

### **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

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.

The activities of the Northwest Tribal Comprehensive Cancer Program are funded by cooperative agreement number U55.CCU021985-04 of the Centers for Disease Control and Prevention.

### **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 Al/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 Al/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 Al/AN receiving cancer treatment, as well as to examine reasons why Al/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
- Snoqualamie Indian Tribe
- Spokane Tribe of Indians
- Squaxin Island Tribe
- Stillaguamish Tribe
- Suguamish 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 American in the I 500'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

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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 chair-person. 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
- loe'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 (Al/AN) both nation-wide 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, Al/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, Al/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 Al/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 Al/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 Al/ANs. For all Al/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 to-bacco-related death and disease, many minority populations, including Al/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 I. 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

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

<sup>&</sup>lt;sup>a</sup> Results from face-to-face interviews of a random sample of tribal enrollees in the Northwest; funded by the CDC.

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 Al/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 Al/AN men (474.6 per 100,000) than for Al/AN women (367.7 per 100,000). In spite of lower incidence rates, Al/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 Al/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 Al/ANs are worse than for other populations. In one Northwest registry, only 45% of Al/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.



<sup>&</sup>lt;sup>b</sup> Results from telephone surveys conducted at the state level and organized by the Centers for Disease Control and Prevention (CDC).

<sup>&</sup>lt;sup>c</sup> Respondents who reported smoking at least 100 cigarettes in their lifetime.

<sup>&</sup>lt;sup>d</sup> Respondents who had smoked at least 100 cigarettes and reported current smoking.

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

<sup>&</sup>lt;sup>f</sup> 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.

### Breast cancer

Breast cancer is the type of cancer with the highest incidence among Northwest Al/AN women at a rate of 99.2 per 100,000 (95% Cl 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 Al/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 Al/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 Al/AN men and women than for the general population in the Northwest. For Al/AN men, colorectal cancer incidence is 68.5 per 100,000 (95% Cl 34.7-102.3) compared with 58.2 (55.9-60.5) for men in the Northwest general population. For Al/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 Al/AN males. For Al/AN men, the rate of prostate cancer incidence is 107.9 per 100,000 (95% Cl 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 Al/AN health centers in the three states.

### Lung cancer

Lung cancer incidence rates in Northwest Al/ANs are similar to those for the Northwest general population. For Al/AN men, the lung cancer incidence rate is 78.0 per 100,000 (95% Cl 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 Al/AN women, at 58.0 (34.5-81.4), than for Al/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 Al/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 <sup>2</sup>	Oregon general population <sup>b</sup>	Washington general population <sup>b</sup>	Idaho general population
Screening			rcent dence Interval)	
Respondents 50 years and older who reported having a fecal occult blood stool test in the last year <sup>c</sup>	19.0	24.6	27.6	16.7
	(14.6, 24.4)	(22.6, 26.8)	(25.8, 29.5)	(15.3, 18.3)
Respondents 50 years and older who reported having a sigmoidoscopy in the last five years	27.5	35.8	37.5	30.8
	(22.3, 33.4)	(33.6, 38.2)	(35.6, 39.6)	(29.1, 32.7)
Male respondents 50 years and older who reported ever having a prostate-specific antigen (PSA) test	54.2	Not	Not	Not
	(44.2, 63.8)	available	available	available
Female respondents <sup>d</sup> who reported having a Pap test within the last three years	80.0	86.4	86.2	81.7
	(76.0, 83.4)	(84.7, 88.2)	(85.2, 87.3)	(80.2, 83.2)
Female respondents 40 years and older who reported having a mammogram within the last two years	62.1	75.1	73.2	64.8
	(56.2, 67.7)	(73.3, 77.0)	(70.8, 75.6)	(62.5, 67.3)

<sup>&</sup>lt;sup>a</sup> Results from face-to-face interviews of a random sample of tribal enrollees in the Northwest; funded by the CDC.

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.



<sup>&</sup>lt;sup>b</sup> Results from telephone surveys conducted at the state level and organized by the Centers for Disease Control and Prevention (CDC).

<sup>&</sup>lt;sup>c</sup> 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.

<sup>&</sup>lt;sup>d</sup> Excluding women who have had hysterectomies.

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, baseline 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



### Comprehensive Cancer Control Plan: Objectives, Strategies & Evaluation

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 I. Sample Breast Cancer Objectives for Tribal Cancer Planning

		,	)
#	Objective		
	• Strategy	• Evaluation	• Data
-	Increase awareness of the risk factors for breast cancer.		
	<ul> <li>Implement community education campaigns (mentoring, media, tribal leaders)</li> <li>Implement community awareness campaigns</li> <li>Plan a "women's health fair" to distribute information about breast health</li> <li>Plan an activity in connection with Breast Cancer Awareness Month (October)</li> <li>Implement Pink Shawl Program</li> </ul>	Conduct BRFSS to assess change in level of awareness of risk fac- tors Health fair attendance	• BRFSS
7	Increase the percentage of AI/AN women who receive regular breast cancer screenings	cer screenings	
	<ul> <li>Support the development and distribution of educational material promoting the importance of regular breast screenings</li> <li>Provide culturally-sensitive education to Primary Care Providers (PCPs) for counseling of patients</li> <li>Provide transportation to screening</li> <li>Provide incentive to get exam</li> <li>Provide childcare services</li> </ul>	Survey PCPs GPRA	• GPRA
က	Increase collaboration with Statewide Breast and Cervical Cancer Early Detection Programs (BCCEDP)	Detection Programs (BCCEDP)	~
	<ul> <li>Integrate Breast and Cervical Cancer Early Detection Programs into cancer plan implementation activities</li> <li>Collaborate with the State Breast and Cervical Cancer Partnerships and others on shared priorities</li> </ul>	<ul> <li>Increase in women screened through BCCEDP</li> </ul>	• BCCEDP
4	Increase the number of tribal Breast and Cervical Cancer Early Detection Programs	n Programs	
	<ul> <li>Support efforts by non-funded tribal organizations to secure funding to develop Breast and Cervical Cancer Early Detection Programs</li> </ul>	Number of new programs	<ul> <li>number of programs</li> </ul>
Ŋ	Increase the number of women diagnosed with breast cancer who have access to appropriate treatment.	ccess to appropriate treatment	ئد
	<ul> <li>Educate PCPs to refer women for breast cancer treatment services</li> <li>Organize community members to provide transportation for women needing daily or weekly treatments</li> </ul>	Record number of PCPs receiving information Count rides given to treatment facilities Record change in percentage of persons receiving treatment	<ul><li>Navigator Program records</li><li>Chart Audit</li></ul>



