Cancer Among Northwest American Indians and Alaska Natives

Northwest Portland Area
Indian Health Board

FOREWORD

This report was developed in an effort to describe recent cancer patterns among the Northwest American Indian and Alaska Native (AI/AN) population. Our goal is to provide quality AI/AN surveillance data to inform public health programs and priorities.

The Northwest Portland Area Indian Health Board (NPAIHB) is a tribal organization governed by the 43 federally recognized tribes of Idaho, Oregon, and Washington. Tribal governments appoint a delegate to represent them on the board, which meets on a quarterly basis. The delegates guide the priorities and programs of the NPAIHB.

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Suquamish Long House

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BACKGROUND

American Indians and Alaska Natives (AI/ANs) in the Pacific Northwest and elsewhere may be uniquely affected by cancer due to a variety of factors, including lifestyle and environmental influences, socioeconomic conditions, and access to care issues. Timely, accurate data for the AI/AN population is often difficult to access due to small numbers of cases and under-counting of cases in central cancer registries. The Indian health care delivery system in the Northwest presents its own set of is barriers regarding access to cancer screening, diagnostic services, and treatment.

This report presents data on cancer patterns among AI/ANs residing in Idaho, Oregon, and Washington. We examined data from the area's three state cancer registries to describe a range of cancer measures from 1996-2007. Tribal leaders provided insights on cancer experiences within their communities, cancer care issues, and the role of traditional lifestyles.

METHODS

We analyzed data on cancer incidence, stage at diagnosis, incidence-based mortality, and trends for AI/ANs living in Idaho, Oregon, and Washington at the time of diagnosis. Data for years 1996-2007 were collected from the Cancer Data Registry of Idaho, the Oregon State Cancer Registry, and the Washington State Cancer Registry, after being corrected for misclassified race information through record linkages. Measures for the non-Hispanic white population (and in some cases, all races combined) were provided for comparison. 95% confidence intervals were calculated around incidence and mortality rates. County-level rates and rate ratios were calculated and presented in maps to show geographic variation across the region. We also collected prevalence estimates of screening coverage for colorectal, breast, and cervical cancer screening from the Indian Health Service (IHS) and state Behavioral Risk Factor Surveillance Systems.

RESULTS

Incidence

Using 2003-2007 data, we present leading sites, overall incidence rates, and site-specific rates for both sexes combined, and broken out by sex.

- The overall cancer incidence rate is significantly lower among Northwest AI/ANs compared to non-Hispanic whites (430 vs. 483 per 100,000 population, respectively).
- For both AI/ANs and non-Hispanic whites, lung and colorectal cancers lead new diagnoses for both sexes combined, and prostate and breast cancers are the most commonly diagnosed sites among males and females, respectively.

Cancer Screening and Stage at Diagnosis

Cancer screening prevalence measures are presented from two sources: 2010 IHS Government Performance and Results Act (GPRA), and state-based 2010 Behavioral Risk Factor Surveillance System (BRFSS) surveys. Cancer registry data were used to calculate stage at diagnosis distributions for colorectal, female breast, and cervical cancers.

- IHS GPRA results indicate that 38% of Indian Health Service, tribal, and urban Indian clinical patients received appropriate colorectal cancer screening in 2010; 38% of active female patients had a mammogram documented in the previous two years, and 56% of eligible female patients had a documented Pap test in the previous three years. These estimates are all below statewide figures for all races combined from Idaho, Oregon, and Washington BRFSS surveys.
- Compared to Northwest non-Hispanic whites, AI/ANs have lower proportions of localized (early) stage diagnoses for all three sites examined, and relatively more regional and distant (late) stage cancers diagnosed.

Mortality

Leading causes of cancer mortality and incidence-based mortality rates are presented for years 2003-2007 (among cases diagnosed 1996 and later), broken out by sex.

- The overall cancer mortality rate among AI/ANs is 202 per 100,000, which is significantly higher than the rate for non-Hispanic whites at 133 per 100,000.
- Compared to Northwest non-Hispanic whites, AI/ANs experience elevated mortality from lung, colorectal, prostate, and breast cancers.

Executive Summary

Trends

Annual incidence rates for 1996-2007 were plotted and annual percent change (APC) was calculated to describe if and how much rates changed over this period of time. The same approach was applied to incidence-based mortality rates for the period 2000-2007.

