

Northern Plains American Indian Comprehensive Cancer Plan

~ A Revision for Years 2013-2017 ~



In honor
and memory of:
Carole Anne Heart,
Rosebud and Yankton
Sioux and Executive
Director of AATCHB

"So that the people may live"



"Hecel OyateKin Nipi Kte"

Cheyenne River
Sioux Tribe

June 19, 2014

Crow Creek
Sioux Tribe

Flandreau Santee
Sioux Tribe

Anpetu Waste Tribal Advocate,

Lower Brule
Sioux Tribe

The Northern Plains Cancer Plan was developed to assist tribal community advocates in the important conversations they have with their community members, tribal health, and tribal leadership on comprehensive cancer control and prevention. 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 (AI). This cancer plan was developed to assist tribes, organizations, entities and individuals to achieve mutual goals to reduce occurrences of cancer and to live in a good way.

Mandan, Hidatsa &
Arikara Nation(Three
Affiliated Tribes)

Oglala Sioux Tribe

Omaha Tribe
of Nebraska

Many of the leading cancers among Northern Plains American Indians are preventable with lifestyle changes such as making healthier food choices and increasing physical activity. However, the most important change we can make for ourselves and our children is to quit smoking commercial tobacco. Commercial tobacco use is the number one cause of cancer in our region.

Ponca Tribe
of Nebraska

Rosebud Sioux Tribe

Although great strides have been made, the Northern Plains AI communities continue to suffer from higher rates of cancer and cancer deaths compared to non-native populations. The best way to protect our youth, elders and loved ones from cancer is to encourage tribal, county and state public health initiatives to incorporate culturally appropriate policy, systems and environmental changes into current efforts to decrease tobacco use, increase physical activity and improve nutrition. Fostering change requires a multi-prong approach that respects tribal sovereignty and honors tradition to create healthy lifestyle changes.

Sac & Fox Tribe of the
Mississippi Indians ir
Iowa/Meskaki Nation

Santee Sioux Tribe
of Nebraska

Sisseton-Wahpeton
Oyate of the Lake
Traverse Reservation

As a community advocate you already realize the importance of empowering communities to make decisions that promote personal health and well-being. It is our hope that you will turn to the Northern Plains Cancer Plan as your resource in addressing cancer prevention and control in your community. Wopila (Thank you) for all your hard work on this very important and sacred issue!

Spirit Lake Tribe

Standing Rock
Sioux Tribe

Trenton Indian
Service Area

Respectfully,

Turtle Mountain Band of
Chippewa Indians

Winnebago Tribe
of Nebraska

Jerilyn Church, MSW Chief Executive Officer
Great Plains Tribal Chairmen's Health Board

Yankton Sioux Tribe

DEDICATION

Dedicated in honor of all Northern Plains Native Americans taking the cancer journey, including the survivors and those who have walked 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 ACKNOWLEDGMENT TO:

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Comprehensive Cancer Control Coalition
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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

EXECUTIVE SUMMARY

Cancer continues to be a concern for the Northern Plains American Indian (NPAI) population. Although great strides have been made in education and awareness, early prevention and detection, culturally relevant approaches, and survivorship. NPAI communities continue to suffer from some of the highest rates of cancer and cancer deaths compared to both other Native and non-Native populations. With continuing support from the U.S. Centers for Disease Control and Prevention (CDC) and the Great Plains Tribal Chairmen's Health Board (GPTCHB) the Northern Plains Comprehensive Cancer Control Program has joined with partners from Great Plains tribes, tribal leadership, Indian Health Services, states, universities, and many other cancer control stakeholders to continue working together towards a common goal of strengthening collaborative efforts to prevent cancers 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.*
- ◇ *Set goals and objectives for improvement.*
- ◇ *Propose potential strategies to achieve goals and objectives.*
- ◇ *Provide an outline for action of the many cancer prevention and control areas that need to be improved upon.*
- ◇ *Draw together interested tribes, organizations, entities, and individuals to work collaboratively toward shared goals.*

This revised plan has five main chapters. These five chapters outline the major challenges and barriers, the long-term goals, objectives, and potential strategies for each area. In addition, baseline and target measurements are provided where applicable for outcomes within the five year plan. Please note that this revised and updated cancer plan is streamlined for easy access to goals, objectives, and strategies. The user may refer back to the original Cancer Plan (2008-2012) for a more comprehensive understanding of terminology, definitions, and statistics.

It is true that cancer causes much suffering and fear, but many American Indians also survive cancer and continue their journey with great wisdom and knowledge. Therefore, we must move forward remembering the seriousness of the disease and 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.
- ◇ To 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.
- ◇ Improve a workforce who can provide culturally sensitive/competent comprehensive cancer care for the Northern Plains tribes.
- ◇ 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.
- ◇ Assure that Northern Plains American Indian cancer patients have knowledge about, and access to, advanced care planning.
- ◇ 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.

