

North Dakota's Cancer Control Plan 2006 – 2010



A Special Thank You To:

... all those who gave of their time, expertise and energy to develop North Dakota's Cancer Control Plan.

... the role models in the photos for sharing their stories of courage and grace.

... all of the health-care professionals and researchers who work with cancer in North Dakota for their dedication.

... all of the friends, family, and co-workers of those afflicted with cancer for their care and support.

Working together collectively and collaboratively, we will ease the physical, emotional, spiritual and financial burden of cancer in our state.

Front Cover Photos:

Ashley Andrews, Bowman, N.D.,
Miss Rodeo North Dakota 2006
Hodgkins lymphoma – currently in chemotherapy

Margaret Leas, R.N., Rolla, N.D., two-time survivor of breast cancer North Dakota delegate to the 2006 Lance Armstrong Convention in Washington, D.C.

Dr. Kevin Collins, Minot, N.D., Radiation Oncologist, Trinity Cancer Center Founding chairperson of the North Dakota Cancer Coalition

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Fellow North Dakotans:

The North Dakota Cancer Coalition (NDCC) is pleased to present North Dakota's Cancer Control Plan 2006-2010. To create this plan, NDCC members examined the current burden of cancer and contributing risk factors. This strategic plan provides North Dakota with a comprehensive, integrated plan of action that highlights strategies targeting cancer prevention, early detection, treatment and disease management. It also covers quality of life issues including pain management, palliative care, end of life and survivorship, in addition to cancer disparities and the future of North Dakota's health and allied health workforce.

Partners in the planning process come from many sectors of our North Dakota community, including community-based organizations; health-care organizations; local, state and federal agencies; medical professional organizations; education; academia; research; voluntary organizations; survivors; health-care professionals; and others from across our unique state.

North Dakota's Cancer Control Plan is only the beginning of a long road leading to eventually reducing the burden of cancer. As science and practical experience grow, new challenges, innovative tools, and more effective strategies will emerge based on the needs of North Dakota's residents. The plan is intended to be a starting point – a springboard for use by partner organizations, communities and individuals to create, implement and sustain activities that will reduce the cancer burden.

Cancer affects every one of us: our friends, family members, co-workers. It will take all of us working together to reduce the threat of cancer in our lives. As chairperson of the NDCC, I am extremely thankful for the individuals and their sponsoring organizations who dedicated their time, expertise, skill and talent in developing the plan. It is through this collaborative effort that we now have a blueprint for action to reduce the burden of cancer in North Dakota.

Finally, the plan is an invitation for you to become involved in implementing the strategies for comprehensive cancer control. The hardest work lies ahead – combining our state's talent, skill and resources to implement the plan. Take action by volunteering to assist with a local activity, volunteering to serve on a committee working to achieve a priority, and supporting community or statewide activities focused on cancer control. All North Dakotans have a role in the fight against cancer. Working together, we can transform the vision of a cancer-free North Dakota into a reality.

Charles Kupchella, Chair North Dakota Cancer Coalition

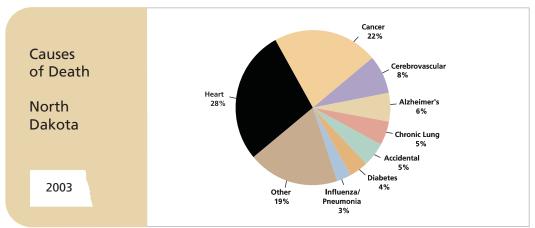
North Dakota XX Cancer Coalition

Executive Summary

Introduction

Cancer issues are a rising concern in North Dakota. Declining birth and death rates mean that North Dakota's population, like that of the rest of the United States, is aging. Overall cancer incidence and mortality increase with age.

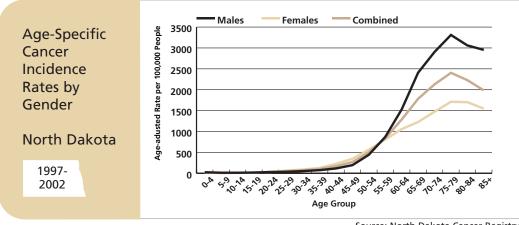
North Dakota faces unique challenges in the coming years. Our population tends to be older, to live longer, and to earn lower incomes. From 2000 to 2010, the number of North Dakotans age 65 and older will increase by 17 percent; the number of North Dakotans age 85 and older will increase by 28 percent. As the population of North Dakota ages, the burden of cancer increases. In 2000, more than half of North Dakota's residents lived in urban areas and tended to be younger. The rural areas contained the higher percentage of elderly residents.



Source: North Dakota Division of Vital Records

North Dakotan's cancer statistics mirror those experienced across the nation. Cancer is the second leading cause of death in North Dakota.

The American Cancer Society estimates that 1,280 North Dakota residents will die from cancer in 2006. During the same year, 3,170 individuals will receive a cancer diagnosis.



Source: North Dakota Cancer Registry

In North Dakota, overall cancer incidence and mortality rates rise dramatically after age 54 for both sexes, but particularly for males.

Four cancer sites–lung, colorectal, breast and prostate–account for well over half of all cancer cases in North Dakota.

The financial burden created by cancer in North Dakota is also challenging. Estimated annual direct medical costs for cancer care in North Dakota was about \$318,248,000 in 2002.

Comprehensive Cancer Control

With support from the U.S. Centers for Disease Control and Prevention (CDC), the North Dakota Cancer Coalition joined with partners from many sectors of the North Dakota community to develop the state's first comprehensive cancer control plan. Gaining an understanding from others' perspectives through a series of coalition and workgroup meetings allowed organizations and individuals to work together toward a common goal and strengthened collaborations among agencies.

The burden of cancer in North Dakota can be reduced by implementing effective interventions to decrease incidence of preventable cancers, detect cancers early, and ensure access to quality cancer care services from diagnosis through survivorship or end of life. Successful comprehensive cancer control begins with a collaborative approach to developing a cancer plan.

The purpose of North Dakota's Cancer Control Plan is to:

- Provide a blueprint for coordinated and integrated statewide efforts to reduce the burden of cancer.
- Highlight important cancer issues for future prioritization.

- Set goals and objectives for improvement.
- Propose evidence-based or theory-based strategies to achieve goals and objectives.
- Draw together interested organizations and individuals to work collaboratively toward shared goals to reduce the burden of cancer.

Goals for Cancer Prevention and Control

The goals of North Dakota's Cancer Control Plan focus on important cancer issues in North Dakota across the cancer continuum. The goals are the result of a detailed assessment of the state's surveillance data and statistics, review of results of cancer research and recommendations from local cancer experts and cancer care providers. This strategic plan provides North Dakota with a comprehensive, integrated plan of action that highlights strategies targeting cancer prevention, early detection, treatment and disease management, quality of life including pain management, palliative care, end of life and survivorship, workforce of the future, and cancer disparities.

The goals of the plan:

- Prevent cancer by reducing risks and improving healthy behaviors of North Dakota citizens.
- Lead the nation in appropriate screening and early detection of cancer.
- Increase access to effective cancer treatment and care.
- Optimize the quality of life for every person affected by cancer.
- Ensure an adequate supply and competently trained workforce to provide comprehensive cancer care in North Dakota.
- Continually and respectfully work to identify and reduce cancer disparities in North Dakota.

Progress in cancer control and prevention will result from the collective work of a multitude of organizations including government, business, health care, research and non-profit organizations. Partnerships among agencies will allow organizations to work together toward the common goal of reducing cancer incidence and mortality among North Dakotans.



Banking on a Healthy Future

"If your mind sees it, your body will believe it. See yourself healthy. Believe."

Gail Hove, Grand Forks, N.D. Wife, mother, mortgage loan officer Ovarian, breast and colon cancer survivor

Burden of Cancer

Burden of Cancer in North Dakota

Estimated annual direct medical costs for cancer care in North Dakota in 2002 – \$318,248,000.

Everyone has a personal experience with the disease, whether it is the diagnosis of a family member, a friend, a patient, or of self. The purpose of this chapter is to examine current data to illuminate the great burden cancer puts upon North Dakotans. The burden of cancer hits home physically, emotionally, spiritually and financially.

In 2003, the leading causes of death for North Dakota residents were heart disease and cancer. Every year more than 3,100 North Dakotans are diagnosed with cancer, and nearly 1,300 die from the disease.

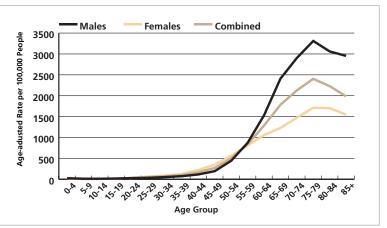
Although cancer is a constellation of more than 200 different diseases, a few types – lung, breast, colorectal and prostate – account for the 55 percent of cancer cases and about 50 percent of the cancer deaths in our state.

Overall, cancer incidence and mortality rates rise dramatically after age 54 for both sexes, but especially for males.

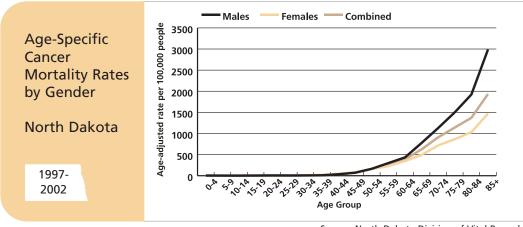
Age-Specific Cancer Incidence Rates by Gender

North Dakota

1997-2002



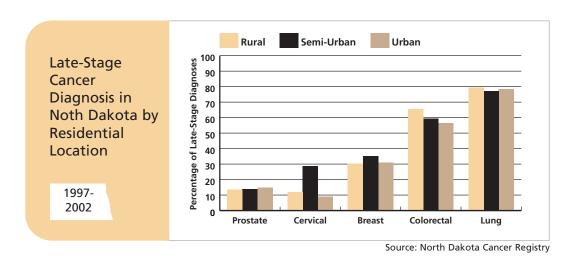
Source: North Dakota Cancer Registry



Source: North Dakota Division of Vital Records

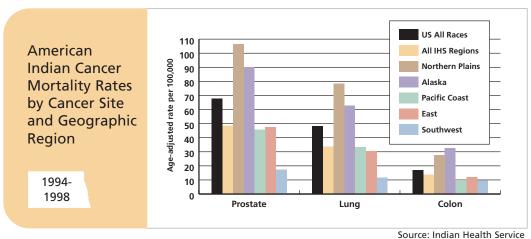
Although people of all ages contract cancer, it is primarily an older person's disease. About three-quarters of all cancers are diagnosed in people 55 years and older. Overall, cancer incidence and mortality rates rise dramatically after age 54 for both sexes, but especially for males.

By gender, U.S. males have a 50 percent chance of developing cancer in their lifetime; for females, it is approximately 33 percent. North Dakota data indicate that between 1997 and 2002, 10,061 men and 8,366 women were diagnosed with cancer. In general, North Dakota males were more likely than females to contract and die from the disease.

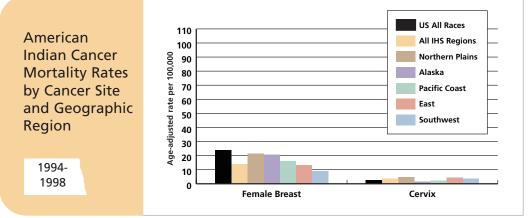


Late stage diagnosis of cancer occurs most often in lung, colorectal and female breast cancer. Rural residents were more likely to have been diagnosed with late-stage colorectal cancer compared to their urban counterparts. Rural women with cervical cancer were more likely to have been diagnosed at late-stage compared to their urban and semi-urban counterparts. Semi-urban residents with bladder cancer were much more likely to have been diagnosed at late-stage.

Cancer disparities exist by race/ethnicity, socioeconomic status, geography, gender, sexual orientation, and insurance status. Possible explanations for the existence of these disparities include differences in health behavior, beliefs and attitudes, access to health care, quality of health care, and genetics.



