Comprehensive Cancer Plan *for the* Alaska Tribal Health System

• *2005-2010* •

ALASKA NATIVE TRIBAL HEALTH CONSORTIUM
CANCER PROGRAM

Dedication:

Dedicated to Alaska Natives who make the cancer journey.
May their pain and suffering return as skills and knowledge
so that Alaska Natives and all people can be cancer-free.

Acknowledgements:

To honor the waterways that are so important to Alaska Native life, the Alaska Native Tribal Health Consortium Cancer Program logo shows a boat with a cancer patient at the bow navigating the way. Behind the patient are family, friends, and healthcare providers supporting the cancer journey.

The patient is the focus of the journey and takes charge of fighting the disease—spiritually, mentally, emotionally, and physically. However, the patient does not make the journey alone.

We make the journey together.

Special thanks to:

The planning work groups and chairs whose energy, interest and dedication to our vision became the foundation for this plan.

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The development of the Alaska Tribal Health System Comprehensive Cancer Plan was facilitated by the staff of the Alaska Native Tribal Health Consortium, Office of Alaska Native Health Research.

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VISION

Alaska Natives will be cancer-free

MISSION

Provide Alaska Natives with cancer prevention, screening, diagnosis, treatment, survivorship and palliative education and care through a comprehensive, integrated Alaska Native cancer program

GOAL

Reduce cancer death and disease among Alaska Natives

EXECUTIVE SUMMARY

CANCER is the leading cause of death for Alaska Natives. Patterns of cancer for Alaska Natives differ from all other racial groups in the United States. Cancer rates among Alaska Natives also differ from other American Indian groups.

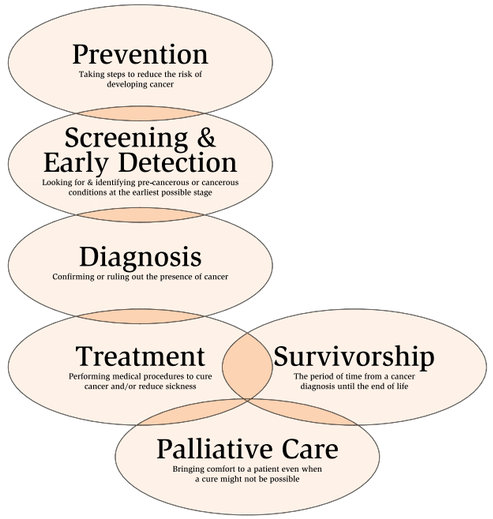
Cancer creates a physical, psychological, social and economic burden on individuals, families, and communities. This burden can be dramatically reduced as advances in prevention, early detection, diagnosis, treatment, survivorship, and palliative care are made available to Alaska Natives. Recognizing this need, the Alaska Native Tribal Health Consortium (ANTHC) completed a systematic planning process to begin to address the cancer care needs of Alaska Natives through a comprehensive approach.

In 2003, ANTHC received a planning grant from the Centers for Disease Control and Prevention (CDC) to develop the first comprehensive cancer plan for Alaska Natives.

A comprehensive approach to cancer planning was undertaken with the following guiding principles:

- *Development of goals, objectives and strategies was data driven. The Alaska Tribal Health System (ATHS) has thirty-five years of cancer incidence and mortality data from the Alaska Native Tumor Registry.*
- *The full spectrum of cancer was addressed, from prevention and early detection through survivorship and palliative care.*
- *Alaska Native leadership from tribal health organizations around the state appointed representatives to workgroups to participate in the planning process.*
- *Efforts were made to identify all cancer-related activities within the ATHS, with a desire to provide cancer care as close to home as possible.*
- *Workgroups included representatives from the National Cancer Institute, the American Cancer Society and the State of Alaska Comprehensive Cancer Control Program to coordinate and integrate resources.*
- *The planning process was multidisciplinary, including representatives from administration, epidemiology, health education, program services, surveillance, clinical services, and cancer survivors.*

All cancer component sections were developed by representatives from throughout the ATHS and other partners who worked many hours as members of one or more workgroups. There were six major workgroups: Prevention, Screening/Early Detection, Diagnosis, Treatment, Survivorship, and Palliative Care. In addition, there were three sub-groups within Prevention (tobacco, nutrition, physical activity and alcohol and environmental contamination). A Core Planning Group (CPG) oversaw the plan development. Cancer planning workgroup members, tribal boards and others formed a partnership to address the cancer burden in a cooperative and comprehensive manner.



The ATHS comprehensive cancer plan addresses the burden of cancer in Alaska Natives and proposes goals, objectives and strategies to help reduce the cancer burden.

The plan will be reviewed annually to determine if the goals, objectives and strategies remain relevant and updates made as needed. Work plans to implement the goals will be developed and resources identified to help move the plan forward. It will also serve as a resource for tribes and tribal organizations who wish to focus on their own specific cancer issues with grants and other support.

60 percent of Alaska Natives live in small, remote communities not connected to a road system.

The challenges faced in delivering comprehensive cancer care to Alaska Natives are well documented. Vast geographic distances, extreme weather conditions, subsistence lifestyles, cultural differences, transportation challenges, medical disparities, language barriers, limited resources, and a widely dispersed and variable health care delivery system are all factors that were taken into consideration in developing the ATHS Cancer Plan.

While all cancers and all cancer care components are important, four specific areas are identified in the plan as high priorities. These are tobacco, colorectal cancer screening, patient navigation, and palliative care.

Some cancers can be prevented. For many cancers, it is not easy to identify the cause, but when a cause can be identified, steps can be taken to prevent the disease. Avoiding tobacco, eating a healthy diet, being physically active, maintaining a healthy weight, and avoiding exposure to certain chemicals have been shown to prevent some cancers.

Some cancers can be detected early. Screening tests are done on people who have no signs or symptoms of cancer. Screening can detect some cancers when they have just begun to grow. Pap tests, mammograms, and colorectal exams are examples of cancer screening tests. Unfortunately, there are no proven and effective screening tests for most kinds of cancer.

Alaska has 229 federally recognized tribes scattered across the 586,412 square miles of predominantly roadless state. According to the 2005 U.S. Census estimates, the total number of Alaska Native residents is 126,095. The geography of Alaska presents special challenges to Alaska Natives – 60 percent of Alaska Natives live in small, remote communities not connected to a road system.

One challenge is coordinating cancer treatment. A patient may be treated in multiple clinics within the Alaska Native Medical Center (ANMC), as well as radiation, laboratory, and other departments. Other facilities, in or outside of Anchorage, may also be involved. Cancer treatment may mean leaving home and many trips to Anchorage; and long absences from family, jobs, traditional foods, spiritual support and familiar social settings. Treatment may require traveling among care providers located at different facilities. People may encounter unfamiliar settings with problems of travel, language, and cultural differences. Navigating this system is difficult and it is important to find ways to help minimize issues that arise when a cancer diagnosis is made.

Our vision is that Alaska Natives will be cancer-free. Within the Alaska Tribal Health System Comprehensive Cancer Plan are the goals, objectives and strategies to make that vision a reality.

Alaska Tribal Health System

Regional Health Consortia

Area Map Key by Region

REGION NUMBER	ORGANIZATION
	Alaska Native Tribal Health Consortium
1	Arctic Slope Native Association
2	Maniilaq Association
3	Norton Sound Health Corporation
4	Yukon-Kuskokwim Health Corporation
5	Bristol Bay Area Health Corporation
6	Aleutian/Pribilof Islands Association
7	Eastern Aleutian Tribes
8	Kodiak Area Native Association
9	Southcentral Alaska Alaska Native Medical Center (jointly managed by ANTHC & SCF) Southcentral Foundation
10	Chugachmiut
11	Copper River Native Association
12	Mt. Sanford Tribal Consortium
13	SouthEast Alaska Regional Health Consortium
16	Tanana Chiefs Conference

Tribal and/or Local Health Programs

REGION NUMBER	ORGANIZATION
1	UIC (Barrow)
3	Diomede, Native Village of
4	Kwinhagak, Native Village of Akiachak Native Community
6	St. George Traditional Council
8	Karluk, Native Village of
9	Southcentral Alaska • Eklutna, Native Village of • Ninilchik Village Traditional Council • Seldovia Village Tribe • Chickaloon Village Traditional Council • Knik Tribal Council • Tyonek, Native Village of • Kenaitze Indian Tribe, IRA
10	Valdez Native Tribe Eyak, Native Village of
11	Chitina Traditional Council
13	Hoonah Indian Association Yakutat Tlingit Tribe
14	Ketchikan Indian Corporation
15	Metlakatla Indian Community
17	Council of Athabascan Tribal Governments

ARCTIC OCEAN

BEAUFORT SEA

CHUKCHI SEA

BERING SEA

BRISTOL BAY

NORTON SOUND

GULF OF ALASKA

PACIFIC OCEAN

ARCTIC CIRCLE

Barrow
UIC
Wainwright
Atqasuk
Point Lay
Nuiqsut
Prudhoe Bay
Kaktovik
Point Hope
Kivalina
Noatak
Anaktuvuk Pass
Arctic Village
Kotzebue
Kiana
Noorvik
Selawik
Ambler
Kobuk
Shungnak
Wiseman
Venetie
Chalkyitsik
Fort Yukon
Evansville
Bettles
Alatna
Allakaket
Beaver
Birch Creek
Shishmaref
Diomede
Wales
Deering
Buckland
Hughes
Stevens Village
Circle
Central
Brevig Mission
Teller
King Island
Huslia
Rampart
Livengood
Council
White Mountain
Koyuk
Tanana
Minto
Fairbanks
Eagle
Gambell
Savoonga
Nome
Solomon
Golovin
Elim
Koyukuk
Galena
Nulato
Ruby
Manley Hot Springs
Nenana
North Pole
Shaktoolik
Kaltag
Unalakleet
Delta Junction
Healy Lake
Dot Lake
Dry Creek
Tok
Tetlin
Tanacross
Lake Minchumina
Healy
Cantwell
Northway
Mentasta Lake
Paxson
Slana
Telida
Mt. McKinley
Takotna
McGrath
Medfra
Nikolai
Chistochina
Nabesna
Stebbins
Saint Michael
Chuloonawick
Kotlik
Bill Moore Slough
Hamilton
Emmonak
Alakanuk
Numan Iqua
Grayling
Anvik
Shageluk
Gulkana
Gakona
Tazlina
Copper Center
Talkeetna
Mountain Village
Saint Mary's
Andreafski
Marshall
Pitkas Point
Pilot Station
Russian Mission
Scammon Bay
Paimiut
Hooper Bay
Chevak
Holy Cross
Ohogamiut
Upper Kalskag
Lower Kalskag
Crooked Creek
Chuathbaluk
Aniak
Napamiute
Georgetown
Sleetmute
Stony River
Red Devil
Skwentna
Willow
Susitna
Wasilla
Palmer
Knik
Eklutna
Chickaloon
Sutton
Chitina
McCarthy
Newtok
Tuluksak
Nunapitchuk
Kasigluk
Atmautluak
Akiak
Akiachak
Kwethluk
Tununak
Umkumiute
Mekoryuk
Toksook Bay
Nightmute
Bethel
Napakiak
Oscarville
Napaskiak
Lime Village
Anchorage
Tyonek
Hope
Whittier
Tatitlek
Valdez
Eyak
Cordova
Chefornak
Tuntutuliak
Eek
Kenaitze
Nikiski
Kenai
Soldotna
Kasilof
Clam Gulch
Ninilchik
Nikolaevsk
Kachemak
Homer
Seldovia
Seward
Chenega Bay
Kipnuk
Kongiganak
Kwigillingok
Quinhagak
Port Alsworth
Nondalton
Pedro Bay
Iliamna
Newhalen
Koliganek
New Stuyahok
Goodnews Bay
Platinum
Twin Hills
Togiak
Aleknagik
Ekwok
Dillingham
Manokotak
Igiugig
Levelock
Portage Creek
Ekuk
Clark's Point
Naknek
South Naknek
King Salmon
Kokhanok
Nanwalek
Port Graham
Egegik
Yakutat
Klukwan
Skagway
Haines
Juneau
Hoonah
Pelican
Tenakee Springs
Angoon
Kake
Sitka
Petersburg
Wrangell
Hyder
Afognak
Ouzinkie
Kodiak
Port Lions
Pilot Point
Ugashik
Karluk
Larsen Bay
Old Harbor
Akhiok
Port Heiden
Chignik Lagoon
Chignik
Chignik Lake
Nelson Lagoon
Ivanof Bay
Perryville
Cold Bay
False Pass
King Cove
Sand Point
Unga
Pauloff Harbor
Saint Paul
Saint George
Attu
Shemya Station
Adak Station
Atka
Akutan
Dutch Harbor
Unalaska
Fort Glenn
Nikolski
Ketchikan
Saxman
Klawock
Craig
Kasaan
Metlakatla
Hydaburg