Focus on Policy, Systems, & Environmental Change

~ Adapted from the Cancer Plan Minnesota

The Northern Plains Comprehensive Cancer Plan includes strategies and interventions that are intended to encourage public health efforts the region to move toward a focus on policy, systems and environmental changes that will provide a foundation for change in the Northern Plains American Indians. Long-lasting and sustainable change to tobacco use, physical activity and nutrition requires systems change driven by new and improved policies.¹ Policy, systems and environmental changes make it inherently easier for individuals to adopt healthier choices than to choose unhealthy options.

- ◇ Policy interventions may be laws, resolutions, mandates, regulations or rules. Examples are laws and regulations that restrict smoking in public buildings and organizational rules that promote healthy food choices in a work site. Policy change refers not only to the enactment of new policies, but also to a change in or enforcement of existing policies.
- ◇ Systems interventions are changes that impact all elements of an organization, institution or system; they may include a policy or environmental change strategy. Two examples include a school district providing healthy lunch menu options in all school cafeterias in the district and a health plan adopting a health reminder intervention system wide. As the Kellogg Foundation states, the school system, the transportation system, parks and recreation and community design/land use influence the built and physical environment. All of these interdependent systems influence the presence or absence of opportunities to be healthy.²
- ◇ Environmental interventions involve physical or material changes to the economic, social or physical environment. Examples are incorporating sidewalks, walking paths and recreation areas into community development design or a high school making healthy snacks and beverages available in all of its vending machines. There is growing recognition that the built environment — the physical structures and infrastructure of communities — plays a significant role in shaping health. The designated use, layout and design of a community's physical structures, including its housing, businesses, transportation systems and recreational resources, affect patterns of living (behaviors) that, in turn, influence health.³



¹ W.K. Kellogg Foundation. *Policy and Systems Change, 2008*: www.wkkf.org/knowledge-center/resources/2008/12/Policy-And-Systems-Change-Webcast-1.aspx.

² W.K. Kellogg Foundation. *Policy and Systems Change, 2008*: www.wkkf.org/knowledge-center/resources/2008/12/Policy-And-Systems-Change-Webcast-1.aspx.

³ Prevention Institute. *The Built Environment and Health: 11 Profiles of Neighborhood Transformation, 2004*:



Chapter One

Prevention

Prevention

It is well known that a healthy lifestyle of being commercial tobacco free, being physically active, and having good eating habits are very important to the prevention of cancers. It is also proven effective to prevent cancers through protection from sun radiation and other environmental exposures such as radon, as well as for young women and young men to be vaccinated with the HPV vaccine. Commercial tobacco use is the most significant preventable cause of cancer. Commercial tobacco contains 7,000 compounds of which at least 70 are established human carcinogens and are known to cause the following cancers: lung, liver, pancreas, kidney, bladder, uterine, cervix, colorectal, oral cavity, trachea, bronchus, acute myeloid leukemia, stomach and oropharynx, larynx, and esophagus. Maintaining a healthy weight through active living and eating well are also significant in the prevention of cancer. Eating a diet rich in fruits and vegetables reduces the chance of developing colorectal, stomach, lung, and esophageal cancers. Most American Indians in the Northern Plains are unable to achieve their optimal health status. Environmental factors, including lack of access to full-service grocery stores, increasing costs of healthy foods and the lower cost of unhealthy foods, and lack of access to safe places to play and exercise, all contribute to the increase in unhealthy weight by inhibiting or preventing healthy eating and active living behaviors.

*There is no risk-free level
of exposure to tobacco smoke, and
there is no safe tobacco product.
~ Surgeon General Report 2014*

Challenges, Issues and Barriers to Prevention of Cancer

- ◇ Prevention can be a low priority for health care systems.
- ◇ Education needs to be ongoing, empowering, and tailored for each tribal community.
- ◇ Tribal councils and leadership sometimes lack awareness and understanding of cancer prevention issues.
- ◇ There are limited prevention and education related services available.
- ◇ 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 fresh produce & fruits.

Prevention Goals, Objectives, & Strategies

PREVENTION 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.

Objective 1:

1. Decrease the percentage of youth who currently use spit tobacco in the pas 12 months from 17% to 16% by 2017.
2. Decrease the percentage of middle school youth that identify themselves as smokers from 23% to 21% by 2017.
3. Increase the percentage of facilities that offer tobacco education programs from 75% to 78% by 2017.

Strategies:

- 1 a. Increase the tax on cigarettes and other tobacco products.
- 1 b. Change social norms around tobacco use and exposure.
- 1 c. Enforce/expand policies that limit visibility of and access to tobacco products.

Objective 2:

- 2.1. Decrease the percentage of students who are exposed to secondhand smoke in the home from 79% to 75% by 2017.

Strategies:

- 2 a. Advance policies that reduce exposure to secondhand smoke.
- 2 b. Conduct messaging campaigns about the dangers of secondhand smoke.

1 South Dakota Youth Tobacco Survey 2007

2 Capacity for Caring American Indian Patients in the 4-State Northern Plains Region

- Survey of Tribal and Indian Health Services Facilities 2011-2012

Prevention Goals, Objectives, & Strategies

Objective 3:

1. Decrease the number of adult smokers in the Northern Plains region from 60.8% to 57% by 2017.
2. Decrease the number of adult smokers in the state of South Dakota from 48% to 45% by 2017.
3. Increase the number of facilities that are offering tobacco education from 75% to 78% by 2017.