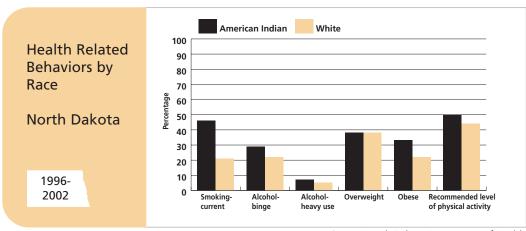
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Source: Indian Health Service

American Indians are by far the largest racial minority group in North Dakota, comprising approximately 5 percent of the population. According to the Indian Health Service, Northern Plains Indians have higher cancer mortality rates than the U.S. population for prostate, lung, colorectal and cervical cancer.

Moreover, Northern Plains Indians have higher cancer mortality rates compared to all other Indian Health Service regions for prostate, lung, female breast and cervical cancer.



Source: North Dakota Department of Health

Compared to whites, American Indians possessed higher percentages of current smokers, binge drinkers, heavy drinkers and obesity.

Also, American Indians were less likely than whites to have had recent Pap, blood stool, colonoscopy or sigmoidoscopy tests.

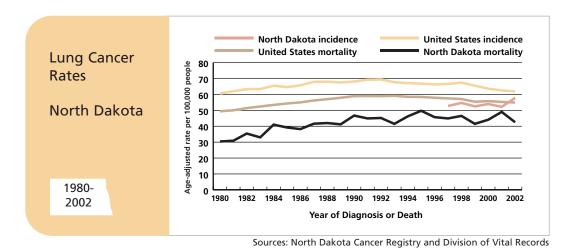
Five-Year Cancer Survival Rates by Stage		Prostate (%)	Breast (%)	Cervix (%)	Colorectal (%)	Lung (%)
at Diagnosis	Local	100	98	92	90	49
U.S.	Regional	N/A	80	53	67	16
	Distant	34	26	17	10	2
1995- 2000		!	!	!		
				Source	American Cano	er Society 2005

Source: American Cancer Society, 2005

Cancer survival rates for the U.S. have steadily increased over the past several decades. This may be due to several factors, including higher rates of cancer screening, fewer late-stage diagnoses and improvements in health-care technology and treatment. When diagnosed in the local or regional stage, the five-year survival rate is greater. This is especially true for screenable cancers. Overall, five-year cancer survival rates are highest for prostate, breast, cervix and colorectal, and lowest for lung.

Lung Cancer

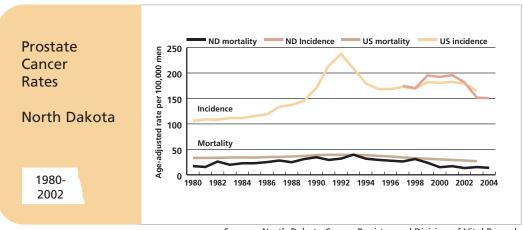
North Dakota has about 375 new cases of lung cancer each year. The incidence and mortality from lung cancer has been increasing over the past 20 years. Smoking causes about 87 percent of lung cancer deaths. There is poor survival even when diagnosed early. The mortality rate for women has steadily increased over the past two decades and is approaching the same rate as lung cancer mortality in men.



Men Women **Lung Cancer** Age-adjusted rate per 100,000 people 80 Mortality by 70 Gender 60 50 North Dakota 40 30 20 10 1980-1981 1983 1985 1987 1989 1991 1993 1995 1997 1999 2001 2003 2003 Year of Death

Source: Division of Vital Records

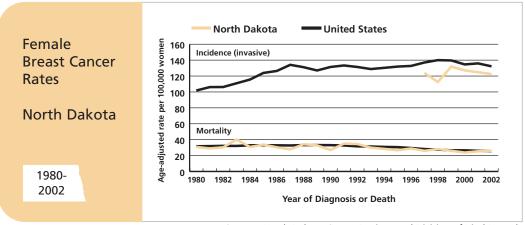
Prostate Cancer



Sources: North Dakota Cancer Registry and Division of Vital Records

About 580 new prostate cancers are diagnosed per year. Prostate cancer is the second leading cause of cancer death among men. There is excellent survival when diagnosed early. More than 90 percent are diagnosed early. In 2000, there were an estimated 3,700 prostate cancer survivors in North Dakota.

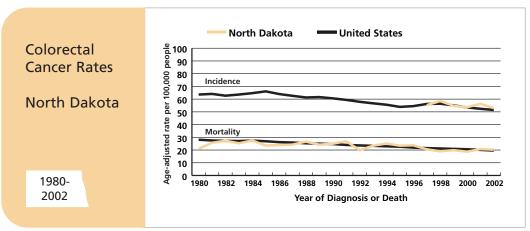
Breast Cancer



Sources: North Dakota Cancer Registry and Division of Vital Records

Breast cancer is the most commonly diagnosed cancer for women, with 450 new cases per year in North Dakota. It is the second leading cause of cancer deaths in women. About 5,000 North Dakota women were breast cancer survivors in 2000.

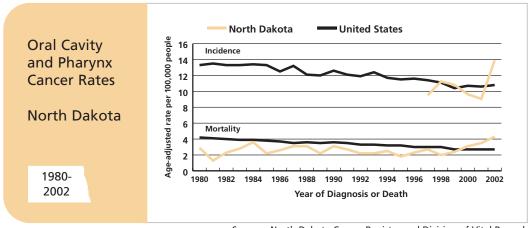
Colorectal Cancer



Sources: North Dakota Cancer Registry and Division of Vital Records

About 2,300 North Dakotans were colorectal cancer survivors in 2000. Each year, 400 new cases are diagnosed. Screening prevents colorectal cancer by finding and removing polyps. Obesity, lack of exercise, alcohol consumption, smoking and poor diet may increase the risk for colorectal cancer. North Dakota males generally have higher rates of colorectal cancer than do North Dakota females.

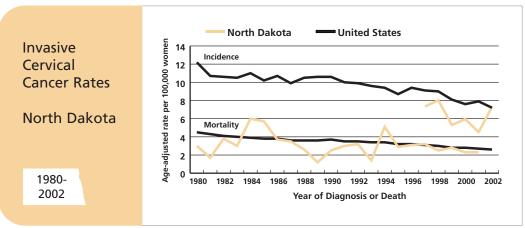
Oral and Pharynx Cancer



Sources: North Dakota Cancer Registry and Division of Vital Records

In 2002, incidence rates of oral and pharyngeal cancer experienced a sharp increase. Similarly, oral and pharyngeal cancer mortality rates have increased among North Dakotans in 2001 and 2002, and have edged above the mortality rates for the nation as a whole. Risk factors include cigarette, cigar and pipe smoking; use of smokeless tobacco; and excessive alcohol consumption.

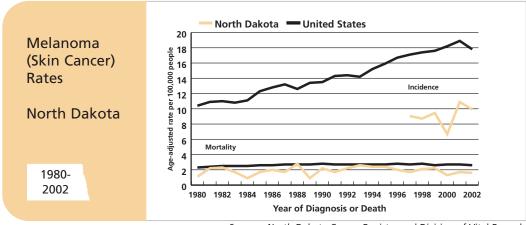
Cervical Cancer



Sources: North Dakota Cancer Registry and Division of Vital Records

From 1997 to 2001, cervical cancer occurred among North Dakota women at rates that were somewhat lower than national rates. However, in 2002, incidence rates of cervical cancer in North Dakota increased, pulling even with the national rate. There are about 20 newly diagnosed cases per year. Cervical cancer is preventable with screening because abnormal findings can be treated. It is presumed that most cases are linked to human papillomavirus (HPV).

Melanoma



Sources: North Dakota Cancer Registry and Division of Vital Records

Each year, about 60 new cases of melanoma are diagnosed. Melanoma (skin cancer) incidence rates for North Dakota were substantially lower than national rates for the years 1997 through 2002. However, according to staff at the North Dakota Cancer Registry, one of the reasons for the lower observed rates for North Dakota is under-reporting of the disease by health-care providers.

Summary

Many cancers can be prevented; in fact, all cancers caused by tobacco smoking and heavy alcohol consumption are entirely preventable. About one-third of the annual cancer deaths in the U.S. are related to the following mutable factors: poor nutrition, sedentary lifestyle, and excessive body weight.

The full burden of cancer upon the lives of North Dakotans cannot be measured. However, analysis of available secondary data has indicated that cancer levies a substantial burden on North Dakotans and, consequently, on their friends, families, loved ones and caregivers. The principal, most problematic cancers facing North Dakotans are the same ones that profoundly, adversely affect all U.S. residents: lung cancer, prostate cancer, breast cancer and colorectal cancer.



Compassionate Care

"Every cancer patient has a story. Everyone wants to know they made a difference."

Jan Bierschbach, Bismarck, N.D. Hospice and St. Alexius Medical Center Chaplain

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History and Vision

History

In June 1989, the North Dakota Cancer Coalition (NDCC) was formed to assist the North Dakota Department of Health in preparing a state cancer plan as part of the requirements for a seven-year National Cancer Institute (NCI) grant. As part of this early effort, committees were established to focus on American Indians as a special population, tobacco use, cancer screening and quality of cancer care. The committees remained active through 1993 – the American Indian subcommittee until 1995 – when the focus moved from comprehensive cancer control to *Women's Way*, the breast and cervical cancer early detection and screening program.

Later, under the aegis of the U.S. Centers for Disease Control and Prevention (CDC), the *Women's Way* formed a program coalition that remained active until 1998. A leadership council was formed, vision and mission statements were developed, and a coalition of more than 40 member organizations kept the idea of a cancer control coalition moving forward. Subcommittees were established to focus on quality assurance, American Indian needs, and public and professional education. Ultimately, the program coalition transitioned to the Medical Advisory Board for *Women's Way*. Since its inception in 1997, *Women's Way* has served more than 9,000 women and diagnosed 118 breast cancers and 714 cervical cancers and abnormalities requiring follow-up by a health-care professional.

At the national level, comprehensive cancer control plans were encouraged as blueprints for action that states, tribes and territories could use to guide coordination and integration of their cancer control programs.

While North Dakota was establishing its partnerships to address cancer control, efforts to develop comprehensive approaches to cancer control were underway at the national level. At the national level, comprehensive cancer control plans were encouraged as blueprints for action that states, tribes and territories could use to guide coordination and integration of their cancer control programs.

Between the spring of 1995 and the fall of 1998, CDC gathered input on the feasibility of implementing comprehensive cancer control programs (CCCP) at the state level. Key concepts and products generated include a framework for comprehensive cancer control (CCC), the identification of essential elements of CCC, and a planning model.

In 1998, CDC provided funding to five states and one tribal health board that had existing CCC plans. Since then, the number of programs participating in CDC's National Comprehensive Cancer Control Program (NCCCP) has grown from six to 63. With approximately \$15 million in Congressional appropriations in fiscal year 2005, CDC provided support for building coordinated and focused cancer control

programs in all states, the District of Columbia, six tribes and tribal organizations, and six U.S. Associated Pacific Islands/Territories. Additional CDC funding to NCCCP grantees has supported colorectal, prostate, ovarian and skin cancer control activities within CCC plans.

As part of this effort, the CDC and its national partners sponsored a series of leadership institutes to which key stakeholders in cancer control from each state – North Dakota included – were invited to participate in "how to" conferences designed to help foster the idea of a CCCP in each state. This led to the revitalization or reformation of the NDCC, with membership from the North Dakota Department of Health, institutions of higher education, interested individuals, voluntary organizations and various health-care groups throughout the state.