9	Increase payment coverage of screening and treatment of breast cancer		
	<ul> <li>Educate policy-makers about the importance for government or insurance</li> <li>R</li> <li>e</li> <li>e</li> <li>o</li> </ul>	Obtain baseline measure of how screening and treatment are paid Record # of policy-makers educated about the importance of payment coverage	Contract Health Chart Audit
7	Increase available support and quality of life for women being treated for and survivors of breast cancer	nd survivors of breast cancer	
	Organize a breast cancer support group     Solutions	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	Chart Audit
<b>∞</b>	Increase available support to caregivers of women living with breast cance		
	<ul> <li>C</li> <li>Provide training to caregivers</li> <li>Organize a caregivers' support group</li> <li>A</li> <li>R</li> <li>A</li> <li>C</li> <li>C<td>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</td><td>Survey Survivors Training rosters Pre/Post test eval</td></li></ul>	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	Survey Survivors Training rosters Pre/Post test eval



# Table 2. Sample Cervical Cancer Objectives for Tribal Cancer Planning

#	Objective		
	• Strategy	• Evaluation	• Data
6	Increase awareness of the risk factors for cervical cancer		
	<ul> <li>Implement community education campaigns (mentoring, media, tribal leaders)</li> <li>Implement community awareness campaigns</li> <li>Plan a "women's health fair" to distribute information about cervical health</li> <li>Plan an activity during Cervical Cancer Awareness Month (January)</li> </ul>	<ul> <li>Conduct BRFSS to assess change in level of awareness of risk factors</li> <li>Health fair attendance</li> </ul>	• BRFSS
2	Increase awareness among AI/AN of the relationship between Human Papiloma Virus (HPV) and cervical cancer and availability of vaccinations.	apiloma Virus (HPV) and cervic	al cancer
	<ul> <li>Develop media messages on HPV vaccinations and cancer.</li> <li>Partner with IHS and State Vaccine for Children programs</li> </ul>	<ul> <li>Number of families educated about HPV</li> <li>Number of children vaccinated through State Childhood Immunization Programs</li> </ul>	• State Childhood Immu- nization records
=	Increase the percentage of AI/AN women who receive regular pap tests		
	<ul> <li>Support the development and distribution of educational material promoting the importance of regular pap tests</li> <li>Provide culturally-sensitive education to PCPs for counseling of patients</li> <li>Provide transportation to screening</li> <li>Provide incentive to get exam</li> <li>Provide childcare services</li> </ul>	<ul><li>Survey PCPs</li><li>GPRA</li></ul>	• GPRA
12	Increase collaboration with Statewide Breast and Cervical Cancer Early Detection Programs (BCCEDP)	/ Detection Programs (BCCEDP	
	<ul> <li>Integrate Breast and Cervical Cancer Early Detection Programs into cancer plan implementation activities</li> <li>Collaborate with the State Breast and Cervical Cancer Partnerships and others on shared priorities</li> </ul>	<ul> <li>Increase in women screened through BCCEDP</li> </ul>	• BCCEDP
<u>2</u>	Increase the number of tribal Breast and Cervical Cancer Early Detection Programs	ion Programs	
	<ul> <li>Support efforts by non-funded tribal organizations to secure funding to develop Breast and Cervical Cancer Early Detection Programs</li> </ul>	<ul> <li>Number of new programs</li> </ul>	<ul> <li>number of programs</li> </ul>



### Sample Objectives for Tribal Cancer Planning

4	Increase the number of women diagnosed with cervical cancer who have access to appropriate treatment	access to appropriate treatment	
	<ul> <li>Educate PCPs to refer women for cervical cancer treatment services</li> <li>Organize community members to provide transportation for women needing daily or weekly treatments</li> </ul>	Record number of PCPs receive  Ing information Count rides given to treatment facilities Record change in percentage of Au Pro	Navigator Program records Chart Audit
2	Increase payment coverage of screening and treatment of cervical cancer	_	
	<ul> <li>Educate policy-makers about the importance for government or insurance coverage of costs of PAP tests and treatment of cervical cancer</li> </ul>	<ul> <li>Obtain baseline measure of how screening and treatment are paid He</li> <li>Record # of policy-makers educated about the importance Au</li> </ul>	Contract Health Chart Audit
9	Increase available support and quality of life for women being treated for and survivors of cervical cancer	and survivors of cervical cancer	
	Organize a cervical cancer support group	Obtain baseline measure of number of women eligible to attend support group Survey for quality of life of Au support group members Number of women attending the support group	Chart Audit
17	Increase available support to caregivers of women living with cervical cancer	ncer	
	<ul> <li>Provide training to caregivers</li> <li>Organize a caregivers' support group</li> </ul>	ntain baseline measure of nber of potential caregivers vey for knowledge of care ing and quality of life cord the number of caregivers o receive training sess for change in knowledge care giving cord the number of caregivers o attend the support group sess for quality of life	Survey Survivors Training rosters Pre/Post test eval

# Table 3. Sample Colorectal Cancer Objectives for Tribal Cancer Planning

	•		)
#	Objective		
	• Strategy	• Evaluation	• Data
8	Increase awareness of the risk factors for colorectal cancer		
	<ul> <li>Implement community education campaigns (mentoring, media, tribal leaders)</li> <li>Implement community awareness campaigns</li> <li>Plan a "family health fair" to distribute information about colorectal health</li> <li>Plan an activity in connection with Colorectal Cancer Awareness Month (March)</li> </ul>	<ul> <li>Conduct BRFSS to assess change in level of awareness of risk fac- tors</li> <li>Health fair attendance</li> </ul>	• BRFSS
6	Increase the percentage of persons who receive age appropriate screening for colorectal cancer (FOBT, sigmoidoscopy, colonoscopy)	ning for colorectal cancer	
	• Provide incentive to get exam	Obtain baseline measures on	
	<ul> <li>Frovide transportation to clinic site</li> <li>Survey the capacity of facilities to provide colorectal cancer screening</li> </ul>	percentage wno receive screening	
	<ul> <li>Support programs to train mid-level providers to perform flexible sigmoid- oscopy/colonoscopy and to establish ongoing screening programs in regional</li> </ul>	<ul> <li>Record number who receive incentive to get screening</li> </ul>	• GPRA • Chart
	facilities  • Support programs to disenose colorectal cancer stages and reduce or elimi-	<ul> <li>Count rides given to screening facilities</li> </ul>	Audit • Provider
	nate unnecessary preoperative chemotherapy and radiation treatment	Record change in the number of	Survey
	• Increase AI/AN specific colorectal cancer screening education to make sure		• IHS
	that comprenensive, cuiturally appropriate media messages reach the intended audience	<ul> <li>tests for colorectal cancer</li> <li>Number of PCPs who receive</li> </ul>	
	<ul> <li>Investigate innovative ways of organizing healthcare providers to enhance screening rates in rural communities</li> </ul>	training in performing colonos-copy /or sigmoidoscopy	
70	Increase access to appropriate treatment for colorectal cancer		
		<ul> <li>Number of PCPs receiving information</li> </ul>	Navigator     Program
	<ul> <li>Educate PCPs to refer persons for colorectal cancer services</li> <li>Provide transportation to treatment site</li> </ul>	<ul> <li>Count rides given to treatment facilities</li> </ul>	records • Chart
		<ul> <li>Record change in number of persons receiving treatment</li> </ul>	Audit



