



WORKING TOWARD CANCER-FREE TRIBAL COMMUNITIES

TWENTY-YEAR COMPREHENSIVE
CANCER CONTROL PLAN

Northwest Tribal Cancer Coalition

*Northwest Portland Area
Indian Health Board*



Dedication

This is dedicated to all our community members who have ever been diagnosed with cancer and to their loved ones who have cared for them through the course of this disease. More and more, people are living far beyond their diagnosis. However, far too often we have experienced the feelings of heartache and helplessness as cancer takes its toll in our communities. The efforts of many are helping to ease the cancer burden in our communities. This document represents the work of those who dare to envision cancer-free tribal communities for generations to come.



Yakama Office of Native Cancer Survivorship

Back Row: Connie Adams, Ellen Doublerunner, Cat Miller

Front Row: Delilah Martinez, Catherine Sampson, Patricia Ike

Not Pictured: Hollyanna Cougartracks Pinkham

Cover beadwork is courtesy Greg Vann, Cherokee

The mission of the Northwest Tribal Comprehensive Cancer Program is to envision and work toward cancer-free tribal communities by taking an integrated and coordinated approach to cancer control. In collaboration with the 43 Northwest tribes, the Northwest Tribal Cancer Control Project is implementing strategies that will reduce the cancer burden for American Indians and Alaska Natives in the Pacific Northwest.

Acknowledgements

In July 1998, the delegates of the Northwest Portland Area Indian Health Board ratified the original Comprehensive Cancer Control Plan for the Northwest Tribal Cancer Control Project. At the same time, the delegates established the Northwest Tribal Cancer Coalition whose first members were named in January 1999. In 2000, membership expanded, recruiting more tribal participation and agencies committed to cancer prevention, and in April 2001, the development of a comprehensive tribal cancer plan was set in motion.

It is through the dedicated work of the members of the Northwest Tribal Cancer Coalition that this plan has emerged. Over the past eight years, countless individuals and organizations have attended Coalition meetings; sharing with one another resources, expertise, and visions of cancer-free tribal communities. We would like to thank the coalition and work group members who have contributed tirelessly to this document over the years. We would also like to thank the health professionals, individuals and family members who have worked so diligently to help decrease the cancer burden in our Northwest Native communities.

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Executive Summary

The Northwest Portland Area Indian Health Board

The Northwest Portland Area Indian Health Board (NPAIHB) is a tribal organization governed by the 43 federally recognized tribes of Oregon, Washington and Idaho. NPAIHB represents 190,000 American Indian/Alaska Native (AI/AN) people.

The Northwest Tribal Comprehensive Cancer Program

In 1999, NPAIHB was the first Tribal organization to receive a CDC Comprehensive Cancer Grant. The Northwest Tribal Comprehensive Cancer Control Project (NTCCP) was the first program to form a tribal cancer coalition covering multiple states, develop a tribal comprehensive cancer plan, design a tribal behavioral risk factor survey, and collaborate with a wide network of partners including federal, state, academic, non-profit, and private industry partners.

The NTCCP provides technical assistance to tribes on tribal action plans for local cancer activities, resource information, cancer data and cancer education training through a variety of venues including the Clinical Director's Update, Cancer 101, and Risky Business. NTCCP also participates in tribal health fairs, events, conferences, and trainings.

Northwest Tribal Cancer Coalition

The heart of the NTCCP is the Northwest Tribal Cancer Coalition. The coalition is comprised of many diverse stakeholders, including representatives from the 43 NPAIHB member tribes along with representatives from state, federal, education, non-profit, and cancer treatment organizations. The Coalition meets quarterly with tribal and comprehensive cancer partners to address cancer prevention and control. Coalition meetings allow members to build partnerships, share wisdom, data, cancer resources, to identify and address common priorities, and develop strategies to eliminate cancer health disparities.

Northwest American Indian/Alaska Native (AI/AN) Cancer Burden

Cancer is the second leading cause of death for AI/ANs in the Pacific Northwest, led by breast cancer, lung cancer, and colorectal cancer in descending order. Studies in the Northwest have also shown that AI/ANs have high risk factors for cancer, the poorest survival rates for cancer, and lack access to cancer treatment and screening. There are multiple reasons that contribute to this dilemma, ranging from transportation, child-care, and time to more complex economic and cultural barriers.

The Twenty-Year Comprehensive Cancer Control Plan

One of the most important accomplishments of the coalition was the development of a comprehensive tribal cancer control plan. This plan, "*Working Toward Cancer-free Tribal Communities: Twenty-Year Comprehensive Cancer Control Plan*," was written with the vision of a future with lower cancer rates, higher survival and better quality of life for cancer patients and their families.

The vision of the plan is for tribal communities to utilize it as a guide for developing and implementing components of cancer prevention, screening, treatment and survivor needs in their own communities. The plan has gone through three major updates, (2001, 2003 and current), and will continue to be a document subject to change, clinical updates, and revitalization.

Coalition members developed a template for the plan, organizing prevention, early detection and screening, diagnosis and treatment, rehabilitation, palliation, and survivorship activities around five identified cancer



sites: lung, breast, cervical, colorectal, and prostate. The plan also now includes two additional sections for other cancers, including childhood cancers. The Coalition chose a familiar and easy to use matrix layout for the plan, with short and long term goals, objectives, strategies (activities), as well as measurable data for evaluative purposes.

Considerations that NTCCP and the Coalition have taken into account in working on and updating the Plan include community strengths, evidence-based interventions (including behavioral and policy interventions), Healthy People 2010 leading health indicators, and barriers to reducing cancer burdens in tribal communities.

The Twenty-Year Plan: Future Cancer Plan Strategies

In the next five-year cycle, we will have an emphasis on the data concerns and establishing baseline data. Twenty-two of the NPAIHB tribes have tracked Government Performance Results Act (GPRA) measures for five years. A survey with tribal clinicians was administered on cancer screenings, referrals, and follow up. The survey made a request of the interest of tribal clinics in trending the GPRA indicators over a five-year period, and established the process of who to meet with in order to present a data sharing agreement. In addition, NTCCP is developing a tribal cancer control toolkit. There is also a new project in place to work with survivors and family members to determine the obstacles for AI/AN receiving cancer treatment, as well as to examine reasons why AI/AN drop out of treatment at higher rates.

The components of The Northwest Tribal 20 Year Cancer Plan follow the recommendations of the Coalition. This report includes: information about NPAIHB, NTCCP, and the Coalition; a short background and history of the tribes in the Pacific Northwest; a description of the cancer burden; a delineated twenty year plan addressing short and long term goals, objectives, strategies, as well as identified evaluative measures for prevention, early detection and screening, diagnosis and treatment, rehabilitation, palliation, and survivorship for lung, breast, cervical, colorectal, prostate and other cancers for Northwest Tribal communities; an examination of cultural strengths, evidence based interventions including behavioral changes, and of the challenges of comprehensive cancer at the tribal level. Following in the Appendix are selected tribal highlights of implementation of cancer activities in our Northwest communities; there are many more events that could not be included; CDC logic model and framework for comprehensive cancer programs; and references.



Introduction

The Northwest tribes have long recognized the need to exercise control over the design and development of healthcare delivery systems in their local communities. To this end, in 1972 they formed the Northwest Portland Area Indian Health Board (NPAIHB or Health Board). The NPAIHB is a tribal organization governed by the 43 federally recognized tribes of Oregon, Washington and Idaho. Tribes become members of the Board through Public Law 93-638, authorizing resolutions passed by the governing body of the tribe. Tribal governments appoint a delegate to represent them on the Board of Directors, which meets on a quarterly basis. NPAIHB represents 190,000 American Indian/Alaska Native (AI/AN) people.

NPAIHB's mission is to assist Northwest tribes to improve the health status and quality of life of member tribes and Indian people in their delivery of culturally appropriate and holistic health care. The NPAIHB provides education and technical support for its 43 member tribes on issues related to health, health promotion, and disease prevention.

While its core funding comes from the Indian Health Service (IHS), NPAIHB seeks funds from other federal and state agencies as well as private foundations. The Board currently utilizes funds from the Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), National Cancer Institute (NCI), Robert Wood Johnson Foundation, and Washington and Oregon State Health Departments. All funding opportunities are first reviewed and then endorsed through formal resolution by our tribal delegates.

Comprised of high-caliber healthcare professionals, over 80% of whom are enrolled tribal members, the NPAIHB has a wealth of experience providing culturally appropriate services to the tribes of the Northwest. Board project directors and staff are both regionally and nationally recognized for their efforts in their respective fields. They are often called upon to provide position papers at national Indian health meetings, present project information or findings at national conferences, and provide expertise to county, state, and federal agencies. In recognition of its excellence in self-governance, the Board received "Honors" in 2003 from Harvard's Kennedy School of Government *Honoring Nations Award*, and was chosen among the "100 Best Companies to work for in Oregon" by *Oregon Business Magazine* in 2004 and 2006.

NPAIHB currently administers the following projects: Northwest Tribal Comprehensive Cancer Program,, Women's Health Promotion Program, Western and National Tobacco Projects, and the Northwest Tribal Epidemiology Center. EpiCenter Projects include: RPMS Training, Northwest Tribal Registry Project, Preventing Toddler Overweight and Tooth Decay Project, Fetal Alcohol Syndrome Project, Project Red Talon: STD/HIV Prevention, Tribal Dental Support Project, Tribal EpiCenter Consortium, Data into Action Project, NPAIHB Immunization Program, Western and National Diabetes Programs, and Northwest Tribal Research Center for Health. Archived projects include: The Tribal Tobacco Policy Project, Northwest Tribal Recruitment Project, Women's Health Promotions Project, STOP Chlamydia Project, Indian Community Health Profile Project, Northwest Tribal Elder Diet and Nutrition Project, Health Professions Education Project, Hanford Tribal Service Program, Circle of Health Information Infrastructure for Northwest Tribes, Northwest Tribal Dementia Project, Northwest Injury Prevention Project, Northwest Tribal Welfare Information Project, and Northwest Tribal Infant Mortality Project.



Northwest Portland Area Indian Health Board Member Tribes

- Burns Paiute Tribe
- Coeur d'Alene Tribe
- Confederated Tribes of the Chehalis
- Confederated Tribes of the Colville Reservation
- Confederated Tribes of the Coos, Lower Umpqua & Siuslaw Indians
- Confederated Tribes of the Grand Ronde
- Confederated Tribes of the Siletz Indians of Oregon
- Confederated Tribes of the Umatilla Indian Reservation
- Confederated Tribes of Warm Springs Reservation of Oregon
- Coquille Tribe
- Cow Creek Band of Umpqua Tribe of Indians
- Cowlitz Indian Tribe
- Hoh Tribe
- Jamestown S'Klallam Tribe
- Kalispel Tribe of Indians
- Klamath Tribes
- Kootenai Tribe
- Lower Elwha Klallam Tribe
- Lummi Nation
- Makah Indian Nation
- Muckleshoot Indian Tribe
- Nez Perce Tribe
- Nisqually Tribe
- Nooksack Tribe
- Northwest Band of Shoshone Indians
- Port Gamble S'Klallam Tribe
- Puyallup Tribe of Indians
- Quileute Tribe
- Quinault Nation
- Samish Indian Tribe
- Sauk-Suiattle Indian Tribe
- Shoalwater Bay Indian Tribe
- Shoshone-Bannock Tribes
- Skokomish Tribal Nation
- Snoqualmie Indian Tribe
- Spokane Tribe of Indians
- Squaxin Island Tribe
- Stillaguamish Tribe
- Suquamish Tribe
- Swinomish Indian Tribal Community
- Tulalip Tribes
- Upper Skagit Tribe
- Yakama Nation



Map of the 43 Federally Recognized Tribes in the Portland Area



As the map on the previous page illustrates, the 43 tribes are dispersed over a vast area in the three contiguous Northwest states, and are federally-recognized as sovereign nations. The tribes include three distinct cultural groups with very different histories: Northwest Coastal tribes, Great Basin tribes, and Plateau tribes. Not only are geographic areas highly diverse for these three main cultures, but economic resources, linguistic traditions, material culture, religious beliefs, and customs are also heterogeneous in these three areas.

The Northwest Coast tribes extend from southern Oregon to Alaska, and are characterized historically by economies that relied heavily on fishing, harvesting sea mammals, and gathering. Travel was frequently conducted by open canoes (vs. sailing vessels), and elaborate winter ceremonies took place as a means for distribution of resources (and for gaining recognition). In both the Great Basin and Plateau areas, travel occurred on rivers by canoe, and on open land by foot, and later by horseback after the Spanish reintroduced horses into North America in the 1500's. (The Nez Perce tribe in Idaho are famous for their breed of horses, and historically, for their skill on horseback.) Hunting and gathering, including salmon fishing, were important economic activities in the Great Basin and Plateau areas.

Social networks among all tribal peoples in the Pacific Northwest were broad and complex, and periodic gatherings among various tribes (especially during salmon runs or during other resource harvesting opportunities) brought distant tribes to specific locations over the past several thousand years to share in resource gathering. Although such gatherings still occur among tribal peoples in the Pacific Northwest, tribal members are now more likely to have steady employment in cities or in areas on or near home reservations—and far less likely to depend heavily on resources that are harvested seasonally. Income from casinos and other tribal ventures has resulted in more stable economies on certain reservations than was the case 50 years ago, although a high proportion of tribal people in the Northwest still live below the poverty level.

Not surprisingly, histories of relations with newcomers to this part of the country are also very different among the diverse tribes represented by the Board. As was observed in the other parts of the country, competition for finite resources between Natives and settlers in the Pacific Northwest resulted in wars and in displacement of families, as well as of entire tribes. 'Historical trauma', a term that relates to tribes' continued awareness of past injustices is well documented in these tribes (Ball et al, 2001). The effects of historical trauma include behavioral and health consequences. However, the role that historical trauma has played on disease incidence rates in all the tribes, including cancer incidence, is difficult to measure. From our experience in working with each of the tribes in the Pacific Northwest (NW), every tribal member can recite the wars, treaties, treaty violations, effects of gold rushes, aftermath of measles and small pox epidemics, and other events and injustices that are part of the recent histories of the tribes. Tribal elders also commonly report that in their youth, they were aware of few cancer cases in their own tribes, although we recognize that many factors influence the elders' perceptions that cancer was rare 75 to 80 years ago. Many elders are convinced that tribal adoption of western lifestyles is to blame for the high cancer rates observed in some of the tribes today.



The Northwest Tribal Comprehensive Cancer Program

In 1999, the NPAIHB was the first Tribal organization to receive a CDC Comprehensive Cancer Grant. The Northwest Tribal Comprehensive Cancer Control Project (NTCCP) was the first program to form a tribal cancer coalition covering multiple states, develop a tribal comprehensive cancer plan, design a tribal behavioral risk factor survey, and collaborate with a wide network of partners including federal, state, academic, non profit, and private industry partners.

The NTCCP provides technical assistance to tribes on tribal action plans for local cancer activities, resource information, cancer data and cancer education training through a variety of venues including the Clinical Director's Update, Cancer 101, and Risky Business. NTCCP also participates in tribal health fairs, events, conferences, and trainings.

