

Comprehensive  
Cancer Plan  
*for the*  
Alaska Tribal  
Health System  
• 2005-2010 •



ALASKA NATIVE TRIBAL  
HEALTH CONSORTIUM  
CANCER PROGRAM



## Dedication:

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*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:

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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:

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



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.

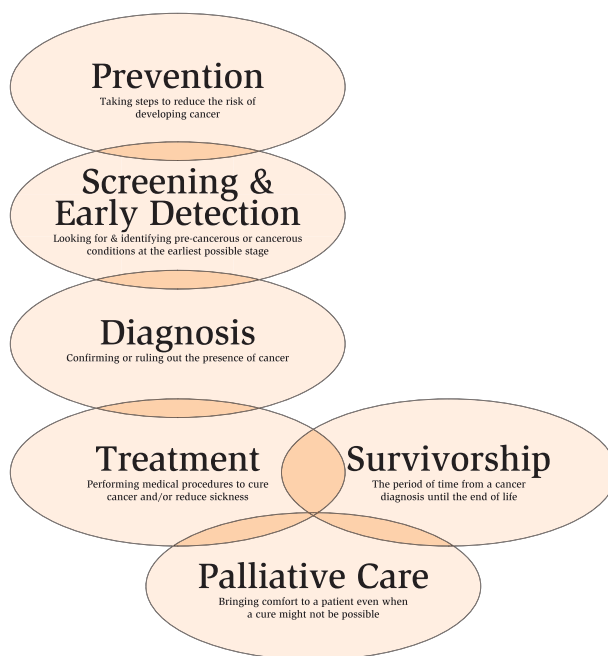
In 2003, ANTHC received a planning grant from the Centers for Disease Control and Prevention (CDC) to develop the first comprehensive cancer plan for Alaska Natives.

**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.

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.**

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

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# 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

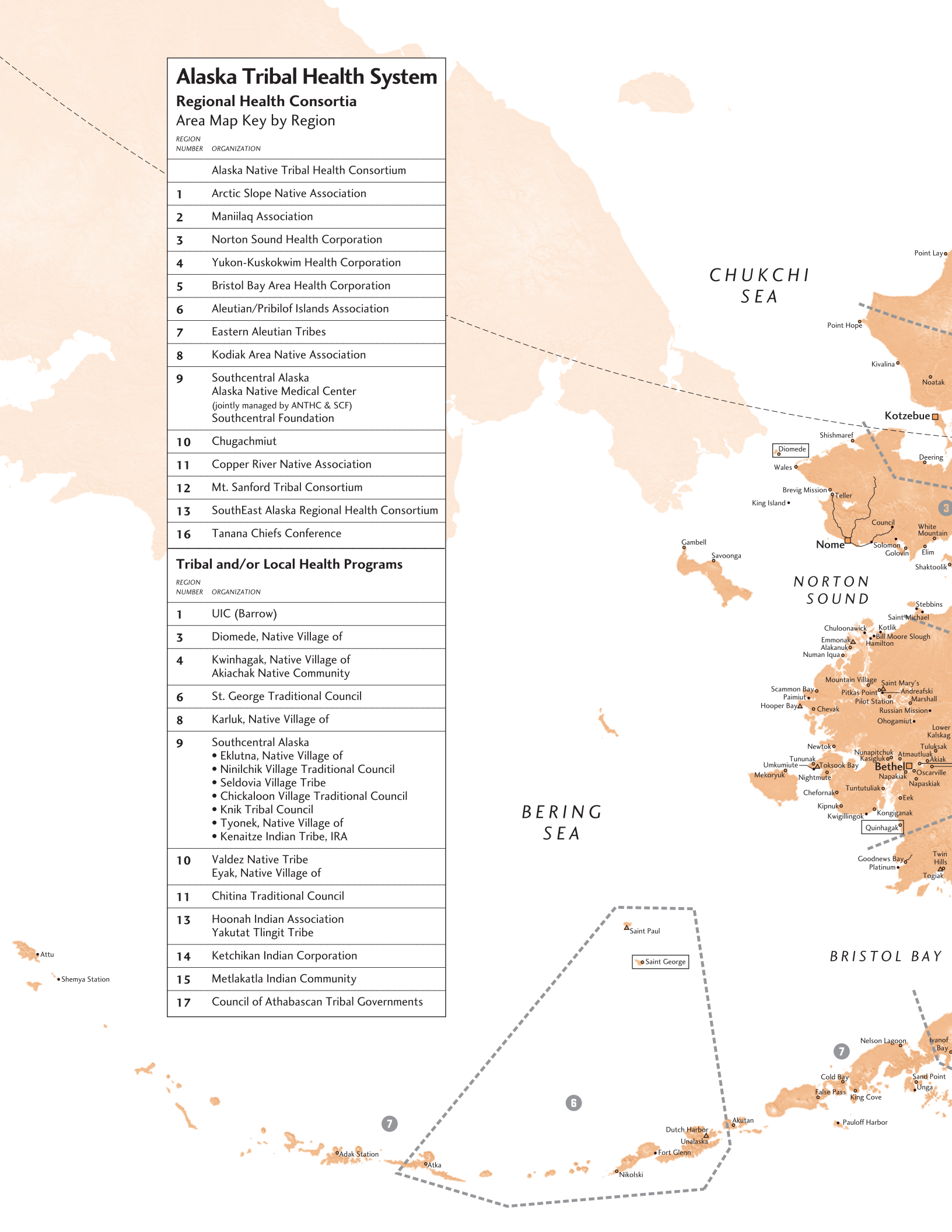
1	UIC (Barrow)
3	Diomede, Native Village of
4	Kwinhagak, Native Village of Akiachak Native Community
6	St. George Traditional Council
8	Karluk, Native Village of
9	Southcentral Alaska <ul style="list-style-type: none"> <li>Eklutna, Native Village of</li> <li>Ninilchik Village Traditional Council</li> <li>Seldovia Village Tribe</li> <li>Chickaloon Village Traditional Council</li> <li>Knik Tribal Council</li> <li>Tyonek, Native Village of</li> <li>Kenaitze Indian Tribe, IRA</li> </ul>
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

CHUKCHI  
SEA

NORTON  
SOUND

BERING  
SEA

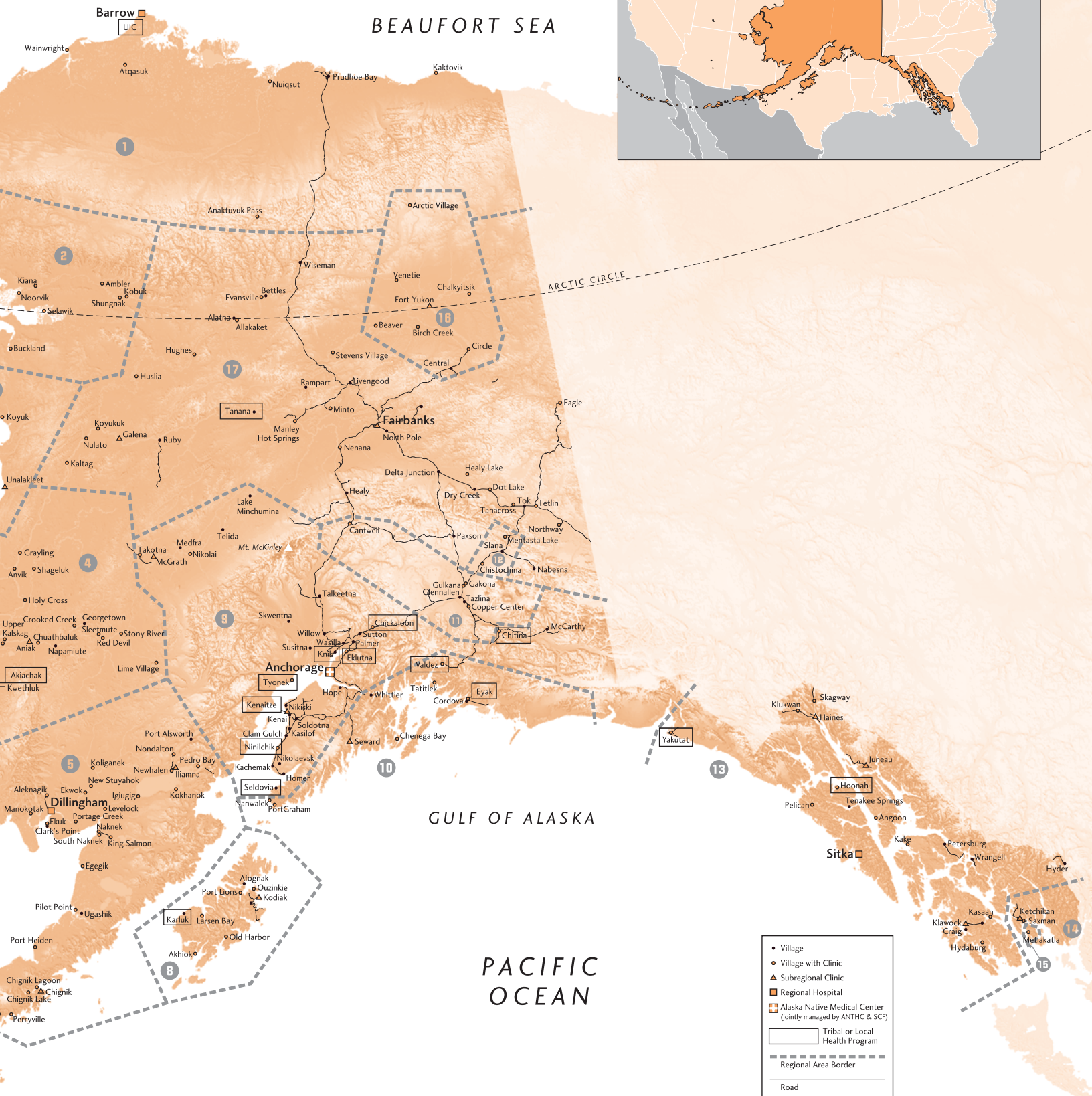
BRISTOL BAY





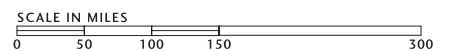
ARCTIC OCEAN

BEAUFORT SEA



GULF OF ALASKA

PACIFIC OCEAN





## 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.

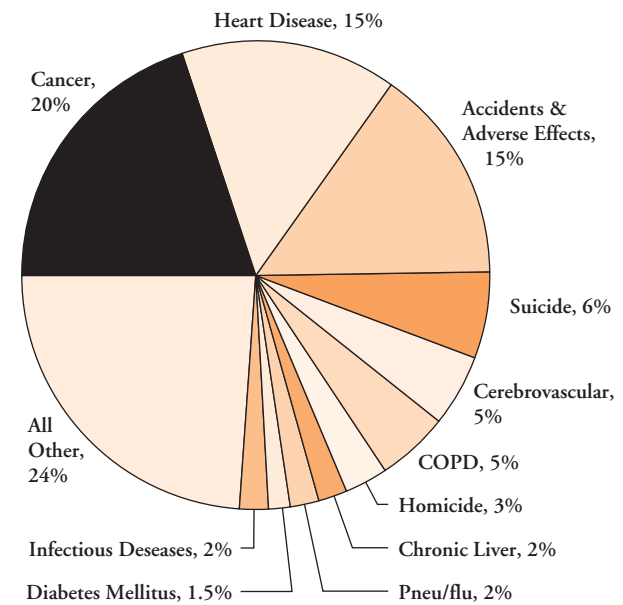
Cancer was not a major cause of death in Alaska Natives during the first part of the 20th century. The main causes of death at that time were infectious diseases. In 1943, 43 percent of all Alaska Native deaths were due to tuberculosis. By the early 1990s cancer was the leading cause of death for Alaska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

**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.

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*In the United States,  
the overall cancer  
death rate declined  
throughout the 1990s.  
In contrast, Alaska  
Native cancer death  
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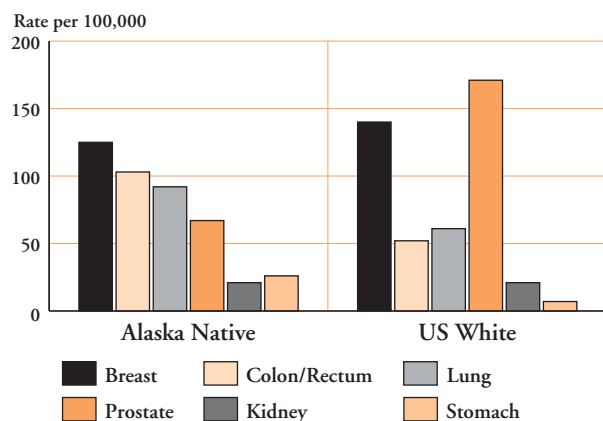
# THE BURDEN OF CANCER IN ALASKA NATIVES

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.

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

Source: Alaska Native Tumor Registry

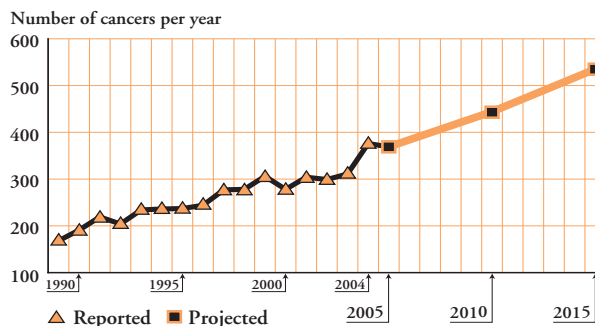


Patterns of cancer for Alaska Natives differ from all other racial groups in the U.S. including Whites, Blacks, and other minority populations. Cancer rates among Alaska Natives also differ from those of American Indians of New Mexico and Arizona. In particular, rates among Alaska Natives are nearly 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.<sup>1</sup>

## Number of Invasive Cancers among Alaska Natives Reported During 1999-2004 and Projected Numbers of Cancers for Years 2010-2015

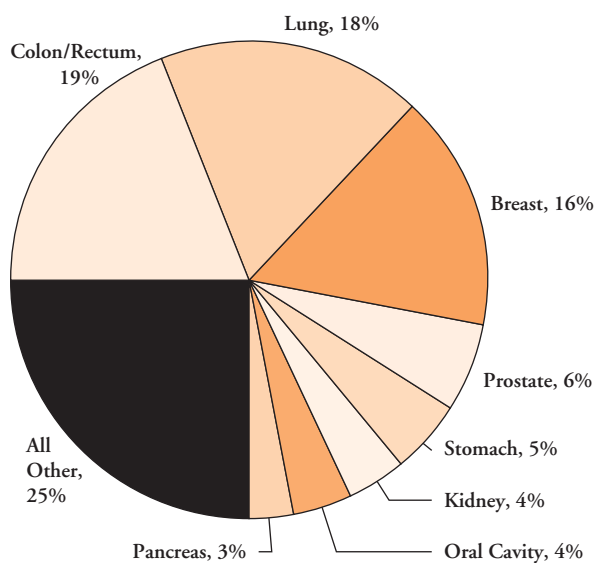
Source: Alaska Native Tumor Registry



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.

## Percent of New Invasive Cancers Diagnosed Among Alaska Natives in 1999-2003

Source: Alaska Native Tumor Registry



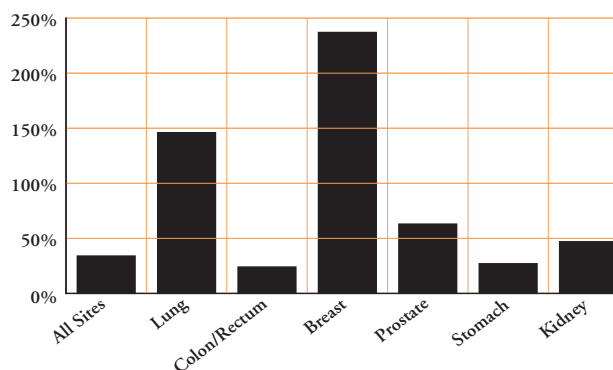
The rate of new cancer patients diagnosed each year increased 34 percent between the five-year period from 1969-1973 to the period 1999-2003.<sup>2</sup> About 300 Alaska Natives are diagnosed with invasive cancer each year.

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



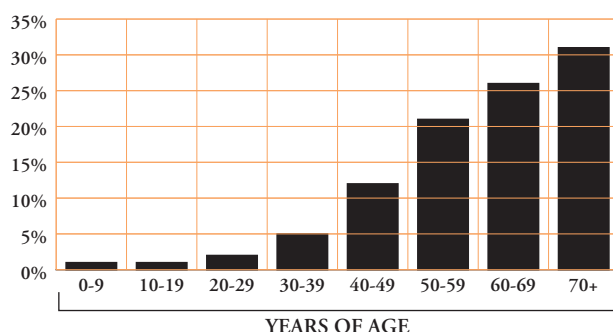
Most cancers are diagnosed in older people. In Alaska Natives, 88 percent of cancers are diagnosed in patients 40 years of age and older. Aging of the population and an increase in life expectancy contributes, in part, to the increase in the number of new cancer patients.<sup>3</sup>

Calculations of cancer survival show that among Alaska Native patients diagnosed with cancer, less than half (37%) will be alive five years after diagnosis.<sup>4</sup> 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.

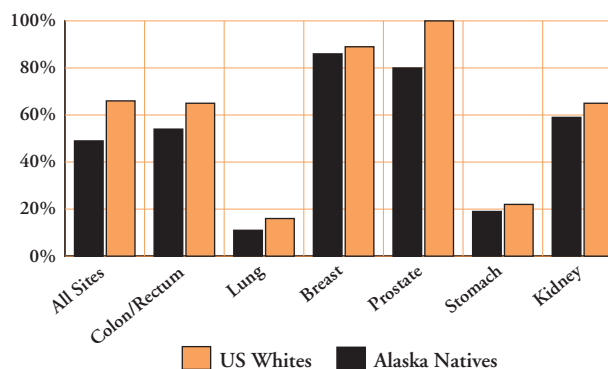
### Percent of All Cancers by Age at Diagnosis Alaska Native Men and Women Combined, 1999-2003

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).<sup>5</sup> In 1999, the cancer death rate was 238/100,000 for Alaska Natives and 193/100,000 for all Alaskans.<sup>6</sup> 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.<sup>7</sup>

### 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.



# 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 is 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 prevalence 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.<sup>8</sup>

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.<sup>9</sup> 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.

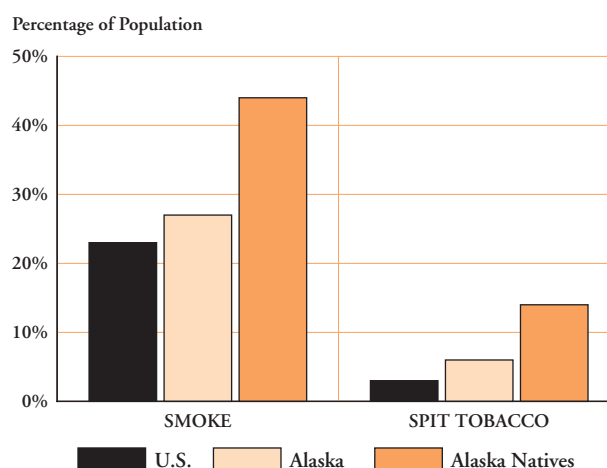
Tobacco kills not just those who choose to smoke, but also non-smokers who are exposed to smoke from other people's cigarettes. ETS, also called secondhand smoke, causes 3,000 lung cancer deaths among non-smokers each year in the United States.<sup>10</sup> ETS exposure is associated with an increased 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.<sup>11</sup>

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.<sup>12</sup> It is estimated that 120 Alaskans died as a result of secondhand smoke exposure in 2001.<sup>13</sup> 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.<sup>14,15</sup> However, its use has been associated with oral cancer and other oral diseases.<sup>16</sup>

## **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.<sup>17,18</sup> Similarly, the prevalence of smokeless tobacco use is 14 percent among Alaska Native adults versus 4 percent in the total U.S. population.<sup>19,20</sup>

Nationally, American Indian and Alaska Native women as a group have the highest prevalence of tobacco use among ethnic minorities in the United States.<sup>21 22 23</sup> 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.



### Youth Tobacco Use Rates

Alaska Native youth are four times more likely than their non-Native classmates are to have started smoking before age 13 (21% versus 5%). Not only do they start smoking at a younger age, but Alaska Native high school students are also much more likely than non-Native high school students to have ever tried smoking (83% versus 48%), to currently be a smoker (44% versus 11%), and to smoke frequently (19% versus 5%). Alaska Native youth also use spit tobacco at higher rates than non-Native youth. Alaska Native high school boys are more than twice as likely as non-Native high school boys to use spit tobacco (32% versus 12%); Alaska Native high school girls are nine times more likely as non-Native high school girls to use ST (18% versus 2%). Unfortunately, this gap between Alaska Native and non-Native girls' spit tobacco use appears to be getting larger, not smaller. In comparison to data from 1995, Alaska Native and non-Native high school boys and girls are smoking less now than in past years. While rates of spit tobacco use by high school age youth have dropped among Alaska Native boys and non-Native girls and boys, rates increased among Alaska Native high school girls.<sup>24</sup>

Preventing tobacco use among young people will greatly limit long-term health consequences.<sup>25</sup> From national studies, we know the earlier a child first tries smoking the higher their chances of ultimately becoming a regular smoker and the less likely they are to quit.<sup>26</sup> Early onset of tobacco use is associated with heavier use in adulthood. In the United States, eight out of ten smokers began smoking before age 18.<sup>27</sup> Among Alaska Natives, use begins earlier. Additional research on youth tobacco use in Alaska is needed. There is significant interest by the ATHS and the communities it serves to expand the prevention efforts reaching youth to assure future generations grow up healthy and tobacco free.

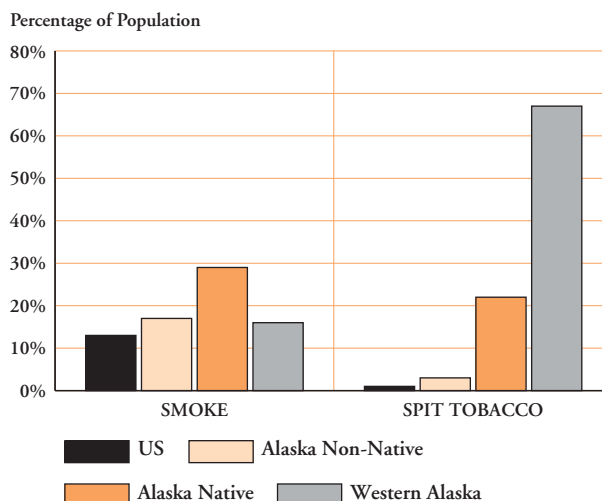
### Pregnant Women Tobacco Use Rates

Data from the 2003 Alaska Pregnancy Risk Assessment Monitoring System (PRAMS) indicates a higher percentage of Alaska Native (29%) versus White women (17%) smoked cigarettes during the last three months of their pregnancy. There is a relatively high rate of ST use among Alaska Native pregnant women (22%), and higher among Alaska Native pregnant women who live in Western Alaska (57%) compared to non-Native Alaskan pregnant women.

Research on tobacco use shows that smoking during pregnancy increases the risk of pregnancy complications, premature delivery, low birth-weight infants, stillbirth, and SIDS. The nicotine in cigarettes may cause constrictions in the blood vessels of the umbilical cord and uterus and decrease the amount of oxygen available to the fetus. Nicotine may also reduce the amount of

### Tobacco Use Rates in Pregnant Women, 2004

Source: PRAMS



blood in the fetal cardiovascular system.<sup>28</sup> Babies of mothers who smoked during pregnancy have lower birth weights. Low birth weight is a leading cause of infant deaths, resulting in more than 300,000 deaths annually among newborns in the United States.<sup>29</sup>

Recognizing that women using tobacco are much more likely to quit smoking and quit using smokeless tobacco around the time of pregnancy than at any other time, this is a critical time to help women stop using tobacco. Unfortunately, women who quit during pregnancy also have extremely high rates of relapse (30%) during the months immediately following delivery. To achieve and maintain an increase in post-partum tobacco abstinence requires significant cessation support.<sup>30</sup>

### Impact of Tobacco on Alaska Native Health

Lung cancer is the leading cause of cancer death, and cigarette smoking causes the majority of lung cancers. Ninety 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 related 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.<sup>31</sup> The 2004 Report of the U.S. Surgeon General concluded that smoking causes cancers of the oral cavity, pharynx, larynx, esophagus, lung, bladder, stomach, cervix, kidney, pancreas and acute myeloid leukemia. Tobacco use also contributes to the risk of heart disease, stroke, and lung diseases, all of which can lead to premature death.

## Spit Tobacco

When spit tobacco is used throughout the day nicotine consumption levels are comparable to those observed in smokers.<sup>32</sup> In focus groups conducted in western Alaska, Alaska Natives stated that they thought spit tobacco was a safer product. However, its use does result in exposure to nicotine and carcinogens that can increase the risk of oral cancers, and may serve as a gateway drug to cigarette use.<sup>33</sup> The spit tobacco most commonly used by Alaska Natives is Copenhagen®, which has the highest pH of all commercially prepared spit tobacco.

“Iqmik” is a homemade form of spit tobacco, sometimes referred to as “Blackbull” or “Dediguss”. Although surveys of use among Alaska Natives do not differentiate between Iqmik and commercially produced products such as Copenhagen®, it is believed that Iqmik is commonly used in some populations of Alaska Natives.<sup>34</sup> Iqmik is prepared by mixing leaf tobacco with ash derived from burning punk fungus (*Phellinus igniarius*), alder or willow bushes, or driftwood. Preparation includes pre-chewing tobacco leaves with ash or mixing with a knife in a bowl. Family members sometimes make the mixture for other members of the family, thus increasing their exposure to nicotine and putting the family member who prepares Iqmik at increased risk of addiction and tobacco associated illness and death. Adding ash to leaf tobacco increases the pH, raising the amount of free nicotine available for absorption by the user.<sup>35</sup> It is unknown if the spread of viruses or bacteria leading to infection or illness could result from this practice. Iqmik has been used by Alaska Natives in western Alaska for over 150 years.<sup>36</sup>

In addition to harm from tobacco, there is additional concern about the use of ash mixed with the tobacco.<sup>37</sup> Many pregnant women consider it safer than smoking but this is not necessarily true. Nicotine withdrawal has been documented among neonates of Alaska Native women who use Iqmik. In addition two studies outside Alaska on spit tobacco use and pregnancy



*Preparing Iqmik - mixing ash with leaf tobacco*

outcomes, found spit tobacco use associated with an increase risk for preterm delivery and preeclampsia. It continues to be considered by some Alaska Natives as a safe remedy for teething and is given to children as young as age three.<sup>38</sup>

Beyond the perception of being a safer product, anecdotal reports also point to the lower cost of Iqmik, suggesting that Alaska Natives switch from commercially prepared to home-made tobacco products when they cannot afford them. Similar anecdotal reports suggest an increase in the use of hand-rolled cigarettes since the tobacco tax increase took place in July 2004.

Currently, it is unclear what proportion of the spit tobacco consumed by Alaska Natives is Iqmik. It is unclear how extensive the practice of mixing tobacco and ash really is. Because of this gap, the State of Alaska in collaboration with ANTHC, began asking Iqmik specific questions in 2004 in both PRAMS and BRFSS. Having more information about Iqmik use will allow for the development of a more effective public health strategy targeting this behavior.