	<ul><li>Contract Health</li><li>Chart</li><li>Audit</li></ul>	<u>.</u>	• Chart Audit		<ul> <li>Survey Survivors</li> <li>Training rosters</li> <li>Pre/Post test eval</li> </ul>
ancer	<ul> <li>Obtain baseline measure of how screening and treatment are paid</li> <li>Record # of policy-makers educated about the importance of payment coverage</li> </ul>	of life for those being treated for and survivors of colorectal cancer	<ul> <li>Obtain baseline measure of number of women eligible to attend support group</li> <li>Survey for quality of life of support group members</li> <li>Number attending the support group</li> </ul>	cancer	<ul> <li>Obtain baseline measure of number of potential caregivers</li> <li>Survey for knowledge of care giving and quality of life</li> <li>Number of caregivers who receive training</li> <li>Assess for change in knowledge of care giving</li> <li>Number of caregivers who attend the support group</li> <li>Assess for quality of life</li> </ul>
Increase payment coverage of screening and treatment of colorectal cancer	<ul> <li>Educate policy-makers about the importance for government or insurance coverage of colorectal cancer screening and treatment</li> </ul>	Increase available support and quality of life for those being treated fo	Organize a colorectal cancer support group	Increase available support to caregivers of those living with colorectal cancer	<ul> <li>Provide training to caregivers</li> <li>Organize a caregivers' support group</li> </ul>
71		22		23	



# Table 4. Sample Prostate Cancer Objectives for Tribal Cancer Planning

1			
<b>‡</b>	Strategy	• Evaluation	• Data
			i i
24	Increase awareness of the risk factors for prostate cancer		
	<ul> <li>Implement community education campaigns (mentoring, media, tribal leaders)</li> <li>Implement community awareness campaigns</li> <li>Plan a "men's health fair" to distribute information about cervical health</li> <li>Plan an activity during Prostate Cancer Awareness Month (September)</li> </ul>	<ul> <li>Conduct BRFSS to assess change in level of awareness of risk factors</li> <li>Health fair attendance</li> </ul>	<ul><li>BRFSS</li><li>Health fair roster</li></ul>
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	about having a digital rectal exar	n and PSA
	<ul> <li>Develop community awareness campaign</li> <li>Plan a "men's health day" to distribute information about prostate health</li> <li>Plan an activity in connection with Prostate Cancer Awareness Month (September)</li> </ul>	<ul> <li>Activities of awareness campaign</li> <li>Number of persons served at men's health day</li> <li>Measure awareness of importance of screening</li> <li>Survey community for change in level of awareness</li> </ul>	• BRFSS • Health fair roster
<b>7</b>	Increase access to appropriate treatment for prostate cancer		
	<ul> <li>Educate PCPs to refer men for prostate cancer services</li> <li>Provide transportation to treatment site</li> </ul>	<ul> <li>Number of PCPs receiving information</li> <li>Count rides given to treatment facilities</li> <li>Change in number of persons receiving treatment</li> </ul>	<ul> <li>Navigator</li> <li>Program</li> <li>records</li> <li>Chart</li> <li>Audit</li> </ul>
27	Increase payment coverage of diagnosis and treatment of prostate cancer	er	
27	<ul> <li>Educate policy-makers about the importance for government or insurance coverage of costs of screening and treatment of prostate cancer</li> </ul>	<ul> <li>Obtain baseline measure of how screening and treatment are paid</li> <li>Number of policy-makers educated</li> <li>Survey PCPs for change from private parties to insurance or public entities</li> </ul>	<ul><li>Contract</li><li>Health</li><li>Clinic</li><li>Survey</li></ul>



28	Increase available support and quality of life for those being treated for and survivors of prostate cancer	and survivors of prostate cancer	
	Organize a prostate cancer support group	<ul> <li>Obtain baseline measure of number of men eligible to attend support group</li> <li>Survey for quality of life of support group members</li> <li>Number attending the support group</li> </ul>	• Chart Audit
29	Increase available support to caregivers of those living with prostate cancer	icer	
	<ul> <li>Provide training to caregivers</li> <li>Organize a caregivers' support group</li> </ul>	<ul> <li>Obtain baseline measure of number of potential caregivers</li> <li>Survey for knowledge of care giving and quality of life</li> <li>Number of caregivers who receive training</li> <li>Assess for change in knowledge of care giving</li> <li>Number of caregivers who attend the support group</li> <li>Assess for quality of life</li> </ul>	<ul> <li>Survey         Survivors         Training         rosters         Pre/Post         test eval     </li> </ul>



### Table 5. Sample Lung Cancer Objectives for Tribal Cancer Planning

48	Table 3. Sample Fung Cancer Objectives for the		۰.
	# Objective		
	• Strategy	Evaluation	• Data
m	30 Increase awareness of the risk factors for lung cancer		
	<ul> <li>Implement community education campaigns (mentoring, media, tribal leaders)</li> <li>in the community education campaigns (mentoring, media, tribal leaders)</li> <li>in the community education campaigns (mentoring, media, tribal leaders)</li> </ul>	Number of people who received information on risk factors Conduct Tribal BRFSS	• BRFSS
m	3   Contribute to the knowledge and understanding of the risk of tobacco use among AI/AN to tribal leadership and communities	among AI/AN to tribal leader	ship and
	<ul> <li>Present research findings and evidence based best practices to tribal leadership</li> <li>at local, regional and statewide gatherings and conferences</li> </ul>	Regional Tobacco Policy Conference attendance	
m	32 Increase percentage of PCPs and dentists who ask patients 6 years and older about tobacco use at every visit	er about tobacco use at every	, visit
	<ul> <li>S</li> <li>Provide culturally-sensitive education to PCPs for counseling of patient</li> <li>Y</li> <li>C</li> </ul>	Survey PCPs Number of providers who re- ceive information Yearly chart audit to see if rate changes	<ul><li>Chart Audit</li><li>Survey to Providers</li></ul>
m	33 Reduce the percentage of adult current tobacco users		
	<ul> <li>Promote a ban on advertising of tobacco products</li> <li>Implement a community education campaign (mentoring, media, tribal leaders)</li> <li>Establish tribal anti-tobacco councils</li> <li>Increase cost of tobacco products</li> <li>Promote smoke-free environments in tribal communities</li> <li>Encourage community event to be commercial tobacco free</li> <li>Encourage community event to be commercial tobacco free</li> </ul>	Obtain baseline data on use from BRFSS/YTS Obtain baseline data on media advertising efforts Report of activities of tribal antitobacco councils Report on tobacco product price Survey media for changes in frequency of advertising Survey users for change in percentage of adult current tobacco	BRFSS     Tribal     BRFSS     Oregon     Healthy     Teens     YTS
20		quit within six months	