Since 1998, the Northwest Tribal Comprehensive Cancer Program (NTCCP) has worked to reduce the burden of cancer affecting Northwest tribal communities. This daunting task was tackled using an integrated and coordinated approach to cancer control, bridging prevention, screening and early detection, diagnosis, treatment, rehabilitation, and palliation.

The goals of the NTCCP are to:

1. Facilitate a process for Northwest tribes to promote cancer risk reduction strategies.
2. Provide information on the most current early detection, screening and treatment practices through education and resource materials.
3. Provide education regarding quality of life for cancer patients, their families and caretakers.
4. Coordinate and collaborate with local and national cancer organizations and individuals.
5. Improve Indian-specific cancer control data.

Strategies:

1. The Northwest Tribal Cancer Control Twenty Year Plan - *Working Toward Cancer-free Tribal Communities*
2. The Northwest Tribal Cancer Coalition meets quarterly with tribal and other comprehensive cancer control partners to address:
 - Cancer prevention and control by building partnerships.
 - Provide a forum for networking and sharing new information on resources, screening, educational, clinical, and policy updates.
 - Empower Tribal communities that have the ability to influence public policy and effect change.
 - Provide National, regional, state and local cancer data, research, and evaluation tools for making decisions about cancer prevention and control.
3. Provide technical assistance in tribal action plan development to help promote local activities in screening, prevention, and education activities in tribal communities.
4. Provide cancer education training through a variety of venues including the Clinical Director's Update, Cancer 101, Risky Business and coalition meetings.
5. Provide resource information to tribal communities on cancer related issues.



The Northwest Tribal Cancer Coalition

The heart of the NTCCP is the Northwest Tribal Cancer Coalition. The coalition has had strong tribal leadership and over the nine-year life of the project has had two dedicated and visible tribal leaders as chairperson. The Coalition meets quarterly with tribal and comprehensive cancer partners to address cancer prevention and control. Coalition meetings allow members to build partnerships, share wisdom, data, cancer resources, to identify and address common priorities, and develop strategies to eliminate cancer health disparities. The Coalition has grown over time, from meetings of 12-15 people initially to 60 participants at the January 2007 coalition meeting.

The coalition is comprised of representatives from the 43 NPAIHB member tribes along with representatives from State, Federal, Education, Non-profit, and Cancer Treatment organizations. Representatives include:

- American Cancer Society
- Angel Flight West
- Association of Oncology Social Work
- Cancer Care
- Cancer Care Resources
- Cancer Data Registry of Idaho
- Cancer Lifeline
- Cancer Patient Care
- CDC Cancer Division
- Coeur d'Alene Komen
- Community Action Partnership Organizations
- Eastern Washington Candlelighters
- Eastern Washington Komen
- Everett Cancer Center
- Fred Hutchinson Cancer Center
- Friend's of Avery
- Gilda's Club Seattle
- Glaxo Smith-Kline
- Great West ACS Division
- Idaho Breast & Cervical Program
- Idaho Comprehensive Cancer Program
- Idaho Leukemia & Lymphoma Society
- Idaho Tobacco Control Program
- Intercultural Cancer Council
- Joe's House
- Lance Armstrong Foundation
- Leukemia & Lymphoma Society
- Mayo University Cancer Center
- National Indian
- National Marrow Donor Program
- Native American Cancer Research
- Native CIRCLE
- Native People's Circle of Hope
- Native WEB
- NCI Cancer Information Service
- Northwest Tribal Epidemiology Center
- Northwest Tribal Navigator Program
- Olympic Medical Center
- Oregon & SW Washington Komen
- Oregon American College of Surgeons Cancer Liaison
- Oregon Breast & Cervical Program
- Oregon Health & Science University
- Oregon Health Science Women's Center
- Oregon Leukemia & Lymphoma Society
- Oregon Partnership for Cancer Control
- Oregon Research Institute
- Oregon State Cancer Registry
- Oregon Tobacco Control Program
- Patient Advocate Foundation
- Project Red Talon
- Providence Cancer Center
- Puget Sound Komen
- Seattle Cancer Care Alliance
- South Puget Intertribal Planning Agency Comprehensive Cancer Program
- Spirit of EAGLES
- Statewide Association of Hospice Organizations
- University of Washington
- Washington Breast & Cervical Program
- Washington Comprehensive Cancer Program
- Washington Leukemia & Lymphoma Society
- Washington State Cancer Registry
- Washington Tobacco Control Program
- Western Tobacco Prevention Project
- Western Tribal Diabetes Program
- Women's Health Promotion Program
- Women's Health Resource Center
- Yakama Office of Native Cancer Survivorship



Cancer Burden

Introduction

Cancer is the second leading cause of death for American Indians and Alaska Natives (AI/AN) both nationwide and in the Pacific Northwest (Idaho, Oregon, and Washington). Cancer describes abnormal growth of a body tissue that becomes “malignant,” usually meaning that it has the ability to spread throughout the body. A cancer (also called a “neoplasm”) can arise in nearly all organs and tissues, and the severity of a cancer is partly defined by the organ (“anatomic site”) in which it arises. The various types of cancer, identified by the anatomic site, differ markedly in incidence and mortality rates; for this reason, health agencies usually report separate rates for each major type of neoplasm.

Reducing the cancer burden is an urgent task for American Indian and Alaskan Natives. According to Healthy People 2010 (2000), the rate of cancer death is around 129 per 100,000 for American Indians and Alaska Natives, compared to 202 per 100,000 for all US residents. Although this rate is apparently lower than the overall mortality rate, AI/AN have the worst overall cancer survival rate in comparison with all other racial and ethnic groups (CDC, 2001). Among the reasons for this discrepancy may be the underreporting of cases, the effect of co-morbidities, or lack of access to screening and treatment facilities.

Cancer in the Northwest

Information about cancer among AI/ANs in the Northwest has improved dramatically over the past decade, thanks to a series of studies that improved the quality of data in cancer registries. Cancer registries are the main source of information about cancer incidence and mortality. They gather clinical and demographic variables from medical facilities’ reports; these numbers are used in the numerators of cancer incidence rates. When race or ethnicity is reported to the cancer registry, it is not always based on an individual’s self-report.

Particularly in the Northwest, AI/ANs are often misclassified as members of other racial or ethnic groups. The denominators for rate calculations, on the other hand, typically come from the U.S. census, in which every person has a chance to identify his or her own background. This makes cancer incidence for AI/ANs appear lower than it actually is.

The Northwest Tribal Registry Project (Registry Project), started by the NTCCP, has improved cancer incidence data by linking records from Indian Health Service (IHS) and tribal clinics to the cancer registries in Washington, Oregon, and Idaho. When the state cancer registry data for 1996-1997 was linked to the IHS service user population, 412 matches were found, 215 of which (52.2%) were originally misclassified by the state.

A number of methods exist for recalculating cancer incidence rates to reflect corrected racial and ethnic classifications in the state cancer registries. The methods produce different cancer incidence estimates, but all of these estimates are higher than rates calculated before the linkage studies were implemented. According to the Registry Project’s analysis of 1996-1999 data for the state cancer registries, if the linkage had not been performed, the age-adjusted cancer incidence rate for AI/ANs would have been 201.1 per 100,000 population, compared to 467.7 among all races. Using only IHS service users with matched records in the registry, the overall cancer incidence rate rises to 332.9 for AI/ANs. For all AI/ANs in the state registries (and not just IHS service users), the overall cancer incidence rate is 409.0 – more than double the rate as traditionally calculated.



Calculating cancer incidence and mortality rates provides some sense of the burden of cancer in a population and allows comparisons between populations. Unfortunately, calculating rates is not practical among most tribal groups because of the very small numbers of cancer cases (the numerator) occurring among a small population (the denominator), which do not allow for calculation of meaningful rates. Instead, tribal health planners might be interested in accurate numbers of cases, for budgetary and program planning purposes, risk factor information for prevention purposes, as well as stage at diagnosis and rates of screening, because early detection can increase chances of long-term survival.

Risk Factors in the Northwest

Known modifiable risk factors for cancer include tobacco use, obesity, and an inactive lifestyle. As with other rural and minority populations, smoking and obesity are found in high proportions in Indian communities, including Northwest Native communities.

While the United States as a whole has enjoyed vast improvements over the last decade in its rates of tobacco-related death and disease, many minority populations, including AI/ANs, have not shared in this success. In a 2001 survey of enrolled members of the tribes of Oregon, Idaho, and Washington, 41.8% of tribal members currently smoked; 69.0% had ever been smokers. In Washington, the Northwest state with the highest prevalence of smoking, only 21.7% of the general population were smokers in 2001, and 49.3% had ever smoked. Commercial tobacco use is now known to cause lung cancer, laryngeal cancer, oral cavity and pharyngeal cancers, esophageal cancer, pancreatic cancer, renal cell, renal pelvis, and bladder cancers, cervical cancer, stomach cancer, acute leukemia, and has been associated with colorectal cancer and liver cancer. In addition, studies have linked secondhand smoke to heart disease, respiratory problems, and many types of cancers, including lung cancers, cervical cancer and bladder cancer.

In addition, obesity, estimated using a body mass index (bmi) of 30 or higher, was common among Northwest tribal members. Almost half (47.4%) of survey respondents in 2001 were obese, compared with 18.8% of the Oregon general population, and even lower percentages in the general population in Washington and Idaho. In addition to increasing the risk of coronary heart disease, stroke, high blood pressure, and diabetes, obesity increases the risk of cancers of the breast (postmenopausal), endometrium (the lining of the uterus), colon, kidney, and esophagus.

Further, a majority of tribal respondents (61.4%) did not have any regular physical activity. Regular physical activity can improve health by: helping to control weight, maintaining healthy bones, muscles and joints, reducing the risk of developing high blood pressure and diabetes, promoting psychological well-being, reducing the risk of death from heart disease, and reducing the risk of premature death. In addition to these health benefits, researchers are learning that physical activity can also affect cancer risk. There is convincing evidence that physical activity is associated with a reduced risk of cancers of the colon and breast. Several studies also have reported links between physical activity and a reduced risk of cancers of the prostate, lung, and lining of the uterus (endometrial cancer).

The following table illustrates the high risk factors for cancer among Northwest tribal members, summarizing the data described above, specifically the percent of adult respondents to the Northwest Tribal Behavioral Risk Factor Surveillance System (BRFSS) survey and the BRFSS in Oregon, Washington, and Idaho who reported selected behavioral risk factors for cancer in 2001.



Table 1. Percent of adult respondents to the Northwest Tribal Behavioral Risk Factor Surveillance System (BRFSS) survey and the BRFSS in Oregon, Washington, and Idaho who reported selected behavioral risk factors for cancer, 2001

| Risk Factor | Tribal BRFSS ^a | Oregon general population ^b | Washington general population ^b | Idaho general population ^b |
|---|--------------------------------------|--|--|---------------------------------------|
| | Percent (95% Confidence Interval) | | | |
| Ever smoked ^c | 69.0 (66.1, 71.8) | 49.0 (48.0, 50.0) | 49.3 (48.3, 50.3) | 45.5 (44.2, 46.9) |
| Current smoking ^d | 41.8 (38.8, 44.9) | 20.9 (20.2, 21.7) | 21.7 (20.9, 22.5) | 20.9 (20.0, 21.8) |
| Obese ^e | 47.4 (44.3, 50.5) | 18.8 (17.8, 19.9) | 17.2 (16.3, 18.2) | 17.6 (16.6, 18.6) |
| No regular physical activity ^f | 61.4 (58.3, 64.3) | Not available | Not available | Not available |

^a Results from face-to-face interviews of a random sample of tribal enrollees in the Northwest; funded by the CDC.

^b Results from telephone surveys conducted at the state level and organized by the Centers for Disease Control and Prevention (CDC).

^c Respondents who reported smoking at least 100 cigarettes in their lifetime.

^d Respondents who had smoked at least 100 cigarettes and reported current smoking.

^e Based on self-reported height and weight; obesity is defined as having a body mass index (BMI) ≥ 30 .
 $BMI = (Weight \text{ in Pounds} / ((Height \text{ in inches}) \times (Height \text{ in inches}))) \times 703$.

^f Based on self-reported type and frequency of physical activity; state BRFSS includes questions about physical activity but those questions were asked differently and are not comparable to the Tribal BRFSS.

Source: Romero F, Hasty F, Rose R, et al. *Northwest Tribal Behavioral Risk Factor Surveillance System (BRFSS) Project, Aggregate Final Report*. Portland, OR: Northwest Portland Area Indian Health Board; 2003.

Health professionals may be able to influence these risk factors by counseling patients. Of the Northwest Tribal BRFSS respondents who reported current tobacco use (smoking or chewing), 48.7 % said that a health professional had advised them to quit. Among all respondents, 29.3% said that a health professional had advised them to increase physical activity or exercise.

Cancer Incidence in the Northwest

Between 1996 and 1999, an average of 372 AI/AN cancer cases were diagnosed each year in the Northwest, with an overall cancer incidence rate of 409.0 per 100,000 (95% CI = 362.1 – 455.9). This rate was lower than for all races combined in Oregon, Idaho, and Washington, where the overall cancer incidence rate was 467.7 (463.4 – 472.0). Incidence was higher for AI/AN men (474.6 per 100,000) than for AI/AN women (367.7 per 100,000). In spite of lower incidence rates, AI/ANs tend to be diagnosed at later stages than Non-Hispanic Whites, which affects their quality of life and survival. In a similar period, only 39.3% of all AI/AN cancers were diagnosed during early stages (in situ or local), compared with 49.4% of White cases. Results were similar for screenable cancers, including breast, prostate, and colorectal.

Consistent with late-stage cancer diagnoses, survival rates for AI/ANs are worse than for other populations. In one Northwest registry, only 45% of AI/ANs survived 5 years after the diagnosis of cancer. A number of characteristics are associated with poorer survival: age (fifty and older) at diagnosis; lack of surgery or chemotherapy treatment; male sex; late-stage diagnosis; and blood quantum greater than fifty percent. Although blood quantum may be a marker for sociologic and/or biologic factors, it is clearly a component of importance and one that should continue to direct cancer prevention activities.



Breast cancer

Breast cancer is the type of cancer with the highest incidence among Northwest AI/AN women at a rate of 99.2 per 100,000 (95% CI 71.5 – 126.8). While this rate is lower than the rate of 140.0 (136.8 – 143.2) for the all-races population in the Northwest, it is substantially higher than rates published earlier using methods that undercount AI/ANs due to racial misclassification.

Some risk factors for breast cancer in American Indian women (including obesity, which is related to post-menopausal breast cancer) appear to be more prevalent in AI/ANs than in non-Natives. Mammography is not readily available at most Indian clinics in the Northwest, and the observed lower incidence rates may be related to less access to screening, resulting in under-ascertainment. The data on stage of disease at diagnosis also lend urgency to efforts aimed at increasing the availability of mammography among tribal communities.

Colorectal cancer

Colorectal cancer incidence rates are higher for AI/AN men and women than for the general population in the Northwest. For AI/AN men, colorectal cancer incidence is 68.5 per 100,000 (95% CI 34.7 – 102.3) compared with 58.2 (55.9 – 60.5) for men in the Northwest general population. For AI/AN women, the rate is 44.3 (23.2 – 65.3), compared with 43.2 (41.5 – 45.0) in the general female population. These recent data contradict earlier estimates, which reflected approximately half these rates.