- For all sites combined, cancer incidence among AI/ANs decreased slightly but significantly over time, at an average rate of -1.4% per year. Rates among non-Hispanic whites remained relatively stable (APC = -0.2%, trend not significant). Prostate cancer incidence for AI/AN men decreased significantly and more rapidly than that for non-Hispanic white men, at -3.4% per year (vs. -0.8% for non-Hispanic whites).
- From 2000-2007, overall cancer mortality rates remained relatively stable for both AI/ANs and non-Hispanic whites. Lung cancer mortality decreased faster among AI/ANs than for non-Hispanic whites (significant trend of -4.6% per year, vs. -0.9%, respectively).

DISCUSSION

Many agencies do not report cancer data specifically on the AI/AN population, or race-specific numbers may be aggregated nationally where they are less meaningful for individual tribes and local program planning. This report provides comprehensive measures of AI/AN cancer burden at a regional level from cancer registries which have been routinely corrected for misclassified race. Ongoing cancer control efforts in the northwest have greatly increased the awareness of cancer in tribal communities. This report is meant to further that effort, by providing relevant and accessible data to inform and guide northwest tribes in the development of appropriate prevention, intervention, and research programs.

While incidence rates and patterns do not differ substantially between Northwest AI/ANs and non-Hispanic whites, screening, stage, and mortality measures are generally less favorable for AI/ANs. Recent trend data indicate that modest advances have been made in decreasing incidence and mortality among AI/ANs. The causes of the disparities seen in this report are complex and not thoroughly understood. However, cultural and language barriers, poverty, educational and employment opportunities, continuity of care in a fractured system, lack of insurance and access to care most certainly all play a role.

We offer a case study on cancer patient navigation as one promising method that can assist patients, families, and communities through the entire cancer experience. In tribal communities, navigators may touch upon all facets of cancer care, from prevention and screening through treatment, survivorship, and end-of-life care.

RECOMMENDATIONS

1. Promote increased collaboration and partnership between the Indian Health Service, tribes and tribal health programs, tribal epidemiology centers, research institutions, and other public health partners to translate these data into targeted, meaningful, and culturally-appropriate cancer control programs.
2. Increase cancer screening through culturally relevant education and outreach, clinical tracking system utilization, and decreased barriers to patients, including greater participation in state Breast and Cervical Cancer Early Detection programs. Promote increased training for health care providers in the latest screening recommendations and best practices.
3. Focus on prevention including smoking prevention and cessation and lifestyle modification. Policy and programs promoting wellness and prevention should be holistic and comprehensive, with a multi-disciplinary approach.
4. Develop and implement clinical tracking systems for cancer screening, diagnostic, and treatment follow-up to improve clinical quality and continuity of care and to enable increased surveillance of patient outcomes.
5. Continue meaningful partnerships with state cancer registries to ensure data quality, accessibility, and ongoing surveillance to inform tribal cancer control efforts.

Canoe Journey 2007 "Paddle to Lummi" - Lummi Nation

SECTION I: BACKGROUND

Introduction

"Coming through these doors is a very, very big step for a lot of our people. This is not really within our cultural realm to talk about things like this."

Stella Washines, Tribal Council, Yakama Nation, Washington

Courtesy: 2002 President's Cancer Panel

Most Native languages do not have a word for *cancer*. In many tribal communities, cancer experiences have only recently been acknowledged and discussed openly. Fish, game, roots, and berries native to the region remain important to the diets of many tribal people, but mining and agricultural operations have raised concerns about heavy metals and other contaminants potentially raising cancer risk[1]. Lifestyle factors such as commercial tobacco use, alcohol use, sedentary lifestyle, and obesity contribute to unequal cancer burden among American Indians and Alaska Natives (AI/ANs). In the Pacific Northwest and elsewhere, AI/ANs are more likely to report that they have no usual source of health care[2].

