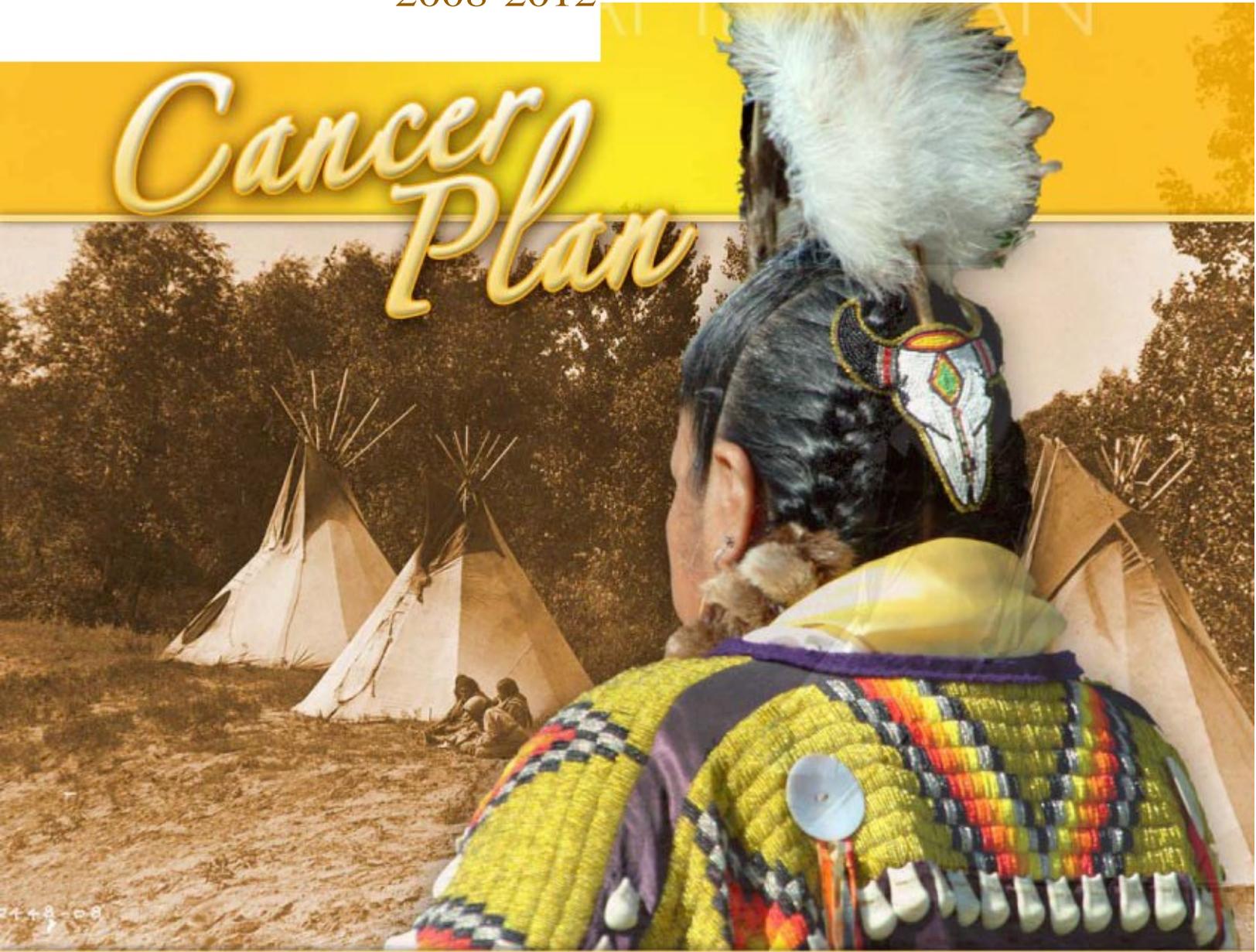


NORTHERN PLAINS NATIVE AMERICAN  
2008-2012

# *Cancer Plan*



NORTHERN PLAINS COMPREHENSIVE CANCER CONTROL PLAN

We sincerely thank the following for their generous support for the printing costs of this plan:



**NEBRASKA'S HEALTH SCIENCE CENTER**

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COLLEGE OF PUBLIC HEALTH

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NORTHERN PLAINS NATIVE AMERICAN CANCER PLAN  
(2008-2012)

Fall 2007

A Project of the Northern Plains Cancer Coalition

Aberdeen Area Tribal Chairmen's Health Board



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## DEDICATION

Dedicated in honor of all Northern Plains Native Americans taking the cancer journey, including the survivors and those who have journeyed on to the Spirit World.

May we learn from their strength and wisdom as we work together to make all American Indians cancer free.

## SPECIAL THANKS AND ACKNOWLEDGEMENT TO:

The Northern Plains Cancer Coalition Steering Committee members and Workgroup Chairs whose dedication and effort were the foundation for this plan

All those who participated in the Northern Plains Cancer Coalition Workgroups and Cancer Plan Meetings that enriched the content of this plan

The support provided by the Centers for Disease Control and Prevention (CDC Grant #Uss-CCU824797) to make this plan possible

Marie Randall for leading the blessings and prayers at the Northern Plains American Indian Cancer Summit (November 14-1s, 2006)



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# NORTHERN PLAINS CANCER COALITION

## MISSION

Enhance and increase the quality of life and survivorship of cancer for American Indians\* in the Northern Plains by providing a forum for input, advocacy, education, collaboration, planning, and action along the cancer control continuum. This group of tribal and community stakeholders will work to achieve all of their goals in a manner that values the importance of traditional healing and medicine, embraces the spiritual components of life for many, and above all else respects individual, tribal, and cultural differences.

## LONG TERM GOALS

For American Indians in the Northern Plains:

- Decrease the number that get cancer
- Increase the quality of life for those who are affected by cancer
- Decrease the number that die from cancer

## PHILOSOPHY & FRAMEWORK

- Tribal Sovereignty
- Culturally appropriate programs
- Promising or evidence-based and outcome-oriented interventions
- Continuum of Cancer Control
- Medicine-Wheel Concept of Health



\*Please note that American Indian and Native American are used interchangeably throughout this document.

## EXECUTIVE SUMMARY

Cancer is a growing concern for the Northern Plains Native American population. This population has some of the highest rates of cancer and cancer deaths compared to both other Native and non-Native populations. With support from the U.S. Centers for Disease Control and Prevention (CDC), the Aberdeen Area Tribal Chairmen's Health Board (AATCHB) joined with partners from tribes, Indian Health Service, states, universities, and many other cancer control stakeholders to develop the region's first comprehensive cancer control plan. During recent years, a series of coalition, workgroup, and planning meetings allowed organizations and individuals to work together toward a common goal and strengthen collaborations among agencies. The quality of life and survivorship from cancer for Northern Plains Native Americans can be improved by collaborative efforts to prevent cancers, detect cancers earlier, and increase access to quality cancer care services from diagnosis through survivorship or end of life.

The purpose of this plan is to:

- Highlight and raise awareness about the important cancer issues, challenges, and barriers faced by Northern Plains American Indians
- Provide an outline of the many cancer prevention and control areas that need to be acted on
- Set goals and objectives for improvement
- Propose potential action steps to achieve goals and objectives
- Draw together interested tribes, organizations, entities, and individuals to work collaboratively toward shared goals

This plan has ten chapters. The first four chapters provide introductory and background information, and the last six chapters lay out plans for different areas of cancer prevention and control. These six chapters outline the major issues, challenges, and barriers, the long-term goal/s, the objectives, and the potential action steps for each area. In addition, there is a section beginning each chapter called "The Basics." This section presents a few questions and answers individuals might have about each section.

It is true that cancer causes much suffering and fear, but many Native Americans also survive cancer and continue their journey with great wisdom and knowledge. Therefore, we must move forward remembering the seriousness of the disease but the strength we have by working together to prevent cancer and improve the quality of life of those affected by it.



## PLAN GOALS

- Reduce the incidence and mortality rates of cancer in Northern Plains American Indian communities by promoting healthy lifestyles and reducing cancer related risk factors
- Increase appropriate cancer screening for Northern Plains American Indians so cancer is detected at earlier stages
- Ensure that all Northern Plains American Indians with cancer receive access to quality western and traditional cancer care services and aftercare.
- Assure that Northern Plains American Indian cancer patients, their families, and their caregivers will have access to programs and services that address their physical, mental, and spiritual needs to improve the length and quality of life.
- Assure the best quality of life and access to needed comfort care services for Northern Plains American Indians affected by cancer, their families, and their caregivers
- Improve a trained workforce who can provide culturally sensitive/competent comprehensive cancer care for the Northern Plains tribes
- Make complete, accurate, and timely data on cancer available and accessible to the Northern Plains American Indian tribal communities in order to inform and improve cancer health status
- Increase awareness of cancer research projects and facilitate clinical trials and community-based participatory research to improve cancer health status among Northern Plains American Indians.



# CHAPTER 1

## CANCER PLAN HISTORY AND DEVELOPMENT



### NORTHERN PLAINS COMPREHENSIVE CANCER CONTROL PLAN

This plan is dedicated in honor and memory of Carole Anne Heart, Rosebud and Yankton Sioux and Executive Director of the AATCHB

Carole Anne continued her cancer journey into the Spirit World on January 25, 2008. Her Lakota name is Waste Wayankapi Win, meaning "When People See You, They See Something Good." She advocated throughout her life to improve education and health for Native Americans. Her enthusiastic support, strong leadership, and humorous outlook touched the lives of many. We know her spirit will continue to guide us as we strive to achieve the overall mission set forth by this plan, to improve the survivorship and quality of life for all those affected by cancer.

# CHAPTER 1

## CANCER PLAN HISTORY AND DEVELOPMENT

### Introduction

This plan has been developed through a process that has brought together many different Native American cancer prevention and control stakeholders in the Northern Plains. This chapter describes the process that has led to the development of this plan.

### Aberdeen Area Tribal Chairmen's Health Board Background

The Aberdeen Area Tribal Chairmen's Health Board (AATCHB) is a non-profit organization created in 1986, and incorporated in the State of South Dakota in 1992, by the Tribal Councils of the 18 American Indian Reservations<sup>a</sup> in the Aberdeen Area of the Indian Health Service<sup>b</sup>. The organization's purpose is to provide advocacy for and development of programs to address the unmet health needs of tribal people in North Dakota, South Dakota, Nebraska, and Iowa through a unified, consolidated approach. In January and July 2004, the AATCHB Board of Directors (the chairperson of each of the Aberdeen Area tribes) and the Aberdeen Area IHS, the primary health care provider on the Reservations, met to develop a long-range strategic health plan. Cancer was identified as a priority concern.



### Northern Plains Tribal Epidemiology Center

The Northern Plains Tribal Epidemiology Center (NPTEC) was established in 2003 by AATCHB in order to provide leadership, technical assistance, support, and advocacy to Northern Plains tribal nations and communities in order to eliminate the disparities in health that currently exist for tribal people of the area. NPTEC has been crucial to the development of additional programs and resources for the Northern Plains tribes, including the Northern Plains Comprehensive Cancer Control Program (NPCCCCP).

### Northern Plains Comprehensive Cancer Control Program Background

Because cancer had been established as a priority concern, NPTEC collaborated with several partners to hold the first ever Northern Plains American Indian Cancer Summit in 2004. The success of this summit provided the momentum for AATCHB to begin the Northern Plains Comprehensive Cancer Control Program (NPCCCCP) in 2000s with funding from the Centers for Disease Control and Prevention (CDC).

<sup>a</sup> The Trenton Indian Service Area in western North Dakota and eastern Montana is not a Reservation; it consists of BIA trust lands allotted to members of the Turtle Mountain Band of Chippewa; it has a tribal council, chairman, and an Indian Health Service Health Center. This Service Area is counted as a Reservation in this document in order to simplify the text.

<sup>b</sup> The Indian Health Service is an agency of the Department of Health and Human Resources that provides primary health care to populations of American Indian Reservations. The United States is divided into 12 Indian Health Service "Areas". Aberdeen Area includes the states of North Dakota, South Dakota, Nebraska, and Iowa.

## Northern Plains Cancer Coalition (NPCC) Background

Since late 2000s, NPCCCP has been facilitating a process which has culminated in the production of this Cancer Plan. NPCCCP staff helped to organize and begin a Northern Plains Cancer Coalition (NPCC) in December 2000. Since then the NPCC has grown to over 70 members.

The NPCC has a Steering Committee made up of several tribal, state, university, and IHS stakeholders who have provided leadership and guidance throughout the development of this Cancer Plan, and six NPCC workgroups have provided the core effort to develop the details of Cancer Plan.

## Steering Committee Members

- Donna Breland-Baker, Health Education Director, Turtle Mountain Chippewa
- Roberta Cahill, Health Initiatives Coordinator, American Cancer Society
- Lisa Dillon, Tribal Health Administrator, Oglala Sioux Tribe
- Willeen Druley, Women's Health Nurse Consultant, Aberdeen Area Indian Health Service
- Tinka Duran, Outreach Coordinator, NPCCCP
- John Eagle Shield, CHR Director, Standing Rock Sioux Tribe
- Jodie Fetsch, Home and Men's Health Coordinator, Custer Health
- Leah Frerichs, Program Manager, NPCCCP-AATCHB
- Jessica Gilbertson, Partnership Program Coordinator, Spirit of Eagles/Cancer Information Service
- Elaine Keeps Eagle, CHR Assistant, Standing Rock Sioux Tribe
- Favian Kennedy, Program Director, Northern Plain Tobacco Prevention Project - AATCHB
- Jolene Keplin, Health Education, Turtle Mountain Chippewa
- Kevin Molloy, Clinical Research Coordinator, Walking Forward Program – Rapid City Regional Hospital
- Terry Salway, Tobacco Training Specialist, Northern Plains Tobacco Prevention Project - AATCHB
- Norma Schmidt, Chronic Disease Team Leader, South Dakota Department of Health
- Delf Schmidt-Grimming, Assistant Professor, University of South Dakota
- Nichole Vetter, Public Health Nurse, Winnebago Tribe of Nebraska
- Shinobu Watanabe-Galloway, Program Director, NPCCCP/Assistant Professor, University of Nebraska Medical Center (UNMC)



## Northern Plains Cancer Coalition Workgroup Participants

The first two sessions for NPCC workgroups were held during the Northern Plains American Indian Cancer Summit, November 14-15, 2006. The following is a list of individuals who participated in each workgroup. Many individuals continued to meet by conference call after the Summit to draft each chapter of this Plan.

### Prevention and Education:

- Martha Campbell, Santee Sioux Tribe, Health Educator
- Ronald Galloway, Winnebago Tribe of Nebraska, CHR/EMS Coordinator

- Bette Goings, Oglala Sioux Tribe, Community Member
- Janelle Jacobson, Nebraska CARES/Cancer Information Service, Partnership Program Coordinator
- Favian Kennedy, Northern Plains Tobacco Prevention Project, Program Director
- Karen Red Star, Oglala Sioux Tribe, Health Educator
- Terry Salway, Northern Plains Tobacco Prevention Project, Tobacco Training Specialist
- Mary Tobacco, Oglala Sioux Tribe, Health Educator
- Ronald Valandra, Rosebud Sioux Tribe, Tribal Health Director

#### Screening and Early Detection:

- Arlene Black Bird, Cheyenne River Sioux Tribe CDC Winyan Wicozani, Director
- Jodie Fetsch, Custer Health, Home and Men's Health Coordinator
- Raylene Miner, Rapid City Regional Hospital Walking Forward Program, Community Research Representative
- Kevin Molloy, Rapid City Regional Hospital Walking Forward Program, Patient Navigator/Research Coordinator
- June Ryan, Nebraska CARES, Program Manager
- Caroline Spotted Tail, Rapid City Regional Hospital Walking Forward Program, Community Research Representative
- Brenda Two Shields, Cheyenne River Sioux Tribe Wisdom Keepers, Volunteer Elder Aide Trainee
- Shannon Wright, Winnebago Tribe of Nebraska, Public Health Nurse
- Joyce Sayler, Custer Health, Women's Way Coordinator
- Neva Zephier, Black Hills Center for American Indian Health, Outreach Coordinator

#### Treatment and Traditional Healing:

- Goldie Burnham, South Dakota Foundation for Medical Care, Project Manager
- Patty Conroy, Rapid City Regional Hospital Walking Forward Program, Community Research Representative
- Cathy Ducheneaux, Cheyenne River Sioux Tribe
- Jessica Gilbertson, Spirit of Eagles/Cancer Information Service, Partnership Program Coordinator
- Valerie Grajeda, Minne Tohe Health Center, Patient Benefits Coordinator
- Elaine Keeps Eagle, Standing Rock Sioux Tribe, CHR Administrative Assistant
- Danny Kenneweg, Centers for Disease Control and Prevention, Regional Public Health Advisor
- JoAnne Marcellais, Minne Tohe Health Center, Director of Managed Care
- Dr. Daniel Petereit, Rapid City Regional Hospital Walking Forward Program, Oncologist/Principle Investigator
- Rosella Pongah, Northern Cheyenne, Oncology Coordinator
- Butch Artichoker, Rosebud Sioux Tribe
- John Eagle Shield, Standing Rock Sioux Tribe, CHR Director



#### Cancer Journey:

- Donna Baker, Turtle Mountain Tribal Health Education, Director
- Julie Bassette, Winnebago Tribe of Nebraska, Outreach Worker
- Roberta Cahill, American Cancer Society, Health Promotions Coordinator
- Clementine Day, Cheyenne River Sioux Tribe Wisdom Keepers, Volunteer
- Willeen Druley, Aberdeen Area Indian Health Service, Woman's Health Consultant
- Gayle Dupris, Cheyenne River Sioux Tribe Wisdom Keepers, Volunteer
- Leanne Eagleman, Chamberlain High School, Prevention Specialist
- Betty High Elk, Cheyenne River Sioux Tribe Wisdom Keepers, Trainer/Counselor
- Patty Keoke, Cheyenne River Sioux Tribal Member, Retired Social Service Manager
- Sid Kills In Water, Rosebud Sioux Tribe, CHR Director
- Theodora LaBelle, Sisseton Wahpeton Oyate, Community Health Education
- Mary Little Sky, Cheyenne River Sioux Tribe, Community Member
- Cathy Rost, Rapid City Regional Hospital Walking Forward Program, NIH Research Program Manager
- Iva Jo Ruff, Oglala Sioux Tribe, Community Member
- Dr. Karen Schumacher, University of Nebraska Medical Center, College of Nursing, Associate Professor
- Linda Todd, Hospice of Siouxland, Hospice Director
- Nichole Vetter, Winnebago Tribe of Nebraska, Public Health Nurse
- Tinka Duran, Northern Plains Comprehensive Cancer Control Program, Outreach Coordinator
- Paul Wounded Head, Oglala Sioux Tribe, Community Member

#### Workforce:

- Leah Frerichs, Northern Plains Comprehensive Cancer Control Program, Program Manager
- Sarah Kitchell, Iowa Consortium for Comprehensive Cancer Control/Cancer Information Service, Partnership Program Manager
- Denise Steinbach, North Dakota Department of Health, Comprehensive Cancer Control, Program Coordinator
- Janelle Trotter, Aberdeen Area Indian Health Service, Aberdeen Area Health Educator
- Stephanie Bolman, University of Colorado, Consultant/Community Health Advocate

#### Research and Surveillance:

- Alfreda Bear Track, Black Hills Special Services, Tobacco Prevention Coordinator
- Ed Cut Grass, Rapid City Service Unit, CHR
- Petra Helbig, Rapid City Regional Hospital NIH Grant, Clinical Research Associate
- Marlys Knell, North Dakota Department of Health, Cancer Registry Coordinator
- Dr. Delf Schmidt-Grimminger, Sanford School of Medicine, University of South Dakota, Assistant Professor



- Dr. Shinobu Watanabe-Galloway, NPCCCP/UNMC, Program Director
- Larry Rouillard, Santee Health Center, CHR
- Dr. Lillian Tom-Orme, University of Utah, Research Assistant Professor/NCI Native American Research Liaison
- Deleen Lamb, Cheyenne River Sioux Tribe
- Dr. Sara Becker, South Dakota State University, Assistant Professor

## Cancer Plan Meetings

From March to June 2007, NPCCCP staff and other partners held a series of 17 meetings with tribal leaders, health workers, Indian Health Service representatives, cancer survivors, and other concerned community members at tribal locations. Approximately 100 individuals attended these meetings, and helped to bring the Cancer Plan into focus as a collaborative and community driven document.