The high prevalence of obesity in some of the tribes suggests that high dietary fat consumption, low dietary fiber intake, and low levels of exercise may contribute to colorectal cancer among tribal people.

Prostate cancer

Prostate cancer is the most commonly reported cancer diagnosis among Northwest AI/AN males. For AI/AN men, the rate of prostate cancer incidence is 107.9 per 100,000 (95% CI 67.7 – 148.0). For the male general population in the three Northwest states, prostate cancer incidence is 156.9 per 100,000 (153.2 – 160.6). Screening practices for prostate cancer appear to vary widely in the diverse AI/AN health centers in the three states.

Lung cancer

Lung cancer incidence rates in Northwest AI/ANs are similar to those for the Northwest general population. For AI/AN men, the lung cancer incidence rate is 78.0 per 100,000 (95% CI 47.4 – 108.7), slightly less than the rate among men in the general population, 83.7 (80.9 – 86.4). The lung cancer incidence rate is lower for AI/AN women, at 58.0 (34.5 – 81.4), than for AI/AN men, but slightly higher than in the female general population, at 56.0 (54.0 – 58.0). This finding is somewhat surprising given the high prevalence of cigarette use among tribal members as assessed by surveys in Northwest tribes. In a 2002 tribal survey, 42% of AI/ANs reported smoking cigarettes.

Cancer Screening in the Northwest

The screening tests for breast, cervical, and colorectal cancers have reduced mortality from those diseases by detecting the cancers before symptoms show. Screening tests for prostate cancer – digital rectal examinations and prostate-specific antigen tests – have not shown the same levels of benefits and are often offered only to men who are known to be at higher risk for developing prostate cancer.



Most clinics serving primarily AI/AN patients in the Northwest cannot provide screenings such as mammograms and colonoscopies onsite and must refer patients to private contractors for those services. Many clinics provide onsite Pap tests and clinical breast exams. Many also provide their clients with fecal occult blood test cards to take home and return later.

In a 2001 survey of enrolled members of tribes in Oregon, Idaho, and Washington, only 19% of adults 50 and older reported having a fecal occult blood stool test in the preceding year. (Respondents were asked only if they had received the test, not whether they had completed it.) A larger proportion, 27.5%, reported having a sigmoidoscopy within the previous five years. In the same survey, 80% of eligible females had been screened for cervical cancer in the previous three years, and 62.1% of women 40 and older said they had gotten a mammogram in the previous two years.

Screening levels in this survey were all lower for tribal respondents than for the general populations of Oregon and Washington at a statistically significant level. These levels were similar to screening for the general population in Idaho. It should be noted in making these comparisons that the tribal survey was conducted in person, while state surveys are administered over the phone using random-digit dialing.

The following table illustrates the percent of adult respondents to the Northwest Tribal Behavioral Risk Factor Surveillance System (BRFSS) survey and the BRFSS survey in Oregon and Washington who reported having been screened for cancer, 2001.

Table 2. Percent of adult respondents to the Northwest Tribal Behavioral Risk Factor Surveillance System (BRFSS) survey in selected American Indian tribes in the Northwest and the BRFSS survey in Oregon, Washington, who reported having been screened for cancer, 2001

| | Tribal BRFSS ^a | Oregon general population ^b | Washington general population ^b | Idaho general population ^b |
|--|--------------------------------------|--|--|---------------------------------------|
| Screening | Percent (95% Confidence Interval) | | | |
| Respondents 50 years and older who reported having a fecal occult blood stool test in the last year ^c | 19.0 (14.6, 24.4) | 24.6 (22.6, 26.8) | 27.6 (25.8, 29.5) | 16.7 (15.3, 18.3) |
| Respondents 50 years and older who reported having a sigmoidoscopy in the last five years | 27.5 (22.3, 33.4) | 35.8 (33.6, 38.2) | 37.5 (35.6, 39.6) | 30.8 (29.1, 32.7) |
| Male respondents 50 years and older who reported ever having a prostate-specific antigen (PSA) test | 54.2 (44.2, 63.8) | Not available | Not available | Not available |
| Female respondents ^d who reported having a Pap test within the last three years | 80.0 (76.0, 83.4) | 86.4 (84.7, 88.2) | 86.2 (85.2, 87.3) | 81.7 (80.2, 83.2) |
| Female respondents 40 years and older who reported having a mammogram within the last two years | 62.1 (56.2, 67.7) | 75.1 (73.3, 77.0) | 73.2 (70.8, 75.6) | 64.8 (62.5, 67.3) |

^a Results from face-to-face interviews of a random sample of tribal enrollees in the Northwest; funded by the CDC.

^b Results from telephone surveys conducted at the state level and organized by the Centers for Disease Control and Prevention (CDC).

^c Note that respondents were asked only if they had had a fecal occult blood stool test, and not whether they had completed the test. Anecdotally, clinicians report low completion rates for these tests.

^d Excluding women who have had hysterectomies.

Source: Romero FC, Hasty F, Rose R, Charles K, Jimmicum C, Seth L, Jones T, Alvarez S, Keegan E, Becker T, Ramsey K, Smith N, King J, Romero MD, McDavid K. Northwest Tribal Behavioral Risk Factor Surveillance System (BRFSS) Project, Aggregate Final Report. Portland, OR: Northwest Portland Area Indian Health Board, 2003.



For clinics that use the IHS-standard Resource and Patient Management System (RPMS) for electronic chart abstraction, the Clinical Reporting System (formerly GPRA+) is a tool for ascertaining how many eligible patients are accessing cancer screening at the clinic.

In closing, it is important to note that the Indian Health Service is significantly under-funded and over-burdened with need. An investigation by the Government Accountability Office in September 2005 concluded: “American Indians often do not have adequate access to healthcare.” Transportation, long wait times, few specialists, and rural geography further contribute to poor access to cancer services.



Comprehensive Cancer Control Plan: Objectives, Strategies & Evaluation

The following is a comprehensive, community-driven plan developed to address the growing cancer problem among the tribes of the NPAIHB. The purpose of this Plan is to prioritize issues that affect the full continuum of cancer: cancer prevention, early detection, diagnosis, treatment, recovery, quality of life and palliative care. The experiences of those who are diagnosed with this disease, as well as the issues of their family members and loved ones were considered by the coalition in the Plan's creation. The Plan prioritizes community-based strategies to address these issues through culturally appropriate and geographically relevant interventions. Care was also taken to ensure integration of a comprehensive evaluation schematic to track progress and success specific to each recommendation in the plan and the community.

Coalition members developed the template for the plan, organizing prevention, early detection and screening, diagnosis and treatment, rehabilitation, palliation, and survivorship activities around five identified cancer sites: lung, breast, cervical, colorectal, and prostate. The plan also now includes two additional sections for other cancers, including childhood cancers. The Coalition chose a familiar and easy to use matrix layout for the plan, with cells for short and long term goals, objectives, strategies (activities), as well as data to measure and outcome measures for evaluative purposes.

Planning for the next twenty years of comprehensive cancer control is a challenging task. Many changes in science, medicine, technology, and society will occur over that period. The Twenty-year Plan, "Working Toward Cancer-free Tribal Communities," presented here, has incorporated a number of mechanisms that will allow flexibility for the future. Strategies in the plan will lead to assessment and re-evaluation, and then adjustments to keep the plan on track. In addition, the matrix includes a workable long-term evaluation plan that uses cycles of review to keep the plan up to date with changes that will surely occur over time. The Centers for Disease Control recommend this Framework for Comprehensive Cancer Prevention and Control to serve this purpose (Abed et al., 2000).

The objectives in the following seven tables are measurable aims that together will lead toward the goal of approaching cancer-free tribal communities. To the right of each objective is a set of strategies to help reach the objective, and to the right of each set of strategies is a set of evaluations, to test whether the strategies were effective.

Strategies are the actions that will be taken to reduce the cancer burden for American Indians and Alaskan Natives. A "strategy is a means to accomplish an objective, which in turn is a means of achieving a goal. A strategy may be a health intervention on an individual or population level, but can also refer to such things as a systems change initiative (e.g., education or legislation) or further data collection." (Hare et al., 1999)

Evaluation is the method for determining whether change has occurred as the result of a strategy. First, base-line data will be collected to establish a starting point against which progress can be measured. For tribes that are using the Resource Patient Management System and Government Performance Reporting Act (GPRA) indicators there are numerous reports and datasets that can be extracted for base-line measures. Tribes that are not tracking these measures have an option to use the NPAIHB Tribal BRFSS, state, or county data to create baseline measures for future comparisons.

Additional data collections will take place at intervals to see whether change is occurring, and whether it is in the desired direction. Some of these data will be used to measure the effectiveness of program operations (process evaluation), so that programs can be altered if they are not working as expected. For example, if data



showed no change as the result of a media program to increase awareness of a tobacco cessation service, then the media program could be changed or eliminated.

Data will also inform outcome evaluation, which measures change in knowledge, attitudes, behavior, and status of program participants. An example of outcome data would be an increase in the number of tribal members who receive screening for colorectal cancer. An example of a short term evaluation would be counting the number of participants in a cancer prevention program, to see if this number increased as a result of some promotional activity. A long-term evaluation would look at reduction in deaths as a result of a multiple-year effort to reduce cancer.

The following seven tables present our short and long term goals, objectives, strategies, as well as identified evaluative measures for prevention, early detection and screening, diagnosis and treatment, rehabilitation, palliation, and survivorship for lung, breast, cervical, colorectal, prostate and other cancers for Northwest Tribal Communities.





Table 1. Sample Breast Cancer Objectives for Tribal Cancer Planning

| # | Objective | |
|---|---|--|
| | Strategy | Evaluation |
| 1 | Increase awareness of the risk factors for breast cancer. <ul style="list-style-type: none"> Implement community education campaigns (mentoring, media, tribal leaders) Implement community awareness campaigns Plan a “women’s health fair” to distribute information about breast health Plan an activity in connection with Breast Cancer Awareness Month (October) Implement Pink Shawl Program | <ul style="list-style-type: none"> Conduct BRFSS to assess change in level of awareness of risk factors Health fair attendance |
| | | <ul style="list-style-type: none"> BRFSS |
| 2 | Increase the percentage of AI/AN women who receive regular breast cancer screenings <ul style="list-style-type: none"> Support the development and distribution of educational material promoting the importance of regular breast screenings Provide culturally-sensitive education to Primary Care Providers (PCPs) for counseling of patients Provide transportation to screening Provide incentive to get exam Provide childcare services | <ul style="list-style-type: none"> Survey PCPs GPRA |
| | | <ul style="list-style-type: none"> GPRA |
| 3 | Increase collaboration with Statewide Breast and Cervical Cancer Early Detection Programs (BCCEDP) <ul style="list-style-type: none"> Integrate Breast and Cervical Cancer Early Detection Programs into cancer plan implementation activities Collaborate with the State Breast and Cervical Cancer Partnerships and others on shared priorities | <ul style="list-style-type: none"> Increase in women screened through BCCEDP |
| | | <ul style="list-style-type: none"> BCCEDP |
| 4 | Increase the number of tribal Breast and Cervical Cancer Early Detection Programs <ul style="list-style-type: none"> Support efforts by non-funded tribal organizations to secure funding to develop Breast and Cervical Cancer Early Detection Programs | <ul style="list-style-type: none"> Number of new programs |
| | | <ul style="list-style-type: none"> number of programs |
| 5 | Increase the number of women diagnosed with breast cancer who have access to appropriate treatment. <ul style="list-style-type: none"> Educate PCPs to refer women for breast cancer treatment services Organize community members to provide transportation for women needing daily or weekly treatments | <ul style="list-style-type: none"> Record number of PCPs receiving information Count rides given to treatment facilities Record change in percentage of persons receiving treatment |
| | | <ul style="list-style-type: none"> Navigator Program records Chart Audit |

| | | | | |
|----------|--|---|---|--|
| 6 | Increase payment coverage of screening and treatment of breast cancer | <ul style="list-style-type: none"> Educate policy-makers about the importance for government or insurance coverage of costs of mammograms and treatment of breast cancer | <ul style="list-style-type: none"> Obtain baseline measure of how screening and treatment are paid Record # of policy-makers educated about the importance of payment coverage | <ul style="list-style-type: none"> Contract Health Chart Audit |
| 7 | Increase available support and quality of life for women being treated for and survivors of breast cancer | <ul style="list-style-type: none"> Organize a breast cancer support group | <ul style="list-style-type: none"> Obtain baseline measure of number of women eligible to attend support group Survey for quality of life of support group members Number of women attending the support group | <ul style="list-style-type: none"> Chart Audit |
| 8 | Increase available support to caregivers of women living with breast cancer | <ul style="list-style-type: none"> Provide training to caregivers Organize a caregivers' support group | <ul style="list-style-type: none"> Obtain baseline measure of number of potential caregivers Survey for knowledge of care giving and quality of life Record the number of caregivers who receive training Assess for change in knowledge of care giving Record the number of caregivers who attend the support group Assess for quality of life | <ul style="list-style-type: none"> Survey Survivors Training rosters Pre/Post test eval |





Table 2. Sample Cervical Cancer Objectives for Tribal Cancer Planning

| # | Objective | Evaluation | Data |
|----|--|--|--------------------------------------|
| 9 | Increase awareness of the risk factors for cervical cancer | | |
| | Implement community education campaigns (mentoring, media, tribal leaders) | Conduct BRFSS to assess change in level of awareness of risk factors Health fair attendance | BRFSS |
| | Implement community awareness campaigns | | |
| | Plan a “women’s health fair” to distribute information about cervical health | | |
| | Plan an activity during Cervical Cancer Awareness Month (January) | | |
| 10 | Increase awareness among AI/AN of the relationship between Human Papiloma Virus (HPV) and cervical cancer and availability of vaccinations. | | |
| | Develop media messages on HPV vaccinations and cancer. Partner with IHS and State Vaccine for Children programs | Number of families educated about HPV Number of children vaccinated through State Childhood Immunization Programs | State Childhood Immunization records |
| 11 | Increase the percentage of AI/AN women who receive regular pap tests | | |
| | Support the development and distribution of educational material promoting the importance of regular pap tests | Survey PCPs GPRA | GPRA |
| | Provide culturally-sensitive education to PCPs for counseling of patients | | |
| | Provide transportation to screening | | |
| | Provide incentive to get exam Provide childcare services | | |
| 12 | Increase collaboration with Statewide Breast and Cervical Cancer Early Detection Programs (BCCEDP) | | |
| | Integrate Breast and Cervical Cancer Early Detection Programs into cancer plan implementation activities Collaborate with the State Breast and Cervical Cancer Partnerships and others on shared priorities | Increase in women screened through BCCEDP | BCCEDP |
| 13 | Increase the number of tribal Breast and Cervical Cancer Early Detection Programs | | |
| | Support efforts by non-funded tribal organizations to secure funding to develop Breast and Cervical Cancer Early Detection Programs | Number of new programs | number of programs |

| | | | | |
|-----------|--|---|---|--|
| 14 | Increase the number of women diagnosed with cervical cancer who have access to appropriate treatment | <ul style="list-style-type: none"> Educate PCPs to refer women for cervical cancer treatment services Organize community members to provide transportation for women needing daily or weekly treatments | <ul style="list-style-type: none"> Record number of PCPs receiving information Count rides given to treatment facilities Record change in percentage of persons receiving treatment | <ul style="list-style-type: none"> Navigator Program records Chart Audit |
| 15 | Increase payment coverage of screening and treatment of cervical cancer | <ul style="list-style-type: none"> Educate policy-makers about the importance for government or insurance coverage of costs of PAP tests and treatment of cervical cancer | <ul style="list-style-type: none"> Obtain baseline measure of how screening and treatment are paid Record # of policy-makers educated about the importance of payment coverage | <ul style="list-style-type: none"> Contract Health Chart Audit |
| 16 | Increase available support and quality of life for women being treated for and survivors of cervical cancer | <ul style="list-style-type: none"> Organize a cervical cancer support group | <ul style="list-style-type: none"> Obtain baseline measure of number of women eligible to attend support group Survey for quality of life of support group members Number of women attending the support group | <ul style="list-style-type: none"> Chart Audit |
| 17 | Increase available support to caregivers of women living with cervical cancer | <ul style="list-style-type: none"> Provide training to caregivers Organize a caregivers' support group | <ul style="list-style-type: none"> Obtain baseline measure of number of potential caregivers Survey for knowledge of care giving and quality of life Record the number of caregivers who receive training Assess for change in knowledge of care giving Record the number of caregivers who attend the support group Assess for quality of life | <ul style="list-style-type: none"> Survey Survivors Training rosters Pre/Post test eval |