In 2001, Dr. Charles Kupchella, President of the University of North Dakota, as a collaborating partner in a national organization then called the "National Dialogue on Cancer," began discussions with the Governor's office about the possibility of a state CCCP. Governor John Hoeven subsequently called on the Department of Health and the University of North Dakota to partner in the development of the Healthy North Dakota program, with cancer control as part of that initiative. Rather than a narrow focus on cancer as a single chronic disease, the state engaged in an overarching comprehensive approach to good health and wellness for citizens. Since that time, the state CCCP has taken the form of a component of an overall Healthy North Dakota program. In this context, the NDCC expanded its membership and was revitalized with a grant from the CDC to help plan a CCCP for the state. The grant was submitted by the North Dakota Department of Health, with Ms. Danielle Kenneweg named as director of the program in 2004. An outline of the state's CCC plan was agreed to by the coalition in 2004, and the plan presented here was completed by summer 2006.



Lassoing A Cure

"It was a shock when I found out I had cancer. A 21 year-old isn't supposed to have cancer. The Cancer Plan means we are going to make progress in North Dakota."

Ashley Andrews (with horse Chancy), Bowman, N.D. Youngest of six children, age 21 Miss Rodeo North Dakota 2006 Hodgkin's lymphoma – currently in chemotherapy

1995

NDCC transitions to Women's Way Council

1997

Women's Way screening began in ND

1998

Women's Way Council transforms into Medical Advisory Board

1998

North Dakota Cancer Coalition (NDCC) founded

2001

Revitalization of NDCC

2001

ND team members attended CCC Leadership Institute

2002

Healthy North Dakota founded

2003

NDDoH received comprehensive cancer planning money

2004

Comp cancer planning initiated

2005

Workgroups organized to write chapters in state cancer plan

2006

- Launch of North Dakota's Cancer Control Plan
- Transition to plan implementation
- ND team members attend CCC Leadership Institute 3

The Vision

The goal of the NDCC is to reduce the number of new cancer cases, as well as the illness, disability and death caused by cancer for all North Dakotans.

It is well known that cancer is a leading cause of death and illness in North Dakota. Every year more than 3,100 North Dakotans are diagnosed with cancer, and nearly 1,300 die from the disease. Although cancer is a constellation of more than 200 different diseases, a few types – namely lung, breast, colorectal and prostate – account for the majority of cancer cases and about 50 percent of the deaths in our state. Healthy People 2010 and other national sources estimate more than one-third of cancer deaths could be prevented through the adoption of healthier lifestyles by preventing diseases from happening in the first place and through greater uses of screening and detection – making it more likely that cancers can be cured.

Given all of the above, the vision outlined in this plan is that we will, through collaboration between and among all the coalition members, work collectively and collaboratively to prevent cancers; detect cancer at its earliest stages; treat all cancer patients with the most effective treatment methods; improve the quality of life for every patient and family member touched by cancer; eliminate disparities between and among different subsets of our population from the impact of cancer; positively change modifiable risk factors; and ensure an adequate cancer prevention and control workforce.

The idea was to come up with a plan by which all of these concerns would be addressed in a comprehensive way with the work coming from existing organizations like the American Cancer Society, existing health-care organizations, tertiary care services, community-based organizations, local and state public agencies and more – anyone who might make an impact and play a role in achieving the goals articulated above.

At the outset, we recognized that all we do must be based on good data that documents the cancer burden. In addition, data is needed to document the health behaviors of North Dakotans which will likely lead to reduction in risk or an increase in survival. These measures would be tracked over time to assess progress.

Much of the CCCP outlined here focuses on prevention, i.e., keeping cancer from happening in the first place, because this is where the likelihood of positive impact is greatest. This is cancer control's "low hanging fruit." The plan is based on advocating for things such as active lifestyles, good nutrition, reducing exposures to environmental hazards, avoiding excessive alcohol use and avoiding tobacco. These are strategies that have been proven effective in preventing the onset and retarding the progression of cancer. It is based on the reality that too many North Dakotans smoke cigarettes, are physically inactive, and are overweight and obese. The plan sets actual numerical targets, not only for the ultimate outcomes of a drop in per capita cancer incidence and death rates, but also for the goals of a decrease in the number of overweight and obese North Dakotans, a decrease in those using tobacco, a decrease in chronic and binge drinking and an increase in the number of North Dakotans following good health practices. All of this will be achieved through the creation of greater public awareness about healthy lifestyles, designing and implementing public policies that support disease prevention, fostering effective and systematic check-up and screening programs, and increasing workplace wellness programs and third-party payers' role in prevention. These

People who have been diagnosed with cancer, and the others in their lives, are challenged by many physical, spiritual and emotional issues affecting their quality of life.

strides will create a culture that prevents, manages and treats cancer more effectively.

This CCCP also extends to the early screening and detection of cancer. Research has long shown that the prognosis for cancer is much more positive when cancer is detected early. Thus, the plan proposes optimal use of screening and early detection tests covered by workplace wellness and health insurance programs. Strategies include public

education concerning the optimal use and application of screening and early detection tests and provider education about screening guidelines and recommendations.

A well-planned CCCP seeks to optimize treatment of cancer. It will engage hospitals, clinics and tertiary care centers to ensure optimal cancer treatment. Discussion among key stakeholders will result in objectives and strategies surrounding key issues such as high-quality care options for all North Dakotans, improved patient knowledge about treatment options and clinical trials, and improved health-care provider and patient communications. In addition, socioeconomic and insurance barriers to treatment and clinical trials will be reduced.

People who have been diagnosed with cancer and the others in their lives are challenged by many physical, spiritual, financial and emotional issues affecting their quality of life. This plan proposes strategies to assist with survivorship issues, including increasing knowledge about resources and services available, health-care provider training to further develop skills in pain management, palliative care and managing long-term survivorship, as well as end-of-life decision making.

Cancer is a disease of the aging. As North Dakota's population increases in age, there is concern about a future workforce that is trained and prepared to deal with more cancer incidents. This state cancer plan presents objectives and strategies that address the level of preparedness of the health-care and allied-health workforce.

It has been known for many years that cancer death rates are much higher in poor counties than they are in more affluent ones. In a 1986 study, the American Cancer Society reported that poor Americans, irrespective of race, have a 10 to 15 percent lower five-year survival rate. As part of any comprehensive plan, we need to address the needs of special populations by using unique strategies that are proven effective. As with other chronic diseases, cancer has significant impact on people of a given social position, economic status, culture, race, gender, geographic location, sexual orientation and environment. We need to recognize any disparity that comes from these factors; we do so in this comprehensive cancer control plan.

Summary

In summary, while CCC addresses the need for improvement in cancer control across a wide spectrum, this plan emphasizes prevention and early detection. For too long now, medicine has emphasized treating disease once it has appeared and has not given attention to the full spectrum of the disease to warrant the likelihood of making a positive impact. The fact is, there are behaviors that we North Dakotans should avoid, and there are practices we should follow if we are to be as healthy as possible. Thus, this plan will reduce cancer's impact mainly through the attention to the adoption of healthy practices and the elimination of those shown to increase the risk of cancer.

The vision, goals, objectives and strategies identified in this cancer plan are the result of several years' worth of data gathering and two years of North Dakotans meeting to share ideas and make a difference in the cancer burden in our state. There are thousands of hours invested in this project, given by hundreds of people who have generously shared their time and talents.

Cancer touches all of our lives. We all have a parent, friend, relative or patient who has been diagnosed. The shock that comes with diagnosis is followed by fear, trepidation – then hope. Working together, we can use this state cancer plan to embrace the hope. We can make a difference. Cancer can be lessened. We can improve the quality of life and longevity for North Dakotans.

Thank You to the History and Vision Work Group

Charles Kupchella Ann Lunde Kathleen Mangskau Bev Martinson Melissa Olson Arvy Smith University of North Dakota North Dakota Department of Health North Dakota Department of Health Reach Partners, Inc. North Dakota Department of Health

North Dakota Department of Health

Bismarck, ND Bismarck, ND Fargo, ND Bismarck, ND Bismarck, ND

Grand Forks, ND



Cancer Advocacy

"We, as physicians, need to step out of our comfort zone and get involved. You can't just be a doctor in your office. You have to get up and really be an advocate."

Dr. Kevin Collins, Minot, N.D. Radiation Oncologist, Trinity Cancer Center Founding Chairperson of the North Dakota Cancer Coalition

Prevention

North Dakotans who engage in unhealthy behaviors are at increased risk for cancer. Scientific evidence suggests that one-third of cancer deaths are preventable because they are related to poor nutrition, physical inactivity and overweight or obesity. All cancers caused by cigarette smoking, tobacco use and heavy use of alcohol can be prevented. Exposure to the sun and other environmental hazards increase the risk of a cancer diagnosis. There is much work to be done to reduce risk and prevent cancer for North Dakotans.

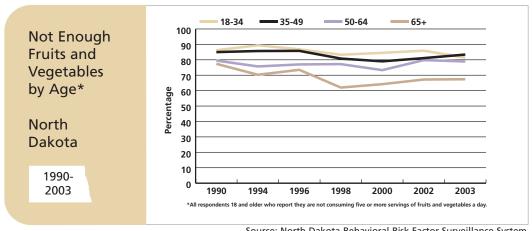


Prevent cancer by reducing risks and improving healthy behaviors of North Dakota citizens.

Nutrition

OBJECTIVE 1:

By 2010, the percentage of North Dakotans who consume five or more fruits and vegetables daily will increase by 10 percent above 2003 rates.



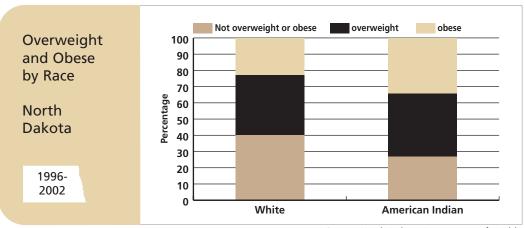
Source: North Dakota Behavioral Risk Factor Surveillance System

Strategies:

- A. Support the state Nutrition Action Plan.
- B. Incorporate fruit and vegetable messages into *Healthy North Dakota* worksite wellness and environmental supports.
- C. Support Department of Public Instruction projects that promote increase of fruit and vegetable consumption.
- D. Collaborate with food-assistance programs to increase the number of people participating in the programs.
 - E. Work with Department of Agriculture to promote North Dakota grown fruit and vegetables.
 - F. Maintain a state-level presence with the National 5-A-Day Program.
 - G. Advocate for legislative policies that direct state and local public school authorities to address issues of nutrition in their cafeterias and vending machines by providing nutritious food supplies.

OBJECTIVE 2:

By 2010, 60 percent of North Dakotans will be within normal weight range.



Source: North Dakota Department of Health

- A. Support 5+5 programs.
- B. Support USDA Team Nutrition and local school wellness policy development and implementation.
- C. Support coordinated school health initiatives.
 - D. Support work of *Healthy North Dakota* Healthy Weight Council.

OBJECTIVE 3:

By 2010, breastfeeding initiation at birth will be 75 percent. Maintain 50 percent breastfeeding at age 6 months, and 25 percent at age 1 year.

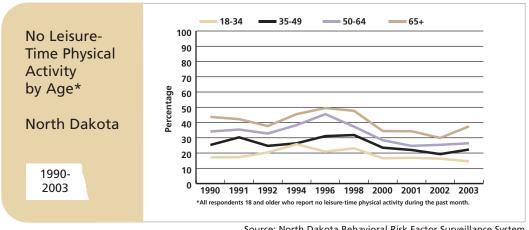
Strategies:

- A. Support Maternal and Child Health and Women, Infants and Children initiatives
- B. Support worksite wellness initiatives that encourage breastfeeding.
- C. Encourage baby-friendly practices in North Dakota hospitals.
- D. Encourage organizations and agencies to disseminate positive breastfeeding messages.

Physical Activity

OBJECTIVE 4:

By 2010, the proportion of North Dakotans who engage in daily, moderate physical activity will increase by 10 percent above 2003 rates.



Source: North Dakota Behavioral Risk Factor Surveillance System

- A. Conduct programs to increase physical activity through schools, worksites, communities and health-care settings.
- B. Conduct community-wide campaigns to increase awareness of choices for and health benefits resulting from regular physical activity.
- C. Increase access to physical activity through sustained environmental changes.
 - D. Promote regular physical activity through counseling and education from health-care providers and organizations.