TRIBE	LOCATION	DATE
Standing Rock Sioux	Standing Rock Sioux Tribal Office	March 26, 2007
Three Affiliated	Three Affiliated Tribal Council Chambers	March 27, 2007
Trenton Indian Service Area	TISA Community Hall	March 27, 2007
Turtle Mountain	Sky Dancer Hotel	March 28, 2007
Oglala Sioux	OST Oyate Blihelya Conference Room	April 18, 2007
Rosebud Sioux	Rosebud Tribal Administration Building	April 19, 2007
Cheyenne River Sioux	CRST Wellness Center	April 30, 2007
Lower Brule Sioux	Lower Brule Tribal Administration	May 1, 2007
Crow Creek Sioux	Lode Star Motel Conference Room	May 1, 2007
Sisseton Wahpeton Oyate	Sisseton Wahpeton Oyate Health Care Center	May 8, 2007
Flandreau Santee Sioux	Flandreau Santee Sioux Tribal Health Clinic	May 10, 2007
Yankton Sioux	Fort Randall Casino	May 11, 2007
Santee Sioux	David Frazier Memorial Building	May 14, 2007
Winnebago Tribe of Nebraska	Ho-Chunk Hope Conference Room	May 14, 2007
Ponca Tribe of Nebraska	Fred Leroy Health and Wellness Center	May 1s, 2007
Omaha Tribe of Nebraska	Carl T. Curtis Education Center	May 1s, 2007
Spirit Lake	Held by conference call	June 18, 2007

### Cancer Priorities and Needs Assessment

NPCCCP also fielded a survey with tribal health directors (or their designee) in the Northern Plains to establish major cancer needs and priorities. This and information gathered from the Cancer Plan Meetings was used to identify the major priorities for each chapter of the Cancer Plan. These are highlighted at the beginning of each chapter.

# CHAPTER 2

NORTHERN PLAINS AMERICAN INDIAN  
CANCER BURDEN



NORTHERN PLAINS COMPREHENSIVE CANCER CONTROL PLAN

**"We are a caring people with a caring heart and a caring spirit. The human body is a sacred body. We need to respect ourselves and remember our traditional Lakota ways to maintain a healthy body and soul. Our young people need to be encouraged to study the herbs, leaves and roots of plants from Mother Earth for medicine use. Perhaps we can regain a healthy lifestyle once again."**

***– Gladys Hawk, Standing Rock Sioux Tribe, Breast Cancer Survivor***

Photo Credit: KAT Communications

# CHAPTER 2

## NORTHERN PLAINS AMERICAN INDIAN CANCER BURDEN

### The Basics of Cancer Data

#### What is cancer incidence?

- The number of new people that develop cancer in a certain population during a specified time period

#### What is a cancer mortality?

- The number of deaths from cancer in a certain population during a specific time period

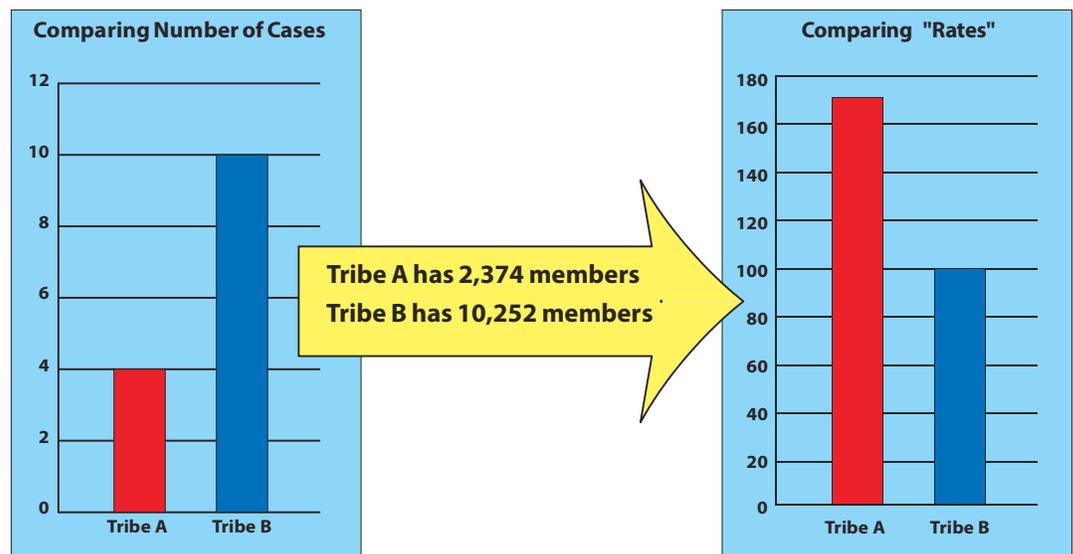
#### Why do we use “rates” instead of numbers or “counts” of cases?

- “Counts” do not account for population size, and if we look only at “counts” we might have an unfair comparison.
- Example of counts vs. rates: “Tribe A” has 4 and “Tribe B” has 10 new cases of cancer in one year. If we compare counts we might say that Tribe B has more cancer cases and greater problems with cancer. However, we also know that “Tribe A” has 2,374 members and “Tribe B” has 10,252. In order to take into account this difference in population size, we calculate the incidence “rate” per 100,000 persons.

Tribe A = 4 cases / 2,374 people x 100,000 = 168.49 per 100,000 population

Tribe B = 10 cases / 10,252 people x 100,000 = 97.54 per 100,000 population

This means that if Tribe A and Tribe B had the same population size (e.g. 100,000 people) then we expect Tribe A to have 168.49 and Tribe B to have 97.54 new cases. Therefore the burden of cancer is actually greater in Tribe A than in Tribe B.



### What does it mean when a rate is age-adjusted?

- This is when a rate is calculated to take into account that some populations have different numbers of people in different age groups. For example, the White population may have more older people than the Native population. Since older people are more likely to get cancer this can effect how rates compare between populations. Age-adjusted rates account for that difference so that rates can be compared.

### What does it mean when there is a statistically significant difference between two rates?

- Sometimes when you compare two rates, one rate may be higher than the other. However, sometimes those differences can occur just by chance. Therefore, certain statistical methods are used to calculate how certain we are that the difference is likely to be explained by something other than just chance and is “statistically significant.”

## The Basics of Cancer for Northern Plains American Indians

### What cancers do Native Americans in the Northern Plains get most often?

- People can get cancer at many different sites in the body. There are a couple sites where people get cancer the most often.
- For Native Americans in the Northern Plains: Women get breast cancer most often, and men get prostate cancer most often. Lung and Colon-Rectum cancer are also two cancers that both men and women get often.

### What cancers do Native Americans in the Northern Plains die from most often?

- Cancers at certain sites kill more people than cancers that occur at other sites.
- For both men and women, more Northern Plains American Indians die from Lung cancer than any other type of cancer.
- Colon and Rectum cancer takes the lives of the second most number of Northern Plains Native Americans than other types of cancer
- Many women also die from Breast cancer, and many men die from Prostate cancer.

### Do Northern Plains Native Americans get cancer more often than non-natives or Native Americans in other areas of the U.S.?

- It appears that they do, especially for certain sites. Preliminary analyses have shown that Native Americans in the Northern Plains have higher rates of certain cancers than the general population and Native populations in other regions. This information is to be published late 2007.

### Do Northern Plains Native Americans die from cancer more than non-natives or Native Americans in other areas of the U.S.?

- Yes, this is true for overall cancer, and especially certain cancer sites such as cervical cancer (for women), stomach, liver, lung, and colon/rectum cancers.



## Overview

Cancer is a serious concern for Native Americans in the Northern Plains. This chapter outlines some of the data and statistics that show the cancer burden on this population.

## Data Limitations

Cancer data for Native Americans (as well as other races/ethnicities such as Hispanics, Asians, etc.) are lacking compared to the White and Black populations, and data that is available often has many limitations.<sup>1</sup> The major limitations of Native American cancer data are due to racial misclassification, undercounting, coding errors, inclusion of insufficient numbers of the racial group, and geographic differences. Incidence and risk behavior rates (e.g., tobacco use, cancer screening, etc.) are especially difficult to obtain due to the relatively small population size of Northern Plains American Indians. Existing data are often imprecise and therefore must be averaged over several years in order to have stable results.

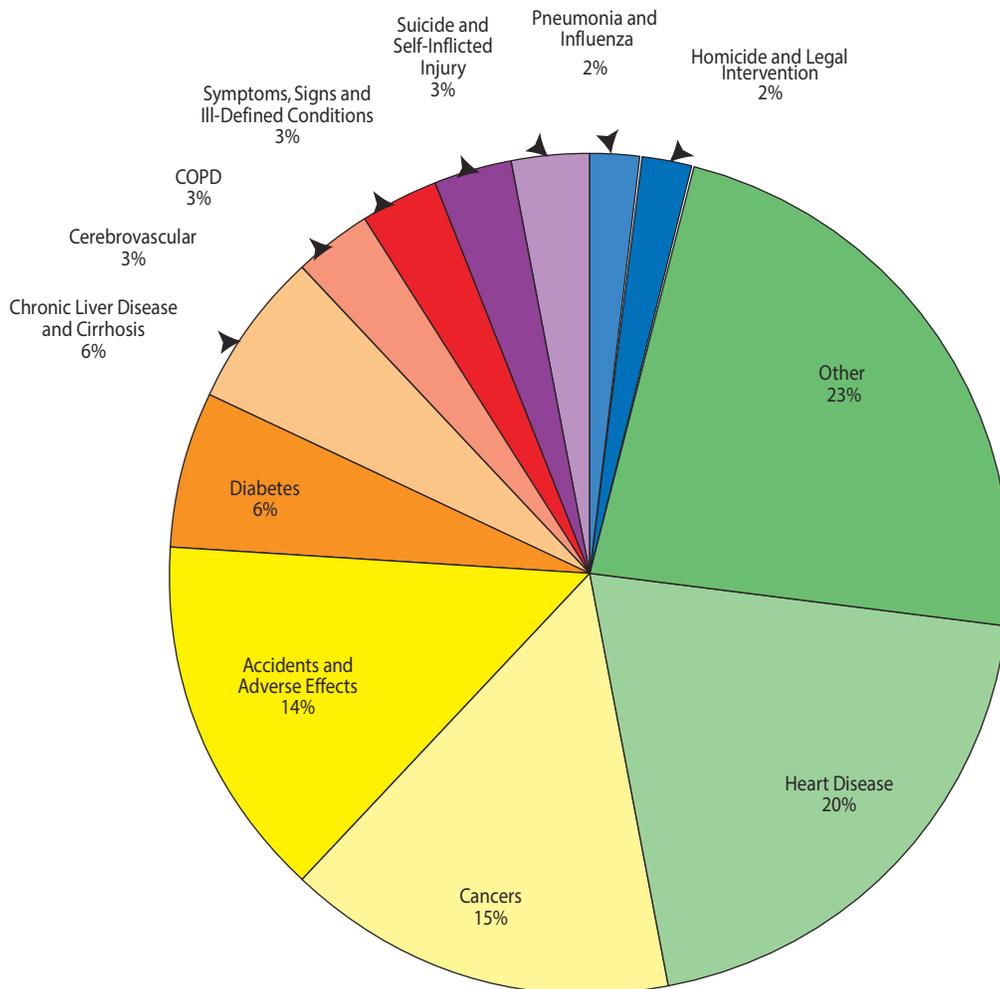
Because of these issues, some of the data that are presented in this plan should be interpreted with caution. As updated and more accurate information is available this plan will be updated. Thus this plan has the important chapter on Surveillance and Research, which seeks to move forward some of that progress. This chapter will apply to many aspects of this plan so data and the ability to evaluate progress is improved.



# Leading Causes of Death among American Indians in the Northern Plains

In the past cancer was a low health concern for Native populations, infectious disease instead was a major killer.<sup>2</sup> However, chronic diseases such as cancer, heart disease, and diabetes now account for nearly one-half of all deaths. Cancer itself causes approximately 15% of all deaths among American Indians in the Northern Plains, second only to heart disease (Figure 1). Cancer for Native populations in different regions of the US remains comparable or lower to the general U.S. population; however, Natives in certain geographic areas including the Northern Plains have been found to have some of the highest cancer rates compared to both Native and non-Native populations.<sup>3</sup>

Figure 1. Leading Causes of Death among Northern Plains American Indians (2001-2003)<sup>4</sup>



## Northern Plains American Indian Cancer Mortality (Death) Rates

Lung cancer accounts for nearly one-third of all cancer deaths for the Northern Plains Native population (Figure 2). Other major sites of cancer death include, colorectal, breast (for women), and prostate (for men). Stomach, Leukemia, Liver, Pancreas, Kidney, and Non-Hodgkin's Lymphoma also cause many cancer deaths for this population.

Figure 2. Leading Cancer Site Deaths among Northern Plains American Indians (1994-2003)<sup>4</sup>

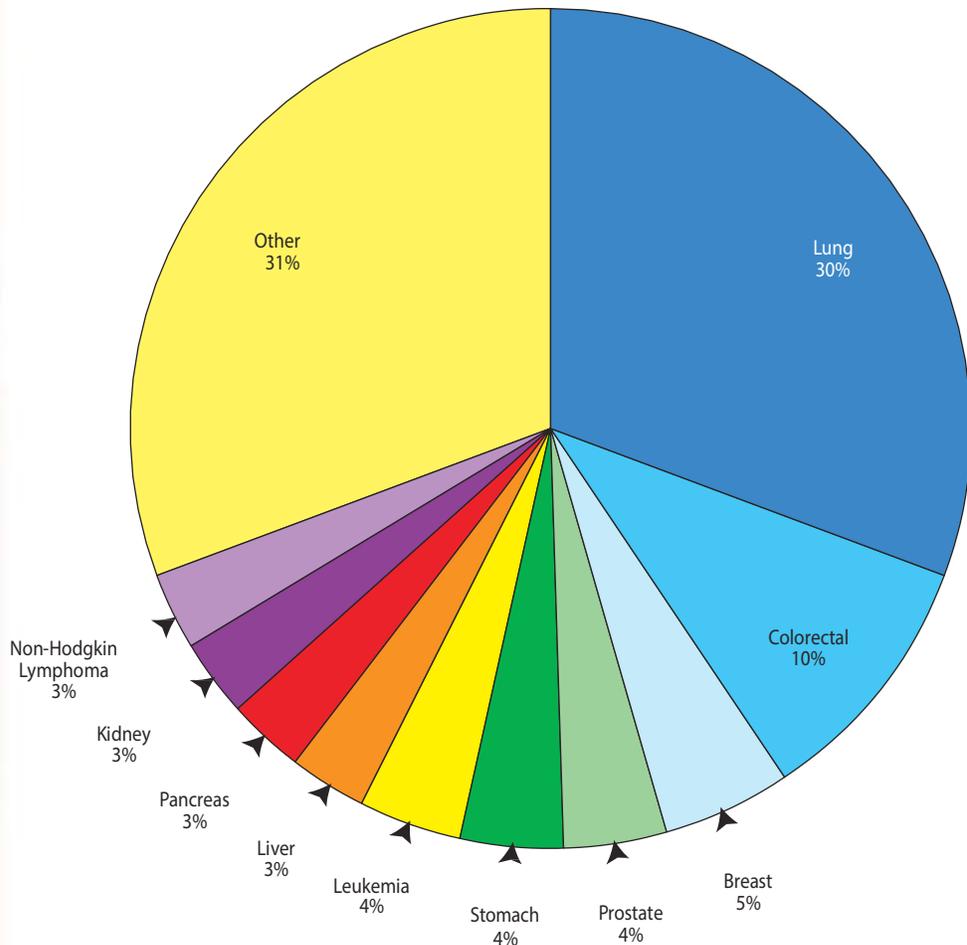


Table 1. Leading Sites of Cancer Death among Northern Plains American Indians by Sex (1994-2003)<sup>4</sup>

WOMEN		MEN	
Lung	24%	Lung	3s%
Colorectal	11%	Colorectal	10%
Breast	11%	Prostate	9%
Cervix Uteri	s%	Liver	s%
Ovary	4%	Stomach	4%
Leukemia	4%	Kidney	4%
Pancreas	4%	Pancreas	3%
Non-Hodgkin Lymphoma	3%	Leukemia	3%
Stomach	3%	Non-Hodgkin Lymphoma	3%
Kidney	3%	Oral Cavity and Phayrnx	2%
Other	29%	Other	21%

## Northern Plains American Indian Cancer Death Disparities

Overall, Northern Plains American Indian cancer mortality rates are significantly higher than the White population (see Tables 2 and 3). AI also suffer more from certain cancer sites compared to the White population (see Table 3). Several of the major sites are higher, such as lung, colorectal, stomach, and liver. Additionally, Native American women suffer from relatively high rates of cervical cancer.