Table 3. Sample Colorectal Cancer Objectives for Tribal Cancer Planning

| # | Objective | Sample Objectives for Tribal Cancer Planning | |
|----|--|--|--|
| | | • Evaluation | • Data |
| 18 | Increase awareness of the risk factors for colorectal cancer | <ul style="list-style-type: none"> • Implement community education campaigns (mentoring, media, tribal leaders) • Implement community awareness campaigns • Plan a “family health fair” to distribute information about colorectal health • Plan an activity in connection with Colorectal Cancer Awareness Month (March) | <ul style="list-style-type: none"> • Conduct BRFSS to assess change in level of awareness of risk factors • BRFSS |
| | | | <ul style="list-style-type: none"> • Health fair attendance |
| 19 | Increase the percentage of persons who receive age appropriate screening for colorectal cancer (FOBT, sigmoidoscopy, colonoscopy) | <ul style="list-style-type: none"> • Provide incentive to get exam • Provide transportation to clinic site • Survey the capacity of facilities to provide colorectal cancer screening • Support programs to train mid-level providers to perform flexible sigmoidoscopy/colonoscopy and to establish ongoing screening programs in regional facilities • Support programs to diagnose colorectal cancer stages and reduce or eliminate unnecessary preoperative chemotherapy and radiation treatment • Increase A/AN specific colorectal cancer screening education to make sure that comprehensive, culturally appropriate media messages reach the intended audience • Investigate innovative ways of organizing healthcare providers to enhance screening rates in rural communities | <ul style="list-style-type: none"> • Obtain baseline measures on percentage who receive screening • Record number who receive incentive to get screening • Count rides given to screening facilities • Record change in the number of persons who receive diagnostic tests for colorectal cancer • Number of PCPs who receive training in performing colonoscopy /or sigmoidoscopy • GPRA • Chart Audit • Provider Survey • IHS |
| | | | |
| 20 | Increase access to appropriate treatment for colorectal cancer | <ul style="list-style-type: none"> • Educate PCPs to refer persons for colorectal cancer services • Provide transportation to treatment site | <ul style="list-style-type: none"> • Number of PCPs receiving information • Count rides given to treatment facilities • Record change in number of persons receiving treatment • Navigator Program records • Chart Audit |
| | | | |

| | | | | |
|----|--|--|---|--|
| 21 | Increase payment coverage of screening and treatment of colorectal cancer | <ul style="list-style-type: none"> Educate policy-makers about the importance for government or insurance coverage of colorectal cancer screening and treatment | <ul style="list-style-type: none"> Obtain baseline measure of how screening and treatment are paid Record # of policy-makers educated about the importance of payment coverage | <ul style="list-style-type: none"> Contract Health Chart Audit |
| 22 | Increase available support and quality of life for those being treated for and survivors of colorectal cancer | <ul style="list-style-type: none"> Organize a colorectal cancer support group | <ul style="list-style-type: none"> Obtain baseline measure of number of women eligible to attend support group Survey for quality of life of support group members Number attending the support group | <ul style="list-style-type: none"> Chart Audit |
| 23 | Increase available support to caregivers of those living with colorectal cancer | <ul style="list-style-type: none"> Provide training to caregivers Organize a caregivers' support group | <ul style="list-style-type: none"> Obtain baseline measure of number of potential caregivers Survey for knowledge of care giving and quality of life Number of caregivers who receive training Assess for change in knowledge of care giving Number of caregivers who attend the support group Assess for quality of life | <ul style="list-style-type: none"> Survey Survivors Training rosters Pre/Post test eval |





Table 4. Sample Prostate Cancer Objectives for Tribal Cancer Planning

| # | Objective | |
|----|--|--|
| | Strategy | Evaluation |
| 24 | Increase awareness of the risk factors for prostate cancer | |
| | <ul style="list-style-type: none"> Implement community education campaigns (mentoring, media, tribal leaders) Implement community awareness campaigns Plan a “men’s health fair” to distribute information about cervical health Plan an activity during Prostate Cancer Awareness Month (September) | <ul style="list-style-type: none"> Conduct BRFSS to assess change in level of awareness of risk factors Health fair attendance BRFSS Health fair roster |
| 25 | Increase awareness of the importance of making an informed decision about having a digital rectal exam and PSA blood test for early detection of prostate cancer | |
| | <ul style="list-style-type: none"> Develop community awareness campaign Plan a “men’s health day” to distribute information about prostate health Plan an activity in connection with Prostate Cancer Awareness Month (September) | <ul style="list-style-type: none"> Activities of awareness campaign Number of persons served at men’s health day Measure awareness of importance of screening Survey community for change in level of awareness BRFSS Health fair roster |
| 26 | Increase access to appropriate treatment for prostate cancer | |
| | <ul style="list-style-type: none"> Educate PCPs to refer men for prostate cancer services Provide transportation to treatment site | <ul style="list-style-type: none"> Number of PCPs receiving information Count rides given to treatment facilities Change in number of persons receiving treatment Navigator Program records Chart Audit |
| 27 | Increase payment coverage of diagnosis and treatment of prostate cancer | |
| | <ul style="list-style-type: none"> Educate policy-makers about the importance for government or insurance coverage of costs of screening and treatment of prostate cancer | <ul style="list-style-type: none"> Obtain baseline measure of how screening and treatment are paid Number of policy-makers educated Survey PCPs for change from private parties to insurance or public entities Contract Health Clinic Survey |

| | | | | |
|----|---|--|---|--|
| 28 | <p>Increase available support and quality of life for those being treated for and survivors of prostate cancer</p> | <ul style="list-style-type: none"> Organize a prostate cancer support group | <ul style="list-style-type: none"> Obtain baseline measure of number of men eligible to attend support group Survey for quality of life of support group members Number attending the support group | <ul style="list-style-type: none"> Chart Audit |
| 29 | <p>Increase available support to caregivers of those living with prostate cancer</p> | <ul style="list-style-type: none"> Provide training to caregivers Organize a caregivers' support group | <ul style="list-style-type: none"> Obtain baseline measure of number of potential caregivers Survey for knowledge of care giving and quality of life Number of caregivers who receive training Assess for change in knowledge of care giving Number of caregivers who attend the support group Assess for quality of life | <ul style="list-style-type: none"> Survey Survivors Training rosters Pre/Post test eval |





Table 5. Sample Lung Cancer Objectives for Tribal Cancer Planning

| # | Objective | | |
|-----------|--|---|--|
| | • Strategy | • Evaluation | • Data |
| 30 | Increase awareness of the risk factors for lung cancer | | |
| | <ul style="list-style-type: none"> Implement community education campaigns (mentoring, media, tribal leaders) | <ul style="list-style-type: none"> Number of people who received information on risk factors Conduct Tribal BRFSS | <ul style="list-style-type: none"> BRFSS |
| 31 | Contribute to the knowledge and understanding of the risk of tobacco use among AI/AN to tribal leadership and communities | | |
| | <ul style="list-style-type: none"> Present research findings and evidence based best practices to tribal leadership at local, regional and statewide gatherings and conferences | <ul style="list-style-type: none"> Regional Tobacco Policy Conference attendance | |
| 32 | Increase percentage of PCPs and dentists who ask patients 6 years and older about tobacco use at every visit | | |
| | <ul style="list-style-type: none"> Provide culturally-sensitive education to PCPs for counseling of patient | <ul style="list-style-type: none"> Survey PCPs Number of providers who receive information Yearly chart audit to see if rate changes | <ul style="list-style-type: none"> Chart Audit Survey to Providers |
| 33 | Reduce the percentage of adult current tobacco users | | |
| | <ul style="list-style-type: none"> Promote a ban on advertising of tobacco products Implement a community education campaign (mentoring, media, tribal leaders) Establish tribal anti-tobacco councils Increase cost of tobacco products Promote smoke-free environments in tribal communities Encourage community event to be commercial tobacco free | <ul style="list-style-type: none"> Obtain baseline data on use from BRFSS/YTS Obtain baseline data on media advertising efforts Report of activities of tribal anti-tobacco councils Report on tobacco product price Survey media for changes in frequency of advertising Survey users for change in percentage of adult current tobacco users and those who intend to quit within six months | <ul style="list-style-type: none"> BRFSS Tribal BRFSS Oregon Healthy Teens YTS |

| | | | |
|------------------|---|--|--|
| <p>34</p> | <p>Reduce percentage of youth under 18 years who have ever tried tobacco products</p> <ul style="list-style-type: none"> • Increase A/AN specific tobacco control media and education initiatives addressing youth to assure comprehensive, culturally appropriate messages reach the intended audience • Develop and assess the efficacy of A/AN specific tobacco use interventions for youth, to assure comprehensive, culturally appropriate education efforts • Improve systems to have health care providers ask each patient, including parents of young children and youth, at each visit if they use tobacco and if tobacco is used in their homes, to determine their readiness to quit and advise them accordingly • Form parent support group • Encourage tribal health programs to continue to collaborate with local community providers and schools to use established tobacco cessation curriculums for youth, including CDC endorsed curriculums • Provide community technical assistance in addressing tobacco control issues targeting youth | <ul style="list-style-type: none"> • Conduct BRFSS/YTS • Record curriculum addition • Count parents who attend support group • Count media program contacts • Count number of youths educated about ritual use • Number of tribal health programs collaborating with local providers | <ul style="list-style-type: none"> • YTS • Oregon Health Teens • Parent support group rosters |
| <p>35</p> | <p>Reduce smoking among pregnant women</p> <ul style="list-style-type: none"> • Develop community awareness campaign • Target WIC and First Steps users • Provide education materials to Primary Care Providers | <ul style="list-style-type: none"> • BRFSS/YTS for baseline data • Number of pregnant women contacted about smoking • Survey pregnant women for changes in smoking patterns | <ul style="list-style-type: none"> • Birth certificate files • Tribal activity log |
| <p>36</p> | <p>Reduce the percentage of adult tobacco smokers</p> <ul style="list-style-type: none"> • Ensure that all A/AN who wish to stop using tobacco have access to evidence based cessation interventions • Increase A/AN specific tobacco control initiatives to assure comprehensive, culturally appropriate media messages reach the intended audience • Support collaborative advocacy efforts to pass statewide clean indoor air policy • Support local communities' advocacy efforts to enact or retain clean indoor air policies | <ul style="list-style-type: none"> • BRFSS • Monitor state tobacco policy • Monitor local tobacco policy | <ul style="list-style-type: none"> • BRFSS • State tobacco policy • Local Tobacco policy |



| | | | |
|----|--|--|---|
| 37 | <p>Increase availability of tobacco use cessation services</p> <ul style="list-style-type: none"> Expand the number of health care providers offering nicotine dependence treatment Improve systems by which a provider can refer patients to nicotine dependence treatment Expand patient education and offer nicotine dependence treatment for patients receiving care Provide technical assistance to nicotine dependence treatment providers to bill Medicaid, Medicare and third party insurers for services | <ul style="list-style-type: none"> Obtain baseline data on existing cessation services Obtain report of use and success rates Count number of PCPs who treat Record successful attempts to obtain funding Survey for changes in number of existing cessation services | <ul style="list-style-type: none"> State quitlines number of AI/AN users |
| 38 | <p>Increase awareness of tobacco use cessation services</p> <ul style="list-style-type: none"> Develop media campaign to increase awareness Develop and distribute a listing of tobacco cessation services | <ul style="list-style-type: none"> Obtain baseline data from YTS Count media campaign contacts Survey for changes in awareness of cessation services | <ul style="list-style-type: none"> YTS Tribal activity log |
| 39 | <p>Increase environmental tobacco smoke (ETS) free homes and daycare sites</p> <ul style="list-style-type: none"> Implement a community education campaign (mentoring, media, tribal leaders) | <ul style="list-style-type: none"> Tribal BRFSS Count number of community areas with anti-ETS policies Yearly site visits by CHRs to obtain data on change in rates of ETS in homes and daycare sites | <ul style="list-style-type: none"> BRFSS |
| 40 | <p>Increase/strengthen environmental tobacco smoke (ETS) policy in tribal facilities</p> <ul style="list-style-type: none"> Institute a weekly smoke-free day at casinos Implement locally developed policies on clean indoor air in community areas Showcase efforts of early adopters | <ul style="list-style-type: none"> Obtain baseline data on ETS in community areas Random visits to ascertain compliance with request at casinos and community areas | <ul style="list-style-type: none"> Tribal activity log |
| 41 | <p>Increase enforcement of laws regulating sales of tobacco products to minors</p> <ul style="list-style-type: none"> Inform all local sellers of tobacco products about increased enforcement Implement protocol for reporting illegal sales without revealing identity of informant | <ul style="list-style-type: none"> Obtain baseline of state SYNAR records Observational survey to see change in compliance with law | <ul style="list-style-type: none"> SYNAR data |



| | | | |
|----|---|--|--|
| 42 | <p>Increase access to appropriate diagnosis and treatment of lung cancer</p> <ul style="list-style-type: none"> Educate PCPs to refer persons for lung cancer services Provide transportation to clinic or treatment site Provide incentive to get diagnosis/treatment Provide childcare | <ul style="list-style-type: none"> Survey PCPs on referrals Number of PCPs who receive information on how to refer Rides to treatment facilities Number of persons receiving incentive Yearly chart audit for change in number of persons receiving treatment | <ul style="list-style-type: none"> Navigator Program records Chart Audit |
| 43 | <p>Increase payment coverage of screening and treatment of lung cancer</p> <ul style="list-style-type: none"> Educate policy-makers about the importance for use of Tobacco Settlement money to fund diagnosis and treatment of lung cancer Educate policy-makers about the importance for government or insurance coverage of lung cancer treatment | <ul style="list-style-type: none"> Obtain baseline measure of how screening and treatment are paid Record # of policy-makers educated about the importance of payment coverage | <ul style="list-style-type: none"> Contract Health Chart Audit |
| 44 | <p>Increase available support and quality of life for those being treated for and survivors of lung cancer</p> <ul style="list-style-type: none"> Organize a lung cancer support group | <ul style="list-style-type: none"> Obtain baseline measure of number of women eligible to attend support group Survey for quality of life of support group members Number attending the support group | <ul style="list-style-type: none"> Chart Audit |
| 45 | <p>Increase available support to caregivers of those living with lung cancer</p> <ul style="list-style-type: none"> Provide training to caregivers Organize a caregivers' support group | <ul style="list-style-type: none"> Obtain baseline measure of number of potential caregivers Survey for knowledge of care giving and quality of life Number of caregivers who receive training Number of caregivers who attend the support group Assess for quality of life | <ul style="list-style-type: none"> Survey Survivors Training rosters Pre/Post test eval |