Relative Size of Alaska and the Contiguous United States

- Village
- Village with Clinic
- Subregional Clinic
- Regional Hospital
- Alaska Native Medical Center (jointly managed by ANTHC & SCF)
- Tribal or Local Health Program
- Regional Area Border
- Road

N

SCALE IN MILES

0 50 100 150 300

7/2004

CHAPTER 1

INTRODUCTION

CANCER occurs when some of the millions of cells in our bodies become damaged and grow without control and order. Cancer can develop anywhere in the body. It can develop in an organ, such as the stomach, or it can start in places where solid cancers do not form, such as in the blood or bone marrow.

Cancer is not just one disease, but more than 100 different diseases. Not only are there many kinds of cancer, there are many different causes of cancer. Still, all cancers have things in common. Cancer cells grow and divide rapidly, robbing nutrients from healthy cells. Normally, growth of new cells and loss of old cells is kept in balance. With cancer, the balance is lost.

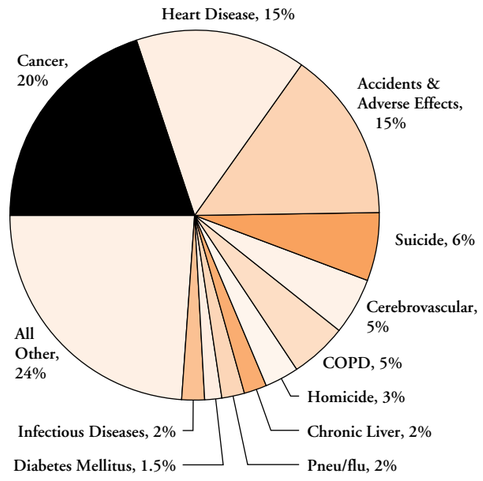
Cancer was not a major cause of death in Alaska Natives during the first part of the 20th century. The main causes of death at that time were infectious diseases. In 1943, 43 percent of all Alaska Native deaths were due to tuberculosis. By the early 1990s cancer was the leading cause of death for Alaska Natives and remains so today.

In the United States, the overall cancer death rate declined throughout the 1990s. In contrast, Alaska Native cancer death rates increased. Alaska Native women have the highest cancer death rate of all racial and ethnic groups, while Alaska Native men rank third after African American and Hawaiian men. The number of new patients diagnosed with cancer each year continues to rise.

The Alaska Native population continues to increase and the elder age group (65+) is the fastest growing group. The increase in the Alaska Native population and increased life expectancy has resulted in an increased demand on the Alaska Native health care system. The aging population will require additional health care services for chronic illnesses, including cancer.

Leading causes of death among Alaska Natives 1998-2002

Source: Alaska Native Tumor Registry



Incidence for all cancers combined among Alaska Natives is similar to U.S. Whites. However, rates for selective cancers differ significantly from U.S. Whites:

- *Lung cancer in Alaska Natives exceeds U.S. Whites rate among men and women by 48 percent,*
- *Cancers of the oral cavity, digestive tract sites and the kidney are several fold higher than U.S. Whites,*
- *Breast cancer has increased and is now as high or higher than in U.S. White women,*
- *Prostate cancer occurs less often but is increasing over time,*
- *Cervical cancer, once several times higher in Alaska Native women, now occurs at a rate similar to U.S. White women,*
- *Several cancers occur less often in Alaska Natives than U.S. Whites. Melanoma of the skin, lymphoma (Hodgkin's and non-Hodgkin's), and cancers of the urinary bladder, uterus and brain occur less often.*

Some cancers can be prevented. For instance, the best way to prevent lung cancer is to avoid smoking tobacco. For many cancers, it is not easy to identify the cause.

Some cancers can be detected early. Screening tests (for people without symptoms) can detect some cancers at an early stage. Pap tests, mammograms, and colorectal exams are examples of cancer screening tests. Unfortunately, there are no proven and effective screening tests for most kinds of cancer. The earlier cancer is diagnosed, the more likely it can be treated and cured. Many cancer screenings cannot be done in rural communities. Alaska Natives may have to travel hundreds of miles to be screened for some common cancers. Costs of travel to receive the test and any follow-up care needed may exceed the costs to conduct the test itself.

The earlier cancer is diagnosed, the more likely it can be treated and cured. An accurate diagnosis requires a tissue biopsy and examination under the microscope by a pathologist. Staging is a procedure used to identify the extent cancer has spread and thus the severity of the cancer. Diagnostic procedures are varied, complex, and require special expertise, equipment, and facilities available in only a few larger communities in Alaska.

In the United States, the overall cancer death rate declined throughout the 1990s. In contrast, Alaska Native cancer death rates increased.

Cancer treatment includes a wide range of available options that can cure the disease or increase length of life. Although most diagnostic procedures are available in Alaska, not all treatment programs are available in the state. For Alaska Natives, the problems associated with a cancer treatment are even greater than for people living in less remote communities.

Cancer survivors have special concerns. People who receive a cancer diagnosis face problems such as an increased risk or fear that cancer will recur; late-appearing side effects stemming from treatment; changes in family roles and daily activities; rehabilitation care; and the financial impact of cancer treatment and short- or long-term disability. Alaska Native cancer survivors also have unique challenges, including returning to their communities after having been away for extended periods of time; difficulty traveling long distances for continuing care; inability to hunt and fish or obtain subsistence foods as before; and lack of support groups in the villages.

Palliative care is important when a cure may not be possible. This care concentrates on preventing or lessening the severity of pain and other symptoms to achieve the best quality of life for people dying or suffering from a life-threatening disease. It does not exclude treatments such as chemotherapy and radiation. End-of-life decisions are complicated when rural communities lack health care providers, pharmaceuticals, equipment, and supplies to assist individuals and families with this stage of life.

Surveillance describes the collection, analysis and interpretation of health data. In order to make good decisions on how to best use resources to address concerns about cancer, it is important to have accurate and timely data. All aspects of the cancer plan, from defining the problem and guiding the planning to evaluating programs, rely on strong surveillance activities.

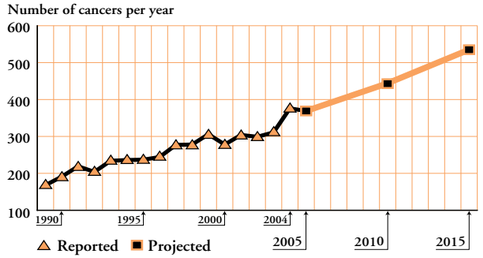
CHAPTER 2

THE BURDEN OF CANCER IN ALASKA NATIVES

CANCER incidence data for Alaska Natives was first reported in 1976. The most important finding at that time was that the overall cancer incidence rate among Alaska Natives was slightly lower than in U.S. Whites, but higher than expected. It also showed that cancer patterns and mortality rates among Alaska Natives were different from U.S. Whites and for certain cancers rates were several times higher than in U.S. Whites. For instance, Alaska Native rates were higher for cancers of the nasopharynx, stomach, liver, gallbladder, cervix, and kidney. On the other hand Alaska Native rates were lower for prostate, breast, uterus, bladder, and brain cancers as well as leukemia and lymphoma.

Recent data (1999-2003) show that cancer rates have increased 35 percent since the original report, and rates have increased markedly for cancers of the lung, breast, prostate, and slightly for uterine cancer. Alaska Natives now have higher incidence rates of lung, colon/rectum, kidney, stomach and all other digestive system sites. Compared to U.S. Whites, cancer rates among Alaska Natives continue to be relatively lower for cancers of the prostate, urinary bladder, melanoma, leukemia, and lymphoma.

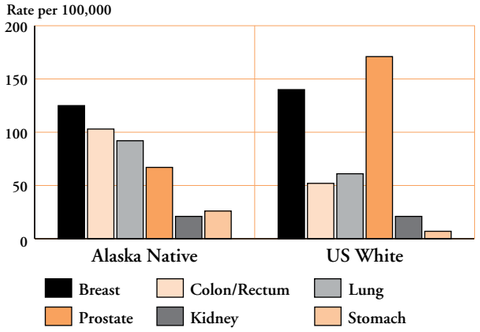
Number of Invasive Cancers among Alaska Natives Reported During 1999-2004 and Projected Numbers of Cancers for Years 2010-2015 *Source: Alaska Native Tumor Registry*



Rates for Alaska Native males are slightly lower than U.S. males while rates for Alaska Native females are eighteen percent higher. For the years 1999 to 2003, the five most frequently diagnosed cancers were colon/rectum, lung, breast, prostate, and stomach. For males, the leading cancer sites are lung, colorectal, and prostate. Among Alaska Native women, breast cancer is the leading cancer followed by colorectal and lung.