Count parents who attend support group Count media program contacts Count number of youths educated about ritual use REFSS/YTS for baseline data Number of pregnant women Contacted about smoking patterns Corrigion Corri
contact: hs edu- n pro- th local omen ng n for terns
them accordingly  Form parent support group  Form parent support group  Encourage tribal health programs to continue to collaborate with local community providers and schools to use established tobacco cessation curriculums  Provide community technical assistance in addressing tobacco control issues  Provide smoking among pregnant women  BRFSS/YTS for baseline data contacted about ritual use  Number of tribal health programs collaborating with local providers  BRFSS/YTS for baseline data  Number of pregnant women contacted about smoking patterns  Survey pregnant women for changes in smoking patterns
Form parent support group  Form parent support group  Encourage tribal health programs to continue to collaborate with local community providers and schools to use established tobacco cessation curriculums  Provide community technical assistance in addressing tobacco control issues targeting youth  Reduce smoking among pregnant women  Reduce smoking among pregnant women  BRFSS/Y  Oevelop community awareness campaign  Target WIC and First Steps users  Provide education materials to Primary Care Providers  Survey F  Cated ab
·
• Providers

					Sample Object	tive	s for Tribal Ca	nce	er Planning
	State quitlines number of AI/AN users		• YTS • Tribal activity log		• BRFSS		<ul> <li>Tribal activity log</li> </ul>		• SYNAR data
	<ul> <li>Obtain baseline data on existing cessation services</li> <li>Obtain report of use and success rates</li> <li>Count number of PCPs who treat</li> <li>Record successful attempts to obtain funding</li> <li>Survey for changes in number of existing cessation services</li> </ul>		<ul> <li>Obtain baseline data from YTS</li> <li>Count media campaign contacts</li> <li>Survey for changes in awareness of cessation services</li> </ul>	sites	<ul> <li>Tribal BRFSS</li> <li>Count number of community areas with anti-ETS policies</li> <li>Yearly site visits by CHRs to obtain data on change in rates of ETS in homes and daycare sites</li> </ul>	Il facilities	<ul> <li>Obtain baseline data on ETS in community areas</li> <li>Random visits to ascertain compliance with request at casinos and community areas</li> </ul>	inors	<ul> <li>Obtain baseline of state SYNAR records</li> <li>Observational survey to see change in compliance with law</li> </ul>
Increase availability of tobacco use cessation services	<ul> <li>Expand the number of health care providers offering nicotine dependence treatment</li> <li>Improve systems by which a provider can refer patients to nicotine dependence treatment</li> <li>Expand patient education and offer nicotine dependence treatment for patients receiving care</li> <li>Provide technical assistance to nicotine dependence treatment providers to bill Medicaid, Medicare and third party insurers for services</li> </ul>	Increase awareness of tobacco use cessation services	<ul> <li>Develop media campaign to increase awareness</li> <li>Develop and distribute a listing of tobacco cessation services</li> </ul>	Increase environmental tobacco smoke (ETS) free homes and daycare sites	• Implement a community education campaign (mentoring, media, tribal leaders)	Increase/strengthen environmental tobacco smoke (ETS) policy in tribal facilities	<ul> <li>Institute a weekly smoke-free day at casinos</li> <li>Implement locally developed policies on clean indoor air in community areas</li> <li>Showcase efforts of early adopters</li> </ul>	Increase enforcement of laws regulating sales of tobacco products to minors	<ul> <li>Inform all local sellers of tobacco products about increased enforcement</li> <li>Implement protocol for reporting illegal sales without revealing identify of informant</li> </ul>
37		38		39		4		4	



### Sample Objectives for Tribal Cancer Planning

		3	aii	ipie Objectives ioi	111	bal Cancer Planning
Navigator     Program     records     Chart     Audit		<ul><li>Contract</li><li>Health</li><li>Chart</li><li>Audit</li></ul>		• Chart Audit		<ul> <li>Survey</li> <li>Survivors</li> <li>Training</li> <li>rosters</li> <li>Pre/Post</li> <li>test eval</li> </ul>
<ul> <li>Survey PCPs on referrals</li> <li>Number of PCPs who receive information on how to refer</li> <li>Rides to treatment facilities</li> <li>Number of persons receiving incentive</li> <li>Yearly chart audit for change in number of persons receiving treatment</li> </ul>		<ul> <li>Obtain baseline measure of how screening and treatment are paid</li> <li>Record # of policy-makers educated about the importance of payment coverage</li> </ul>	and survivors of lung cancer	<ul> <li>Obtain baseline measure of number of women eligible to attend support group</li> <li>Survey for quality of life of support group members</li> <li>Number attending the support group</li> </ul>		<ul> <li>Obtain baseline measure of number of potential caregivers</li> <li>Survey for knowledge of care giving and quality of life</li> <li>Number of caregivers who receive training</li> <li>Number of caregivers who attend the support group</li> <li>Assess for quality of life</li> </ul>
<ul> <li>Educate PCPs to refer persons for lung cancer services</li> <li>Provide transportation to clinic or treatment site</li> <li>Provide incentive to get diagnosis/treatment</li> <li>Provide childcare</li> </ul>	Increase payment coverage of screening and treatment of lung cancer	<ul> <li>Educate policy-makers about the importance for use of Tobacco Settlement money to fund diagnosis and treatment of lung cancer</li> <li>Educate policy-makers about the importance for government or insurance coverage of lung cancer treatment</li> </ul>	Increase available support and quality of life for those being treated for	Organize a lung cancer support group	Increase available support to caregivers of those living with lung cancer	<ul> <li>Provide training to caregivers</li> <li>Organize a caregivers' support group</li> </ul>
	43		4		45	
	<ul> <li>Survey PCPs on referrals</li> <li>Number of PCPs who receive information on how to refer</li> <li>Rides to treatment facilities</li> <li>Number of persons receiving incentive</li> <li>Yearly chart audit for change in number of persons receiving treatment</li> </ul>	<ul> <li>Educate PCPs to refer persons for lung cancer services</li> <li>Provide transportation to clinic or treatment site</li> <li>Provide childcare</li> <li>Provide childcare</li></ul>	<ul> <li>Educate PCPs to refer persons for lung cancer services</li> <li>Provide transportation to clinic or treatment site</li> <li>Provide transportation to clinic or treatment</li> <li>Program records incentive</li> <li>Chart</li> <li>Audit</li> <li>Contract</li> <li>Contract</li> <li>Educate policy-makers about the importance for government or insurance coverage of lung cancer treatment</li> <li>Educate policy-makers about the importance for government or insurance coverage of lung cancer treatment</li> <li>Educate policy-makers about the importance for government or insurance of payment coverage</li> </ul>	<ul> <li>Educate PCPs to refer persons for lung cancer services</li> <li>Educate PCPs to refer persons for lung cancer services</li> <li>Provide transportation to clinic or treatment</li> <li>Provide childcare</li> <li>Provide childcare</li> <li>Provide childcare</li> <li>Provide childcare</li> <li>Provide childcare</li> <li>Provide childcare</li> <li>Chart</li> <li>Chart</li> <li>Audit</li> <li>Audit</li> <li>Audit</li> <li>Audit</li> <li>Audit</li> </ul>	<ul> <li>Educate PCPs to refer persons for lung cancer services</li> <li>Provide transportation to clinic or treatment site</li> <li>Provide transportation to clinic or treatment</li> <li>Provide childcare</li> <li>Number of persons receiving incentive</li> <li>Vaery chart audit for change in number of persons receiving treatment</li> <li>Educate policy-makers about the importance for use of Tobacco Settlement or insurance</li> <li>Coverage of lung cancer treatment</li> <li>Increase available support and quality of life for those being treated for and survivors of lung cancer</li> <li>Organize a lung cancer support group</li> <li>Organize a lung cancer support group</li> <li>Survey for quality of life of support group members</li> <li>Number attending the support</li> </ul>	<ul> <li>Educate PCPs to refer persons for lung cancer services</li> <li>Provide transportation to clinic or treatment site</li> <li>Provide childcare</li> <li>Provi</li></ul>