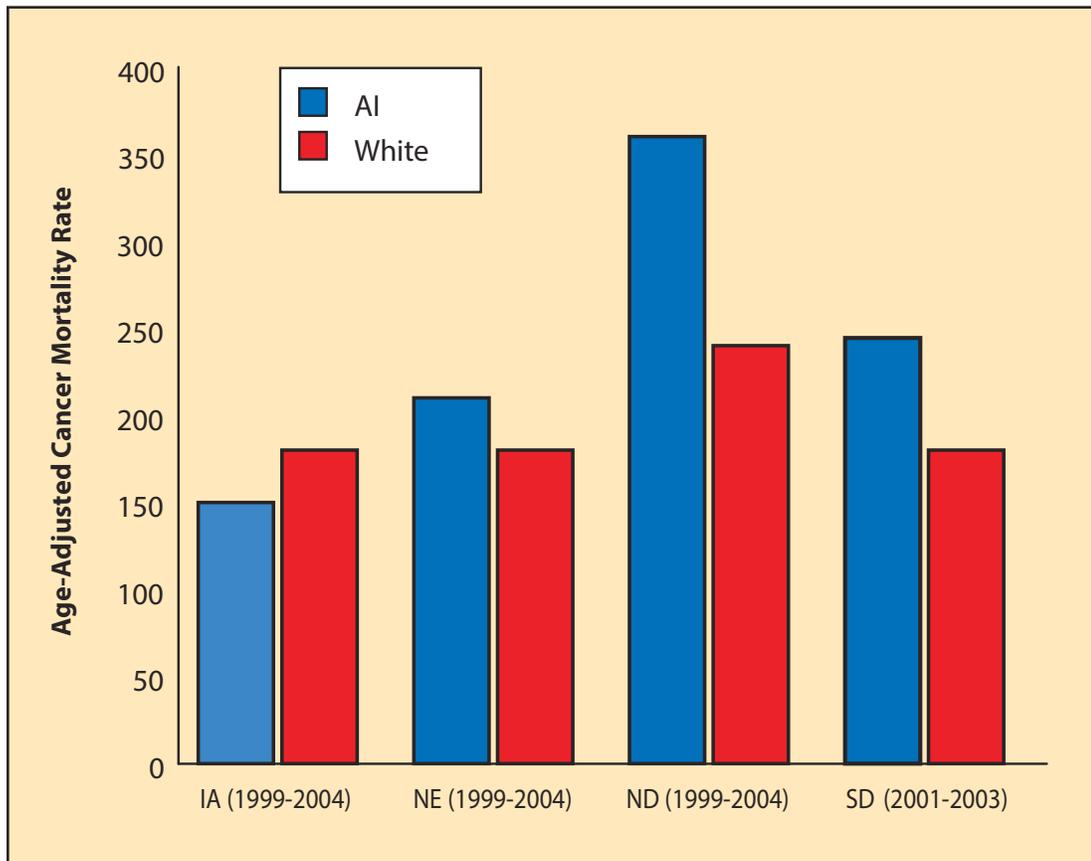
Table 2. Northern Plains Cancer Mortality Rates by Gender and Age (1999-2003)<sup>4</sup>

	MALE AND FEMALE		MALE		FEMALE	
	AI	White	AI	White	AI	White
ALL AGES	237.8*	18s.7	288.3*	231.9	210.2*	1ss.4
0-19	1.7	2.8	1.4	3.4	2.1	2.3
20-44	19.1	18.s	14.s	16.3	23.s	20.8
4s-64	233.7*	193.7	211.4	204.7	2s3.3*	182.7
6s-84	1,240.s*	997.0	1,s42.0*	1,260.1	1,022.8*	794.s
8s+	1,932.4	1,714.s	3,040.0	2,s26.7	1,s13.3	1,384.9

Notes. Rates for "All Ages" are per 100,000 and age-adjusted to the 2000 US Std Population.

\*Indicates that the rate for American Indian is significantly different from the rate for White (p<.0s)

Figure 3. AI and White Age-Adjusted Cancer Mortality Rates by State<sup>s</sup>



Notes. Rates are per 100,000 and age-adjusted to the 2000 US Std Population.

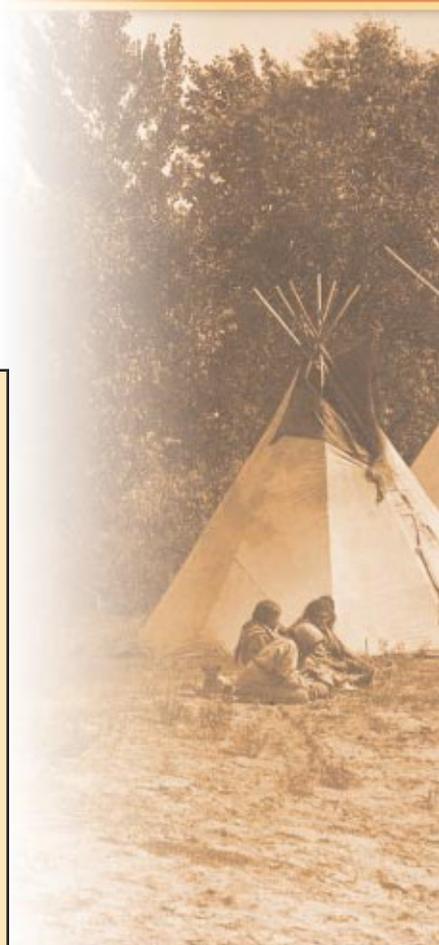


Table 3. Northern Plains Cancer Site Mortality Rates by Gender (1994-2003)<sup>4</sup>

	MALE AND FEMALE		MALE		FEMALE	
	AI	White	AI	White	AI	White
All Cancers	262.4*	187.8	329.1*	237.4	22s.8*	1ss.9
Lung and Bronchus	79.6*	s0.1	11s*	72	s6.s*	34.4
Prostate (M)	39.s	31.3	39.s	31.3		
Colon and Rectum	29.4*	21.8	37.3*	26.s	26.2*	18.4
Breast (F)	21.6	2s.9			21.6	2s.9
Pancreas	9.3	9.8	11.6	11.3	8.1	8.6
Stomach	9.3*	3.3	10.8*	4.8	7.6*	2.2
Liver	8.8*	3.1	13.2*	4.4	s.1*	2.1
Ovary (F)	8.8	9.1			8.8	9.1
Leukemia	8.6	8.2	9.3	11.3	8.2	6
Cervix Uteri (F)	7.9*	2.3			7.9*	2.3
Non-Hodgkin's Lymphoma	7.8	8.7	8.1	10.7	7.8	7.2
Kidney	7.s*	4.8	9.2	7	6*	3.1
Corpus and Uterus, NOS (F)	6.1	4.2			6.1	4.2
Oral Cavity and Pharynx	s*	2.3	s.8	3.s	4.3*	1.4
Esophagus	4.6	4.1	6.7	7.4	3.1	1.s
Myeloma	4	3.8	4	4.7	4.3	3.1
Brain and other ONS	3.6	s.s	4.3	6.4	3.1	4.6
Urinary Bladder	3.2	3.9	6.8	7	1.3	1.9
Gallbladder	2.8*	0.9	1.3	0.s	3.8*	1.1
Penis (M)	2.7*	0.2	2.7*	0.2		

Notes. Rates are per 100,000 and age-adjusted to the 2000 US Std Population.

\*Indicates that the rate for American Indian is significantly different from the rate for White (p<.0s)

Figures 4 and s graphically show the differences between the rates of cancer for Northern Plains American Indians and Whites. The overall cancer mortality rate was significantly higher among American Indians compared to whites. Notably, the mortality rate for stomach, liver, gallbladder, and cervical cancer are about three times greater among American Indians than whites.

Figure 4. Northern Plains American Indian and White Cancer Mortality Rates by Site (1994-2003)<sup>4</sup>

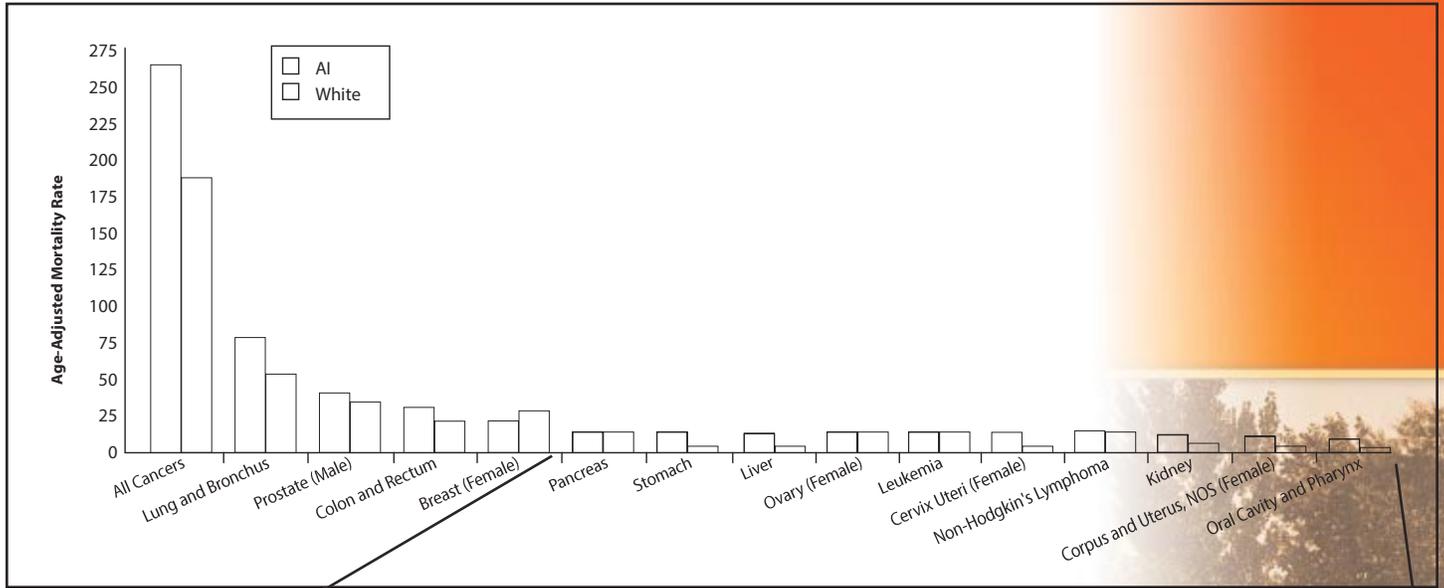
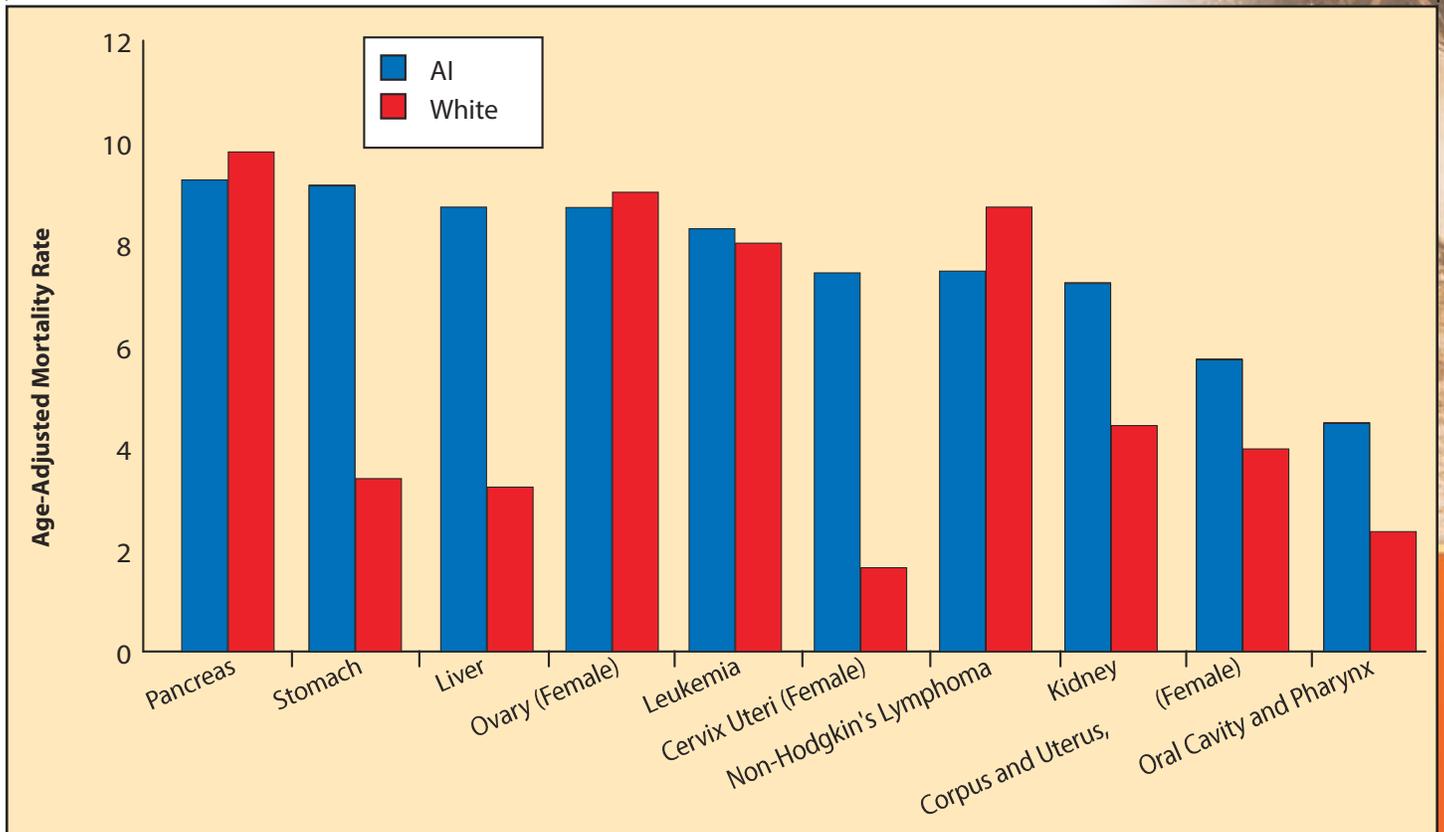


Figure 5. Northern Plains American Indian and White Cancer Mortality Rates by Site (1994-2003)<sup>4</sup>



## Northern Plains American Indian Cancer Incidence Rates

Cancer incidence data for Northern Plains American Indians are more limited than mortality data. Table 4 shows the AI overall and incidence rates by state, and Figure 6 outlines the four major sites of cancer incidence for AI (Breast for women, Prostate for men, Lung and Colorectal). These data indicate that the overall cancer incidence rate is higher in North and South Dakota than the US. While incidence rate appears to be lower for Iowa and Nebraska, this must be interpreted with caution given the smaller American Indian population size.

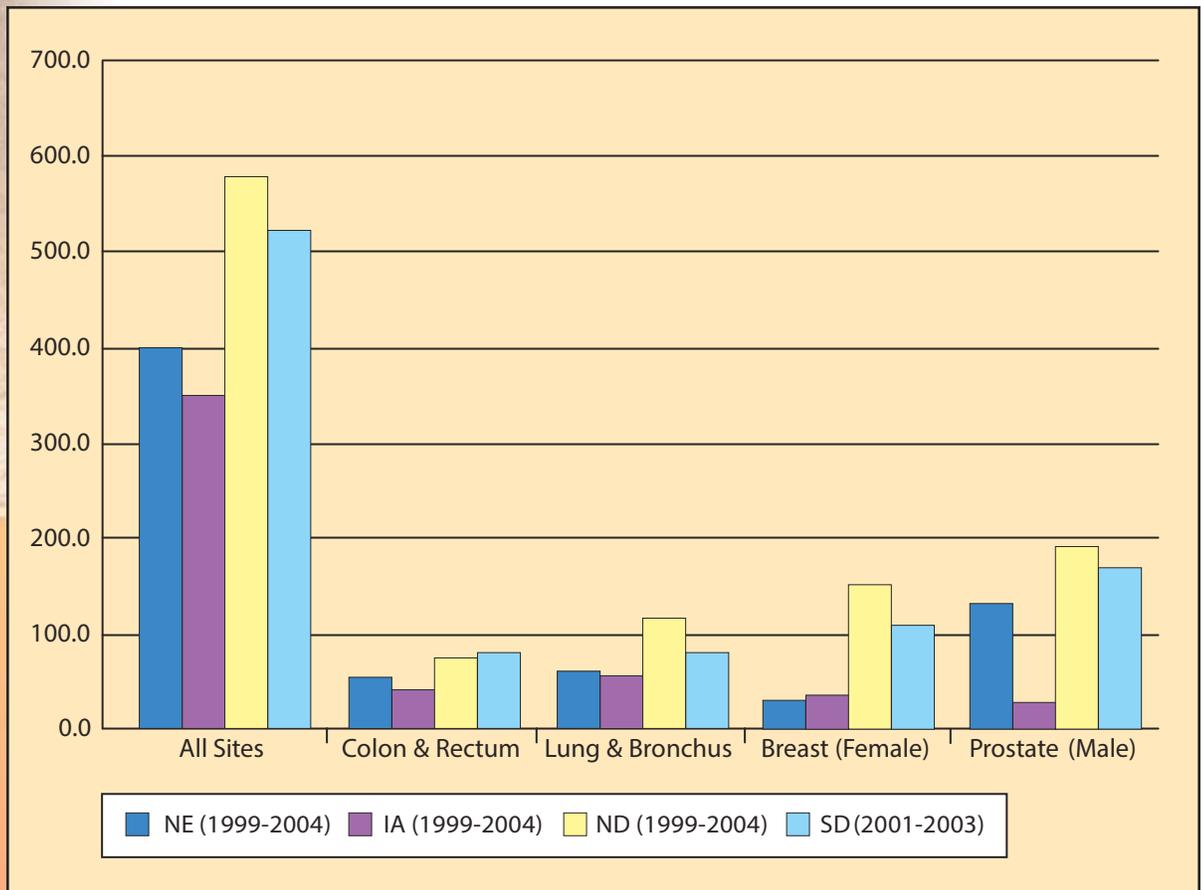
Table 4. Northern Plains AI Cancer Incidence Rates by Age Group

	US (2000-2003) <sup>6</sup>	Iowa (1999-2004) <sup>7</sup>	Nebraska (1999-2004) <sup>7</sup>	North Dakota (1999-2004) <sup>7</sup>	South Dakota (2001-2003) <sup>7</sup>
All Races	AI	AI	AI	AI	
All Ages	47s.8	188.9	397.s	s76.1	s19.3
0-19	16.6	0.0	10.0	16.0	N/A*
20-44	108.s	70.4	83.4	94.7	N/A*
4s-64	69s.s	s28.7	609.2	789.4	N/A*
6s-84	2187.6	2607.6	1790.2	2699.6	N/A*
8s+	2219.7	<s	2272.7	294s.s	N/A*

Notes. Rates for "All Ages" are per 100,000 and age-adjusted to the 2000 US Std Population.

\*Data currently unavailable due to data limitations.

Figure 6. AI Age-Adjusted Cancer Incidence Rates by State<sup>7</sup>



# NORTHERN PLAINS NATIVE AMERICAN CANCER PLAN

## CHAPTER 3

### IMPLEMENTATION



NORTHERN PLAINS COMPREHENSIVE CANCER CONTROL PLAN

**– Matthew Pilcher, Winnebago Tribe of Nebraska,  
Tribal Chairman and Colon Cancer Survivor**

**Photo Credit: Northern Plains Healthy Start**

# CHAPTER 3

## IMPLEMENTATION

Implementing this Plan will not be a simple task and will take a synergistic and collaborative effort of the entire region. This chapter describes how people can get involved in the effort to implement this plan and reach its goals and objectives. There are many ways anyone, whether a health care provider, cancer survivor, or a tribal leader, can be involved in helping to reach the goals and objectives set forth in this Cancer Plan. The following highlights just some of the ways to become involved.

### Join the Northern Plains Cancer Coalition so you can:

- Join meetings and learn about what is going on for cancer control and prevention
- Be kept up-to-date about how the Plan is being implemented
- Learn about trainings, activities, and events that may be of interest to you
- Hear about resources that may be available to you
- Share what you are doing for cancer prevention and control in your own community
- Serve on a workgroup to help move forward a cancer control activity

### Join a Northern Plains Cancer Coalition Workgroup so you can:

- Provide leadership and guidance for implementing cancer control and prevention activities
- Help determine priorities to focus on
- Advise the development of projects and activities
- Help find funding and resources to implement activities

### As a health leader in your own community you can:

- Be a leader and advocate for creating or collaborating on more cancer prevention and awareness activities
- Encourage your tribe or health program to develop men's and women's wellness programs
- Support tobacco free policies and environments

### You can even implement this plan as an individual by doing activities such as:

- Quit smoking or encourage a loved one to
- Live a healthier lifestyle by eating more traditional and natural foods
- If you are diagnosed with cancer, consider enrolling in a clinical trial if available

[To join the Coalition please complete the registration form on the last page of this booklet!](#)



# NORTHERN PLAINS NATIVE AMERICAN CANCER PLAN

## CHAPTER 4

### EVALUATING AND MONITORING



#### NORTHERN PLAINS COMPREHENSIVE CANCER CONTROL PLAN

"I am good at having my check ups, the way I found out I had cancer I was a little sore so I went in to get a check up and thought this is my body and it's beginning to hurt and I want it tested. Every woman should have all her tests done, your mammogram, your pap, I really believe in women getting their annual check ups. When your body hurts and it doesn't go away you need to go to your doctor."