5 Year Average Annual Age-Adjusted Cancer Incidence Rates in Alaska Natives and US Whites 1999-2003

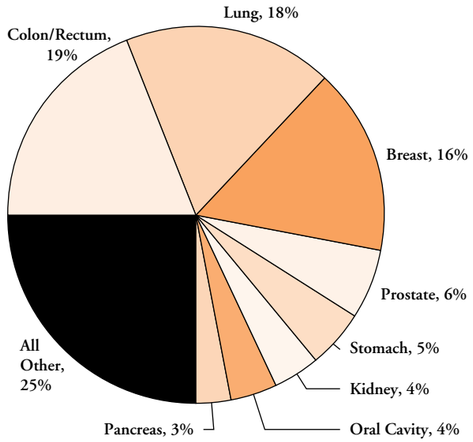
Source: Alaska Native Tumor Registry



Patterns of cancer for Alaska Natives differ from all other racial groups in the U.S. including Whites, Blacks, and other minority populations. Cancer rates among Alaska Natives also differ from those of American Indians of New Mexico and Arizona. In particular, rates among Alaska Natives are nearly two-fold higher overall and for almost all cancer sites compared to American Indians in New Mexico.

Since 1969 numbers of new invasive cancers diagnosed each year has increased over four-fold. The rate of new cancers diagnosed each year is now similar for Alaska Natives and U.S. Whites.[1]

Percent of New Invasive Cancers Diagnosed Among Alaska Natives in 1999-2003 *Source: Alaska Native Tumor Registry*

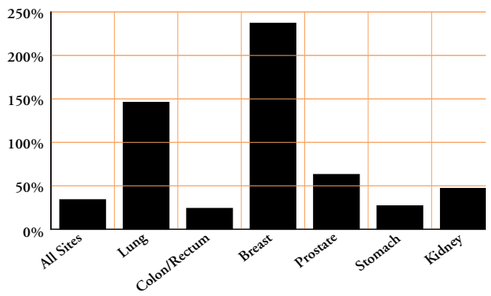


The rate of new cancer patients diagnosed each year increased 34 percent between the five-year period from 1969-1973 to the period 1999-2003.[2] About 300 Alaska Natives are diagnosed with invasive cancer each year.

Life expectancy (69.4 years) for Alaska Natives still lags behind other racial and ethnic groups. However, it has increased dramatically since 1950 when life expectancy at birth was 47 years.

Percent Change of Cancer Incidence Rates from Five Year Period 1969-1973 to 1999-2003 Alaska Native Men and Women Combined

Source: Alaska Native Tumor Registry



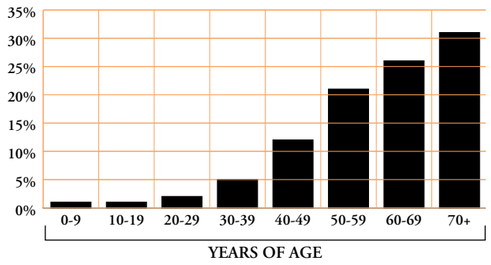
Most cancers are diagnosed in older people. In Alaska Natives, 88 percent of cancers are diagnosed in patients 40 years of age and older. Aging of the population and an increase in life expectancy contributes, in part, to the increase in the number of new cancer patients.[3]

Calculations of cancer survival show that among Alaska Native patients diagnosed with cancer, less than half (37%) will be alive five years after diagnosis.[4] However, the survival rate is improving. For patients diagnosed with cancer from 1984 to 1998, the five-year survival rate was six percent higher than for those diagnosed from 1969 to 1983.

Comparison of Alaska Native and U.S. White five-year survival rates (1992-2002) show that for all cancers combined, Alaska Natives have a seventeen percent lower five-year survival rate. Differences in survival rates between Alaska Natives and U.S. Whites are due, in part, to the types of cancer that occur more frequently in Alaska Natives. Many cancers with poor survival rates occur more often in Alaska Natives including cancers of the lung, esophagus, pancreas, gallbladder and nasopharynx. For breast, stomach, prostate, and cervical cancer, Alaska Native survival rates are similar to U.S. Whites. For two sites, liver and uterus, Alaska Natives are more likely than U.S. Whites to survive five years.

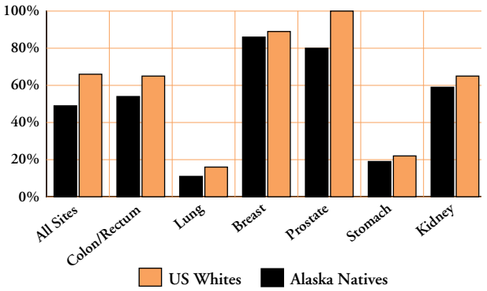
Percent of All Cancers by Age at Diagnosis Alaska Native Men and Women Combined, 1999-2003

Source: Alaska Native Tumor Registry



Percent Surviving Five Years after Diagnosis Alaska Natives and US Whites 1992-2002

Source: Alaska Native Tumor Registry



The death rate for all cancer sites is higher for Alaska Natives than for all Alaskans (1991-1998).[5] In 1999, the cancer death rate was 238/100,000 for Alaska Natives and 193/100,000 for all Alaskans.[6] Although overall U.S. cancer death rates declined throughout the 1990s, Alaska Native cancer death rates did not decline.

In the ten-year period from 1992 to 2002, Alaska Native mortality rates from cancer were 35 percent higher than for U.S. Whites. For the period from 1998 to 2002, cancer mortality rates among Alaska Native women were the highest of any racial or ethnic group in the United States, while Alaska Native men ranked second after African American men.[7]

Alaska Native Tumor Registry

The Alaska Native Tumor Registry (ANTR) provides data on cancer in Alaska Natives since 1969. Over the years, the ANTR has received strong support from the National Cancer Institute. In 2000, ANTR became a full participant in the National Cancer Institute Surveillance Epidemiology and End Results (SEER) Program. The ANTR has consistently adhered to SEER standards and guidelines for case identification, data collection, coding, and follow-up methods. The registry records invasive cancers diagnosed in Alaska Natives who are residents of Alaska at the time of diagnosis and who provide documentation of eligibility for healthcare from the Indian Health Service. Alaska Native cancer patients are identified statewide from hospital tumor registries, hospital and outpatient lists of discharge diagnoses and purpose of visit, pathology reports, death certificates, and from the Cancer Surveillance System at Fred Hutchinson Cancer Research Center in Seattle, Washington. Follow-up status is determined at least annually for all patients by review of medical and death records.

The ANTR tracks changes in cancer rates, as well as diagnosis, treatment, and survival rates. It provides information on trends and helps identify areas needing intervention and research. It serves as an information base to compare cancer patterns in Alaska Natives to other populations.

CHAPTER 3

PREVENTION

Prevention identifies factors such as lifestyle, heredity and environment that can lead to the development of cancer, and provides interventions to help reduce risk of cancer.

Goal for Prevention: Work together to prevent cancer among Alaska Natives

Cancer is the result of a complex mixture of factors related to lifestyle, heredity, and environment. Some of these factors are within an individual's control, while others are not. For example, a person can choose not to use tobacco, but has no control over inherited factors associated with sex or race.

Risk factors are conditions that increase the likelihood that cancer might occur. Protective factors are conditions that decrease the likelihood that cancer might occur. For example, smoking is a risk factor for lung cancer whereas maintaining a healthy weight is a protective factor for breast cancer.

Primary prevention of cancer includes actions taken by individuals, communities, tribes, governments, or other groups to prevent the occurrence of cancer, such as health-promoting lifestyle choices and through control of environmental risk factors.

Much of the promise for cancer prevention comes from studies that show strong associations between lifestyle factors and specific cancers. The most consistent finding, over decades of research by the National Cancer Institute (NCI) and other cancer research agencies worldwide, is the strong association between tobacco use and various cancers. For example, lung cancer death rates in the United States mirror smoking patterns – decreases in lung cancer death rates follow decreases in smoking.

Other examples of modifiable cancer risk factors include alcohol consumption associated with oral, esophageal, and breast cancers; physical inactivity associated with colon and breast cancers; and obesity associated with increased risk of colon, breast and endometrial cancers. In summary, avoiding excessive alcohol consumption, being physically active, maintaining a recommended body mass index (BMI), and eating foods low in fat and high in whole grains, fruits and vegetables may be protective factors. However, when compared with tobacco exposure, the effect of factors such as environmental contaminants appear smaller, and the strength of evidence less strong.

TOBACCO

Introduction

Cancer in now the leading cause of death in Alaska, with 42 percent of cancer deaths attributed to tobacco use. At a time when cancer-related death has been declining among most ethnic groups in the United States, cancer deaths are increasing among Alaska Natives. Lung cancer has been the leading cause of cancer death among Alaska Natives since 1997. Alaska Natives have the highest rates of tobacco use among all populations in Alaska. The prevalence of cigarette smoking in Alaska Natives/American Indians is 43 percent (the highest of any group in the United States), while the prevelance of smoking in the general U.S. population is 23 percent. Consistent with their high rate of tobacco use, Alaska Natives experience disproportionate rates of tobacco-related deaths. Tobacco use also causes heart disease, stroke, and lung disease and is an independent risk factor for diabetes. It can lead to premature death and contributes to Sudden Infant Death Syndrome (SIDS). The burden of tobacco use among Alaska Natives is significant both in quality and length of life and monetary costs. The annual cost of treating tobacco-related diseases in Alaska is estimated to be over $50 million.

Tobacco kills not just those who choose to smoke, but also non-smokers who are exposed to smoke from other people's cigarettes. Exposure to environmental tobacco smoke (ETS) is associated with an increased risk of lower respiratory tract infections, bronchitis and pneumonia, increased prevalence of fluid in the middle ear, increased severity of asthma symptoms in children and increased risk for new cases of asthma in children who have not previously displayed symptoms. Clean Indoor Air policies that prohibit use of tobacco in workplaces, in public, and other areas, strive to eliminate exposure to ETS.

Though the use of spit tobacco (ST) is generally thought to be less harmful to an individual than smoking, ST use results in exposure to nicotine and carcinogens that can increase the risk of oral cancers, and may serve as a gateway drug to cigarette use. "Iqmik" is a homemade form of spit tobacco, sometimes referred to as "Blackbull" or "Dediguss" commonly used in some Alaska Native populations. Use of ST among Alaska Native young women is increasing. In some regions of Alaska, more than half of pregnant women use spit tobacco products.

Readiness for change of tobacco use behaviors has evolved since the first Clean Indoor Air ordinance in 1998 in the Alaska Native community of Bethel. Contributing factors in the shift in community attitude around tobacco use include the development of culturally appropriate ways of communicating, identifying opportunities for communities to address tobacco use and success through nicotine dependence treatment. Recognition among Alaska tribes and tribal leaders about tobacco use and opportunities for tobacco control have grown substantially.

Tobacco Attributable Cancer Burden

The 2004 Report of the U.S. Surgeon General added evidence to a previous conclusion that smoking causes cancers of the oral cavity, pharynx, larynx, esophagus, lung, and bladder. The same report further identified additional cancers caused by smoking, including cancers of the stomach, cervix, kidney, and pancreas as well as acute myeloid leukemia.

