from a major NE business or employer or hospital?

Provide professional education to clinic professionals who have more time than physicians to talk to women about screening.

Improve navigational systems

Develop a listing of navigators and promotoras in the state.

Recruit navigators from all regions in Nebraska and from different race, ethnic and cultural backgrounds.

Build the system so that when they are diagnosed, there is a script explaining patient navigation aids.

Recruit and train cultural brokers/medical interpreters/those with mediation training/skills into healthcare fields as lay health ambassadors.

Train peer educators to do education that providers do not have the time to do.

Use state program staff who received training in chronic disease self-management program to train local outreach staff to help patients with physician advocacy.

Improve consumer and health provider education

Form collaborations with agreements on the roles of each group in developing culturally-appropriate, age-appropriate and language-appropriate materials and programming. Agree on how this will be done to maximize involvement of the communities and women who need to be reached.

Use more pictures and fewer words in printed materials.

Create a materials clearinghouse.

Find the survivors who are willing to speak on behalf of all women in the state and make the survivors and caregivers the voice and vision of what is in/on materials.

Recruit women from all priority groups to tell their stories. The women could be cancer survivors, someone helped by EWM, and/or someone who was reluctant to be screened and glad to have overcome the reluctance. The stories could be written, or the women could agree to orally tell their stories to news media, groups of women, etc. There are some stories already recorded through a DVD developed by EWM.

Need publicity photos and stories featuring actual Nebraska residents, especially those in the most underserved populations, like older rural women, Latina women, etc.

Establish a listing of survivors and others who would be willing to speak about their experiences and the things they learned. (Speakers Bureau)

Encourage media reporting on good things that are available out there for women's health regardless of income, age, race and location.

Use Facebook or social networks to get the info out there. Utilize current popular computer/cell phone technology for outreach.

Keep targeting educational messages to young women – junior high and up—about the need to get screened, how to be a good self-advocate, etc. Systemic change will happen with the younger people.

Leave materials in hotel rooms, senior diners. Cancer Corners are appearing in libraries in Kearney, Grand Island and Lincoln.

Promote and expand supportive services

Get feedback from patients on what we can do to better serve them.

Consider enlisting survivor group members to provide transportation for clients needing a ride for clinical breast exams or mammograms; these ladies would be well aware of the importance and it may be a "one time only" commitment. (This is similar to the ACS volunteer group who assist with transportation for cancer treatment patients.)

Partners develop a transportation system to be made available to women who need assistance.

Provide vouchers and advertising in city buses and Handivans in the metro areas.

Systemic change is needed to provide emotional support to cancer patients as part of treatment without diagnostic mental health labeling. Much of this is done unofficially by nurses and social workers at hospitals, but since it's not an "official" job duty, the support gets cut short when budget, time, or staffing is short.

Increase delivery of interventions via other methods than in-person, i.e. telephone, computer websites, active chatrooms, etc.

Expand "Time to Heal" to other parts of the state. It's currently in 13 communities across Nebraska with 2-6 trained facilitators at each site. It can be used with patients or with patients and adult family members. Research shows it works. Need to experiment with various formats to make access easier for people who can't make a long commitment of 12 weeks. (like a weekend format, once a month format, internet format?)

Publish the support groups in church bulletins that are available in communities and many churches have nurse type advocates who may have connections individuals who would offer support (especially emotional & spiritual).

Recognize that the needs of newly diagnosed first time patients are different from people with recurrent cancer or chronic, ongoing treatment. Support groups usually meet the needs of one group better than the other.

While support groups can be wonderful, training an individual support person who can be ready when a patient needs help might make support more accessible. Reach to Recovery has a good model; promotoras are similarly good. Maybe TV ads and brochures telling patients how to connect with Reach or a promotora could be helpful since patients are not in the hospital long enough to get services and some doctors/hospitals don't make referrals. Phone support could be effective, too – it doesn't have to be in person.

Regarding support groups – my knowledge of other cultures tells me that most clients of other cultures look to their own families for support as they are uncomfortable with others. If we could find a way to assist the family to support them during this time and the only thing that comes to mind is the Chronic Disease Self-Management workshop (CDSMP). It is a six week long course once a week for 2.5 hours. Family members, the client, and close friends that the client trusts can attend. Right now in Nebraska we are training leaders to give this workshop across Nebraska and soon we should be able to reach any rural area.

Make and publicize descriptions of ways that family, friends, and colleagues can help women after a cancer diagnosis. Obtain the ideas from survivors through surveys or focus groups.

There needs to be better education of physicians and other health care providers about the need for these issues to be addressed. During their educational process I would strongly suggest that physicians, PA's, Nurse Practitioners—are assigned to a hospice family as well as a children's cancer center family to better understand the complexity of dealing with the issues of cancer.