Figure 1 - Portland Area Tribes
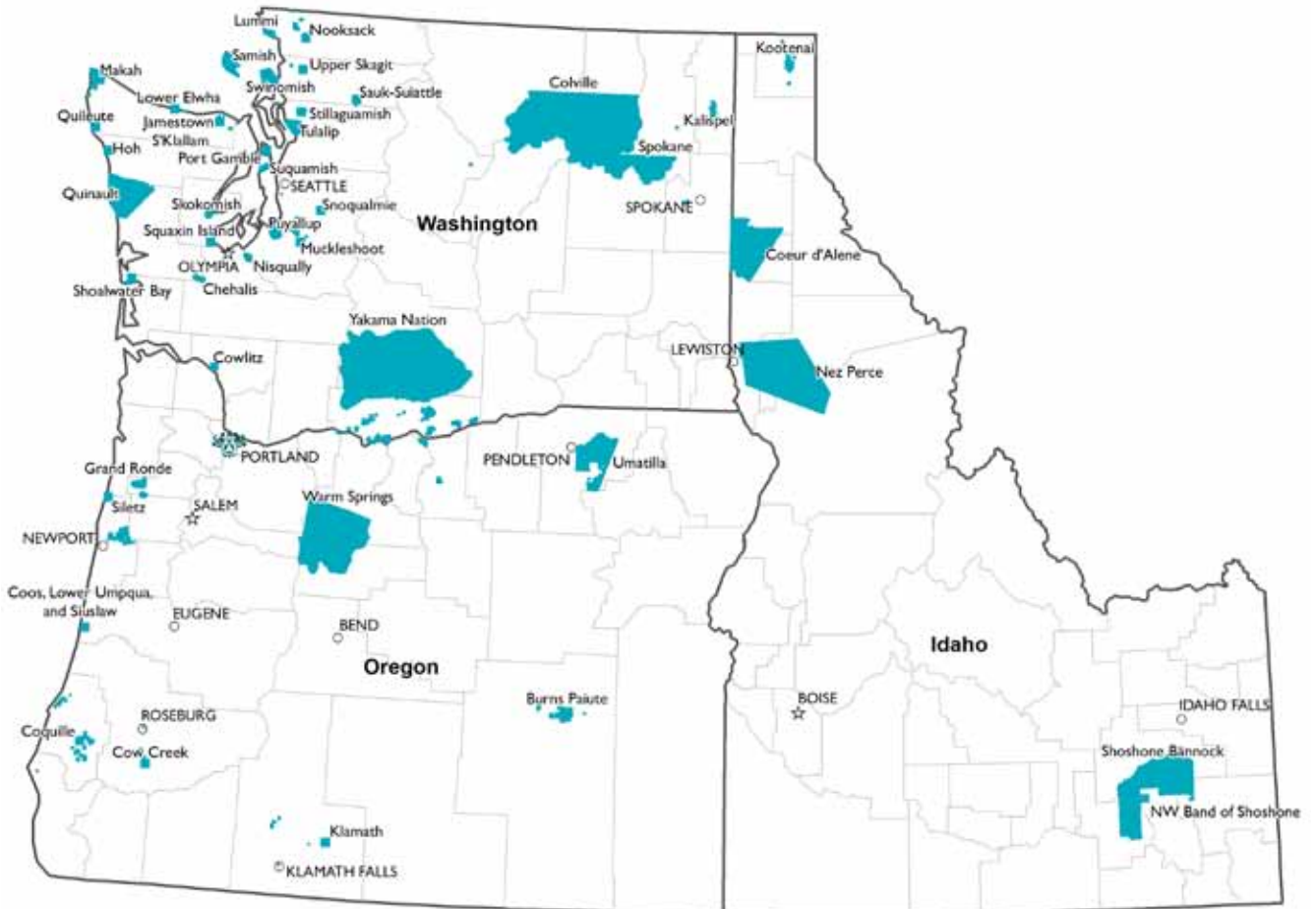
Northwest AI/AN Population

The Pacific Northwest is home to 43 federally-recognized tribes: five in Idaho, nine in Oregon, and twenty-nine in Washington (Figure 1). Tribes range in size from a few hundred to over 9,000 members. According to 2008 census estimates, AI/ANs comprise about 1.7% of the state population in both Idaho and Oregon, and 1.9% of Washington's population. Approximately 6.4% of the nation's AI/AN population resides in this three-state region[3].

Many tribal lands in the Northwest are located in remote areas with limited economic opportunities, education options, and access to hospitals where cancer-related screening, diagnostic, and treatment services are centered. More AI/ANs now live in urban areas than rural locations (Figure 2), but urban Indians experience their own unique set of health care barriers[4]. AI/ANs living in both rural and urban areas continue to experience lower education levels, greater poverty, and poorer health status than their counterparts of other races and ethnicities[2].