Table 6. Sample Childhood Cancer Objectives for Tribal Cancer Planning

| # | Objective | |
|-----------|--|---|
| | • Strategy | • Evaluation • Data |
| 46 | Increase the percentage of primary care providers (PCPs) who recognize childhood cancer signs | |
| | <ul style="list-style-type: none"> Educate PCPs about childhood cancer signs Promote idea within professional organizations | <ul style="list-style-type: none"> Survey PCPs Count number of PCPs who receive information on childhood cancers Survey to Providers |
| 47 | Increase access and referrals to appropriate treatment for childhood cancer | |
| | <ul style="list-style-type: none"> Educate PCPs to refer children to childhood cancer centers Provide transportation to treatment site Provide housing at treatment site | <ul style="list-style-type: none"> Record number of PCPs receiving information Rides to treatment facilities Count number of days housing provided to family Record change in number of persons receiving treatment Navigator Program records Chart Audit |
| 48 | Increase payment coverage for treatment of childhood cancer | |
| | <ul style="list-style-type: none"> Educate policy-makers about the importance for government or insurance coverage of costs of treatment of childhood cancer Educate PCP about high risk pool and family insurance assistance programs | <ul style="list-style-type: none"> Obtain baseline measure of how treatment is paid Record # of policy-makers educated about the importance of payment coverage Survey PCPs for change in payers from private parties to insurance or public entities Contract Health Clinic Survey |
| 49 | Increase available support to persons being treated for and survivors of childhood cancer | |
| | <ul style="list-style-type: none"> Organize a childhood cancer support group Refer to existing cancer support groups | <ul style="list-style-type: none"> Obtain baseline measure of number of persons eligible to attend support group Survey for quality of life before support group begins Survey of Childhood Cancer Survivors Support group roster |

| | | | |
|----|---|---|--|
| 50 | Increase available support to parents/caregivers of persons living with childhood cancer | | |
| | <ul style="list-style-type: none"> • Provide training to caregivers • Organize a parents and caregivers' support group • Survey existing resources • Refer parent/caregiver to existing resources | <ul style="list-style-type: none"> • Obtain baseline measure of number of potential caregivers • Survey for knowledge of care giving and quality of life • Record the number of caregivers who receive training • Assess for change in knowledge of care giving • Record the number of caregivers who attend the support group • Assess for quality of life | <ul style="list-style-type: none"> • Survey of Childhood Cancer Survivors • Caregiver training rosters • Pre/Port test eval |
| 51 | Increase education of school personnel and primary care providers about late and long term effects of childhood cancer | | |
| | <ul style="list-style-type: none"> • Partner with Leukemia & Lymphoma Society for Welcome Back program | <ul style="list-style-type: none"> • Baseline of childhood cancer survivors • Survey Knowledge of providers and teachers | <ul style="list-style-type: none"> • Survey of Providers • Survey of Teachers |





Table 7. Sample Cancer Objectives for Tribal Cancer Planning

| # | Objective | | |
|-----------|--|---|---|
| | • Strategy | • Evaluation | • Data |
| 52 | Increase Tribal Cancer Control Capacity | | |
| | <ul style="list-style-type: none"> Participate in Northwest Tribal Cancer Coalition | <ul style="list-style-type: none"> Coalition Evaluation | <ul style="list-style-type: none"> NTCCP Coalition Evaluation and Signin Sheets |
| 53 | Support the gathering and maintenance of data systems to understand the cancer related needs of AI/ANs. | | |
| | <ul style="list-style-type: none"> Support the efforts of the Northwest Tribal Registry Project to continue to gather and report cancer data on AI/ANs. Support the establishment of an Tribal family cancer risk registry to identify persons at high risk due to family history and predisposing conditions, and assure appropriate screenings and follow-up. Maintain a database of cancer research being undertaken among AI/ANs and secure additional funding for priority research needs. | <ul style="list-style-type: none"> Number of tribal data linkages Change in reclassified cancer cases Establishment of cancer registry | <ul style="list-style-type: none"> Tribal cancer registry Tribal registry linkage |
| 54 | Increase awareness of the risk factors for all cancers | | |
| | <ul style="list-style-type: none"> Implement a community education campaign (mentoring, media, tribal leaders) | <ul style="list-style-type: none"> Number of people who received information on risk factors BRFSS | <ul style="list-style-type: none"> BRFSS |
| 55 | Educate physicians on accessing clinical guidelines | | |
| | <ul style="list-style-type: none"> Plan, implement, and evaluate training for providers | <ul style="list-style-type: none"> Numhber of providers trained Training Evaluation | <ul style="list-style-type: none"> Training Responses |
| 56 | Increase the availability and effectiveness of culturally relevant cancer prevention & risk reduction materials and programs for AI/AN | | |
| | <ul style="list-style-type: none"> Create brochures, handouts, posters on healthy lifestyles for cancer prevention Develop educational materials to help AI/ANs learn to use familiar, inexpensive, and readily available foods to improve their diets and meet nutritional recommendations for cancer prevention Increase the number of health education materials that are presented in culturally appropriate ways | <ul style="list-style-type: none"> Native CIRCLE catalog inclusion Use satisfaction survey | <ul style="list-style-type: none"> Native CIRCLE |

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|-----------|---|--|--|--|
| 57 | Increase the proportion of AI/AN adults 18 and older who eat at least five servings of fruits & vegetables every day | <ul style="list-style-type: none"> Develop media messages aimed at AI/AN adults to increase their awareness of the importance of eating five or more servings of fruits & vegetables every day | <ul style="list-style-type: none"> BRFSS | <ul style="list-style-type: none"> BRFSS |
| 58 | Increase the proportion of AI/AN adults 18 and older who meet Healthy People 2010 recommendations for moderate and vigorous activity | <ul style="list-style-type: none"> Increase public awareness of the benefits of physical activity Increase the number of worksites that provide opportunities and policies that promote physical activity Promote physical activity in local communities Encourage communities to provide physical activity opportunities and establish policies that promote physical activity Partner with transportation and land use planners to increase walk-ability and bike-ability of communities Collaborate with faith organizations to increase opportunities for physical activity within their organization and for their entire community Develop and disseminate physical activity materials, including model physical activity prescription forms, for use by health professionals | <ul style="list-style-type: none"> BRFSS | <ul style="list-style-type: none"> BRFSS |
| 59 | Implement new cancer screening and early detection tests as they become recommended by national organizations | <ul style="list-style-type: none"> Track new screening and early detections test and recommendations | <ul style="list-style-type: none"> Number of new screening implemented | <ul style="list-style-type: none"> National Cancer Institute |
| 60 | Increase access to appropriate diagnosis and treatment for all cancers | <ul style="list-style-type: none"> Educate PCPs to refer persons for appropriate diagnostic and treatment services Provide transportation to treatment site | <ul style="list-style-type: none"> Record number of PCPs receiving information Count rides given to treatment facilities Record change in number of persons receiving treatment | <ul style="list-style-type: none"> Navigator Program records Chart Audit |
| 61 | Inform AI/AN cancer patients of the opportunity to participate in clinical trials | <ul style="list-style-type: none"> Determine availability/appropriateness of developing a formal relationship with an NCI designated comprehensive cancer center to assist in areas such as clinical trials. | <ul style="list-style-type: none"> Number of patients enrolled in clinical trials | <ul style="list-style-type: none"> NCI clinical trials |





Sample Objectives for Tribal Cancer Planning

| | | | | |
|----|---|---|---|---|
| 62 | Develop patient diagnostic and treatment services to reduce the need for cancer patients to travel to multiple locations and healthcare facilities for diagnosis and treatment | <ul style="list-style-type: none"> Determine the feasibility of developing a comprehensive cancer center. Support the development of the Oncology Support Program (OSP) to provide primary care and cancer support services for AI/AN who live outside urban areas who remain for cancer care. Incorporate complementary and integrative care into the program Encourage partnerships with in-state and out-of-state healthcare providers when treatment modalities are not available and when a cost/benefit analysis indicates that partnering is appropriate Assist tribal sites with training and physician consulting support so cancer patients can receive care closer to home | <ul style="list-style-type: none"> Economic analysis Number of partner organizations Examine distance patients travel for care | <ul style="list-style-type: none"> IHS Chart Audit NTCCP |
| 63 | Increase payment coverage of treatment of all cancers | <ul style="list-style-type: none"> Educate policy-makers about the importance for government or insurance coverage of costs of treatment of all cancers | <ul style="list-style-type: none"> Obtain baseline measure of how treatment is paid Number of policy-makers educated about payment coverage | <ul style="list-style-type: none"> Contract Health Clinic Survey |
| 64 | Establish a patient navigation program to ensure timely and efficient cancer care coordination | <ul style="list-style-type: none"> Establish a cancer patient tracking system to monitor long-term cancer side effects and recurrence. Identify collaborative and financial means to support establishing a coordinated patient navigation program Provide each cancer patient at the completion of treatment with an “end of treatment” summary | <ul style="list-style-type: none"> Number of new programs implemented Financial support for programs Patients receiving care summary | <ul style="list-style-type: none"> Patient navigation programs |
| 65 | Create and maintain interdisciplinary palliative care team | <ul style="list-style-type: none"> Assess resources available including: physician, nurse, pharmacist, social services, behavioral health, and spiritual support Invite participants from available disciplines Convene regular team meetings Provide training for palliative care team members | <ul style="list-style-type: none"> Survey of available resources Team roster Meeting schedule Trainings attended | <ul style="list-style-type: none"> Clinic Protocol |
| 66 | Create a palliative plan of care for cancer survivors | <ul style="list-style-type: none"> Comprehensive assessment of patient with guidance of interdisciplinary team Education patient and caregiver about the specific cancer and its care Address survivor goals, values, and needs | <ul style="list-style-type: none"> Patient Care Plan Survey of Patient and Family | <ul style="list-style-type: none"> Chart Audit |

| | | | | |
|-----------|--|---|--|--|
| 67 | Establish a palliative care program to provide support for dying at or near home | <ul style="list-style-type: none"> • Implement a modified <i>Helping Hands Program</i> • Develop culturally appropriate advance directives and education programs that adhere to all legal requirements and allow for a “natural” death • Establish a system wide grief and bereavement program • Assist families and clinics in identifying and establishing respite services • Develop culturally appropriate palliative care materials for providers, family members and community members | <ul style="list-style-type: none"> • End of life programs established • Count of those assisted | <ul style="list-style-type: none"> • Survey of Clinics |
| 68 | Develop a comprehensive survivorship program to support cancer survivors and address issues facing them | <ul style="list-style-type: none"> • Educate patients to reduce cancer risks through modification of behavioral risk factors • Maintain an updated cancer patient resource guide and cancer care support kit • Expand spiritual support for patients and families who are away from home for lengthy periods of time • Develop community based support groups working with patients and families of survivors to provide assistance to cancer patients returning home after cancer treatment • Offer training for individuals willing to facilitate cancer support groups. • Conduct a needs assessment of AI/AN cancer survivors • Develop a nutrition guide that recommends traditional and subsistence foods, which can be substituted for standard recommended healthy foods, for AI/AN patients during and after treatment • Collaborate with the Fred Hutchinson Cancer Research Center Survivorship Center of Excellence efforts to establish survivorship clinics | <ul style="list-style-type: none"> • Need assessments conducted • Number of programs established • Patients enrolled in program | <ul style="list-style-type: none"> • Chart Audit |
| 69 | Increase available support to caregivers of persons living with cancer | <ul style="list-style-type: none"> • Provide training to caregivers • Organize a caregivers’ support group • Partner with Cancer Navigator if available | <ul style="list-style-type: none"> • Obtain baseline measure of number of potential caregivers • Survey for knowledge of care giving and quality of life • Number who receive training • Assess for change in knowledge • Number of caregivers who attend the support group • Assess for quality of life | <ul style="list-style-type: none"> • Survey Survivors • Training rosters • Pre/Post test eval |



American Indian & Alaska Native Cultural Strengths

A “strengths-based” approach focuses on building and enhancing strengths of a community, rather than focusing on reducing or mitigating problems. (Nissen, 2001) Culture is a resource that shapes how people see their world and structure their community and family life.

The cultural strengths of American Indians and Alaskan Natives can act as protective factors that buffer the effects of cancer and illness, as well as enrich daily life under less stressful conditions (Hungary Smith, 2001; R. Jensen, personal communication, June 14, 2000; Oxendine, 2000; Ross, 2000). “Community traditions, and spiritual or religious healing or beliefs, play a major role in maintaining health and returning people to balance” (Baseline Measures Workgroup, 1996, p. 3).

Among these cultural strengths are a strong sense of family and community. Family and extended family relationships have influence in many areas, including the support and respect for children and the elderly. Family can be especially helpful in sharing in the care of the sick and administering medicines. Family members can remind each other to get appropriate cancer screening tests, and provide encouragement to follow up on symptoms of disease by getting an appointment to see a healthcare practitioner.

Strong connections exist between tribes; some of these connections have been formalized, as with the Affiliated Tribes of Northwest Indians (ATNI). In general, tribal members are interested in sharing information, resources and knowledge about what’s happening in the community. The wide dispersal of tribes outside urban areas means that some resources found at one location could be drawn in for use elsewhere.

Other values that draw together AI/AN people include a respect for tribal authority and other leaders, and a high value placed on preserving traditional ways. Ties to the land are important, as is the preservation of family and tribal histories. Traditional community events such as pow-wows, sports, and music also are cultural strengths that bring people together in the community. A further sense of community can be found in the spiritual belief in a Creator or higher power that is held by many AI/AN.

Traditional foods are another cultural strength. Many AI/AN have access to food sources, such as berries, roots, fish, wild game and fowl, not available in grocery stores. These are foods that are not sprayed with pesticides, have no additives, and in some cases provide physical activity in hunting and gathering and may help improve nutrition.

Many AI/AN take a holistic outlook on health, which may make a return to traditional ways of living and other healthy behaviors. Health may be viewed in relation to the Earth, and traditional medicines used. A preference for traditional medicines may make tribal healers a natural path for referring patients for cancer treatment. Healers can be strong advocates for their patients, explaining to other healthcare providers about cultural beliefs regarding health (for example, a focus on breast health, not breast cancer). Healers can be very helpful in advocating for improvement in health behaviors.