## Tobacco in Alaska – A Brief History

At their first exposure to tobacco, Alaska Natives had no interest in tobacco and no desire to trade for it.<sup>39</sup> However, it quickly found its place among Alaska's first people. In 1741, Georg W. Steller, Captain Vitus Bering's physician and naturalist, went ashore in Alaska at Kayak Island near the mouth of Prince William Sound to explore the plants and animals, and to meet indigenous people of the island. There, Captain Bering ordered that the crew leave a pound of tobacco and a Chinese pipe in a dug out cellar site in exchange for the artifacts and food they had carried away. Steller later wrote in his journal "...they would look on such [leaving tobacco] as a hostile sign, that war was being declared against them ... especially if they tried it out wrongly, they could conclude that we wanted to do them in."<sup>40</sup>

By 1778, only 37 years later, one of Captain James Cook's surgeons wrote that the people of Unalaska "perfectly understood the use of tobacco, which they asked for by that name."<sup>41</sup> Indeed, tobacco made a long journey to Alaska, originally coming from American Indians of the contiguous United States to the Europeans, who returned home with tobacco only to cross the European continent, where Russians and others introduced it to, and then traded it with, Alaska Natives for fur pelts and ivory. Traders used tobacco as a gift, reward, or inducement to service, which eventually led to widespread use among Alaska Natives.

Historically, Alaska Natives have not used tobacco products ceremonially.<sup>42</sup> Since its introduction, tobacco was used by Alaska Natives in one or more of three ways: smoked, chewed

(either by itself or mixed with ash), or as snuff. It was and is used in different ways by men and women. Historically, while men use it in all three ways, women usually chewed it or took it in the form of snuff, but rarely smoked it.<sup>43</sup> Cigar and pipe smoking are rare in this population.<sup>44</sup>

## *Tobacco Control Efforts*

Alaska Native tobacco control efforts have evolved significantly since the formation of the Alaska Tobacco Control Alliance (ATCA) in 1993. This statewide coalition, though not focused specifically on Alaska Natives, agreed that tobacco control among Alaska Natives should be one of the highest priorities of state tobacco control efforts. The use of tobacco among Alaska Natives is nearly twice that of non-Native Alaskans.

The Robert Wood Johnson Foundation Smokeless State grant was awarded to Alaska in 1993, resulting in a series of grants and projects that systematically focused on taxation, securing state tobacco settlement dollars, clean indoor air laws, and more recently, cessation efforts. In 1997, statewide efforts resulted in the passage of the highest tobacco tax in the nation at that time.

More recent efforts have focused on local clean indoor air ordinances, the first of which passed in 1998 in Bethel, a predominantly Alaska Native community. To date, approximately three-quarters of the Alaskan population is protected by clean indoor air laws and many of the communities with such protection have a predominantly Alaska Native population. Additionally, in a 2004 survey by the Alaska Native Health Board, over 70 percent of rural communities across Alaska have some form of clean indoor air rule or tribal understanding.

Currently there are several Alaska Native specific tobacco control efforts in existence, addressing five areas of tobacco control defined by the CDC Best Practices Guidelines: counter marketing, cessation programs, school-based programs, enforcement, and community programs.

Counter marketing efforts have been conducted via regional newspapers, radio, posters, flyers, and brochure advertisements. The State of Alaska Department of Health and Social Services published some “special population” print and radio ads and developed several Alaska Native specific tobacco videos. There is a need to increase the number of Alaska Native specific tobacco control media efforts to assure a comprehensive, culturally appropriate media campaign reaches its intended audience.

Cessation programs exist in a few Alaska Native communities. The ANTHC Nicotine Research and Control Program provides centralized assistance to regional tribal health care facilities with their cessation efforts. A state-funded Alaska QuitLine

service is offered throughout the state to all Alaskans, regardless of race. Limited information is currently available on how well this service is used by Alaska Natives.

School-based programs are offered by school districts when time and funds are available. It is estimated that programs are offered in one-fourth of Alaskan schools, however, very few schools offer CDC curriculum approved programs.<sup>45</sup> Health professionals and nicotine dependence treatment program counselors also respond to requests to speak at schools, to youth groups and at health fairs as time allows.

Enforcement of vendor compliance with laws prohibiting the sale of tobacco to teenagers is conducted by the State of Alaska with a goal of fewer than 20 percent underage tobacco sales by the year 2010. Vendor compliance is monitored by conducting “stings”, where underage youth working with State tobacco staff attempt to purchase tobacco throughout the state. This type of monitoring is difficult to conduct in rural areas of Alaska where virtually all village youth are known or may be related to the storeowners.

Community programs include offering assistance to communities that are interested in passing clean indoor air policies, many of which have a high population of Alaska Natives.

In 2006 tobacco settlement dollars set aside for tobacco control in Alaska are estimated to reach an all-time high of \$8 million, meeting the CDC recommended minimum amount. In 2006 approximately ten percent of that was granted or contracted to tribal health corporations statewide.

## *Alaska Tribal Health System Role in Addressing Tobacco*

In September 2003, ANTHC established the Nicotine Research and Control Program to provide assistance in the development of capacity and infrastructure needed for comprehensive tobacco control programs for Alaska Natives. This program provides assistance to health care centers in the ATHS to develop, expand, or revitalize their nicotine dependence treatment services. Program development is based on the United States Public Health Service (USPHS) recommended strategies to systematically approach tobacco use and treatment. ANTHC is increasing access to nicotine dependence treatment services and building capacity for comprehensive tobacco control to reduce tobacco use among Alaska Natives.

Making cessation services available and accessible are critical parts of a comprehensive approach to reducing tobacco use among current users. Under the leadership of the ANTHC Nicotine Research and Control Program, for the first time, the Alaska Tribal Health System is developing a continuum of care



of nicotine dependence treatment and support for the entire ATHS, from the tertiary care level at ANMC to the primary care level in clinics and regional hospitals across Alaska.

The ANTHC Nicotine Research and Control Program helps to develop and evaluate regional programs, including developing tools to track a patient's tobacco use status and to encourage cessation. This includes delivering a multi-component, culturally tailored, tobacco use intervention with and for Alaska Natives. It includes face-to-face motivational counseling, intensive follow-up and access to state-of-the-art pharmaceuticals for nicotine dependence treatment. Cessation efforts have been enhanced by offering comprehensive support and follow up via telephone contacts by the regional tobacco cessation counselor.

There is increasing support in the ATHS to reduce the use of tobacco, including the approval of the ANMC Tobacco Free Campus Initiative, increasing number of health care providers assessing for tobacco use, and in the number of nicotine dependence treatment programs available throughout the ATHS.

The Nicotine Dependence Treatment Program is designed to help Alaska Natives quit using tobacco and remain tobacco free. The Program provides practical counseling, basic information about tobacco use, problem solving skills and social support, and is located in a clinical setting.

Evidence from the USPHS guidelines demonstrated that the more intense and longer lasting the intervention, the more likely the patient is to stay tobacco-free. The Nicotine Dependence Treatment Program includes an initial in-person assessment and eight follow-up sessions by phone or in person. The sessions are more frequent early on in the quit attempt and last for a total of 52 weeks.

The core of the program is built around a behavior modification strategy, but an integral part of the program includes pharmacological aids such as bupropion (Zyban), and nicotine replacement therapy (NRT). Research has shown that pharmacology coupled with behavior modification strategies yields the best results. Participants of the program are provided with a supply of an appropriate aid (as prescribed by a physician) on the average of a two month supply. All regional hospitals implementing this program have different prescription drugs to help in tobacco cessation.<sup>46</sup> The Nicotine Dependence Treatment Program includes a protocol and a workbook for counselors to use with their patient.

## *Improving Tobacco Screening Rates for Alaska Natives*

Screening for tobacco use by health care providers for every patient at every patient visit reliably decreases tobacco use.<sup>47</sup>

The Government Performance and Results Act (GPRA) is a federal law that monitors IHS performance on selected clinical measures. One clinical measure is the screening rate, which is the number of patients who are asked whether they use tobacco. Tribally operated facilities are not required but are highly encouraged to report on GPRA measures. Standardized reports are available for all ATHS facilities to provide feedback on individual tribal health organization outcomes. Data submitted is linked to annual budget requests for the IHS.

During 2004 the IHS screening rate for tobacco use was 26 percent, based on the aggregate data from six facilities: Bristol Bay Area Health Corporation, SouthEast Alaska Regional Health Consortium, Yukon-Kuskokwim Health Corporation, Maniilaq Health Association, Tanana Chiefs Conference and Alaska Native Medical Center. In 2005, the tobacco screening rates increased to 47 percent. ANTHC has identified a target outcome of increasing screening to 75 percent of all patient visits by 2010.

In addition to the health benefits, the cost savings of offering tobacco cessation services is gaining the attention of tribal leaders. A smoker will incur between \$9,000 and \$10,000 more in medical costs over a lifetime.<sup>48</sup> In Alaska in 1998, a total of \$133 million was spent in medical care for tobacco-related deaths. Lost productivity from tobacco-related deaths cost an additional \$137 million.<sup>49</sup> A national study provided an average percentage of what it costs to care for smoking-related illnesses within the Medicaid system. Based on that 12 percent average, it is estimated that the Alaska Tribal Health System pays \$48 million dollars per year to care for its smoking population, if our smoking rates were equal to the national rates. At present they are almost double.<sup>50</sup>



# 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.

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**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.

**Strategy b:** Expand the number of regional nicotine dependence treatment programs for pregnant and post partum women.

**Strategy c:** Increase Alaska Native specific tobacco control media initiatives and educational resources targeting pregnant and post partum women to assure comprehensive, culturally appropriate media messages reach the intended audience.

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**OBJECTIVE PT7: Design and implement training for an Alaska Native specific tobacco treatment specialist by 2010.**

*Baseline: No training exists in 2005*

**Strategy a:** Develop a tobacco treatment specialist curriculum to be integrated into the Behavioral Health Aide Certification program.

**Strategy b:** Develop a tobacco treatment specialist curriculum to be integrated into the Dental Health Aide Certification program.

**Strategy c:** Include tobacco treatment educational resources in the Community Health Aide Manual.

**Strategy d:** Organize annual statewide and regional ATHS tobacco trainings and conferences.

**Strategy e:** Assist with efforts to establish tobacco treatment counselor certification.

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**OBJECTIVE PT8: Establish a tobacco free campus at the ANMC by 2007.**

*Baseline: ANMC campus is not tobacco free in 2005*

**Strategy a:** Design and implement an ANMC tobacco free campus program, expanding education and tobacco cessation interventions for patients and employees.

**Strategy b:** Develop resources to assist other ATHS facilities implement tobacco free policies successfully.

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**OBJECTIVE PT9: Reduce the percentage of Alaska Native youth smokers to 15% by 2010.**

*Baseline: 29% male and 27% female YRBS 2003*

**Strategy a:** Increase Alaska Native specific tobacco control media and education initiatives addressing youth to assure comprehensive, culturally appropriate messages reach the intended audience.

**Strategy b:** Develop and assess the efficacy of Alaska Native specific tobacco use interventions for youth, to assure comprehensive, culturally appropriate education efforts.

**Strategy c:** Improve systems to have health care providers ask each patient, including parents of young children and youth, at each visit if they use tobacco and if tobacco is used in their homes, to determine their readiness to quit and advise them accordingly.

**Strategy d:** Encourage regional tribal health programs to continue to collaborate with local community providers and schools to use established tobacco cessation curriculums for youth, including CDC endorsed curriculums.

**Strategy e:** Design and implement a strategy to collect tobacco use rates for Alaska Native children (K-6 grade) by 2010.

**Strategy f:** Provide community technical assistance in addressing tobacco control issues targeting youth.

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**OBJECTIVE PT10: Contribute to the knowledge and understanding of the risk of tobacco use among Alaska Natives to tribal leadership and communities in Alaska.**

*Baseline: Twenty-four presentations in 2005*

**Strategy a:** Present research findings and evidence-based best practices to tribal leadership at local, regional and statewide gatherings and conferences in Alaska.



# NUTRITION, PHYSICAL ACTIVITY AND ALCOHOL

## Introduction

Evidence suggests that about one-third of the 550,000 cancer deaths that occur in the United States each year are due to an unhealthy diet and insufficient physical activity. The Harvard Report on Cancer Prevention estimates that cancer deaths in the United States may be reduced by about 30 percent through improvements in nutrition and physical activity.<sup>51</sup>

Among Americans who do not use tobacco, dietary choices and physical activity are the next most important modifiable determinants of cancer risk.<sup>52, 53</sup> According to the Harvard Report approximately 25 percent of all cancers are attributable to poor adult nutrition and obesity, and another five percent to sedentary lifestyles. Factors that affect cancer risks include the type of food eaten, the preparation method, portion size, variety, and overall caloric balance.<sup>54</sup>

Although some data on diet patterns of Alaska Natives exist, there is no consistent, ongoing monitoring program for any population group in Alaska. Many gaps exist, especially on subsistence foods, quantity of fruits and vegetables eaten, nutrient content of Alaska Native foods, and nutrient status of Alaskans, Native and non-Native.

The state of Alaska conducts statewide surveys of adults through the Behavioral Risk Factor Surveillance Survey (BRFSS), and for youth through the Youth Risk Behavior Survey (YRBS). Even though Alaska Natives are over sampled in the statewide BRFSS phone survey, numbers surveyed each year are a small percentage of the total population. Additionally, only a few questions on the BRFSS pertain to diet and physical activity. The YRBS asks a number of questions about diet and physical activities, but major obstacles to administering the survey statewide have limited its usefulness.

## Nutrition

Alaska Natives traditionally have relied on the land and sea to provide them with a healthy diet. The diversity of climates and geography in the state has led to many different adaptations in lifestyle and traditional foods. Those differences can be seen in the various regions of the state.

Alaska can be roughly divided into six geographical regions.<sup>55</sup> These regions have distinct traditional eating habits.

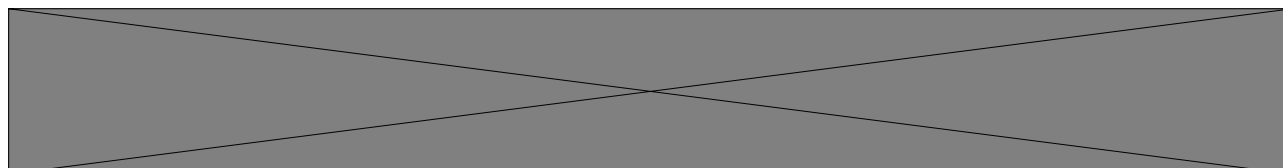
- ♦ *SOUTHEAST – Home to three groups of coastal Indians: the Tlingit, the Haida, and the Tsimshian. Their diet relies on salmon, hooligan (a fish that can be rendered to oil), and salmon*

*and herring eggs. Moose, deer, and mountain goat are eaten, as well as shellfish, seaweed, halibut, several species of seals, greens, and berries.*

- ♦ *SOUTHCENTRAL – Home to Aleuts, Sugpiaq Eskimos, and coastal Athabascan Indians. This region traditionally and currently relies on sea mammals, fish, shellfish and seaweed, as well as greens, roots and berries. The non-coastal Athabascan Indians of the inland areas eat freshwater fish, moose, caribou and waterfowl.*
- ♦ *ALEUTIAN and PRIBILOF ISLANDS – Home of the Aleut people, whose diet relies on various species of seal and whale, including fur seals, as well as fish, bird eggs, berries, greens, and birds.*
- ♦ *SOUTHWESTERN – This region is the home of the Yup'ik and Cupik Eskimos. Inland groups eat salmon and other river fish, caribou, waterfowl, and sometimes moose. Roots and berries are also commonly consumed. The coastal people eat salmon and other fish, as well as seals and whales. Greens, roots, and berries are also collected.*
- ♦ *INTERIOR – Home of interior Athabascan Indians, who hunt for moose, caribou, and waterfowl, and eat salmon and other fish, roots and berries.*
- ♦ *ARCTIC and NORTHWEST – Home of the Inupiaq Eskimos, who have primarily been dependant on marine mammals and fish as well as waterfowl, caribou, and small game. This region continues to support whaling communities.*

Subsistence foods in general are much healthier than store-bought foods, being higher in healthy fats (high in omega-3 fatty acids and low in saturated fats), vitamins (A and C), and minerals (iron, zinc, and calcium). Furthermore, subsistence hunting, trapping, fishing, and gathering requires the expenditure of physical energy, which has other health benefits and, along with foods found in a traditional diet, may decrease the incidence of chronic diseases. However, over the last hundred years, Alaska Natives have experienced profound cultural upheaval and change. This is in great part due to the influence of Western culture on Alaska Native people. Western foods, such as coffee, tea, sugared beverages, bread, rice, and potatoes are now widely available in the village stores. Alaska Natives have integrated these foods into their daily diet.

Overall the health consequences of poor nutrition are costly, through both direct and indirect health care costs. It is estimated that national obesity expenses in 2000 were over \$117 billion, of which \$61 billion were direct medical costs and \$56 billion were indirect costs due to lost and reduced productivity.<sup>56</sup> The total national bill for obesity was approximately 9 percent of the total cost for health care in 2000. The amount spent on obesity is not limited to adults, as costs related to overweight have increased 300 percent since 1981 in the pediatric population.<sup>57</sup> Alaska and the District of Columbia are the highest in the nation in obesity



spending, each accounting for 7 percent of total medical expenditures, and an estimated \$195 million in direct medical costs.<sup>58</sup>

Current scientific understanding about the relationship between diet and disease is limited. However, research studies have associated dietary habits with some cancer risks. Numerous studies have shown that a healthy diet with appropriate caloric intake, reduced animal fat, reduced alcohol consumption, and increased vegetable and fruit consumption can reduce the risks of certain kinds of cancer such as breast, colon, lung, and prostate cancer. Low folic acid intake is associated with cervical, colorectal, and other cancers. High-fat diets are associated with increased risk of colon, prostate, and endometrial cancer.<sup>59</sup> Studies from other countries suggest people who eat a diet that largely includes salted, pickled or smoked foods are at greater risk of stomach cancer.<sup>60, 61</sup> In addition, animal model and epidemiologic studies suggest that other carcinogens in food contribute to cancer in humans. These include benzo-a-pyrene and related compounds in smoke-cured foods, nitrates and nitrites in preserved foods, and naturally occurring carcinogens such as aflatoxins (produced by fungi).<sup>62</sup>

More recent studies indicate that what people choose to eat may be as important as what is avoided. The human diet contains a number of naturally occurring substances that may prevent cancer in laboratory animals. These include vitamin C, vitamin E, selenium, and tocopherols.<sup>63, 64</sup> Dietary fiber, micronutrients and vitamins, along with phytochemicals and a host of non-nutrient components in vegetables and fruits, can lower cancer risk and protect people from cancer. Examples of phytochemicals are ellagic acid and anthocyanins, which are particularly high in blueberries and other wild Alaskan berries. Strong scientific evidence has concluded that diets high in fruits and vegetables have protective effects against cancers of the gastrointestinal tract (for example colon and rectum) and respiratory tract (for example lung and larynx).<sup>65</sup> Diets high in fruits and vegetables, especially allium vegetables (for example onions and garlic) and foods rich in carotenes or vitamin C or vitamin E may also protect against stomach cancer associated with *H pylori*.<sup>66, 67</sup>

In addition to the cancer risk associated with specific diet components, overweight and obesity are associated with an increased risk for some types of cancer, including endometrial (cancer of the lining of the uterus), colon, gallbladder, prostate, kidney, and postmenopausal breast cancer.

Christine Heller and Edward Scott surveyed eleven villages primarily in the north and southwest of Alaska from 1956 to 1961. They concluded that major changes in Alaska Native diets since

aboriginal times include:

- ◆ *Increased consumption of carbohydrates*
- ◆ *Increased use of saturated fats, largely imported*
- ◆ *Increased calcium intake because of the use of milk*
- ◆ *More limited use of local foods as nutrient sources in their diets*<sup>68</sup>

A 1978 survey done in southwest Alaska found that 50 percent of calories in the Alaska Native diet came from carbohydrates, primarily highly refined low-fiber carbohydrates.<sup>69</sup>

Today, Alaska Native diets are made up of both traditional and store-bought foods. A comprehensive survey in various regions found that the proportions of carbohydrates, fats, and proteins consumed are essentially the same as for the general population in the United States.<sup>70</sup> A wide range of store-bought food is available in rural Alaska.

Although there is evidence that fruit and vegetable intake is protective against certain cancers, Alaska's large geographic area and small population present challenges for growing and/or distributing produce. Information from focus group surveys in 1996 found that barriers to fruit and vegetable consumption for Alaska Native and non-Natives included high cost, poor quality, and seasonal availability.<sup>71</sup>

In many rural village stores in Alaska, fresh fruits and vegetables are often in short supply, of poor quality due to long shipping time, or are too expensive to purchase regularly. Because of these factors, there has been an educational campaign to encourage rural residents to purchase and consume canned and frozen vegetables and fruits. These often carry more nutritional value than the "fresh" choices found in the village store, especially those harvested a long time before purchase.

One-third of the Alaska Native population lives in rural communities that are only accessible by airplanes or boats. Medical care, locally provided by Community Health Aides and Practitioners (CHA/Ps), is primarily focused on acute-care issues such as infectious disease control, rather than chronic care issues such as hypertension, diabetes, asthma and heart disease. There is a lack of coordinated messages across agencies; education channels and cancer materials are not always culturally relevant to Alaska Natives; and the best strategies for cancer prevention in this population are not fully understood.

With support from the National Cancer Institute, ANTHC developed a cancer education program for CHA/Ps in Alaska.

*The Path to Understanding* curriculum includes the benefits of cancer risk reduction through proper diet, normal weight, regular physical activity, and the nutritional value of traditional foods. Participants in the project increased their knowledge of cancer prevention, screening and early detection, diagnosis and treatment, as well as their familiarity and comfort level with accessing cancer resources.

Dietary interventions aimed at reducing the risk of cancers must vary by population and setting. Therefore, any cancer prevention program directed towards Alaska Natives needs to consider cultural and geographic diversity when determining the most effective intervention design. In general, however, it appears that interventions including food-related activities, social support, goal setting, and culturally sensitive designs are the most effective in promoting dietary change.<sup>72</sup> To change both dietary practices and physical activity levels, the Institute of Medicine recommends using programs that intervene at many levels (individual, interpersonal, institutional, community, and policy) and with multiple approaches (education, social support, incentives, laws, and policies).<sup>73</sup>

Some diet-related cancer prevention efforts for Alaska Natives include nutrition education through community programs such as SouthEast Alaska Regional Health Consortium's and Southcentral Foundation's "WISEWOMAN" programs. These programs are part of the CDC national efforts to promote heart disease screening and prevention for low-income and middle-aged women.

Another large-scale effort to address nutrition, physical activity, and cancer screening and prevention among Alaska Natives, is the Education And Research Towards Health (EARTH) Study, funded by the National Cancer Institute. EARTH is a prospective research study designed to determine how diet, physical activity, and other lifestyle and cultural factors relate to the development of chronic diseases, such as cancer, cardiovascular disease, and diabetes. This study will provide a better understanding of links between specific factors and these diseases.

Some regional tribal health corporations offer community outreach activities including the Fruit and Veggie Festival in Kotzebue organized by the Maniilaq Health Corporation, regional newspapers, public service announcements, posters, flyers, brochures, television advertisements placed on ARCS (Alaska Rural Communications System), and other media.

Many schools have incorporated diet-related messages into their health curriculum or have reduced or eliminated the use of soda and candy vending machines in the schools. Some schools have participated in a statewide initiative to "Stop the Pop", a program originally developed by ANTHC and the Alaska Native Health Board.

## *Physical Activity*

Regular, consistent physical activity is important for reducing

cancer risk, as well as helpful for other conditions including adult-onset diabetes, heart disease, and depression.

Similar to diet changes, physical activity patterns among Alaska Natives have changed. Traditional subsistence lifestyles were characterized by physical demands of hunting, fishing, and food gathering. Other typical traditional physical activities included travel on snow by dogsled, travel on land by walking, travel on water with a paddle, wood cutting by handsaw, water hauled by hand, or clothes washed by hand.<sup>74</sup> Even today, 33 rural villages lack piped water requiring the daily hauling of ice and water from some distance.<sup>75</sup> Although many of these traditional activities are still practiced, their frequency continues to decline due to increasing modernization of Alaska Native village life and availability of mechanized vehicles.<sup>76</sup> As in other parts of the country, in Alaska recent advances in labor saving devices have decreased the amount of physical activity required in day-to-day life.

The lack of physical activity is increasingly recognized as a risk factor for cancer. Colon, breast and prostate cancer are all associated with low levels of physical activity. A sedentary lifestyle is believed to be associated with five percent of all cancers. Therefore, regular physical activity, as part of a healthy lifestyle, may reduce the risk for cancer.

In 1996, the first U.S. Surgeon General's Report on Physical Activity concluded that the risk of premature death due to cancer could be reduced by regular physical activity.<sup>77</sup> Physical activity may affect cancers of the colon, breast, and other sites. Regular physical activity also helps maintain a healthy body weight by balancing caloric intake with energy expenditure.<sup>78</sup>

A number of studies have shown the positive effects of physical activity on reducing the risk of developing cancer. However, neither the exact mechanism for prevention, nor the optimum time period, duration, frequency, and intensity of physical activity has been established. Alaska has many barriers to physical activity, including extreme temperatures and seasonal daylight limitations. There are special issues to be aware of when exercising in the cold outdoors, such as preventing hypothermia and frostbite. Furthermore, the size of the state and the lack of sports facilities (for example gyms and swimming pools) has limited creation of physical activity programs. Any physical activity program for Alaska must take into consideration the length of winter and design appropriate outdoor and indoor activities that are enjoyable and safe for those of varying physical abilities. Throughout much of rural Alaska, indoor facilities for recreation are limited to the school gymnasium, or are non-existent. Weather conditions are harsh in many parts of the state, and not conducive to outdoor recreation, especially in the winter months. Long hours of darkness, wind, and extreme cold are among the deterrents to outdoor exercise.



In the last ten years, there has been an increase in Alaska Native prevention efforts through physical activity designed mainly by the diabetes mellitus program. Community programs include the “10,000 Steps to Living Healthy” walking program in the Interior and Southeast Alaska, the “Eagle vs. Raven Activity Challenge” and “Exercising Native Traditions” programs in Southeast Alaska. An effort by Dillingham community residents in the Bristol Bay area led to the creation of a paved pedestrian and bike path. Some school-based physical activity programs are included in the “Summercise” program in Nome, as well as open gym night in many rural schools.

Although regular physical activity has been shown to help reduce cancer risk, more than 60 percent of American adults are not regularly active and nearly 50 percent of America’s 12 to 21 year-olds are not active on a regular basis.<sup>79</sup> Physical inactivity is defined as “no leisure time physical activity within the last month”.