Lung cancer is the leading cause of cancer death in 2005, and cigarette smoking causes the majority of lung cancers. Smoking causes about 90 percent of lung cancer deaths in men and almost 80 percent in women. Compared to non-smokers, men who smoke are 23 times more likely, and women who smoke are 13 times more likely, to develop lung cancer. For smoking attributable cancers, the risk generally increases with the number of cigarettes smoked and the number of years of smoking. The risk decreases after quitting completely, though it may take years.[8]

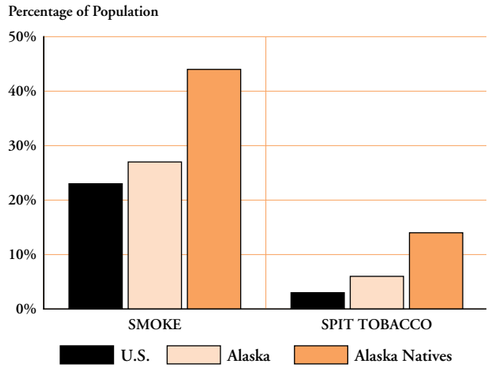
In Alaska, in 2001, it is estimated that 483 deaths were a direct result of smoking. Lung cancer made up one-third of these deaths.[9] A corresponding estimate of tobacco attributable deaths among Alaska Natives is not available. Differences in smoking patterns by race make this number difficult to estimate.

Tobacco kills not just those who choose to smoke, but also non-smokers who are exposed to smoke from other people's cigarettes. ETS, also called secondhand smoke, causes 3,000 lung cancer deaths among non-smokers each year in the United States.[10] ETS exposure is associated with an increased risk of lower respiratory tract infections such as bronchitis and pneumonia. Also associated with ETS is an increased prevalence of fluid in the middle ear, symptoms of upper respiratory tract irritation, and a small, but significant reduction in lung function. Exposure increases the risk and severity of ear infections and asthma symptoms in children.[11]

The 1986 Report of the U.S. Surgeon General concluded that ETS exposure causes lung cancer. Evidence for an increased cancer risk stems from studies that examine the exposure of a non-smoking spouse or child living with an individual who smokes and the exposure of non-smokers to ETS in occupational settings. The 2006 report of the U.S. Surgeon General concluded there is no safe level of exposure to environmental tobacco smoke.[12] It is estimated that 120 Alaskans died as a result of secondhand smoke exposure in 2001.[13] The use of spit tobacco does not result in exposure to products of combustion and it is generally thought to be less harmful to an individual than smoking. [14,15] However, its use has been associated with oral cancer and other oral diseases.[16]

Tobacco Use Rates in Alaska Natives and US Whites, 2004

Source: State of Alaska, Tobacco in the Greatland



Adult Tobacco Use Rates

In 2004, the State of Alaska published a comprehensive tobacco report, which identified the prevalence of cigarette smoking in Alaska Natives at 43 percent, compared with 23 percent in the general U.S. population. [17,18] Similarly, the prevalence of smokeless tobacco use is 14 percent among Alaska Native adults versus 4 percent in the total U.S. population. [19, 20]

Nationally, American Indian and Alaska Native women as a group have the highest prevalence of tobacco use among ethnic minorities in the United States.[21 22 23] Alaska Native women are about twice as likely to smoke (41 %) compared to U.S. White women (23%) or women from other racial groups (19%). Use of spit tobacco is also much higher among Alaska Native women (10%) compared to White women (0.2%) or women of other races (0.8%).

In Alaska, as well as the United States, young adults are more likely to smoke than are older adults. Thirty-seven percent of adult Alaskans ages 18 to 24 smoke cigarettes, compared to 14 percent of adults age 65 and older. National Behavioral Risk Factor Surveillance System (BRFSS) data show that ten percent of adults age 65 and older are current smokers.

Strategy d: Encourage communities to provide physical activity opportunities and establish policies that promote physical activity.

Strategy e: Partner with transportation and land use planners to increase walk-ability and bike-ability of communities.

Strategy f: Collaborate with faith organizations to increase opportunities for physical activity within their organization and for their entire community.

Strategy g: Develop and disseminate physical activity materials, including model physical activity prescription forms, for use by health professionals.

OBJECTIVE PP2: Increase to 85% the proportion of Alaska Native adolescents grades 9 to 12 who report participating in moderate or vigorous physical activity during the past seven days by 2010.

Baseline: *77% YRBS 2003*

Strategy a: Increase the number of schools that provide physical activity opportunities and establish policies that promote physical activity.

Strategy b: Encourage safe areas for physical activity including playgrounds, sidewalks, and designated areas for walking, basketball, baseball, and similar activities.

Strategy c: Encourage the use of school gyms for community recreation on evenings and weekends.

ALCOHOL OBJECTIVES & STRATEGIES

OBJECTIVE PA1: Increase to 80% the proportion of Alaska Native high school students who report not initiating alcohol use ("other than a few sips") before 13 years of age by 2010.

Baseline: *76% YRBS 2003*

Strategy a: Increase alcohol prevention messages targeted at young children, including pre-school and elementary aged children.

Strategy b: Identify and work with commissions, task forces, funding sources, and providers of alcohol prevention services to incorporate strategies and activities to prevent initiation of alcohol use.

OBJECTIVE PA2: Decrease to 6% the proportion of Alaska Native adults 18 and older who drink more alcohol than the moderate level (adult women one drink per day and adult men two drinks per day) by 2010.

Baseline: *8% BRFSS 2003.*

Strategy a: Disseminate patient educational materials on the harmful effects of alcohol to health care providers.

Strategy b: Implement interventions to increase awareness of the relationship between alcohol use and increased risk for cancer.

Strategy c: Increase advocacy efforts targeting leadership and decision-makers to increase the awareness of the societal costs of alcohol use.

Strategy d: Increase Alaska Native specific alcohol prevention initiatives to assure comprehensive, culturally appropriate media messages reach the intended audience.

Strategy e: Increase community ownership of prevention activities and reduce reliance on outside organizations and agencies.

CANCER EDUCATION OBJECTIVE & STRATEGIES:

OBJECTIVE PCE1: Increase the availability and effectiveness of culturally relevant cancer prevention and risk reduction materials and programs for Alaska Natives by 2010.

Baseline: *Cancer education materials have been developed for CHA/Ps. Limited cancer education specific to Alaska Natives is available in 2005.*

Strategy a: Create brochures, handouts, posters that focus on healthy lifestyles for cancer prevention.

Strategy b: Develop educational materials to help Alaska Natives learn to use familiar, inexpensive, and readily available foods to improve their diets and meet nutritional recommendations for cancer prevention.

Strategy c: Increase the number of health education materials that are presented in culturally appropriate ways.

ENVIRONMENTAL CONTAMINANTS

Introduction

Alaska Natives live in one of the healthiest environments in the world, characterized by clean air and water and an abundance of foods. In many parts of the country and the world, population density, proximity to industry, and other factors make exposure to contaminants a part of every day life. This is not the case for most Alaska Natives. There are instances, however, when Alaska Natives may be exposed to environmental contaminants in concentrations which do pose a risk, such as performing renovations in a home that contains asbestos, eating contaminated food, or drinking water from a well that has high levels of arsenic.

When considering the topic of cancer prevention, it is important to have an appreciation of relative risk. As we all know, life is full of risks. We have control over some and others are largely beyond our control. For many people, the risks that are not well defined, or are beyond our control, are the most worrisome. In the case of contaminants, perception of risk is often greater than actual risk. This is partially due to the fact that people are exposed to contaminants through the essential things that they rely upon every day: air, water, food, and consumer products. Additionally, the high degree of attention paid by the media to contaminants may distort perception.

The data on contaminant exposure, particularly among Alaska Natives, is far from complete. It will take years before health implications are clearly understood. The current understanding is that known risks due to contaminants are small. This is particularly true compared to risk factors such as tobacco use.

Whether you live in New York or Nome, it is possible to come in contact with contaminants every day. It may be while drinking a glass of water, filling up the gas tank, or eating lunch. Contaminants are all around us. For the most part, the levels are very low, with no measurable health effect. But when exposure is high, long term, or the immune system is weak, the risk of cancer can increase.

The word 'contaminant' means anything that makes something impure or unclean through contact or mixture. Some contaminants, such as arsenic or radon, occur naturally. Others, such as polychlorinated biphenyls (PCBs), are man-made. Alaska Natives are exposed to contaminants in the same way as people are all over the world: by inhaling impurities in the air; by drinking or eating polluted water or food; or by touching chemicals that can pass through the skin. Gasoline, which contains the carcinogen benzene, is one example. Gasoline evaporates easily into the air where it can be inhaled; if spilled into drinking water it can be ingested; and gasoline can also pass directly through the skin.[95]

When spilled or released into the environment, contaminants pass into soil, air, and water, and from there into living organisms. In this way they become highly mobile and can travel great distances crossing continents and oceans. Some contaminants are highly resilient. Rather than breaking down or being metabolized and excreted, they persist over time in the tissues of living organisms such as fish, birds, sea mammals, and other land and sea creatures that Alaska Natives depend upon for food.

Because of the circulation of ocean and air currents towards the Arctic, Alaska is a deposit area for contaminants that originate from distant industrial and agricultural countries, particularly in Asia.[96] Contaminants also arrive in commercial products used by the military, industry, businesses, local governments, and families in rural villages.

During the past three decades, awareness has grown about the increase of cancer among Alaska Natives. With cancer rates rising, Alaska Natives have questions about the connection between contaminants and cancer, and about the safety of their homes, communities, and the food upon which they depend.

History

Exposure to natural and manmade contaminants is not a new phenomenon for Alaska Natives. The presence of contaminants in air, water, and food has a history dating back to the very first settlements. The earliest recorded habitation in Alaska is the Mesa Site, located in the Brooks Range. This early campsite is thought to have been first established between 11,700 to 13,600 years ago.[97] The people that made the camp used a wood fire in their homes to keep warm, to smoke meat, and probably to repel insects. Inhaling high levels of indoor wood smoke may be the earliest example of exposure to potential carcinogenic contaminants.

Foreign man-made carcinogens are thought to have arrived with the first Russian explorers and fur traders. In 1784, Grigorii Shelikhov established the first permanent Russian settlement at Three Saints Bay on Kodiak Island.[98] Shelikhov brought tobacco, which was already established as a coveted trade good though contact with earlier foreign traders and expeditions.[99] Alcohol and tobacco were among the first introduced carcinogens to reach Alaska and to be used by Alaska Natives.

The fur trade was the driving force behind the exploits of the Russian Period. With the purchase of Alaska by the United States in 1856, the stage was set for expansion into other industries. Efforts were made to improve the territory's infrastructure to support cod, salmon and whaling stations, and to develop opportunities for mining, fur trade, and timber. In the late 1800's

Goals, Objectives & Strategies for Diagnosis

GOAL
Diagnose cancer using the least invasive and most comprehensive procedures.

OBJECTIVE D1: Identify and consolidate state of the art diagnostic services by 2010.

Strategy a: Work with ANMC Cancer Core Business Group (CCBG) to coordinate cancer diagnostic services.

OBJECTIVED2: Identify pathology/laboratory resources needed to support patients and health-care providers with cancer diagnosis and continuing monitoring.

Strategy a: Work with ANMC Pathology/Laboratory staff to develop a business plan to identify needed staff and equipment.