OBJECTIVE 5:

By 2010, increase the number of policies that support physical activity.

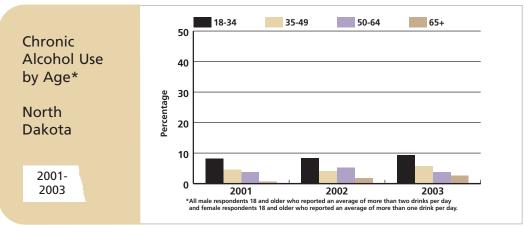
Strategies:

- A. Encourage efforts to gather baseline data about existing policies that support physical activity.
- B. Influence decision-makers to support physical activity policies.
- C. Collaborate with coordinated school health to support policies that provide for quality, daily physical education in grades pre-K through 12.
 - D. Advocate for policies that direct state public schools to address issues of physical activity by implementing the national guidelines for the amount of minutes per week that should be devoted to physical activity.

Alcohol

OBJECTIVE 6:

By 2010, the proportion of North Dakota adults who are chronic alcohol users will decrease by 2 percent compared to 2003 rates.



Source: North Dakota Behavioral Risk Factor Surveillance System

- A. Educate North Dakotans about the relationship between alcohol use and cancer.
- B. Promote awareness among primary health-care providers about the need to screen all patients for alcohol use and abuse and the importance of early intervention.
- C. Increase awareness of substance abuse prevention services available in North Dakota.

OBJECTIVE 7:

By 2010, the proportion of North Dakota youth (grades nine through 12) who are alcohol users will decrease by 5 percent compared to 2003 rates.

Strategies:

- A. Promote the use of evidence-based alcohol prevention curriculum in schools.
 - B. Encourage youth involvement in programs that address risky behaviors.
 - C. Encourage schools to use approved screening tools with students.
 - D. Develop and support community coalitions that address youth alcohol use.

Environmental Issues

OBJECTIVE 8:

By 2010, strengthen public protection from environmental risks.

Strategies:

- A. Collaborate with local public health units to educate the public regarding health concerns from radon, asbestos, lead, mold and other indoor air quality issues.
- B. Provide mold mitigation guidance to communities experiencing flooding.
- C. Expedite regional haze rules to require installation of new and updated pollution controls on older power plants.
- D. Educate contractors on radon-proofing new construction and "fixing" existing structures to increase the number of homes protected from high levels of radon.
- E. Certify and train operators of regulated drinking water and wastewater systems.
- F. Administer loan programs to assist communities to upgrade or construct needed drinking water and wastewater treatment facilities.
- G. Protect drinking water sources from contamination.

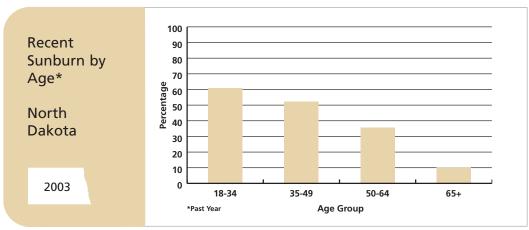
OBJECTIVE 9:

By 2007, strengthen North Dakota's smoke-free law to provide protection from second-hand smoke in all public places and places of employment.

- A. Collaborate with the state tobacco policy committee to advocate for comprehensive statewide smoke-free policies.
- B. Support ongoing media campaigns and advocacy efforts about the dangers of second-hand smoke and the benefits of smoke-free policies.
 - C. Educate local and state policymakers on the need for and benefits of smoke-free policies.
 - D. Educate coalition members, decision-makers, business owners and school administrators about the economic and health benefits of smoke-free policies.
- E. Work with local coalitions to pass comprehensive smoke-free policies at the local level.

OBJECTIVE 10:

By 2010, the number of North Dakotans who use ultraviolet (UV) protective measures will increase.



Source: North Dakota Behavioral Risk Factor Surveillance System

Strategies:

- A. Encourage efforts to gather baseline data about use of UV-protective measures.
- B. Provide education in schools about the effect of UV exposure and the importance of using sunscreen with a SPF of at least 15.
 - C. Provide public awareness campaigns about the effects of UV exposure and the importance of using sunscreen with a SPF of at least 15.
 - D. Educate youth and adults about sun protective measures such as limiting sun exposure and wearing protective clothing and sunglasses with UV protection.
 - E. Provide education about the risks of using tanning beds and booths.
- F. Provide education about sun protection measures in recreational settings.
- G. Advocate for sun protection policies in recreational settings.

Other Health Behaviors

OBJECTIVE 11:

By 2010, decrease the percentage of North Dakotans at risk for exposure to viral or bacterial infections resulting from engaging in risky sexual activities, using recreational injection drugs, and failing to be immunized for vaccine-preventable diseases.

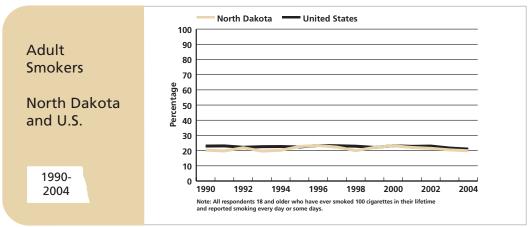
- A. Support and promote Advisory Committee on Immunization Practices (ACIP) and state recommendations for viral hepatitis and Human papillomavirus (HPV) vaccine distribution and administration.
- B. Educate the public about viral hepatitis and HPV disease and vaccination.
- C. Educate health-care providers about how to talk to parents and patients about viral hepatitis and HPV and long-term benefits of the hepatitis B and HPV vaccines.

- D. Educate health-care providers about how to talk to patients for the purpose of risk assessment.
- E. Support the development of comprehensive health education programs in local communities.
- F. Encourage person-to-person provision of information, training or support delivered to individual, small group and community levels.
- G. Support the North Dakota Department of Health Vaccines for Children (VFC) program.
- H. Support efforts to provide viral hepatitis vaccine to high-risk populations.
 - I. Support the development of surveillance capacity for determining high-risk sexual behavior in youth.

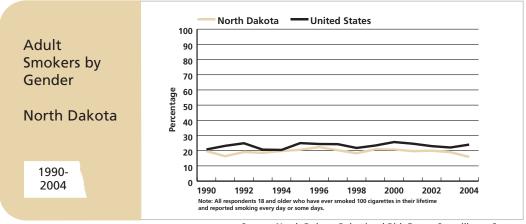
Tobacco

OBJECTIVE 12:

By 2010, decrease from 22 percent in 1999 to 18 percent the percentage of adults who are current smokers.



Source: North Dakota Behavioral Risk Factor Surveillance System



Source: North Dakota Behavioral Risk Factor Surveillance System

Strategies:

- A. Promote the North Dakota Tobacco Quitline and local cessation services.
- B. Promote insurance coverage for cessation services.
- C. Promote health-care provider training on Public Health Service guideline, Treating Tobacco Use and Dependence.
- D. Promote health-care systems change by institutionalizing Preventive Health Service Guidelines.
- E. Advocate for a significant increase in the tax on tobacco products.
 - F. Collaborate with Tobacco Cessation Committee and Quitline Consortium to coordinate service and promote policy change.



No Turning Back to Tobacco

"Before we really didn't know any different, but now I would never go back to a smoking place. Since we've gone smoke-free, we have fewer sick call-ins and I just don't get colds like I used to. I hope those bar workers can get out of that smoky environment, and yes, we are hiring!"

Sherry Sand, Jamestown, N.D. General manager of the Jamestown Truck Plaza Cafe

OBJECTIVE 13:

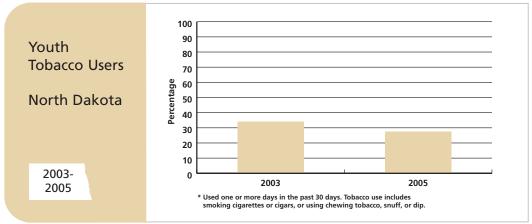
By 2010, decrease from 4 percent in 2001 to 3 percent the percentage of North Dakota adults who currently use chewing tobacco or snuff every day or some days.

Strategies:

- A. Promote the North Dakota Tobacco Quitline and local cessation services.
- B. Promote insurance coverage for cessation services.
- C. Promote health-care provider training on Preventive Health Service Guidelines to prevent tobacco use and addiction.
- D. Promote health-care systems change by institutionalizing Preventive Health Service Guidelines.
- E. Advocate for a significant increase in the tax on tobacco products.
 - F. Collaborate with Tobacco Cessation Committee and Quitline Consortium to coordinate service and promote policy change.

OBJECTIVE 14:

By 2010, decrease from 34 percent in 2003 to 22 percent the percentage of students in grades nine through 12 who are current tobacco users. Tobacco use includes smoking cigarettes or cigars or using chewing tobacco, snuff or dip.

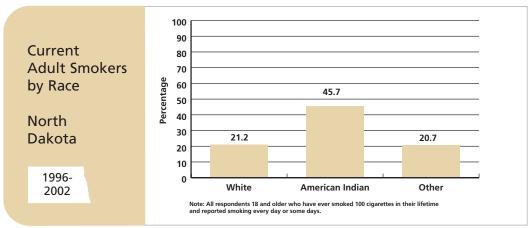


Source: North Dakota Youth Risk Behavioral Factor Surveillance System

- A. Promote the use of evidence-based tobacco prevention curricula in schools.
 - B. Promote adoption of comprehensive tobacco-free school policy.
- C. Promote implementation of the U.S. Centers for Disease Control and Prevention Guidelines for School Health Programs to Prevent Tobacco Use and Addiction.
- D. Provide cessation resources to youth.
- E. Advocate for a significant increase in the tax on tobacco products.
 - F. Conduct compliance checks and retailer education.
 - G. Collaborate with Youth Tobacco Committees to implement prevention strategies.

OBJECTIVE 15:

By June 2010, decrease from 45 percent in 1999/2000 to 40 percent the percentage of American Indian adults who smoke.



Source: North Dakota Department of Health

Strategies:

- A. Collaborate with the *Healthy North Dakota* Disparities Committee.
- ▶ B. Promote the North Dakota Tobacco Quitline and tribal cessation programs.
- C. Promote health-care provider training on the Public Health Service guideline, Treating Tobacco Use and Dependence.
- D. Promote health-care systems change to institutionalize the Public Health Service Guidelines.
- ◆ E. Promote tobacco-free policies in reservation workplaces.
- F. Advocate for increased resources for tribal tobacco prevention and control programs.

OBJECTIVE 16:

By June 2010, decrease from 19 percent in 1999 to 12 percent the percentage of pregnant women who smoke.

Strategies:

- A. Promote the North Dakota Tobacco Quitline and local cessation programs.
- B. Promote health-care provider training on the Public Health Service guideline, Treating Tobacco Use and Dependence.
- C. Promote health-care systems change to institutionalize the Public Health Service Guidelines.
- D. Collaborate with the *Healthy North Dakota* Disparities Committee.
- ◆ E. Advocate for a significant increase in the tax on tobacco products.

OBJECTIVE 17:

By June 2010, institutionalize reducing tobacco-related disparities into the state planning process.

Strategies:

- A. Identify tobacco-related health disparities and related diseases.
- B. Identify policy opportunities to address tobacco-related disparities.
- C. Collaborate with partner agencies and organizations to address tobacco-related disparities.
- D. Collaborate with the Aberdeen Area Tribal Chairmen's Health Board Epidemiology Center on data issues.
- **E.** Collaborate with the *Healthy North Dakota* Health Disparities Committee and the Tobacco Special Populations Committee to address tobacco-related disparities.

OBJECTIVE 18:

By June 2010, establish baseline for the percentage of American Indian adults who report no smoking is allowed in their home.

Strategies:

- A. Educate American Indian adults about the dangers of second-hand smoke.
- B. Educate local policymakers on the need for and benefits of smoke-free environments.