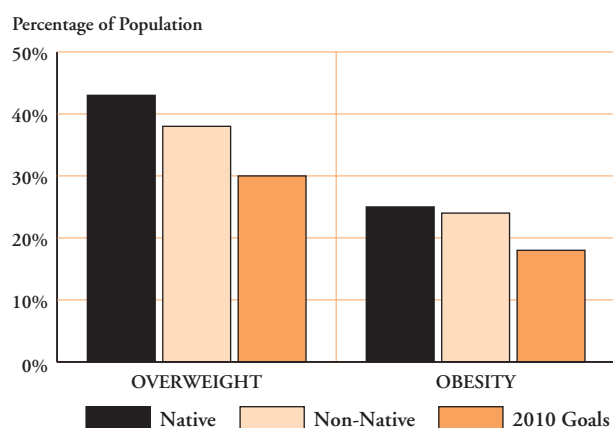
Among Alaskan adults, 19.2 percent were physically inactive according to 2003 BRFSS data. Among Alaska Natives, the percentage of sedentary individuals was higher at 30.5 percent.<sup>80</sup>

Among physically active adults, fewer Alaska Natives (26%) engage in vigorous physical activity (vigorous activity for at least 20 minutes per session on at least 3 days per week) than Alaska non-Natives (37%). A greater percentage of Alaska Native adults (37.5%) are moderately active (physically active for at least 30 minutes per session for at least five days per week), but this is also less than the non-Native adults (45.2%) who are moderately active.<sup>81</sup>

Data from the 2003 Youth Risk Behavioral Survey shows that over 14 percent of Alaska Native youth reported being sedentary. Only about 18 percent reported getting moderate physical activity. A little over half (56%) reported participating in vigorous physical activity, a decline from 62.1 percent in 1995.<sup>82</sup> This was slightly less than the rates reported by U.S. students as a whole (64.8%). Overall, only 60.4 percent of Alaska Native youth met current physical activity recommendations.<sup>83</sup> Unfortunately, be-

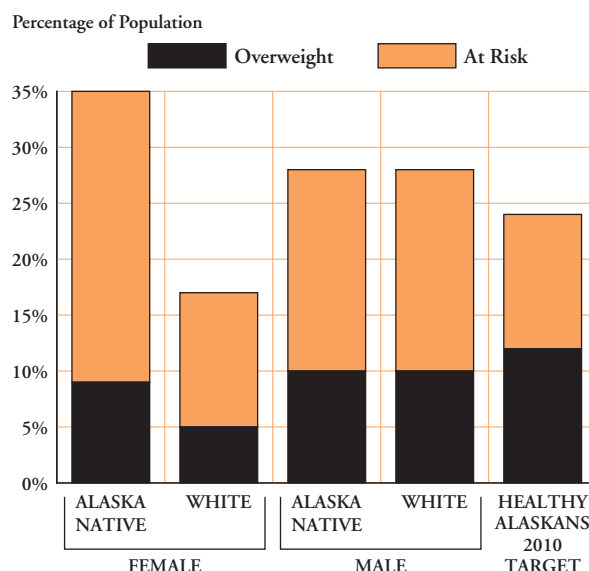
### Overweight and Obesity by Race, Alaska, 2004

Source: BRFSS



### Alaska High School Students at Risk for Overweight of Overweight by Race & Sex, 1999

Source: YRBS



cause there are no data on Alaska Native elementary and middle school aged children, it is unknown how many in this age group are currently getting enough physical activity.

In 2001, the U.S. Task Force on Community Preventive Services identified six interventions that are effective in increasing physical activity levels in a community:

- ◆ *Large-scale, high-intensity and community-wide campaigns with sustained visibility*
- ◆ *Point-of-decision prompts encouraging people to use the stairs*
- ◆ *Individually adapted health behavior change programs*
- ◆ *School-based physical education*
- ◆ *Social support interventions in community settings*
- ◆ *Enhanced access to places for physical activity combined with informational outreach activities*<sup>84</sup>

Physical activity is key to maintaining a healthy body weight, and has positive effects in and of itself. Although regular physical activity has been shown to have a beneficial impact on numerous chronic diseases including cancer, many Alaska Natives are more sedentary than recommended. Promotion of physical activity is important to cancer prevention efforts.

### Alcohol Use

Alcohol was not known or used in Alaska prior to first contact with Europeans in 1741.<sup>85</sup> Russians traders used alcohol as a form of payment and control for the Aleuts of Southwest Alaska and the Indians of Southeast Alaska. They introduced non-distilled alcohol as well as the knowledge of how to make alcohol.

Alcohol has had profound effects on Alaskan communities. Besides social disruption, excess alcohol can increase cancer risk. It is estimated that alcohol abuse accounts for three percent of all cancer deaths.<sup>86</sup> The precise mechanism by which alcohol causes cancer is not completely understood. A possibility is the way alcohol is metabolized may have an effect in the body that makes cells more vulnerable to other carcinogens (cancer causing substances). Another possibility is that alcohol itself increases certain hormone levels, which are, in turn, associated with cancer.<sup>87</sup> There is convincing evidence that alcohol increases the risk of cancers of the mouth, pharynx, larynx, and esophagus.<sup>88</sup> Oral cancers are six times more common in alcohol users than in non-alcohol users.

Smokers who also drink are at much higher risk than those who only smoke or drink.<sup>89</sup> Additionally, alcohol is a primary cause of liver cancer. Alcohol may influence not only liver cancer but other cancers as well by altering the liver's ability to metabolize carcinogens into harmless compounds or to deactivate certain existing carcinogens.<sup>90</sup> Alcohol use is linked with increased risk of breast and colorectal cancer. Poor nutrition, often associated with alcohol abuse, increases the risk of head, neck, and esophageal cancers.

## Nutrition, Physical Activity, and Alcohol Use Data

Much of the epidemiologic surveillance data collected in Alaska has not separated out Alaska Natives from the general population. Therefore, Alaska Native specific data will be presented here as much as possible, but where specific data is lacking, the full Alaska population will be used as a reference.

Data on diet from the Alaska Behavioral Risk Factor Surveillance System (BRFSS) show that in 2003, 23 percent of non-native adult Alaskans (age 18 or older) reported eating five or more

fruits or vegetables per day, while only 21 percent of Alaska Natives reported eating five or more fruits or vegetables per day.<sup>91</sup> Data from the 2003 Alaska Youth Risk Behavior Survey (YRBS) show that only 14.4 percent of Alaska Native youth reported eating five or more servings of fruits and vegetables per day, compared with 22 percent of U.S. students as a whole.<sup>92</sup>

There has been an alarming increase in the number of overweight and obese individuals nation-wide over the last twenty years. The 1999 National Health and Nutrition Examination Survey (NHANES) found that 61 percent of U.S. adults between the ages of 20 and 74 were either overweight or obese. The proportion of Alaska Natives who reported themselves as being overweight or obese was 63.7 percent in 2003, which was lower than non-Natives reported at 70.4 percent.<sup>93</sup>

Body Mass Index (BMI) can be used to identify children and adolescents 2 to 20 years old that are overweight or at risk of becoming overweight. Data do not currently exist for BMI on young children in Alaska, but data from the 2003 Alaska YRBS show that among Alaska Native high school students, 13.7 percent are overweight and 13 percent are at risk for becoming overweight, compared to the national average of 13.5 percent for overweight and 15.4 percent for risk of overweight.

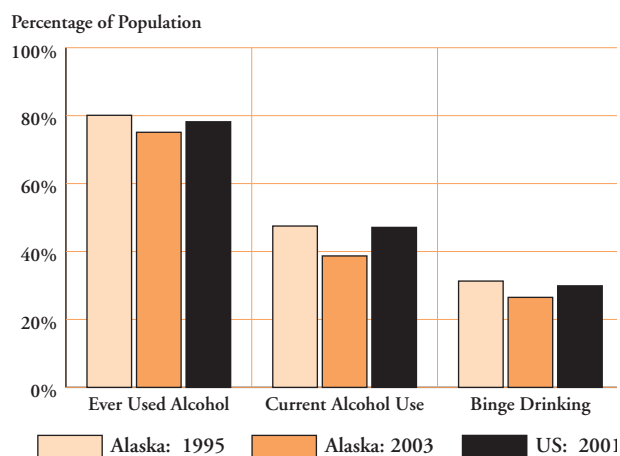
As stated previously, alcohol is a dietary factor that is associated with increased cancer risk. YRBS data from 2003 show that among Alaska high school students, 38.7 percent report having had at least one drink of alcohol in the past 30 days, a decrease from 47.5 percent in 1995. Among Alaska Native high school students, 25.3 percent report having had a first drink of alcohol before age 13, a decrease from 35.7 percent in 1995. Rates for binge drinking and "ever used" alcohol are similar to the U.S., while rates for current alcohol use are significantly lower than the U.S. rate.

Among Alaska Native adults seven percent reported drinking more alcohol than the moderate level (adult women one drink per day and adult men two drinks per day) and 26.5 percent of Alaska Native adults reported they engaged in binge drinking.<sup>94</sup>

Although some data on diet patterns of Alaska Natives exist, many gaps remain. The proportion of Alaska Natives in the statewide BRFSS survey is small compared to their actual numbers. No method exists currently to determine cancer-related risk factors among younger children, such as the percentage of elementary and middle school aged children eating five or more servings of fruits and vegetables. Furthermore, the need for parental consent for the YRBS has made it challenging to collect these data even from high school populations. The data that is collected on high school students is also limited in the number of Alaska Native youth represented.

### Alcohol Use Among Alaska Students

Source: YRBS



# Goals, Objectives & Strategies for Nutrition, Physical Activity, & Alcohol

## GOAL

Alaska Natives will make healthy nutrition, physical activity, and alcohol consumption choices for cancer prevention.

## NUTRITION OBJECTIVES & STRATEGIES

**OBJECTIVE PN1:** Increase to 40% the proportion of Alaska Native adults 18 and older who have a Body Mass Index (BMI) below 25 by 2010.

*Baseline:* 32% BRFSS 2004.

**Strategy a:** Increase the awareness of Alaska Natives about the links between diet and cancer, including the importance of maintaining a diet rich in plant-based foods, reducing the consumption of store-bought animal fat, and attaining and maintaining healthy body weight.

**Strategy b:** Increase opportunities for Alaska Natives to learn healthy cooking methods and disseminate healthy recipes that are ethnically and culturally appropriate and based on available foods.

**Strategy c:** Provide training and resources for health care providers to increase their capacity to educate Alaska Natives on the importance of maintaining a healthy diet.

**Strategy d:** Increase the ability of health care providers to measure and record height and weight of adult patients for obesity prevention.

**OBJECTIVE PN2:** Establish a BMI baseline for Alaska Native adolescents by age and gender by 2010.

*Baseline:* No baseline exists for Alaska Native adolescents. Baseline for all Alaska adolescents is 75% BRFSS 2003

**Strategy a:** Increase the ability of health care providers to measure and record height and weight of adolescent patients for obesity prevention.

**OBJECTIVE PN3:** Increase to 30% the proportion of Alaska Native adults 18 and older who eat at least five servings of fruits and vegetables every day by 2010.

*Baseline:* 21% BRFSS 2003

**Strategy a:** Develop media messages aimed at Alaska Native adults to increase their awareness of the importance of eating five or more servings of fruits and vegetables every day.

**OBJECTIVE PN4:** Increase to 30% the proportion of Alaska Native adolescents who eat at least five servings of fruits and vegetables every day by 2010.

*Baseline:* 14.4% BRFSS 2003

**Strategy a:** Utilize data sources to determine barriers to healthy eating and to plan effective strategies to overcome identified barriers.

**Strategy b:** Develop media messages aimed at Alaska Native adolescents to increase their awareness of the importance of eating five or more servings of fruits and vegetables every day.

## PHYSICAL ACTIVITY OBJECTIVES & STRATEGIES

**OBJECTIVE PP1:** Increase to 28% the proportion of Alaska Native adults 18 and older who meet Healthy People 2010 recommendations for moderate and vigorous activity by 2010.

*Baseline:* 16% BRFSS 2003

**Strategy a:** Increase public awareness of the benefits of physical activity.

**Strategy b:** Increase the number of ATHS worksites that provide opportunities and policies that promote physical activity (e.g., health club membership discounts, workout rooms, flexible work hours, walking groups, on-site fitness classes, and accessible stairways).

**Strategy c:** Promote physical activity in local communities by gathering information on walk-ability and bike-ability and existing policies and programs.

**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.

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**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.

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## 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.

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**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.

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## 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.<sup>95</sup>

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.<sup>96</sup> 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.<sup>97</sup> 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, Grigori Shelikhov established the first permanent Russian settlement at Three Saints Bay on Kodiak Island.<sup>98</sup> Shelikhov brought tobacco, which was already established as a coveted trade good through contact with earlier foreign traders and expeditions.<sup>99</sup> 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

mining of gold placer deposits occurred in many parts of Alaska including Nome. The extraction process used concentrates of arsenic (a carcinogen) and mercury to separate gold from ore. Over the years that followed, arsenic contaminated rock was redistributed as fill for roads and foundations, raising concerns about the potential risks associated with exposure to mine waste.<sup>100</sup>

By the early 1900s, the industrial revolution was introducing products and pollutants at an unprecedented rate with implications even for remote Alaska. As petroleum became more readily available, kerosene replaced seal and whale oil in lamps, and coal was used more often for heat. Stern-wheelers, fueled by the coal mined from the hills of the Kenai Peninsula, began to ply the coastlines and rivers. Prospectors, miners, trappers, fishermen, loggers, and others poured in by the thousands.

Throughout the 20th century, new chemicals were discovered and then applied to improve quality and efficiency in the factory, on the farm, and in the home. Some of these substances and their by-products had potential health consequences. Farmers, local governments, and the military used toxic pesticides and herbicides to encourage crop growth and discourage weeds. Today we know that some of these chemicals, like DDT, devastated bird populations in the lower 48 states, bringing species like the bald eagle to the brink of extinction. Effects on the human population are less clearly understood.

With the bombing of Dutch Harbor in June of 1942, Alaska was thrust into a new role as the nation's northernmost line of defense.<sup>101</sup> Hundreds of military bases and outposts were rapidly constructed. Fort Glenn on Umnak Island in the Aleutians was operational in one year, supporting tens of thousands of military personnel and the facilities to store, transport, and supply hundreds of thousands of gallons of fuel for the vehicles, ships and aircraft needed in the war effort. Hazardous chemicals were used in munitions, electrical plants, and communication facilities to maintain the growing military infrastructure. Today there are 599 Formerly Used Defense (FUD) sites identified in Alaska. Clean-up projects are underway at approximately 130 sites. According to the U.S Army Corps of Engineers, it will take approximately 70 years to complete clean up of the chemical contamination at these sites, with cleanup of munitions taking much longer.<sup>102</sup>

During the 1940s and 1950s there was tremendous development statewide in the transportation infrastructure. This opened up the land and provided opportunities for rural communities to participate in commerce and gain access to products that had never been available to them before. Some were potentially harmful like DDT, fuels containing carcinogenic benzene and lead, PCBs used in power plants, and new building materials containing asbestos. These products made a one-way trip to

villages, ultimately being deposited in the local dump or the environment.

The sight of a thick haze blanketing the horizon in the mid 1950s was one of the first signs that Alaska was being affected by pollution from other parts of the world. Arctic haze was found to consist of soot, soil, and sulfate aerosols carried by winds from Eurasia.<sup>103</sup> Alaska Natives realized that they were no longer isolated from the pollution of the industrialized world.

Through the 1950s and 1960s, Alaska had an active role in the Cold War. A network of communication facilities known by their acronym "DEW Line" for Defense Early Warning sites, were installed statewide.<sup>104</sup> "DEW Line" sites are included in FUD site lists and some are known sources of PCB and petroleum contamination.

In 1957, the U.S. Atomic Energy Commission (AEC) established the 'Plowshare Program' to "investigate and develop peaceful uses for nuclear explosives." AEC selected a site approximately 30 miles southeast of the Inupiat Eskimo village of Point Hope for an experimental harbor excavation to be called Project Chariot. The concept involved detonating an atomic bomb to excavate the harbor. Late in 1962, after extensive scientific studies, the AEC announced that it was canceling the project due in part to public criticism.<sup>105</sup>

During the 1960s, the debate over using Amchitka Island in the Aleutians as an underground test site for nuclear weapons was hotly contested by Alaska's political leadership, environmental organizations such as Green Peace, and the Aleut League which lobbied against the use of Native lands for atomic weapons testing. Nevertheless, the AEC jointly with the Department of Defense detonated three underground nuclear tests at Amchitka between 1965 and 1971. The final test called "Cannikin" detonated a five million-ton bomb. It was the largest underground atomic test ever performed and created an underground nuclear dumpsite beneath Amchitka Island, in the middle of one of the world's richest marine resource areas.

In 1970 the Environmental Protection Agency was established and over the next two decades, landmark legislation was enacted protecting surface water sources, drinking water, and air, and regulating hazardous substances. Other environmental milestones included the Superfund legislation for clean up of contaminated sites, the phase out of lead from gasoline, banning underground nuclear testing, and banning the manufacture of some carcinogenic chemicals such as PCBs and asbestos.

In the 1990s new global environmental concerns surfaced in Alaska. Atmospheric research revealed that the ozone layer was deteriorating and as a result UV related diseases, including skin cancer, were on the rise. Carcinogenic pollutants, although now banned in some countries, began showing up in Arctic wildlife.

The sources of the pollutants were traced from industrial sites thousands of miles away.

Since 2000 the capacity of Alaska Natives to manage health care and environment programs on the local level has steadily grown. Today, as many as 140 Alaska Native tribes have active environmental management programs addressing a wide variety of rural issues, including reducing exposure to contaminants. The military has Alaska Native liaisons for FUD programs. Tribes are actively involved in facilitating the restoration of federal sites, addressing the safe storage of fuels, opening new sanitary landfills, testing air and water quality, monitoring traditional foods for contaminants, and assessing local contamination sources.

### *Cancer burden attributable to environmental contaminant*

The use of many man-made contaminants in Alaska is relatively new, some having been introduced as recently as the 1940s. Examples include PCBs, vinyl chloride, DDT, and sources of ionizing radiation. Alaska Natives today are among the first generations to spend their developing years in an environment vastly different from that of their forefathers. The effects from lifetime exposure to low levels of these contaminants, either alone or in combination, are not clearly understood. The actual cancer hazard to an individual posed by any particular contaminant depends on the carcinogenicity of the substance, the duration of exposure, an individual's genetic susceptibility to the effects of the contaminant, and other environmental influences such as exposure to other contaminants.

The International Agency for Research on Cancer (IARC) classifies over 20 chemicals as human carcinogens including arsenic, asbestos, silica, benzene, chromium, radon, vinyl chloride, and formaldehyde.<sup>106</sup> Housed within the World Health Organization, IARC coordinates and conducts research on the causes of human cancer and develops scientific strategies for cancer control.

It is not known how many cancers diagnosed in Alaska Natives can be attributed to environmental contaminants. Based on existing worldwide research, it is estimated that contaminants account for only a small percentage of the overall number of cancers in the Alaska Native population.

Over thirty years of cancer data from the Alaska Native Tumor Registry has not revealed any obvious associations of cancer with contaminant exposure.<sup>107</sup> This does not suggest that some contaminant related cancers do not occur. Rather it is an indication of the difficulties in linking cancer with an environmental source.

### **Linking contaminants to cancer is challenging for many reasons, including:**

1) There are only a few cancers worldwide that have been linked to a specific contaminant. If an individual had exposure to other known risk factors (such as tobacco), the implication of low-level contaminants is difficult to determine.

2) It is very difficult to link cancer to a low-level exposure.

Those cancers which have been linked to contaminant exposure have involved mostly long-term or high-level occupational exposures, such as lung cancer from asbestos exposure of miners (outside Alaska).

3) The latency period for contaminant related cancer is generally quite long. It can take 20 to 30 years after an exposure has occurred for cancer to develop. Such a long latency period makes it very difficult to identify causal factors, not only because the exposure may not be documented or known, but also because individuals and populations are exposed to many different risk factors over a lifetime.

4) The very small populations of Alaska communities make it difficult to determine or observe any unusual incidence of cancers. It is difficult to detect unusual incidence of cancers even in large populations, and the problem is exacerbated by small populations in Alaska villages.

At this time there is limited scientific data on contaminant related cancer incidence among Alaska Natives. Unlike other causal factors such as tobacco, poor nutrition or infectious agents, no cancer clusters have been found that can be singularly or primarily identified with everyday contaminant exposure.

Growing awareness about detection of contaminants, in human blood and tissues of subsistence animals, has raised anxiety in the Alaska Native population. In some instances it has resulted in behavior and lifestyle changes. The public perception is that the risk of cancer from contaminants is very high.

Unfounded concerns over contaminants have caused some people to abandon some traditional foods. As an alternative they have sometimes switched to store-bought foods which may have their own contaminant levels.<sup>108</sup> Many processed foods are known to contain low levels of PCBs and other contaminants. Diet changes could result in less healthy store-bought foods being substituted for highly nutritious subsistence foods.

There are instances where, due to localized contaminant problems such as industrial use, military activity, or presence of a known hazardous waste, traditional foods should be harvested with caution. In locations where there has been a contaminated site designation by the State of Alaska or where local knowledge

indicates that there may be a threat to food safety, restrictions on some traditional food consumption may be necessary. In these locations, guidance from public health and environmental experts is warranted to determine what is safe and what should be avoided.

Studies to date have shown traditional foods are safe and the benefits far outweigh the small amount of risk associated with trace levels of contaminants.<sup>109</sup> Based upon current knowledge it is recommended that consumption of traditional foods be encouraged for good nutrition and overall wellness.<sup>110</sup>

Providing reliable information and raising awareness about the relative risks associated with environmental contaminants in the Alaska Native subsistence diet, is an important prevention strategy for reducing cancers associated with diet and obesity, as well as other chronic illness such as diabetes and heart disease.

## *Contaminants of concern*

According to the US Department of Health and Human Service 11th Report on Carcinogens, there are about 58 substances known to cause cancer.<sup>111</sup> An additional 188 are identified as “reasonably anticipated to be a human carcinogen.” Many more are suspected of causing human cancer, but have not been studied sufficiently and so the actual risks are not known.<sup>112</sup>

Some known carcinogens can be found in Alaska Native communities, as can some of the suspected environmental carcinogens. For the purpose of this chapter, seven known and suspected carcinogens that are especially relevant to Alaska Natives have been selected for further discussion.

These include:

- ◆ *Arsenic*
- ◆ *Asbestos*
- ◆ *Benzene*
- ◆ *Ionizing radiation*
- ◆ *Persistent organic pollutants (POPs)*
- ◆ *Radon*
- ◆ *Solar radiation*

**Arsenic** - is a naturally occurring element, which can be released from arsenophrite ore and become a contaminant in soil, water, air, and food. It has no odor or taste and cannot be detected easily. Exposure to arsenic can result in a variety of cancers including skin, bladder, liver, kidneys, prostate, and lungs. Elevated levels of arsenic have been found in some private wells in Fairbanks, Anchorage, the Matanuska Susitna Valley, and the Kenai and

Seward Peninsula. For Alaska Natives, exposure can occur by drinking water from a private well where elevated arsenic levels are present, or drinking from a public water system that does not meet the EPA standard.

One study looking at human exposure to arsenic is the ANTHC Maternal and Infant Monitoring Program, which tests levels of a variety of contaminants in the blood of pregnant mothers and newborn infants. The purpose of testing this group is to focus on some of the most sensitive members of the population, and to evaluate whether even low levels of contaminants could have subtle health effects. Participants were enrolled from the Yukon Kuskokwim Delta, the Aleutian Pribilof Region, and the North Slope. Over 200 maternal specimens have been collected since 2000. Levels of arsenic were found to be similar to the U. S. population mean.<sup>113</sup>

**Asbestos** - is the name given to a group of fibrous minerals valued for their thermal and acoustical properties as well as their high tensile strength.<sup>114</sup> Today the commercial use of asbestos is banned in the United States. Asbestos is easily broken into tiny fibers that can become airborne and then inhaled or ingested. Harmful levels of asbestos have typically occurred in the work place. For instance, miners and mill-workers outside Alaska developed chronic lung diseases and cancer. However, when it comes to cancer, there are no recognized safe levels. Alaska Natives may be exposed to asbestos in old buildings and at dump sites.

High concentrations of asbestos from natural soil minerals were first identified in the Yukon River in 1977.<sup>115</sup> In 1979, U.S. Fish and Wildlife biologists analyzed tissue samples from two fish indicating that natural asbestos fibers in river water could be ingested by fish, and then passed through the gut to lodge in muscle tissue. The Yukon specimens were found to contain 100 times more asbestos fibers than fish analyzed from known polluted areas such as Lake Superior in the Midwest part of the United States. Liver and kidney tissues were found to concentrate fibers as well. Continued tissue analysis during the 1980s of fish, black bear, beaver, raven, and spotted sandpiper confirmed the concentrating effect. The highest concentrations found in water samples were collected near St. Mary's in 1982, with 354 million amphibole fibers and 75 million chrysotile fibers detected per liter.

One of the lingering questions posed is whether there is any health risk associated with ingestion of asbestos fibers. Both cancers associated with asbestos exposure (mesothelioma and lung cancer) are related to inhalation of fibers, not ingestion. Some tribal environmental departments are addressing local asbestos concerns.



**Benzene** - is a highly volatile and flammable compound found in crude oil, gasoline, and cigarettes. In appearance, it is a colorless liquid with a slightly sweet odor. Benzene is used to make chemicals important in the manufacture of plastics, resins, nylon and synthetic fibers.<sup>116</sup> Benzene most commonly enters the environment through industrial releases, fuel vapors, or spills. It is not a persistent contaminant and thus will not accumulate in plants and animals. It is however very volatile and migrates easily into the air. It can also pass through the outer layer of skin and enter the bloodstream.<sup>117</sup> Alaska Natives may be exposed to benzene while smoking, breathing fuel vapors, or through direct contact when handling fuels.

Elevated levels of benzene in homes have been detected in urban areas but information about levels in rural homes is not available. The tight design of Arctic homes combined with the use of interior space for fuel storage and engine maintenance, raises questions about the health risk associated with poor indoor air quality.

The primary concern with benzene for Alaska Natives is related to levels in the air, both outdoors and indoors. Alaska has higher levels of benzene in gasoline than in the rest of the country, which can translate into higher levels in the air. There has been research in urban areas where homes with attached garages are common. The City of Anchorage Department of Health and Social Services performed an indoor air study of 137 homes between 1994 and 1996.<sup>118</sup> Of 137 homes, 91 had attached garages. In the homes with attached garages, significantly higher levels of benzene were detected. The Agency for Toxic Substances and Disease Registry (ATSDR) reports that 4 ppb benzene exposure daily increases the lifetime risk of cancer by 1 in 10,000. Twenty-five percent of the homes tested in Anchorage had levels that at 16 ppb, four times higher the ATSDR standard. The report stated that the elevated levels were mainly attributable to rooms above garages, the storage of cars, small engines, fuel in attached garages, and forced air heating.<sup>119</sup>

**Ionizing Radiation** – comes in different forms, each varying in the amount of energy released and the degree of health risk. Most radiation originates from elements or atoms such as plutonium, uranium and radium that are unstable and result in radionuclides as the products of decay. Radionuclides enter the body primarily through inhalation or ingestion. They may also settle on the skin. Once in the body, they disperse in different ways concentrating in bones, the thyroid, and in other parts of the body.<sup>120</sup> Of the known exposure to ionizing radiation, 55 percent is from low dose medical diagnosis (x-rays), 43 percent are from sources such as radon, and about two percent from scientific research, nuclear power and nuclear testing and accidents.<sup>121</sup>

Alaska Natives can be exposed to ionizing radiation from atmospheric fallout, including global transport from atmospheric testing, releases from the Chernobyl power plant accident, and from nuclear reprocessing plants.<sup>122</sup>

Radiation has been generated as the result of government activities in Alaska, such as the underground nuclear testing on Amchitka Island; but there has been no evidence of significant non-occupational human exposure. Cancers associated with radiation include leukemia, thyroid and breast cancer as well as myeloma, and cancer of the lung, stomach, colon, esophagus, bladder and ovaries. There are no known safe levels of nuclear radiation exposure. Currently, there is no evidence linking non-occupational exposure to ionizing radiation with cancer among Alaska Natives.