-Eleanor Baxter, Omaha Tribe of Nebraska, Tribal Council Member and Cancer Survivor

Photo Credit: Northern Plains Healthy Start

# CHAPTER 4

## EVALUATION AND MONITORING

### The Basics of Evaluation

#### What is evaluation?

- Evaluation is a process of measuring something's significance or worth. Health program evaluation does not just look at the end result, but what is needed, how things need to be designed, and the way things happen.

#### Why do we evaluate?

- It is important to know how well something is working so changes can be made to make it work better or help more people

#### What is a goal?

- A broad statement of what a program hopes to accomplish

#### What is an objective?

- A statement of a result a program will try to accomplish within a particular time period that will help reach a goal

#### What is “process” evaluation?

- Evaluating how well something develops or proceeds
- For example, process evaluation may look at how satisfied someone is with a training, while impact or outcome evaluation would look at if someone learned something from a training

#### What is “impact” and “outcome” evaluation?

- Impact evaluation looks at if we are reaching our objectives, while outcome evaluation looks at if we are reaching our goals



## Overview

Evaluation is an important part of all health programs. The following chapter provides a brief overview of how this plan will be evaluated and monitored for effectiveness.

## Background

Often people think of evaluation as numbers and statistics at the end of a program or activity in order to satisfy the requirements given by the funding organization and prove that the program was worthwhile. This is only a small portion of evaluation. Evaluation is a continual and circular process that should be integrated into a program and its activities.

Evaluation of this plan will allow stakeholders to understand answers to questions such as: “What is working well?”, “What could be done better?”, “How can we do it better?”, “What impact does a particular activity have?”, “Are goals and objectives being met?”, etc.

In order to do this type of evaluation, Northern Plains Comprehensive Cancer Control Program (NPCCCP) will need to integrate process (measurements of activities and tasks), impact (measurements of objectives) and outcomes (measurements of goals) evaluation as ongoing aspects in all program activities. Different strategies and tools will be used to collect, compile, analyze, and report evaluation information.

## Description of Measures

### Process Evaluation

Process evaluation allows staff to modify how program components are being administered to improve efficiency and cultural acceptability. Process evaluation typically asks questions such as, “Is our program being implemented well?” Likewise, each objective has relevant process evaluation questions. Coalition members assess how well they feel the Coalition is functioning and how they would like processes or procedures revised to improve the comfort levels and efficiency of the group. Examples of Process Evaluation Questions include, but are not limited to:

1. To what extent is the Plan being implemented?
2. Where do funds come from to implement the Plan (CDC vs. external grants)
3. To what extent are products developed for the Plan appropriate for literacy, language, visual (e.g., 14-16 point font size for products designed for elders), visually appealing, and cost effective?

### Impact Evaluation

The impact evaluation will measure if objectives are being reached. Baseline data is presented for some objectives for which data are available (e.g., tobacco use rates, cancer screening rates, etc.), in order to set a marker from which progress can be measured. However, many objectives do not include the amount of percent change because of the limitations or unavailability of this data. Therefore, the evaluation data collection for each Cancer Plan objective will vary. Some short and intermediate term impact measures on objectives will be collected based on the activities being implemented. Additional objectives impact measures may use population-based sources such as Behavioral Risk Factor Surveillance System (BRFSS), and IHS clinical data to measure items such as tobacco use and cancer screening.

### Outcome Evaluation

Outcome evaluation is directly related to the Cancer Plan Goals. To attain the goals,



both the relevant process and impact evaluation need to be implemented. Collectively they contribute to determining the attainment of the goals. Most outcome evaluation is collected annually for the proposed Cancer Plan Goals. However, the Comprehensive Cancer Plan includes outcome measures that cannot accurately be collected until 5 or 10 years after implementation of the Northern Plains Comprehensive Cancer Plan (e.g., reduced cancer mortality or improved survivorship requires 10 years of Plan implementation before measurable improvements are feasible to detect within surveillance data). Cancer Plan long-term (10-15-year) outcome measures may show improvements in the intended population (Native children through elders) in data indicators such as:

1. Health status
2. Improved diet and physical activity
3. Reduced exposure to environmental contaminants
4. Screening service usage
5. Cancer diagnosed at stages 1 or 2 rather than stages 3 and 4
6. Reduced cancer morbidity and mortality
7. Increased participation in cancer clinical trials (QOL)
8. Improved Quality of Life (QOL) among cancer patients and their families in comparison to current QOL among these same populations

## Example Program Evaluation Strategies

There are multiple strategies used by NPCCCP in order to ensure proper data are collected in the areas outlined above. The following describes examples of these strategies:

### Tracking data

Tracking data are collected for process and impact evaluation. Collectively, tracking data contribute to outcome measures. NPCCCP staff store hard copies of documents such as meeting minutes, agenda, rosters of attending participants and when appropriate, products drafted or refined by the meeting participants.

### Pre/Post Assessments

Some presentations, but all workshops and trainings will use an electronic Audience Response System to collect demographics, pre-session knowledge, embedded items on opinions or beliefs, post-session knowledge and overall session evaluation.

### Cancer Burden and Risk Factor Surveillance

NPCCCP will compile cancer burden statistics (i.e., indicator lists of incidence, mortality, BRFSS, YRBS, etc.) on an annual basis to track long-term outcomes.



# NORTHERN PLAINS CHAPTER 5 CANCER PLAN PREVENTION AND EDUCATION

GOALS, OBJECTIVES & ACTION STEPS FOR PREVENTION & EDUCATION



NORTHERN PLAINS COMPREHENSIVE CANCER CONTROL PLAN

"I've been praying a lot to make sure that I'm cancer free. What I went through is a story that I feel if heard, would help another human being, another Native American - that would make me happy. We need to walk a dean path, stay away from chemicals, eat healthy, and keep regular visits to the doctor."

-Paul Wounded Head, Oglala Sioux, Esophageal Cancer Survivor

Photo Credit: Stephanie Bolman

# CHAPTER 5

## PREVENTION AND EDUCATION

### The Basics of Cancer Prevention

#### How can we prevent or keep people from getting cancer?

- There is no one thing that we can do to guarantee we will not get cancer. However, we can greatly reduce our chances of getting cancer by eliminating “risk factors.” We can learn ways to protect ourselves by learning about these risk factors and reducing them.
- Things we can do to prevent cancer, also can help prevent diabetes, heart disease, and other chronic illnesses

#### What is a “risk factor”?

- A risk factor is a condition that can increase the chance cancer might occur. Risk factors can be related to heredity (e.g., genes passed from parent to child), or lifestyle (e.g., using commercial tobacco products), or environment (e.g., toxins in the air or water).

#### What are the hereditary risk factors for cancer?

- Scientists have discovered that some cancers run in families. If someone has a parent or sibling with cancer, they may have a greater chance of also developing cancer. It is very important for someone with an immediate family member with cancer to discuss this with their health care provider because he/she may need to have health check-ups or cancer screenings earlier or more often than normal.

#### What are the lifestyle changes I can make to reduce my chances of getting cancer?

- The following things can reduce your risk of getting cancer:
  - Don't begin to smoke or quit smoking
  - Maintain a healthy weight
  - Be physically active
  - Eat a healthy diet
  - Limit alcohol consumption
  - Protect yourself from the sun
  - Protect yourself and your partner from sexually transmitted diseases

#### What is the number one cause of cancer and cancer death that can be prevented?

- Use of commercial tobacco products
- It is estimated that tobacco use accounts for about 30% of all cancer deaths

#### What in the environment can cause cancer?

- Sometimes when people talk about the “environment” they mean things such as chemicals and radiation in the land and water, but also things in the air that are put there by lifestyle choices (such as second-hand smoke) or infectious agents (such as the Human Papilloma Virus) that are known to cause cancer
- Taking all these things into account, there are over 200 different agents that have been identified to cause or suspected to cause cancer



## Overview

Cancer can be prevented, but more education and resources are needed in order to create awareness and help people make changes. This chapter highlights the prevention areas that need to be improved.

## Background

Cancer is the result of a complex mixture of factors related to heredity, environment, and lifestyle. Some of these factors can be modified by an individual in order to decrease their risk of developing cancer. The purpose of this chapter is to promote healthy lifestyles that can potentially lead to the prevention of cancer. Additionally this chapter focuses on general cancer awareness and knowledge. Basic knowledge about cancer can empower people to make decisions that can affect their own, their family's, and their loved one's quality of life related to all areas of cancer including prevention, screening, treatment, survivorship and end-of-life.

One of the major risk factors for cancer is commercial tobacco use,<sup>8</sup> and American Indians/Alaska Natives are more likely to smoke than any other racial and ethnic groups.<sup>9</sup> This is especially true for the Northern Plains American Indian population with rates nearly twice as high as national rates: current smoking rates for Northern Plains American Indian adults are around 44-49% (Table P1) compared to national rates of 20.s%.<sup>10</sup> Smoking among Native American youth is also an important issue to address. National data puts high school current smoking rates at 23.0%,<sup>11</sup> but according to Native American Youth Tobacco Surveys conducted in Nebraska and South Dakota, approximately 30% of middle school and s0% of high school students are current smokers (Table P2). These data reflect the magnitude and urgency of problems with smoking that American Indian communities are facing. Comprehensive tobacco control and prevention strategies, including enforceable tobacco policies, are needed.

Diet, nutrition and physical activity also play an important role in cancer prevention. Scientific evidence suggests that 30% of cancer deaths are linked to nutrition, physical activity, and overweight or obesity.<sup>12</sup> Also related to diet, alcohol use can be connected to cancer risk.<sup>13</sup> Native Americans in the Northern Plains also have high and significantly higher rates of overweight and obesity compared to the white population (Table P4). Activity levels are low and diets appear to be poor, though this is not significantly different from the White population (Tables P4 and Ps).

Some infectious agents have been shown to increase one's risk for developing certain types of cancer. In particular, some types of the Human Papilloma Virus (HPV) can cause cervical cancer. A vaccine is now available that protects against 4 HPV types thought to cause approximately 70% of cervical cancers.<sup>14</sup>



## Goals, Objectives & Action Steps for Prevention & Education

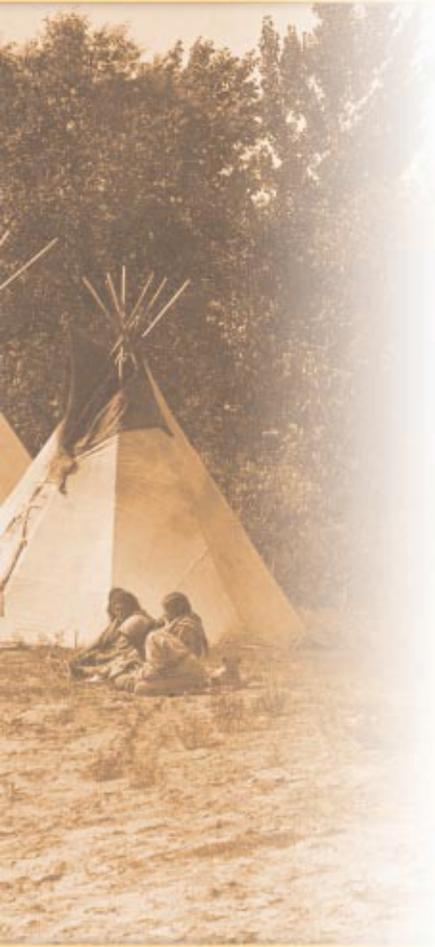
**PREVENTION & EDUCATION GOAL:** Reduce the incidence and mortality rates of cancer in Northern Plains American Indian communities by promoting healthy lifestyles and reducing cancer related risk factors

### Major Issues, Challenges, and Barriers Identified by Coalition and Tribal Partners:

- ◆ Access to tobacco is too easy for both adults and children
- ◆ Tobacco policies do not exist or are not enforceable
- ◆ There is an increase in sedentary lifestyles and poor diets
- ◆ There is a lack of access to nutritious food on the reservations
- ◆ There are limited prevention and education related services available
- ◆ Prevention can be a low priority for health care systems
- ◆ Tribal councils and leadership sometimes lack awareness and understanding of cancer prevention issues
- ◆ Education needs to be ongoing, empowering, and tailored for each tribal community

### Priority Areas:

- ◆ High rates of commercial tobacco use
- ◆ Low rates of physical activity



## GENERAL CANCER PREVENTION

**Objective P1.** By 2009, increase tribal community knowledge and awareness regarding cancer

### Baseline and Rationale:

Knowledge and awareness are at the core of enacting change. If people are unaware of health risks, services and resources available, they do not have the power to make informed decisions or ask for their basic rights.

Currently there is no known population-based data source regarding the knowledge, attitudes, and beliefs regarding cancer prevention and control for Northern Plains American Indians. Pre to post changes in knowledge, attitudes, and beliefs of cancer can be collected from presentations, trainings, and workshops.

### Potential Action Steps:

Action Step a. Implement Cancer 101 training for tribal communities

Action Step b. Create and disseminate public service announcements regarding cancer risks and cancer screening tests available utilizing local cancer survivors

Action Step c. Create awareness on carcinogenic environmental contaminants, such as asbestos, radon, secondhand smoke, and ultraviolet sun exposure

**Objective P2.** By 2011, increase the knowledge, attitudes, and beliefs of Native American youth regarding the prevention of cancer.

### Baseline and Rationale:

It is important to start education at a young age. Cancer and other leading causes of death (diabetes, heart disease, etc.) can be reduced by preventing lifestyle risk factors that often begin during youth including tobacco and other substance abuse, diet, and physical activity.

Currently there is no known population-based data source regarding the knowledge, attitudes, and beliefs regarding cancer prevention and control for Northern Plains AI. Pre to post changes in knowledge, attitudes, and beliefs of cancer can be collected from presentations, trainings, and workshops.

### Potential Action Steps:

Action Step a. Partner with youth programs to add cancer prevention projects and curriculums into their services

Action Step b. Utilize youth centered events such as basketball tournaments to promote healthy lifestyles for the prevention of cancer



# TOBACCO

**Objective P3.** By 2012, reduce the number of American Indian adults habitually using commercial tobacco

### Baseline and Rationale:

There is a well-established link between tobacco use and at least 10 different cancers including many of the major sites of cancer death for American Indians in the Northern Plains (including lung, stomach, pancreatic, kidney, and cervical).<sup>8</sup> The currently available data on smoking among Northern Plains American Indians comes from Behavioral Risk Factor Surveillance System (BRFSS).<sup>a</sup> According to these data the prevalence of adult smokers in our region clearly exceeds the national average of 20.5% by two times.

Some of this objective's action steps are recommended by national experts. For example, the U.S. Preventive Services Task Force highly recommends that clinicians screen all adults for tobacco use and provide tobacco cessation interventions for those who use tobacco products. Also the Task Force on Community Preventive Services recommends smoking bans and restrictions.

Table P1. Northern Plains American Indian Adult Tobacco Use Data

State/Area	Source Year	Tobacco Measure											
		Percent Current Smokers			Percent Current Who Attempted to Quit			Percent Current Smokers			Percent Current Smokless Tobacco Users		
		All	Male	Female	All	Male	Female	All	Male	Female	All	Male	Female
Northern Plains**	BRFSS 1997-2000 <sup>15</sup>	44.1*	48.3*	39.6*									
SD	BRFSS 2000s <sup>16</sup>	44.4*	44.7*	44.0*							7.9	13.1	3.1
ND	BRFSS 1996-2002 <sup>17</sup>	48.7*			8.6			23.5					
NE	BRFSS 1990s-2004 <sup>18</sup>	49.0*			3.9			22.7					

\*rates found to be statistically different from white rates.

\*\*Northern Plains for this source includes states ND, SD, NE, and IA plus WY, MT, MN, WI, IN, MI

### Potential Action Steps:

Action Step a. Train health care providers on the appropriate ways to identify, counsel, and refer adults for tobacco cessation services (e.g. State Quit Lines)

Action Step b. Strengthen Northern Plains tribal smoke-free laws to provide protection from secondhand smoke in all public places and places of employment

Action Step c. Promote, expand, and empower efforts by tribal tobacco coalitions

<sup>a</sup> Several tribes in the Northern Plains additionally have or are completing Adult Tobacco Surveys. This data belongs expressly to the individual tribes and is not currently available to others.

Action Step d. Advocate to tribal leadership to improve their understanding of the economic and societal costs of commercial tobacco use

Action Step e. Seek funding and resources to help decrease the cost of tobacco cessation products

**Objective P4.** By 2012, decrease the rate of tobacco use among American Indian youth

**Baseline and Rationale:**

Preventing tobacco use in youth can have a large impact on their health later in life.<sup>19</sup> Native American Youth Tobacco Surveys (YTS) provide the baseline information about the prevalence of tobacco product use among American Indian youth in the Northern Plains. As shown in Table P2, there is a high rate of American Indian youth using tobacco in the Northern Plains than other populations. These rates need to be lowered and youth prevented from initiating commercial tobacco use. There are current tobacco education programs being implemented for youth in the Northern Plains, but further evaluation of these programs needs to be conducted in order to improve and ensure evidence based guidelines are followed.

Table P2. Northern Plains American Indian Youth Tobacco Use Data

State/Area	Source Year	Grades	Tobacco Measure			Percent Who Smoked Cigarettes Daily			Percent Current Smokers			Percent Currently Use Spit Tobacco		
			Percent Current Smokers			Percent Who Smoked Cigarettes Daily			Percent Current Smokers			Percent Currently Use Spit Tobacco		
			All	Male	Female	All	Male	Female	All	Male	Female	All	Male	Female
Northern	YTS 2004 <sup>20</sup>	6-8	31.8	21.3	41.7	2.1	0.9	3.3	7.s	7.2	7.7	s.1	2.7	7.4
		9-12	s2.1	48.6	s6.3	10.4	10.4	10.4	19.4	23.2	14.9	9.s	12.2	6.1
		6-12	41.s	3s.0	48.2	6.1	s.7	6.s	13.1	1s.2	10.9	7.3	7.4	7.1
SD	YTS 200s <sup>21</sup>	6-8	30			17			34			17		

\* Definitions: Current Smoker — smoked on one or more days in the past 30 days; Smoked Cigarettes Daily (NE definition) – in past 30 days, smoked on all 30 days; Smoked Cigarettes Daily ( SD definition) – smoked at least one cigarette daily for 30 days; Currently Use Spit Tobacco - used spit tobacco on one or more days in past 30

\*\* Grades 6-8 = Middle School; Grades 9-12 = High School

**Potential Action Steps:**

Action Step a. Develop tobacco education programs to target students in Northern Plains tribal schools

Action Step b. Evaluate current tobacco education activities targeting students in Northern Plains tribal schools

Action Step c. Limit youth access and exposure to tobacco products

Action Step d. Educate and support tribal, public, and private schools within reservation boundaries about tobacco free school policies

Action Step e. Increase anti-tobacco efforts, such as advertising and adult role modeling

Action Step f. Promote smoke free homes and vehicles campaigns

## PHYSICAL ACTIVITY

**Objective Ps.** By 2012, increase the number of American Indians who participate in daily, moderate physical activity as it relates to the prevention of cancer

### Baseline and Rationale:

In South Dakota, BRFSS data indicates that over half of American Indians do not get moderate activity. This lack of active lifestyles contributes to health problems including cancer. (Table P3)

The Task Force on Community Preventive Services recommends informational approaches such as community-wide campaigns to improve physical activity rates. Also, policy changes are an area of recommendation.