Expand funding base

Attempt to get hospitals/service providers aligned around the mission statement. The ideal would be to have them each contribute $ to a statewide education fund – instead of each producing their own "logo-ed" brochures, agree to use a coalition-chosen brochure (each contributing hospital's name could be listed on the brochure). In addition, the funding might be used to train peer educators and promotoras to work in the various locations where they are most needed.

Seek funding beyond state EWM program funding, e.g. non-federal grants.

Create a non-profit entity to augment the state funded program and to serve all women not just those who are low income.

Research and apply for funding opportunities to offset the cost of providers screening women that do not have insurance. Assure the providers that if client needs diagnostic or treatment services that the funds will be available.

Seek out private funding sources willing to help undocumented women receive services.

Provide financial support from partners to pay for counselors for support groups and to host the groups, especially for rural groups and those for racial/ethnic minorities.

Advocate for policy change

Support policy changes to raise funds for screening women outside the federal parameters through such means as legislation for check-offs or to allow people to donate extra money when buying license plates.

Encourage insurance companies to provide mental health counseling for persons with cancer diagnoses. Find a way to eliminate the stigma of seeing someone in the psych area – how does the hospice and grief support groups handle this?

We need to support the health care reform law as it will make services available to many more people.

Inform Nebraska Legislators of the need to provide women who are not eligible for Every Woman Matters with screening services and medical care.

Work with Appleseed or similar organizations re: unserved women.

Expand Partnerships

Maximize use of public health department system in NE – How could Telehealth system be used?

Work with UNMC College of Nursing on 5 campuses (Omaha, Lincoln, Kearney, Norfolk, and Scottsbluff)

Help build coalitions of women in racial/ethnic minority communities to determine and eliminate barriers. Provide support to the coalitions.

Recruit assistance in outreach to rural women from the Rural Health Association, Women in Farm Economics (WIFE), and the Rural Response Hotline.

Partner with organizations where women belong- i.e. churches, at their children/grandchildren/s schools, Y, to reduce the barriers to screening in that location.

Partner with sponsors of community events and health fairs.

What partnerships can be made between public school system and the BCCP? Many small towns do not have facilities to exercise except at schools or churches. To have a gym available for cancer patients to walk would be great and hopefully convenient.

Let's consider approaching high school groups such as FCCLA and see whether they would take on breast cancer as a statewide project. One group that doesn't get served are the teens who have a mother with breast cancer. This is a huge issue for teens.

Perhaps school nurses as part of an outreach program could get districts to offer health fairs. There seems to be fewer health fairs than in the past. It would be a great community project for high school students to initiate planning for them. Churches could do more too.

What about forming partnerships with educational entities that have psychology programs, interns can then see clients at no cost since they have to have somewhere between 1500-4000 counseling hours dependent on the type of degree before they can get a license to practice.

I would like to see a major effort with African American women in Omaha; they need to be included in the project design; perhaps the College of Public Health would be interested in a community participatory research project with this community in collaboration with EWM.

Other

There are success stories out there. Collect those ideas through a survey or other means and facilitate the distribution of those ideas. Develop a system that takes those best practices and expand it to a statewide idea/intervention.

Could a group of medical professionals like "Doctors Without Borders" provide needed services for breast cancer to begin with that could be expanded to cervical and colorectal cancers?

What can we learn from other states? What about a breast cancer *policy* symposium?

Appendix D: Survivor Comments from Town Hall Meeting 10/14/2010

What I needed most…
Access to support systems post-treatment
Someone to sort out the information overload
Someone who would just hold me and tell me they cared – without expecting conversation or anything in return
To talk to survivors who knew how troublesome the chemo was
A rehab program for breast cancer patients (like cardiac rehab or stroke rehab)
Direction… what do I do now?
Someone who could help to convince me I would not lose something of extreme importance to who I am
Friends engaged in helping me to "live" – occasional housecleaning :>)
Information and help to decide my treatment
Encouraging words from the many survivors who are now my heroes

One thing I learned I would like to share with others…
Don't try to hide or ignore it. It won't go away!
If you look you can always find someone who can help!
There are people out there to support you
You have to become an educated consumer (ask and expect to get answers)
You are stronger than you think! You can do it! Don't give up!
Early detection saves months of treatment and pain…
Do not rely on mammograms alone – self breast checks work!
To live your best life possible – no matter what the circumstances
It's ok to ask for help – you don't have to be all things to all people
Your feelings are your feelings – no right or wrong
You don't come out unchanged!
You need to be your own advocate… ask for copies of your own medical records and don't be afraid to get second/third opinions. :>)
Don't ignore a lump, be aggressive and ask for follow-up sooner than a year

What I am thankful for…

My friends and family and breast cancer friends who gave me love and support
That I am a survivor
My friends bought my wig!
That I came on the bus tour!
Life after cancer!
For the strength I didn't know I had!
My faith and my husband!
God, my loving family, my healthcare providers, my breast friends!
Friends, family, supporters of all ages, my faith
My out-of-town brother paid for monthly housecleaning for a year