Childhood

Survivors

Cancer

number of persons eligible to

Obtain baseline measure of

Support

Survey for quality of life before

support group begins

attend support group

group roster

### Survey to Survey of **Providers** Navigator Program Contract records Survey Health Chart Clinic Audit • Data Table 6. Sample Childhood Cancer Objectives for Tribal Cancer Planning Obtain baseline measure of how Record number of PCPs receiv-Record # of policy-makers edu-Count number of days housing cated about the importance of Survey PCPs for change in pay-Count number of PCPs who Record change in number of persons receiving treatment Rides to treatment facilities insurance or public entities ers from private parties to Increase the percentage of primary care providers (PCPs) who recognize childhood cancer signs receive information on childhood cancers payment coverage provided to family treatment is paid Increase available support to persons being treated for and survivors of childhood cancer ing information Survey PCPs Evaluation Increase access and referrals to appropriate treatment for childhood cancer Educate PCP about high risk pool and family insurance assistance programs Educate policy-makers about the importance for government or insurance Increase payment coverage for treatment of childhood cancer Educate PCPs to refer children to childhood cancer centers coverage of costs of treatment of childhood cancer Promote idea within professional organizations Educate PCPs about childhood cancer signs Provide transportation to treatment site Provide housing at treatment site Objective Strategy



#

46

47

Organize a childhood cancer support group

4

Refer to existing cancer support groups

**4**8

20	Increase available support to parents/caregivers of persons living with childhood cancer	nildhood cancer	
	<ul> <li>Provide training to caregivers</li> <li>Organize a parents and caregivers' support group</li> <li>Survey existing resources</li> <li>Refer parent/caregiver to existing resources</li> </ul>	<ul> <li>Obtain baseline measure of number of potential caregivers</li> <li>Survey for knowledge of care giving and quality of life</li> <li>Record the number of caregivers who receive training</li> <li>Assess for change in knowledge of care giving</li> <li>Record the number of caregivers who attend the support group</li> <li>Assess for quality of life</li> </ul>	<ul> <li>Survey of Childhood Cancer</li> <li>Survivors</li> <li>Caregiver training rosters</li> <li>Pre/Port test eval</li> </ul>
2	Increase education of school personnel and primary care providers about late and long term effects of childhood cancer	ıt late and long term effects of ch	hildhood
	• Partner with Leukemia & Lymphoma Society for Welcome Back program	<ul> <li>Baseline of childhood cancer survivors</li> <li>Survey Knowledge of providers and teachers</li> </ul>	<ul><li>Survey of Providers</li><li>Survey of Teachers</li></ul>



### Table 7. Sample Cancer Objectives for Tribal Cancer Planning

#		Objective		
	•	Strategy	• Evaluation	• Data
52		Increase Tribal Cancer Control Capacity		
	•	Participate in Northwest Tribal Cancer Coalition	• Coalition Evaluation	NTCCP Coalition Evaluation and Signin Sheets
53		Support the gathering and maintenance of data systems to understand the cancer related needs of AI/ANs.	ne cancer related needs of AI/A	Ns.
	• •	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.	Number of tribal data linkages Change in reclassified cancer cases Establishment of cancer registry	<ul><li>Tribal cancer registry</li><li>Tribal registry linkage</li></ul>
54		Increase awareness of the risk factors for all cancers		
	•	Implement a community education campaign (mentoring, media, tribal leaders)	Number of people who received information on risk factors BRFSS	• BRFSS
55		Educate physicians on accessing clinical guidelines		
	•	Plan, implement, and evaluate training for providers	Numhber of providers trained Training Evaluation	<ul> <li>Training Responses</li> </ul>
26		Increase the availability and effectiveness of culturally relevant cancer prevention & risk reduction materials and programs for AI/AN	evention & risk reduction mate	rials and
25	• •	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	Native CIRCLE catalog inclusion Use satisfaction survey	• Native CIRCLE



27	Increase the proportion of AI/AN adults 18 and older who eat at least five servings of fruits & vegetables every day	e servings of fruits & vegetables	every day	
	• 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	• BRFSS	• BRFSS	
28	Increase the proportion of AI/AN adults 18 and older who meet Healthy People 2010 recommendations for moderate and vigorous activity	People 2010 recommendations	for	
	<ul> <li>Increase public awareness of the benefits of physical activity</li> <li>Increase the number of worksites that provide opportunities and policies that promote physical activity</li> <li>Promote physical activity</li> <li>Encourage communities to provide physical activity opportunities and establish policies that promote physical activity</li> <li>Partner with transportation and land use planners to increase walk-ability and bike-ability of communities</li> <li>Collaborate with faith organizations to increase opportunities for physical activity within their organization and for their entire community</li> <li>Develop and disseminate physical activity materials, including model physical</li> </ul>	BRFSS	• BRFSS	
	activity prescription forms, for use by health professionals		J	2
29	Implement new cancer screening and early detection tests as they become recommended by national organizations	ne recommended by national or		am
	<ul> <li>Track new screening and early detections test and recommendations</li> </ul>	<ul> <li>Number of new screening implemented</li> </ul>	National     Cancer     Institute	pie Obje
09	Increase access to appropriate diagnosis and treatment for all cancers		CCI	ecti
	<ul> <li>Educate PCPs to refer persons for appropriate diagnostic and treatment services</li> <li>Provide transportation to treatment site</li> </ul>	Record number of PCPs receiving information Count rides given to treatment facilities Record change in number of persons receiving treatment	Navigator     Program     records     Chart     Audit	ves for Iribal Ca
19	Inform AI/AN cancer patients of the opportunity to participate in clinical trials	l trials		nce
	• Determine availability/appropriateness of developing a formal relationship with an NCI designated comprehensive cancer center to assist in areas such as clinical trials.	• Number of patients enrolled in clinical trials	NCI     clinical     trials	r Plannin
			8	g