**Persistent Organic Pollutants (POPs)** – are highly persistent contaminants that build up in the tissues of living organisms. Some of these organisms are the fish, birds, sea mammals, and other land and sea creatures that Alaska Natives depend upon for food. POPs originating from other global sources are readily transported to Alaska by air and water currents. They are fat soluble, so animals high on the food chain with greater amounts of body fat, such as marine mammals, polar bears and killer whales, have the highest levels. Seal and walrus have lower concentrations and fish and terrestrial animals have the lowest.<sup>123</sup> POP use was banned in 1977 due to concerns over the effects on public health and the environment. The levels of banned POPs such as PCBs have been gradually declining in the Arctic since the 1970s.<sup>124</sup>

A small number of blood serum samples collected from Alaska Native women in the 1980s were tested for organic pollutants. Just as with the general population, quantifiable levels of most organics pollutants were detected.<sup>125</sup> In 1999 the State of Alaska Department of Health and Social Services (DHHS) tested levels of POPs in blood samples collected from 166 participants in five Aleut villages.<sup>126</sup> Again, quantifiable levels of many of the tested organic chemicals were found. The findings did not change any recommendations regarding consumption of traditional foods because the benefits from these foods outweighed the potential risks. DHSS recommended that further studies be performed.

**Radon** – is a natural occurring form of ionizing radiation that occurs under specific geologic conditions. What makes radon unique is that it is a gas and therefore has a natural pathway into the lungs. If a structure is built in a radon-prone area, the gas can pass through the foundation and gather in crawl spaces, sumps or basements. Four conditions are necessary in order for radon to gather in concentrations that pose a risk. The four conditions are: uranium in the local geology to act as a source; permeable soil to allow for rapid soil gas movement to the structure; cracks or per-

forations in the foundation to allow a pathway into the occupied space; and lower pressure inside the structure than outside, to allow the radon to enter.

The degree of risk related to low level radon exposure continues to be the subject of debate. Due to the high radon levels found in some areas of the country, it is thought to be the second leading cause of lung cancer behind smoking tobacco.<sup>127</sup> Nationally, radon accounts for twelve percent of all lung cancer deaths, between 15,000 and 22,000 cases each year.

Radon levels in Alaska are generally low, although elevated levels have been measured during EPA surveys of homes in some parts of Interior, Southcentral and Southeast Alaska. Permafrost and some arctic building practices, such as the use of pilings, effectively eliminate the radon risk in some areas.<sup>128</sup> The Alaska Range has “moderate potential” for generating radon at levels that could be considered a health risk. This means structures that are built on-grade or below-grade may allow for radon migration into the living space. A structure built on glacial soils or near bedrock may be on a radon prone area.

The EPA conducted home radon sampling in Alaska in 1988 and 1989. Although not all parts of the state were included, a total of 1,240 separate sites were tested in five sub-regions including: Anchorage, the Interior, Southeast, Southcentral and Western /Northern Alaska. Levels were generally low with the exception of the Interior, where approximately 17 percent of the 363 homes tested exceeded the EPA Remedial Action Level and Southcentral, where approximately 13 percent of the 295 homes tested exceeded the EPA standard.<sup>129</sup>

Two years of additional testing confirmed that Fairbanks is a radon risk area. Other communities in Alaska have the conditions that may also pose a radon risk. In Barrow residents were exposed to radon pumped from natural gas wells into their homes.<sup>130</sup> In Nome homes have been constructed over fill taken from old gold mining operation tailings.<sup>131</sup> Communities constructed on glacial deposits such as in the Matanuska Susitna Valley, or on volcanic geology such as in the Aleutians also deserve analysis. Seasonal variations are thought to occur so sampling during the summer and winter may be necessary to evaluate average concentrations.

The long cold seasons in Alaska as well as Arctic home construction methods contribute to radon transport as oil-fired combustion systems provide negative pressure and tight home construction minimize air exchanges and can concentrate radon inside the home. There are ways to reduce exposure to radon, such as changing the pressure differential, managing airflow, and sealing cracks in foundations and other penetrations.

**Solar Radiation** - Ultraviolet radiation from sunlight has been

linked to skin cancer. This type of radiation is different from that resulting from nuclear energy production or atomic bombs. The radiation in sunlight is non-ionizing. This means that it has enough energy to change chemicals and cells, but not enough energy to change atoms.

In Alaska, depletion of the ozone layer is reducing the protective properties of the atmosphere, resulting in an increase in solar radiation. At the same time, global climate change is resulting in warmer weather and an opportunity for Alaskans to wear less clothing and expose more skin to the effects of the sun. Skin cancer from over exposure to solar radiation is the most common malignancy in humans. It accounts for one-third of newly diagnosed cancer in the United States and will affect approximately one in five Americans during their lifetimes.<sup>132</sup> Based on over 30 years of ANTR data, there is no evidence of a significant increase in the incidence of melanoma among Alaska Natives.

Skin cancer is largely preventable when sun protection measures (e.g., sunscreen, protective clothing) are used consistently. Most skin cancers are curable if detected in the earliest stages.



# Goals, Objectives & Strategies for Environmental Contaminants

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## GOAL

Reduce the exposure of Alaska Natives to harmful levels of carcinogenic environmental contaminants.

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### OBJECTIVE PE1: Educate Alaska Natives about ways to reduce harmful exposure to contaminants.

*Baseline:* Few environmental education programs exist in 2005.

**Strategy a:** Increase awareness about health risks associated with asbestos in rural villages.

**Strategy b:** Raise awareness about the benefits and risks associated with traditional diets.

**Strategy c:** Inform people who live in radon prone areas about the risks of radon and ways to reduce those risks.

**Strategy d:** Develop materials about sun exposure and the risk for skin cancer.

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### OBJECTIVE PE2: Increase the understanding of the benefits of traditional foods as well as the risk considerations when studying contaminants in traditional foods.

*Baseline:* Few educational resources are available that emphasize both benefits and risks of traditional foods.

**Strategy a:** Support the development of material specific to benefits and risks of traditional foods in Alaska.

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### OBJECTIVE PE3: Support efforts by the State of Alaska, Environmental Protection Agency and others to establish a standardized system for statewide monitoring of contaminants.

*Baseline:* A statewide standardized system does not exist in 2005.

**Strategy a:** Investigate possibilities for establishing a system for statewide monitoring of contaminants.

### OBJECTIVE PE4: Advocate at the local, state, federal, and international levels to promote a cooperative strategy for contaminant related cancer risk prevention.

*Baseline:* Prioritization of advocacy activities relevant to environmental health occurs annually within the Alaska Native Health Board and the ANTHC Department of Environmental Health and Engineering.

**Strategy a:** Encourage proper management and clean-up of abandoned and active asbestos contaminated buildings and waste sites.

**Strategy b:** Seek appropriate changes to real estate law to require sampling of well water for arsenic as part of real estate transactions.

**Strategy c:** Seek adequate federal funding for public water systems to meet mandate for testing and treatment.

**Strategy d:** Provide safe drinking water (within allowable standards) to all Alaska Natives.

**Strategy e:** Advocate for reduction in global use of carcinogenic contaminants.

**Strategy f:** Raise awareness about the risks associated with continued application of carcinogenic compounds in the environment.

**Strategy g:** Encourage greater cooperation between the State of Alaska and neighboring countries regarding the monitoring and control of contaminants in the environment.

**Strategy h:** Encourage continued funding and coordination between responsible parties, State and Federal Agencies and ANTHC in efforts to clean up contaminated sites.

**Strategy i:** Support efforts to develop building codes that decrease risk of exposure to indoor air pollutants.

**Strategy j:** Support development of long term monitoring strategies for the environment and subsistence resources of Amchitka Island.

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**OBJECTIVE PE5: Encourage research on Alaska Native exposure to contaminants and incidence of contaminant related cancer.**

***Baseline:** There is no comprehensive database that identifies and tracks research on the effects of the environment on cancer in Alaska Natives in 2005.*

**Strategy a:** Investigate naturally occurring asbestos in Alaska.

**Strategy b:** Evaluate the extent of the problem of arsenic in private water wells.

**Strategy c:** Review tumor registry data to assess bladder, liver, kidneys and other arsenic-associated cancers in high arsenic areas.

**Strategy d:** Research health issues related to air quality in rural housing.

**Strategy e:** Explore opportunities for reducing exposure to harmful levels of benzene and other constituents of fuel.

**Strategy f:** Evaluate levels of carcinogenic air pollutants in rural homes, boats, and buildings.

**Strategy g:** Monitor levels of persistent organic pollutants (POPs) in Alaska Native population.

**Strategy h:** Encourage comprehensive testing of homes for environmental contaminants in susceptible areas.

**Strategy i:** Generate data regarding levels of sun exposure among Alaska Natives by including sun exposure questions on the Alaska Behavior Risk Factor Survey.



# INFECTIOUS AGENTS & CANCER

## *Introduction*

Certain viruses and bacteria, such as Human Papilloma Virus (HPV), Hepatitis B, Hepatitis C, Epstein-Barr, Kaposi's sarcoma-associated Herpesvirus, and *Helicobacter pylori* (*H. pylori*) are proven carcinogens. A brief discussion of each agent and relationship to cancer is described below.

### **Human Papilloma Viruses**

Cervical cancer are linked to human papilloma virus (HPV), an extremely common sexually transmitted infection that typically does not have symptoms and is harmless. Of the 30 known types of HPV that are sexually transmitted, more than 13 types may lead to cervical cancer. Two of these types, HPV16 and 18 are associated with 70 percent of all cases of cervical cancer.

HPV vaccines were approved by the FDA in 2006. The vaccines will be given through a series of three injections over a six-month period. One vaccine would protect against four types of HPV, including two that cause most (70%) cervical cancers. These vaccines have been found to be highly effective in preventing infection with the targeted types of HPV. They also have been found to be 100% effective in preventing conditions caused by those HPV types.

The length of immunity as a result of the vaccination is not known. Research is being done to find out how long protection will last and if a booster vaccine is needed. The Advisory Committee on Immunization Practices, the American Academy of Pediatrics, the American Association of Family Physicians and the American Medical Association jointly identified ages 11-12 years as the optimal time for adolescent immunizations

Because these vaccines will not protect against all types of HPV, they will not prevent all cases of cervical cancer and cervical screening (pap tests) will continue to be necessary.

### **Hepatitis B and Hepatitis C**

Infections with hepatitis B (HBV) and hepatitis C (HCV) viruses can result in liver cancer. HBV infection risk factors include occupational exposure to blood products, injection drug use, and high-risk sexual behavior (unprotected sex with multiple partners). Currently there are vaccines for HBV, but not HCV. Since the early 1970's, Alaska Natives were known to have a high rate of HBV infections. Some people can get rid of the virus and become immune, while others cannot and become chronic hepatitis B surface antigen (HbsAg) carriers at increased risk of developing liver cancer. The Alaska State Hepatitis B Virus (HBV) Immunization Program began in late 1982. No child born in Alaska. Since HBV immunization became available no child born in Alaska has been diagnosed with hepatocellular cancer, a cancer diagnosed in Alaska Native children prior to the availability of HBV immunization.

Screening of carriers has led to detection of liver cancer at an earlier stage and contributed to improved survival. Indeed, 60 percent of Alaska Natives with liver cancer diagnosed from 1984 to 1994 had liver disease detected at an early stage, compared to

21 percent of U.S. White liver cancer patients.<sup>133</sup>

The rising incidence of liver cancer in the United States is thought to be due to HCV. The strongest risk factor for HCV infection is injection drug use, but sexual transmission is also possible. People who received a blood transfusion prior to 1989 may also be infected with this virus. Currently there is no vaccine for HCV.<sup>134</sup>

### **Epstein-Barr Virus and Kaposi's Sarcoma-Associated Herpes Virus**

Epstein-Barr Virus (EBV) causes infectious mononucleosis, a benign disease generally diagnosed in young adults. Almost all persons are infected at sometime in their lives with EBV and at earlier ages in developing countries than in developed nations. It has been associated with some types of lymphoma and nasopharyngeal carcinoma (NPC), a cancer that occurs at very high rates in Alaska Natives. Another cancer-associated virus is Kaposi's Sarcoma-Associated Herpesvirus (KSHV); infection only occurs through close person-to-person contacts. The risk of cancer for people infected with either EBV or KSHV is low, except for those with weakened immune systems, such as people infected with the Human Immunodeficiency Virus (HIV/ AIDS), persons on chemotherapy, and post transplant patients on immune suppressant drugs.

### ***Helicobacter-pylori* (*H. pylori*)**

*H. pylori* is a bacterium that can live in the stomach and in the duodenum. It is the most common cause of ulcers. Ulcers can also be caused by some medications or too much stomach acid, but the most common cause is *H. pylori* infection. It is not known how *H. pylori* passes from one person to another, but the bacterium have been found in saliva, dental plaque, and in the stools of children. Close contact with others in households may increase the spread of infection.

*H. pylori* infection is very common in the United States., but most people do not have any symptoms. Only a small percentage goes on to develop any disease. In addition to ulcers, infection with *H. pylori* can also cause gastritis, and infected people have two to six times the risk of developing lymphoma and gastric cancer when compared with uninfected people.

Attention was focused on *H. pylori* among Alaska Natives when it was discovered that anemia caused by blood loss in the stool appeared to be associated with *H. pylori*. High rates of iron deficiency anemia had been observed among Alaska Natives dating back to the 1950s. This led to the discovery that 99 percent of those with increased fecal blood loss had chronic gastritis caused by *H. pylori*.<sup>135</sup>

Because of the high rates of gastric cancer in Alaska Natives, and its association with *H. pylori* infection, the CDC Arctic Investigations Program and ANTHC are developing studies to better understand gastric cancer in the Alaska Native population and determine if it is associated with *H. pylori* infection in this population. Another goal is to look for factors that might predict which of the many persons with *H. pylori* infection will go on to develop more severe problems such as ulcers or cancer.



## Goals, Objectives & Strategies for Infectious Agents

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### GOAL

Reduce cancer deaths in Alaska Natives due to infectious agents.

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**OBJECTIVE PI1:** Increase awareness among Alaska Natives of the relationship between certain infectious diseases and cancers emphasizing vaccinations.

***Baseline:** Current information available to Alaska Natives is very limited in 2005.*

**Strategy a:** Develop media messages on infectious disease vaccinations and cancer.

**Strategy b:** Monitor emerging science investigating the relationship between infectious agents and cancer.

# SCREENING AND EARLY DETECTION

*Screening and early detection provide procedures and tests to aid in the identification of pre-cancerous or cancerous conditions at the earliest possible stage.*

## Introduction

It is easier to treat and cure cancer when it is found early. There are many different types of cancer, but most begin when cells keep dividing when new cells are not needed. These extra cells form a tumor. Cells in cancerous, or malignant, tumors are abnormal and divide without control or order. If the tumor is found when it is small, curing the cancer can be easy. If the tumor continues to grow, it can invade and damage nearby tissues and organs. Cancer cells can also break away from the tumor, enter the bloodstream or lymphatic system, and spread to other parts of the body. When that happens, treatment becomes more difficult. Detecting cancer early is important to increase the chance of treating it successfully.

Early detection may help save lives and reduce suffering from cancers of the breast, colon, rectum, cervix, prostate, testicles, oral cavity, and skin. Some of these cancers can be found early by self-examinations (breast, testicle and skin), physical examinations by a health professional (breast, thyroid, mouth, skin, colon and rectum, testicles and prostate), and by imaging or laboratory tests (mammography and Pap test). In many cases, a combination of two or more early detection approaches is the most effective strategy.

Screening refers to procedures to detect disease early in people without symptoms. Results of examinations, tests, or procedures used in cancer screening alone usually do not result in a cancer diagnosis. They identify persons with findings suggestive of cancer who need further evaluation. If screening results are positive, further testing may be required to identify cancer or pre-cancerous lesions or to rule out cancer. Unfortunately, there are no effective screenings or early detection tests for many cancers.

Organizations such as the National Cancer Institute and the American Cancer Society provide guidelines for cancer screening for individuals at average risk for cancer without specific symptoms. Individuals known to be at increased risk for certain cancers require a different screening schedule, such as starting at an earlier age or being screened more often. Anyone with symptoms that could be related to cancer should see their health care provider right away.

This section focuses on four cancers—breast, cervical, colorectal, and prostate. Each of these cancers has well established screening

programs. The first three cancers have strong scientific evidence supporting screening, while the fourth, prostate cancer, is currently under evaluation.

## Breast & Cervical Cancer Screening

Within the Alaska Tribal Health System (ATHS), four programs are currently funded by the Center for Disease Control and Prevention (CDC) National Breast and Cervical Cancer Early Detection Program (NBCCEDP):

- ◆ *Arctic Slope Native Association / North Slope Borough*
- ◆ *Southcentral Foundation*
- ◆ *SouthEast Alaska Regional Health Consortium*
- ◆ *Yukon-Kuskokwim Health Corporation*

In addition to these tribal programs, the State of Alaska Breast and Cervical Health Check Program screens Alaska Native women in communities where there is no funded tribal program.

These programs offer breast and cervical health screening services, diagnostic services, case management and access to referral for cancer treatment, as necessary. As the “Alaska Breast and Cervical Health Partnership,” they collaborate to offer cancer information and education to the community, to train health care providers, to monitor screening quality, and maintain a database of screening.

Currently, all six regional hospitals within the ATHS have mammography units for breast cancer screening. However, mammogram availability fluctuates because of workforce shortage and/or lack of certified staff. Itinerant mammography technicians are used in at least one region to provide breast health clinics four or five times each year. In this case, the mammography films must be sent to Anchorage or another site to be read by a radiologist, which causes an additional delay in getting information back to a patient and her health care provider. Another region supplements its hospital-based mammography by contracting with a private service, which uses riverboats to transport the equipment from village to village during the summer. Even with such creative solutions, delays exist. Recent experience indicates delays surpassing six weeks to obtain the results of mammography tests in some regions.

If a suspicious lump is found as a result of screening, many Alaska Native women living in rural communities must travel to Anchorage for diagnostic imaging and other services needed to rule out or confirm a cancer diagnosis.

Cervical cancer screening availability also fluctuates, with rural women most likely to receive cervical cancer screening when seen by an itinerant primary care physician, mid-level practitioner or public health nurse. If the screening is not available in the home community, a patient must travel to regional or sub-regional hub clinics, primarily by plane, and often hundreds of miles away.

Significant strides have been made in reducing the death rate from cervical cancer in Alaska Natives through early detection and screening programs. From a rate several times higher than the national rate several decades ago, the rate of invasive cervical cancer incidence is now comparable to U.S. Whites.

Despite gains in recent years, access to screening for breast and cervical cancer for Alaska Native women is not consistently available in several areas of the state, including the Gulf Coast, Interior, and Northwest Arctic villages.

#### Breast and Cervical Cancer Screening Rates

It is difficult to calculate an accurate rate for breast and cervical cancer screening of Alaska Native women. Three sources of available data provide different estimates of cancer screening rates for Alaska Natives.

The first data source is information gathered through the Indian Health Service mandated performance measures for federal agencies (GPRA). Close to three-quarters of ATHS facilities were included in the report for the fiscal year ending June 30, 2005. Rates are based not on population census figures, but on the “user” population, which is defined as beneficiaries who have used an Indian Health Service (IHS) or tribal facility at least once in the prior three years. There is further concern that screening procedures performed may not be accurately documented and coded. Given these limitations, the following are the 2005 GRPA Summary Report screening rates of the American Indian/Alaska Native (AI/AN) user population in Alaska:

- ♦ *Fifty-nine percent of eligible women ages 52 to 64 years underwent mammography screening in the previous two years; and*
- ♦ *Seventy-five percent of eligible women ages 21 to 64 years had Pap test done in the previous three years.*

The second data source is the number of procedures performed at ATHS sites. The SouthCentral Foundation Breast and Cervical Cancer Early Detection Program reports a 36 percent breast cancer screening rate for women 40 years or older and a 67 percent breast cancer screening rate for women 50 years or older.

The third data source is the Behavioral Risk Factor Survey (BRFSS) based on randomized telephone interviews.<sup>136</sup> The BRFSS incorporates sufficient numbers of Alaska Native respondents to estimate statewide screening rates. Findings of the BRFSS include:

- ♦ *Eighty-four percent of non-native Alaska women and 87 percent of Alaska Native women 40 years or older reported having a mammogram and breast exam within the past two years; and,*
- ♦ *Ninety-five percent of Alaska Native women 18 and older reported having Pap tests within the last three years.*

BRFSS data may be overestimated. A number of factors may contribute to the BRFSS over estimation of mammography and cervical screenings among Alaska Natives, including recall bias, confusion about the terminology used, and problems associated with telephone access. For many Alaska Natives, English is not the primary language. They may also have difficulty understanding English speakers from outside their communities interviewing them on the telephone.

## Colorectal Cancer Screening

Screening for colorectal cancer before a person has symptoms can help the doctor find polyps or cancer early. Finding and removing polyps may prevent colorectal cancer. Treatment for colorectal cancer is more likely to be effective when the disease is found early.

Screening to detect colorectal cancer at an early stage includes looking at the inside of the colon. The colon can be viewed directly with a colonoscope (a fiber optic, lighted instrument that views the entire colon from the rectum to the cecum) or with a flexible sigmoidoscope (a similar, shorter instrument that views the rectum, sigmoid and descending colon). During a colonoscopy, a polyp or other suspicious area can be biopsied (sample taken) or removed, then sent to the laboratory for tissue identification. Removal of a polyp not only allows diagnosis of cancer, if present, but also prevents the spread of cancer from that polyp.

Another type of colorectal cancer screening is the fecal occult blood test. While this is a commonly recommended screening test, health care providers do not currently recommend this test for Alaska Natives. Extensive testing in the past, especially in rural areas, resulted in an exceedingly high number of (false) positive results due to chronic blood loss from H. pylori infection related to chronic gastritis.

Alaska Natives are diagnosed with colorectal cancer at twice the rate of U.S. Whites. Colorectal cancer screening resources are not readily available outside of Alaska's larger communities. Three problems contribute to this situation. One is the high



demand on health care providers to provide acute care services. The second is that flexible sigmoidoscopy and colonoscopy are generally performed by physicians and specialists (gastroenterologists), who are only available at the tertiary care centers and intermittently at the regional hubs. A third problem is the high cost of transportation to locations where screening services and follow-up care are consistently available.

To address these concerns, ATHS has focused initial efforts at enhancing colorectal screening in the Anchorage area, by use of trained nurses/mid-level practitioners to perform flexible sigmoidoscopy. One nurse practitioner is also certified to conduct colonoscopy. A training program for mid-level providers in colorectal screening is under development in which certified nurse practitioners and physician assistants will be trained to provide sigmoidoscopy and colonoscopy in regional hubs and larger communities. In general, screening resources in the ATHS for colorectal cancer are insufficient to address the recommendation that all persons over age 50 be screened with colonoscopy.

In 2006, the Alaska State Legislature passed a law making insurance coverage for colorectal cancer screening mandatory for insurance companies doing business in the state.

## Prostate Cancer Screening

Prostate cancer is the growth of cancerous cells in the prostate. It is the most common cancer among men in most populations in the developing world, but ranks third behind lung and colorectal cancer in Alaska Native men. In the United States in general, by age 75, approximately 50 to 75 percent of men will have prostate cancer that can be identified through a biopsy. Prostate cancer is the fifth leading cause of cancer deaths for Alaska males. In the United States, prostate cancer deaths has shown a declining trend since 1995. In Alaska, with only an average of 26 prostate cancer deaths per year, there is no identifiable trend. Mortality rates are generally lower, and were “better than” the U.S. rates in 1996 and 1999. The average annual age-adjusted prostate cancer incidence rate for the period of 1996 to 2000 for Alaska Natives was 34 per 100,000 as compared to 72 per 100,000 for U.S. Whites.

Compared with other cancers, prostate cancer tends to grow slowly. In some men prostate cancers grow so slowly they produce no symptoms and may never be life threatening. For a small percentage of patients, prostate cancer may progress rapidly and spread aggressively. Although prostate cancer is a major cause of cancer deaths, many more men are diagnosed with this cancer than die from it. Many symptoms such as difficult urinating, blood in the urine or pain in the lower back may also be caused by benign prostatic hyperplasia (enlargement of the prostate or BPH). Once these symptoms occur, it is important to see a health care provider who will conduct an examination, and if

needed, refer the patient to a urology specialist.

The two principal methods of screening for prostate cancer are the digital rectal examination (DRE) to identify abnormal nodules in the prostate, and the prostate specific antigen (PSA) blood test to identify abnormal antigen levels. The DRE is a physical exam in which the health care provider inserts a gloved and lubricated finger into the rectum to feel the prostate gland. The PSA is a protein that is produced by the prostate, circulates in the blood, and can be detected and measured with a blood test. PSA levels may be elevated in men who have prostate cancer, BPH, or prostatitis.

Studies are underway to test the effectiveness of prostate screening to determine if screening decreases prostate cancer death. Recommendations for prostate cancer screening are not consistent. The American Cancer Society currently recommends offering PSA and DRE to men beginning at age 50 when they have at least 10-years of life expectancy and beginning at age 40 or 45 if they are at higher risk. They also make some specific points about communicating potential benefits and limitations of testing and decision making.

The U.S. Preventive Services Task Force (USPSTF) concluded in 2002 that “the evidence is insufficient to recommend for or against routine screening for prostate cancer using PSA testing or digital rectal examination.” The USPSTF found good evidence that PSA and DRE screening can detect prostate cancer in its early stages, but found mixed and inconclusive evidence that such early detection reduces prostate cancer deaths or improves health outcomes. The National Cancer Institute continues to provide information on prostate cancer screening. However, at this time the NCI has not made screening recommendations or issued screening guidelines, because “the evidence is insufficient to determine whether screening for prostate cancer with PSA or DRE reduces mortality from prostate cancer.” In addition to lack of evidence that PSA screening reduces deaths from prostate cancer, there is evidence that treatment of prostate cancers can cause significant, adverse, undesirable outcomes and even death. At this time physicians in the ATHS do not routinely recommend that men without symptoms be screened for prostate cancer using the PSA.



# Goals, Objectives & Strategies for Screening & Early Detection

## GENERAL GOALS

- Detect conditions that may lead to cancer.
- Find cancer in its earliest stages.