Thank You to the Prevention Work Group

Dati A. I	N d D L d D d d d D L d d d	D' L ND
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Early Detection is Key

"The earlier you can detect cancer, the better you are. I have to remember where I was and where I am now. I'm a survivor and I always have to be thankful for that."

Keith Peltier with wife Cathy, Harvey, N.D. Husband and father Owner of Proseeds, Inc. Colorectal cancer survivor

Early Detection and Screening

There are many barriers to cancer screening for North Dakotans. These barriers can be grouped into four major areas – financial and insurance restrictions, limited provider knowledge and referral, lack of consumer awareness and system inadequacies. These factors all contribute to low screening rates among special populations and the need to change the approach to cancer screening and early detection in North Dakota.



Lead the nation in appropriate screening for and early detection of cancer.

All Screenable Cancers

OBJECTIVE 19:

By 2010, increase the percentage of North Dakotans who receive appropriate cancer screenings.

- A. Provider Education
 - Encourage providers to obtain detailed family history to identify inherited predisposition for cancer that can initiate appropriate testing and screening.
 - 2. Educate health-care providers and students about screening and follow-up.
 - 3. Develop a common tracking tool for providers and health-care systems for cancer screening.
 - 4. Disseminate screening and follow-up guidelines to all health-care providers.
 - 5. Educate primary-care providers about symptom recognition.
 - 6. Advocate for inclusion of patient communication skills curricula in health-care provider training.
- B. Geographic Barriers
 - 1. Encourage the "one-stop shop" concept to make screening more convenient.
 - 2. Explore opportunities to provide local access to screening.

- C. Out-of-Pocket Expenses
 - 1. Increase awareness and knowledge of insurance plan coverage options and other non-traditional payment options.
 - 2. Support and advocate for free or low-cost screening services for people such as is offered at Community Health Centers, by *Women's Way*, and by others.
 - D. Multi-component media and public education campaigns
 - 1. Educate the public about screenings at age 50 and older.
 - 2. Educate the public about symptom recognition.
 - 3. Strengthen statewide stakeholder networks to support media campaigns, outreach and education.
 - 4. Promote the business case for early detection and screening.

Bladder Cancer

A method of early detection and screening for bladder cancer is not available at this time. Scientific research investigating early detection of bladder cancer should be monitored on an on-going basis.

Breast Cancer

OBJECTIVE 20:

By 2010, increase number of health-care providers who deliver consistent and appropriate messages to help women make informed decisions about breast cancer screening and follow-up.

- A. Adopt and promote a common set of breast cancer screening and follow-up guidelines for all health-care plans and health-care systems.
- B. Encourage efforts to gather baseline data.



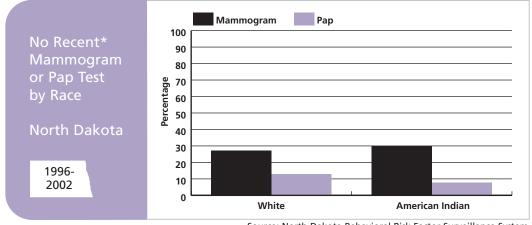
Funding Needed

"We want to make cancer a national priority again. We need federal and state funding to keep partnerships going and to address cancer control and prevention in North Dakota."

Margaret Leas, R.N., Rolla, N.D. Two-time survivor of breast cancer; N.D. delegate to the 2006 Lance Armstrong Convention in Washington D.C.

OBJECTIVE 21:

By 2010, the percentage of age-appropriate women who receive breast cancer screening will increase by 10 percent above 2002 rates.



Source: North Dakota Behavioral Risk Factor Surveillance System

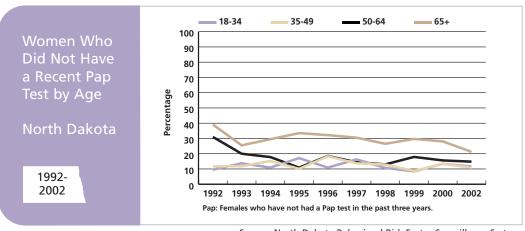
Strategy:

• A. Reduce barriers to breast cancer screenings, especially financial, geographic and access issues.

Cervical Cancer

OBJECTIVE 22:

By 2010, the percentage of women age 18 years and older who have had a Pap test within the past three years will increase by 7.5 percent above the 2002 rate.



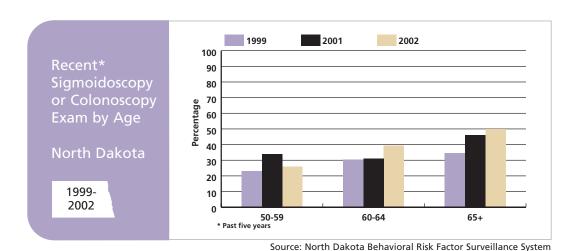
Source: North Dakota Behavioral Risk Factor Surveillance System

- A. Develop a comprehensive media plan to educate women on the importance of cervical cancer screening and the connection between HPV and cervical cancer.
- B. Develop systematic approaches for providers to recommend cervical cancer screenings.
- C. Create partnerships to reach women who are not being screened for cervical cancer.
- D. Create and strengthen community outreach based on interventions to promote cervical cancer screenings.
- E. Advocate for system changes that meet the needs of American Indian women in North Dakota, such as access to female health-care providers and culturally appropriate cervical cancer screening education.

Colorectal Cancer

OBJECTIVE 23:

By 2010, the percentage of North Dakotans 50 and older who have been screened for colorectal cancer within the past 10 years will increase to 75 percent.



Strategies:

- A. Advocate for inclusion of colorectal cancer screening tests in all health insurance plans.
- B. Encourage a state written agreement with insurers to cover colorectal screening.
- C. Advocate for state employee insurance coverage to include colorectal screening.
- D. Advocate for state funding to provide colorectal screening to the uninsured.
- E. Advocate for Medicaid coverage for colorectal screening.
- F. Advocate for client reminders about screening.
- G. Reduce structural barriers such as location, hours of operation and availability of child care.

Lung Cancer

A method of early detection and screening for lung cancer is not available at this time. Scientific research investigating early detection of lung cancer should be monitored on an ongoing basis.

Melanoma

OBJECTIVE 24:

By 2010, the rate of melanoma detected early (< 1.0 mm Breslow depth on in situ stage) by physician will increase.

Strategies:

- A. Establish current rate by conducting study using registry data.
- B. Promote skin self-examinations by people at high risk.
- C. Promote skin cancer screening events.

OBJECTIVE 25:

By 2010, decrease the melanoma mortality age-adjusted rate to 2 per 100,000 people.

Strategies:

- A. Increase public education about skin self-examinations and regular screenings.
- B. Promote skin cancer screening events.

OBJECTIVE 26:

By 2010, the number of health-care providers who report diagnosed melanoma cases will increase over the number reporting in 2004.

Strategy:

A. Implement activities through the cancer registry to encourage health-care providers to comply with state law about disease reporting.

Oral and Pharyngeal Cancer

OBJECTIVE 27:

By 2010, the percentage of oral and pharyngeal cancers detected at the earliest stage will increase to 50 percent compared to 35 percent in 1995.

Strategies:

- A. Increase oral cancer screenings by physicians to 25 percent.
- B. Increase oral cancer screening by dentists to 100 percent.
- C. Promote screening for all adult patients, regardless of risk.

OBJECTIVE 28:

By 2010, the percentage of adults who report having had an oral and pharyngeal cancer examination in the past year will increase to 50 percent compared to 35 percent in 1995.

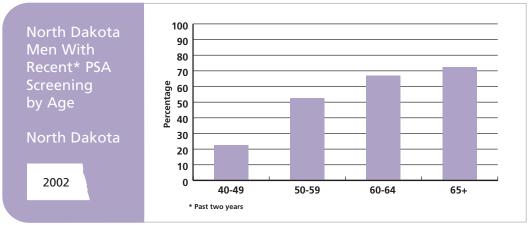
Strategies:

- A. Promote continuing education for health-care professionals on oral cancer screening techniques.
- B. Develop a resource tool to assist physicians in identifying suspicious lesions.
- C. Provide current cancer data trends to dental professionals. This will allow comparison to the rest of the state and nation.
- D. Conduct an education campaign about oral cancer risk factors.
- E. Develop an awareness campaign for American Indian and Medicaid dental provider populations.

Prostate Cancer

OBJECTIVE 29:

By 2010, the percentage of men 50 and older who have annual Prostate Specific Antigen tests (PSA) and Digital Rectal Examinations (DRE) will increase to 80 percent compared to the 2002 rate.



Source: North Dakota Behavioral Risk Factor Surveillance System

Strategies:

- A. Encourage development of creative programs that increase prostate screening rates such as a traveling mobile screening RV for events frequented by men and/or requiring PSA screening results to get hunting and fishing licenses.
- B. Develop a list of questions for patients to ask their health-care providers about prostate cancer.
- C. Encourage third-party payers and employers to promote PSA/DRE to members and employees.
- D. Encourage men to engage in informed decision-making with their health-care providers regarding prostate screening.



Cancer Check

"Not looking for cancer is like not checking oil pressure in a car. You might ignore it for a while, but it will catch up with you. There needs to be a push from the medical and public sectors to look for cancer, face it, and fix it."

Allen Lund, prostate cancer patient and Dr. Mark Andrews, family physician Stanley, N.D.

OBJECTIVE 30:

By 2010, the number of physicians who recommend and administer PSA/DRE for male patients age 50 and older will increase.

Strategies:

- A. Provide health-care providers with feedback about the number of patients 50 and over who have annual PSA/DREs.
- B. Develop and distribute talking points for physicians.
- C. Conduct a communication campaign targeted to primary-care providers.
- D. Encourage providers to engage patients in informed decision-making.

OBJECTIVE 31:

By 2010, the number of high-risk men who receive prostate cancer screenings beginning at age 35 will increase.

- A. Distribute consumer education materials about prostate cancer risk.
- B. Distribute information to primary-care physicians about factors that put patients in a high-risk category.
- C. Encourage efforts to gather baseline data.

Thank You to the Early Detection Work Group

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Walsh County Health District **American Cancer Society** Medcenter One Ransom County Public Health Department North Dakota Department of Health Upper Missouri District Health Unit Altru Health System North Dakota Department of Health North Dakota State University North Dakota Health Care Review, Inc. Dakota Clinic Ltd. Reach Partners, Inc. MeritCare Roger Maris Cancer Center Standing Rock Sioux CHR Program Altru Health System North Dakota Prostate Cancer Coalition St. Andrews Health Center Medcenter One Aberdeen Area Tribal Chairmen's Health Board North Dakota Prostate Cancer Coalition Community Health Care Association of the Dakota's North Dakota Department of Health American Cancer Society MeritCare Medical Group

Grafton, ND Bismarck, ND Bismarck, ND Lisbon, ND Bismarck, ND Williston, ND Grand Forks, ND Bismarck, ND Fargo, ND Minot, ND Fargo, ND Fargo, ND Fargo, ND Fort Yates, ND Grand Forks, ND Bismarck, ND Bottineau, ND Bismarck, ND Rapid City, SD Mandan, ND Ft. Pierre, SD Bismarck, ND Bismarck, ND Fargo, ND

Treatment, Disease Management and Clinical Trials

Several factors can interfere with access to effective cancer treatment and care in North Dakota. Lack of patient knowledge, limitations on the quality of available care, inadequate provider-patient communication, insurance coverage and socioeconomic status are all potential issues affecting cancer treatment and access to clinical trials for North Dakotans.



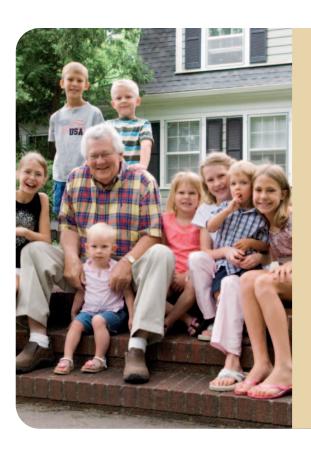
Increase access to effective cancer treatment and care.