				ample Objective	C3 1	or Tribal Canc		laillillig
• IHS • Chart Audit		<ul><li>Contract Health</li><li>Clinic Survey</li></ul>		<ul> <li>Patient navigation programs</li> </ul>		Clinic     Protocol		• Chart Audit
Economic analysis     Number of partner     organizations     Examine distance patients travel     for care		<ul> <li>Obtain baseline measure of how treatment is paid</li> <li>Number of policy-makers educated about payment coverage</li> </ul>	ancer care coordination	<ul> <li>Number of new programs implemented</li> <li>Financial support for programs</li> <li>Patients receiving care summary</li> </ul>		<ul> <li>Survey of available resources</li> <li>Team roster</li> <li>Meeting schedule</li> <li>Trainings attended</li> </ul>		<ul><li>Patient Care Plan</li><li>Survey of Patient and Family</li></ul>
<ul> <li>Determine the feasibility of developing a comprehensive cancer center.</li> <li>Support the development of the Oncology Support Program (OSP) to provide primary care and cancer support services for Al/AN who live outside urban areas who remain for cancer care. Incorporate complementary and integrative care into the program</li> <li>Economic analysis</li> <li>HS</li> <li>Cha</li> <li>Cha</li> <li>Wumber of partner</li> <li>Cha</li> <li>Cha</li> <li>Mumber of partner</li> <li>NTCha</li> <li>Examine distance patients travel indicates that partnering is appropriate</li> <li>Assist tribal sites with training and physician consulting support so cancer patients can receive care closer to home</li> </ul>	Increase payment coverage of treatment of all cancers	<ul> <li>Educate policy-makers about the importance for government or insurance coverage of costs of treatment of all cancers</li> </ul>	Establish a patient navigation program to ensure timely and efficient cancer care coordination	<ul> <li>Establish a cancer patient tracking system to monitor long-term cancer side effects and recurrence.</li> <li>Identify collaborative and financial means to support establishing a coordinated patient navigation program</li> <li>Provide each cancer patient at the completion of treatment with an "end of treatment" summary</li> </ul>	Create and maintain interdisciplinary palliative care team	<ul> <li>Assess resources available including: physician, nurse, pharmacist, social services, behavioral health, and spiritual support</li> <li>Invite participants from available disciplines</li> <li>Convene regular team meetings</li> <li>Provide training for palliative care team members</li> </ul>	Create a palliative plan of care for cancer survivors	<ul> <li>Comprehensive assessment of patient with guidance of interdisciplinary team</li> <li>Education patient and caregiver about the specific cancer and its care</li> <li>Address survivor goals, values, and needs</li> </ul>
<b>62</b>	63		64		<b>6</b> 2		99	



<b>67</b>	Establish a palliative care program to provide support for dying at or near home	r home	
	<ul> <li>Implement a modified Helping Hands Program</li> <li>Develop culturally appropriate advance directives and education programs that adhere to all legal requirements and allow for a "natural" death</li> <li>Establish a system wide grief and bereavement program</li> <li>Assist families and clinics in identifying and establishing respite services</li> <li>Develop culturally appropriate palliative care materials for providers, family members and community members</li> </ul>	End of life programs established Count of those assisted	Survey of Clinics
89	Develop a comprehensive survivorship program to support cancer survivors and address issues facing them	ors and address issues facing th	em
	<ul> <li>Educate patients to reduce cancer risks through modification of behavioral risk factors</li> <li>Maintain an updated cancer patient resource guide and cancer care support kit</li> <li>Expand spiritual support for patients and families who are away from home for lengthy periods of time</li> <li>Develop community based support groups working with patients and families of survivors to provide assistance to cancer patients returning home after cancer treatment</li> <li>Offer training for individuals willing to facilitate cancer support groups.</li> </ul>	Need assessments conducted Number of programs established Patients enrolled in program	• Chart Audit
	<ul> <li>Conduct a needs assessment of Al/AN cancer survivors</li> <li>Develop a nutrition guide that recommends traditional and subsistence foods, which can be substituted for standard recommended healthy foods, for Al/AN patients during and after treatment</li> <li>Collaborate with the Fred Hutchinson Cancer Research Center Survivorship Center of Excellence efforts to establish survivorship clinics</li> </ul>		
69	Increase available support to caregivers of persons living with cancer		
	<ul> <li>Provide training to caregivers</li> <li>Organize a caregivers' support group</li> <li>Partner with Cancer Navigator if available</li> </ul>	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> <li>Survey Survivors</li> <li>Training rosters</li> <li>Pre/Post test eval</li> </ul>

### **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 Al/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 Al/AN.

Traditional foods are another cultural strength. Many Al/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 Al/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 Al/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 I) 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.

#### I) 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 Al/AN men and 40.9% of Al/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 Al/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 Al/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.

<u>Environmental Tobacco Smoke and Cancer</u> - The Environmental Protection Agency has classified second-hand 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 Al/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., BRFSS/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-Al/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 Al/AN input into materials development
  - · Develop our own materials, using native leaders and role models
  - Utilize Al/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**



Obj	jective	Increase resources available for Cancer Treatment of Tribal Patients
Stra	ntegy	Organize Cancer Health Fair
Org	ganizers	Val Vargas-Thomas, Colville Tribal Health Program Manager Cliff Evans, Cancer Patient Care Eric Vinson, Northwest Portland Area Indian Health Board
Prir	mary audience	IHS Clinicians, Tribal Health Department, External Cancer Programs
Activity	Location	Nespelem Community Center
Acti	Date(s) & time(s)	November 15th, 2006 at 10 a.m.
Out	tcomes	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		
Rep	orted by	Val Vargas-Thomas Eric Vinson





## **Colville Confederated Tribes**

Obj	ective	Increase cancer education
Stra	tegy	Host Cancer 101 Training
Org	ganizers	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
Prin	nary audience	Colville Tribal Health Department, Coville Tribal Community Members
/ity	Location	Nespelem Tribal Longhouse
Activity	Date(s) & time(s)	March 26th & 27th 2007 8:00 am to 4:00 pm
Out	ccomes	15 participants. Presentations by Cancer Information Service, Northwest Portland Area Indian Health Board, Leukemia & Lymphoma Society
Additional comments		
Rep	orted by	Val Vargas-Thomas Eric Vinson



# Confederated Tribes of Warm Springs



Obj	ective	<ul> <li>Increase awareness of breast and cervical cancer issues</li> <li>Educate women about cervical and breast cancer screenings</li> <li>Increase health literacy of women</li> </ul>
Stra	itegy	<ol> <li>Monthly hour long Women of Wellness (W.O.W.) meetings during lunch</li> <li>Nutrition education through lunch preparation</li> <li>Provide craft activity in a half-hour or less</li> <li>Present a new and different health education topic every month</li> <li>Offer opportunities to learn Breast Self-Examination (BSE)</li> </ol>
Org	ganizers	Judith E. Charley, Community Health Information Specialist
Prin	nary audience	All women in Warm Springs community, especially women aged forty years and older
ity	Location	Warm Springs I.H.S. Health and Wellness Center Atrium
Activity	Date(s) & time(s)	Planning meeting: first Wednesday of each month W.O.W. education forum: second Thursday of each month
Out	tcomes	Monthly W.O.W. meetings Positive evaluation and continuous funding since 1996
Additional comments		
Rep	orted by	Judith E. Charley