## BREAST & CERVICAL CANCER GOAL

Reduce death from breast and cervical cancer.

## BREAST & CERVICAL CANCER OBJECTIVES & STRATEGIES

**OBJECTIVE SB1:** Increase the percentage of Alaska Native women who receive regular breast and cervical cancer screenings.

*Baseline:* 59% women ages 52 to 64 years had mammography screening in the previous two years; and 75% of Alaska Native women had a Pap test done in the previous three years. GPRA 2005.

**Strategy a:** Support the development and distribution of educational material promoting the importance of regular breast and cervical screenings.

**OBJECTIVE SB2:** Increase collaboration with the Alaska Breast and Cervical Cancer Early Detection Programs.

*Baseline:* Best areas for collaboration have not been identified in 2005.

**Strategy a:** Integrate Breast and Cervical Cancer Early Detection Programs into cancer plan implementation activities.

**Strategy b:** Collaborate with the Alaska Breast and Cervical Cancer Partnership and others on shared priorities.

**OBJECTIVE SB3:** Increase the number of tribal Breast and Cervical Cancer Early Detection Programs to six by 2010.

*Baseline:* There are four programs in 2005.

**Strategy a:** Support efforts by non-funded tribal organizations to secure funding to develop Breast and Cervical Cancer Early Detection Programs.

## COLORECTAL CANCER GOAL

Reduce death and illness from colorectal cancer.

## COLORECTAL CANCER OBJECTIVES & STRATEGIES

**OBJECTIVE SC1:** Increase the colorectal cancer screening rates by 10% among Alaska Natives by 2010.

*Baseline:* 19% IHS 2004

**Strategy a:** Survey the capacity of regional facilities to provide colorectal cancer screening.

**Strategy b:** Support programs to train mid-level providers to perform flexible sigmoidoscopy/colonoscopy and to establish ongoing screening programs in regional facilities.

**Strategy c:** Support programs to diagnose colorectal cancer stages and reduce or eliminate unnecessary pre-operative chemotherapy and radiation treatment.

**Strategy d:** Increase Alaska Native specific colorectal cancer screening education to make sure that comprehensive, culturally appropriate media messages reach the intended audience.

**Strategy e:** Investigate innovative ways of organizing healthcare providers to enhance screening rates in rural communities.

**OBJECTIVE SC2:** Develop a colorectal screening database for Alaska Natives for clinical case management and surveillance purposes by 2010.

*Baseline:* An ATHS database specific to colorectal cancer does not exist in 2005.

**Strategy a:** Support development of a tracking procedure that will interface with the Resource and Patient Management System (RPMS) to track screening needs and follow-up of patients for colorectal screening.

**Strategy b:** Support development of a database for tracking first degree relatives of colorectal cancer patients.

## PROSTATE CANCER GOAL

Increase informed decision making regarding prostate screening among Alaska Native men.

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### PROSTATE CANCER OBJECTIVES & STRATEGIES

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**OBJECTIVE SP1:** Provide education to Alaska Native men and their health care providers regarding prostate screening recommendations by 2010.

*Baseline:* Limited educational materials specific to Alaska Native men exist in 2005

**Strategy a:** Provide primary care providers with the latest information regarding recommendations for prostate screening.

**Strategy b:** Develop Alaska Native specific patient information.

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**OBJECTIVE SP2:** Develop a prostate screening database of Alaska Native men for clinical case management and data analysis purposes by 2010.

*Baseline:* A system-wide database specific to prostate cancer does not exist in 2005.

**Strategy a:** Develop a database of first-degree relatives of prostate cancer patients.

**Strategy b:** Determine the percentage of Alaska Native men who have received a prostate-specific antigen test.

## EMERGING SCIENCE GOAL

Investigate and determine effectiveness of new tests and procedures to detect and screen for cancer and incorporate them in the cancer program as appropriate.

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### EMERGING SCIENCE OBJECTIVES & STRATEGIES

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**OBJECTIVE SO1:** Implement new cancer screening and early detection tests as they become recommended by national organizations by 2010.

*Baseline:* No formal tracking system of new screening tests exists in 2005.

**Strategy a:** Track new screening and early detections test and recommendations.

# DIAGNOSIS

*Diagnosis confirms or rules out the presence of cancer. It begins with an abnormal finding on a screening test or when a healthcare provider observes signs and symptoms that may indicate the presence of cancer and refers the patient for additional testing.*

## Introduction

A cancer diagnosis affects everyone – patient, family, friends, and community. Facing cancer has consequences far beyond an individual's medical condition. It affects the mental, emotional, spiritual, and financial well-being of the patient, family, and the community.

Of all cancer cases diagnosed in the Alaska Tribal Health System (ATHS) between 1989 and 2003, 36 percent were diagnosed in patients living in the Anchorage Service Unit, while 64 percent were diagnosed in patients living in other locations in Alaska.<sup>137</sup> Cancer patients who live outside of Anchorage and off the road system experience the additional challenges of transportation, housing, and separation from family and community when they are diagnosed with cancer.

Confirming or ruling out a cancer diagnosis may take a longer time for many Alaska Natives. This is due to a shortage of trained personnel and equipment, as well as the difficulty coordinating healthcare services and travel logistics. Patients may travel hundreds of miles from villages or from regional hospitals to Anchorage several times before a diagnosis can be confirmed. Weather, family situations and other issues can result in appointment cancellations and rescheduling. Except for Alaska Natives living in the Anchorage area, it is highly unlikely that a patient can travel to Anchorage, complete required medical procedures, and return home the same day.

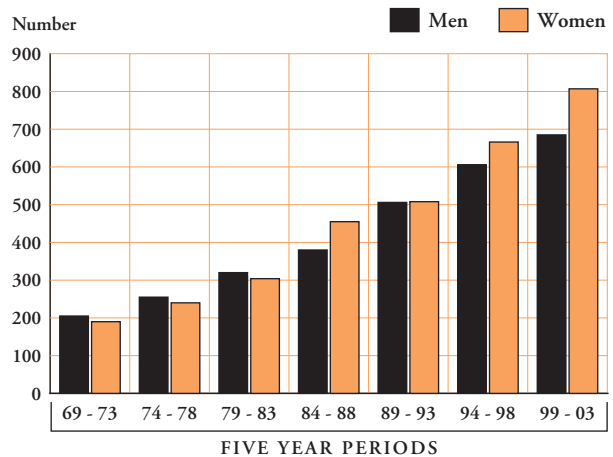
Factors that affect the increasing demand for cancer services include: increases in the Alaska Native population, life expectancy, incidence of cancer, and the number of types of treatment patients may receive.

## Diagnosis Data

The rate of new cancer patients diagnosed each year increased 34 percent between the five-year period from 1969 to 1973 and the period 1999 to 2003.<sup>138</sup> Approximately 300 Alaska Native patients are diagnosed with cancer each year. For the five-year period from 1969 to 1973, there were 396 invasive cancer cases diagnosed. In the five-year period from 1998 to 2003, 1,498 invasive cancer cases were diagnosed.<sup>139</sup>

**Number of Invasive Cancers by Five-Year Periods  
Alaska Natives 1969-2003**

Source: Alaska Native Tumor Registry



## Diagnostic Procedures

Often, a combination of surgical and radiological procedures is used to diagnose cancer, determine the stage of the cancer, and design a treatment plan. Interventional radiology training allows radiologists to perform biopsies and some procedures. ANMC surgeons perform cancer surgery for diagnosis and treatment.

Some diagnostic surgical procedures, such as biopsies and colonoscopies, can be done at regional hospitals and contracted facilities, with patients then referred to ANMC with a confirmed or suspected cancer diagnosis for additional evaluation or definitive treatment. Due to scheduling difficulties and availability of equipment and personnel, patients may have to return home between tests and surgeries.

Computed tomography (CT scans), Magnetic Resonance Imaging (MRI), retrograde cholangiopancreatography (ERCP), sentinel node biopsy, and x-ray guided biopsy diagnostic tools are available at ANMC. Positron emission tomography (PET) scans and bone scans are currently contracted to other facilities in Anchorage. Since nuclear medicine is not available at ANMC, dye injections for sentinel node biopsy will continue to be contracted to a non-ATHS facility. Space limitations at



ANMC affect the availability to expand diagnostic testing.

PET scans became available in the Anchorage area in 2003 at two locations. Previously, patients went to Seattle to receive the scans. It is likely that the availability of an in-state PET scanner will result in the increased use of PET in conjunction with MRI and CT. When MRI was introduced in the United States, it was thought that the MRI would replace CT. Instead, both diagnostic tools continued to be used.

A cancer diagnosis is confirmed through a pathology report. In general, a suspicious tissue sample is taken from a patient by a physician in one of several departments at ANMC or at other healthcare facilities, and submitted for testing and analysis to the Department of Pathology and Laboratory Medicine at ANMC. If necessary, ANMC pathologists send the specimen to nationally recognized consultants for comment. When the testing and analysis are completed, a diagnosis is made and communicated to the oncologist or other physician. Over 50 percent of ANMC lab volume is cancer-related and growing. ANMC pathologists utilize a number of reference labs as needed to assist in diagnosing cancer. Once a sample of tissue is obtained, the tissue must be processed and then read by a pathologist. It takes at least 24 hours before a definitive confirmation of cancer can be made.

Approximately 75 percent of newly diagnosed cancer cases are reviewed with pathology/laboratory personnel at the weekly interdisciplinary ANMC Tumor Board meeting. The weekly Tumor Board meeting, chaired by the Oncology/Hematology Medical Director, brings together many specialty physicians who examine the specifics of a case, share knowledge and determine the best treatment plan for the cancer patient. Mid-level practitioners, nurses, dietitians, social workers, and students also are part of the Tumor Board audience. Recommendations of the Tumor Board are shared with the patient and family. Currently, regional ATHS healthcare providers do not to participate in the Tumor Board meetings. Preliminary research indicates that their schedules do not permit them to participate in the weekly meetings. However, they have expressed interest in attending by video-conferencing, or teleconferencing when specific patients from their region have cases presented at the meeting.

## Breast Cancer Diagnosis

Breast cancer is the leading cancer among Alaska Native women. The availability of mammography services at some regional hospitals and increased awareness about breast cancer has resulted in earlier detection and staging of disease. This, in turn, has resulted in improved clinical outcomes among women diagnosed with breast cancer.

However, when cancer is suspected, there may be an extended period of time before the breast cancer is confirmed (or ruled out) and before treatment and follow-up care is completed. Coordinating diagnostic imaging, radiology reports, meetings with surgeons, and pathology findings becomes complex. The patient is under tremendous stress waiting for the test results.

When breast cancer is suspected, a patient may have to make several trips before the type and extent of breast cancer is confirmed (or ruled out). Navigating the ATHS and other medical facilities during this time to receive a final diagnosis so a treatment plan can begin can be overwhelming from a patient's point of view and frustrating for health care providers. A study completed in 2002 identified the following concerns from the ATHS providers and breast cancer survivors:

- ◆ *Imperfect system for the discharge of patients and transfer of patient data between ANMC, regional hospitals, and villages;*
- ◆ *Periodic lack of staff at the regional hospitals to provide mammography services (because of high staff turnover);*
- ◆ *Inadequate system for addressing travel and lodging issues when patients and escorts arrive in Anchorage, particularly for elderly patients;*
- ◆ *Few or no services available for long-term patients who need advanced care, such as palliative care; and*
- ◆ *Travel policies do not accommodate escort travel when breast cancer patients travel to Anchorage for evaluation or advanced treatment.* <sup>140</sup>

ANMC is considering the need for a dedicated breast cancer center as part of a comprehensive cancer center to provide coordinated, timely, and culturally sensitive services to women seeking care at ANMC as a result of a suspected diagnosis of breast cancer and other benign breast disease. The center would work to streamline the breast cancer diagnosis, treatment and follow-up process while supporting women and their families by providing convenient and integrated care.



## Goals, Objectives & Strategies for Diagnosis

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### GOAL

Diagnose cancer using the least invasive and most comprehensive procedures.

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**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.

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**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.

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**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.

# 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.

There is currently one nurse in the ANMC Oncology Clinic certified to provide oncology chemotherapy and biotherapy courses to regional hospital nursing staff. This training and certification allows regional hospital nurses to administer chemotherapy that is part of the treatment plan developed by the medical team with patient input, and allows some patients to receive treatment closer to home.

## Children with Cancer

Compared with adult cancers, childhood cancers are rare. In the United States they make up about one percent of all cancers. The rate among all Alaska Native children (both sexes) for all cancers combined is similar to U.S. Whites. When cancer is suspected in Alaska Native children, they are generally referred to Children's Hospital in Seattle (part of the Seattle Cancer Care Alliance) for diagnosis and treatment. Some follow-up care, including inpatient chemotherapy, is provided at ANMC when possible. A consulting pediatric oncologist conducts a regularly scheduled clinic at ANMC to follow children who received care at Seattle Children's Hospital. An ongoing issue is whether the number of children diagnosed with cancer in Alaska is sufficient to encourage a pediatric oncologist to maintain a practice in Alaska. In 2006 there is one pediatric oncologist in Anchorage who sees children with cancer at ANMC as well as other Anchorage hospitals.

## Treatment Concerns

Sixty percent of Alaska Natives live in 200 small communities spread over a geographic area comparable to five large states. This rural distribution presents problems and challenges. One is the coordination of treatment. A patient is seen in multiple clinics within ANMC, as well as radiation, laboratory, and other departments. Other facilities, in or outside of Anchorage, may also be involved. Treatment may mean leaving home and require long absences from family, jobs, traditional foods, spiritual support, and familiar social settings. Treatment requires traveling between care providers often located at different facilities in an unfamiliar setting with problems of travel, language, and cultural differences.

Some cancer therapies may not be available in the ATHS. New diagnostic and treatment techniques and procedures currently under development may help Alaska Natives remain closer to home; reduce the time away from home; and reduce the pain and symptoms associated with cancer treatment.

## Clinical Trials

Clinical trials are research studies in which people help doctors find ways to improve health and cancer care. Each study tries to

answer scientific questions and to find better ways to prevent, diagnose, or treat cancer.

A clinical trial is one of the final stages of a long and careful cancer research process. Studies are done with cancer patients to find out whether promising approaches to cancer prevention, diagnosis, and treatment are safe and effective. Acceptance into a clinical trial is dependent on many factors including the type of cancer, condition of the patient and availability of the needed clinical trials.

People who join clinical trials may be among the first to benefit if a new approach is shown to be effective. If participants do not benefit directly, they still make an important contribution to medicine by helping researchers better understand the disease.

### There are five different types of clinical trials:

- ◆ **Treatment trials** test new treatments such as a new cancer drug, new approach to surgery or radiation therapy, new combinations of treatments, or new methods such as gene therapy.
- ◆ **Prevention trials** test new approaches like medicines, vitamins, minerals, or other supplements that doctors believe may lower the risk of a certain type of cancer. These trials look for the best way to prevent cancer in people who have never had cancer or to prevent cancer from coming back or a new cancer occurring in people who have already had cancer.
- ◆ **Screening trials** seek to find new ways of detecting cancer in people before they have any symptoms.
- ◆ **Diagnostic trials** seek to find how new tests or procedures can identify cancer more accurately and at an earlier stage.
- ◆ **Quality of Life trials** (also called Supportive Care trials) explore ways to improve comfort and quality of life for cancer patients.

Most clinical research that involves the testing of a new drug progresses in an orderly series of steps, called phases. This allows researchers to ask and answer questions in a way that results in reliable information about the drug and protects the patients.

The goals of clinical trials are to find better ways to treat cancer and help patients. It is important that patients participate in clinical trials, as it is the way that scientific advances are made to improve cancer outcomes.

At the present time, Alaska Native cancer patients do not have access to clinical trials at ANMC, but may participate in clinical trials at other medical facilities.





# Goals, Objectives & Strategies for Treatment

## GOALS

When cancer is diagnosed, treat the patient and family with the most appropriate therapy as close to home as possible.

**OBJECTIVE T1:** ANMC will be certified by the American College of Surgeons Commission on Cancer (ACoS) by 2010.

*Baseline:* ANMC is not ACoS certified in 2005

**Strategy a:** Hire a coordinator to assist ANMC with coordinating the necessary steps to prepare for ACoS site review.

**Strategy b:** Assist ANMC staff with site review.

**OBJECTIVE T2:** Increase the number of ANMC and ATHS oncology nurses certified by the Oncology Nursing Society by 25% by 2010.

*Baseline:* Four nurses within the ATHS were certified in 2005.

**Strategy a:** Identify and train ANMC/ATHS nurses interested in becoming a certification instructor.

**OBJECTIVE T3:** Establish a patient navigation program to ensure timely and efficient cancer care coordination by 2010.

*Baseline:* There is no coordinated patient navigation program within ATHS in 2005.

**Strategy a:** Establish a cancer patient tracking system to monitor long-term cancer side effects and recurrence.

**Strategy b:** Identify collaborative and financial means to support establishing a coordinated patient navigation program.

**OBJECTIVE DT4:** Consolidate patient diagnostic and treatment services through training and resource acquisition to reduce the need for cancer patients to travel to several healthcare facilities for diagnosis and treatment and allow patients to be treated as close to home as possible by 2010.

*Baseline:* Cancer patients must often travel between three Anchorage hospitals for diagnosis and treatment services in 2005.

**Strategy a:** Determine the feasibility of developing a comprehensive cancer center.

**Strategy b:** Support the expansion of current Oncology Clinic and Tumor Registry staff to help address unmet needs and proposed volume increase to be generated by a second oncologist and cancer case projections.

**Strategy c:** Support the enlargement of the Oncology Clinic and Tumor Registry physical space.

**Strategy d:** Support the development of the Oncology Support Program (OSP) to provide primary care and cancer support services for Alaska Natives who live outside the Anchorage Service Unit who remain in Anchorage for cancer care. Incorporate complementary and integrative care into the program.

**Strategy e:** Establish a mechanism to update regularly all members of the cancer care team about new diagnostic tests and treatment procedures.

**Strategy f:** Encourage partnerships with in-state and out-of-state healthcare providers when treatment modalities are not available at ANMC, and when a cost/benefit analysis indicates that partnering is appropriate.

**Strategy g:** Assist regional sites with training and physician consulting support so cancer patients can receive care closer to home

**Strategy h:** Work with ANMC Cancer Core Business Group (CCBG) to coordinate ANMC cancer diagnostic and treatment services.

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**OBJECTIVE T5: Establish a pain and symptom management program to ensure that cancer patients receive timely and effective pain and symptom therapy regardless of whether they are treated at ANMC, regional hospitals, or the villages by 2010.**

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

**Strategy a:** Collaborate with ANMC Pharmacy, palliative care providers, and other resources to initiate a pain and symptom management program.

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**OBJECTIVE T6: Educate physicians on accessing clinical guidelines by 2010.**

*Baseline: Some physicians within ATHS are not familiar with how to access clinical guidelines in 2005.*

**Strategy a:** Plan, implement, and evaluate training for physicians.

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**OBJECTIVE T7: Establish a mechanism for regional physicians to attend ANMC weekly Tumor Board meetings remotely by 2010.**

*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.

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**OBJECTIVE T8: Offer Alaska Native cancer patients the opportunity to participate in ANMC-based clinical trials by 2010.**

*Baseline: ANMC does not offer clinical trials in 2005.*

**Strategy a:** Determine availability/appropriateness of developing a formal relationship with an NCI designated comprehensive cancer center to assist in areas such as clinical trials.

**Strategy b:** Identify an ANMC Oncology clinic staff person to assist in setting up clinical trials as appropriate.

# SURVIVORSHIP

*Survivorship addresses the physical, mental and spiritual issues of a patient with a confirmed cancer diagnosis. It begins when a cancer diagnosis is made and continues through the remainder of life.*

## Introduction

Recent advances in the prevention, early detection, diagnosis, and treatment of cancer help cancer patients live longer. As a result the number of cancer survivors is increasing. There is a recognition of the complications of both cancer and its treatment, and the resulting physical, social, and mental challenges encountered by survivors over the near and long term following a cancer diagnosis and the practical daily issues of living with cancer. As of January 2000, there were approximately 9.8 million cancer survivors in the United States.<sup>141</sup>

**A National Action Plan for Cancer Survivorship:**<sup>142</sup> defines “cancer survivors” as those people who have been diagnosed with cancer and the people in their lives who are affected by their diagnosis. This broader definition of a cancer survivor includes their families, caregivers, friends, and communities who are also impacted by cancer.

Cancer survivorship is a continuum that begins with diagnosis and continues through the remainder of a survivor’s life. Even after treatment is finished cancer survivors have concerns about the disease. Survivors face a myriad of concerns including: an increased risk of cancer returning, fear of a cancer recurrence, increased risk of a second cancer, late appearing side effects resulting from treatment, fatigue, cognitive problems, sexual dysfunction or fertility problems, changes in family roles and daily activities, financial impact of cancer treatment, employment issues, and disability.

In addition to the survivorship concerns previously mentioned, Alaska Natives also have unique problems as cancer survivors. These may include returning to their communities after having been away for extended periods of time for treatment; difficulty and expense of traveling long distances to access care; community members fear of getting cancer themselves; cancer care interfering with seasonal subsistence activities; difficulty keeping appointments for treatment and follow-up care; inability to hunt and fish as before; difficulty maintaining a subsistence lifestyle and providing food for their families; and the lack of support groups in the villages. The practical issues of living with cancer can include addressing concerns like how to haul water when

there is no village-wide water system. Hauling water requires physical strength and stamina that may be reduced by the effects of cancer treatment.

## Survivorship Data

Five-year survival rates help patients understand how long people generally live with their specific type of cancer. Calculations of cancer survival, 1969-1994, show that among Alaska Native patients diagnosed with cancer, less than half (37%) will be alive five years after diagnosis. A larger percent of women (45%) than men (32%) survived five years after their cancer diagnosis.

The survival rate for some cancers is improving. For Alaska Native 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. Cancer treatment changes frequently with new medical advances which may help extend a patient’s life.

Comparison of Alaska Native and U.S. White five-year survival rates (1984 to 1994) show that for all cancers combined, Alaska Natives had an 11 percent lower five-year survival rate. The lower overall survival rate of Alaska Natives was due, in part, to the types of cancer that occur more frequently in Alaska Natives. Cancers of the esophagus, pancreas, lung, gallbladder, and nasopharynx have low survival rates in all populations, and account for a greater percentage of cancers diagnosed in Alaska Natives. (For example, cancer of the nasopharynx is 16.5 times more likely to occur in Alaska Natives than in U.S. Whites, and cancer of the gallbladder is 5.1 times more likely to occur in Alaska Natives than in U.S. Whites.)<sup>143</sup> For breast, stomach, prostate and cervical cancer, Alaska Native survival rates were similar to U.S. Whites. For two sites, liver and uterus, Alaska Natives are more likely than U.S. Whites to survive five years.<sup>144</sup>

For all U.S. population groups, the likelihood of surviving five years varies by the cancer site (disease and organ of the body in which the cancer first appeared). For instance, nearly all patients diagnosed with cancer of the thyroid, testis, and uterus are alive five years after diagnosis, while very few of those with cancers of the lung, esophagus, or pancreas survive five years.

In addition to the cancer site, the extent to which the disease has

## Cancer Stages

<b>Local</b>	Cells have not gone beyond the original site (organ in which the cancer first developed, for example the breast).
<b>Regional</b>	Cells have gone beyond the original site, but not beyond the surrounding lymph nodes and adjacent tissue.
<b>Distant</b>	Cells have spread extensively to other parts of the body.

spread (stage) at the time of diagnosis also determines length of survival. Nearly all cancers diagnosed and treated while the stage is still “local” (has not spread beyond the original organ) have a chance of a cure. Between 1984 and 1994, less than 40 percent of all cancers in Alaska Natives were diagnosed at the local stage, and for these years Alaska Natives had a higher proportion of cancers diagnosed at later stages than the U.S. Whites. When cancer in Alaska Natives and U.S. Whites is diagnosed at the same stage, five-year survival rates are similar.

Living longer after a diagnosis of cancer is an important outcome of cancer treatment. However, it also means more cancer patients need continued medical follow-up. In Alaska, this type of medical care for survivors is the responsibility of primary care providers. As general practitioners, they may not be up-to-date with follow-up medical concerns for all types of cancer. In addition, primary care providers change constantly, medical records grow extensively and cancer survivors may not willingly tell healthcare providers that they were diagnosed with cancer at some point in their lives. The need for practice guidelines for the care of long-term cancer survivors is being addressed nationally. Examples include the American Society of Clinical Oncology (ASCO), the National Comprehensive Cancer Network (NCCN), and the Lance Armstrong Foundation. Healthcare providers at regional hospitals can access ANMC specialty cancer follow-up guidelines through an extranet service provided by ANMC physician specialists.

## Stages of Survivorship

As individuals move through the diagnosis and treatment of cancer it is helpful to consider the three stages of survivorship: acute, extended, and permanent.<sup>145</sup>

**The acute stage** begins with diagnosis and continues throughout active treatment efforts. Feelings of fear, anxiety, and pain resulting from both illness and treatment are important and constant elements of this stage. For many Alaska Natives this stage will take them far from family and friends to unfamiliar surroundings

without their customary comfort foods, spiritual leaders, and community support. This stage may be referred to as *living with cancer*.

**The extended stage** of survival begins when the survivor goes into remission or completes treatment. Psychologically, this stage is a time of watchful waiting, with the individual wondering if symptoms of illness may be signs of recurrence, side effects of treatment, or just a part of every day life. Because treatment is complete, this stage also includes reduced contact with the health care team that has supported the individual through the treatment process and to whom the cancer survivor may have become emotionally and psychologically attached. Physically the individual may be limited by the disease and treatment, although their family might see the disease as over and want life to return to “normal”. This stage may be referred to as *living through cancer*.

**The permanent stage** is defined as a time when the likelihood of the return of cancer is sufficiently small and that the cancer can be considered “cured”. In many cases this may be five years after diagnosis with no recurrence. This may not however mark the “end” of the process, as the survivor may still be experiencing social and economic challenges, psychological changes including the fear of recurrence; and secondary effects from previous cancer treatment. This stage may be referred to as *living beyond cancer*.<sup>146</sup>

Although these stages as defined are progressive, they may overlap and will vary from person to person.

## Alaska Native Cancer Survivorship

In Alaska, vast distances, remoteness of rural communities, and differences in language and culture influence the care and support of survivors. The challenge of survivorship is to assist the patient and family through the stages of cancer, the diagnosis and treatment process, the post treatment check-ups, and the period of readjustment after cancer treatment.

The cancer burden may be greatest on Alaska Natives living in remote rural communities who must travel to Anchorage or out of state for their care. Crowds of unfamiliar people, strange living arrangements, unusual foods and transportation problems, along with uncomfortable treatments and the uncertainty of the disease are understandably confusing and frightening for someone who has lived most of his or her life in a small rural community. No formal studies have been done to assess the survivorship needs of Alaska Natives.

Children surviving cancer have special treatment needs. They often suffer late effects that occur many years after they were treated in pediatric cancer centers. Most childhood cancer



survivors have severe health problems by age 45 years.<sup>147</sup> The Children's Oncology Group has developed national guidelines for survivors of childhood, adolescent and young adult cancers.