Quality of Care

OBJECTIVE 32:

By 2010, improve provider and patient awareness of available treatment options, including clinical trials among cancer patients in North Dakota.

- A. Use media to increase awareness about treatment options and clinical trials.
- B. Develop and distribute a brochure that summarizes available resources with links to most recent information.
- C. Support the use of properly trained and culturally competent community health workers or navigators in communities experiencing cancer health disparities.
- D. Establish a clinical trials education network.
 - ◆ E. Support informed, shared and empathetic decision-making regarding clinical trials and cancer treatment.
 - F. Highlight participants in past clinical trials and stress the value of clinical trials through campaigns sponsored by nonprofit organizations.
 - G. Advocate for insurance coverage of clinical trials.



Family Matters

"They tell me it's gone, but you always wonder if it will come back and where it will come back. We need to work to remove the stumbling blocks in clinical trials. We also need to be working towards common goals."

John Resell, Fargo, N.D. Husband, father and grandfather Lung cancer survivor

OBJECTIVE 33:

By 2010, the percentage of primary-care providers who have nationally recognized treatment guidelines available will be at least 75 percent.

Strategies:

- A. Distribute National Comprehensive Cancer Network (NCCN) Guidelines to all health-care providers.
- B. Conduct provider education on standard treatment protocols and guidelines.
- C. Ensure that treatment facilities have equipment necessary to provide services.
- D. Use North Dakota Cancer Registry data to review stage specific treatment.

OBJECTIVE 34:

By 2010, work to increase the administration of chemotherapy in rural facilities.

- A. Assess the current availability of rural health-care facilities providing chemotherapy treatment.
- B. Ensure appropriate nurse training.
- C. Explore feasibility of rural chemotherapy centers/satellite centers.
- D. Seek on-site physicians or mid-level practitioners to oversee local treatment.
- E. Advocate for increased state funding for rural health-care facilities to increase access.

OBJECTIVE 35:

By 2010, the number of lymphedema referrals for post-mastectomy and lumpectomy patients will increase to the optimal level.

Strategy:

A. Determine the percentage of patient referrals by comparing the number of breast cancer patients for a given period against the number of lymphedema referral codes on hospital billings.

OBJECTIVE 36:

By 2010, patient knowledge about cancer, treatment and treatment alternatives will improve.

Strategies:

- A. Conduct a pre- and post-intervention survey of oncology patients regarding knowledge of treatment options and their satisfaction and perception of care.
- B. Develop the North Dakota Cancer Connection brochure that will direct patients to reliable websites, refer patients to evidence-based treatments and encourage sharing alternative treatment information with health-care providers.
- C. Support the use of properly trained and culturally competent community health workers or navigators in communities experiencing cancer health disparities.

OBJECTIVE 37:

By 2010, the number of cancer patients seeking and completing treatment and follow-up care following NCCN cancer guidelines for Stage III colon cancer and breast lumpectomy followed by radiation will increase.

Strategies:

- A. Reduce barriers including but not limited to transportation, cost of medication and procedures, access to lodging, availability of treatment protocols and knowledge about co-pays.
- B. Develop a cancer treatment access guide that profiles treatment facilities in the state, as well as housing and transportation options available.

OBJECTIVE 38:

By 2010, the number of treatment centers with patient navigators will increase from one to six.

- A. Encourage family members' involvement in the treatment process to deal with barriers such as language, hearing, sight, etc.
- B. Conduct survey of patients regarding satisfaction and perception of quality of care.

OBJECTIVE 39:

By 2010, support efforts that increase knowledge of policymakers and decision-makers related to issues of health insurance and care, including, but not limited to, the poor, underinsured, uninsured, geographically challenged, people of color, and Medicare and Medicaid populations.

Strategies:

- A. Partner with existing lobbying groups to inform lawmakers.
- B. Dialogue with third-party payers.

OBJECTIVE 40:

By 2010, advocate for inclusion of preventive care, screening and clinical trials in all health insurance packages offered in North Dakota.

Strategies:

- A. Use data to show cost savings.
- B. Educate elected officials.
- C. Support advocacy group efforts to achieve stated objectives.

Thank You to the Treatment Work Group

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Northern Plains Tribal EPI Center
North Dakota Long Term Care Association
St. Joseph's Hospital & Health Center
University of North Dakota
Mid Dakota Clinic

Minot, ND Bismarck, ND Portland, OR Bismarck, ND Bismarck, ND Rolla, ND Bismarck, ND Grand Forks, ND Rapid City, SD Bismarck, ND Dickinson, ND Grand Forks, ND Bismarck, ND

Bismarck, ND

Quality of Life

Improvements in the early detection and treatment of cancer have resulted in more people living longer after being diagnosed with the disease. People who have been diagnosed with cancer and others in their lives are challenged by a host of short-and long-term issues affecting the quality of their lives, including physical, spiritual, emotional, pain control and for some, decisions about end-of-life care. There is a general lack of knowledge among health-care providers and the public about resources and services available to North Dakotans.



Optimize the quality of life for every person affected by cancer.

OBJECTIVE 41:

By 2010, improve provider and consumer knowledge and understanding of pain control and symptom management.

Strategies:

- A. Collaborate with health-care organizations to ensure awareness of all health-care providers about the numerous resources available for pain management, such as the World Health Organization's three-step analgesic-ladder approach and the American Pain Society's Principles of Analgesic Use in the Treatment of Acute Pain and Cancer Pain.
- B. Encourage health-care professionals to attend advanced training.
- C Encourage alternative methodology for delivery of training in home communities.
- D. Collaborate with the North Dakota Department of Health to ensure pain management is a part of the state regulatory requirements for state-surveyed health-care facilities.

OBJECTIVE 42:

By 2010, ensure North Dakotans who have been diagnosed with cancer can access appropriate palliative care through all phases of cancer treatment and hospice care at end of life.

Strategies:

- A. Provide information that describes treatment intent including palliative care along with educational materials to cancer patients and their families.
- B. Encourage health-care professionals to attend advanced training in hospice and palliative care.
- C. Increase the number of health-care professionals credentialed in hospice and palliative care.
- D. Support the recommendations of the North Dakota End-of-Life Care Project, including secure funding to assess the End-of-Life Care Project recommendations and work with the End-of-Life Care work groups to continue and advance initiatives.
- **E.** Increase the number of trained health-care providers who serve disparate populations.
 - F. Develop a database of hospice and palliative care providers that is readily accessible to patients, families and health-care providers for identification and linkage to resources.
- G. Increase the availability of culturally appropriate hospice and palliative services throughout all parts of North Dakota.

OBJECTIVE 43:

By 2010, maximize the use of services that support the short-term and long-term needs (e.g., symptom control and emotional, economic and spiritual needs) and that improve quality of life of cancer survivors and their families.

- A. Investigate and research the feasibility of patient navigators for North Dakota.
- B. Develop, maintain and promote an inventory of resources that support the short- and long-term needs of cancer survivors and their families.
- C. Promote access to support groups or services throughout North Dakota.
- D. Encourage efforts to gather baseline information from cancer survivors and family members or caretakers.
- E. Educate health-care providers, patients and their families about the short- and long-term issues that affect the quality of life of cancer survivors and their families following initial treatment.



Reaching for Results

"In order for this plan to work, we need a group of do-ers. If the plan reaches the community level, that will determine the success. If we can do that, we will see results."

Dr. John Joyce, Hettinger, N.D. Family Medicine, West River Health Services

OBJECTIVE 44:

By 2010, optimize continuity of care for North Dakota cancer survivors beyond the initial course of treatment.

- A. Develop and promote methods to facilitate the exchange of information among all health-care providers involved in the care of cancer survivors.
- B. Educate cancer survivors and their families about the importance of seeking information about the short- and long-term plans for follow-up.
- C. Link with existing resources that are useful in short- and long-term follow-up and continued survivorship.
- D. Educate policymakers about the needs of survivors beyond the initial course of treatment.
- E. Encourage health-care providers to develop survivorship care plans for all patients.

OBJECTIVE 45:

By 2010, improve public perception about cancer survivorship.

Strategies:

- A. Utilize survivors as role models in public awareness campaigns.
- B. Educate employers and public officials about the short- and long-term issues that affect the quality of life of cancer survivors and their families.
- C. Create a public awareness campaign celebrating survivorship by expanding the relationship with the North Dakota Division of the American Cancer Society and Relay for Life.
- D. Publicize survival data.
- E. Support efforts to gather survivorship data.

OBJECTIVE 46:

By 2010, ensure that quality care at the end of life, especially the management of cancer-related pain and timely referral to palliative and hospice care is available throughout North Dakota.

Strategies:

- A. Advocate for improvement of pain management in North Dakota.
- B. Support legislation to promote awareness and adoption of Cancer Pain Management practice guidelines as a standard of care for pain control.
- C. Collaborate with the Matters of Life and Death Coalition partners who have made a commitment to improving end-of-life care in North Dakota and can serve as conduits for proposed policy initiatives.
- D. Work with the North Dakota Hospice Organization to implement cancer referral guidelines to assist referral sources in making timely referrals.

Thank You to the Quality of Life Work Group

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Workforce of the Future

The cancer care workforce is broad and includes many support services outside the health-care setting. At the current time, the depth and breadth of workforce issues related to cancer prevention and control are unknown. What we do know is that North Dakota's population is aging. The state's population has need for health professionals to work with people diagnosed with and surviving cancer. The health-care workforce in the state will be challenged by this changing demographic and the potential decrease in number of adequately trained health-care providers. North Dakotans deserve a health-care workforce that is appropriately trained through a consistent curriculum. Job opportunities exist in cancer career areas that contribute to the economic well-being of communities if North Dakota can find ways to encourage young professionals to live and work here.



Ensure an adequate supply and competently trained workforce to provide comprehensive cancer care in North Dakota.

OBJECTIVE 47:

By 2008, identify current gaps and needs in the current and future North Dakota cancer care workforce.

- A. Gather and publish baseline data regarding the current cancer workforce.
- B. Identify a process for ongoing monitoring of the North Dakota cancer care workforce.
- C. Partner with North Dakota Job Service, the North Dakota University System and other partners to gather appropriate data.

OBJECTIVE 48:

By 2008, ensure that the current and future workforce is adequately prepared to prevent, diagnose and treat cancer; provide palliative care; deal with end-of-life issues; and support cancer survivors.

Strategies:

- A. Provide continuing education regarding cancer care to health-care professionals.
- B. Encourage health-care facilities to provide comprehensive cancer care orientation to all new employees who are working with cancer patients.
- C. Train community members as health mentors so that all caregivers (family members, friends, neighbors, church members, etc.) will have access to education and support.

OBJECTIVE 49:

By 2010, ensure and enhance the availability of cancer-care providers to underserved, minority and rural areas.

Strategies:

- A. Educate North Dakotans about areas where shortages of workforce exist through public trainings and other venues.
- B. Pursue trainings and authorization for nurse practitioners, nurses and other professionals to provide screenings for specific sites.

OBJECTIVE 50:

By 2010, achieve an optimal supply of cancer-care providers in all related professions, especially where shortages have been demonstrated. This includes but is not limited to nurses, physicians, specialty physicians, mid-level practitioners, cancer registrars, social workers, medical record staffers, radiation technologists, public health and prevention specialists, hospice workers, medical transcriptionists, home health workers, researchers and others.

- A. Establish speakers' bureau using people from all cancer-related career areas to increase recruitment into both traditional and non-traditional professions.
- B. Support the use of a model curriculum for cancer care in schools of medicine, nursing and other allied health professions.

OBJECTIVE 51:

By 2010, increase the number of health-care providers providing culturally competent healthcare in North Dakota.

Strategies:

- A. Support the use of properly trained and culturally competent community health workers or navigators in communities experiencing cancer health disparities.
- B. Support ongoing cultural competency education opportunities for health-care providers.
- C. Increase the number of racial and ethnic minority individuals in the health-care field.