# **Confederated Tribes of Warm Springs**

Obj	ective	<ul> <li>Increase Awareness of Cancer</li> <li>Educate community about comprehensive cancer issues</li> <li>Increase financial resources available for Cancer Survivors</li> <li>Increase health literacy of women</li> </ul>
Stra	itegy	<ol> <li>Performance of the play "Understanding" written by Shane Mitchell</li> <li>Pi-ume-sha Health Fair including:         <ul> <li>Pamphlets and Education Information</li> <li>Breastfeeding friendly area</li> <li>20 Booths included: Nutrition, Diabetes &amp; Cancer Screening, Transportation safety, Healthy Traditional lifestyle, Cancer Information</li> <li>Participants completed 16 or more booths to receive a complete Passport, Nike T-shirt and water bottle.</li> </ul> </li> </ol>
Org	ganizers	Yvonne Iverson, Warm Springs Community Health Programs Celeste Whitewolf, JD, Native Peoples Circle of Hope
Prin	nary 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
Act	Date(s) & time(s)	June 23-27, 2004
Out	tcomes	25 community members attended "Understanding" play 320 participated and 248 completed <i>Passport</i> and received incentives
Additional comments		<ul> <li>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</li> <li>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</li> </ul>
Rep	orted by	Yvonne Iverson



## Lower Elwha Tribe



Obj	ective	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 Canoe Journey  3. Participate in Komen Race for the Cure  4. Health Fair  5. Cancer Support Group  6. Lymphedema Prevention Excercise Group
Org	ganizers	Roberta Kimberly, Community Health Representative
Prin	nary audience	Native women on the Olympic Peninsula
>-	Location	Health Fair, Cancer Support Group, and Exercise Group: Lower Elwha Tribe Canoe Journey: Varies depending year and host
Activity	Date(s) & time(s)	Health Fair: Monthly Cancer Support Group: Monthly Lymphedema Prevention Excercise Group: Monthly Canoe Journey: Weekly during Spring and Summer
Outcomes		Pink Paddle Project distribution and sharing of cancer education materials during Canoe Journey (5,000+ attendance) Ongoing education and support meetings
Additional comments		
Reported by		Roberta Kimberly



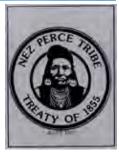


### **Nez Perce Tribe**

Obj	ective	Address comprehensive cancer needs in Nez Perce Tribe and community
Stra	itegy	<ul> <li>Nez Perce Tribal Cancer Coalition</li> <li>I. Weekly meetings to discuss current issues</li> <li>2. Organize training for Nimiipuu healthcare providers (primary, dental, pharmacy, and community)</li> </ul>
Org	ganizers	Susie Ellenwood, Alina George, Jaci McCormack, and Margrett McCormack
Prin	nary audience	Nez Perce Tribal Community, Nimiipuu Health, Cancer Survivors, Cancer Caregivers
Activity	Location	Nimiipuu Health Center
Acti	Date(s) & time(s)	Weekly on Wednesday
Out	tcomes	8 coalition members attend Organized fundraisers for cancer survivor support include: • September 2007 Benefit Golf Tournament
Additional comments		
Rep	orted by	Susie Ellenwood



### **Nez Perce Tribe**



Obj	ective	<ol> <li>To increase awareness of cancer and cancer survivor issues</li> <li>Reduce the risk of cancer and to enhance recovery from a cancer diagnosis</li> <li>To encourage walking as a part of a program of regular excercise</li> </ol>
Stra	tegy	<ol> <li>Conquer Cancer Fair &amp; Women's Health Check (May 10, 2004)</li> <li>Community health walk, cancer education, and screening</li> <li>Participants receive pedometers, supporting health information, and walking journal from the Support Group</li> <li>Presentation by Cancer Survivors</li> </ol>
Org	anizers	Celeste Whitewolf, JD, Native Peoples Circle of Hope Veronica "Mae" Taylor, Nez Perce Tribe, Cancer Support Group Chair
Prim	nary audience	Nez Perce community, Cancer Survivors, Family of Cancer Survivors, Cancer Caregivers
Activity	Location	Nez Perce Track
Act	Date(s) & time(s)	May 10, 2004
Out	comes	45 participants
Additional comments		
Rep	orted by	Veronica "Mae" Taylor, Nez Perce Tribe, Cancer Support Group Chair





## **Nooksack Tribe**

Obj	ective	<ol> <li>To raise community awareness on the need for cancer prevention screening for all age groups and particularly men</li> <li>To pilot some specific science based interventions to influence screening seeking behaviors that link health services with the education program</li> <li>To address the needs of cancer survivors and caretakers</li> <li>To address grief and loss for those who have lost loved ones to cancer</li> </ol>
Stra	tegy	<ol> <li>Share the work the Tribe has done in Cancer Control with the community,</li> <li>Feature cancer survivors and caregivers as guest speakers.</li> <li>Identify further needs and to explore strategies to address them</li> <li>Provide baseline screening information for all age groups including men and women.</li> </ol>
Org	anizers	Molissa Leyva, Nooksack Clinic Manager June Strickland, PhD, Univeristy of Washington Teresa Guthrie RN,MN, Spirit of EAGLES
Prin	nary audience	Families in the Nooksack Tribe
Activity	Location	Nooksack Tribe
Acti	Date(s) & time(s)	7pm - 10:00 pm June 3, 2004
Out	comes	50 participants
Additional comments		
Reported by		Molissa Leyva, Nooksack Clinic Manager



## **Suquamish Tribe**



Obj	ective	<ul> <li>Increase Awareness of Cancer</li> <li>Educate community about cancer risk factors</li> <li>Reduce Prevalence of Smoking</li> </ul>
Strategy		<ul> <li>Community Health Fair</li> <li>Information provided on cancer, resources, prevention (appropriate diet, exercise, and healthy lifestyles), and screening.</li> <li>Smokers interested in quitting are provided information and referrals to cessation resources for individualized intervention</li> <li>Nutrition Bingo <ul> <li>Includes: low fat, high fiber, reducing sodium, and food safety</li> <li>Correct responses receive prizes such as bean soup mix (high fiber)</li> </ul> </li> <li>Annual Women's Health Day</li> <li>Lunch and discussion of breast and cervical cancer prevention and screening. Speaker is usually a cancer survivor, if possible a tribal member.</li> <li>Calendar Project</li> <li>Calendar with nutrition, tobacco, diabetes, cancer and physical activity tips, pictures of tribal members engaged in healthy activity produced yearly.</li> <li>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.</li> </ul>
Org	ganizers	Barbara Hoffman, Community Health Nurse
Prin	nary audience	Tribal Elders, members and employees
	Location	Suquamish Tribal Center
Activity	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**