The existing network of health clinics is historically an achievement in the light of the poverty and stark living conditions experienced by the AI/AN population. The gains occurred in spite of chronically low funding and can be attributed to the combination of vision, stubbornness, and political savvy of the agency’s physician directors and the support of a handful of tribal leaders and powerful allies in the Congress and the White House. The issue of level of need funding is the real culprit.

Finally, a sense of humor is among the most important cultural strengths shared by American Indians and Alaska Natives. The ability to laugh and joke when life is difficult is a rare gift.



Behavior Change for Wellness (Evidence Based Interventions)

Although cancer cannot always be avoided, people can reduce their risk of getting cancer and other diseases by practicing healthy behaviors, as well as good health maintenance behaviors, such as cancer screenings (annual mammograms, for example). If, however, a person already has cancer or some other condition that threatens her or his health, risk reduction is still a good strategy for returning to health and preventing further illness.

Primary prevention (risk reduction) includes decreasing exposure to second-hand smoke, changing behaviors, such as smoking cessation, improving diet (eating 5 a day), increasing daily exercise, and practicing safe sexual behavior. Next to primary prevention, early detection and screening are vital to cancer control. Lack of information about cancer screening can lead to negative attitudes towards screening, as well as to fear and denial about its value. Since attitude change comes before behavioral change, it is important to work on strategies that change attitudes and increase screening behaviors. The screening tests for breast, cervical, and colorectal cancers have been shown to reduce mortality from those diseases by detecting the cancers before symptoms show.

Good behavioral targets are 1) related to health outcomes, 2) a good fit with community priorities (cultural factors), and 3) amenable to change (Bowen, 2001). You must change the context or setting in order to change behavior. In the example of tobacco use, change behaviors through changing cues (e.g. avoiding other people who smoke), changing supports (e.g., family-based and community-based interventions), offering “good” choices (e.g., public no-smoking areas), and changing awareness, knowledge, skills, and resources (e.g., through education and smoking cessation programs).

The socio-ecological approach to individual behavior change and maintenance argues that you can not separate the individual from his or her environment when contemplating and promoting individual behavior change. Healthy communities help support healthy behaviors by making it easier for people to practice them. They can set priorities that have an impact on multiple issues, rather than just one. “Evidence-based” activities (i.e., those backed by research) are the most reliable for changing behaviors (e.g., tobacco-use reduction). Under the leadership of Dr. Everett Rhoades, the Indian Health Service initiated no smoking policies in our clinics leading to expanded smoke-free tribal facilities.

The NPAIHB has had many successful projects that have impacted individual behavior through community policy interventions. These public health policy projects include:

- Tribal Tobacco Policy Project
 - 32 of the 34 NPAIHB tribes adopted tribal tobacco policy in tribal facilities in 1995
- Seat belt survey and law
 - 1997 observational surveys showed that 17% of the Indian population was buckling up
 - After the one year campaign 41% were buckling up
- Childhood Immunizations
 - Indian Health Service and Tribal Clinics have tracked and increased childhood immunizations
 - immunization rate 63% (2002)
 - increased 16% to 79% (2006)
- Childhood obesity and tooth decay study
 - Led to change in physical environment to support breast feeding and limiting sugar beverage consumption 2000-present



In addition many tribal programs have adopted health policy projects:

- Tobacco policy
 - Tobacco governments adopted no smoking policies
- Healthy food options
 - Vending machines, restaurant menu and store restrict junk food and offer health options
- Childhood obesity projects
 - Tribal resolution passed to restrict the purchase of sugar beverages
 - Tribal facilities created breast feeding rooms
- SDPI Non and Competitive Grants
 - Cardio Vascular Disease grants implementing “Healthy Heart Curriculum”
 - Primary Prevention grants implementing 16 week lifestyle intervention classes
- Safe walking trails
 - State grants for lighting and safe trails
- Primary seat belt laws on reservation lands
- Child safety seat promotional grants
 - Tribal programs provided safety seats to new moms
 - Tribal programs provided bike helmets for safety



Healthy People 2010 Leading Health Indicators

Six of the Leading Health Indicators listed in Healthy People 2010 were considered by NTCCP and the Coalition in creating the Plan because they are cancer-related. They include: increasing physical activity, decreasing obesity, decreasing tobacco use, practicing responsible sexual behavior, improving environmental quality, and assuring access to health care.

1) Physical Activity

- Increase the proportion of adolescents who engage in vigorous physical activity that promotes cardio respiratory fitness three or more days per week for twenty or more minutes per occasion.
- Increase the proportion of adults who engage regularly, preferably daily, in moderate physical activity for at least thirty minutes per day.

There is convincing evidence that physical activity is associated with a reduced risk of cancers of the colon and breast. Several studies also have reported links between physical activity and a reduced risk of cancers of the prostate, lung, and lining of the uterus (endometrial cancer).

2) Obesity

- Reduce the proportion of children and adolescents who are obese.
- Reduce the proportion of adults who are obese.

In addition to increasing the risk of coronary heart disease, stroke, high blood pressure, and diabetes, obesity increases the risk of cancers of the breast (postmenopausal), endometrium (the lining of the uterus), colon, kidney, and esophagus.

3) Tobacco Use

- Reduce cigarette smoking by adolescents and adults.

Nationally, American Indians and Alaska Natives have the highest rates of commercial tobacco use among nearly every age, gender, and ethnic category. In 2002, 40.5% of AI/AN men and 40.9% of AI/AN women reported current cigarette use.

Not coincidentally, cancer is the second leading cause of death among American Indians and Alaska Natives nationally, with lung cancer being the most common cause of cancer death. Nearly three times as many AI/AN people die of lung, bronchial, or tracheal cancer than the next leading type, accounting for over 26% of all cancer deaths. In 1998, lung cancer took the life of 362 American Indian and Alaska Native adults.

For men, over 90% of lung cancer cases are caused by tobacco use, while nearly 80% are caused by commercial tobacco use among women. Consequently, over 300 AI/AN men and women now die from tobacco-related lung cancer each year. Commercial tobacco use is now known to cause lung cancer, laryngeal cancer, oral cavity and pharyngeal cancers, esophageal cancer, pancreatic cancer, renal cell, renal pelvis, and bladder cancers, cervical cancer, stomach cancer, acute leukemia, and has been associated with colorectal cancer and liver cancer.



4) Sexual Behavior

- Increase responsible sexual behavior.
- Increase the proportion of adolescents who abstain from sexual intercourse or use condoms if currently sexually active.

Human papillomaviruses (HPV) are a group of more than 100 viruses, 30 of which can be passed from one person to another through sexual contact. Most HPV infections occur without any symptoms and go away without any treatment over the course of a few years. However, HPV infection sometimes persists for many years. Some types of HPV are associated with certain types of cancer, and are called “high-risk” oncogenic or carcinogenic HPVs. Having many sexual partners is a risk factor for HPV infection.

HPVs is now recognized as the major cause of cervical cancer. In 2006, an estimated 10,000 women in the United States will be diagnosed with this type of cancer and nearly 4,000 will die from it. Studies suggest that HPV may also play a role in cancers of the anus, vulva, vagina, and some cancers of the oropharynx (the middle part of the throat that includes the soft palate, the base of the tongue, and the tonsils). Data from several studies also suggest that infection with HPV is a risk factor for penile cancer (cancer of the penis).

5) Environmental Quality

- Reduce the proportion of persons exposed to air that does not meet the U.S. Environmental Protection Agency’s health-based standards for ozone.
- Reduce the proportion of nonsmokers exposed to environmental tobacco smoke.

Ozone and Cancer - Exposure to ultraviolet (UV) radiation from the sun can seriously threaten our health. The ozone layer absorbs UV rays and serves as a protective shield, but it is not the same over the entire surface of the Earth. UV rays can cause cancer by damaging cells’ genetic material. The damage allows cells to form cancerous tumors. Skin cancer is the most dangerous and deadly risk of UV radiation.

Environmental Tobacco Smoke and Cancer - The Environmental Protection Agency has classified secondhand smoke as a substance that is “known to cause cancer in humans.” This classification is the highest level of warning given to carcinogens. Scientific studies have linked secondhand smoke to heart disease, respiratory problems, and many types of cancers, including lung cancers, cervical cancer and bladder cancer. Each year, secondhand smoke causes nearly 65,000 deaths among non-smokers.

Northwest Consideration: Salmon contamination in the Columbia river; Hanford Nuclear power plant; Uranium mines in Spokane

6) Access to Health Care

- Expand insurance coverage to include cancer screening, early detection, quality treatment and palliative care.
- Increase the proportion of persons with health insurance.
- Increase the proportion of persons who have a specific source of ongoing care.

According to the 2000 Census twice the proportion of AI/ANs lived below the official poverty level in 1999 than the total U.S. population. The Indian Health Service is significantly under-funded and over-burdened with need. Transportation, long wait times, few specialists, and rural geography further contribute to poor access to cancer services.



Barriers to Implementation and Strategies to Overcome

Barriers to achieving comprehensive cancer control exist at all levels and must be acknowledged and addressed so that work can proceed successfully. Some potential barriers are concrete and relatively easy to address; others are more abstract, but may help the project set reasonable timelines and priorities.

In 2002, NTCCP convened a work group to identify barriers to implementing the cancer plans. The group represented agencies and programs at multiple levels of cancer knowledge and areas of expertise. Attendees were tribal front line workers, tribal health directors, tribal health educators, tribal and urban directors from the NBCCP, community members, cancer survivors, academics, and non-profit agency professionals.

The work group identified the following barriers and strategies to overcome them:

- Lack of community education about the importance of cancer screening.
 - Assess community educational level and implement an appropriate educational program
- Lack of outreach to urban populations.
 - Identify urban Indian organizations, community centers, educational programs, and pow-wows and connect with urban populations' cancer control activities.
- Challenge of tribal economic gain from profits of commercial tobacco use. Tribes get income from the sale of tobacco. Cigarettes are often sold singly, or packaged in small quantities that are affordable by youth. Tobacco may be placed in store displays so it can be easily stolen, following the theory that losses now are more than recovered when the person becomes addicted to nicotine.
 - Perform an economic impact survey and assessment of costs vs. benefits
- Lack of tribal leadership support for cancer as a priority
 - Involve leaders in goal setting and planning
 - Recruit people to serve on the Council who will support health initiatives
 - Educate leadership about tribal needs around cancer by using cancer surveillance and other data to inform leadership of relevant cancer concerns
- Data concerns.
 - Disseminate data to the public to promote ownership
 - The terminology and findings should be clear and understandable to the layperson
 - Establish a tribal website for reporting information on the cancer control effort
 - Existing periodic surveys (e.g., BRFS/YRBS/YTS) should be examined with three-state cooperation to obtain a sample size adequate for drawing conclusions
- Lack of AI/AN scientists and health professionals
 - Strengthen the skill level of current AI/AN health professionals and healthcare employees
 - Provide financial support for training and education
 - Strengthen the science curriculum in schools, talk about careers in health at the Head Start level, begin exposure to research in middle school, and offer research experience in high school
 - Hold Career Days to increase awareness of opportunities to work in science and health careers
 - Identify mentors and role models (including non-AI/AN individuals) to mentor youth/young adults into the academic and health care workforce
 - Develop a "Day with a (doctor, scientist...)" program to expose youth to one-on-one mentoring in a workplace situation
- Lack of IHS funding for treatment, Contract Health Service (CHS), pharmaceuticals
 - Increase public and government awareness about the level of funding needed and change current allocations of funds
 - Lobby Congress to make the IHS an entitlement program, and to increase funding for cancer



- treatment
 - Include urban and newly federally recognized tribes in the funding stream
 - Tribes and health boards can act as advocates to raise awareness that current formulas are inequitable, especially for NW Treaty tribes
 - Identify key partners who can help lobby for change
 - Write letters to Congressional committees
 - Raise physician awareness of how to access low-cost medications
 - Support tribes with health centers equally
 - Change IHS policy regarding CHS
 - Identify strategies that stretch CHS dollars
 - Initiate one or two model projects offering comprehensive care prescription service
 - Use the insurance plan for billing
 - Encourage IHS utilizers to buy insurance
- Lack of funding for the work of cancer control
 - Advocate for tribal cigarette tax to fund tobacco education programs or health promotion activities
 - Apply for funding from the federal government and its agencies
 - Apply for funding from private foundations and businesses
 - Educate the community about these “hidden” funding resources
 - Approach drug companies for support
 - Organize fundraising activities
 - Work for legislative changes to increase funding
 - Educate leaders on the benefit of lobbying
 - Appropriate funds at the Congressional level for prevention and screening, as well as treatment
 - Maximize existing resources by creating and maintaining linkages with related agencies
 - Emphasize prevention to reduce costs
 - Use hospital charity care policies (Hill-Burton Act)
- Lack of age-specific educational and culturally relevant materials on cancer control
 - Advocate with agencies to produce appropriate materials and for AI/AN input into materials development
 - Develop our own materials, using native leaders and role models
 - Utilize AI/AN design, develop, illustrate, produce, and market educational materials to Native communities
 - Involve the community in creating social marketing materials
 - Develop interactive, computerized health education materials with graphics
 - Develop curricula on topics of interest in cancer control
- Barriers encountered by patients seeking cancer screening or treatment
 - CHR/Staff to help navigate the complicated system
 - Help patient look into insurance
 - Rural areas – long distances for services
 - Provide Transportation – child care
 - Work with employer to understand the time required for treatment
- Problems in meeting the needs of family caregivers
 - Establish resources for caregivers to family members with cancer
 - Develop ways to prevent caretaker “burn out”
 - Provide resource books and videos for caregivers
 - Establish support groups



Barriers to Implementation and Strategies to Overcome

- Develop a website for family caregivers, and an online information exchange, so they can share their insights and get support from others in similar situations
- Provide funding for caregivers
- Offer ongoing training for caregivers
- Train family members to provide respite for the primary caregiver
- Assisted living facilities (ALF) and comprehensive care centers should be built to meet the ongoing needs of an aging population
- Turnover in Staffing
 - Provide comparable pay scale
 - Provide incentive, health insurance, positive work environment
 - Promote ownership of intervention at the tribal level
- Lack of resources or poor coordination of resources.
 - Establish easy and frequent opportunities for people/organizations to share stories and experiences
 - Create a clearinghouse or web page to help communication between these partners
 - Develop a tribal website of links
 - Ensure that the coordination of resources benefits all stakeholders
- Lack of community role models (individuals and families)
 - Identify the attributes of persons who could serve as role models
 - Recruit role models to promote tribal cancer efforts
 - Recognize, reward, and publish positive role models for all ages/groups

State Level barriers to Tribal Implementation

As identified in the previous section there are a variety of barriers faced locally by Tribes implementing their Comprehensive Cancer Control plans. There are also barriers that Tribes face from external entities. The following is a list of barriers at the state level that Abed et al. (2000) identified with strategies to address them:

- Turnover in Staffing
 - Communicate with staff to ensure knowledge of changes
 - Prepare information on tribal program to distribute to new staff
- Change in state government
 - Communicate with American Cancer Society to understand current cancer legislation
 - Communicate with Tribal-State liaison
- Varying levels of development and resources
 - Advocate and educate state program personnel about local data and issues
- Funding cycle limitation
 - Communicate with Tribal health planner and grants person to develop additional /or replacement funding
- Organizational Structure
 - Research State health programs organizational structure
 - Network via already established contacts
- Categorical funding
 - Communicate with funding program to incorporate other topics in activities
 - Negotiate scope of work to include other topics



Federal Level barriers to Tribal Implementation

There are also barriers that Tribes face at the federal level when implementing their Comprehensive Cancer Control plans. The following is a list that Abed et al. (2000) identified with strategies to address them:

- Change in federal government public health policy
- Funding cycle limitation
- Categorical funding
- Organizational Structure

These local, state, and federal barriers to reducing cancer burdens in tribal communities and the strategies to overcome them were essential considerations of NTCCP and the Coalition in creating the “*Twenty-Year Comprehensive Cancer Control Plan*”.