OBJECTIVE D3T8: Establish a mechanism for regional physicians to attend ANMC weekly Tumor Board meetings remotely by 2010 (this objective overlaps with treatment).

***Baseline**: Onsite attendance is the only means to participate in Tumor Board meetings in 2005.*

Strategy a: Identify barriers to implementing a teleconference and video teleconference link for regional physicians to attend ANMC Tumor Board meetings remotely.

Strategy b: Develop a plan to address barriers and provide opportunities for remote provider attendance at ANMC Tumor Board meetings.

CHAPTER 6

TREATMENT

Treatment identifies the best means to address a confirmed diagnosis of cancer in order to cure the disease, and/or reduce illness and sustain quality of life.

Introduction

Alaska Natives receive health care at one of six primary care regional hospitals and clinics (which provide varying levels of cancer care) and at the Alaska Native Medical Center (ANMC), a multi-specialty inpatient and outpatient facility in Anchorage. Approximately 75 percent of all Alaska Natives diagnosed with cancer receive some portion of cancer treatment at ANMC. However, only patients living on the limited road system can drive to ANMC. Others must fly to Anchorage for treatment and may need to remain in the city for weeks or months depending on the duration and type of treatment they receive. They return to Anchorage for additional treatment and follow-up.

Cancer treatment generally involves one or a combination of treatments including: surgery, radiation, chemotherapy, immunotherapy, and hormonal therapy. For some cancers, only surgery is needed. For others, a combination of two and sometimes three treatments (surgery, radiation, and chemotherapy) are needed. The patient's physician, with consultation from other physicians, develops a treatment plan based on the type and stage of cancer, the patient's overall physical health and recommended treatment protocols based on National Comprehensive Cancer Network (NCCN) guidelines. The treatment plan designed for each patient offers the best chance of long-term survival.

With certain cancer diagnoses or disease progression, a decision may be made by the patient to receive only palliative services. These may include palliative radiation and/or chemotherapy.

Cancer surgery is primarily performed by ANMC physicians. To a lesser extent, Alaska Native cancer surgery is also performed at Mt. Edgecombe and under contract with non-Native hospitals. Radiation therapy is outsourced to other Alaska hospitals. In Alaska the only communities that have radiation therapy available are Anchorage and Fairbanks. Chemotherapy is performed primarily in the ANMC outpatient clinic and some regional facilities. Immunotherapy and hormone therapy are also provided at the ANMC Oncology Clinic. Neither gene nor molecular therapies are provided at ANMC. Complementary and integrative therapy, often requested by cancer patients, is only available for Anchorage Service Unit patients at the SCF Primary Care Center. To a lesser extent it is available at some regional hospitals.

Optimal treatment for cancer changes rapidly. Cancer research findings, new drugs and clinical trials provide new ways to treat patients, reduce side effects, and increase survival rates. Advances in surgery have resulted in less invasive surgery including smaller incisions and shorter recovery time. Some of these advances result in increased use of outpatient services and shortened hospital stays. As cancer survivors live longer their need for follow-up care is extended. The most up-to-date cancer treatment recommendations are monitored by ANMC Oncology clinic staff and other healthcare providers. When available and appropriate, they are offered to cancer patients.

Treatment Team

Cancer treatment takes more than the patient and one doctor. It requires an interdisciplinary team approach that may include the patient, family, multiple physician specialists, nurses, nutritionists, social workers, radiology and laboratory staff, community health aides/practitioners and many others.

ANMC staff includes experienced general and sub-specialty surgeons who provide cancer surgery and follow-up care to cancer patients. There is only one oncologist in the Alaska Tribal Health System to meet the needs of newly diagnosed cancer patients as well as provide care for patients undergoing treatment. The oncologist and surgical and medical staff at ANMC also provide consultative support to physicians at the six regional hospitals when patients return home.

Weekly ANMC Tumor Board meetings are held and attended by many medical providers involved with the diagnosis of cancer including oncologists, surgeons, pathologists, radiologists, physician specialists and others. They focus on developing treatment plans for patients using the knowledge and experience of physicians representing various specialties. Primary care physicians, located at regional hospitals, currently cannot participate in Tumor Board meetings by teleconference or with telemedicine to allow "real-time" video and audio participation.

In the regional tribal hospitals there are limited numbers of nurses trained to administer chemotherapy. If trained nursing positions are vacant (and the turnover rate of health care professionals working in remote hospitals is high), patients must travel to ANMC for chemotherapy until other nurses are trained.

Goal, Objectives & Strategies for Survivorship

GOAL
Alaska Native cancer patients and their families will have access to programs and services that address their physical, mental, and spiritual needs to improve the length and quality of life. Access will include addressing the practical issues cancer survivors face on a daily basis during and after cancer treatment.

OBJECTIVE SS1: Enhance clinical care management and follow-up care for cancer patients throughout survivorship to minimize recurrences, detect secondary cancers early, and ensure maximum years of quality of life by 2010.

Baseline: *A formal program for providing follow-up care to patients at 'end of cancer treatment' does not exist within the ATHS in 2005.*

Strategy a: Complete an 'end of cancer treatment' summary for each cancer patient and incorporate it into medical records that are easily accessible to follow-up care providers throughout the ATHS.

Strategy b: Educate and train providers to assess cancer patients for potential complications of cancer treatment, and provide appropriate treatment and referral using National Comprehensive Cancer Network (NCCN) guidelines for treatment of cancer and survivorship.

Strategy c: Develop a tracking system to monitor care of survivors and provide recommended early detection and screening programs

OBJECTIVE SS2: Develop a comprehensive survivorship program to support and guide cancer survivors, family, and friends to address physical, mental, spiritual, and practical issues throughout cancer survivorship by 2010.

Baseline: *There is no comprehensive survivorship program within the ATHS in 2005.*

Strategy a: Provide each cancer patient at the completion of treatment with an "end of treatment" summary.

Strategy b: Educate patients to reduce cancer risks through modification of behavioral risk factors.

Strategy c: Maintain an updated cancer patient information guide and cancer care support kit.

Strategy d: Develop a patient navigation program to improve coordination of care.

Strategy e: Expand spiritual support for patients and families who are away from home for lengthy periods of time.

Strategy f: Identify specific cancer education needs of Alaska Native men, and implement ways to help them understand their own cancer, as well as cancer in that of family and friends.

Strategy g: Develop community based support groups working with patients and families of survivors to provide assistance to cancer patients returning home after cancer treatment.

Strategy h: Offer training for individuals willing to facilitate cancer support groups.

Strategy i: Conduct a needs assessment of Alaska Native cancer survivors.

Strategy j: Develop a nutrition guide that recommends traditional and subsistence foods, which can be substituted for standard recommended healthy foods, for Alaska Native patients during and after treatment.

Strategy k: Collaborate with the Fred Hutchinson Cancer Research Center (FHCRC) Survivorship Center of Excellence and its efforts to establish survivorship clinics in Alaska. Make certain the special survivorship needs of Alaska Natives are addressed.

CHAPTER 8

PALLIATIVE CARE

Palliative Care is the active total care of the body, mind, and spirit of the patient and family. The purpose of palliative care is to prevent or lessen the severity of pain and other symptoms and to achieve the best quality of life for people dying or suffering from a life-altering disease. Palliative care does not exclude therapies aimed at cure, but seeks to complement them.

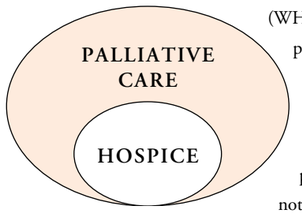
"Our goal should be to help elders live out their lives in comfort, not taking medications they don't need, and not living where they don't want to."

– Andrew Jimmie, Chair
Alaska Native Elder Health Advisor Committee (ANEHAC)[148]

Introduction

Prior to the development and use of the term palliative care, the word hospice was used to indicate care that was provided to patients as they neared the end of life. The word hospice originates from Roman times. Throughout the early centuries the religious community ran establishments dedicated to the care of the sick and dying. These early hospices took a very holistic approach to care and focused on the specific needs of a dying individual.

The distinction between hospice care and palliative care can be confusing. From a medical perspective, palliative care is considered to be a broader term covering all forms of the prevention and treatment of suffering, while hospice is generally seen as a subset of palliative care directed to those nearing the end of life. Palliative care is appropriate whenever symptoms causing pain and suffering are present. The term palliative care was first used during the 1970's. Dr. Balfour Mount opened a hospital-based palliative care program at the Royal Victoria Hospital of McGill University in Montreal, Canada focusing on research and education regarding pain control. He felt the need for a term that was broader than hospice.



The World Health Organization (WHO) developed their palliative care definition in 1990:

Palliative care is the active, total care of patients whose disease is not responsive to curative treatment. Control of pain, other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of illness, in conjunction with cancer treatment. Palliative care:

- *Affirms life and regards dying as a normal process;*
- *Neither hastens nor postpones death;*
- *Provides relief from pain and other distressing symptoms;*
- *Integrates the psychological and spiritual aspects of patient care;*
- *Offers a support system to help patients live as actively as possible until death;*
- *Offers a support system to help the family cope during the patient's illness…and in their own bereavement.*[149]

This definition stresses the terminal nature of chronic diseases such as cancer. However, the term can also be used more generally to refer to anything that alleviates symptoms, even if there is also hope of a cure by other means.

A more recent WHO statement calls palliative care an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness. In some cases, palliative treatments may be used to alleviate the side effects of curative treatments, such as relieving the nausea associated with chemotherapy.

The term palliative care is not generally used when addressing the treatment of certain chronic diseases such as diabetes which, although currently incurable, has treatments that are (ideally) effective enough that it is not considered a progressive or life-threatening disease in the same sense as cancer.

Though the concept of palliative care is not new, in the past most doctors concentrated on aggressively trying to cure patients. Concentrating on making a patient comfortable was seen as

"giving up" on them. As the understanding of the concept of palliative care and its focus on the individual's and family's quality of life, has become more widespread, it is now accepted in the healthcare system as a standard of care. Some systems and organizations have embraced the word "palliative" as an addition to "hospice", such as the National Hospice and Palliative Care Association (NHPCO). As the term "palliative care" becomes more widely used, it is important to recognize that hospice care does not equal palliative care.

As the hospice movement expanded in the United States, so did the national legislative role in hospice and palliative care. The Medicare Hospice Benefit became permanent in 1986, but payments remain low and the requirements for Medicare certified hospices are difficult to meet. In 1991, hospice care was authorized for military hospitals and the Veteran's Administration. In 1992 hospice care was recommended to be included in thee Indian Health Service scope of care. However, no additional funding was allocated to the IHS to develop hospice care.