Neighbors Helping Neighbors

"We are chemo, home-care, and hospice nurses. We help people through each stage, whether they are successful in the battle or face the end stages. We set up a rapport in the beginning and follow through. This is unique for rural care."

Sandy Lessard, R.N., Grafton, N.D. Home-care, hospice and chemotherapy nurse

Thank You to the Workforce of the Future Work Group

Ruth Bachmeier Marsha Lembke Donna O'Shaughnessy Fargo Cass Public Health North Dakota Department of Transportation North Dakota Department of Health Fargo, ND Bismarck, ND Bismarck, ND



Rural Resources

"I am a prostate cancer survivor and I am very thankful that the Men's Health Clinic was started here on Standing Rock."

Del LeCompte, Fort Yates, N.D. Enrolled member of the Standing Rock Sioux Nation Land coordinator for Standing Rock Prostate cancer survivor

Cancer Disparities

It has been well documented that health disparities exist for groups within a given population. The same holds true for cancer. Disparities in cancer incidence, mortality and survival have been described in terms of race and ethnicity, gender, age and geography. Further disparities exist in terms of socioeconomic status, sexual orientation and insurance status. Recent research findings indicate that members of racial and ethnic minority groups are less likely than whites to receive needed medical care. This may partially explain some cancer-related health disparities. Other issues related to health disparities in North Dakota involve prevention, access to care, screening, treatment, clinical trials, quality of life, workforce preparation and data/surveillance.



To continually and respectfully work to identify and reduce cancer disparities in North Dakota.

OBJECTIVE 52:

By 2010, establish an ongoing and coordinated system that accurately monitors and documents cancer health disparities in North Dakota.

- A. Support efforts to improve the availability and completeness of data collection in terms of race/ethnicity classification.
- B. Strengthen the accuracy of reporting to the statewide cancer registry.
- C. Develop and strengthen data linkages, particularly with Indian Health Service and third-party payers.
- D. Periodically publicize cancer health disparities information.
- E. Develop and maintain a centralized repository of disparities data and resources.
- F. Recommend including questions about sexual orientation and gender identity on data collection forms in health-care facilities, on surveys, by cancer registries, and at other pertinent venues to increase knowledge about associations between sexual orientation or gender identity and cancer health status.

OBJECTIVE 53:

By 2010, increase the number of health-care providers and systems providing culturally competent health care in North Dakota.

Strategies:

- A. Support the use of properly trained and culturally competent community health workers or navigators in communities experiencing cancer health disparities.
- B. Support ongoing cultural competency education opportunities for health-care providers.
- C. Develop and maintain a centralized repository of disparities data and resources.
- D. Support the local development of culturally appropriate cancer education materials.
- E. Support informed/shared/empathic decision-making regarding clinical trials, screening, treatment, palliation and end-of-life care.
- F. Increase the number of racial and ethnic minority individuals in the health-care field.
- G. Work with partners to establish a North Dakota Office of Minority Health.
- H. Encourage a greater proportion of community-based participatory research (CBPR) models, particularly with tribal communities in North Dakota.
- I. Ensure the diversity of cultural competency trainings by supporting education in the following areas: including but not limited to gender; race or ethnicity; education, income, or employment; refugee or immigrant status; age; geographic location; physical or mental status; and sexual orientation or gender identity.



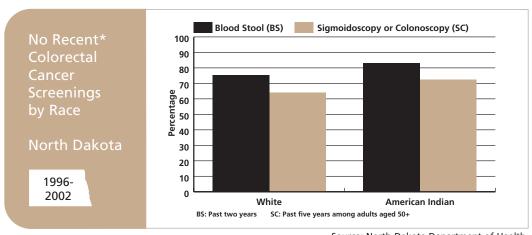
Access to Care

"Look at our data. We have the highest rates of cancer for all Indian people. We need access to specialty clinics. We need funding, access and leadership representation."

Penny Wilkie, M.D., (with Kelli Quick Bear) New Town, N.D. IHS Minne-Tohe Health Center Physician Enrolled member of the Turtle Mountain Band of Chippewa

OBJECTIVE 54:

By 2010, ensure that all North Dakotans will have access to cancer-related services.



Source: North Dakota Department of Health

Strategies:

- A. Support and encourage community programs that provide transportation and housing for cancer-related services.
- B. Support the use of properly trained and culturally competent community health workers or navigators in communities and health-care settings within communities experiencing cancer health disparities.
- C. Increase the availability of insurance for medically underserved populations.
- D. Increase the number of rural health-care facilities that provide cancer treatment.
- E. Increase availability of cancer treatment drugs for medically underserved populations.
- F. Establish a baseline and then work to increase knowledge among disparate populations about how to access cancer services.
- G. Ensure the diversity of disparate groups targeted to receive access information by supporting efforts in the following areas: including but not limited to gender; race or ethnicity; education, income, or employment; refugee or immigrant status; age; geographic location; physical or mental status; and sexual orientation or gender identity.

OBJECTIVE 55:

By 2010, develop a culturally appropriate system of coordination among organizations that improve the continuity of cancer care and improve the dissemination of cancer resources available to disparate populations.

Strategies:

- A. Support the use of properly trained and culturally competent community health workers or navigators in communities experiencing cancer health disparities.
- B. Increase community legislative capacity to address cancer control needs through public policy measures.
- C. Increase culturally appropriate environments throughout the cancer continuum.
- D. Develop relationships with organizations serving the following groups: including but not limited to gender; race or ethnicity; education, income, or employment; refugee or immigrant status; age; geographic location; physical or mental status; sexual orientation or gender identity to develop culturally competent methods of reaching communities affected by cancer health disparities.

Integrated Objectives & Strategies About Disparities

Note: In addition to the cross-cutting disparities issues above,

objectives and strategies that are specific to the disparate populations in

North Dakota have been integrated in the individual chapters.

These items also are repeated below.



Prevention

(Repeated from pages 21 to 31.)

OBJECTIVE 1:

By 2010, the percentage of North Dakotans who consume five or more fruits and vegetables daily will increase by 10 percent above 2003 rates.

Strategy:

D. Collaborate with food-assistance programs to increase the number of people participating in the programs.

OBJECTIVE 11:

By 2010, decrease percentage of North Dakotans at risk for exposure to viral or bacterial infections resulting from engaging in risky sexual activities, using recreational injection drugs, and failing to be immunized for vaccine-preventable diseases.

Strategy:

- ◆ F. Encourage person-to-person provision of information, training or support delivered to individual, small group and community levels.
 - G. Support the North Dakota Department of Health Vaccines for Children (VFC) program.
 - H. Support efforts to provide viral hepatitis vaccine to high-risk populations.

OBJECTIVE 15:

By June 2010, decrease from 45 percent in 1999/2000 to 40 percent the percentage of American Indian adults who smoke.

Strategies:

- A. Collaborate with the Healthy North Dakota Disparities Committee.
- ◆ B. Promote the North Dakota Tobacco Quitline and tribal cessation programs.
- ◆ C. Promote health-care provider training on the Public Health Service guideline, Treating Tobacco Use and Dependence.
- ◆ D. Promote health-care systems change to institutionalize the Public Health Service Guidelines.
- E. Promote tobacco-free policies in reservation workplaces.
 - F. Advocate for increased resources for tribal tobacco prevention and control programs.

OBJECTIVE 16:

By June 2010, decrease from 19 percent in 1999 to 12 percent the percentage of pregnant women who smoke.

Strategies:

- ◆ A. Promote the North Dakota Tobacco Quitline and local cessation programs.
- ◆ B. Promote health-care provider training on the Public Health Service guideline, Treating Tobacco Use and Dependence.
- ◆ C. Promote health-care systems change to institutionalize the Public Health Service Guidelines.
 - D. Collaborate with the *Healthy North Dakota* Disparities Committee.
- E. Advocate for a significant increase in the tax on tobacco products.

OBJECTIVE 17:

By June 2010, institutionalize reducing tobacco-related disparities into the state planning process.

- A. Identify tobacco-related health disparities and related diseases.
- B. Identify policy opportunities to address tobacco-related disparities.
- C. Collaborate with partner agencies and organizations to address tobacco-related disparities.
- D. Collaborate with the Aberdeen Area Tribal Chairmen's Health Board Epidemiology Center on data issues.
- E. Collaborate with the *Healthy North Dakota* Health Disparities Committee and the Tobacco Special Populations Committee to address tobacco-related disparities.

OBJECTIVE 18:

By June 2010, establish baseline for the percentage of American Indian adults who report no smoking is allowed in their home.

Strategies:

- A. Educate American Indian adults on the dangers of second-hand smoke.
- B. Educate local policymakers on the need for and benefits of smoke-free environments.

Early Detection and Screening

(Repeated from pages 33 to 42.)

OBJECTIVE 19:

Increase the percentage of North Dakotans who receive appropriate cancer screenings.

Strategies:

- B. Geographic Barriers
 - 1. Encourage the "one-stop shop" concept to make screening more convenient.
 - 2. Explore opportunities to provide local access to screening.
- C. Out-of-Pocket Expenses
 - 1. Increase awareness and knowledge of insurance plan coverage options and other non-traditional payment options.
 - 2. Support and advocate for free or low-cost screening services for people such as is offered at Community Health Centers, by *Women's Way*, and others.

OBJECTIVE 21:

By 2010, the percentage of age-appropriate women who receive breast cancer screening will increase by 10 percent above 2002 rates.

Strategy:

 A. Reduce barriers to breast cancer screenings, especially financial, geographic and access issues.

OBJECTIVE 22:

By 2010, the percentage of women age 18 years and older who have had a Pap test within the past three years will increase by 7.5 percent above the 2002 rate.

- ◆ C. Create partnerships to reach women who are not being screened for cervical cancer.
- ◆ E. Advocate for system changes that meet the needs of American Indian women in North Dakota, such as access to female health-care providers and culturally appropriate cervical cancer screening education.

OBJECTIVE 28:

By 2010, the percentage of adults who report having had an oral and pharyngeal cancer examination in the past year will increase to 50 percent compared to 35 percent in 1995.

Strategy:

E Develop an awareness campaign for American Indian and Medicaid dental provider populations.

Treatment, Disease Management and Clinical Trials

(Repeated from pages 43 to 46.)

OBJECTIVE 32:

By 2010, improve provider and patient awareness of available treatment options, including clinical trials among cancer patients in North Dakota.

Strategies:

- C. Support the use of properly trained and culturally competent community health workers or navigators in communities experiencing cancer health disparities.
- D. Establish a clinical trials education network.

OBJECTIVE 34:

By 2010, work to increase the administration of chemotherapy in rural facilities.

Strategies:

- A. Assess the current availability or rural health-care facilities providing chemotherapy treatment.
- B. Ensure appropriate nurse training.
- C. Explore feasibility of rural chemotherapy centers/satellite centers.
- D. Seek on-site physicians or mid-level practitioners to oversee local treatment.
- E. Advocate for increased state funding for rural health-care facilities to increase access.

OBJECTIVE 36:

By 2010, improve patient knowledge about cancer, treatment and treatment alternatives.

Strategy:

C. Support the use of properly trained and culturally competent community health workers or navigators in communities experiencing cancer health disparities.



(Repeated from pages 47 to 50.)

OBJECTIVE 42:

Ensure North Dakotans who have been diagnosed with cancer can access appropriate palliative care and hospice care through all phases of cancer treatment.

Strategies:

- E. Increase the number of trained health-care providers who serve disparate populations.
- G. Increase the availability of culturally appropriate hospice and palliative services throughout all parts of North Dakota.

Workforce of the Future

(Repeated from pages 51 to 54.)

OBJECTIVE 49:

By 2010, ensure and enhance the availability of cancer-care providers to underserved, minority and rural areas.