Strategies:

- 3 a. Expand comprehensive tobacco cessation benefits to all the Northern Plains American Indians.
- 3 b. Promote utilization of comprehensive smoking cessation services.
- 3 c. Deliver cessation services for population groups with higher prevalence rates of tobacco use.
- 3 d. Leverage policy changes that promote quitting.

Objective 4:

- 4.1. Advocate for consistent and reliable funding for tobacco control in the Northern Plains states in order to increase tobacco control funding and services for the Northern Plains Tribes.

Strategies:

- 4 a. Educate the public and the policymakers regarding the current allocation of tobacco settlement dollars in the Great Plains region. Also to include how tobacco is still serving as the leading cause of preventable death and disease in the state.
- 4 b. Advocate for equal State funding to counties and tribes.

Objective 5:

- 5.1. Increase the number of clinics in the Northern Plains region who offer physical activity programs from 83% to 87% to reach more people who participate in daily, moderate physical activity as it relates to the prevention of cancer.

Strategies:

- 5 a. Increase the number of policies that support physical activity.
- 5 b. Promote programs that encourage traditional and social dance as healthy activities.
- 5 c. Promote activity through local community events such as awareness walks or pow-wows.
- 5 d. Identify and utilize local athletes as spokespersons/mentors of healthy active lifestyles.
- 5 e. Promote and support the use of recreation centers by holding special events and activity contests.

American Indian Adult Tobacco Survey

South Dakota BRFSS 2005-2009

Capacity for Caring American Indian Patients in the 4-State Northern Plains Region

- Survey of Tribal and Indian Health Services Facilities 2011-2012

Prevention Goals, Objectives, & Strategies

Objective 6:

1. Decrease the amount of American Indian adults who are overweight or obese in the Northern Plains from 70% to 66% by 2017.
2. Increase the percentage of facilities in the Northern Plains who offer nutrition programs from 75% to 78% by 2017.
3. Increase the percentage of facilities in the Northern Plains who offer weight control programs from 58% to 61% by 2017.

Strategies:

- 6a. Increase the availability and affordability of healthful foods in Tribal communities by advocating for sustained funding for local and statewide programs.

Objective 7:

1. Increase tribally appropriate efforts to make the Human Papilloma Virus (HPV) vaccine accessible and available to Northern Plains American Indians by increasing the percent-age of facilities that offer HPV education from 93% to 98% by 2017.
2. Increase tribally appropriate efforts to make the Human Papilloma Virus (HPV) vaccine accessible and available to Northern Plains American Indians by increasing the percent-age of facilities that offer HOV vaccine clinic from 23% to 24% by 2017.

Strategies:

- 7 a. Increase HPV education and vaccination in all sites.
- 7 b. Distribution of educational materials on HPV in community settings.
- 7 c. Educating providers on the patient reminder system or the three-part series shots.
- 7 d. Provide education on the need for HPV utilizing available data (GPRA measures).

Objective 8:

- 8.1. Educate Northern Plains Tribal members on the importance of sun safety by increasing the number of cultural and cancer prevention related events attended per year from 0 events to 10 events by 2017.

Strategies:

- 8a. Distribute education packets to students and adults.
- 8b. Promote the use of sun protection at cultural activities that have high exposure to sun; incorporating culturally appropriate messaging.

5 BRFSS 2005

2 Capacity for Caring American Indian Patients in the 4-State Northern Plains Region

- Survey of Tribal and Indian Health Services Facilities 2011-2012

2 Capacity for Caring American Indian Patients in the 4-State Northern Plains Region

- Survey of Tribal and Indian Health Services Facilities 2011-2012

Prevention Goals, Objectives, & Strategies

Objective 9:

9.1. Support efforts to increase knowledge and awareness about the links between environmental contaminants and cancer by increasing the state EPA meetings and conferences attended by Tribal representatives from 0% to 5% by 2017.

Strategies:

9 a. Collaborate and support Tribal and State EPA staff in environmental issues related to cancer.





Chapter 2

Screening & Early Detection

Screening & Early Detection

The Screening & Early Detection chapter plans out objectives and strategies for breast, colorectal, prostate, cervical, and lung cancers.

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 screening and early detection of cancer. "Capacity for Caring American Indian Patients in the 4-State Northern Plains



Region - Survey of Tribal and Indian Health Services Facilities 2011-2012, showed that 75% of the clinics that responded to the survey did not offer any diagnostic testing. 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. Sadly, screening tests or exams for cancer would rarely be approved given the funding and priorities of contract health care.

Challenges, Issues and Barriers to Screening & Early Detection of Cancer

- ◇ *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.*
- ◇ *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.*
- ◇ *Transportation, access, available screening (colonoscopy, mammography, etc.).*

Screening & Early Detection Goals, Objectives, & Strategies

SCREENING & EARLY DETECTION GOAL

To increase appropriate cancer screening for Northern Plain American Indians so cancer is detected at earlier stages.