In 2002 "Means to a Better End: A Report on Dying in America Today." was published.[150] It was the first attempt to develop a comprehensive report on the status of care available for those who are approaching the end of life. State by state it asked:

- *Do state policies support good advance care planning?*
- *What proportion of the state's deaths occur at home?*
- *Is hospice care widely used in the state?*
- *Do hospitals in the state offer pain and palliative care services?*
- *How many elders spend a week or more in intensive care units during the last six months of life?*
- *How well do the state's nursing homes manage their patients' pain?*
- *Do state policies encourage good pain control?*
- *Does the state have enough physicians and nurses who are trained and certified in palliative care?*

The United States as a whole did not "score" well on the report card. While some states did score well in some areas, Alaska did not score well in most categories. Since the report was published, some changes have occurred in Alaska, including a revision of the state's advance care policies, the recognition of the need for palliative care, and the introduction of more palliative care training. However, there is still much work to be done to make palliative care services available to everyone who needs this type of care. Pain management, an integral part of palliative care, remains difficult to provide, particularly in Alaska's remote villages.

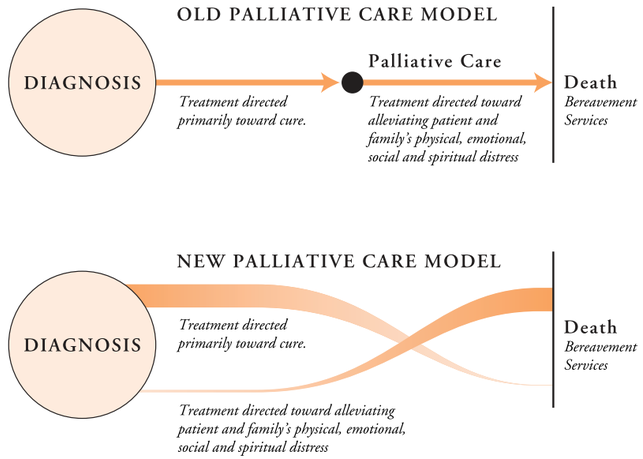
Models of Palliative Care

There are a number of different ways to provide hospice and palliative care. A palliative care consult team may be called in to assist physicians when it is difficult to manage a severely ill patient's pain and symptoms. A palliative care review may occur at the time a patient is diagnosed with a specific disease or when the disease becomes substantially worse. Interdisciplinary palliative care includes several types of healthcare providers and addresses the patient's and family's needs that include pain and symptom management, as well as practical, spiritual and emotional issues. Palliative interventions can improve a patient's quality of life regardless of diagnosis or the ultimate goal of care.[151]

The recognition of palliative care as an area of specialization is growing. Board certification for physicians in palliative care is available through the American Board of Hospice and Palliative Medicine. Certification for nurses and pharmacists in palliative care is now recognized as an important part of an interdisciplinary palliative care team.

The first model of palliative/hospice care integration required it to be provided later in a patient's care. The patient received active curative treatment only. When it became apparent that the patient's disease was not curable, hospice care was suggested. It was often an abrupt and difficult change for patients and their families.

Today, palliative care services recognize the importance of including a palliative care consultation from the time a diagnosis is made even though most of the patient's care is directed toward a cure for the disease.



American Indians/Alaska Natives and Palliative Care

Overall, the life span of AI/ANs has increased about 15 percent in the last 20 years. The life expectancy for Alaska Natives was 47 years in 1950, 67 years in 1984, and 69.4 years in 1998 (Alaska Dept. of Labor). The increase in life expectancy for Alaska Natives is due, in part, to the availability of vaccines and increased access to health care services.

The Spanish Influenza epidemic of 1918 was responsible for the death of thousands of Alaska Natives. Surviving children were often placed in orphanages in Alaska and Washington. Whole villages ceased to exist when the high number of deaths wiped out most of the population. In addition, tuberculosis (TB) contributed significantly to a low life expectancy. By 1900, TB was already exacting a terrible toll in Alaska. During the first half of the 20th century, the presence of the disease continued to increase, posing a serious threat to the survival of Alaska Natives. In 1943, 43 percent of all Alaska Native deaths were due to tuberculosis.

As more health care services became available, the care was directed to disease prevention and acute medical services to meet the needs of the young population. As life expectancy increases, and the first generation of influenza epidemic survivors becomes elders, there is a growing need for health care services that address chronic diseases, aging issues, such as cancer and heart disease, palliative, and end-of-life care. A model of service delivery and funding for services, which primarily originates from the Indian Health Service (IHS), is not readily available to address health care issues of an aging population.

Living longer brings with it increased chronic illness and disability associated with cancer, diabetes, heart disease and other conditions. With chronic diseases, the disease progression and dying process generally occurs more slowly, extends over time and is often highly technological. While the spread of western medicine eradicated many deadly diseases among Alaska Natives, it also shifted the location of dying from the familiarity and psychosocial comfort of the home to hospitals and nursing homes

Although end-of-life programs that provide an option for terminally ill patients to die at home or close to home are available in most communities throughout the United States, Alaska Natives who live in remote Alaska villages often die alone in hospitals and nursing homes hundreds of miles away from home. In rural Alaska, hospitals and nursing homes are usually hundreds of miles away from villages. Transport of ill patients is costly and logistically difficult. Weather, terrain, and distance issues result in most villages being accessible only by airplane. Terminally ill elders often spend the last part of their lives in unfamiliar surroundings and may die alone without the emotional support of family and friends.

There are no funeral homes in many villages. When someone dies a natural death in the village, burials are handled by village residents–involving them in the circle of life and death. Only sixty years ago, Alaska Native elders died at home surrounded by family and friends in the small villages where they had lived most of their lives.

As more Alaska Natives work outside the home, caregivers are torn between family and work obligations. They express concern about the lack of adequate skill and knowledge in caring for elders with complex chronic illnesses.[152]

Medical evacuation by airplane often signals the final departure of a village elder. Unaccustomed to detachment from nature, traditional foods, routines, and the "sterility" of hospitals and nursing homes, many elders fail to thrive and do not survive very long after they leave their village. Family and friends who live in the village are denied an opportunity to share in the elder's wisdom and knowledge and to participate in cultural practices surrounding end-of-life and death. It is difficult for them to bring closure to a loved one's death. Grief is often compounded and complicated.

AI/AN communities are often not aware that the current Western model of health care continues to provide life-prolonging efforts unless specific alternate plans are made. This process is called "advance directives." The patient decides, in advance, what kind of medical care is provided if they can no longer make their wishes known. They sign a legal document directing care providers what services can be provided and those that shouldn't be provided.

In general, the advance directive process does not take into account cultural norms and practices of Native people. The reluctance by clinical providers and families to discuss advance directives may be influenced by cultural sensitivity to talking about a future event that could lead to its occurrence. AI/AN cultures generally rely on the passage of time for decisions of importance to become clear.

"To make decisions about things that might happen around death might cause death." [153]

There is also a sense among many AI/AN families that they have experienced discrimination in access to appropriate life-sustaining healthcare services. Historical mistrust based on racial prejudice and related social disadvantage have skewed their end-of-life decision-making toward fear of declining or withdrawing aggressive, futile interventions.[154] Anecdotally, Alaska Native parents of children dying from diseases such as cancer may be looked down upon by community members if they choose to have their children remain at home at the end-of-life rather than in the hospital in Anchorage.

AI/AN families want a system of care that honors the dying person's individual and family issues. The values include celebrating life, respect for traditional ways, hope for a peaceful death and access to palliative comfort care while surrounded by family and in familiar surroundings. Even in tribes where "death" is taboo for public discussion, caring for someone during this transition is not taboo and palliative care concepts are congruent with traditional beliefs.[155]

Palliative care embraces both the Western clinical processes of pain and symptom management and traditional medicine and spiritual healing which is a natural part of Native life. AI/AN community palliative care programs can develop services based on historic and contemporary local values and beliefs. Collaborative services between agencies and organizations can help the patient and family maintain their role as caregivers and decision makers.

In 1998, to address end-of-life needs of Alaska Natives in the remote villages of Bristol Bay in southwest Alaska, the Robert Wood Johnson Excellence in End-of –Life Care program funded a demonstration project. Because of the high cost and difficulties encountered in trying to deliver end-of-life care services to remote communities, a village-focused volunteer and palliative care program combined with a regionally-based physician and home health nurse to deliver multi-disciplinary palliative care was developed. *The Helping Hands Program* Model blends cultural practices with contemporary medicine to allow Alaska Natives and others living in remote communities to be cared for at home through the end-of-life.

The most important finding of *Helping Hands Program* implementation is that contemporary palliative care combined with traditional customs can create a cost effective, culturally sensitive, palliative care program. By developing a program that incorporates a traditional way of life, indigenous people and others living in remote settings can remain at home, in familiar surroundings, as the end-of-life nears.

The Helping Hands Program demonstrated that the increased number of home deaths has a clear impact on the decrease of costly resources including medical evacuations by airplane and hospitalizations.[156] The modified *Helping Hands Program* model provides an opportunity for other regions in the state to put a practical palliative care program in place. In general, most patients prefer to spend the last part of life in their home community. Developing a palliative care program that begins with the premise that the patient *will* go home, provides an opportunity to identify unique village, regional, ANMC, governmental and private resources to assist the patient. Therefore, it is important that a palliative care discussion takes place at the time of diagnosis, or soon afterwards.

"The hardest part of having Grandma Rose over in Anchorage in a nursing home was the everyday kind of things we couldn't share with her anymore. If we had fresh fried spruce chicken, we couldn't run a plate to her. It saddens me knowing that what she missed was the smell of the water blowing over the bluff on Nushagak Bay. The soft cackle of geese far off in the springtime evening. The warm kiss of a grandchild contrasted with chilly cheeks from playing outdoors. The excitement of the king salmon hitting the beach nets when her sons and daughters, all flecked with scales and gray mud, would bring fresh boiled head and tail chowder. The fragrance of salmonberries on the breeze blowing from the summer tundra. How the fluffy cotton grass bobbed back and forth in the wind. The lonesome wail of the sand hill cranes as they settle down for the night. But the saddest part of all was that the only way she was able to come home was in a casket." — excerpt from a letter

Palliative Care Projects

In 2004, the National Cancer Institute's (NCI) Quality of Cancer Care Committee (QCCC) in collaboration with Indian Health Service provided funds to develop pilot projects that addressed the needs for palliative care in Indian Country. As part of the project, ANTHC received funds to administer and analyze a palliative care survey of healthcare providers (physicians, midlevel practitioners, nurses, pharmacists and social workers). The summary report from the Alaska Native Palliative Care Provider Survey provided information that will help to determine palliative care training and information needs for healthcare providers of Alaska Natives.[157]

Respondents were asked to indicate the greatest unmet needs of Alaska Native patients and families facing terminal illness.

The primary unmet needs were:

- *Hospice/palliative care services*
- *Ability to go home with support services and home care (including care coordination services)*
- *Pain management*
- *Education/information for patients and families about diseases, the dying process, and options for treatment and care*
- *Psychosocial, mental health, and grief support*
- *A place for families to stay when patients are in the hospital*
- *Information for family caregivers and others (to help them care for the terminal patient)*

Although 69 percent of respondents care for patients with palliative care needs, only 27 percent of providers (in both rural and urban settings) reported that they have had any training in palliative care. There were no significant differences across disciplines, but 90 percent of pharmacists indicate that they had had no training in palliative care. These data are consistent with the reports of only moderate confidence and comfort with palliative care for all disciplines, and with the particularly low confidence and comfort scores of pharmacists. Interestingly, respondents who reported having more patients who need palliative care are more likely to have had training. (Note that the training for these providers may increase their recognition of palliative care needs leading to their report of more patients with these needs.)