Some studies were done in the late 1980s and early 1990s (such as the Strong Heart Study) that included physical activity rates, but no current population-based data sources known for AI Youth Physical Activity Rates.

Table P3. Northern Plains AI Adult Physical Activity Rates

State/Area	Source Year/s	Physical Activity Measured								
		Percent With No Leisure Time Activity			Percent with No Moderate Activity			Percent With No Vigorous Activity		
		All	Male	Female	All	Male	Female	All	Male	Female
Northern Plains**	BRFSS 1997-2000 <sup>15</sup>	28.8	24.s	33.4						
SD	BRFSS 200s <sup>16</sup>	26.6	24.s	28.7	s1.9	s0.3	s3.3	78.s	70.3	86.1
ND	BRFSS 1996-2002 <sup>17</sup>	28.6								
NE	BRFSS 199s-2004 <sup>18</sup>	26.2								

\*rates found to be statistically different from white rates.

\*\*Northern Plains for this source includes states ND, SD, NE, and IA plus WY, MT, MN, WI, IN, MI

### Potential Action Steps:

Action Step a. Promote programs that encourage traditional and social dance as healthy activities

Action Step b. Promote activity through local community events such as awareness walks or pow-wows

Action Step c. Increase the number of policies that support physical activity

Action Step d. Identify and utilize local athletes as spokespersons/mentors of healthy active lifestyles

Action Step e. Promote and support the use of tribal recreation centers by holding special events and activity contests

## HEALTHY WEIGHT AND NUTRITION

**Objective P6.** By 2012, improve American Indian healthy dietary behaviors in order to lower rates of overweight and obesity

### Baseline and Rationale:

Healthy eating is important for the prevention of cancer. The rates of overweight and obesity for U.S. adults and youth are at epidemic proportions,<sup>22</sup> and rates for adult AI appear to be even higher than the general population (Table P4). A 200s Institute of Medicine Report discussed an expert committee’s action plan for the prevention of childhood obesity.<sup>23</sup> One of the recommendations for community organizations was to “provide opportunities for healthful eating and physical activity in existing and new community programs, particularly for high-risk populations.” Therefore action steps below include ideas for community programming such as community gardens and cooking classes. Policy changes should also be explored.

**Table P4. Northern Plains AI Adult Weight and Diet**

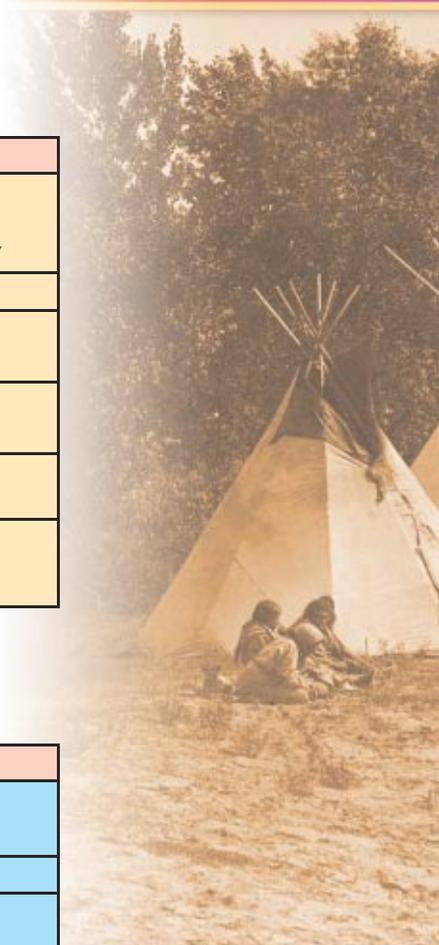
State/Area	Source Year/s	Measure								
		Percent Overweight or Obese			Percent Obese			Percent With Less than five fruits/vegetables per day		
		All	Male	Female	All	Male	Female	All	Male	Female
Northern Plains**	BRFSS 1997-2000 <sup>15</sup>	24.2	22.8	2s.7						
SD	BRFSS 200s <sup>16</sup>	74.0*	76.s	71.s*	40.8*	41.6*	40.0*	82.s	87.4	77.9
ND	BRFSS 1996-2002 <sup>17</sup>	71.2*			32.9*					
NE	BRFSS 199s-2004 <sup>18</sup>	6s.2*			32.7*					

\*rates found to be statistically different from white rates.

\*\*Northern Plains in this source refers to ND, SD, NE, IA and additional states of WY, MT, MN, WI, IN, MI

**Table Ps. Northern Plains AI Youth Weight**

State/Area	Source	Measure					
		Percent			Percent At Risk of Overweight and		
		All	Male	Female	All	Male	Female
SD	SD Height and Weight Report School year 2004-200s <sup>24</sup>	26.1			44.8		
Aberdeen Area	AAIHS School year 199s-1996 <sup>2s</sup>			18.0		39.1	38.0



### Potential Action Steps:

Action Step a. Develop and promote community gardens to increase the availability of fresh fruits and vegetables

Action Step b. Promote programs that hold tribal community cooking classes to teach healthy traditional and contemporary recipes

Action Step c. Advocate for grocery stores and food outlets to stock healthier food choices

**Objective P7.** By 2012, decrease the rate of Northern Plains American Indians who use alcohol more than moderate amounts.

#### Baseline and Rationale:

Long-term and heavy drinking increases ones risk of developing certain cancers including those of the colon and rectum, esophagus, mouth, throat, and larynx.<sup>26</sup> U.S.

Preventive Services Task Force recommends that adults be screened and receive behavioral counseling in primary care settings to reduce alcohol misuse.

Table P6. AI Adult Alcohol Use

State/Area	Source Year/s	Alcohol Measure					
		Percent Heavy Drinking			Percent Binge Drinking		
		All	Male	Female	All	Male	Female
Northern Plains**	BRFSS, 1997-2000 <sup>15</sup>	2.6	2.7	2.5	18.7	24.9	10.4
SD	BRFSS, 2005 <sup>16</sup>	7.0			21.0	26.4	15.7*
ND	BRFSS, 1996-2002 <sup>17</sup>	4.7			28.9		
NE	BRFSS, 1998-2004 <sup>18</sup>				22.7*		

\*Significantly higher than White population

\*\*Northern Plains in this source refers to ND, SD, NE, IA and additional states of WY, MT, MN, WI, IN, MI

### Potential Action Steps:

Action Step a. Develop campaigns to increase awareness of the relationship between excessive alcohol use and cancer

Action Step b. Train health care providers on the appropriate ways to identify, counsel, and refer adults for alcohol use

## ENVIRONMENT

**Objective P8.** By 2012, support efforts to increase knowledge and awareness about the links between environmental contaminants and cancer.

### Baseline and Rationale:

The contribution of environment toxins, such as that in the air and water are thought to be less than 5% of all cancers.<sup>27</sup> However, because these types of factors are difficult to study, scientists are less certain of these estimates, and many are concerned about this issue. Therefore, knowledge about current evidence needs to be increased, as well as further effort to clarify the possible links between environment and cancer.

### Potential Action Steps:

Action Step a. Review existing evidence of environmental links to cancer

Action Step b. Determine and partner with appropriate entities involved in environmental issues

Action Step c. Seek funding in order to study links between environmental contaminants and cancer

## INFECTIOUS AGENTS

**Objective P9.** By 2012, increase tribally appropriate efforts to make the Human Papilloma Virus (HPV) vaccine accessible and available to American Indians in the Northern Plains

### Baseline and Rationale:

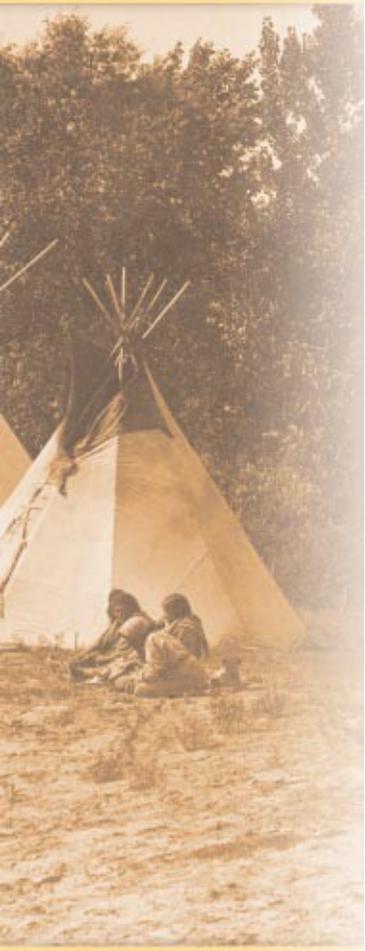
Cervical cancer incidence and death rates are high for Northern Plains American Indians compared to other populations (Figure 5). The HPV Vaccine is fairly new, and therefore more people need to be made aware of HPV and what it is so they can make informed decisions related to getting the vaccine. Additionally, researchers from the University of South Dakota have done preliminary research on major HPV types in the Northern Plains Native population, and found a higher percent of different high risk types than those covered by the vaccine.<sup>28</sup> Therefore, efforts need to be made to expand the vaccine coverage as appropriate.

### Potential Action Steps:

Action Step a. Develop media messages and educational materials to promote awareness of the HPV vaccine

Action Step b. Advocate and collaborate with drug companies to provide the most effective HPV vaccine as possible to American Indians





# NORTHERN PLAINS CHAPTER 6 CANCER PLAN SCREENING AND EARLY DETECTION

GOALS, OBJECTIVES & ACTION STEPS FOR SCREENING & EARLY DETECTION



NORTHERN PLAINS COMPREHENSIVE CANCER CONTROL PLAN

"Our population of Native American people are often diagnosed with cancer at late stages, decreasing chances of survival. That is why we need to educate and create better access to care! By the time cancer is detected earlier when it's more treatable."

John Eagle Shield, Standing Rock Sioux Tribe, CHR Director

Photo Credit: KAT Communications

# CHAPTER 6

## SCREENING AND EARLY DETECTION

### The Basics of Cancer Screening

#### What is a cancer screening?

- Screening is a health test or exam that can help find cancer at its early stages when it is more treatable.

#### What are cancer stages?

- Doctors use “stages” to describe how far a cancer has spread in the body.
- There are four common stages used
  - ✦ In Situ – early cancer and has not spread to other tissues
  - ✦ Local – cancer is found only in the organ where it started to grow
  - ✦ Regional – cancer has spread to surrounding tissues or lymph nodes
  - ✦ Distant – cancer has spread to other organs or systems in the body

#### What are Screening Guidelines?

- Specially formed groups, committees, and organizations look over the potential benefits and harms of screening tests for a group of people and make recommendations about what tests should be given to what age groups.

#### What screening tests are currently recommended for cancers?

- The following are some of the tests generally recommended for people who are at average risk for cancer and do not have any specified symptoms:
- For Breast Cancer:
  - ✦ Mammogram (an x-ray of the breast) every year for women 40 years and older
  - ✦ Clinical Breast Exam (health care provider checks for lumps or changes in the breast) every three years for women in their 20s and 30s, and every year for women over 40.
  - ✦ Breast Self Exam (women can check their own breasts to feel and report any changes) is an option for women starting in their 20s
- For Colon and Rectal Cancer - beginning at age 50 both men and women should receive one of the following options of tests
  - ✦ Fecal Occult Blood Test (FOBT) (a lab test which checks for signs of blood in the stool) each year
  - ✦ Flexible Sigmoidoscopy (a procedure where a health care provider inserts a tube into part of your colon in order to look for polyps which can cause cancer) every five years
  - ✦ Yearly FOBT, plus a Flexible Sigmoidoscopy every five years
  - ✦ Double Contrast Barium Enema (DCBE) (a procedure where the colon is filled with a material called barium and then an x-ray is taken to look for changes or problems) every five years
  - ✦ Colonoscopy (a procedure where a health care provider inserts a tube into your whole colon in order to look for polyps which can cause cancer) every five years
- For Cervical Cancer
  - ✦ Pap Test or Pap Smear (a test where a health care provider will collect cells from a women’s cervix and look at them for any problems) each year for women after the onset of sexual activity but no later than 21 years old.
- For Prostate Cancer
  - ✦ Prostate Specific Antigen (PSA) (a blood test that looks for high levels of a protein which may mean cancer is present) every year for men 50 and older



## Overview

When cancer is detected early, the better a person's chances are for surviving. The purpose of this chapter is to outline the major areas needed to improve screening and early detection.

## Background

The sooner cancer is detected and treated, the better a person's chance for a full recovery. Several screening tests are available for some of the major cancer sites. The U.S. Preventive Services Task Force recommends regular screening of age, gender, and guideline appropriate individuals for breast, cervical, and colorectal cancer.

Mammogram is recommended for women 40 and over to screen for breast cancer, pap smear is recommended for women who are sexually active and have a cervix to screen for cervical cancer, and Fecal Occult Blood Tests and/or Sigmoidoscopy is recommended for men and women over 50 to screen for colon cancer. The focus of this chapter is to increase the accessibility and use of appropriate cancer screenings for the Northern Plains Native population.

There are considerable differences in the estimate of screening use by Northern Plains American Indians between data sources. For example, screening rates from BRFSS indicate between 70-90% of age-appropriate women are receiving mammograms and pap smears. However, data from Indian Health Service clinical records indicate the rate is much lower, 38% of women having had mammograms, and 6% having had pap smears. Regardless of the differences, it is clear that there is a portion of the American Indian population who are not receiving appropriate cancer screening. Also, statistics from Rapid City Regional Hospital's Tumor Registry (1990-2000) indicate that Native Americans are more likely than other patients to present with advanced (stage III or IV disease) breast, cervical and colorectal cancer.<sup>29</sup> Increases in regular screening would potentially lead to earlier diagnosis and better survival from cancer.

The general consensus among health care providers and community members in the Northern Plains is that the access to cancer screening is severely limited due to the shortage and capacity of area facilities that provide on-site screening services. Therefore, individuals have to travel long distances to receive a screening. Additionally, when a cancer screening is not available in the IHS service region, an individual would need contract health care approval to have the screening paid for off-site. A 'screening' exam would rarely be approved given the funding and priorities of contract health care.



## Goals, Objectives & Action Steps for Screening and Early Detection

SCREENING AND EARLY DETECTION GOAL: Increase appropriate cancer screening for Northern Plains American Indians so cancer is detected at earlier stages

### Major Issues, Challenges, and Barriers Identified by Coalition and Tribal Partners:

- ◆ There is a lack of access to cancer screening due to travel distances and a lack of transportation
- ◆ Funding for screening is an issue because not all tests are covered by Indian Health Service, and screening is not a priority for Contract Health Care dollars
- ◆ Cultural beliefs, fear of cancer, and lack of knowledge can be a barrier for some to get screened
- ◆ There needs to be more continuity of care from screening, follow-up, and on
- ◆ There is a lack of consistency among providers of using certain standards of care for cancer screening

### Priority Areas:

- ◆ Breast Cancer Screening
- ◆ Colorectal Cancer Screening



**Objective S1.** By 2010, promote the use of cancer screening guidelines for Northern Plains Native Americans

**Baseline and Rationale:**

The U.S Preventive Services Task Force and American Cancer Society have developed guidelines for screening that are widely accepted. One of the first steps is to evaluate these existing guidelines for cultural appropriateness, and then formal policies should be developed with and adopted by the health care facilities in the Northern Plains. The standardized guidelines will help promote uniform messages about cancer screenings and increase the likelihood that screening and follow-ups are done more appropriately.

It is not known how many Indian Health Service Units currently have formal policies or adoption of screening guidelines. Potential indicators for this objective include the number of Service Units who adopt developed guidelines.

**Potential Action Steps:**

Action Step a. Adapt the existing cancer screening guidelines for cultural appropriateness

Action Step b. Promote the development and adaptation of promising and “Best Practice Guidelines,” evidence based guidelines based on a formal assessment of cultural and population appropriateness

Action Step c. Develop and disseminate materials to providers regarding best practices for increasing screening and appropriate follow up

Action Step d. Conduct training on guidelines and best practices for health care providers

**Objective S2.** By 2009, improve cancer screening knowledge, attitudes, and beliefs of the Northern Plains Native American community members.

**Baseline and Rationale:**

The Task Force on Community Preventive Services recommends that informed decision-making be used to promote cancer screening. Therefore the action steps proposed involve empowering individuals to participate in decisions related to their health care.

Information on the knowledge, attitudes, and beliefs of cancer screening can be collected as evaluation pieces for specific activities implemented such as pre and post surveys during trainings.

**Potential Action Steps:**

Action Step a. Support education programs and trainings for tribal community members

Action Step b. Develop and disseminate public service announcements which promote cancer screening awareness and benefits



Action Step c. Promote the coordination, creation and implementation of activities that raise awareness and education of cancer prevention and screening recognizing the health literacy of communities

Action Step d. Promote the importance and benefits of personal empowerment cancer screening messages

Action Step e. Establish wellness programs for men and for women that encourages men and women to receive annual exams that include appropriate screenings

**Objective S3.** By 2010, improve the cancer screening and follow up knowledge, attitudes, and beliefs of health care providers who work with the Northern Plains Native American population

#### Baseline and Rationale:

Northern Plains healthcare clinical settings experience a very high turn-over in physicians and other health professionals (e.g., 18 months for selected clinics).<sup>30</sup> Often new physicians are unaware of the excessive cancer mortality experienced by Northern Plains American Indians and need both cultural and clinical in-service training to improve their referral and appropriate follow-up to cancer screening, diagnostic services and subsequent care.

#### Potential Action Steps:

Action Step a. Support educational programs for health care providers that include issues of cultural sensitivity/competency in promoting cancer screenings to patients

Action Step b. Develop a system to regularly disseminate information on evidence-based cancer screening practices

**Objective S4.** By 2012, increase the accessibility of recommended cancer screening to guidelines-appropriate Northern Plains Native Americans

#### Baseline and Rationale:

Lack of access to screening is a barrier to the Native population in the Northern Plains. Many live in rural areas and have to travel long distances to receive health care. Also, not all Indian Health Service Units in the region have the ability to do screening mammograms or sigmoidoscopies/colonoscopies. Therefore, cancer screening is literally not available to many populations because IHS is unable to pay for the referral to a contract health care facility for screening.

There are no known developed indicators or population-based sources to measure accessibility. Possible indicators that could be used would involve the number of health facilities with mammogram units, the distance individuals need to travel in order to receive screening services, the number of health facilities with providers who can provide certain cancer screenings (i.e., Pap Smears, Sigmoidoscopy, etc.).