Objective 1:

1. Increase risk-appropriate screening for breast cancer in Northern Plains American Indian women by maintaining 100% of the facilities in our region offer clinical breast exam.
2. Increase risk-appropriate screening for breast cancer in Northern Plains American Indian women by increasing the percentage of facilities in our region offering mammograms from 67% to 70.35% by 2017.
3. Increase risk-appropriate screening for breast cancer in Northern Plains American Indian women by increasing the percentage of facilities in our region offering diagnostic services for breast cancer from 17% to 17% by 2017.
4. Increase risk-appropriate screening for breast cancer in Northern Plains American Indian women by increasing the percentage of reminder systems for mammography by email from 0% to 5% by 2017.
5. Increase risk-appropriate screening for breast cancer in Northern Plains American Indian women by increasing the percentage of reminder systems for mammography by phone from 46% to 48% by 2017.

Strategies:

- 1 a. Provide appropriate breast cancer screening information utilizing evidence based interventions.
- 1 b. Reduce the financial barriers to breast cancer screening.
- 1 c. Conduct targeted outreach using client reminders, small media campaigns.

Capacity for Caring American Indian Patients in the 4-State Northern Plains Region

- Survey of Tribal and Indian Health

Services Facilities 2011-2012

Screening & Early Detection Goals, Objectives, & Strategies

Strategies:

1. Increase risk-appropriate screening for colorectal cancer in the Northern Plains American Indians by increasing the percentage of facilities that offer fecal occult blood testing from 92% to 97% by 2017.
2. Increase risk-appropriate screening for colorectal cancer in the Northern Plains American Indians by increasing the percentage of facilities that offer fecal occult blood testing from 92% to 97% by 2017.
3. Increase risk-appropriate screening for colorectal cancer in the Northern Plains American Indians by increasing the percentage of facilities that offer Immunochemical Fecal Occult Blood Test (iFOBT) testing from 75% to 78% by 2017.
4. Increase risk-appropriate screening for colorectal cancer in the Northern Plains American Indians by increasing the percentage of facilities that offer colonoscopy from 17% to 20% by 2017.
5. Increase risk-appropriate screening for colorectal cancer in the Northern Plains American Indians by increasing the percentage of facilities that offer sigmoidoscopy from 8% to 10% by 2017.
6. Increase risk-appropriate screening for colorectal cancer in the Northern Plains American Indians by increasing the percentage of facilities that offer reminder systems for email from 0% to 5% by 2017.
7. Increase risk-appropriate screening for colorectal cancer in the Northern Plains American Indians by increasing the percentage of facilities that offer reminder systems for phone from 15% to 20% by 2017.
8. Increase risk-appropriate screening for colorectal cancer in the Northern Plains American Indians by increasing the percentage of facilities that offer reminder systems for US mail from 15% to 18% by 2017.
9. Increase risk-appropriate screening for colorectal cancer in the Northern Plains American Indians by increasing the percentage of facilities that offer reminder systems for FOBT/ iFOBT – email from 0% to 5% by 2017.
10. Increase risk-appropriate screening for colorectal cancer in the Northern Plains American Indians by increasing the percentage of facilities that offer reminder systems for FOB-T/iFOBT – phone from 15% to 17% by 2017.
11. Increase risk-appropriate screening for colorectal cancer in the Northern Plains American Indians by increasing the percentage of facilities that offer reminder systems for FOB-T/iFOBT – US Mail from 23% to 27% by 2017.
12. Increase risk-appropriate screening for colorectal cancer in the Northern Plains American Indians by increasing the percentage of facilities that offer reminder systems for sigmoid colonoscopy – email from 0% to 5% by 2017.
13. Increase risk-appropriate screening for colorectal cancer in the Northern Plains American Indians by increasing the percentage of facilities that offer reminder systems for sigmoid colonoscopy – phone from 8% to 12% by 2017.
14. Increase risk-appropriate screening for colorectal cancer in the Northern Plains American Indians by increasing the percentage of facilities that offer reminder systems for sigmoid colonoscopy – US Mail from 8% to 12% by 2017.

Screening & Early Detection Goals, Objectives, & Strategies

Strategies:

- 2 a. Implement changes within health systems that increase risk appropriate screening.
- 2 b. Increase consumer demand for colorectal cancer screening.
- 2 c. Conduct targeted outreach using client reminders and small media campaigns to increase the demand for screening among groups that experience high mortality rates from colorectal cancer.
- 2 d. Reduce financial barriers to colorectal cancer screening.

Objective 3:

- 1. Promote shared decision making for prostate cancer screening and treatment to individuals and providers in the Northern Plains Tribal Communities by maintaining the percentage of facilities that offer the Prostate specific antigen test (PSA) at 100% through 2017.
- 2. Promote shared decision making for prostate cancer screening and treatment to individuals and providers in the Northern Plains Tribal Communities by maintaining the percentage of facilities that offer the Digital rectal exam at 100% through 2017.
- 3. Promote shared decision making for prostate cancer screening and treatment to individuals and providers in the Northern Plains Tribal Communities by increasing the percentage of facilities that offer diagnostic testing for prostate cancer from 8% to 12% by 2017.