Difficulties with communication between levels of health care providers, families, and the patient are not uncommon. When cultural and language differences exist, a patient's concerns may go unasked and fears unresolved. The need for easier ways to navigate the treatment system and better understand the resources available to cancer survivors exists at all levels of care.

A resource book developed by ANTHC in 2005, "A Patient's Guide to Cancer Care within the Alaska Tribal Health System," was designed to assist a patient in understanding treatments, tracking appointments, and monitoring medications. This Guide is available to cancer patients and their health care providers along with a "Cancer Care Support Kit" containing items useful to the patient while undergoing treatment away from home. All patients treated for cancer at ANMC receive the Guide and Support Kit. Anecdotally, the patients who use the book indicate it is helpful.

Continuing cancer care education for health care providers is essential in rural communities to assure they understand cancer terminology, various treatments, symptom management, stages of survivorship, recommended follow-up, and the consequences of treatment. With this knowledge, when the patient completes treatment and returns to the village, local health providers are better able to assist the patient in ongoing treatment, cancer check-ups, and returning to normal daily activities.

Most survivors living in rural communities receive their medical care from Community Health Aide/Practitioners (CHA/Ps). CHA/Ps receive extensive training in many issues but with very little time available to address cancer issues. A course and resource guide, *Path to Understanding Cancer*, was developed in 1999 as an optional training course for CHA/Ps who want more training about cancer. The guide includes modules on cancer diagnosis, risk factors, prevention, screening and detection, pain management, loss and grief, and provider self-care and burnout. Videos and CD's are also available for self-study.

Health care providers can assist family members in knowing what to expect when the patient returns and what adaptations to the home or the lifestyle might be necessary. Providers may also be able to support long-term survivors in offering support groups for those having experienced similar diagnoses and treatment, and assuring recommended follow-up care is provided. There are no formal Alaska Native cancer support groups.

The psychosocial challenges facing Alaska Native men in dealing with their own diagnosis of cancer, or that of a family member, are especially problematic. This may be related to the strong traditional roles of men in the Alaska Native culture and their

role as providers through subsistence activities for their families. When cancer treatment schedules conflict with hunting and fishing seasons, some men choose to postpone or forego treatment. Additional work is needed to help Alaska Native men understand their own cancer, and assist them in receiving appropriate treatment without compromising their families well being.

Two-thirds of Alaska Native cancer patients live in areas distant from the state's urban center of Anchorage. Yet, regardless of where they live, Alaska Natives value subsistence foods and most consume some or many traditional foods throughout their lives. Maintaining a healthy diet is critical for cancer survivors. Standard food recommendations for a healthy diet are frequently unfamiliar to Alaska Natives, many of whom rely primarily on traditional foods obtained through subsistence activities. At a time when comfort foods are most needed, there is no information that identifies traditional plants and animals (known to be nutritious) that can be substituted for recommended foods. Foods typically recommended in cancer literature may be unavailable or unaffordable in remote communities. Information is needed that will allow healthy dietary substitution of traditional foods for Alaska Native cancer patients during and after cancer treatment. In 2005, ANTHC received a grant from the Lance Armstrong Foundation to develop a user-friendly food guide, integrating subsistence and other natural Alaska foods for cancer patients, allowing them to substitute nutritional familiar foods for standard recommended foods that may be unfamiliar or unavailable.

*"They told me to eat kale.  
I don't even know what kale is,  
I want sea asparagus."*

– Ethel Lund, Tlingit cancer survivor



## 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.

# 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.”*

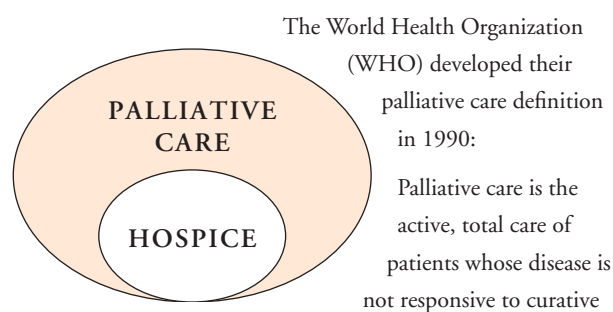
– Andrew Jimmie, Chair

Alaska Native Elder Health Advisor Committee (ANEHAC)<sup>148</sup>

## 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.



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.<sup>149</sup>

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 the 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.<sup>150</sup> 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.

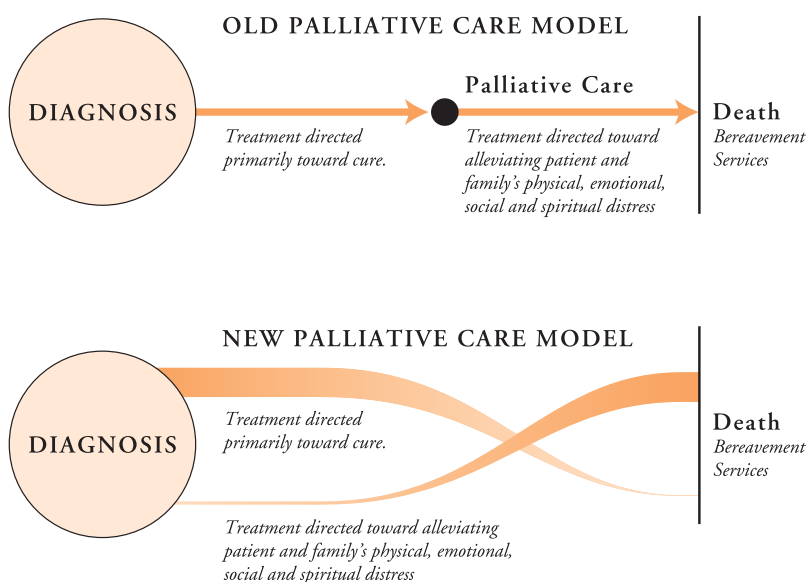
## Models of Palliative Care

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.<sup>151</sup>

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.<sup>152</sup>

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.”<sup>153</sup>*

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.<sup>154</sup> 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.<sup>155</sup>

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.<sup>156</sup> 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.<sup>157</sup>

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.<sup>158</sup> 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).<sup>159</sup> 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.<sup>160</sup> The review showed an absence



of firm data and peer reviewed publications addressing the state of palliative care in the Indian Health System and its contractors and a perceived lack of access to palliative expertise and services in that system. Clinicians site a lack of consultative resources, and healthcare administrators and community advocates identify a need for program development.<sup>161</sup>

In order to further the understanding of the need for culturally appropriate palliative care for AI/ANs, stakeholder dialogue groups at the Spirit of EAGLES National Cancer Conference in September 2004 made the following recommendations:

- ◆ *Build collaborative relationships across disciplines*
- ◆ *Learn from diagnostic and treatment process of well-established programs such as diabetes*
- ◆ *Adapt and use successful palliative care programs found in other underserved settings*
- ◆ *Partner with private hospices for palliative care training and delivery*
- ◆ *Set standards of care*
- ◆ *Educate on all levels*<sup>162</sup>

The report confirmed that AI/AN life expectancy has increased, making the burden of chronic diseases including cancer significant. It noted that “there is a clear need for investment in research, training and innovative models of care delivery to improve capacity within the Indian Health System. Only then can there be improved access to palliative and end-of-life care for AI/AN”.

## Palliative Care Issues Shared by Aboriginal People of Canada

The Aboriginal People of Canada face many of the same health issues as Alaska Natives<sup>163</sup> including the growing incidence of longer life expectancy and chronic diseases such as cancer. There is a need for a palliative care that incorporates a holistic approach encompassing spiritual, physical, emotional, mental and social attributes of people. Such a holistic view allows for balance and connectedness for individuals, families and communities in relation to the natural world. When death occurs “in balance” all attributes of the dying and deceased are managed until the person ‘passes to the other side’ safely and family and loved ones are returned to a state of being in balance.<sup>164</sup>

The Inuit of Canada have a holistic vision of the individual much like that of AI/AN. A human being is one with his or her surroundings, a part of a whole that draws its meaning from the relationships that the human being has with whatever is living and whatever surrounds him—a strong connection with the en-

vironment. Well-being flows from balance and harmony among all elements of personal and group life.<sup>165</sup>

Unique and significant barriers exist in providing support to Aboriginal People anywhere in the Arctic. These include: language, lack of understanding of traditional beliefs, values and practices around death and dying, literacy levels and lack of materials in the primary language are some. Problems with space available for privacy and comfort in delivering patient care, e.g. the hospital bed in the living room or space to use a wheelchair, lack of access to basic sanitation, unlimited water, indoor plumbing, and affordable wholesome foods may also be a concern. Prevalence of smoking and wood stoves in the home present problems in managing air quality and the use of oxygen.<sup>166</sup> AI/AN in Alaska face many of these same issues.

Aboriginal People have diverse cultural and spiritual belief systems. Programs must allow for the expression of beliefs and the practicing of individual and family traditions and ceremonies. Cultural and spiritual practices can be a significant source of strength when difficult times are encountered. Extended family and community supports can also be of great assistance.

The Aboriginal Nurses Association of Canada identified training and education needs to help further the availability of palliative care.

### **These same needs are applicable for Alaska Natives.**

- ◆ *Cross-cultural orientation; cultural perspectives on death and dying; working with cultural and language interpretation services; palliative care models that work in Aboriginal communities of all sizes; death and dying in the aboriginal family and community context; ethical guidance specific to Aboriginal values and belief systems.*
- ◆ *Personal awareness and coping/processing skills; assisting and supporting the dying patient; pain management in various healthcare settings; symptom management at home and in “transit” between care locations.*
- ◆ *Communication with patients and families, including “bad news” in a culturally sensitive manner; supporting end-of-life/palliative care decision making; conflict resolution appropriate to Aboriginal families.*
- ◆ *Counseling support about grieving and bereavement; working with pastoral care staff, clergy and Aboriginal spiritual helpers; developing systems to provide access to traditional healing and medicine practices.*<sup>167</sup>

## Death

Across cultures people may differ in what they believe and understand about life and death, what they feel, what elicits those feelings, the perceived implications of those feelings, the ways they express those feelings, the appropriateness of certain feelings and the techniques for dealing with those feelings that cannot be directly expressed.<sup>168</sup>

AI/ANs have many different beliefs and practices around death. For example, the Apache regard a dead person's body as an empty shell; the Lakota speak to the body, visit it and understand it to be sacred. The Navajo do not believe in an afterlife, while most of the other Native American nations do.<sup>169</sup> Native American religious life has been influenced by its incorporation of Christianity at various levels for more than 100 years. Many AI/ANs practice a combination of both Christian and tribal beliefs.<sup>170</sup>

In Alaska, Christianity came in the late 18th century and was introduced to Alaska Natives by Russian Orthodox priests. In the late 1880's denominational districts were roughly defined. Generally the Baptists centered their efforts in Kodiak and the upper part of the Alaska Peninsula, the Episcopalians, the Interior areas; the Swedish Covenant, Nunivak Island and the Presbyterians in the Southeast, St. Lawrence Island and the North Slope. Quaker missionaries went to the Kotzebue area, Methodists to the Aleutians and the Moravians to Bristol Bay and the Kuskokwim.<sup>171</sup>

In traditional Yup'ik Eskimo culture, no one passes away out of existence. Through the naming process, the essence of being human is passed on from one generation to the next. The cycling of human souls is important when considering the traditional belief that the souls of seals must be cared for by the successful hunter in order that they too will be born again. Human and animal souls are continually in motion. The birth of a baby is the rebirth of a member of its grandparental generation. The death of a seal means life to the village.<sup>172</sup>



## *The Yup'ik Drum – The Mother's Heartbeat – The Cycle of Life*

*The Yup'ik drum is symbolic of the cosmology of the Yup'ik people of Alaska. The drum is circular with a handle. It is constructed with wood, seal membrane and string made out of seal skin.*

*The circular shape of the drum represents the cycle of life beginning at conception and continuing through old age. When a person has reached the crest of the drum they are able to look back on their own life and predict what the future holds for them. At this stage they are also given the honor of now helping to prepare by teaching those that have just started the path. Once the crest is reached this person starts to descend down. In this sense the body begins to weaken, but the mind remains strong and full of knowledge.*

*The cycle of life does not end with old age but continues in the circular motion and life continues with the birth canal represented by the wooden drum handle. At this stage life continues with the newborns of close relatives. Those newborns are named for those that have entered the birth canal. The smooth interior part of the drum signifies life when the proper rules in life are followed—creating a rhythm in life. The rough outer edges represent life without a rhythm. Rules have not been properly followed thus creating a hard life. The string that is used in tying the seal skin membrane down represents the umbilical cord. The string is always wrapped following the direction of the sun and tied down in the same manner. The sound of the drum represents the mother's heartbeat beating within the body. In conception the first thing that was heard was the mother's heartbeat. As the drum beats, the dancers bounce and sway to the rhythm of the beat. This motion and action represent the mother's movement as she carries the newly created life in her womb. The drum has strength that no other musical instrument can claim. It pulls people together to create a bond that strengthens their ties and relationships. It brings people together for celebrations.*

*During these celebrations traditional Yup'ik Eskimos brought food and items to share with the whole community. The elders were especially honored during this time. They were given food and other items needed to live in the harsh environment. It was also a time when the widows and orphans were provided for too.<sup>173</sup>*

*"I do not want to die a death of a thousand needles.  
There is no death—only a change of worlds. The goal is not to  
prevent death but to prevent unkindly and untimely death.  
Let me die with dignity, not with pity." <sup>174</sup>*



## Objectives & Strategies for Palliative Care

**OBJECTIVE PC1:** The percentage of Alaska Native cancer patients dying in hospitals will be reduced by 20 percent by 2010.

*Baseline:* 57% of Alaskans die in Hospitals or Nursing Homes. Bureau of Vital Statistics. 2004.

**Strategy a:** Coordinate a pediatric palliative care program with Seattle Children's Hospital and other specialty services that provide care for Alaska Native pediatric cancer patients.

**Strategy b:** Collaborate with other palliative care providers and organizations to maximize palliative care resources.

**OBJECTIVE PC2:** Train seventy percent of the healthcare providers of Alaska Natives through an ANTHC palliative care program by 2010.

*Baseline:* 2004 ANTHC Palliative care survey: 69% of healthcare providers have not received palliative care training.

**Strategy a:** Encourage and support national palliative care certification for healthcare providers including physicians, nurses, social workers, and pharmacists.

**Strategy b:** Establish a palliative care training program and curriculum for healthcare providers of Alaska Natives.

**OBJECTIVE PC3:** Establish a palliative care program to provide the option of dying at home or close to home with medical and community support by 2010.

*Baseline:* Bristol Bay Area Health Corporation is the only region with a palliative care program.

**Strategy a:** Expand a modified Helping Hands Program statewide

**Strategy b:** Develop culturally appropriate advance directives and education programs that adhere to all legal requirements and allow for a "natural" death.

**Strategy c:** Establish a system wide grief and bereavement program.

**Strategy d:** Assist families, regions, and ANMC in identifying and establishing respite services.

**Strategy e:** Develop culturally appropriate palliative care materials for providers, family members and community members.

**OBJECTIVE PC4:** Establish a palliative care program/team at ANMC offering appropriate services in pediatrics, medical, surgery, ICU and other areas as needed by 2010.

*Baseline:* Currently there is no palliative care program at ANMC.

**Strategy a:** Increase the number of board certified palliative care physicians in the Alaska Tribal Health System.

**Strategy b:** Establish a palliative care ANMC based consultation team to assist providers at ANMC, regional hospitals and villages with palliative and end of life care.

**Strategy c:** Integrate traditional and complementary care into palliative care services.

**Strategy d:** Integrate palliative care into ANMC medical, surgical, ICU and other services.

*"Over there, our spirit is going. It is good. I am going over there. I am happy to go over there. The sun is going down. It is good. Over there, I will be reborn. From the hoot of the owl, I will fly." 175*

# SURVEILLANCE AND RESEARCH

*“We can’t assume the incidence of cancer in Alaska Native people is the same as in the U.S. general population. In fact, it isn’t. It also isn’t the same as in other American Indian tribes. Cancer surveillance data help focus our efforts to fight this disease just as evidence based medicine and screening helps us determine where to put our limited resources.”* – Anne Lanier, M.D., MPH

It is important to have accurate and timely data to make informed decisions on how to best use resources to address the cancer burden of Alaska Natives. The term “surveillance” is used to describe the systematic collection, analysis, and interpretation of health data for planning, implementing, and evaluating health programs. All aspects of the Comprehensive Cancer Program, from defining the burden of cancer and guiding planning activities to monitoring changes and evaluating intervention efforts, rely upon the availability of strong and relevant surveillance activities.

In surveillance, data is gathered on the occurrence of cancer (incidence), cancer deaths (mortality), risk factors for the development of cancer (tobacco use, overweight, fruit and vegetable intake), cancer screening activities (use of mammography, colonoscopy, Pap tests), and the use of diagnostic and treatment services. Timely and high quality data are changed into information that is easily accessible to help develop studies, programs, and services to help prevent, manage, and research cancer.

**In the Alaska Tribal Health System (ATHS), cancer surveillance provides important information for use in:**

- ◆ *Identifying people at increased risk for cancer who would benefit from cancer information and follow-up*
- ◆ *Describing and monitoring cancer trends so that appropriate and timely interventions can be made*

- ◆ *Planning and evaluating cancer and educational programs*
- ◆ *Planning for future needs for diagnostic and treatment services (hospital beds, physician and nurse staffing, outpatient surgery and chemotherapy services, and rehabilitative and home care)*
- ◆ *Investigating public concerns about suspected high numbers of cancer cases*
- ◆ *Providing data to raise awareness of public health problems and support the development of policies*
- ◆ *Conducting and advancing research related to the cause, prevention, and treatment of cancer*

## Surveillance

Cancer surveillance is supported by data from a variety of sources including the Alaska Native Tumor Registry (ANTR), the Alaska Cancer Registry (ACR), the Alaska Behavioral Risk Factor Surveillance System (BRFSS), Healthy People 2010 (HP 2010), Healthy Alaskans 2010 (HA 2010), Pregnancy Risk Assessment Monitoring System (PRAMS), Youth Risk Behavior Survey (YRBS), the Government Performance and Results Act (GPRA), the National Cancer Institute’s Surveillance, Epidemiology, and End Results Program (SEER). State of Alaska and U.S. databases are useful for comparing Alaska Native data with other populations in the state or nation.

### ***Alaska Native Tumor Registry (ANTR)***

The ANTR was established in 1974. It contains cancer information about newly diagnosed patients from 1969 to the present. Information on stage at diagnosis, treatment, and follow-up care was added to the registry in 1984. Agreements with state and national registries help make certain that all Alaska Native cancer patients diagnosed with cancer while living in Alaska are identified.

More than 300 new invasive cancer cases are added the the ANTR each year. Approximately one-fourth of the diagnosed cancers are adults between the age of 50-59 and one-third of them older than 70 years.

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

The ANTR submits data to the Alaska Cancer Registry (ACR) within the Alaska Department of Health and Social Services, and works closely with the ACR to report all Alaska Native data for inclusion in state statistics. The ANTR is a member of National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program since 2001. Since its inception, ANTR has consistently adhered to SEER standards for case identification, data collection, coding, and follow-up methods.

Invasive cancer diagnosed in Alaska Natives who are residents of Alaska at the time of diagnosis and who provide documentation of eligibility for health care from the Indian Health Service are recorded in the ANTR. Alaska Native cancer patients are identified statewide from hospital tumor registries, 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. The medical records of cancer patients are reviewed at least annually beginning with the year of their diagnosis.

Patients who have no current records in the Alaska Area Native Health Service, and are not being actively followed by the tumor registry ("lost to follow-up"), and have no death certificate recorded in Alaska are submitted to the National Death Index. This national system identifies patients who were once diagnosed with cancer in Alaska and may or may not still be living.

### ***Alaska Cancer Registry (ACR)***

The Alaska Cancer Registry (ACR) is a population-based, statewide cancer registry. The primary purpose of the registry is to collect information on all reportable cancer cases in Alaska. The registry maintains data on newly diagnosed cancer cases and pertinent information about that cancer. The ACR is funded by the CDC National Program of Cancer Registries (NPCR) grant.

The registry began collecting information January 1, 1996. Alaska hospitals, physicians and other health care practitioners are required by state law to report information to the ACR within six months of diagnosis. Reported cancer cases are analyzed to identify cancer trends, patterns, and geographic variations. The ACR then creates and disseminates reports on the burden of cancer in Alaska. Cancer incidence and mortality data is critical for targeting public health programs. Data from incidence trends for cancer of different sites will be used to plan intervention strategies to prevent or reduce the occurrence of disease and its impact.

### ***Behavioral Risk Factor Surveillance System (BRFSS)***

Alaska BRFSS is part of an ongoing national telephone survey conducted by the State of Alaska Department of Health and Social Services Division of Public Health, funded by a grant from the CDC. It utilizes standard protocol and interviewing methods developed by the CDC. Alaska began participating in the BRFSS

in 1990. The survey includes questions about health status and perceptions, preventive health practices, and risky behaviors that influence the occurrence of chronic diseases, injury, and preventable infectious diseases.

The BRFSS is a standardized telephone interview conducted with a computer-assisted script. There is a fixed core of questions asked by all states every year and a rotating core asked by all states in alternate years. In addition, there are a number of optional modules that states may choose to use. States may also add questions of their own. Interviews are conducted every month of the year. Each month over 200 Alaska residents age 18 and older are interviewed over the telephone, to reach an annual sample size of 2500.

A stratified random sampling design is used on the Alaska BRFSS. The Alaska sample is stratified into five regions. An equal number of interviews are conducted in each region, which purposely over-samples the very large rural areas of Alaska.

Participation is random, anonymous, and confidential. Respondents are randomly selected from among the adult members of the household. Only those living in households are surveyed. Those living in institutions (e.g. military barracks, dormitories, nursing homes), and other group living situations are excluded. Apart from that exclusion, each state's sample is designed to be representative of the state population. Respondents are contacted by telephone using a selection process based on area codes and prefixes that are highly likely to be associated with residential listings. Alaska uses an additional sampling procedure to take into account differences in telephone coverage by geographic and economic factors. It is estimated that 97 percent of the households in the state have telephones, but the percentage is substantially lower in some geographic areas and among groups of low socioeconomic status.

The analysis of BRFSS data requires complex statistical procedures to take into account the fact that not every adult resident of the state has an equal chance of being contacted for an interview. The analysis assigns a probability to each respondent, which reflects his or her likelihood of being contacted. In addition, each person interviewed is treated as a representative for other, similar persons. The probability factor and assumption of representativeness are used to calculate a statistical weighting factor to use in analysis to draw inferences about the overall population.

BRFSS data are believed to be overestimated for Alaska Natives. A number of factors are believed to contribute to the BRFSS over-estimation among Alaska Natives, including recall bias, confusion among Alaska Natives about the terminology used, and higher screening and health care utilization among respondents with telephone access. For many Alaska Natives, English is not

the primary language. They may also have difficulty understanding English speakers from outside their communities during a telephone interview.

### ***Healthy People 2010 (HP2010)***

HP 2010 is the plan that serves as a framework for health policy development in the United States. HP 2010 contains a comprehensive set of disease prevention and health promotion objectives to achieve over the first decade of the new century. HP 2010 identifies a wide range of public health priorities and specific, measurable objectives.

HP 2010 objectives are designed to achieve two goals: increase quality and years of healthy life and eliminate disparities. These two goals are supported by specific objectives in 28 focus areas, one of which is cancer, where the goal is to reduce the number of new cancer cases and to reduce the illness, disability, and death caused by cancer. Each objective was developed with a target to be achieved by the year 2010. Specific objectives within the cancer focus area include reducing lung cancer deaths, reducing the harmful effects of sun exposure, and providing counseling about preventive measures. HP 2010 indicators are useful for setting cancer control baselines and objectives where other data sources are not available.

### ***Healthy Alaskans 2010 (HA2010)***

Using the framework of Healthy People 2010, Healthy Alaskans 2010 (HA 2010) outlines the targets and strategies for improved health in Alaska. HA 2010 reflects Alaska's priorities and objectives for improving health status; modifying exposures to health risks; and strengthening health care services and environmental and occupational conditions. A chapter is dedicated to Cancer.

### ***Pregnancy Risk Assessment Monitoring System (PRAMS)***

PRAMS is a surveillance project funded by the CDC and conducted by the State of Alaska Department of Health and Social Services Division of Public Health. PRAMS collects Alaska data on maternal attitudes and experiences before, during, and shortly after pregnancy. The project was initiated by the CDC in 1987, because infant mortality rates were no longer declining as rapidly as they had in prior years. In addition, the incidence of low birth weight infants had also not declined in the previous 20 years. Research indicates maternal behaviors during pregnancy may influence infant birth weight and mortality rates.

The goal of the PRAMS project is to improve the health of mothers and infants by reducing adverse outcomes such as low birth weight, infant mortality and morbidity, and maternal morbidity. PRAMS data are used by ATHS to monitor changes in prenatal smoking and smokeless tobacco use. Participants are selected from birth certificate data using a stratified random sample that over sample for underrepresented populations. Survey information is collected by mail through a self-administered questionnaire with telephone follow-up of non-responders.

Alaska uses an additional sampling procedure for Alaska Natives. Because the same data collection methods are used in all states, PRAMS also allows for comparisons between participating states.

### ***Youth Behavior Risk Survey (YRBS)***

The YRBS is part of an epidemiological surveillance system of youth grades 9-12 who are attending public high schools established in 1988 by the CDC to help monitor the prevalence of behaviors that not only influence adolescent health, but also put youth at risk for significant health and social problems that can occur during adolescence and adulthood. Prevention coordinators, community mobilization coalitions, community public health and safety networks, and others use this information to guide policy and programs that serve youth.

The YRBS survey is designed to be administered every two years by distribution in randomly selected schools throughout the state. YRBS measures cancer specific risk behaviors regarding tobacco use, unhealthy dietary behaviors, and inadequate physical activity. Data from the YRBS is self-report.

Alaska first participated in the YRBS survey in 1995 at both the high school and middle school levels and obtained weighted (representative) statewide data. Due to external factors, the YRBS was not administered in 1997. It was administered in 1999; however the 1999 sample did not include the Anchorage School District, the state's largest school district. Without Anchorage, the data were not representative of the state as a whole.

The YRBS survey was administered in 2001 statewide, however not enough student responses statewide were collected, and so no data were analyzed. A major obstacle in 2001 was the active parental consent law that had just gone into effect at the end of the 1999. In 2003, the survey was administered statewide with active parental consent and weighted (representative) data were obtained. YRBS response in 2005, regrettably, was insufficient to validate the results.

### ***Government Performance and Results Act (GPRA)***

GPRA requires federal agencies, such as the Indian Health Service, to show that they are using federal funds effectively. The Act requires that federal agencies have a five-year strategic plan that describes long-term goals of the agency. It also requires that they submit annual performance plans and reports with their budget requests. The annual performance plan describes what the agency intends to accomplish toward those goals with their annual budget. The plan contains specific performance measures for a one-year period and the annual performance report describes how the agency measured up against the performance targets set by IHS in the performance plan.