## Potential Action Steps:

Action Step b. Conduct a community assessment regarding existing screening resources available to Northern Plains Indian reservations and identify the resources needed to meet needs

Action Step c. Support efforts to provide onsite mammography and other cancer screening for each reservation for all age appropriate Native American women by 2010

Action Step d. Increase the number of regional and local partnerships that offer onsite mammography and other cancer screening

Action Step e. Work with existing programs that offer screening to promote and use their resources more effectively (i.e., State Breast and Cervical Cancer Early Detection Programs)

Action Step f. Assess and develop appropriate training programs to increase the number of providers able to provide cancer screenings on reservations

**Objective Ss.** By 2012, increase the percent of Northern Plains Native Americans who receive regular guideline appropriate cancer screenings.

### Baseline and Rationale:

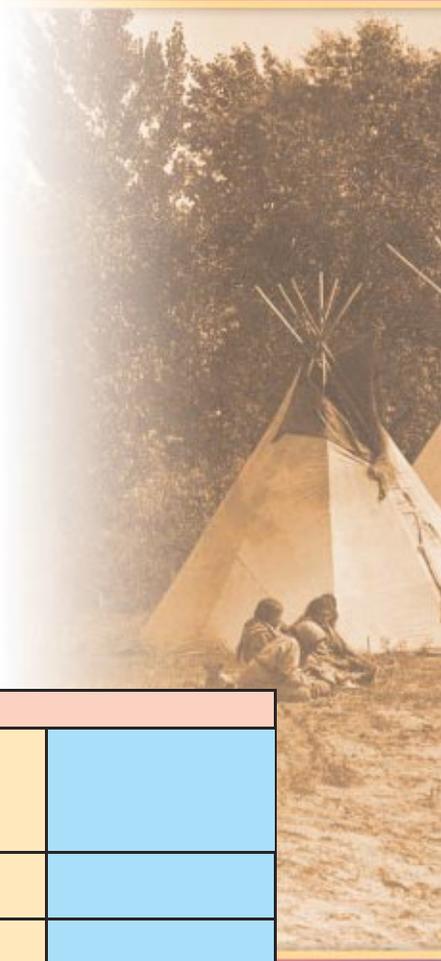
The Task Force on Community Preventive Services recommends client reminders for breast, cervical, and colorectal cancer screening (see Action Step b), and reducing structural barriers for both breast and colorectal cancer (Action Step c). Media in combination with other strategies is also recommended.

The current baseline data for screening is shown in Table S1. However, these rates show variation depending on the source.

Table S1. Northern Plains American Indian Screening Rates

State/Area	Source, Year/s				
		Percent women 40+ who had a mammogram in past two years	Percent women 18+ who had a Pap Smear (in past n years)	Percent ages 50+ who had FOBT in past two years	
Northern Plains*	BRFSS <sup>15</sup> 1997-2000		84.0 (past three years)		
SD	BRFSS <sup>16</sup> 2004	71.6	87.8 (past three years)	22.4	
ND	BRFSS <sup>17</sup> 1996-2002	89.2	83.2 (past two years)		
NE	BRFSS <sup>18</sup> 199s-2004	72.4	72.3 (past two years)		
Aberdeen Area	IHS GPRA <sup>31</sup> 200s	38 (active female clinical patients s2-64)	s6 (in past three years) active female clinical patients ages 21-64		

\*Northern Plains in this source refers to ND, SD, NE, IA and additional states of WY, MT, MN, WI, IN, MI



## Potential Action Steps:

Action Step a. Conduct public education campaign utilizing various media sources for the awareness of cancer risks factors, screening tests and individual roles and responsibilities

Action Step b. Work with appropriate partners to develop and implement tracking systems to improve reminders and follow up for patients and providers.

Action Step c. Identify and develop programs and resources to reduce common barriers to screening

Action Step d. Develop partnerships with agencies that provide cancer screening to unify services



# NORTHERN PLAINS CHAPTER 7

## TREATMENT AND TRADITIONAL MEDICINE

GOALS, OBJECTIVES & ACTION STEPS FOR TREATMENT & TRADITIONAL MEDICINE



NORTHERN PLAINS COMPREHENSIVE CANCER CONTROL PLAN

"Cancer patients in the Northern Plains are in need of better access and continuity of care during and after their treatment. The Walking Forward program has made a great impact on these issues through patient navigation, but we need these types of services to be continued and expanded to reach more Native Americans."

Kevin Molloy, Walking Forward Program,  
Clinical Research Coordinator and Patient Navigator

# CHAPTER 7

## TREATMENT AND TRADITIONAL MEDICINE

### The Basics of Cancer Treatment

#### How is cancer treated?

- There is no one way a cancer will be treated
- The treatment will vary depending on the type, the size, the location, and the stage of the cancer and the general health of the individual, and
- An individual's preferences for using western and traditional medicine should be honored

#### What are the types of cancer treatment?

- The following are some western medicine ways to treat cancer
- Surgery – removes the cancer tumor and possibly surrounding tissue and lymph nodes
- Chemotherapy – drugs are used to kill cancer cells
- Radiation – high energy rays are used to kill cancer cells or stop them from growing
- Hormone Therapy – used for certain cancers that need hormones to grow
- Biologic Therapy – helps the bodies natural ability (the immune system) to fight disease and protect the body from side effects

#### What is a side effect?

- A side effect is the result when cancer treatment damages healthy cells and tissues in addition to the cancer cells
- Side effects depend on the type and extent of treatment



## Overview

Cancer treatment can be very difficult and costly, and there are many barriers to treatment for Native American patients in the Northern Plains. This chapter describes the areas that need to be improved for better cancer treatment and treatment outcomes.

## Background

Because of the advances of science and cancer treatments for some common cancers, survival has increased dramatically when the disease is diagnosed early. Progress made in innovative treatment modalities has turned cancer from a life-threatening illness into a chronic disease. However, among Native Americans, cancer is more life-threatening than other populations.

There are numerous, well-documented barriers that may influence the type of cancer care Native Americans receive including: (1) lack of knowledge about state of the art cancer care; (2) fear and distrust of the health care system; (3) lack of access to cancer care (not referred or unable to access due to finances, lack of child care, etc); (4) geographic isolation (travel distances); (5) socioeconomic factors such as age, education, income, family status, and lack of insurance; (6) gender and race (sexism and racism); (7) fear of diagnostic tests, treatment, and side effects (disfigurement, pain, nausea, etc); and (8) differing cultural views of health and disease processes.<sup>32,33</sup> One of the first steps to improve the access to appropriate and timely cancer treatment is to begin implementing programs that would eliminate or reduce these barriers.

Many Native Americans have a holistic outlook on health, and follow more traditional ways of living including traditional medicines used to heal not only the body, but the whole person and the community. Traditional healers can be strong advocates for people with cancer, explaining to other health care providers about cultural beliefs regarding health. Healers can be also helpful in advocating for improvement in health behaviors.



## Goals, Objectives & Action Steps for Treatment and Traditional Medicine

TREATMENT & TRADITIONAL MEDICINE GOAL: Ensure that all Northern Plains American Indians with cancer receive access to quality western and traditional cancer care services and aftercare.

### Major Issues, Challenges, and Barriers Identified by Coalition and Tribal Partners:

- ◆ There is a need for community education about cancer because cancer treatment and terminology is difficult to understand and many do not want to discuss it with others
- ◆ There are issues with the timeliness of diagnosis and obtaining treatment
- ◆ There are many issues with the high cost of cancer treatment: cancer is not a high priority for contract health care, cancer patients can have their credit damaged because they cannot pay their treatment costs, and in general Indian Health Service and Contract Health Care are severely underfunded
- ◆ Providers are often not familiar with their patients and do not have a good understanding or acceptance of traditional healing
- ◆ Individuals must make lengthy trips to receive their cancer treatment at places away from their homes and families. Many families lack financial resources to cover their travel costs.

#### Priority Areas

- ◆ Covering the cost of treatment
- ◆ Improving timeliness of beginning cancer treatment



**Objective T1.** By 2012, increase awareness and use of most current and culturally appropriate clinical guidelines for cancer treatment among health care providers

**Baseline and Rationale:**

In 1999 the President’s Cancer Panel evaluated the public and private cancer research and delivery components and found that there was a disconnect between proven effective cancer care and the extent to which that care was provided to those with cancer.<sup>34</sup> In order to assure that patients get appropriate cancer treatment and care, providers need to be aware and encouraged to follow clinical guidelines that are current and culturally appropriate.

Information on knowledge and awareness can be collected from pre to post surveys during presentations, trainings, and workshops.

**Potential Action Steps:**

Action Step a. Provide “Cancer 101” and “Train the Trainer” classes for CHRs and other community health providers so they can provide patients cancer treatment education

Action Step b. Work with partners such as tribal colleges to develop culturally appropriate materials on cancer treatment.

Action Step c. Develop materials or system for providers to access current professional cancer treatment and care resources and information

Action Step d. Arrange for continuing professional education about current clinical guidelines for cancer treatment and care

Action Step e. Work with Quality Improvement Organizations in the state to encourage physicians and health care professionals to take cultural competence training

**Objective T2.** By 2012, increase knowledge and awareness about current and culturally appropriate cancer treatment of Native cancer patients, family members and caregivers.

**Baseline and Rationale:**

One of the barriers to appropriate cancer treatment is lack of knowledge. By providing information and education on cancer care to patients, families and caregivers, we can empower them to increase the use of appropriate cancer treatment.

Information on knowledge and awareness can be collected from pre to post surveys during presentations, trainings, and workshops.

**Potential Action Steps:**

Action Step a. Encourage patients to take someone along with them for treatment

Action Step b. Provide cancer patients education at discharge



Action Step b. Promote awareness of educational materials currently available from sources such as Cancer Information Service and the American Cancer Society

Action Step d. Make resources more available by partnering with tribal community college librarians and Tribal Health Educators

Action Step e. Provide Cancer 101 in tribal communities for various audiences including but not limited to: tribal health boards/committees, community colleges, community forums

Action Step f. Use existing and/or develop new culturally appropriate materials to be available to American Indian cancer patients regarding treatment and treatment concerns

**Objective T3.** By 2012, increase the financial and travel support available to Native American Cancer Patients.

**Baseline and Rationale:**

Many people in the Northern Plains live in small rural communities away from cancer treatment centers. Treatment may mean leaving home and require long absences from family and jobs. It is important we work together to improve financial and travel support in order to increase the access to adequate and timely care.

**Potential Action Steps:**

Action Step a. Advocate for additional funds through Congress to develop tribal programs that can reduce financial and travel barriers

Action Step b. Develop a resource guide/directory that indicates resources available to help with financial, transportation and treatment supply issues

Action Step c. Assess feasibility of making more cancer treatment, such as chemotherapy, available on reservations

**Objective T4.** By 2012, increase efforts that will lead to the improvement of payment for care.

**Baseline and Rationale:**

Access to cancer treatment and care needs to be addressed not only at individual patient or provider level but also at the policy or program-level.

**Potential Action Steps:**

Action Step a. Assess policies and procedures regarding IHS Contract Health Service priority system

Action Step b. Work with appropriate partners such as the Aberdeen Area Tribal Chairmen's Health Board on high level policy issues

Action Step c. Develop programs to increase use of Medicare/Medicaid enrollment



**Objective Ts.** By 2012, improve continuity of care and access to appropriate resources for Native cancer patients during their cancer treatment.

#### Baseline and Rationale:

Without a support or advocate, a person with cancer can easily get lost in complex, fragmented health care system. For instance, lack of communication among providers can lead to delay in diagnosis or initiation of treatment. Therefore, it is important primary care providers at IHS facilities receive information about their patients from the cancer care facilities. A navigator and other patient advocates can help facilitate culturally appropriate communication.

There are no known indicators or region-wide population-based sources to measure continuity of care. Possible indicators that could be used: the number of health facilities with patient navigator programs, the amount of time between diagnosis to treatment, the cancer patients perceived quality of care, the distance individuals need to travel in order to receive screening services, and the number of health facilities.

#### Potential Action Steps:

Action Step a. Develop resource guides that address available information on logistical, financial, and support service needs that cancer patients have during their treatment

Action Step b. Work with hospital associations to improve the sharing of cancer patient information back to appropriate IHS facilities

Action Step c. Partner with and/or advocate to cancer treatment facilities to develop culturally appropriate patient navigator programs

Action Step d. Assess feasibility of making more cancer treatments available on reservations

**Objective T6.** By 2012, improve access and support for cultural, traditional, and spiritual treatment services for American Indian cancer patients.

#### Baseline and Rationale:

Many cancer care providers have very limited knowledge about cultural, traditional, and spiritual practices among American Indian patients. Also, often there is little collaboration between providers who practice western medicine and those who practice traditional medicine. The majority of cancer treatment facilities lack policies that support accessibility of traditional medicine. Possible indicators for this objective include pre to post changes in cultural attitudes and beliefs during workshops, or numbers of facilities with culturally sensitive policies and procedures.

#### Potential Action Steps:

Action Step a. Provide education to health care providers on cultural, traditional, and spiritual practices that may be practiced by Northern Plains American Indian population

Action Step b. Work with Cancer Treatment Facilities to implement policies that support accessibility of cultural, traditional, and spiritual practices to American Indian cancer patients





# NORTHERN PLAINS CHAPTER 8

## THE CANCER JOURNEY CHAPTER

GOALS, OBJECTIVES & ACTION STEPS FOR SURVIVORS/CAREGIVERS  
& PALLIATIVE CARE/END OF LIFE



NORTHERN PLAINS COMPREHENSIVE CANCER CONTROL PLAN

**“Cancer is no longer a death sentence - it can be prevented and many cancers can be treated. But now survivors live longer, and cancer treatment and the aftercare is difficult. Traveling to treatments, missing work, it played me out...we need to support each other, support our cancer survivors through these difficult times.”**

**– Elliot Rhoades, Standing Rock Sioux Tribe, Colon Cancer Survivor**

# CHAPTER 8

## THE CANCER JOURNEY CHAPTER

The Basics of Survivorship, Caregiver, Palliative and End of Life Care

### Who is a Cancer Survivor?

- The Lance Armstrong Foundation and the Centers for Disease Control and Prevention define cancer survivors as, “those people who have been diagnosed with cancer and the people in their lives who are affected by their diagnosis, including family members, friends and caregivers.”
- A person becomes a cancer survivor at the time of diagnosis and continues to be a survivor throughout the remainder of his or her life.
- Survivorship includes anyone ever diagnosed with cancer who is still living and any friend or family members who experienced the effects of a cancer diagnosis.

### What is Palliative Care?

- Palliative care aims to relieve suffering and improve quality of life for cancer survivors and their supportive network.
- Palliative care aims to ease the physical and emotional pain or symptoms caused by the disease and its treatment, and should be offered regardless of the stage of the disease (from diagnoses onward), and would end in hospice care as one nears the end of life.

### Who are Caregivers?

- Caregivers can include family members, friends, other cancer patients, community members who provide emotional, spiritual, and/or practical support to the cancer patient.
- Cancer patients who receive support from caregivers are often better able to cope with their illness, and caregivers often benefit by being able to give something meaningful to the cancer patient.

### Who are “Native Families”?

- For the Native population in the Northern Plains, emotional, spiritual, and practical support can be offered by family members, friends, other cancer patients, traditional healers, and community health providers.
- In this chapter we call this broad support system “Native Families.”

### What is Hospice?

- Hospice focuses on caring for the individual who is dying, but not curing them.
- Hospice care includes comfort, treatment choices, respect for dignity, and emotional and spiritual support for the cancer patient and families.
- Hospice can include any health facility, program or family that provides care to a person at the end of their life.
- Hospice operates with the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.
- All hospices provide palliative care, but not all palliative care is hospice.



## Overview

Once a person is diagnosed with cancer, their families and caregivers can face many challenges to maintain a high quality of life. This chapter focuses on the issues that need to be improved or changes in order to help survivors have a high quality of life from diagnosis onward.

## Background

A Cancer Journey is the journey the patient and native families undergo when the person is diagnosed with cancer and through the remainder of their life. Recent advances in prevention, early detection, diagnosis, and treatment of cancer have helped cancer survivors, and as a result the number of cancer survivors is increasing. Research findings indicate members of racial and ethnic minority groups are less likely than whites to receive needed medical care.<sup>35</sup> An individual becomes a cancer survivor at the moment they are diagnosed with cancer. Therefore, the “Cancer Journey” includes many issues including that related to cancer treatment. However, objectives related to direct treatment for cancer survivors are outlined in the Treatment and Traditional Healing Chapter. This chapter focuses on goals and objectives about helping a cancer survivor and their families to be not only physically, but mentally, socially, and spiritually well.

For the Native population in the Northern Plains, emotional, spiritual, and practical support can be offered by family members, friends, other cancer patients, traditional healers, and community health providers. In this chapter we call this broad support system “Native Families.” These caregivers are also a focus of this chapter. Little is currently known about Northern Plains Native cancer survivors or their caregivers. Anecdotal evidence shows there are cancer survivors in the region and many are interested in helping to increase the knowledge and awareness about the issues cancer patients face.

Palliative care is also important during the “Cancer Journey”. According to the National Hospice and Palliative Care Organization, palliative care is care given to, “improve the quality of a seriously ill person’s life and to support that person and their family during and after treatment.” This type of care can be given at any time during a patient’s illness from diagnosis on (it does not just focus on care during the end of a person’s life). End-of-life care is often talked about as “Hospice.” This type of care is given to provide physical, social, emotional, and spiritual care to terminally ill patients and their families when the life expectancy is around six months and they are no longer seeking cure-oriented treatments.

Again, little is known about the palliative and end-of-life care experience of the Native population in the Northern Plains. A thorough literature review revealed very few published reports or data related to palliative care for American Indians. The “Dying to Know” survey done in 2000s, assessed South Dakotan’s attitudes and knowledge about dying and end-of-life care. A small sample of American Indians completed the survey (3% of the total sample), and some statistically significant results were found.<sup>36</sup> In regards to palliative care, Native Americans were more likely to believe that good patients don’t talk about pain, and that their doctors would not believe or treat their pain. In regards to end-of-life issues, Native Americans were less familiar with hospice, less likely to want hospice, less likely to want outside help for their families, and less likely to trust their doctors to provide information on end-of-life issues. They were also more likely to believe that reviewing life history with their family is important.



## Goals, Objectives & Action Steps for Survivorship/Caregivers

**SURVIVORSHIP/CAREGIVERS GOAL:** Assure that Northern Plains American Indian cancer patients, their families, and their caregivers will have access to programs and services that address their physical, mental, and spiritual needs to improve the length and quality of life.

### Major Issues, Challenges, and Barriers Identified by Coalition and Tribal Partners:

- ◆ Native cancer survivors often “get lost” in the system during diagnosis, treatment and beyond, and have difficulty navigating through the health care system
- ◆ Cancer treatment facilities are often far away and there is little money available for food, gas money, and lodging expenses for the cancer survivor or their caregivers
- ◆ Cancer treatment is expensive and contract health care services may be limited or a patient is ineligible
- ◆ Cancer survivors and their caregivers are in need of more social, mental, spiritual support
- ◆ Faith, spirituality, and traditional methods are not always understood or accepted by cancer care providers
- ◆ Cancer survivors have difficulties with missing work and running out of vacation/leave time

### Priority Areas

- ◆ Support for caregivers



**Objective J1.** By 2010, increase the celebration and awareness of Native American cancer survivors in the Northern Plains

**Baseline and Rationale:**

Cancer is often feared by the Native American population in the Northern Plains. However, there are many who do survive cancer. This group of individuals needs to be celebrated, and their wisdom and knowledge used to improve the cancer journey for others. A potential indicator for this objective include the number of community-based cancer awareness activities.