Strategies:

- 3 a. Partner with providers, clinics, and health systems to support shared decision making.
- 3 b. Provide targeted education that incorporates the principles of informed decision making.

2 Capacity for Caring American Indian Patients in the 4-State Northern Plains
Region - Survey of Tribal and Indian Health Services Facilities 2011-2012

3 Regional differences in Indian Health Services Facilities GPRA, 2012

Screening & Early Detection Goals, Objectives, & Strategies

Objective 4:

4.1. Increase risk-appropriate screening for lung cancer in Northern Plains American Indians by increasing the percentage of facilities that are referring for diagnostic testing of lung cancer from 0% to 5% by 2017.

Strategies:

4 a. Advocate for lung cancer screening to be covered under preventative services.

4 b. Encourage providers to assess risk factors for lung cancer and need for screening.

Objective 5:

1. Increase risk-appropriate screening for cervical cancer in Northern Plains American Indian women by increasing the percentage of facilities offering pap smears from 93% to 97% by 2017.

2. Increase risk-appropriate screening for cervical cancer in Northern Plains American Indian women by increasing the percentage of facilities that offer diagnostic services for cervical cancer from 23% to 27% by 2017.

3. Increase risk-appropriate screening for cervical cancer in Northern Plains American Indian women by increasing the percentage of facilities that offer diagnostic testing for cervical cancer from 8% to 10% by 2017.

Strategies:

5 a. Ensure appropriate follow-up for women who receive abnormal test results.

5 b. Promote cervical cancer screening in Northern Plains Tribal Women.

5 c. Reduce financial barriers to cervical cancer screening and follow-up testing (i.e. colposcopy).

5 d. Educate Northern Plains women about risk factors for cancer.

5 e. Encourage and educate providers to assess women for greater risk for cancer and personal history starting at age 18.

Objective 6:

6.1 Encourage providers to conduct periodic health examinations with cancer related check-ups in Northern Plains American Indians.

Strategies:

6 a. Educate on cancers of thyroid, testicles, ovaries, lymph nodes, cavity, and skin.

6 b. Educate about tobacco, sun exposure, diet and nutrition, risk factors, sexual practices, and environmental and occupational exposures.

Capacity for Caring American Indian Patients in the 4-State Northern Plains Region

- Survey of Tribal and Indian Health Services Facilities 2011-2012



Chapter 3

*Treatment
& Traditional Medicine*

Treatment & Traditional Medicine

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.

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. Providers and Traditional Healers are encouraged to dialogue and work together for the health and wholeness of Northern Plains American Indians.

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.



Treatment & Traditional Medicine

Challenges, Issues and Barriers to Treatment & Traditional Medicine for Cancer

- ◇ 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 can not 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.



Challenges, Issues and Barriers related to the Workforce in Cancer

- ◇ 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 work loads.
- ◇ 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.

Treatment & Traditional Medicine Goals, Objectives, & Strategies

TREATMENT & TRADITIONAL MEDICINE GOAL

TREATMENT GOAL: To increase trainings and professional development for cancer care workforce to decrease the delay in diagnosis and treatment.

TRADITIONAL MEDICINE GOAL: To increase knowledge and access of cancer resources and services using culturally relevant approaches for Great Plains Tribes.

Objective 1:

1. Improve upon provider knowledge on cancer diagnosis, treatment, and other related services to improve cancer care for Northern Plains Indians by increasing the percentage of facilities that offer radiation therapy from 0% to 5% by 2017.
2. Improve upon provider knowledge on cancer diagnosis, treatment, and other related services to improve cancer care for Northern Plains Indians by increasing the percentage of facilities that offer chemotherapy from 67% to 70% by 2017.
3. Improve upon provider knowledge on cancer diagnosis, treatment, and other related services to improve cancer care for Northern Plains Indians by increasing the percentage of facilities that offer hormone therapy from 8% to 10% by 2017.
4. Improve upon provider knowledge on cancer diagnosis, treatment, and other related services to improve cancer care for Northern Plains Indians by increasing the percentage of facilities that offer cancer surgeries from 0% to 5% by 2017.
5. Improve upon provider knowledge on cancer diagnosis, treatment, and other related services to improve cancer care for Northern Plains Indians by increasing the percentage of clinics that offer clinical trials from 0% to 5% by 2017.
6. Improve upon provider knowledge on cancer diagnosis, treatment, and other related services to improve cancer care for Northern Plains Indians by decreasing the percentage of facilities that do not offer any of the above treatments from 92% to 96% by 2017.

Strategies:

- 1 a. Increase collaboration and communication efforts between Tribal Communities and Cancer Centers.
- 1 b. Improve cancer treatment education through culturally appropriate materials.
- 1 c. Promote awareness and implementation of the National Comprehensive Cancer Network Treatment Guidelines and the Physician Data Query standards by providers and consumers to the cancer care centers in the Northern Plains.
- 1 d. Support health-care professional education that promotes shared decision making regarding treatment options.
- 1 e. Conduct education for health care professionals about cancer treatment options, clinical trials, and genetic testing.
- 1 f. Increase the number of sites that utilize cancer clinical guidelines.