The Indian Health Service (IHS) performance measures include several indicators that can be used to evaluate cancer programs and the strategies contained in the Comprehensive Cancer Care



Plan for Alaska Natives. Those measures include Pap smear, mammogram, and colorectal screening rates, tobacco use assessment, and obesity assessment.

### ***Surveillance, Epidemiology, and End Results (SEER) Program***

The National Cancer Institute's SEER Program is a source of information on cancer incidence and survival. It is the only comprehensive source of population-based information in the United States that includes stage of cancer at the time of diagnosis and survival rates within each state. Initiated in 1973, the SEER Program is considered the standard for quality among cancer registries around the world. Alaska Native specific data are often compared against SEER data on U.S. Whites and other populations.

### ***Family Cancer Registries/Cancer Genetic Networks***

At this time ATHS does not have a system-wide family cancer risk registry for collecting and tracking family history of disease. An accurate family history is a well-established method to recognize genetic disorders and susceptibilities that may pose risks for future health problems. Early identification of families with increased risk for chronic disease such as heart disease, diabetes, and certain cancers, (e.g., breast, prostate, or colorectal) can often improve, delay, or even prevent adverse health outcomes to individual members. Examples of prevention and treatment options include increased surveillance, lifestyle changes, prophylactic medical measures, surgical intervention, or genetic testing.

## **Research**

The ANTHC Cancer Program is part of the Office of Alaska Native Health Research (OANHR). The OANHR identifies health research needs and priorities, enhances capacity to conduct research, increases participation of Alaska Natives in the conduct of health research, pursues funds for conducting research projects, develops a database of health research involving Alaska Natives, and coordinates all research involving Alaska Native health occurring in the state.

### **ANTHC cancer-related projects include:**

***EARTH – A Prospective Study of Alaska Natives and American Indians*** – documents how diet, physical activity, and other lifestyle and cultural factors relate to the development of chronic diseases, such as cancer, cardiovascular disease, and diabetes. This national study includes Alaska Natives and American Indians who are being enrolled at study sites in Arizona, Utah and the Dakotas. This study will help give us a better understanding of any links between specific factors and these diseases. About 4,000 Alaska Natives will be enrolled during the first five years of the grant and an additional 10,000 in the contiguous United States. Project organizers plan eventually to enroll

80,000 Alaska Natives and American Indians nationwide in this long-term cohort study. *NCI funded.*

***NARCH – Native American Research Center for Health*** – develops the capacity of Alaska Native Tribes and individuals to conduct health research. NARCH III was funded in 2005 and includes seven Alaska projects: the prevalence of disabilities children; re-infection with *H. pylori*; chronic Hepatitis B in Alaska Natives, maternal nutrition and pregnancy outcomes; dietary and subsistence food assessment; telehealth and chronic otitis media. *NIH funded.*

***Colorectal Cancer Training Program for Flexible Sigmoidoscopy*** – funds the development of a Flexible Sigmoidoscopy Training Program for mid-level practitioners working in rural Alaska to increase colorectal cancer screening. *CDC funded.*

***Cancer Education for Community Health Aide Practitioners (CHA/P) in Alaska*** – cancer education curriculum for CHA/Ps from each of the 178 rural health clinics. *NCI grant.*

***Nicotine Research Program and Control Program*** – conducts nicotine research and provides technical assistance to develop nicotine dependency programs at regional health corporations. *Multiple funding sources.*

***Palliative Care Education for Healthcare Providers of Alaska Natives*** – creates a comprehensive, culturally sensitive, palliative care curriculum for clinical providers who provide healthcare services to Alaska Natives. *NCI funded.*





## Goals, Objectives & Strategies for Surveillance & Research

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### GOAL

Collect complete, accurate, and timely data on cancer in Alaska Natives.

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### SURVEILLANCE, RESEARCH, AND EVALUATION OBJECTIVE AND STRATEGIES

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**OBJECTIVE SR1:** Support the gathering and maintenance of data systems to understand the cancer related needs of Alaska Natives.

*Baseline:* Although the Alaska Native Tumor Registry is in place, no family cancer risk registry exists within ATHS in 2005.

**Strategy a.** Support the efforts of the Alaska Native Tumor Registry to continue to gather and report cancer data on Alaska Natives.

**Strategy b.** Support the establishment of an ATHS family cancer risk registry to identify persons at high risk due to family history and predisposing conditions, and assure appropriate screenings and follow-up.

**Strategy c.** Maintain a database of cancer research being undertaken among Alaska Natives and secure additional funding for priority research needs.

## ENDNOTES

1 All rates are age-adjusted, average annual rates. Age-adjusted: Rates have been mathematically weighted to allow comparisons of populations with different age distributions. Average annual: Cases for several years are added together and divided by the number of years to give an average annual number. This number is divided by population. This number is the rate of cancer cases. It is usually shown as per 100,000 populations.

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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.

**Strategy b:** Expand the number of regional nicotine dependence treatment programs for pregnant and post partum women.

**Strategy c:** Increase Alaska Native specific tobacco control media initiatives and educational resources targeting pregnant and post partum women to assure comprehensive, culturally appropriate media messages reach the intended audience.

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**OBJECTIVE PT7: Design and implement training for an Alaska Native specific tobacco treatment specialist by 2010.**

*Baseline: No training exists in 2005*

**Strategy a:** Develop a tobacco treatment specialist curriculum to be integrated into the Behavioral Health Aide Certification program.

**Strategy b:** Develop a tobacco treatment specialist curriculum to be integrated into the Dental Health Aide Certification program.

**Strategy c:** Include tobacco treatment educational resources in the Community Health Aide Manual.

**Strategy d:** Organize annual statewide and regional ATHS tobacco trainings and conferences.

**Strategy e:** Assist with efforts to establish tobacco treatment counselor certification.

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**OBJECTIVE PT8: Establish a tobacco free campus at the ANMC by 2007.**

*Baseline: ANMC campus is not tobacco free in 2006*

**Strategy a:** Design and implement an ANMC tobacco free campus program, expanding education and tobacco cessation interventions for patients and employees.

**Strategy b:** Develop resources to assist other ATHS facilities implement tobacco free policies successfully.

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**OBJECTIVE PT9: Reduce the percentage of Alaska Native youth smokers to 15% by 2010.**

*Baseline: 29% male and 27% female YRBS 2003*

**Strategy a:** Increase Alaska Native specific tobacco control media and education initiatives addressing youth to assure comprehensive, culturally appropriate messages reach the intended audience.

**Strategy b:** Develop and assess the efficacy of Alaska Native specific tobacco use interventions for youth, to assure comprehensive, culturally appropriate education efforts.

**Strategy c:** Improve systems to have health care providers ask each patient, including parents of young children and youth, at each visit if they use tobacco and if tobacco is used in their homes, to determine their readiness to quit and advise them accordingly.

**Strategy d:** Encourage regional tribal health programs to continue to collaborate with local community providers and schools to use established tobacco cessation curriculums for youth, including CDC endorsed curriculums.

**Strategy e:** Design and implement a strategy to collect tobacco use rates for Alaska Native children (K-6 grade) by 2010.

**Strategy f:** Provide community technical assistance in addressing tobacco control issues targeting youth.

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**OBJECTIVE PT10: Contribute to the knowledge and understanding of the risk of tobacco use among Alaska Natives to tribal leadership and communities in Alaska.**

*Baseline: Twenty-four presentations in 2005*

**Strategy a:** Present research findings and evidence-based best practices to tribal leadership at local, regional and statewide gatherings and conferences in Alaska.

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## Goals, Objectives & Strategies for Nutrition, Physical Activity, & Alcohol

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### GOAL

Alaska Natives will make healthy nutrition, physical activity, and alcohol consumption choices for cancer prevention.

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### NUTRITION OBJECTIVES & STRATEGIES

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**OBJECTIVE PN1: Increase to 40% the proportion of Alaska Native adults 18 and older who have a Body Mass Index (BMI) below 25 by 2010.**

*Baseline: 32% BRFSS 2004.*

**Strategy a:** Increase the awareness of Alaska Natives about the links between diet and cancer, including the importance of maintaining a diet rich in plant-based foods, reducing the consumption of store-bought animal fat, and attaining and maintaining healthy body weight.

**Strategy b:** Increase opportunities for Alaska Natives to learn healthy cooking methods and disseminate healthy recipes that are ethnically and culturally appropriate and based on available foods.

**Strategy c:** Provide training and resources for health care providers to increase their capacity to educate Alaska Natives on the importance of maintaining a healthy diet.

**Strategy d:** Increase the ability of health care providers to measure and record height and weight of adult patients for obesity prevention.

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**OBJECTIVE PN2: Establish a BMI baseline for Alaska Native adolescents by age and gender by 2010.**

*Baseline: No baseline exists for Alaska Native adolescents. Baseline for all Alaska adolescents is 75% BRFSS 2003*

**Strategy a:** Increase the ability of health care providers to measure and record height and weight of adolescent patients for obesity prevention.

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**OBJECTIVE PN3: Increase to 30% the proportion of Alaska Native adults 18 and older who eat at least five servings of fruits and vegetables every day by 2010.**

*Baseline: 21% BRFSS 2003*

**Strategy a:** Develop media messages aimed at Alaska Native adults to increase their awareness of the importance of eating five or more servings of fruits and vegetables every day.

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**OBJECTIVE PN4: Increase to 30% the proportion of Alaska Native adolescents who eat at least five servings of fruits and vegetables every day by 2010.**

*Baseline: 14.4% BRFSS 2003*

**Strategy a:** Utilize data sources to determine barriers to healthy eating and to plan effective strategies to overcome identified barriers.

**Strategy b:** Develop media messages aimed at Alaska Native adolescents to increase their awareness of the importance of eating five or more servings of fruits and vegetables every day.

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**PHYSICAL ACTIVITY OBJECTIVES & STRATEGIES**

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**OBJECTIVE PP1: Increase to 28% the proportion of Alaska Native adults 18 and older who meet Healthy People 2010 recommendations for moderate and vigorous activity by 2010.**

*Baseline: 16% BRFSS 2003*

**Strategy a:** Increase public awareness of the benefits of physical activity.

**Strategy b:** Increase the number of AHS worksites that provide opportunities and policies that promote physical activity (e.g., health club membership discounts, workout rooms, flexible work hours, walking groups, on-site fitness classes, and accessible stairways).

**Strategy c:** Promote physical activity in local communities by gathering information on walk-ability and bike-ability and existing policies and programs.

**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.

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**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.

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**ALCOHOL OBJECTIVES & STRATEGIES**

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**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.

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**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.

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## CANCER EDUCATION OBJECTIVE & STRATEGIES:

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**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.

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## Goals, Objectives & Strategies for Environmental Contaminants

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### GOAL

Reduce the exposure of Alaska Natives to harmful levels of carcinogenic environmental contaminants.

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**OBJECTIVE PE1:** Educate Alaska Natives about ways to reduce harmful exposure to contaminants.

*Baseline:* Few environmental education programs exist in 2005.

**Strategy a:** Increase awareness about health risks associated with asbestos in rural villages.

**Strategy b:** Raise awareness about the benefits and risks associated with traditional diets.

**Strategy c:** Inform people who live in radon prone areas about the risks of radon and ways to reduce those risks.

**Strategy d:** Develop materials about sun exposure and the risk for skin cancer.

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**OBJECTIVE PE2:** Increase the understanding of the benefits of traditional foods as well as the risk considerations when studying contaminants in traditional foods.

*Baseline:* Few educational resources are available that emphasize both benefits and risks of traditional foods.

**Strategy a:** Support the development of material specific to benefits and risks of traditional foods in Alaska.

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**OBJECTIVE PE3:** Support efforts by the State of Alaska, Environmental Protection Agency and others to establish a standardized system for statewide monitoring of contaminants.

*Baseline:* A statewide standardized system does not exist in 2005.

**Strategy a:** Investigate possibilities for establishing a system for statewide monitoring of contaminants.

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**OBJECTIVE PE4:** Advocate at the local, state, federal, and international levels to promote a cooperative strategy for contaminant related cancer risk prevention.

*Baseline:* Prioritization of advocacy activities relevant to environmental health occurs annually within the Alaska Native Health Board and the ANTHC Department of Environmental Health and Engineering.

**Strategy a:** Encourage proper management and clean-up of abandoned and active asbestos contaminated buildings and waste sites.

**Strategy b:** Seek appropriate changes to real estate law to require sampling of well water for arsenic as part of real estate transactions.

**Strategy c:** Seek adequate federal funding for public water systems to meet mandate for testing and treatment.

**Strategy d:** Provide safe drinking water (within allowable standards) to all Alaska Natives.

**Strategy e:** Advocate for reduction in global use of carcinogenic contaminants.

**Strategy f:** Raise awareness about the risks associated with continued application of carcinogenic compounds in the environment.

**Strategy g:** Encourage greater cooperation between the State of Alaska and neighboring countries regarding the monitoring and control of contaminants in the environment.

**Strategy h:** Encourage continued funding and coordination between responsible parties, State and Federal Agencies and ANTHC in efforts to clean up contaminated sites.



**Strategy i:** Support efforts to develop building codes that decrease risk of exposure to indoor air pollutants.

**Strategy j:** Support development of long term monitoring strategies for the environment and subsistence resources of Amchitka Island.

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**OBJECTIVE PE5:** Encourage research on Alaska Native exposure to contaminants and incidence of contaminant related cancer.

*Baseline:* There is no comprehensive database that identifies and tracks research on the effects of the environment on cancer in Alaska Natives in 2005.

**Strategy a:** Investigate naturally occurring asbestos in Alaska.

**Strategy b:** Evaluate the extent of the problem of arsenic in private water wells.

**Strategy c:** Review tumor registry data to assess bladder, liver, kidneys and other arsenic-associated cancers in high arsenic areas.

**Strategy d:** Research health issues related to air quality in rural housing.

**Strategy e:** Explore opportunities for reducing exposure to harmful levels of benzene and other constituents of fuel.

**Strategy f:** Evaluate levels of carcinogenic air pollutants in rural homes, boats, and buildings.

**Strategy g:** Monitor levels of persistent organic pollutants (POPs) in Alaska Native population.

**Strategy h:** Encourage comprehensive testing of homes for environmental contaminants in susceptible areas.

**Strategy i:** Generate data regarding levels of sun exposure among Alaska Natives by including sun exposure questions on the Alaska Behavior Risk Factor Survey.

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## Goals, Objectives & Strategies for Infectious Agents

### GOAL

Reduce cancer deaths in Alaska Natives due to infectious agents.

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**OBJECTIVE PI1:** Increase awareness among Alaska Natives of the relationship between certain infectious diseases and cancers emphasizing vaccinations.

*Baseline:* Current information available to Alaska Natives is very limited in 2005.

**Strategy a:** Develop media messages on infectious disease vaccinations and cancer.

**Strategy b:** Monitor emerging science investigating the relationship between infectious agents and cancer.

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## Goals, Objectives & Strategies for Screening & Early Detection

### GENERAL GOALS

- Detect conditions that may lead to cancer.
- Find cancer in its earliest stages.

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### BREAST & CERVICAL CANCER GOAL

Reduce death from breast and cervical cancer.

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### BREAST & CERVICAL CANCER OBJECTIVES & STRATEGIES

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**OBJECTIVE SB1:** Increase the percentage of Alaska Native women who receive regular breast and cervical cancer screenings.

*Baseline:* 59% women ages 52 to 64 years had mammography screening in the previous two years; and 75% of Alaska Native women had a Pap test done in the previous three years. GPRA 2005.

**Strategy a:** Support the development and distribution of educational material promoting the importance of regular breast and cervical screenings.

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**OBJECTIVE SB2:** Increase collaboration with the Alaska Breast and Cervical Cancer Early Detection Programs.

*Baseline:* Best areas for collaboration have not been identified in 2005.

**Strategy a:** Integrate Breast and Cervical Cancer Early Detection Programs into cancer plan implementation activities.

**Strategy b:** Collaborate with the Alaska Breast and Cervical Cancer Partnership and others on shared priorities.

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**OBJECTIVE SB3:** Increase the number of tribal Breast and Cervical Cancer Early Detection Programs to six by 2010.

*Baseline:* There are four programs in 2005.

**Strategy a:** Support efforts by non-funded tribal organizations to secure funding to develop Breast and Cervical Cancer Early Detection Programs.

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## COLORECTAL CANCER GOAL

Reduce death and illness from colorectal cancer.

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### COLORECTAL CANCER OBJECTIVES & STRATEGIES

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**OBJECTIVE SC1:** Increase the colorectal cancer screening rates by 10% among Alaska Natives by 2010.

*Baseline:* 19% IHS 2004

**Strategy a:** Survey the capacity of regional facilities to provide colorectal cancer screening.

**Strategy b:** Support programs to train mid-level providers to perform flexible sigmoidoscopy/colonoscopy and to establish ongoing screening programs in regional facilities.

**Strategy c:** Support programs to diagnose colorectal cancer stages and reduce or eliminate unnecessary pre-operative chemotherapy and radiation treatment.

**Strategy d:** Increase Alaska Native specific colorectal cancer screening education to make sure that comprehensive, culturally appropriate media messages reach the intended audience.

**Strategy e:** Investigate innovative ways of organizing healthcare providers to enhance screening rates in rural communities.

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**OBJECTIVE SC2:** Develop a colorectal screening database for Alaska Natives for clinical case management and surveillance purposes by 2010.

*Baseline:* An AHS database specific to colorectal cancer does not exist in 2005.

**Strategy a:** Support development of a tracking procedure that will interface with the Resource and Patient Management System (RPMS) to track screening needs and follow-up of patients for colorectal screening.

**Strategy b:** Support development of a database for tracking first degree relatives of colorectal cancer patients.

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## PROSTATE CANCER GOAL

Increase informed decision making regarding prostate screening among Alaska Native men.

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### PROSTATE CANCER OBJECTIVES & STRATEGIES

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**OBJECTIVE SP1:** Provide education to Alaska Native men and their health care providers regarding prostate screening recommendations by 2010.

*Baseline:* Limited educational materials specific to Alaska Native men exist in 2005

**Strategy a:** Provide primary care providers with the latest information regarding recommendations for prostate screening.

**Strategy b:** Develop Alaska Native specific patient information.

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**OBJECTIVE SP2:** Develop a prostate screening database of Alaska Native men for clinical case management and data analysis purposes by 2010.

*Baseline:* A system-wide database specific to prostate cancer does not exist in 2005.

**Strategy a:** Develop a database of first-degree relatives of prostate cancer patients.

**Strategy b:** Determine the percentage of Alaska Native men who have received a prostate-specific antigen test.

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## EMERGING SCIENCE GOAL

Investigate and determine effectiveness of new tests and procedures to detect and screen for cancer and incorporate them in the cancer program as appropriate.

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### EMERGING SCIENCE OBJECTIVES & STRATEGIES

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**OBJECTIVE SO1:** Implement new cancer screening and early detection tests as they become recommended by national organizations by 2010.

*Baseline:* No formal tracking system of new screening tests exists in 2005.

**Strategy a:** Track new screening and early detections test and recommendations.

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## Goals, Objectives & Strategies for Diagnosis

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### GOAL

Diagnose cancer using the least invasive and most comprehensive procedures.

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**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.

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**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.

## Goals, Objectives & Strategies for Treatment

### GOALS

When cancer is diagnosed, treat the patient and family with the most appropriate therapy as close to home as possible.

**OBJECTIVE T1:** ANMC will be certified by the American College of Surgeons Commission on Cancer (ACoS) by 2010.

*Baseline:* ANMC is not ACoS certified in 2005

**Strategy a:** Hire a coordinator to assist ANMC with coordinating the necessary steps to prepare for ACoS site review.

**Strategy b:** Assist ANMC staff with site review.

**OBJECTIVE T2:** Increase the number of ANMC and AHS oncology nurses certified by the Oncology Nursing Society by 25% by 2010.

*Baseline:* Four nurses within the AHS were certified in 2005.

**Strategy a:** Identify and train ANMC/AHS nurses interested in becoming a certification instructor.

**OBJECTIVE T3:** Establish a patient navigation program to ensure timely and efficient cancer care coordination by 2010.

*Baseline:* There is no coordinated patient navigation program within AHS in 2005.

**Strategy a:** Establish a cancer patient tracking system to monitor long-term cancer side effects and recurrence.

**Strategy b:** Identify collaborative and financial means

to support establishing a coordinated patient navigation program.

**OBJECTIVE DT4:** Consolidate patient diagnostic and treatment services through training and resource acquisition to reduce the need for cancer patients to travel to several healthcare facilities for diagnosis and treatment and allow patients to be treated as close to home as possible by 2010.

*Baseline:* Cancer patients must often travel between three Anchorage hospitals for diagnosis and treatment services in 2005.

**Strategy a:** Determine the feasibility of developing a comprehensive cancer center.

**Strategy b:** Support the expansion of current Oncology Clinic and Tumor Registry staff to help address unmet needs and proposed volume increase to be generated by a second oncologist and cancer case projections.

**Strategy c:** Support the enlargement of the Oncology Clinic and Tumor Registry physical space.

**Strategy d:** Support the development of the Oncology Support Program (OSP) to provide primary care and cancer support services for Alaska Natives who live outside the Anchorage Service Unit who remain in Anchorage for cancer care. Incorporate complementary and integrative care into the program.

**Strategy e:** Establish a mechanism to update regularly all members of the cancer care team about new diagnostic tests and treatment procedures.

**Strategy f:** Encourage partnerships with in-state and out-of-state healthcare providers when treatment modalities are not available at ANMC, and when a cost/benefit analysis indicates that partnering is appropriate.

**Strategy g:** Assist regional sites with training and physician consulting support so cancer patients can receive care closer to home

**Strategy h:** Work with ANMC Cancer Core Business Group (CCBG) to coordinate ANMC cancer diagnostic and treatment services.

**OBJECTIVE T5:** Establish a pain and symptom management program to ensure that cancer patients receive timely and effective pain and symptom therapy regardless of whether they are treated at ANMC, regional hospitals, or the villages by 2010.

*Baseline:* There is no comprehensive pain program within the AHS in 2005.

**Strategy a:** Collaborate with ANMC Pharmacy, palliative care providers, and other resources to initiate a pain and symptom management program.

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**OBJECTIVE T6: Educate physicians on accessing clinical guidelines by 2010.**

*Baseline: Some physicians within ATHS are not familiar with how to access clinical guidelines in 2005.*

**Strategy a:** Plan, implement, and evaluate training for physicians.

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**OBJECTIVE T7: Establish a mechanism for regional physicians to attend ANMC weekly Tumor Board meetings remotely by 2010.**

*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.

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**OBJECTIVE T8: Offer Alaska Native cancer patients the opportunity to participate in ANMC-based clinical trials by 2010.**

*Baseline: ANMC does not offer clinical trials in 2005.*

**Strategy a:** Determine availability/appropriateness of developing a formal relationship with an NCI designated comprehensive cancer center to assist in areas such as clinical trials.

**Strategy b:** Identify an ANMC Oncology clinic staff person to assist in setting up clinical trials as appropriate.

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## Goal, Objectives & Strategies for Survivorship

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### 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.

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**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

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**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.

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## Objectives & Strategies for Palliative Care

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**OBJECTIVE PC1:** The percentage of Alaska Native cancer patients dying in hospitals will be reduced by 20 percent by 2010.

*Baseline:* 57% of Alaskans die in Hospitals or Nursing Homes. Bureau of Vital Statistics. 2004.

**Strategy a:** Coordinate a pediatric palliative care program with Seattle Children's Hospital and other specialty services that provide care for Alaska Native pediatric cancer patients.

**Strategy b:** Collaborate with other palliative care providers and organizations to maximize palliative care resources.

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**OBJECTIVE PC2:** Train seventy percent of the healthcare providers of Alaska Natives through an ANTHC palliative care program by 2010.

*Baseline:* 2004 ANTHC Palliative care survey: 69% of healthcare providers have not received palliative care training.

**Strategy a:** Encourage and support national palliative care certification for healthcare providers including physicians, nurses, social workers, and pharmacists.

**Strategy b:** Establish a palliative care training program and curriculum for healthcare providers of Alaska Natives.

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**OBJECTIVE PC3:** Establish a palliative care program to provide the option of dying at home or close to home with medical and community support by 2010.

*Baseline:* Bristol Bay Area Health Corporation is the only region with a palliative care program.

**Strategy a:** Expand a modified Helping Hands Program statewide

**Strategy b:** Develop culturally appropriate advance directives and education programs that adhere to all legal requirements and allow for a "natural" death.

**Strategy c:** Establish a system wide grief and bereavement program.

**Strategy d:** Assist families, regions, and ANMC in identifying and establishing respite services.

**Strategy e:** Develop culturally appropriate palliative care materials for providers, family members and community members.

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**OBJECTIVE PC4:** Establish a palliative care program/team at ANMC offering appropriate ser-

vices in pediatrics, medical, surgery, ICU and other areas as needed by 2010.

*Baseline:* Currently there is no palliative care program at ANMC.

**Strategy a:** Increase the number of board certified palliative care physicians in the Alaska Tribal Health System.

**Strategy b:** Establish a palliative care ANMC based consultation team to assist providers at ANMC, regional hospitals and villages with palliative and end of life care.

**Strategy c:** Integrate traditional and complementary care into palliative care services.

**Strategy d:** Integrate palliative care into ANMC medical, surgical, ICU and other services.

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## Goals, Objectives & Strategies for Surveillance & Research

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### GOAL

Collect complete, accurate, and timely data on cancer in Alaska Natives.

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### SURVEILLANCE, RESEARCH, AND EVALUATION OBJECTIVE AND STRATEGIES

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**OBJECTIVE SR1:** Support the gathering and maintenance of data systems to understand the cancer related needs of Alaska Natives.

*Baseline:* Although the Alaska Native Tumor Registry is in place, no family cancer risk registry exists within ATHS in 2005.

**Strategy a.** Support the efforts of the Alaska Native Tumor Registry to continue to gather and report cancer data on Alaska Natives.

**Strategy b.** Support the establishment of an ATHS family cancer risk registry to identify persons at high risk due to family history and predisposing conditions, and assure appropriate screenings and follow-up.

**Strategy c.** Maintain a database of cancer research being undertaken among Alaska Natives and secure additional funding for priority research needs.



## APPENDIX 2

### The Alaska Native Tribal Health Consortium, the Alaska Tribal Health System, and the History of Cancer Planning in Alaska/Evaluation of Cancer Plan

#### The Alaska Native Tribal Health Consortium,

Since 1970, a statewide system of regional and local tribal health providers has been in existence to provide health care to Alaska Natives. This unique system provides access to a comprehensive, integrated, and tribally owned and controlled health care delivery system.

For more than 30 years, the Alaska Native Health Board (ANHB) served as a statewide organization for the purpose of “promoting the spiritual, physical, mental, social and cultural well-being and pride of Alaska Native People.” Primarily an advocacy organization for Alaska Natives, the ANHB Board of Directors represented the tribes and tribal organizations that carried out health programs throughout Alaska. Through ANHB, tribes and tribal organizations coordinated activities to develop common objectives and undertake statewide projects.