Appendix A: Highlights: Working Toward Cancer-free Tribal Communities

Great things are happening in Indian Country. Many people are working to fulfill their vision for a healthy community for themselves and their loved ones. For example, take a look below for examples of these efforts. Members of staff serving northwest tribal communities submitted highlights of their cancer control efforts, which are organized in alphabetical order.



Colville Confederated Tribes



| | | |
|---------------------|---|--------------------------------|
| Objective | Increase resources available for Cancer Treatment of Tribal Patients | |
| Strategy | Organize Cancer Health Fair | |
| Organizers | Val Vargas-Thomas, Colville Tribal Health Program Manager Cliff Evans, Cancer Patient Care Eric Vinson, Northwest Portland Area Indian Health Board | |
| Primary audience | IHS Clinicians, Tribal Health Department, External Cancer Programs | |
| Activity | Location | Nespelem Community Center |
| | Date(s) & time(s) | November 15th, 2006 at 10 a.m. |
| Outcomes | 45 participants. Presentations by: American Cancer Society, Leukemia & Lymphoma Society, Cancer Patient Care, Spokane Health District BCCP, Wanatchee Valley BCCP, and Providence Cancer Center | |
| Additional comments | | |
| Reported by | Val Vargas-Thomas Eric Vinson | |



Colville Confederated Tribes

| | | |
|---------------------|-------------------|---|
| Objective | | Increase cancer education |
| Strategy | | Host Cancer 101 Training |
| Organizers | | Val Vargas-Thomas, Colville Tribal Health Program Manager Eric Vinson, Northwest Portland Area Indian Health Board Jackie Personett, Leukemia & Lymphoma Society Teresa Gutheie, Spirit of EAGLES, Cancer Information Service Sharlynn Rima, Cancer Information Service |
| Primary audience | | Colville Tribal Health Department, Coville Tribal Community Members |
| Activity | Location | Nespelem Tribal Longhouse |
| | Date(s) & time(s) | March 26th & 27th 2007 8:00 am to 4:00 pm |
| Outcomes | | 15 participants. Presentations by Cancer Information Service, Northwest Portland Area Indian Health Board, Leukemia & Lymphoma Society |
| Additional comments | | |
| Reported by | | Val Vargas-Thomas Eric Vinson |



Confederated Tribes of Warm Springs



| | | |
|---------------------|-------------------|---|
| Objective | | <ul style="list-style-type: none"> • Increase awareness of breast and cervical cancer issues • Educate women about cervical and breast cancer screenings • Increase health literacy of women |
| Strategy | | <ol style="list-style-type: none"> 1. Monthly hour long Women of Wellness (W.O.W.) meetings during lunch 2. Nutrition education through lunch preparation 3. Provide craft activity in a half-hour or less 4. Present a new and different health education topic every month 5. Offer opportunities to learn Breast Self-Examination (BSE) |
| Organizers | | Judith E. Charley, Community Health Information Specialist |
| Primary audience | | All women in Warm Springs community, especially women aged forty years and older |
| Activity | Location | Warm Springs I.H.S. Health and Wellness Center Atrium |
| | Date(s) & time(s) | Planning meeting: first Wednesday of each month W.O.W. education forum: second Thursday of each month |
| Outcomes | | Monthly W.O.W. meetings Positive evaluation and continuous funding since 1996 |
| Additional comments | | |
| Reported by | | Judith E. Charley |





Confederated Tribes of Warm Springs

| | | |
|---------------------|-------------------|--|
| Objective | | <ul style="list-style-type: none"> • Increase Awareness of Cancer • Educate community about comprehensive cancer issues • Increase financial resources available for Cancer Survivors • Increase health literacy of women |
| Strategy | | <ol style="list-style-type: none"> 1. Performance of the play “Understanding” written by Shane Mitchell 2. Pi-ume-sha Health Fair including: <ul style="list-style-type: none"> • Pamphlets and Education Information • Breastfeeding friendly area • 20 Booths included: Nutrition, Diabetes & Cancer Screening, Transportation safety, Healthy Traditional lifestyle, Cancer Information • Participants completed 16 or more booths to receive a complete <i>Passport</i>, Nike T-shirt and water bottle. |
| Organizers | | Yvonne Iverson, Warm Springs Community Health Programs Celeste Whitewolf, JD, Native Peoples Circle of Hope |
| Primary audience | | Warm Springs community, especially women aged forty years and older |
| Activity | Location | “Understanding” play: Museum at Warm Springs Pi-Ume-Sha Health Fair: Pi-Ume-Sha Field, Warm Springs, Oregon |
| | Date(s) & time(s) | June 23-27, 2004 |
| Outcomes | | 25 community members attended “Understanding” play 320 participated and 248 completed <i>Passport</i> and received incentives |
| Additional comments | | <ul style="list-style-type: none"> • One audience member shared that the anniversary of her mother’s death from stomach cancer was the day before and she really related to the part of Vera in the play • Cece Whitewolf shared that the presentation of the play in October will be done in the memory of Sylvia Montero who helped write the play and lost her fight with cancer last October |
| Reported by | | Yvonne Iverson |





Lower Elwha Tribe

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|---------------------|-------------------|---|
| Objective | | Address cancer needs for women in the Lower Elwha Tribe and community |
| Strategy | | Pink Paddle Project 1. Breast Cancer Education events 2. Organize native breast cancer survivors to pull in <i>Canoe Journey</i> 3. Participate in Komen Race for the Cure 4. Health Fair 5. Cancer Support Group 6. Lymphedema Prevention Exercise Group |
| Organizers | | Roberta Kimberly, Community Health Representative |
| Primary audience | | Native women on the Olympic Peninsula |
| Activity | Location | Health Fair, Cancer Support Group, and Exercise Group: Lower Elwha Tribe <i>Canoe Journey</i> :Varies depending year and host |
| | Date(s) & time(s) | Health Fair: Monthly Cancer Support Group: Monthly Lymphedema Prevention Exercise Group: Monthly <i>Canoe Journey</i> :Weekly during Spring and Summer |
| Outcomes | | Pink Paddle Project distribution and sharing of cancer education materials during <i>Canoe Journey</i> (5,000+ attendance) Ongoing education and support meetings |
| Additional comments | | |
| Reported by | | Roberta Kimberly |





Nez Perce Tribe

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|---------------------|-------------------|--|
| Objective | | Address comprehensive cancer needs in Nez Perce Tribe and community |
| Strategy | | <p>Nez Perce Tribal Cancer Coalition</p> <ol style="list-style-type: none"> 1. Weekly meetings to discuss current issues 2. Organize training for Nimiipuu healthcare providers (primary, dental, pharmacy, and community) |
| Organizers | | Susie Ellenwood, Alina George, Jaci McCormack, and Margrett McCormack |
| Primary audience | | Nez Perce Tribal Community, Nimiipuu Health, Cancer Survivors, Cancer Caregivers |
| Activity | Location | Nimiipuu Health Center |
| | Date(s) & time(s) | Weekly on Wednesday |
| Outcomes | | <p>8 coalition members attend</p> <p>Organized fundraisers for cancer survivor support include:</p> <ul style="list-style-type: none"> • September 2007 Benefit Golf Tournament |
| Additional comments | | |
| Reported by | | Susie Ellenwood |



Nez Perce Tribe



| | | |
|---------------------|-------------------|---|
| Objective | | <ol style="list-style-type: none"> 1. To increase awareness of cancer and cancer survivor issues 2. Reduce the risk of cancer and to enhance recovery from a cancer diagnosis 3. To encourage walking as a part of a program of regular exercise |
| Strategy | | <ol style="list-style-type: none"> 1. Conquer Cancer Fair & Women's Health Check (May 10, 2004) 2. Community health walk, cancer education, and screening 3. Participants receive pedometers, supporting health information, and walking journal from the Support Group 4. Presentation by Cancer Survivors |
| Organizers | | Celeste Whitewolf, JD, Native Peoples Circle of Hope Veronica "Mae" Taylor, Nez Perce Tribe, Cancer Support Group Chair |
| Primary audience | | Nez Perce community, Cancer Survivors, Family of Cancer Survivors, Cancer Caregivers |
| Activity | Location | Nez Perce Track |
| | Date(s) & time(s) | May 10, 2004 |
| Outcomes | | 45 participants |
| Additional comments | | |
| Reported by | | Veronica "Mae" Taylor, Nez Perce Tribe, Cancer Support Group Chair |



Nooksack Tribe

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|---------------------|---|
| Objective | <ol style="list-style-type: none"> 1. To raise community awareness on the need for cancer prevention screening for all age groups and particularly men 2. To pilot some specific science based interventions to influence screening seeking behaviors that link health services with the education program 3. To address the needs of cancer survivors and caretakers 4. To address grief and loss for those who have lost loved ones to cancer |
| Strategy | <ol style="list-style-type: none"> 1. Share the work the Tribe has done in Cancer Control with the community, 2. Feature cancer survivors and caregivers as guest speakers. 3. Identify further needs and to explore strategies to address them 4. Provide baseline screening information for all age groups including men and women. |
| Organizers | <p>Molissa Leyva, Nooksack Clinic Manager June Strickland, PhD, Univeristy of Washington Teresa Guthrie RN,MN, Spirit of EAGLES</p> |
| Primary audience | Families in the Nooksack Tribe |
| Activity | Location Nooksack Tribe |
| | Date(s) & time(s) 7pm - 10:00 pm June 3, 2004 |
| Outcomes | 50 participants |
| Additional comments | |
| Reported by | Molissa Leyva, Nooksack Clinic Manager |



Suquamish Tribe



| | | |
|---------------------|-------------------|---|
| Objective | | <ul style="list-style-type: none">• Increase Awareness of Cancer• Educate community about cancer risk factors• Reduce Prevalence of Smoking |
| Strategy | | <p>Community Health Fair</p> <ul style="list-style-type: none">• Information provided on cancer, resources, prevention (appropriate diet, exercise, and healthy lifestyles), and screening.• Smokers interested in quitting are provided information and referrals to cessation resources for individualized intervention• Nutrition Bingo<ul style="list-style-type: none">• Includes: low fat, high fiber, reducing sodium, and food safety• Correct responses receive prizes such as bean soup mix (high fiber) <p>Annual Women’s Health Day</p> <ul style="list-style-type: none">• Lunch and discussion of breast and cervical cancer prevention and screening. Speaker is usually a cancer survivor, if possible a tribal member. <p>Calendar Project</p> <ul style="list-style-type: none">• Calendar with nutrition, tobacco, diabetes, cancer and physical activity tips, pictures of tribal members engaged in healthy activity produced yearly. <p>In addition to displays and games the Community Health Nurse and Nutritionist sit on the planning committees to make sure that activities and food are healthy, for example decreased sweets and increased fruits and vegetables being served.</p> |
| Organizers | | Barbara Hoffman, Community Health Nurse |
| Primary audience | | Tribal Elders, members and employees |
| Activity | Location | Suquamish Tribal Center |
| | Date(s) & time(s) | May: Women’s Health Day March/April : Easter Party October: Halloween Party, Health Fair August: Chief Seattle Days |
| Outcomes | | Surveys, participant feedback, mammogram and pap test rates, sigmoidoscopy rates, PSA rates. Tobacco use rates. |
| Additional comments | | Small changes in the community norms such as what is served at community events. Children in particular appear be interested and seek us out at community events. Elders enjoy playing nutrition Bingo with us. |
| Reported by | | Barbara Hoffman |



Suquamish Tribe

| | | |
|---------------------|-------------------|---|
| Objective | | <ul style="list-style-type: none">• Increase Awareness of Cancer• Educate community about cancer risk factors• Reduce Prevalence of Smoking |
| Strategy | | <p>Tobacco Cessation</p> <ul style="list-style-type: none">• Provide NRT or other drugs to assist in smoking cessation. Provide individual counseling. Provide information about tobacco quit line at community events. <p>Second Hand Smoke Exposure Reduction</p> <ul style="list-style-type: none">• 2005 mail out to all Tribal homes information about SHS included car air fresheners, refrigerator magnets, smoke-free homes and cars. Displays are put up at most community events. <p>Tobacco Prevention</p> <ul style="list-style-type: none">• Adults and children play games and earn prizes at community events by answering questions about the dangers of tobacco use and second hand smoke exposure. <p>Nutrition Education</p> <ul style="list-style-type: none">• Provided in a variety of settings such as the Head Start program, the after school program, the youth center, community events, and the elders lunch program. Games, displays and activities are used to stimulate interest. Emphasis is placed on fruit and vegetable consumption. |
| Organizers | | Barbara Hoffman, Community Health Nurse |
| Primary audience | | Tribal Elders, members and employees |
| Activity | Location | Suquamish Tribal Center |
| | Date(s) & time(s) | School Year: Head Start and After School Program |
| Outcomes | | Surveys, participant feedback. Tobacco use rates, number of requests for NRT. |
| Additional comments | | Small changes in the community norms such as what is served at community events. Children in particular appear be interested and seek us out at community events. Elders enjoy playing nutrition Bingo with us. |
| Reported by | | Barbara Hoffman, Community Health Nurse |



Shoshone-Bannock Tribes



| | | |
|---------------------|-------------------|--|
| Objective | | <ol style="list-style-type: none"> 1. Increase awareness of Cancer among men in Fort Hall community 2. Educate men about cancer, cancer prevention, and cancer screening |
| Strategy | | <ol style="list-style-type: none"> 1. Advertise event in the local Shoshone-Bannock Newspaper and post flyers throughout the community at central locations 2. Provide incentives (screwdrivers, socket sets, chain saw) from Home Depot 3. General cancer educational sessions include: <ul style="list-style-type: none"> • Cancer Survivors • Local healthcare providers • Resource providers • Educational booths <p>Health Fair sessions will be interactive with participants actively involved with an emphasis on spirituality, healing, and up-to-date information on cancer.</p> |
| Organizers | | Roanna Stump, CHR Shoshone-Bannock Tribal Health |
| Primary audience | | Men in the Fort Hall community |
| Activity | Location | Tribal Business Center, Dome Room, Fort Hall, Idaho |
| | Date(s) & time(s) | June 17, 2004 |
| Outcomes | | 40 participants |
| Additional comments | | |
| Reported by | | Roanna Stump, Shoshone-Bannock Tribe |