Capacity for Caring American Indian Patients in the 4-State Northern Plains Region

- Survey of Tribal and Indian Health

Services Facilities 2011-2012

Treatment & Traditional Medicine Goals, Objectives, & Strategies

Objective 2:

2.1. Ensure that all Northern Plains American Indians receive access to quality cancer care services by increasing the percentage of facilities that offer traditional medicine to cancer patients from 8% to 12% by 2017.

Strategies:

2 a. Advocate for support services to incorporate Traditional Medicine as part of the treatment plan, such as Great Plains Access to Recovery (ATR) services (SAMHSA funded program) in all Northern Plains states.

2 b. Incorporate traditional healing into Western Medicine or cancer care.

2 c. Develop guidelines and educate providers, cancer care centers, and other stakeholders to communicate and incorporate Traditional Medicine into the continuum of care.

2 d. Improve access to cancer care services for Northern Plains American Indians.

2 e. Identify locations and resources for access to care in the Northern Plains Communities.

Objective 3:

3.1. Ensure that cancer patients and their families do not get lost in the complex system of health care, which may result in delay in diagnosis and treatment, discontinuation of treatment or less than optimal care .

Strategies:

3 a. Improve access to cancer care services for Northern Plains American Indians

3 b. Identify locations and resources for access to care in the Northern Plains Communities.

Capacity for Caring American Indian Patients in the 4-State Northern Plains Region

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Treatment & Traditional Medicine Goals, Objectives, & Strategies

Objective 4:

4.1 Ensure that cancer patients and their families do not get lost in the complex system of health care, which may result in delay in diagnosis and treatment, discontinuation of treatment or less than optimal care.

Strategies:

- 4 a. Improve and increase cancer navigation in tribal communities.
- 4 b. Support efforts to provide cancer care funding resources for Northern Plains American Indians.
- 4 c. Support efforts to fund patient navigators in cancer treatment centers and in Tribal communities.
- 4 d. Support a collaborative Tribal community network that provides transportation and housing as needed for cancer treatment.

Objective 5:

5.1. Optimize access to resources including but not limited to transportation, lodging, and financial assistance that support cancer care from diagnosis through treatment and follow-up.

Strategies:

- 5 a. Support and engage Tribal communities in identifying and solving access to care issues.
- 5 b. Support partnerships to facilitate access to specialty services for rural patients and providers through methods such as telemedicine.
- 5c. Provide community education regarding navigation of access to care resources.





Chapter 4

Quality of Life

Quality of Life

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. We call this broad support system “Native Families.” Little is currently known about Northern Plains American Indian 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. Little is also known about the palliative and end-of-life care experience of the American Indian population in the Northern Plains. A thorough literature review revealed very few published reports or data related to palliative care for American Indians.

Challenges, Issues and Barriers to Quality of Life with Cancer

- ◇ 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.

Quality of Life Goals, Objectives, & Strategies

QUALITY OF LIFE GOALS

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.

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.

Objective 1:

1. Improve continuity of care for Northern Plains American Indian cancer survivors and their families by increasing the number of facilities that offer nutrition counseling to cancer patients from 83% to 87% by 2017.
2. Improve continuity of care for Northern Plains American Indian cancer survivors and their families by increasing the number of facilities that offer psychosocial services to cancer patients from 83% to 87% by 2017.
3. Improve continuity of care for Northern Plains American Indian cancer survivors and their families by increasing the number of facilities that offer spiritual/religious counseling services to cancer patients from 0% to 5% by 2017.

Strategies:

- 1 a. Establish coordinated and systematic communications between IHS, Cancer Centers, and Tribal Health Sites.
- 1 b. Identify and address deficiencies and gaps in service coordination.
- 1 c. Develop and promote methods to facilitate the exchange of information among all healthcare professionals involved in the development of cancer survivorship care plans.
- 1 d. Encourage and support venues for cancer survivors to share their journey through story telling or talking circles to help others going through the continuum of care.

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Quality of Life Goals, Objectives, & Strategies

Objective 2:

1. Ensure that all Northern Plains American Indians receive access to quality cancer care services by increasing facilities that offer nutrition palliative care services to cancer patients from 58% to 62% by 2017.

2. Ensure that all Northern Plains American Indians receive access to quality cancer care services by increasing facilities that offer end of life hospice services to cancer patients from 8% to 10% by 2017.

Strategies:

2 a. Assess availability and increase end-of-life hospice facilities and resources.

2 b. Communicate resources to community and to Tribal clinics.

2 c. Improve cultural communications between providers and patients.

2 d. Promote systems change to integrate palliative care practice guidelines (such as the Institute for Clinical Systems Improvement or National Comprehensive Cancer Network) into routine cancer care.

Objective 3:

3.1. Increase the number of Northern plains American Indians who have Advance Care Directives or Planning by 2017.

Strategies:

3 a. Improve Provider/Patient conversation about end of life and document completion of advanced care planning health care directive.