Obj	ective	<ul> <li>Increase Awareness of Cancer</li> <li>Educate community about cancer risk factors</li> <li>Reduce Prevalence of Smoking</li> </ul>
Stra	itegy	<ul> <li>Tobacco Cessation</li> <li>Provide NRT or other drugs to assist in smoking cessation. Provide individual counseling. Provide information about tobacco quit line at community events.</li> <li>Second Hand Smoke Exposure Reduction</li> <li>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.</li> <li>Tobacco Prevention</li> <li>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.</li> <li>Nutrition Education</li> <li>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.</li> </ul>
Org	ganizers	Barbara Hoffman, Community Health Nurse
Prin	nary audience	Tribal Elders, members and employees
Activity	Location	Suquamish Tribal Center
Act	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> <li>Increase awareness of Cancer among men in Fort Hall community</li> <li>Educate men about cancer, cancer prevention, and cancer screening</li> </ol>
Strategy		<ol> <li>Advertise event in the local Shoshone-Bannock Newspaper and post flyers throughout the community at central locations</li> <li>Provide incentives (screwdrivers, socket sets, chain saw) from from Home Depot</li> <li>General cancer educational sessions include:         <ul> <li>Cancer Survivors</li> <li>Local healthcare providers</li> <li>Resource providers</li> <li>Educational booths</li> </ul> </li> <li>Health Fair sessions will be interactive with participants actively involved with an emphasis on spirituality, healing, and up-to-date information on cancer.</li> </ol>
Organizers		Roanna Stump, CHR Shoshone-Bannock Tribal Health
Primary audience		Men in the Fort Hall community
vity	Location	Tribal Business Center, Dome Room, Fort Hall, Idaho
Activity	Date(s) & time(s)	June 17, 2004
Outcomes		40 participants
Additional comments		
Reported by		Roanna Stump, Shoshone-Bannock Tribe





## Stillaguamish Tribe

Objective		<ol> <li>Lung cancer and heart disease risk and reduction</li> <li>Quit smoking</li> <li>Breast exams and mammograms</li> <li>Lump awareness</li> </ol>
Strategy		<ol> <li>Smoking Cessation Classes</li> <li>Tobacco focused exam</li> <li>Postcards, fliers at fair booths</li> <li>Free patches, pills and gum</li> <li>October month – targeted for Breast Cancer reduction, exams and Cancer reduction beads</li> <li>Identify smoker by questions</li> </ol>
Organizers		Anne Hurd ARNP – Clinic Director Melanie Hein – Chemical Dependency Supervisor and Tobacco Coordinator
Primary audience		The attendees to the "Baby Boomers 50,000 Mile Check-up.
Activity	Location	<ol> <li>Clinic – Exam room</li> <li>Conference teaching room</li> <li>Community gatherings</li> <li>Festival of River - August</li> </ol>
	Date(s) & time(s)	Festival on the River: Second weekend in August Clinic: Ongoing
Outcomes		<ul> <li>Scheduled mammograms appointments were attended</li> <li>Fewer complaints about being pancake flat on mammography</li> </ul>
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
ity	Location	Yakama Nation Eagle Selatsee Auditorium, Toppenish, Washington
Activity	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> <li>Unite local survivors, families, providers, and community members</li> <li>Education both prevention, survivor and survivorship issues.</li> <li>Developing partnerships with local organizations and increase the network of support in the community.</li> <li>Engage the community in an activity that centered around wellness.</li> <li>Raise funds for support of American Cancer Society</li> </ol>
Strategy		<ul> <li>Physical activity (Relay on the Rez) that promotes wellness for a cancer prevention and surviorship</li> <li>Resource booths at reception</li> </ul>
Organizers		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
Primary audience		Yakama Tribal members, Yakama Nation and surrounding community
ity	Location	Wapato, Washington
Activity	Date(s) & time(s)	July 15-16, 2006 6:00 pm to 12:00 pm
Outcomes		500 partcipants. 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
Additional comments		
Reported by		Patricia Ike, Yakama Office of Native Survivorship



## Yakama Nation



Objective		<ol> <li>Unite local survivors, families, providers, and community members</li> <li>Education both prevention, survivor and survivorship issues.</li> <li>Developing partnerships with local organizations and increase the network of support in the community .</li> <li>Influence lifestyle trends that lower cancer rates.</li> <li>Engage the community in an activity that centered around wellness.</li> </ol>
Strategy		<ul> <li>Physical activity (Mural Walk) that promotes wellness for a cancer prevention and surviorship</li> <li>Resource booths at reception</li> </ul>
Organizers		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
Primary audience		Yakama Tribal members, Toppenish community
ity	Location	Downtown Toppenish, Washington
Activity	Date(s) & time(s)	May 12, 2006 8:00 am to 4:00 pm
Outcomes		60 partcipants. 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		



### **Appendix B: Constructs for Comprehensive Cancer Control Planning**

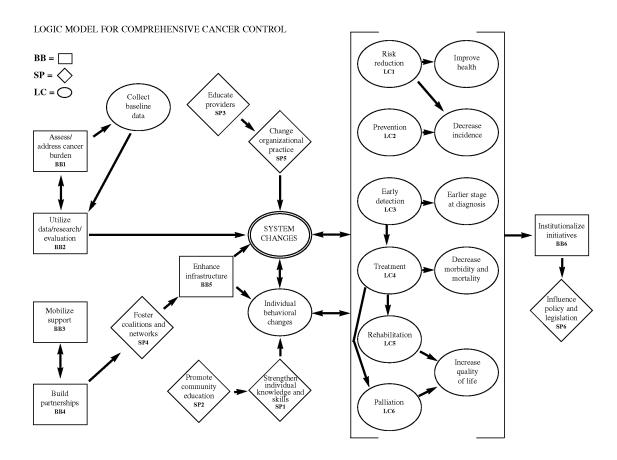
### Framework for Comprehensive Cancer Control

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.

#### Framework for Comprehensive Cancer Prevention and Control What should be done? Phase 1 - Setting Optimal Objectives (data driven) In pertnership with stake-holders b. Identify and assess use fulness of available planning data (e.g., cancer registry, demiclogic, behavioral, environmental, and financial c. Analyze data to identify disease burden populations at risk, risk factors responsible gaps in services, and gaps in data Data or What is achieved? needs, What could be done? unmetneeds Phase 4 - Implementing Effective Strategies re sources Phase 2 - Determining Possible Strategies and data and data gap (outcome driven) (science driven) in consultation with stakeholders. Data from process cooperation with stakeholden Select relevant and affordable a. Review basic research data for use in Knowledge for Data on risk factor counseling, he aith e ducation, intervention strategies impact evaluations Decision Making interventions to target populations and community interventions pplied re sean Review applied research data for rele c. Conduct interventions Monitor and evaluate interventions efficacy, and cost-effectiveness of Data on possible intervention Repeat cycle to evaluate progress Data on enhance programs and coverage strategies ocietal influences target populations d utilization barrie partner resources and fundraising po ssibilities What can be done? Phase 3 - Planning Feasible Strategies (capacity driven) In coordination with stakeholders a. Set realistic priorities Review existing partner programs and coverage c. Identify additional resources Define roles and determine networking approach e. Advocate for additional resources



#### **Building Blocks for Comprehensive Cancer Planning and Implementation**



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.



### **Appendix C: References**

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