**Potential Action Steps:**

Action Step a. Promote activities on National Cancer Survivorship Awareness days

Action Step b. Partner with American Cancer Society to hold Relay for Life for Native communities

**Objective J2.** By 2010, improve the knowledge and skills of Native Families responsible for caring for cancer patients in their homes during and after their treatment

**Baseline and Rationale:**

Family members and friends play an important role in providing care and support to cancer patients. Although there are existing education and trainings about cancer caregiving, they are often underutilized. In order to improve the knowledge and skills among Native Families, educational materials and training programs need to be more accessible. Pre to post knowledge and skill gain can be assessed during trainings and workshops.

**Potential Action Steps:**

Action Step a. Provide educational and training programs to caregivers on care issues, skills, and tools they can utilize

Action Step b. Develop and disseminate culturally appropriate educational materials related to cancer caregiving issues

**Objective J3.** By 2012, increase the social support available to cancer survivors during and after their treatment

**Baseline and Rationale:**

Cancer survivors and their caregivers are in need of more social, mental, spiritual support. Two successful examples of cancer support are Native American cancer support groups and patient navigator programs. We need tribal-level efforts to provide comprehensive support to cancer patient and Native Families.

**Potential Action Steps:**

Action Step a. Develop tribal cancer coalitions/teams comprised of clinicians, community health workers, survivors, family, traditional and spiritual leaders, and community members that provide a multi-function support system for Native Families



Action Step b. Establish Native American cancer survivor support groups

Action Step c. Develop partnerships with cancer centers and other cancer referral centers in order to advocate and facilitate the development of new or the expansion of existing patient navigator programs

**Objective J4.** By 2012, assess and improve workplace policies so they address the needs of cancer survivors and their families

**Baseline and Rationale:**

Cancer survivors have difficulties with missing work and running out of vacation/leave time. We need advocacy for patients to develop policies that address cancer survivor rights.

**Potential Action Steps:**

Action Step a. Research and assess policies and regulations at tribal, state, and federal levels currently in place to address cancer survivor rights

Action Step a. Advocate tribal and non-tribal governments to change or add policies that will address cancer needs such as leave/sick time

Action Step b. Advocate workplaces to support time off for cancer wellness meetings that will enhance a community's ability to care for cancer patients



## Goals, Objectives & Action Steps for Palliative Care/End of Life

PALLIATIVE/END OF LIFE GOAL: Assure the best quality of life and access to needed comfort care services for Northern Plains American Indians affected by cancer, their families, and their caregivers

### Major Issues, Challenges, and Barriers Identified by Coalition and Tribal Partners:

- ◆ There are little to no hospice services on the Northern Plains reservations or surrounding areas
- ◆ Comfort care is often provided by caregivers who need further support for appropriate methods
- ◆ There is often a lack of clear and appropriate communication between health care providers and patients in regards to palliative and end of life care

### Priority Areas

- ◆ Hospice and end-of-life programs



**Objective Js.** By 2010, assess and identify the priority areas of palliative and end of life care services that need to be increased and develop plans to make improvements

**Baseline and Rationale:**

Because little is currently known about the status of palliative and end of life services and resources in the area the needs, priorities, and resources need to be determined, and appropriate plans developed based on this information

**Potential Action Steps:**

Action Step a. Develop and implement an assessment of tribal communities, IHS, etc. on palliative care/end of life care services available

Action Step b. Identify potential sources of funding to support palliative/end-of-life services

Action Step c. Develop a resource directory of palliative/end-of-life services available

Action Step d. Develop partnerships and collaborations with other end-of-life and palliative care programs

**Objective J6.** By 2011, increase knowledge, awareness, and beliefs of Native Families and their medical care providers about the importance and need for culturally appropriate hospice/end of life and palliative care services and programs

**Baseline and Rationale:**

As shown by the South Dakota, Dying to Know survey, Native Americans are less knowledgeable about palliative care and end-of-life programs, and less likely to support these types of services.<sup>36</sup> Therefore more education needs to be given to improve knowledge and understanding of these programs.

**Potential Action Steps:**

Action Step a. Provide educational programs for survivors and caregivers on cancer palliative and end-of-life care

Action Step b. Provide educational programs for healthcare providers on palliative and end of life care which includes a focus on the importance of traditional healing methods for Native cancer patients

Action Step c. Develop train-the-trainer programs on palliative and end-of-life care



**Objective J7.** By 2012, increase the number of end-of-life/hospice programs available, accessible, and utilized by American Indians in the Northern Plains

**Baseline and Rationale:**

There are very few end-of-life/hospice programs accessible and utilized by the Native American population. Therefore, culturally acceptable programs need to be developed, and partnerships need to be made in order to expand and unify services.

**Potential Action Steps:**

Action Step a. Develop partnerships with existing end-of-life/hospice programs

Action Step b. Develop new or alternative programs (i.e., volunteer caregiver program) to provide additional needed services to Northern Plains American Indians

**Objective J8.** By 2010, improve communication between Native Families and their medical care providers in regards to their cancer journey.

**Baseline and Rationale:**

There is sometimes a lack of communication among cancer patients and their various health care providers in regards to palliative and end-of-life care. This can lead to gaps in services and appropriate care received by the patient. Individuals with cancer, their caregivers, and their health care providers need to be educated on ways to better communicate with each other about these issues.

**Potential Action Steps:**

Action Step a. Provide education programs that include tools that patients and families can use to help them communicate with health care providers

Action Step b. Educate health care providers on tools they can use to better communicate with patients including referral sources and ways to be more aware of patient needs for end of life and palliative care services

Action Step c. Advocate for and/or develop patient advocacy and/or patient navigator services

Action Step d. Adapt and tailor existing tools/resources on end of life and palliative care communication and disseminate to Northern Plains Native communities

**Objective J9.** By 2012, improve the quality of pain control and symptom management for Native cancer patients

**Baseline and Rationale:**

There are often issues with pain control medications available to Native cancer patients through IHS pharmacies. Patients are sometimes prescribed medications by their Contract Health Care Provider for pain control which when give to the IHS pharmacy is not able to be filled by the IHS pharmacy.



## Potential Action Steps:

Action Step a. Assess IHS pharmacy policies in regards to cancer pain management

Action Step b. Educate Contract Health Care Providers on IHS pharmacy policies

Action Step c. Provide education to Native Families on rights to pain management in order to improve their ability and empower them to advocate for themselves for proper pain management

Action Step d. Identify, educate, and promote the use of alternative and traditional forms of pain control and symptom management



# NORTHERN PLAINS CHAPTER 9 CANCER PLAN WORKFORCE

GOALS, OBJECTIVES & ACTION STEPS FOR WORKFORCE



NORTHERN PLAINS COMPREHENSIVE CANCER CONTROL PLAN

**"It's important to get your check ups, any lumps or bumps, don't wait - just go in. Take care of your own body, no one else knows your body better than you. Don't wait for anyone else to tell you what to do."**

**- Selena Wolf Black, Cheyenne River Sioux Tribe,  
Breast Cancer Survivor**

# CHAPTER 9

## WORKFORCE

### The Basics of Workforce

#### What does “workforce” mean?

- Workforce means those who are currently employed, volunteer, are in training, or anyone else who is performing the work for a certain area
- For comprehensive cancer control this includes a wide variety of individuals including: CHRs, Health Educators, Nurses, Doctors, Oncologists, Researchers, Cancer Registrars, Community Volunteers, etc



## Overview

In order to provide care for cancer patients, there need to be providers (both professional and community-based) to fill that need. In the Northern Plains, there is often a lack of providers to care for the numbers of patients. This chapter describes the areas of improvement needed in order to have the appropriate numbers and quality of providers.

## Background

This chapter is devoted to the issues and concerns related to the cancer care workforce for the Northern Plains American Indian population. The cancer care workforce encompasses a wide variety of workers who provide care and support services to current and potential cancer patients, their families, and caregivers. This includes individuals who work for Indian Health Service, tribal health programs, as well as those at contract health care facilities and other private medical and research entities, and involves a wide variety of occupations such as clinicians (e.g. nurses, physician assistants), community health and social services professionals (e.g., community health representatives, health educators, patient advocates, and social workers) and other public health related careers (e.g., cancer registrars).

The complete depth and breadth of the workforce issues related to cancer prevention and control for this area and population are currently unknown. However, we do know the recruitment and retention of professional staff and culturally appropriate care and services are issues that are noted as major challenges facing Indian health care<sup>37</sup>. In particular the lack of Native staff and the high rate of turnover appear to be a major issue, and the remote locations of many Native health services compound recruitment problems. The U.S. Department of Health and Human Services recognizes that providing culturally appropriate services has the “potential to improve access to care, quality of care, and, ultimately, health outcomes.”<sup>38</sup> Strategies to improve these areas have the potential to make an impact on the cancer care the American Indian population receives.



## Goals, Objectives & Action Steps for Workforce

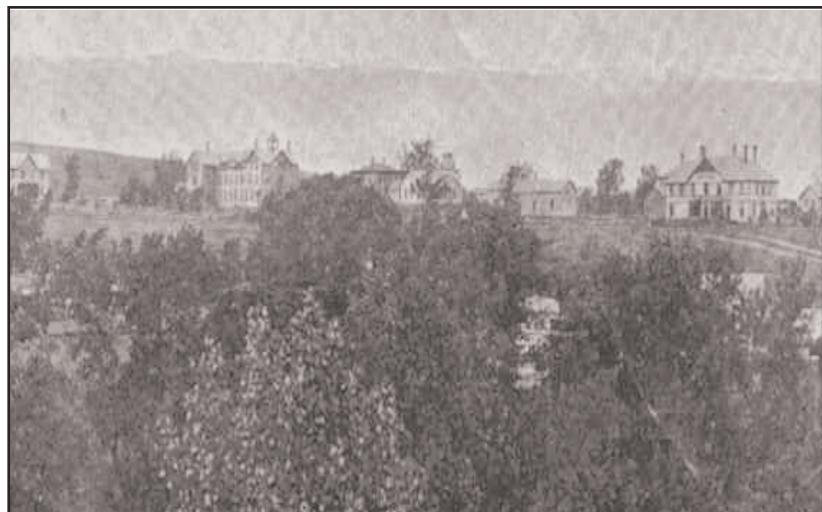
**WORKFORCE GOAL:** Improve a workforce who can provide culturally sensitive/competent comprehensive cancer care for the Northern Plains tribes

### Major Issues, Challenges, and Barriers Identified by Coalition and Tribal Partners:

- ◆ Both clinicians and community health providers are in need of continuing education and training about comprehensive cancer care
- ◆ There is a shortage of cancer care providers, both clinicians and community health providers, for the Northern Plains American Indian population in part due to isolation in geographically remote areas and burnout from continual added responsibilities and overburdened workloads.
- ◆ There is a lack of providers both within the Indian Health Service system and in contract health care facilities that are culturally sensitive/competent
- ◆ Cancer care providers in the Northern Plains often lack knowledge about the Indian Health Service system and the tribe's community health resources

### Priority Areas

- ◆ Culturally sensitive/competent health care providers



**Objective W1.** By 2012, increase the number of individuals receiving support and information that will enhance their ability to enter the comprehensive cancer care workforce for the Northern Plains American Indian population

**Baseline and Rationale:**

Because of the issues Indian Health Service has with the recruitment and retention of health care providers, focus needs to be on ensuring a cancer care workforce is available for cancer patients. Individuals need to be supported in their choices to pursue education in the health field

**Potential Action Steps:**

Action Step a. Identify the current gaps and resources in the Northern Plains American Indian cancer care workforce

Action Step b. Collaborate with appropriate partners, including state cancer coalitions and programs, on cancer care workforce development programs

Action Step c. Educate youth about cancer care careers and provide training programs to students of all ages that will enhance their ability to enter the cancer care workforce

Action Step d. Collaborate with cancer care institutes and providers such as oncologists to provide shadowing and mentorship opportunities for students

**Objective W2.** By 2012, increase and improve the general knowledge, capacity, and quantity of community health workers that can provide support services to cancer patients, their families, and clinicians

**Baseline and Rationale:**

Because research and state-of-the art practices are constantly changing, ongoing cancer education for health workers is needed. This relates to many aspects of cancer care covered in other chapters and is related to many types of health workers.

**Potential Action Steps:**

Action Step a. Provide cancer education to the current community health workforce for the Northern Plains American Indian population (i.e., Community Health Representatives (CHRs), Health Educators, etc.)

Action Step b. Promote and advocate for the funding and development of additional support service positions (e.g. patient navigators) available to Northern Plains American Indian cancer patients

**Objective W3.** By 2012, increase the number of health care providers who receive cultural sensitivity/competency training to improve their ability to care for the Northern Plains American Indian population

**Baseline and Rationale:**

The number of American Indian health care providers within Indian Health Service is increasing, however, there are still many providers who are not knowledgeable about the Native culture and society. Additionally, many Native American patients receive actual cancer treatment at facilities outside the Indian Health Service where even fewer Native American providers exist.



### Potential Action Steps:

Action Step a. Collaborate with higher education institutions to promote and expand existing cultural sensitivity/competency training to cancer care providers

Action Step b. Advocate for the integration of cultural sensitivity/competency training for all Indian Health Service health care providers

**Objective W4.** By 2012, increase health care providers' knowledge of the challenges and barriers Northern Plains American Indians face as they access cancer care through Indian Health Service and contract health facilities

### Baseline and Rationale:

Many health care providers, especially those at contract health care facilities, do not understand or are not aware of the complexities of the Indian Health Service and Contract Health Care processes. Knowledge of these issues could help to reduce gaps in services.

### Potential Action Steps:

Action Step a. Assess and identify the barriers and challenges that American Indian cancer patients face

Action Step b. Develop partnerships with and assess the perceived educational needs of contract health care providers regarding Indian Health Service and contract health care

Action Step c. Develop and implement an Indian Health Service 101 curriculum and educate providers about the challenges AI cancer patients face because of limitations with Indian Health Service and contract health care



# NORTHERN PLAINS CHAPTER 10 SURVEILLANCE & RESEARCH

GOALS, OBJECTIVES & ACTION STEPS FOR SURVEILLANCE & RESEARCH



NORTHERN PLAINS COMPREHENSIVE CANCER CONTROL PLAN

**“As tribal communities, we need more ownership of research and data. Cancer research and tracking cancer data is important so we can identify problems, priorities, and show evidence of health disparities, but we need these efforts to be community driven, community based.”**

**– Roger Trudell, Santee Sioux Tribe, Tribal Chairman**

Photo Credit: Northern Plains Healthy Start

# CHAPTER 10

## SURVEILLANCE AND RESEARCH

### THE BASICS OF SURVEILLANCE AND RESEARCH FACTS

#### What is Surveillance?

- A method used to determine how many people have a disease or a certain health behavior. This information is collected regularly to help take action to prevent and control a disease.

#### Why is Surveillance Important?

- This information is important so we can know cancer incidence, mortality, and cancer survival rates
- This information can then be used to help us see if there are any trends or changes within certain population subgroups (i.e., a certain race/ethnicity), or for different cancer sites (i.e., breast, lung, etc.) that could be of concern, and plan accordingly to try and deal with the area of concern
- Not only do we want to look at cancer cases, but at the health behaviors of a population that we know are linked to cancer (e.g., commercial tobacco use rates, diet, and activity). Similar to cancer surveillance, this information can be used to see where there are areas of concern, and plan activities and programs that deal with that concern

#### How do we track health behaviors?

- There are multiple surveillance systems in place for tracking health behaviors.
- Most data about health behaviors are collected from surveys or interviews with a sample of a population
- An example is the, “Behavioral Risk Factor Surveillance System” often referred to as “BRFSS.” State Departments of Health conduct BRFSS by interviewing large numbers of individuals about their health behaviors by phone
- Other examples of these surveys are the “Youth Behavioral Risk Factor Survey,” the “Adult Tobacco Survey,” and the “Youth Tobacco Survey”

#### How do we track cancer data and what is a cancer registry?

- Cancer is mandated by state laws as a “reportable disease”
- This means when a doctor or health facility diagnoses a patient with cancer, they have to report the case to the state “cancer registry”
- Each state has a cancer registry, a large database of information about cancer cases that have been diagnosed
- Cancer registries have staff called, Certified Tumor Registrars (CTR). CTRs receive specialized training so they can make sure the data is of the highest quality possible

#### What is “Research” and why is it important?

- A process we take to uncover and discover new things
- It is important because it can help identify where problems or issues exist, develop potential solutions to problems, and determine if a potential solution is doable and will produce the desired results

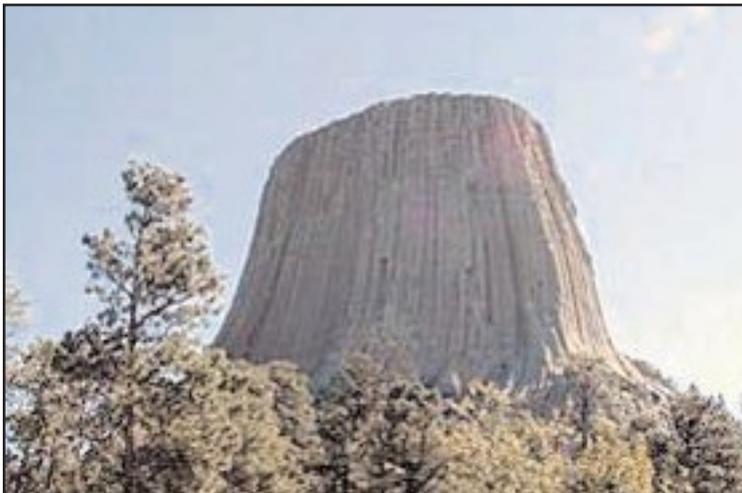


## What are Clinical Trials?

- A research study conducted with people
- A research study designed to find better ways to prevent, screen, diagnose, and treat cancer

## What is Community-Based Participatory Research (CBPR)

- CBPR is research in which the community where research is conducted is actively involved in the process
- The community helps researchers identify the problem, develop the potential strategies and programs to implement, and ensures the results from the study are used in an appropriate manner



## Overview

Improved cancer surveillance is needed to identify priority areas, evaluate interventions, and allocate resources effectively. More community-based and culturally appropriate research is needed for the maximum benefit of tribal communities. This chapter focuses on the areas of data and research that need to be changed in order to improve cancer care for the Northern Plains American Indian population.

## Background

This chapter describes cancer surveillance and research goals, objectives and strategies for Northern Plains tribes. The purpose is to increase cancer surveillance, encourage the dissemination of research findings and data back to tribes and IHS, promote community-based and driven methods of research, and increase cancer patient's awareness of research and encourage those who meet research criteria to enroll in cancer research studies.

Surveillance is the systematic data collection of specific information about a disease. Cancer surveillance activities are conducted at the state level by cancer registries. The surveillance data is kept confidential and the findings are reported in an aggregated manner only. Cancer reporting is important because it allows us to calculate incidence, mortality, and survival rates. Surveillance data are used by epidemiologists to study cancer burden trends and patterns and to provide advice on control and prevention measures. Researchers also use the surveillance data to identify risk factors, develop new ways to detect cancer at its early stages and look at patterns in cancer development.