3 b. Educate clinic staff to facilitate culturally competent conversations about advance care planning.

3 c. Improve accessibility of advanced care planning documents within health care systems' electronic medical records.

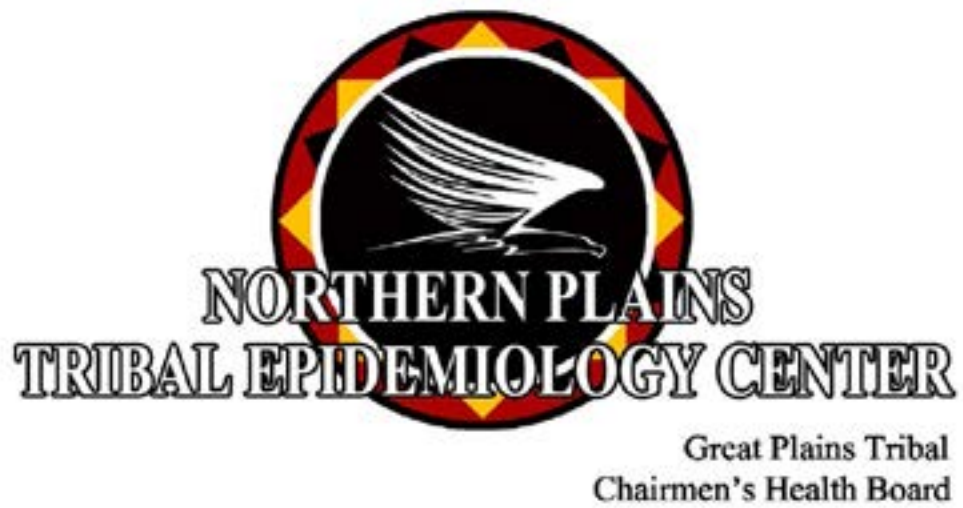
3 d. Educate health professionals and first responders about physician orders for completion and use of life-sustaining treatment (POLST).

Capacity for Caring American Indian Patients in the 4-State Northern Plains Region

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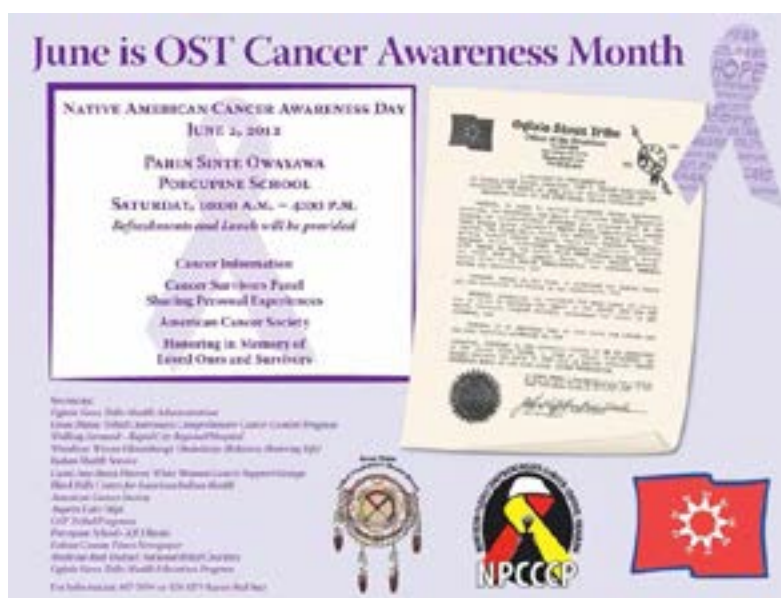


Chapter 5

Surveillance

Surveillance

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. The areas of data and research are needed in order to improve cancer care for the Northern Plains American Indian population. 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.



Challenges, Issues and Barriers to Quality of Life with Cancer

- ◇ 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 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.

Surveillance Goals, Objectives, & Strategies

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.

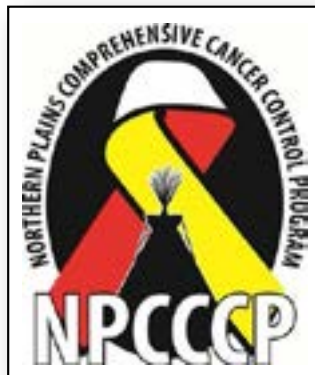
Objective 1:

- 1.1 Obtain Tribal specific surveillance data in Northern Plains Tribes to support and build capacity toward infrastructure by increasing the amount of facilities that exchange cancer information with cancer treatment centers from 58% to 62% by 2017.
2. Obtain Tribal specific surveillance data in Northern Plains Tribes to support and build capacity toward infrastructure by increasing the amount of facilities that exchange cancer information with private physician offices from 58% to 62% by 2017.
3. Obtain Tribal specific surveillance data in Northern Plains Tribes to support and build capacity towards infrastructure by increasing the amount of facilities that exchange cancer information with health insurance plans from 38% to 42% by 2017.
4. Obtain Tribal specific surveillance data in Northern Plains Tribes to support and build capacity towards infrastructure by increasing the amount of facilities that exchange cancer information with pathology laboratories from 42% to 45% by 2017.