The survey results showed that there is considerable provider interest in palliative care indicated by the large number of respondents across settings and disciplines. The survey identified a group of 350 to 400 clinicians who see patients who are in need of palliative care and who offered descriptions of the unmet needs of this patient population.

The survey revealed three ways that ANTHC could begin to improve access to and quality of palliative care for Alaska Natives:

1. develop new and enhance existing palliative care services;

2. increase knowledge, skills, and comfort of clinicians to deliver palliative care; and,

3. increase awareness of palliative care options and how to access them through improved communication to patients and families as well as providers.

With respect to new services, a majority of respondents in all locations noted the need for development and coordination of services so that Alaska Natives can stay at home in their communities and receive high quality palliative care. ANTHC should consider development of home-based care that is hospice-like (interdisciplinary, coordinated, and focused on symptom control and quality of life), along with education/training for family caregivers and community volunteers.

A critical component of any new palliative care services is a group of well-trained clinicians in every discipline. The survey revealed that few clinicians have had formal palliative care training and the majority expressed a willingness to take time for this type of training especially if it is provided via symposia or lectures during working hours. Given the low to moderate levels of confidence and comfort with delivery of palliative care, we recommend that training sessions include experiential learning and practice (role playing and/or standardized patient exercises) in addition to lecture and discussion.

Lastly, many survey respondents indicated a need for more information about what palliative care services are currently available and how they can access them for their patients. Respondents also felt that patients and families lacked information about palliative care options, perhaps because clinicians are not confident about what can be offered, or comfortable starting these conversations. [158] A survey of Community Health Aide/Practitioners regarding palliative care will be completed in 2006.

In 2005, the QCCC provided a grant to the Spirit of EAGLES program at the Mayo Clinic to gather information to determine the status of palliative and hospice care in the Indian Health System (IHS, Tribal, Urban Indian health programs).[159] The Spirit of EAGLES program used the National Consensus Project's Clinical Practice Guidelines for Palliative Care (NCP Guidelines) to help determine what is known and what needs to be known about palliative care in Indian Country. A systematic review of 35 years of relevant literature covering prevalence, assessment and treatment of cancer-related pain, depression and fatigue, rarely addresses palliative care issues in the context of race, ethnicity, culture or minority populations. There are no articles that pertain specifically to AI/AN.[160] The review showed an absence

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APPENDIX 1

Alaska Tribal Health System Comprehensive Cancer Plan Goals, Objectives & Strategies

Goals, Objectives & Strategies for Tobacco Use Prevention

GOAL
Reduce cancer incidence, illness, and death due to tobacco use among Alaska Natives.

OBJECTIVE PT1: Expand and develop the ATHS capacity to address tobacco through culturally appropriate, locally delivered, comprehensive tobacco control programs in twelve regions by 2010.

Baseline: *Three of twelve regional tribal health organizations have comprehensive tobacco control programs in 2005*

Strategy a: Advocate for increased funding of tobacco control programs in Alaska.

Strategy b: Increase funding and state recognition and support of tribal decision making and self-determination to encourage tribal systemic and sustainable change to reduce tobacco-related illness and death.

OBJECTIVE PT2: Increase the number of patients enrolled in ATHS nicotine dependence treatment by 200% by 2010.

Baseline: *646 enrollees in 2004 (ANTHC Tobacco Treatment Database)*

Strategy a: Expand the number of regional health care providers offering nicotine dependence treatment.

Strategy b: Improve systems by which a provider can refer patients to nicotine dependence treatment.

Strategy c: Expand patient education and offer nicotine dependence treatment for patients receiving care at ANMC.

Strategy d: Provide technical assistance to nicotine dependence treatment providers to bill Medicaid, Medicare and third party insurers for services.

OBJECTIVE PT3: Increase the percentage of Alaska Native patients screened for tobacco use in ATHS health care facilities to 75% by 2010.

Baseline: *47% GPRA 2005*

Strategy a: Expand tobacco cessation knowledge and application of the "5 A's" (Ask, Advise, Assess, Assist and Arrange) by offering ongoing training to ATHS providers.

Strategy b: Improve systems to remind health care providers to ask each patient at each visit if they use tobacco and determine their readiness to quit and advise them accordingly, based on the USPHS Clinical Practice Guidelines.

OBJECTIVE PT4: Reduce the percentage of adult Alaska Native smokers to 35% by 2010.

Baseline: *43% BFRSS 2004*

Strategy a: Ensure that all Alaska Natives who wish to stop using tobacco have access to evidence based cessation interventions.

Strategy b: Increase Alaska Native specific tobacco control initiatives to assure comprehensive, culturally appropriate media messages reach the intended audience.

Strategy c: Support collaborative advocacy efforts to pass a statewide clean indoor air policy and to increase tobacco taxes.

Strategy d: Support local communities' advocacy efforts to enact or retain clean indoor air policies and increase local tobacco taxes.

OBJECTIVE PT5: Reduce the percentage of adult Alaska Native spit tobacco users to 10% by 2010.

Baseline: *16% BFRSS 2004*

Strategy a: Ensure that all Alaska Natives who wish to stop using spit tobacco have access to evidence based cessation interventions.

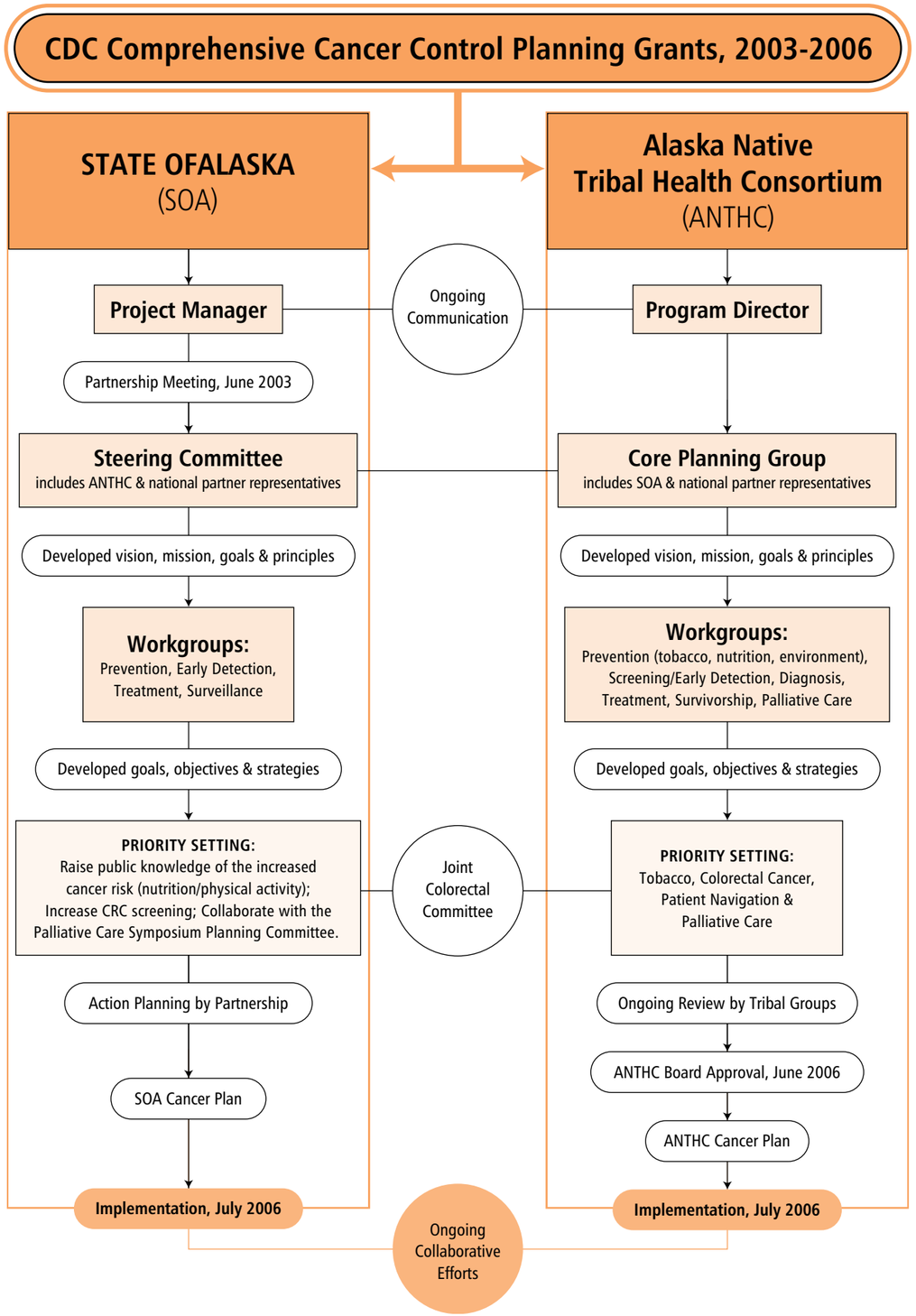
Strategy b: Increase Alaska Native specific spit tobacco control initiatives to assure comprehensive, culturally appropriate media messages reach the intended audience.

Strategy c: Support collaborative advocacy efforts to pass an increase in local and state spit tobacco taxes.

OBJECTIVE PT6: Reduce the number of pregnant women who use tobacco during the last three months of pregnancy to 12% by 2010.

Baseline: *17% PRAMS 2003*

Strategy a: Develop and assess the efficacy of Alaska Native specific tobacco use interventions for women of reproductive age, including pregnant and post partum women.



APPENDIX 3

CANCER GLOSSARY

Adjuvant Treatment used in addition to, and following, the primary therapy (often surgery) to treat a cancer; maybe chemotherapy, radiation therapy, biological or hormonal therapy.

Acute stage The acute stage of survival begins with diagnosis and spans the time of further diagnostic and treatment efforts.

Allogeneic Replacing a patient's bone marrow with the healthy marrow of someone who is not genetically identical.

Angiogenesis The formation of new blood vessels that commonly accompanies malignant tissue growth.

Antibody A protein produced by the body's immune system to fight infection or harmful foreign substances.

Antiemetic Medication to prevent or reduce nausea and vomiting

Antigen Foreign substance in the body that stimulates the body to produce antibodies to fight them.

Aspiration Removal of fluid or a small sample of tissue cells generally using a syringe.

Autologous Using the patient's own body tissue or blood in a transplant treatment.

Benign Abnormal, non-cancerous growth of tissue that does not spread to other parts of the body and is not life threatening.

Biological Therapy Treatments using the body's own immune system to fight cancer.

Biopsy The removal of a sample of tissue (to be examined under a microscope to look for cancer cells).