Stillaguamish Tribe

| | | |
|---------------------|-------------------|--|
| Objective | | <ol style="list-style-type: none"> 1. Lung cancer and heart disease risk and reduction 2. Quit smoking 3. Breast exams and mammograms 4. Lump awareness |
| Strategy | | <ol style="list-style-type: none"> 1. Smoking Cessation Classes 2. Tobacco focused exam 3. Postcards, fliers at fair booths 4. Free patches, pills and gum 5. October month – targeted for Breast Cancer reduction, exams and Cancer reduction beads 6. Identify smoker by questions |
| Organizers | | <p>Anne Hurd ARNP – Clinic Director Melanie Hein – Chemical Dependency Supervisor and Tobacco Coordinator</p> |
| Primary audience | | The attendees to the “Baby Boomers 50,000 Mile Check-up. |
| Activity | Location | <ol style="list-style-type: none"> 1. Clinic – Exam room 2. Conference teaching room 3. Community gatherings 4. Festival of River - August |
| | Date(s) & time(s) | <p>Festival on the River: Second weekend in August Clinic: Ongoing</p> |
| Outcomes | | <ul style="list-style-type: none"> • Scheduled mammograms appointments were attended • Fewer complaints about being pancake flat on mammography |
| Additional comments | | |
| Reported by | | Anne Hurd ARNP – Clinic Director |



Yakama Nation



| | | |
|---------------------|--|--|
| Objective | Educate Federal Agencies about Cancer issues in Indian Country | |
| Strategy | Host President's Cancer Panel | |
| Organizers | Joe Jay Pinkham, Yakama Nation Tribal Council President's Cancer Panel | |
| Primary audience | President's Cancer Panel | |
| Activity | Location | Yakama Nation Eagle Selatsee Auditorium, Toppenish, Washington |
| | Date(s) & time(s) | July 29-30, 2002 9:00 am to 5:00 pm |
| Outcomes | 2002 President's Cancer Panel Report Facing Cancer in Indian Country: The Yakama Nation and Pacific Northwest Tribes 2003 Cooperative Agreement between NCI and IHS for Northwest Pilot Navigator Project | |
| Additional comments | | |
| Reported by | Patricia Ike | |



Yakama Nation

| | |
|---------------------|---|
| Objective | <ol style="list-style-type: none"> 1. Unite local survivors, families, providers, and community members 2. Education both prevention, survivor and survivorship issues. 3. Developing partnerships with local organizations and increase the network of support in the community . 4. Engage the community in an activity that centered around wellness. 5. Raise funds for support of American Cancer Society |
| Strategy | <ul style="list-style-type: none"> • Physical activity (Relay on the Rez) that promotes wellness for a cancer prevention and survivorship • Resource booths at reception |
| Organizers | <p>Hollyanna Pinkham, Yakama Office of Native Cancer Survivorship Diane Sekaquaptewa, Yakama Nation Tobacco Prevention Youth Chair, Yakama Nation Youth Speak-Out Cheri Stoker, American Cancer Society</p> |
| Primary audience | Yakama Tribal members, Yakama Nation and surrounding community |
| Activity | Location Wapato, Washington |
| | Date(s) & time(s) July 15-16, 2006 6:00 pm to 12:00 pm |
| Outcomes | <p>500 participants. Resource Booths from: Yakima Health District Breast and Cervical Program, American Cancer Society, NPAIHB-Western Tobacco Prevention Program, Yakama Nation Juice, Yakama Legends Casino, Yakama Health Program</p> |
| Additional comments | |
| Reported by | Patricia Ike, Yakama Office of Native Survivorship |



Yakama Nation



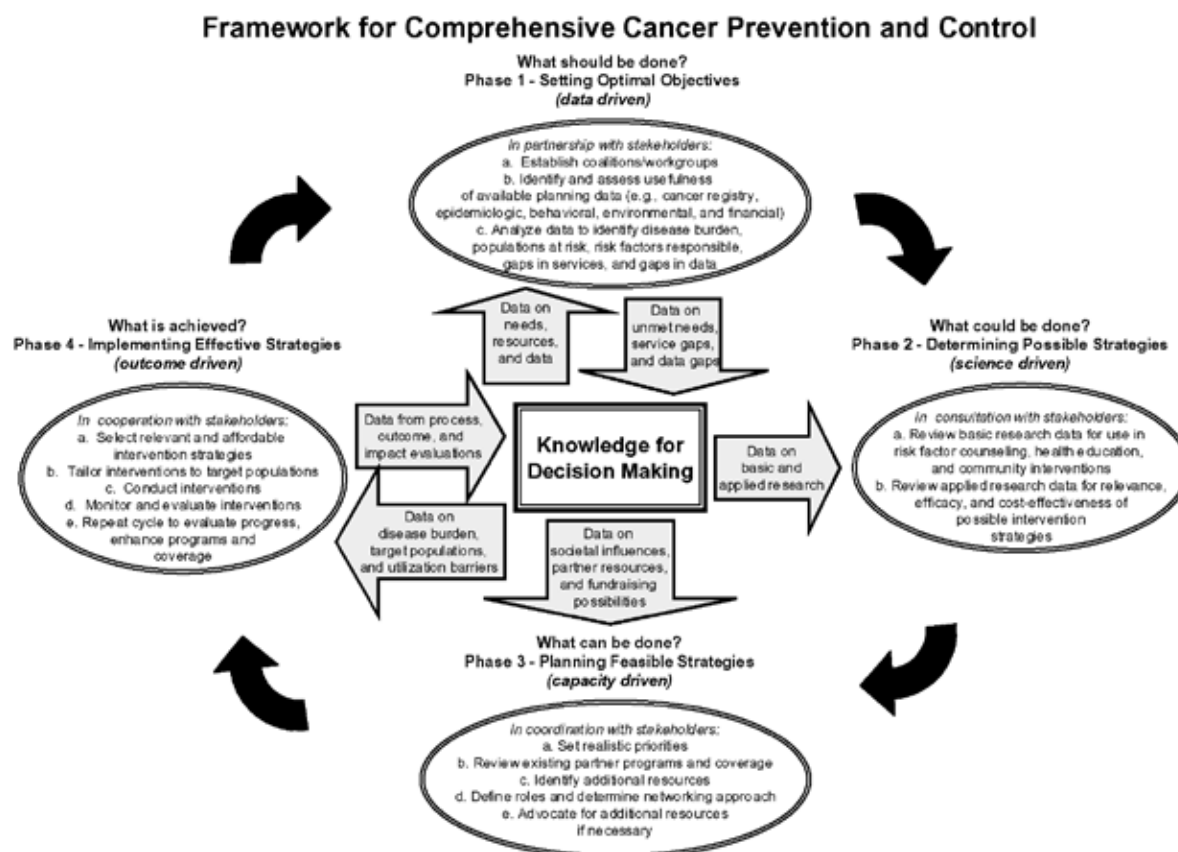
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|---------------------|---|------------------------------------|
| Objective | <ol style="list-style-type: none"> 1. Unite local survivors, families, providers, and community members 2. Education both prevention, survivor and survivorship issues. 3. Developing partnerships with local organizations and increase the network of support in the community . 4. Influence lifestyle trends that lower cancer rates. 5. Engage the community in an activity that centered around wellness. | |
| Strategy | <ul style="list-style-type: none"> • Physical activity (Mural Walk) that promotes wellness for a cancer prevention and survivorship • Resource booths at reception | |
| Organizers | <p> Connie Adams, Yakama Office of Native Cancer Survivorship Ellen Doublerunner, Yakama Office of Native Cancer Survivorship Cat Miller, Yakama Office of Native Cancer Survivorship Delilah Martinez, Yakama Office of Native Cancer Survivorship Catherine Sampson, Yakama Office of Native Cancer Survivorship Patricia Ike, Yakama Office of Native Cancer Survivorship Hollyanna Cougartracks Pinkham, Yakama Office of Native Cancer Survivorship </p> | |
| Primary audience | Yakama Tribal members, Toppenish community | |
| Activity | Location | Downtown Toppenish, Washington |
| | Date(s) & time(s) | May 12, 2006 8:00 am to 4:00 pm |
| Outcomes | 60 participants. Resource Booths from: Cancer Information Service, Yakima Health District Breast and Cervical Program, American Cancer Society, Lance Armstrong Foundation-Livestrong campaign, National Patient Advocate Foundation-Access watch, NPAIHB-NTCCP Program, Yakama Nation Juice, Yakama Legends Casino | |
| Additional comments | | |
| Reported by | Patricia Ike | |



Appendix B: Constructs for Comprehensive Cancer Control Planning

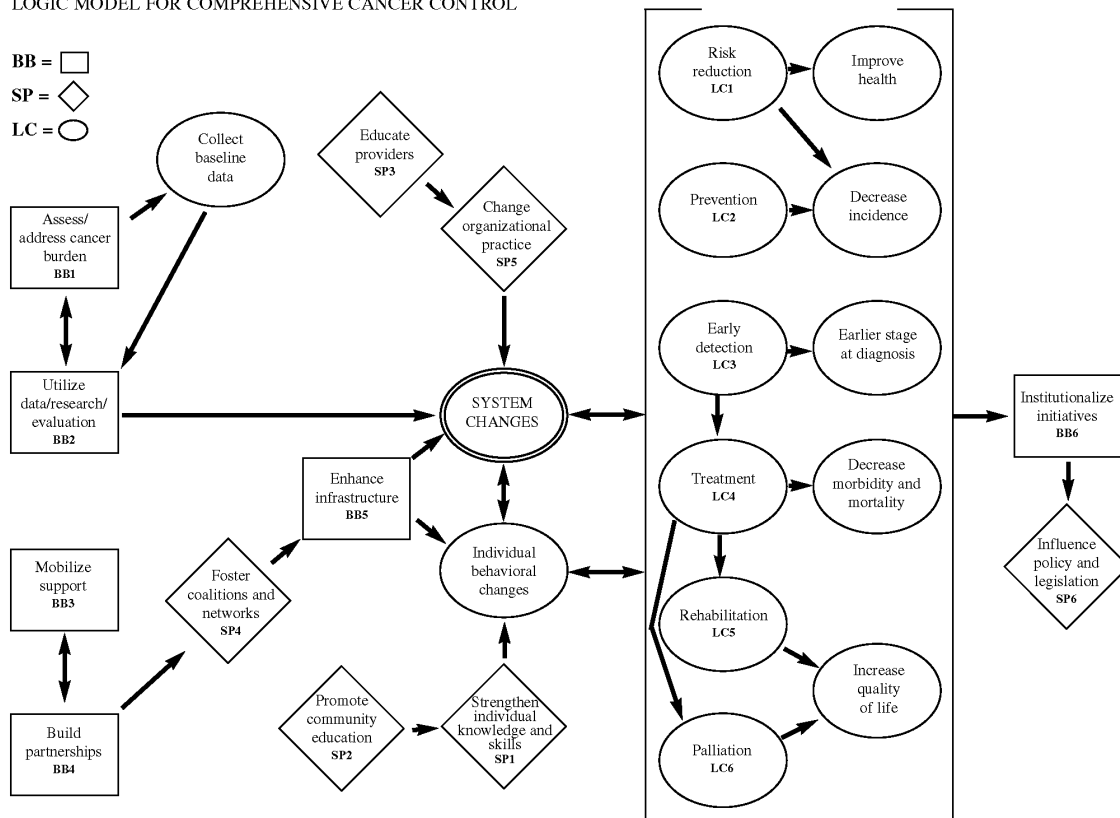
Framework for Comprehensive Cancer Control

In essence, the Framework presents a cyclical process with four phases. In the first phase, the question is, “What should be done?” and the answer is to set optimal objectives using data. In the second phase, the question is, “What could be done?” and the answer is based on determining what is possible to achieve. In the third phase, the question is, “What can be done?” and the answer is determined by capacity and what is feasible. In the fourth phase, the question is, “What is achieved?” (What was done?) And the answer is based on outcomes of the data collected earlier. At this point, the cycle is ready to begin again, with the question, “what should be done?” In this way, progress toward the goal of reducing cancer incidence, morbidity, and mortality among American Indians and Alaska Natives is continually being reviewed. This review, using the Framework, assures the stakeholders in the Twenty-year Plan that it will be able to adjust and remain viable over time.



Building Blocks for Comprehensive Cancer Planning and Implementation

LOGIC MODEL FOR COMPREHENSIVE CANCER CONTROL



The Building Blocks are objectives identified by the Centers for Disease Control in the above logic model for comprehensive cancer prevention and control that should lead to a progressive reduction in the cancer burden. These objectives are a general guide that must be adapted to the needs of American Indians and Alaska Natives. The Building Blocks are explained below:

A. Assessing and addressing the cancer burden involves assessing needs, available resources, and gaps that relate to cancer.

- In the planning phase, target areas for cancer prevention and control are selected and prioritized.
- In the implementation phase, the priority strategies are designed, implemented, and evaluated.
- As a result of addressing the cancer burden, morbidity and mortality rates fall, and disparities between groups are reduced.

B. Utilizing data/research/evaluation means that “evidence-based” strategies are developed to address the needs and disparities that have been identified. Strategies that have been implemented are evaluated for process and outcomes.

- In the planning phase, both planning data (for needs assessment) and research data (for strategy development) are reviewed and used as a basis for decision-making. Data and research gaps are identified.
- In the implementation phase, data that have been collected are used to support planning and setting priorities. Gaps that were identified in the planning stage begin to be addressed.



Appendix B: Constructs for Comprehensive Cancer Control Planning

- Ultimately, a cyclical process is established to assess, strategize, prioritize, implement, and evaluate strategies.

C. Mobilizing support requires priority setting by a broad group of stakeholders. This group builds on the existing efforts and capacities of its partners to develop strategies and expand on them.

- In the planning phase, the group develops priorities for allocating existing resources, and identifies gaps in resources and level of support.
- In the implementation phase, existing resources are being well utilized, while the group develops new resources for cancer control and improves its ability to coordinate the use of these resources.
- As a result of mobilizing support, ongoing support for cancer control (for example, from general revenue funds) is secured.

D. Building partnerships takes place between broad groups of stakeholders, which implements strategies jointly.

- In the planning phase, the original members of the group remain committed as new members join. Coalition and subcommittee meetings are held regularly and are well attended.
- In the implementation phase, members commit to being accountable for implementation. Coordination among programs and services improves, and the atmosphere grows more collaborative.
- As a result of building partnerships, the partners advocate and act in a concerted manner, and adopt a comprehensive approach among them.

E. Enhancing the infrastructure includes mechanisms for coordination, communication, documentation, tracking, monitoring, problem solving, and capacity building for comprehensive cancer prevention and control.

In the planning phase, management and administrative structures and procedures are developed; planning products are produced, disseminated, and archived.

In the implementation phase, sound, yet flexible, structures are in place, including ongoing monitoring. Partnership members assume increasing responsibility.

In the final stage, the partnership becomes a new entity that is greater than the sum of its parts.

F. Institutionalizing the initiative means that there are efforts on multiple fronts to ensure that collaboration is ongoing and self-sustaining.

- In the planning phase, the members represent a broad base, and all feel they are being heard and are benefiting from the association.
- In the implementation phase, the partnership is a visible focal point for cancer policy and activities. Mechanisms are developed to ensure that the collaborative process is sustainable.
- Finally, the comprehensive approach has become the way the business of cancer prevention and control is conducted.



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