Strategies:

- 1 a. Educate Tribal Representatives on how to utilize and benefit from National programs of cancer registry.
- 1 b. Build capacity through educating Tribes on their Tribal specific data.
- 1 c. Establish MOU's with state cancer registries, epidemiology centers, and state department of health.

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Appendix A

Best Practices / Guidelines
Healthy People Objectives
Policy, Systems, and Environmental Change



Chapter	Best Practices / Guidelines	Healthy People 2020 Objectives	Policy, Systems, Environmental Change Examples
Prevention		C-1	
Tobacco	CDC Best Practices for Comprehensive Tobacco Control Programs—2014	TU-1 / 1.1 / 2 / 2.1 / 3.5 / 4 / 4.1 / 6 / 7 / 11 / 11.1 / 11.2 / 11.3 / 12 / 20.3	Implementation of a smoke-free work place. (policy) Increasing federal taxes on commercial tobacco products. (systems)
Physical Activity (PA)	WHO Review of Best Practice in Interventions to Promote PA in Developing Countries; CDC Guide to Strategies to Increase PA in the Community	PA-1 / 2.1 / 3 / 3.1	Policy instituting employee fitness leave. (policy) Creation of a community hiking area or trail. (environmental)
Nutrition	CDC Guide to Strategies to Increase the Consumption of Fruits and Vegetables; CDC Guide to Strategies for Reducing the Consumption of Sugar-Sweetened Beverages; CDC Guide to Strategies to Support Breastfeeding Mothers and Babies	NWS-3 / 4 / 8 / 21.1	Implementation of a school policy to eliminate soda pop machines and replacing with milk or juice vending. (policy and environmental) The addition of a salad bar in the school cafeteria. (environmental)
Vaccination	CDC Advisory Committee on Immunization Practices	STD-9	Institution of all clinics offering HPV Vaccination to NP girls and boys. (systems)
Sun Safety	U.S. Preventive Services Task Force	C-8, / 20 / 20.1 / 20.2 / 20.3 / 20.4 / 5 / 20.6	Education in the classroom regarding harmful effects of excess sun exposure. (systems)
Environmental	CDC Environmental Health	EH-20 / 22	Partnership with EPA regarding environmental toxins in NP region. (systems)
Screening & Early Detection	American Cancer Society; U.S. Preventive Services Task Force	C-2 / 3 / 4 / 5 / 7 / 9 / 10 / 11 / 15 / 16 / 17 / 18 / 18.2 / 19	Adapting clinical guidelines for risk appropriate screening and early detection. (systems)

Chapter	Best Practices / Guidelines	Healthy People 2020 Objectives	Policy, Systems, Environmental Change Examples
Treatment	The National Comprehensive Cancer Network (NCCN) Clinical Guidelines in Oncology; Commission on Cancer	HC/HIT-1 / 1.1 / 1.3 / 3 / 4; PHI-1.2 / 2 / 11 / 12 / 15	Institute a tobacco user identification system at a hospital and/or clinic. (systems)
Access to Care	Affordable Care Act Navigator Program	AHS-1.1 / 2 / 3 / 4.1 / 5.1 / 6.2 / 6.4 / 8.1 / 8.2	Provide transportation services for those who are unable to travel to a clinic for care. (systems)
Patient Navigation	GPTCHB Navigator Program: The Affordable Care Act and Indian Country, NCI Center to Reduce Cancer Health Disparities		Hiring of patient navigators for cancer care within infrastructure. (systems)
Access to Resources	GPTCHB; Northern Plains Comprehensive Cancer Control Program (NPCCCP)	HC/HIT-5 / 5.1 / 5.2 / 6.1 / 6.2 / 6.3 / 10 / 11 / 13	Provide educational materials for patient services for cancer. (environmental, systems)
Workforce	C-Change (Collaborating to Conquer Cancer)	HC/HIT- 2 / 2.1 / 2.2 / 2.3 / 2.4 / 3 / 4	Provide incentives for providers to attend educational in-services . (systems or policy)
Quality of Life		C-12 / 13 / 14; HRQOL/WB-1.1 / 1.2	Increase palliative care services in the NP region. (systems)
Survivorship / Caregiver	National Action Plan for Cancer Survivorship: Advancing Public Health Strategies		Support venues for cancer survivors to share their journey through storytelling. (environmental)
Palliative / End of Life	National Consensus Project for Quality Palliative Care		Create and institute a guideline Improve cultural communications between providers and patients. (system)
Advanced Care Planning	AHRQ - Shared Decision Making Process; NCI - Advanced Care Directives		Improve accessibility of advanced care planning documents within health care systems' electronic medical records. (environmental)
Surveillance	National Action Plan for Cancer Survivorship: Advancing	C-12	Establishment of MOU's with state cancer registries, epi centers, and state

A Project of the Northern Plains Cancer Coalition



Great Plains Tribal Chairmen's Health Board



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