Research plays an important role in the prevention and control of cancer. One type of research is clinical trials. Clinical trials on cancer are carried out so we can study the effectiveness of new cancer care, and determine new and better ways to prevent, screen, detect, and treat various types of cancer. Many of the advances in cancer care that are common now, were once researched by clinical trials. While there are many benefits from trials, the number of American Indian cancer patients who enroll remains low. There are many causes of low enrollment such as lack of awareness, knowledge and access to trials. Also, some data suggests that American Indian patients who are interested in participating in clinical trials are often not eligible for the treatment trial because they are diagnosed at a late stage.

Other forms of non-clinical research will also be needed to overcome health disparities in the Northern Plains. Research that is respectful of American Indian values and beliefs as well as responsive to their needs is important. Community-based participatory research (CBPR) is a process by which the community works directly with the researcher to identify the problem, shape the research and intervention strategies, and ensure results of the research are given back to the community. The objectives and strategies of this plan encourage community-based participatory research in Northern Plains in hope the needs can be met through partnerships with researchers and research institutions.



## Goals, Objectives & Action Steps for Surveillance

**SURVEILLANCE GOAL:** Make complete, accurate, and timely data on cancer available and accessible to the Northern Plains American Indian tribal communities in order to inform and improve cancer health status.

### Major Issues, Challenges, and Barriers Identified by Coalition and Tribal Partners:

- ◆ There is a need for better relationships and increased trust between tribes and surveillance data collectors
- ◆ Research and data collection needs more participation and buy-in from tribal communities and tribal leadership
- ◆ There are issues with the quality of cancer-related data available for Northern Plains American Indians
- ◆ There is a need for regular feedback and reporting to the tribes so they can understand and use the data
- ◆ Tribes lack the resources and funding to implement their own data collection activities

### Priority Areas

- ◆ Improved data management systems



**Objective R1.** By 2012, increase support for the gathering of data, maintenance of data systems, and the dissemination of data back to tribes.

**Baseline and Rationale:**

To ensure reporting of complete, accurate and timely cancer data for Northern Plains American Indians, we will support efforts by existing cancer collection systems.

**Potential Action Steps:**

Action Step a. Support and enhance the efforts of the state cancer registries to gather and report cancer data on Northern Plains American Indians.

Action Step b. Support and enhance the efforts of the states to gather and report data through other existing cancer collection systems such as BRFSS and YRBS.

**Objective R2.** By 2012, increase the support of efforts to collect additional cancer related data for Northern Plains American Indians, ensuring that data collection is conducted in a culturally appropriate and scientifically sound manner.

**Baseline and Rationale:**

In addition to providing ongoing support to existing cancer collection system, we need to work with tribal communities and researchers to facilitate activities to collect information for areas where data gaps exist. It is important that such data are collected in a culturally appropriate manner and data are disseminated in a manner that are useful to tribal communities and respects their ownership of the data.

**Potential Action Steps:**

Action Step a. Identify existing cancer data in order to establish baseline for priority areas included in the Cancer Plan. Also, identify data gaps for priority areas.

Action Step b. Facilitate activities to promote data collections for priority areas included in the Cancer Plan where data are lacking. Work with researchers and tribes to ensure that data collection is done in culturally appropriate and scientific sound manner.

**Objective R3.** By 2012, increase accessibility of cancer related data among tribal communities and key partners.

**Baseline and Rationale:**

It is important that cancer data are not only collected but also disseminated in a format that is easily understood and usable to tribal communities. It is important that we support tribes and the Indian Health Services (IHS) in their efforts to receive reports back from the states, state cancer registries and researchers. Currently, NPCCCP works with state cancer registries to develop and update a Cancer Fact Sheet for Northern Plains American Indians. Other cancer data, such as risk behaviors and screening behaviors, may be added to the Fact Sheet to provide more complete information to the tribal communities and the IHS.



## Potential Action Steps:

Action Step a. Modify Cancer Fact Sheet so they are more easily understood and used by tribal communities.

Action Step b. Use data from state cancer registries, YRFS, and BRFSS and other sources to update and expand the Cancer Fact Sheet on regular basis. Disseminate hard and electronic copies of Cancer Fact Sheet to tribes and make it available on NPCCCP website.

Action Step c. Work with cancer researchers to facilitate the dissemination of results from cancer studies conducted in the Northern Plains (e.g., develop reports for the tribes, hold workshops and conferences)



## Goals, Objectives & Action Steps for Research

**RESEARCH GOAL:** Increase awareness of cancer research projects and facilitate clinical trials and community-based participatory research to improve cancer health status among Northern Plains American Indians.

### Major Issues, Challenges, and Barriers Identified by Coalition and Tribal Partners:

- ◆ There is a need for better relationships and increased trust between tribes and researchers
- ◆ Research and data collection needs more participation and buy-in from tribal communities and tribal leadership
- ◆ There is a need for regular feedback and reporting to the tribes so they can understand and use the research
- ◆ Tribes lack the resources and funding to implement their own research

#### Priority Areas

- ◆ More community-driven and community-based research activities



**Objective R4.** By 2012, establish a database of current cancer research being undertaken among Northern Plains American Indians and disseminate the updated research list to tribal communities and cancer researchers, who are current and potential collaborators with tribal communities, on an annual basis.

**Baseline and Rationale:**

Although cancer research has been conducted among Northern Plains American Indians, we do not have a comprehensive inventory on research activities that has been undertaken.

**Potential Action Steps:**

Action Step a. Work with Aberdeen tribes, IHS office, IRB offices, and cancer researchers to compile a list of cancer research conducted among Northern Plains American Indians

Action Step b. Establish an online reporting system that can be used to update the research list and disseminate the updated list to tribal communities and cancer researchers, who are current and potential collaborators with tribal communities

**Objective Rs.** By 2012, increase training and education on community participatory research models to tribes, and medical and academic institutions.

**Baseline/Rationale:**

Programs have been developed and implemented to educate and train tribal communities and researchers about community participatory research. In order to address research issues that are unique to tribal communities, we need to expand the existing training/education programs on community participatory research so they reach a greater audience.

**Potential Action Steps:**

Action Step a. Work with appropriate partners to expand or improve existing training/educational programs on community participatory research models

Action Step b. Host workshops with tribes, medical and academic institutions on community participatory research models

**Objective R6.** By 2012, increase access to clinical trials for Northern Plains American Indians.

**Baseline and Rationale:**

The number of American Indians who enroll in clinical trials remain low. One reason may be lack of awareness of clinical trials among American Indian patients and their families. There should be more effort to promote communication between health providers and patients about clinical trials so that American Indian patients and their families can make an informative decision about their participation in them. Also we need to continue to make an effort to remove other barriers such as high costs of treatment and lack of transportation to treatment facilities.



## Potential Action Steps:

Action Step a. Collaborate with Cancer Care Institutes and other cancer clinical trial providers to increase the awareness and access of clinical trials among tribal members through education and outreach activities

Action Step b. Provide education/training to cancer clinical trial providers to increase their cultural competency so they can communicate more effectively about clinical trials with American Indian patients and their families

Action Step c. Advocate for programs such as a patient navigator program which enhance the communication between clinical trial providers and American Indian patients and find resources for American Indian patients to participate in the trials

Action Step d. Work with IHS on the development of policies in regard to clinical trial participation, timely decision processes and payment of services



## GLOSSARY OF TERMS

**Aberdeen Area:** The name given to the geographic region of North Dakota, South Dakota, Nebraska, and Iowa, that is one service area for Indian Health Service

**Aberdeen Area Tribal Chairmen’s Health Board (AATCHB):** The Native American tribally-designated organization formed in the late 1980s to serve as a formal representative board for the tribes in the Aberdeen Area to Indian Health Service and other health organizations

**Access:** A term used to describe the ability of getting services, products, etc. For health care, access can be affected by issues such as policies, transportation, cost, and cultural appropriateness.

**Age-adjusted rate:** Rates used to make comparisons of the number of new disease cases and deaths across groups and over time when groups differ by age structure.

**Barriers:** Any issue that keeps cancer survivors from receiving the highest quality of support and care available. This can include issues such as difficulty keeping appointments, expense of traveling long distances to access care, and a lack of support systems. In particular, there are very few Native cancer support groups and survivorship resources in the Northern Plains area.

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

**Behavioral Risk Factor Surveillance System (BRFSS):** A state-based system of health surveys that collects information on health risk behaviors, preventive health practices, and health care access primarily related to chronic disease and injury.

**Body Mass Index (BMI):** A way to state the relationship between height and weight. (weight in kilograms divided by height in meters squared ( $\text{kg}/\text{m}^2$ )). It is used as a measure of obesity or overweight.

**Cancer:** A term for a disease that develops when cells divide and form more cells without control or order. There are more than 100 different types of cancer.

**Cancer Burden:** Overall impact of cancer in a community.

**Cancer Registry:** Each state has a cancer registry, which is basically a large database of information about cancer cases that have been diagnosed. When a doctor or health facility diagnoses a patient with cancer, they have to report the case to the state “cancer registry.”

**Cancer Screening:** A test or procedure done to detect cancer before a patient has symptoms and at cancer’s earliest stages

**Centers for Disease Control and Prevention (CDC):** A federal agency based in Atlanta, GA which is a major operating component of the US Department of Health and Human Service and provides leadership in health promotion, prevention, and preparedness.

**Certified Tumor Registrars (CTR):** CTRs work for cancer registries and receive specialized training so they can ensure the data is of the highest quality possible.

**Chemotherapy:** A type of cancer treatment that uses medicine to kill cancer cells



**Clinical Breast Exam:** An exam where a health care provider checks for lumps or changes in a patient's breasts that could be a sign of breast cancer

**Clinical trials:** A research study conducted with people, to find better ways to prevent, screen, diagnose, and treat disease.

**Colonoscopy:** A procedure where a health care provider inserts a tube into a patient's colon in order to look for polyps which can be a sign of colon cancer

**Commercial Tobacco:** Tobacco products not used for ceremonial or traditional practices.

**Community-Based Participatory Research (CBPR):** Research in which the community that is being researched is actively involved in the process. The community helps the researchers identify the problem, develop the potential strategies and programs to implement, and make sure the results from the study are used in an appropriate manner for the community.

**Community Health Representative (CHR):** CHRs are community-based health care providers who provide services such as health education in the homes of clients and transportation to health care services

**Comprehensive Cancer Control:** A process which attempts to have individuals, programs, organizations work together in order to improve the overall health and well-being of a community as it relates to cancer.

**Contract Health Care or Contract Health Services (CHS):** The system used by IHS to deliver healthcare services for members of federally recognized tribes who reside on or near their reservation at a non-IHS facility or with a non-IHS provider.

**Culturally Sensitivity/Competency:** A term used to describe the ability of a person or organization to provide services and relate to others who are from different cultures.

**Diagnosis:** The determination of a disease from its signs and symptoms.

**Double Contrast Barium Enema –** A health care procedure where a patient's colon is filled with a material called barium and then an x-ray is taken that enables the provider to look for changes or problems that may be a sign of colon cancer.

**Early detection:** Findings of the beginning of the early stages of a disease.

**Epidemiology:** The study of patterns of disease and or health conditions in a population, and the application of this study in order to prevent and control health problems.

**Fecal Occult Blood Test (FOBT) -** a lab test which checks for signs of blood in the stool which may be a sign of colon cancer.

**Flexible Sigmoidoscopy:** A procedure in which a health care provider inserts a tube into part of a patient's colon in order to look for polyps which could be a sign of colon cancer.

**Goal:** A broad statement of what is wanted to be achieved.

**Heredity:** The process through which different traits can be passed from one generation to the next.

**Hospice:** A health facility or program that provides care to a person at the end of their life that is not focused on curing them

**Human Papilloma Virus (HPV):** name for a virus that has over 100 types, a few of which have been found to cause cervical cancer in women. A vaccine has been developed that can protect against some of the types of HPV that cause cervical cancer.

**Incidence:** The number of new events or cases of disease that develop in a population of individuals at risk during a specified period of time.

**Indian Health Service (IHS):** The agency responsible for providing health care services to the Native American population.

**Informed Decision Making:** Happens when a person understands the nature and risks of their cancer diagnosis and treatment options. Informed decisions are reflected by the person's preferences and values.

**Lifestyle Factors:** The term used to describe the risk and health protective behaviors an individual has.

**Mammogram:** An x-ray used to screen for cancer of the breast.

**Mortality:** The number of deaths during a specific time period.

**Northern Plains Comprehensive Cancer Control Program (NPCCCP):** CDC-funded program that is housed at the Aberdeen area Tribal Chairmen's Health Board that facilitates the Northern Plains Cancer Coalition.

**Northern Plains Tribal Epidemiology Center (NPTEC):** Program that is housed at the Aberdeen Area Tribal Chairmen's Health Board, and provides leadership, technical assistance, support, and advocacy to Northern Plains tribal communities in order to eliminate health disparities.

**Obesity:** An adult who has a Body Mass Index of 30 or higher.

**Objective:** A statement of a result a program will try to accomplish within a particular time period that will help reach a goal

**Oncologist:** A medical doctor who specializes in providing care for cancer patients

**Overweight:** An adult who has a Body Mass Index between 25 and 29.9.

**Palliative Care:** Care provided to alleviate physical and mental symptoms of a disease and its treatment

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

**Polyp:** An abnormal growth of tissue found in the colon which can sometimes turn into cancer.

**Prostate Specific Antigen Test (PSA):** A test to detect levels of a blood protein. Elevated levels may indicate prostate cancer, prostate inflammation, or benign prostate conditions.

**Quality of Life:** A term used to describe the overall enjoyment one has of life. It is a measure of someone's sense of well-being and ability to do everyday tasks.

**Risk factors:** Conditions related to lifestyle, environment, and/or heredity that increase the chance that a disease might occur.





**Risk reduction:** Changes in lifestyle factors to help main a healthy life and reduce the risk of cancer and other chronic diseases.

**Screening:** Checking for a disease in a person who does not have any symptoms of the disease.

**Self Breast Exam:** An exam a woman can do herself to look for changes or lumps in her breasts that may be a sign of cancer

**Side effects:** Problems that occur when treatment affects healthy cells. Common side effects of cancer treatment are fatigue, nausea, vomiting, decreased blood cell counts, hair loss, and mouth sores.

**Staging:** A system used to describe the extent or severity of an individual’s cancer based on the original tumor and the extent it has spread to other parts of the body. Stage 0-IV are sometimes used. Stage 0 is cancer that is “In situ”, and Stages I-IV indicate more extensive spread of the cancer (higher numbers indicate more extensive disease).

**In situ Cancer:** Early neoplasm which has not penetrated the membrane surrounding the tissue of origin.

**Localized Cancer:** Invasive malignant cancer confined entirely to the organ where the cancer began.

**Regional Cancer:** Cancer that has extended beyond the original (primary) organ to nearby organs or tissues, or has spread via the lymphatic system to regional lymph nodes or both.

**Distant Cancer:** Cancer that has spread from the original (primary) organ to distant organs or distant lymph nodes.

**Statistical data:** The calculation of figures that provides information about the numbers, patterns, similarities and differences among things/individuals.

**Surveillance:** A method that we use to determine how many people have a disease or a certain health behavior

**Survivorship:** The continuation of life.

**Sustainability:** An approach to develop available resources and information.

**Task Force on Community Preventive Services:** A non-federal group of individuals with expertise in health who review and assess evidence available on how well public health services and interventions work and develops recommendations.

**Tobacco Cessation:** The process of trying to quit using commercial tobacco products

**U.S. Preventive Services Task Force:** A group of health care experts who review evidence and develop recommendations for clinical preventive services.

**Youth Risk Behavior Surveillance System:** A system of health surveys that collect information on health risk behaviors, preventive health practices, and health care access of youth (under age 18)

**Youth Tobacco Survey (YTS):** Health surveys that collect information specifically on tobacco use behaviors among youth.

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## MEMBER INFORMATION

### Background

The Northern Plains Cancer Coalition (NPCC) is a volunteer group of a wide variety of individuals that have an interest in cancer control and prevention for Native Americans in North Dakota, South Dakota, Nebraska and Iowa. NPCC works under the framework of Comprehensive Cancer Control (CCC), and the Northern Plains Comprehensive Cancer Control Program (NPCCCP) staff helps organize and facilitate this group.

### What does it mean to be a Coalition member?

Any individual or organization with an interest in cancer control and prevention in the Northern Plains (North Dakota, South Dakota, Nebraska, and Iowa) can be a member of the Coalition.

As a member you can:

- Join meetings and learn about what's going on in cancer prevention and control in the region
- Be on our email and mailing lists to learn about cancer-related resources, trainings, meetings, and events that may be of interest to you
- Sit on a coalition Workgroup that provides help and advice to move forward cancer efforts in the region
- Be a leader in your own community to advocate for more cancer awareness and activities, and learn and receive support from others who are doing the same

What is a Comprehensive Cancer Control?

- A program that recognizes the importance of bringing everyone together to better use limited resources
- A Program that looks at the entire range of cancer prevention and control - from preventing cancer from occurring to improving the quality of life for cancer patients and their family

How does CCC work?

Members of the Northern Plains Cancer Coalition meet in-person and by conference call to do such activities as review cancer priorities, discuss needs and challenges, educate each other about existing programs and services, and create partnerships.

Please contact NPCCCP staff if you have any other questions or would like more information:

Leah Frerichs, Program Manager	60s-721-1922 ext. 110	epifrerichs@aatchb.org
Tinka Duran, Outreach Coordinator	60s-721-1922 ext. 144	epiduran@aatchb.org





Northern Plains Cancer Coalition  
Northern Plains Comprehensive Cancer Control Program (NPCCCP)  
Aberdeen Area Tribal Chairmen's Health Board (AATCHB)  
1770 Rand Road • Rapid City, SD 57702  
Ph: 605-721-1922 • Fax: 605-721-2876

REGISTRATION FORM

Please return completed form to the address below or fax

Name \_\_\_\_\_ Title: \_\_\_\_\_

Organization: \_\_\_\_\_ Tribal Affiliation (If Applicable): \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Mailing Address Line 1: \_\_\_\_\_ Tribe you work for or serve (If Applicable): \_\_\_\_\_

Mailing Address Line 2: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Email: \_\_\_\_\_

Can we use email as a primary means of communication?  Yes  No

If no, how do you prefer to be contacted? \_\_\_\_\_

Are you a cancer survivor?  Yes  No

What types of areas do you work or have experience in? (Please check all that apply)

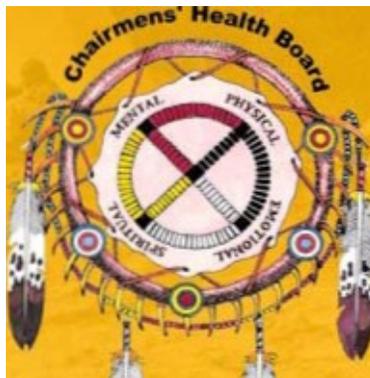
- Research/Data  Western Medicine/Science  Traditional Medicine/Healing
- Health Education  Community Outreach
- Other Please explain: \_\_\_\_\_

What area/s of cancer prevention and control are you most interested in? (Please check all that apply)

- Prevention & Education  Screening  Treatment  Survivorship/Caregivers
- Palliative and End of Life  Research & Surveillance  Workforce
- Other Please explain: \_\_\_\_\_



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## ABERDEEN AREA TRIBAL CHAIRMEN'S HEALTH BOARD

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