Body Mass Index, Adults Describes body weight relative to height. It is equal to weight in kilograms divided by height in meters squared. Overweight for adults is defined as BMI of 25 to 29.9 and obesity is defined as BMI of 30 and above.

Body Mass Index, Children Children with BMI of greater than or equal to the 85th percentile but less than the 95th percentile for age and gender, based on growth charts, are considered at risk for overweight; children with BMI greater than or equal to the 95th percentile are considered overweight.

Bone Marrow The inner, spongy tissue of bones where blood cells are made.

Cancer A term for diseases in which abnormal cells divide without control.

Cancer Survivors People who have been diagnosed with cancer and the people in their lives who are affected by their diagnosis, including family members, friends and caregivers

Carcinogen A substance or agent that causes cancer.

CAT (or CT) scan A diagnostic procedure combing an x-ray with a computer to produce very detailed cross-sectional pictures of the body and/or brain.

Cell The basic unit or building block of human tissue.

Chemotherapy Treatment with cancer fighting drugs to kill cancerous cells.

Chronic Lasting a long time

Clinical Trials Research studies that find better ways to prevent, diagnose, or treat cancer using new drugs or medical devices.

Colonoscopy A procedure that allows the doctor or nurse to look inside the rectum and the colon through a lighted tube.

Colostomy An opening into the colon from the outside of the body. A colostomy provides a new path for waste material to leave the body after part of the colon has been removed.

Comprehensive Cancer Care An integrated and coordinated approach to reducing cancer incidence, morbidity, and death through prevention, screening, early detection, diagnosis, treatment, survivorship and palliative care.

Contaminants Anything that makes something impure or unclean through contact or mixture.

Counter-Marketing An activity developed to contradict an established marketing campaign. Especially campaigns to reduce tobacco use as opposed to the marketing done by tobacco companies to promote tobacco use.

Cryotherapy A surgical procedure using liquid nitrogen or carbon dioxide to destroy a tumor by freezing.

APPENDIX 4

ACRONYMS

A/PIA	Aleutian/Pribilof Islands Association
AANHS	Alaska Area Native Health Service
ACoSC	American College of Surgeons Commission
ACR	Alaska Cancer Registry
ACREC	Alaska Cancer Research and Education Center
ACRH	Alaska Center for Rural Health
ACS	American Cancer Society
AEC	Atomic Energy Commission (U.S.)
AFHCAN	Alaska Federal Health Care Access Network
AFN	Alaska Federation of Natives
AHRQ	Agency for Healthcare Research and Quality
AI/AN	American Indian/Alaska Native
AITC	Alaska Inter-Tribal Council
APCA	Alaska Primary Care Association
ALPHA	Alaska Public Health Association
ANCR	Alaska Native Cancer Registry
ANCSA	Alaska Native Claims Settlement Act
ANEC	Alaska Native Epidemiology
ANHB	Alaska Native Health Board
ANMC	Alaska Native Medical Center
ANTHC	Alaska Native Tribal Health Consortium
ATHS	Alaska Tribal Health System
ANTR	Alaska Native Tumor Registry
ARCS	Alaska Rural Communications System
ASNA	Arctic Slope Native Association
ASRC	Arctic Slope Regional Corporation
ASUTHC	Anchorage Service Unit Tribal Health Council
ATCA	Alaska Tobacco Control Alliance
ATHC	Alaska Tribal Health Compact
AVCP	Association of Village Council Presidents
ATSDR	Agency for Toxic Substances and Disease Registry
BBAHC	Bristol Bay Area Health Corporation
BCHC	Breast and Cervical Health Check Program
BMI	Body Mass Index
BRFSS	Behavioral Risk Factor Surveillance System
BSE	Breast Self Exam
CDC	Centers for Disease Control and Prevention
CHA/P	Community Health Aide/Practitioner
CHAP	Community Health Aide Program
CIS	Cancer Information Service
CRCHD	Center to Reduce Cancer Health Disparities
CWA	Community Wellness Advocates
DEHE	Division of Environmental Health and Engineering
DEW Line	Distant Early Warning communication facilities
DHHS	Department of Health and Human Services (U.S.)
DHSS	Department of Health and Social Services (Alaska)
DPH	Division of Public Health (Alaska)
DRE	Digital Rectal Exam
EARTH	Education And Research Toward Health Study
EAT	Eastern Aleutian Tribes
EBV	Epstein-Barr Virus
EH	Environmental Health
EIS	Environmental Impact Statement
EPA	Environmental Protection Agency (U.S.)
ERCP	Endoscopic Retrograde Cholangiopancreatography
ETS	Environmental Tobacco Smoke (aka Second hand smoke)
FOBT	Fecal Occult Blood Test
FUDS	Formerly Used Defense Sites
GPRA	Government Performance and Results Act
HAV	Hepatitis A Virus
HBV	Hepatitis B Virus
HCV	Hepatitis C Virus
ICD-O	International Classification of Disease Oncology
IRB	Institutional Review Board
IHS	Indian Health Service
HPV	Human Papillomavirus
ICC	Intercultural Cancer Council
IOM	Institute of Medicine
ISDEAA	Indian Self-Determination and Education Assistance Act
KANA	Kodiak Area Native Association
KSHV	Kaposi's Sarcoma-associated Herpes Virus
LAF	Lance Armstrong Foundation
MRI	Magnetic Resonance Imaging
NAAP	National Arthritis Action Plan
NBCCEDP	National Breast and Cervical Cancer Early Detection Program
NHANES	National Health and Nutrition Examination Survey
NCCS	National Coalition for Cancer Survivorship
NCCDPHP	National Center for Chronic Disease Prevention and Health Promotion
NCI	National Cancer Institute
NHIS	National Health Interview Survey
NIH	National Institutes of Health
NPCR	National Program of Cancer Registries
NRT	Nicotine Replacement Therapy
NSB	North Slope Borough
NSHC	Norton Sound Health Corporation
OANHR	Office of Alaska Native Health Research
PCBs	Polychlorinated biphenyls
PET	Positron Emission Tomography
PHFSC	Public Health Functions Steering Committee
PHS	Public Health Service
POPs	Persistent Organic Pollutants
PRAMS	Pregnancy Risk Assessment Monitoring System
RN	Registered Nurse
RPMS	Resource Patient Management System
SCF	SouthCentral Foundation
SEARHC	SouthEast Alaska Regional Health Consortium
SEER	Statistics, Epidemiology, and End Results
ST	Spit Tobacco (aka chewing tobacco)
TCC	Tanana Chiefs Conference
USPSTF	U.S. Preventive Services Task Force
UV	Ultraviolet
YKHC	Yukon-Kuskokwim Health Corporation
YRBS	Youth Risk Behavior Survey

APPENDIX 5

CANCER RESOURCES

RESOURCES FOR GENERAL INFORMATION:

National Cancer Institute
Cancer Information Service (CIS)
Trained information specialists answer questions about cancer and can provide free printed and electronic publications
1.800.4.CANCER
www.cancer.gov

American Cancer Society
Cancer information and support services
1.800.227.2345
1.907.277.8696
www.cancer.org

ACS SUPPORTED PROGRAMS:

Cancer Survivors Network
www.acscsn.org

I Can Cope
www.cancer.org

Look Good .. . Feel Better
www.lookgoodfeelbetter.org

Reach to Recovery
www.cancer.org

PROGRAM SPECIFIC RESOURCES:

Alliance for Lung Cancer Advocacy, Support, and Education
Education designed to help improve the quality of life of people with lung cancer and their families.
1.800.298-2436
www.alcase.org

American Brain Tumor Association
Provides information to help patients make educated decisions about their health care and provides listings of support groups throughout the country.
1.800.886-2282
www.abta.org

American Foundation for Urologic Disease
Education and support for those who have or may be at risk for a urologic disease. They also offer prostate cancer support groups (Prostate Cancer Network)
1.800.828-7866
www.afud.org

American Lung Association
Works to prevent lung disease and lung health through education, community service, advocacy and research
1.800.813.4673 or 907.276.5864
www.lungusa.org

Angel Flight West
Provides free flights for patients who can't afford transportation
1.888. 426.2643
www.angelflight.org

The Brain Tumor Society
Provides information and offers a patient/family telephone network and access to support groups for patients and families living with brain tumors.
1.800.770.8287
www.tbts.org

CancerCare, Inc.
Free support, information, financial assistance and practical help to people with cancer and their loved ones.
1.800.813.HOPE
www.cancercare.org

Cancer Hope Network
Matches patients with trained volunteers who have had cancer. Provides support and hope.
1.877.467.3638
www.cancerhopenetwork.org

Chronic and Acute Medical Assistance
Pays for some health care services for adults and children who do not qualify for Medicaid (State of Alaska)
1.888.804.6330 or 907.269.5777

Colon Cancer Alliance, Inc.
Fights colorectal cancer through patient support, education, research and advocacy
1.877.422.2030
www.ccalliance.org

HOSPICELINK
Helps patients and families find support in their communities and offer information about hospice and palliative care.
1.800.331-1620
www.hospiceworld.org

Kidney Cancer Association
Educational material, support groups, and physician referral.
1.800.850.9132
www.kidneycancerassociation.org

Susan G. Komen Breast Cancer Foundation
People supporting people committed to fighting breast cancer
1.800.462.9273
www.komen.org

Lance Armstrong Foundation
Support for cancer survivors to live strong through education, public health, research and advocacy
1.512.236-8820
www.laf.org

Leukemia and Lymphoma Society
Support and information about blood-related cancers including limited travel funds for Alaska patients seeking out-of-state care.
1.800.955.4572
www.leukemia-lymphoma.org

Living Beyond Breast Cancer
Survivors Hotline, newsletters, publications, library and workshops helping wome make choices about their health and well-being.
610-645-4567
www.lbbc.org

National Alliance of Breast Cancer Organizations (NABCO)
Information and education resource for breast cancer
1.888.806.2226
www.nabco.org

National Coalition for Cancer Survivorship
Network of groups and individuals who offer support, advocacy and quality of life issues.
1.877.622.7937
www.canceradvocacy.org

National Ovarian Cancer coalition
Education, information, referral, and support for women and their families.
1.888.682.7426
www.ovarian.org

National Patient Travel Center
Provides some free or discounted medical transport services
1.800.296.1217
www.PatientTravel.org

Native Cancer Information Resource Center and Learning Exchange (C.I.R.C.L.E.)
A cancer resource center for American Indians/Alaska Natives
1.877.372.1617
www.mayo.edu/nativecircle

Office of Native Cancer Survivorship
Helps identify and coordinates resources for American Indian/Alaska Native cancer patients
1.800.315.8848 or 907.333.2071
www.ONCS.org

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From the frozen Arctic to the Southeast rainforests, Alaska Natives are peoples of the land and the waterways. They live in harmony with all living creatures.

Elders sharing wisdom and knowledge allow the traditions of hunting, fishing and gathering to pass from generation to generation. From this comes food, clothing, a healthy lifestyle and spiritual wellness.

Notes

4000 Ambassador Dr.
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