In 1994, several tribal health organizations joined together to form a compact that provided the opportunity for direct government-to-government negotiations between compact signers and representatives of the federal government through the Indian Health Service (IHS). Tribes and tribal organizations began to manage and operate hospitals and clinics. It allowed them to make faster and more efficient decisions that better addressed the health care needs and concerns of Alaska Natives. Over the past ten years, more tribes and tribal organizations joined the Compact.

In 1997, after years of inter-tribal discussion and negotiation with the IHS, the Alaska Native Tribal Health Consortium (ANTHC) was formed to promote the American Indian/Alaska Native vision of “self-governance and self-determination”. ANTHC is a statewide 501(c) 3 non-profit health services organization owned by Alaska Natives. A 15-member Alaska Native Board of Directors representing 229 tribes and 39 tribal health organizations across Alaska governs ANTHC. The Consortium entered into a self-governance agreement (the Alaska Tribal Health Compact) with the IHS for management of all statewide health services formerly provided by that agency for Alaska Natives. ANTHC is the largest tribal self-governance entity in the United States. Unlike most boards of a corporation of this size, the board is made up of Alaska Native consumers--comprised of fishermen, housewives,

former village-based health workers, community activists, and others appointed by their tribes to represent them. It exists to “provide the highest quality health services for all Alaska Natives.”

The ANTHC vision is for “Alaska Natives to be the healthiest people in the world”. Along with that vision is the goal to have Alaska Natives trained to provide all levels of Alaska Native healthcare. Until there are enough AI/ANs trained as healthcare providers and administrative staff, non-Native people are hired to provide those services. Oversight continues to be provided by the ANTHC Board of Directors. The Board approves plans, programs, services and budgets.

#### The Alaska Tribal Health System

The Alaska Tribal Health System (ATHS) is a large network of village-based clinics, regional hospitals, sub-regional clinics, and a large tertiary care facility (Alaska Native Medical Center or ANMC). ANMC, a 150-bed hospital, is Indian Country’s largest and most sophisticated medical center and is jointly managed by ANTHC and the SouthCentral Foundation. The ATHS is complex in that it includes cradle-to-grave comprehensive care for eligible beneficiaries at multiple facilities of varied capacity, spread across the state.

#### The ATHS is organized around five levels of care:

- ◆ **Village-based services** are provided by Community Health Aide/Practitioners working in village clinics (180 sites in rural Alaska, majority without road access) and other health care workers such as behavioral and dental aides.
- ◆ **Sub-regional services** are provided by mid-level practitioners serving several village
- ◆ **Regional services** are provided at six regional primary care hospitals in Barrow, Nome, Kotzebue, Bethel, Dillingham and Sitka. Many other healthcare services are provided by the tribal organizations in these areas and governed by their own board of directors.
- ◆ **Statewide tertiary and specialty services** are provided at the Alaska Native Medical Center (located in Anchorage). ANMC multi-specialty outpatient clinics

record more than 320,000 visits, perform over 8,000 surgical procedures, and admit over 6,500 patients each year. ANMC has also earned the distinction of being certified as the only Level II Trauma Center hospital in Alaska, placing it as the highest quality emergency treatment provider in the state.

- ◆ **Contact health services** include coverage for private sector referrals beyond the direct care system.

As the major providers of healthcare within the ATHS, ANTHC and ANMC, incorporate organizational behaviors, practices, attitudes, and policies that are respectful and responsive to cultural diversity in the broader definition that includes socioeconomic status, age, religion, sexual orientation, gender, physical and mental capacity and other differences.

### **Cancer Program planning and implementation**

In 1990, the State of Alaska Division of Public Health was awarded a "Data-Based Intervention Research Cooperative Agreement" by the National Cancer Institute to conduct a cancer control project using state cancer data to plan and undertake prevention and control activities. The project focused on tobacco-related, breast, and cervical cancers as they offered significant opportunities for prevention and early detection.

In 1994, the first State of Alaska Cancer Control Plan was written by the Alaska Division of Public Health, Section of Epidemiology and funded by the Division of Cancer Prevention and Control, National Cancer Institute. While these efforts were comprehensive and written to include Alaska Natives, the Alaska Tribal Health System has unique challenges and systems of care which were difficult to address in a statewide plan.

Although overall cancer mortality rates in the United States declined through the 1990s, Alaska Native cancer rates increased. From 1994 to 1998 the Alaska Native age-adjusted average annual mortality rate was thirty percent higher than that of U.S. Whites. Alaska Natives were forty percent more likely to die of lung cancer than U.S. Whites and demonstrated elevated mortality rates for several other smoking-related cancers as well. Also, Alaska Natives are at excess risk for nearly all cancers of the digestive system. Research in the area concluded that the burden of cancer on the Alaska Native healthcare system will continue to increase as the population ages and that intensified efforts to modify behavioral risk factors were needed.

These findings, coupled with the knowledge of the unique cultural differences and geographic barriers faced by

many Alaska Natives, prompted ANTHC to apply to the Centers for Disease Control and Prevention (CDC) for assistance in writing a comprehensive cancer plan for Alaska Natives. In 2004 ANTHC received the grant and began a comprehensive planning process which resulted in this first Alaska Tribal Health System Comprehensive Cancer Plan. The State of Alaska also received a grant to update their 1994 cancer plan. Alaska Natives are the largest minority in Alaska and the ATHS is often the only provider of healthcare in Alaska's remote communities. The ATHS is uniquely positioned to address many issues across the spectrum of cancer planning since it provides healthcare across a large and mostly road less state using innovative approaches refined and tested over many years.

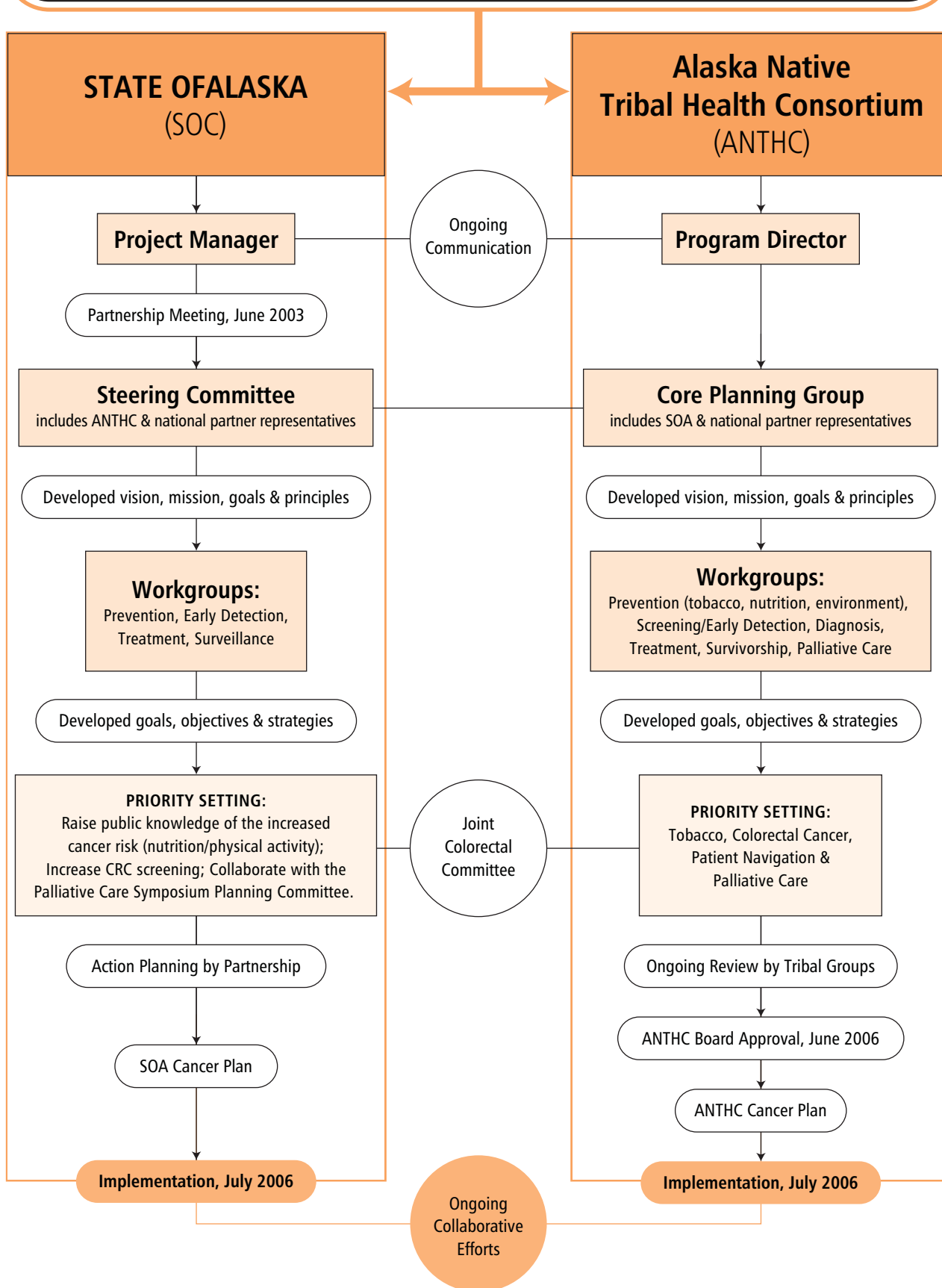
The ATHS Comprehensive Cancer plan, the first of its kind, addresses all aspects of cancer including prevention, screening and early detection, diagnosis, treatment, survivorship and palliative care. Over 130 healthcare providers, tribal health board members, cancer survivors, tribal representatives and others worked hard as part of eight work groups to develop the cancer plan. Many others offered expertise in specific areas. After spending three years of planning, in July 2006 ANTHC received an Implementation Grant from CDC to work on the goals, objectives, and strategies prioritized in this plan. The plan will also be a valuable tool for all Alaska healthcare organizations as they seek to address and provide "the highest quality of health care" for the people throughout the state.

### **Evaluation**

The purpose of developing and implementing a comprehensive cancer plan is ultimately to reduce cancer incidence, morbidity, and mortality and to improve quality of life. To determine whether the purpose is being achieved, the plan will be evaluated.

ANTHC has contracted with a nationally recognized consultant with expertise in cancer programs to provide program evaluation for the Cancer Plan. The evaluation will focus on processes, impacts (short-term results), and outcomes. The process evaluation will gather specific information such as the number of people and organizations who receive a copy of the cancer plan. The impact evaluation focuses on the short-term results of the program and whether the priorities and strategies are being addressed. The outcome evaluation will measure the impact and success of plan objectives. Where possible, measurable objectives have been identified and included in the plan. Baseline data will be used to measure progress and determine the effectiveness of plan strategies.

## CDC Comprehensive Cancer Control Planning Grants, 2003-2006



# 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 combining 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.

**CT Scan** An x-ray procedure using a computer to make detailed pictures of areas of the body.

**Cyst** An irregular sac in the body containing fluid or semi-solid material.

**Diagnosis** The process using symptoms, lab results and physical exam to find out about a disease.

**Differentiated/Undifferentiated** How similar or dissimilar cancer cells are to normal cells—undifferentiated cells are less like normal cells, which are very specialized or differentiated.

**Dysplasia** Abnormal development of size, shape, and organization of cells or tissue. Occurring most often in rapidly reproducing cells. May precede the development of cancer.

**Edema** the swelling of a body part caused by an abnormal build-up of fluids.

**Endoscopy** A diagnostic procedure using a flexible instrument with a lighted tube and optical system (endoscope) to examine the inside of many organs and structures in the body.

**Estrogen** Female hormone primarily produced in the ovaries.

**Extended stage** The “extended “ stage of survival begins when the patient goes into remission or has completed treatment.

**Gene** Biological unit of heredity; a discrete segment of the DNA molecule of a chromosome.

**Genetic** Inherited; having to do with information passed from parents to children through DNA.

**Gene Therapy** Use of genes in the treatment of disease, including cancer, most often by supplying healthy copies of missing or flawed genes.

**Grade** Describing cancer cells in terms of how quickly or slowly they are growing.

**Hormone therapy** Treatment that prevents certain cancer cells from getting the hormones they need to grow.

**Hyperplasia** Abnormal growth of normal cells resulting in the increase in size of a tissue or organ. Not cancerous, but it may become cancerous.

**Immunotherapy** Treatment to stimulate or restore the ability of the immune system to fight infection and disease.

**Incidence** The number of new cases of a disease diagnosed each year.

**Infrastructure** The systems, competencies, relationships, data and information systems, skilled workforce, effective public health organizations, resources, and research that enable performance of the essential public health services in every community.

**Infusion** A procedure by which fluid or medication is given directly into a vein.

**In Situ** The growth of cancer has not extended beyond the level of tissue in which it began.

**Intravenous** Injected into a vein; also call IV.

**Invasive** Spreading into healthy tissue.

**Iqmik** Homemade form of spit tobacco used by some Alaska Natives.

**Leukemia** Cancer of the organs that make the blood, bone marrow and lymph.

**Localized** Cancer only found in the organ where the cancer started.

**Lymph nodes** Small, bean-shaped organs located along the channels of the lymphatic system. Also called lymph glands.

**Malignant** A tumor that is cancerous and has the ability to spread to other parts of the body.

**Mediport** A surgically implanted device used to infuse medications and fluids (venous access device). For people who need frequent blood draws and medication, it eliminates the need to start an IV in the arm every time medication is needed or blood is needed for lab studies.

**Metastasis** The spread of cancer from one part of the body to another part of the body.

**Moderate physical activity** Exercise or participation in sports activities for at least 30 minutes, 5 times per week, that does not cause sweating or heavy breathing.

**Morbidity** A disease or the incidence of disease within a population. Morbidity also refers to adverse effects caused by a treatment.

**Mortality** Deaths due to disease during a given period of time usually expressed as number of deaths per 100,000 population.

**MRI** A procedure using a magnet linked to a computer to make pictures of areas inside the body.

**Neoplasn** Any growth, benign or malignant. A tumor.

**Oncologist** A doctor who specializes in cancer care.



**Palliative care** Addresses care needs of people with serious life-limiting illnesses such as cancer. It focuses on bringing comfort to the patient even when cure may not be possible.

**Pap test** Microscopic examination of cells from the cervix. It is used to detect changes that may be cancer or may lead to cancer.

**Patient navigation** A tool that can be used to ensure that survivors understand their care and their process of care and to enhance optimum care.

**Permanent stage** The “permanent” stage is defined as a time when the “activity of the disease or likelihood of its return is sufficiently small that the cancer can now be considered permanently arrested

**Polyp** Small, non-cancerous growths in the mucous membrane, most commonly found in the colon.

**Primary site** Where the cancer first started.

**Prognosis** The probable outcome of a disease and the chance of recovery.

**Prophylactic** Use of medical treatment to prevent disease.

**Protocol** The outline or plan for use of an experimental treatment or procedure.

**PSA** Prostate Specific Antigen test used to detect prostate disease.

**Radiation Therapy** Treatment with high-energy rays to kill or damage cancer cells.

**Radiation Oncologist** A doctor who specializes in using radiation to treat cancer.

**Recurrent** Reappearance of a cancer; may be local, regional, or metastatic

**Refractory** A cancer that does not respond to therapy.

**Regimen** The plan that outlines the dosage, schedule and duration of treatment.

**Relapse** Reappearance of disease after it has disappeared.

**Remission** Disappearance of the signs and symptoms of cancer. It can be temporary or permanent.

**Risk Factor** Factors that increase a person's chance of developing cancer.

**Screening** Tests or examinations done to detect cancer very early, before the person is aware of the cancer and has symptoms.

**Sedentary** No participation in any physical activities for at least 30 minutes, 5 times per week, that does not cause sweating or heavy breathing.

**Side Effects** Problems that may occur when treatment affects healthy cells such as nausea, feeling tired, vomiting, hair loss and mouth sores.

**Stage** Describes how far the cancer has spread from the original site to other parts of the body (in situ, local, regional, distant).

**Standard Treatment** The best treatment currently known for a cancer, based on results of past research.

**Stereotactic biopsy** A procedure that uses a computer and a three-dimensional scanning device to find a tumor site and guide the removal of tissue for examination under a microscope.

**Sigmoidoscopy** A procedure that allows the doctor or nurse to look inside the rectum and the lower part of the colon through a lighted tube.

**Survivorship** The period from the time cancer is diagnosed until the end of life.

**Systemic** Treatment that reaches and affects cells all over the body.

**Tumor** A general term used for a growth, malignant or benign..

**Tumor Board Review** A treatment planning approach in which a number of doctors, experts in different specialties, review and discuss the medical condition and treatment options of a patient. In cancer treatment, a tumor board review may include that of a medical oncologist (who provides cancer treatment with drugs), a surgical oncologist (who provides cancer treatment with surgery), and a radiation oncologist (who provides cancer treatment with radiation). Also called a multidisciplinary opinion.

**Tumor debulking** Surgical removal of as much of a tumor as possible.

**Ultrasound** A way to locate and measure solid tumors in the body using very high frequency sound waves.

**Vigorous physical activity** Exercise or participation in sports activities for at least 20 minutes, 3 times per week, that causes sweating and heavy breathing.

**White blood cells** Cells that help the body fight infection and disease.

# APPENDIX 4

## ACRONYMS

<b>A/PIA</b>	Aleutian/Pribilof Islands Association	<b>ASUTHC</b>	Anchorage Service Unit Tribal Health Council
<b>AANHS</b>	Alaska Area Native Health Service	<b>ATCA</b>	Alaska Tobacco Control Alliance
<b>ACoSC</b>	American College of Surgeons Commission	<b>ATHC</b>	Alaska Tribal Health Compact
<b>ACR</b>	Alaska Cancer Registry	<b>AVCP</b>	Association of Village Council Presidents
<b>ACREC</b>	Alaska Cancer Research and Education Center	<b>ATSDR</b>	Agency for Toxic Substances and Disease Registry
<b>ACRH</b>	Alaska Center for Rural Health	<b>BBAHC</b>	Bristol Bay Area Health Corporation
<b>ACS</b>	American Cancer Society	<b>BCHC</b>	Breast and Cervical Health Check Program
<b>AEC</b>	Atomic Energy Commission (U.S.)	<b>BMI</b>	Body Mass Index
<b>AFHCAN</b>	Alaska Federal Health Care Access Network	<b>BRFSS</b>	Behavioral Risk Factor Surveillance System
<b>AFN</b>	Alaska Federation of Natives	<b>BSE</b>	Breast Self Exam
<b>AHRQ</b>	Agency for Healthcare Research and Quality	<b>CDC</b>	Centers for Disease Control and Prevention
<b>AI/AN</b>	American Indian/Alaska Native	<b>CHA/P</b>	Community Health Aide/Practitioner
<b>AITC</b>	Alaska Inter-Tribal Council	<b>CHAP</b>	Community Health Aide Program
<b>APCA</b>	Alaska Primary Care Association	<b>CIS</b>	Cancer Information Service
<b>ALPHA</b>	Alaska Public Health Association	<b>CRCHD</b>	Center to Reduce Cancer Health Disparities
<b>ANCR</b>	Alaska Native Cancer Registry	<b>CWA</b>	Community Wellness Advocates
<b>ANCSA</b>	Alaska Native Claims Settlement Act	<b>DEHE</b>	Division of Environmental Health and Engineering
<b>ANEC</b>	Alaska Native Epidemiology	<b>DEW Line</b>	Distant Early Warning communication facilities
<b>ANHB</b>	Alaska Native Health Board	<b>DHHS</b>	Department of Health and Human Services (U.S.)
<b>ANMC</b>	Alaska Native Medical Center	<b>DHSS</b>	Department of Health and Social Services (Alaska)
<b>ANTHC</b>	Alaska Native Tribal Health Consortium	<b>DPH</b>	Division of Public Health (Alaska)
<b>ATHS</b>	Alaska Tribal Health System	<b>DRE</b>	Digital Rectal Exam
<b>ANTR</b>	Alaska Native Tumor Registry		
<b>ARCS</b>	Alaska Rural Communications System		
<b>ASNA</b>	Arctic Slope Native Association		
<b>ASRC</b>	Arctic Slope Regional Corporation		

<b>EARTH</b>	Education And Research Toward Health Study	<b>NCCS</b>	National Coalition for Cancer Survivorship
<b>EAT</b>	Eastern Aleutian Tribes	<b>NCCDPHP</b>	National Center for Chronic Disease Prevention and Health Promotion
<b>EBV</b>	Epstein-Barr Virus	<b>NCI</b>	National Cancer Institute
<b>EH</b>	Environmental Health	<b>NHIS</b>	National Health Interview Survey
<b>EIS</b>	Environmental Impact Statement	<b>NIH</b>	National Institutes of Health
<b>EPA</b>	Environmental Protection Agency (U.S.)	<b>NPCR</b>	National Program of Cancer Registries
<b>ERCP</b>	Endoscopic Retrograde Cholangiopancreatography	<b>NRT</b>	Nicotine Replacement Therapy
<b>ETS</b>	Environmental Tobacco Smoke (aka Second hand smoke)	<b>NSB</b>	North Slope Borough
<b>FOBT</b>	Fecal Occult Blood Test	<b>NSHC</b>	Norton Sound Health Corporation
<b>FUDS</b>	Formerly Used Defense Sites	<b>OANHR</b>	Office of Alaska Native Health Research
<b>GPRA</b>	Government Performance and Results Act	<b>PCBs</b>	Polychlorinated biphenyls
<b>HAV</b>	Hepatitis A Virus	<b>PET</b>	Positron Emission Tomography
<b>HBV</b>	Hepatitis B Virus	<b>PHFSC</b>	Public Health Functions Steering Committee
<b>HCV</b>	Hepatitis C Virus	<b>PHS</b>	Public Health Service
<b>ICD-O</b>	International Classification of Disease Oncology	<b>POPs</b>	Persistent Organic Pollutants
<b>IRB</b>	Institutional Review Board	<b>PRAMS</b>	Pregnancy Risk Assessment Monitoring System
<b>IHS</b>	Indian Health Service	<b>RN</b>	Registered Nurse
<b>HPV</b>	Human Papillomavirus	<b>RPMS</b>	Resource Patient Management System
<b>ICC</b>	Intercultural Cancer Council	<b>SCF</b>	SouthCentral Foundation
<b>IOM</b>	Institute of Medicine	<b>SEARHC</b>	SouthEast Alaska Regional Health Consortium
<b>ISDEAA</b>	Indian Self-Determination and Education Assistance Act	<b>SEER</b>	Statistics, Epidemiology, and End Results
<b>KANA</b>	Kodiak Area Native Association	<b>ST</b>	Spit Tobacco (aka chewing tobacco)
<b>KSHV</b>	Kaposi's Sarcoma-associated Herpes Virus	<b>TCC</b>	Tanana Chiefs Conference
<b>LAF</b>	Lance Armstrong Foundation	<b>USPSTF</b>	U.S. Preventive Services Task Force
<b>MRI</b>	Magnetic Resonance Imaging	<b>UV</b>	Ultraviolet
<b>NAAP</b>	National Arthritis Action Plan	<b>YKHC</b>	Yukon-Kuskokwim Health Corporation
<b>NBCCEDP</b>	National Breast and Cervical Cancer Early Detection Program	<b>YRBS</b>	Youth Risk Behavior Survey
<b>NHANES</b>	National Health and Nutrition Examination 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](http://www.cancer.gov)

#### **American Cancer Society**

Cancer information and support services

1.800.227.2345

1.907.277.8696

[www.cancer.org](http://www.cancer.org)

### ACS SUPPORTED PROGRAMS:

#### **Cancer Survivors Network**

[www.acscsn.org](http://www.acscsn.org)

#### **I Can Cope**

[www.cancer.org](http://www.cancer.org)

#### **Look Good ... Feel Better**

[www.lookgoodfeelbetter.org](http://www.lookgoodfeelbetter.org)

#### **Reach to Recovery**

[www.cancer.org](http://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](http://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](http://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](http://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](http://www.lungusa.org)

#### **Angel Flight West**

Provides free flights for patients who can't afford transportation

1.888. 426.2643

[www.angelflight.org](http://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](http://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](http://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](http://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](http://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](http://www.hospiceworld.org)

**Kidney Cancer Association**

Educational material, support groups, and physician referral.  
1.800.850.9132  
[www.kidneycancerassociation.org](http://www.kidneycancerassociation.org)

**Susan G. Komen Breast Cancer Foundation**

People supporting people committed to fighting breast cancer  
1.800.462.9273  
[www.komen.org](http://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](http://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](http://www.leukemia-lymphoma.org)

**Living Beyond Breast Cancer**

Survivors Hotline, newsletters, publications, library and workshops helping women make choices about their health and well-being.  
610-645-4567  
[www.lbbc.org](http://www.lbbc.org)

**National Alliance of Breast Cancer Organizations (NABCO)**

Information and education resource for breast cancer  
1.888.806.2226  
[www.nabco.org](http://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](http://www.canceradvocacy.org)

**National Ovarian Cancer coalition**

Education, information, referral, and support for women and their families.  
1.888.682.7426  
[www.ovarian.org](http://www.ovarian.org)

**National Patient Travel Center**

Provides some free or discounted medical transport services  
1.800.296.1217  
[www.PatientTravel.org](http://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](http://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](http://www.ONCS.org)



**Oral Cancer Foundation**

On-line forum, message board, chat room for education, prevention and outreach.

949.646.8000

[www.oralcancerfoundation.org](http://www.oralcancerfoundation.org)

**Pancreatic Cancer Action Network**

Raises awareness of latest medical advances, support networks, clinical trials and reimbursement for care.

877-272-6226

[www.pancan.org](http://www.pancan.org)

**Patient Advocate Foundation**

Helps improve access to healthcare services

1.800.532.5274

[www.patientadvocate.org](http://www.patientadvocate.org)

**Prostate Cancer Foundation**

Printed resources for cancer survivors and their families.

800.757.2873

[www.prostatecancerfoundation.org](http://www.prostatecancerfoundation.org)

**Skin Cancer Foundation**

Increases public awareness about prevention and detection of skin cancer.

800-754-6490

[www.skincancer.org](http://www.skincancer.org)

**Starlight Starbright Children's Foundation**

Helps seriously ill children through in-hospital, outpatient, school, and home based programs and services free of charge to children adolescents, and their families.

800.274.7827

[www.slsb.org](http://www.slsb.org)

**Support for People with Oral, Head, and Neck Cancer**

Self help organization offering support group meetings, information, newsletters, and teleconferences. Survivor to survivor network.

800.377.0928

[www.spohnc](http://www.spohnc)

**Thyroid Cancer Survivors' Association, Inc.**

Services provided to survivors, caregivers, families and friends. E-mail support groups, person-to-person support, and survivor's telephone line.

877.588.7904

[www.uoa.org](http://www.uoa.org)

**US TOO! International, Inc.**

Support, counseling and education about prostate cancer

800.808.7866

[www.ustoo.org](http://www.ustoo.org)

**Y-ME National Breast Cancer Organizations, Inc.**

National hotline, early detection workshops, and support groups.

800.221.2141

[www.y-me.org](http://www.y-me.org)

**YWCA - ENCORE Plus Program**

Discussion and exercise program for women who have had breast cancer surgery.

1.907.644.9600

[www.ywcaak.org/health.htm](http://www.ywcaak.org/health.htm)

# APPENDIX 6

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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.