Strategies:

- A. Educate North Dakotans about areas where shortages of workforce exist through public trainings and other venues.
- B. Pursue trainings and authorization for nurse practitioners, nurses and other professionals to provide screenings for specific cancer sites.

OBJECTIVE 51:

By 2010, increase the number of health-care providers providing culturally competent health care in North Dakota.

- A. Support the use of properly trained and culturally competent community health workers or navigators in communities experiencing cancer health disparities.
- B. Support ongoing cultural competency education opportunities for health-care providers.
- C. Increase the number of racial and ethnic minority individuals in the health-care field.

Thank You to the Disparities Work Group

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Implementation and Evaluation

The purpose for developing and implementing this plan is ultimately to reduce cancer incidence, morbidity and mortality and to improve quality of life. The cancer issues reflected by the goals of the plan are priority areas that should be addressed in North Dakota. The plan does not, however, rank the goals in terms of overall importance. Because the scope of the plan is broad and resources are limited, the goals and objectives in the plan must be further prioritized and individual strategies must be embraced and tackled by specific groups and organizations.

Through a systematic process, the North Dakota Cancer Coalition will further prioritize the objectives using specific criteria (e.g., the size of the burden, the strength of the evidence-based solutions known to exist, the likelihood that interventions will lead to significant improvements, the presence of major gaps in current efforts, the existence of important disparities and the feasibility of intervention). The result of the prioritization process will set the direction for initial implementation efforts of the coalition. In addition, partners and other key stakeholders can use the plan to select priorities consistent with their missions.

To achieve the goals and objectives of North Dakota's Cancer Control Plan, evidence-based strategies must be implemented. Only through ongoing, collaborative and coordinated effort by the coalition can we hope to achieve effective implementation of these diverse strategies. Coordinating existing resources and generating new resources to implement strategies will be a key function of the coalition.

In order to determine if the purpose is being achieved, the plan must be evaluated. Evaluation of the plan and the coalition's efforts will be important for determining the success of comprehensive cancer control in North Dakota.



Making Headway

"I truly believe that if we work from these objectives, we will impact the quality of life for North Dakotans."

Linda Kohls, Fargo, N.D.
The American Cancer Society
Executive Director for North Dakota

Resource

Resources

American Cancer Society www.cancer.org

American College of Surgeons, Commission on Cancer www.facs.org/cancer/coc/coc.html

Cancer Care www.cancercare.org/

Cancer Control www.cancercontrolplanet.cancer.gov

Cancer Information Service www.cis.nci.nih.gov/

Cancer Plans www.cancerplan.org

C-Change www.ndoc.org/default.asp

Centers for Disease Control and Prevention Division of Cancer Prevention and Control www.cdc.gov/cancer/

Community-based Cancer Control http://thecommunityguide.org

Intercultural Cancer Council http://iccnetwork.org

Lance Armstrong Foundation www.laf.org

National Cancer Institute www.cancer.gov

North Dakota Department of Health Division of Cancer Prevention and Control www.ndhealth.gov/Cancer/

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National Cancer Institute's Cancer Information Service

North Dakota Health Care Review, Inc.

Nelson Cancer Treatment Center

and Spirit of Eagles

Dakota Cancer Institute

Takeda Abbott Pharmaceutical Scotts Hill and Assoc. North Dakota Pharmacists Association Reach Partners, Inc. MeritCare Roger Maris Cancer Center Dickey County District Health Unit North Dakota Department of Health Centers for Disease Control and Prevention Tribal Health Education Legislator and Self-Employed Farmer Altru Health System North Dakota Department of Health North Dakota Prostate Cancer Coalition American Cancer Society **American Cancer Society** St. Joseph's Hospital and Health Center University of North Dakota Community Health Care Association of the Dakotas Rolette County Public Health

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Jamestown, ND Bismarck, ND

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Glossary

Age-adjusted rates: Cases or deaths divided by the population, adjusted for the age distribution of the population, usually presented per 100,000 people. A standardizing procedure in which the effects of differences in composition for variable(s) among populations being compared have been removed by mathematical procedures. Most often, adjustment is performed on rates. Age is the variable for which adjustment is most often carried out.

Asbestos: A natural material made up of tiny fibers. If the fibers are inhaled, they can lodge in the lungs and lead to cancer.

Baseline: An initial or known value to which later measurements can be compared.

Cancer: The umbrella term to describe many different diseases in which cells grow and reproduce out of control.

Cancer burden: The overall impact of cancer in a given community.

Cervix: The lower, narrow end of the uterus that forms a canal between the uterus and vagina.

Chronic disease: A disease or condition that persists or progresses over a long period of time.

Clinical trials: Research studies that involve patients. Each study is designed to find better ways to prevent, detect, diagnose or treat cancer and to answer scientific questions.

Community-based participatory research (CBPR): A collaborative process of research involving researchers and community representatives. It engages community members, employs local knowledge in the understanding of health problems and the design of interventions and invests community members in the processes and products of research.

Chemotherapy: The treatment of disease by means of chemicals that have a specific toxic effect upon the disease producing microorganisms (antibiotics) or that selectively destroy cancerous tissue (anticancer therapy).

Cultural competency: A set of harmonious behaviors, attitudes and policies that enable effective work in cross-cultural settings.

Diagnosis: The process of identifying a disease by the signs and symptoms.

Digital rectal examination (DRE): An exam to detect cancer. A health-care provider inserts a lubricated, gloved finger into the rectum and feels for abnormal areas.

Distant cancer: Cancer that has spread from the primary organ to distant organs or distant lymph nodes.

End of life: The final stage of survival as a patient approaches death.

Evidence-based: The process of systematically appraising and using contemporaneous research findings as the basis for clinical decisions.

Five-year survival: Percentage of patients who live at least five years after their cancer is diagnosed. The term is commonly used as the statistical basis for successful treatment. A patient with cancer is generally considered cured after five or more years without recurrence of disease.

5+5 Program: A community-based nutrition and physical activity program that encourages North Dakotans to east fruits and vegetables five times a day and to be physically active for 30 minutes at least five days a week. Strategies include promoting awareness for change, developing individuals' skills for making changes and adapting the community environment and policies to encourage and support lifestyle changes.

Follow-up: Monitoring a person's health over time after treatment. This includes keeping track of the health of people who participate in a clinical study or clinical trial for a period of time, both during the study and after the study ends.

Health-care provider: Practitioners in disease prevention, detection, treatment and rehabilitation. They include physicians, nurses, dentists, dietitians, health educators, social workers and therapists, among others.

Health disparities: Differences in the incidence, prevalence, mortality and burden of cancer and related adverse health conditions that exist among specific population groups in the United States.

Healthy North Dakota: A framework supporting North Dakotans in their efforts to make healthy choices by focusing on wellness and prevention – in schools, workplaces, senior centers, homes and anywhere people live, learn, work and play. Healthy North Dakota is a dynamic, statewide partnership that continues to grow as new stakeholders become engaged.

High risk: When the chance for developing cancer is greater for an individual or a group of people than it is for the general population, that individual or group is considered to be at high risk. People may be considered to be at high risk from many factors or combination of factors, including family history of disease, personal habits, or exposure to carcinogens in the environment or in the workplace.

Hospice care: Quality and compassionate care that incorporates a team-oriented approach to medical care, pain management, and emotional and spiritual support tailored to the needs and wishes of a patient facing life-limiting illness or injury.

Human papillomavirus (HPV): More than 100 types of viruses that cause various human warts (as the common warts of the extremities, plantar warts and genital warts) including some associated with the production of cancer. More than 30 of these papilloma viruses are sexually transmitted. High-risk HPV include types 16,18,31,33,35,39,45,51,52,56,58,59,68 and 69. HPVs now are recognized as the major cause of cervical cancer.

Informed decision-making: Choices and preferences stated after the individual understands the nature and risks of the cancer diagnosis and treatment options.

In situ cancer: Early stage of cancer that has not penetrated the membrane surrounding the tissue of origin. Cancer is localized and confined to one area.

Incidence: The number of newly diagnosed cancer cases that occur in a population per unit of time, usually one year. Incidence rate is the number of new cases of cancer diagnosed in one year per 100,000 persons in a population.

Localized cancer: Cancer that is confined to the organ of origin.

Mammography: An x-ray of the breast.

Melanoma: Cancer of the cells that produce pigment in the skin. Melanoma usually begins in a mole.

Metastasis: The spread of cancer cells from the original site to other parts of the body.

Morbidity: Illness or disability resulting from a disease or its treatment.

Mortality rate: A rate expressing the proportion of a population who die of a disease, or of all causes. The numerator is the number of persons dying; the denominator is the total population in which the deaths occurred. The unit of time is usually a calendar year. To produce a rate that is a manageable whole number, the fraction is usually multiplied by 1,000 to produce a rate per 1,000. This rate is also called the crude death rate.

National Comprehensive Cancer Network (NCCN): A not-for-profit alliance of 20 of the world's leading cancer centers dedicated to improving the quality and effectiveness of care provided to patients with cancer.

Nutrition Action Plan: A vision for a plan to improve the nutrition of North Dakota's population.

Obesity: A condition in which a person has abnormally high amounts of unhealthy body fat.

Oncology: The study of diseases that cause cancer.

Overweight: Being too heavy for one's height. Excess body weight can come from fat, muscle, bone and/or water retention. Being overweight does not always mean being obese.

Palliative care: Active and compassionate care of chronically and terminally ill patients with an emphasis on the control of pain and symptoms; incorporates an effort to fulfill physical, emotional, spiritual, social and cultural needs. Palliative care does not alter the course of a disease, but improves the quality of life.

Pap test: A test for cervical cancer that examines cells that are scraped from the cervix; can detect cancer and pre-cancerous conditions.

Physical activity: Any bodily movement produced by skeletal muscles that result in energy expenditure.

Practice guidelines: A medically proven set of guidelines or principles, based on clinical research and professional consensus, to assist physicians and other health-care providers with patient-care decisions and appropriate diagnostic, therapeutic or clinical procedures.

Precancerous: A term used to describe a condition that may or is likely to become cancer.

Quality of life: In cancer treatment and survival, quality of life is the concept of ensuring that cancer patients are able to lead the most comfortable and productive lives possible during and after treatment. New treatment techniques and social and emotional support groups are adding to the quality of life for cancer patients, as well as to their survival.

Radon: A radioactive gas that is released by uranium, a substance found in soil and rock. Exposure can damage lung cells and lead to lung cancer.

Regional cancer: Cancer that has extended beyond the primary organ to nearby organs or tissues, or has spread via the lymphatics to regional lymph nodes or both.

Risk factor: Something that may increase a person's chances of developing a disease. Some examples are age, obesity, tobacco use and genetic predisposition.

Rural: Any county not included under urban or semi-urban.

Screening: Routine medical tests that are given if an individual is over a certain age, or has a family history or other risk factors for any medical condition. Early detection can mean that a serious health problem or problems may be avoided.

Semi-urban: Any county in which the largest zip code tabulation areas is a population of 7,500 to 19,999.

Stage: A distinct phase in the course of a disease. Stages of cancer are typically defined by containment or spread of the tumor: in situ, localized, regional or distant spread.

Survival: Period of time from diagnosis to death.

Survivorship: The experience of living with, through or beyond cancer; a continual, ongoing process that begins at the moment of diagnosis and continues for the remainder of life; composed of stages or phases of survival.

Urban: Any county with one or more zip code tabulation areas with a population of 20,000 or greater.

USDA Team Nutrition: An initiative of the USDA Food and Nutrition Service to support the Child Nutrition Programs through training and technical assistance for foodservice, nutrition education for children and their caregivers, and school and community support for healthy eating and physical activity.



Requesting Research

"There needs to be more cancer research. There are so many types of cancer and then there are so many subtypes of cancer. We need to do more to understand, prevent and treat cancer." Lynda Coenen, Mikayla's mom.

Mikayla Coenen, Warwick, N.D. Eight-year-old daughter of Lynda and Ron Coenen Card making entrepreneur Leukemia patient