Figure 2 - AI/AN population by county
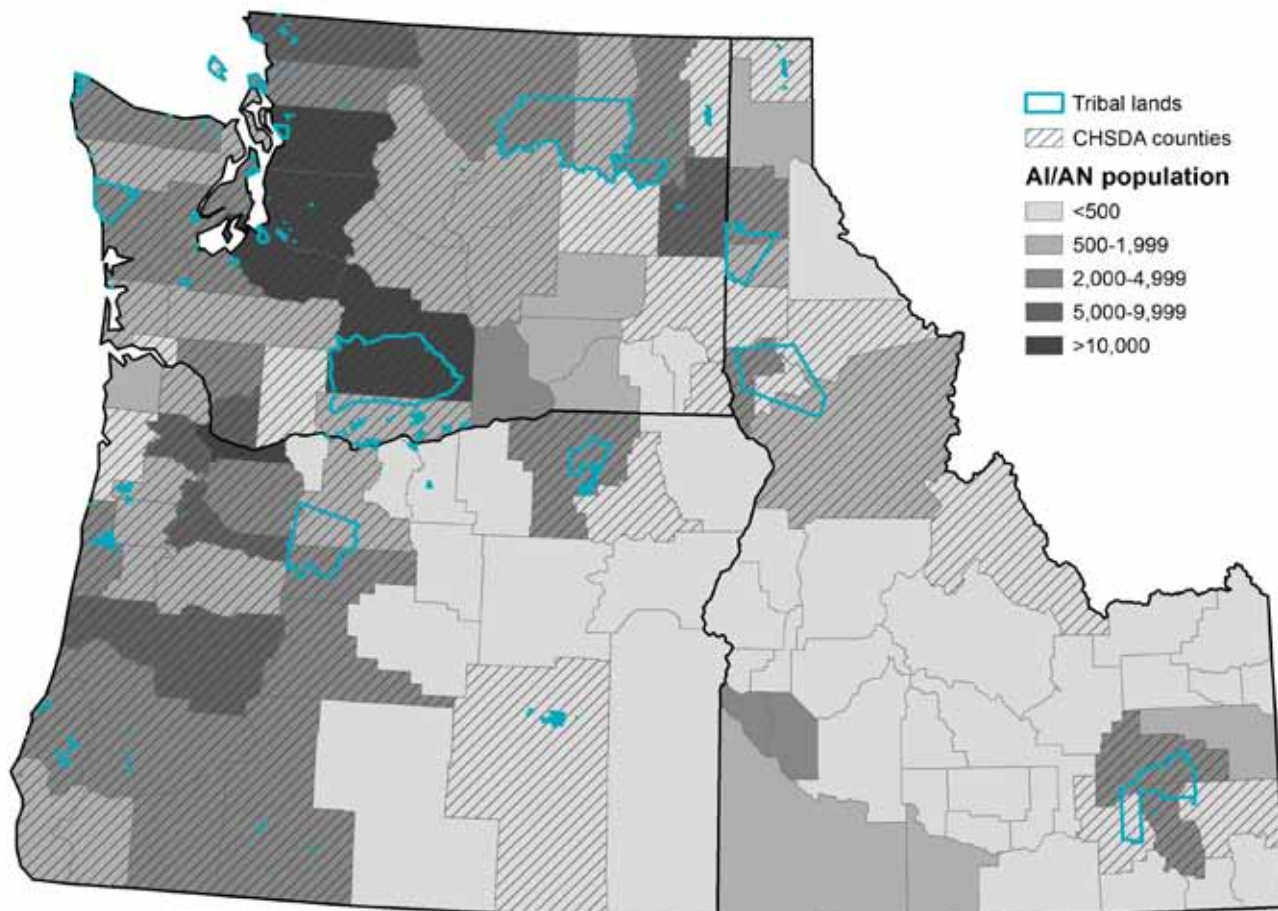
CHSDA = Contract Health Service Delivery Area
Data source: National Center for Health Statistics bridged-race population estimates, 2008.

Northwest Indian Health Care System

"Access to health care and the cancer centers is a barrier. The system for getting there is complicated and cumbersome."

Andy Joseph, Jr.,
Colville Tribal Business Council,
NPAIHB Chairman

The Indian health care delivery system in the Northwest is comprised of a combination of Indian Health Service (IHS) direct service clinics, tribally operated programs, and three urban Indian clinics (collectively referred to as I/T/U programs). Clinical services vary widely by tribe; some tribes have only a single medical provider available once or twice per week, while others offer complete ambulatory and public health services, including lab, dental, optical, and pharmacy on-site. A few tribes have no direct clinical services at all, and instead contract out all health care for their members. All I/T/U facilities in the Northwest provide only outpatient care. No inpatient centers within the Indian health system exist in this region where AI/AN patients could receive cancer-related diagnostic, treatment or surgical services. Specialty services not provided by a given facility may be purchased in the private sector through the Contract Health Services (CHS) program. However, strict limitations are generally placed on CHS eligibility due to severely limited funds[5].

Racial Misclassification and Record Linkages

American Indians and Alaska Natives are frequently misclassified as another race in cancer registries, resulting in under-counting of cancer cases and deaths; this yields spuriously low reported incidence and mortality rates. Racial misclassification can occur when assumptions are made based on appearance, or when a friend of family member supplies this information on behalf of the patient. Patients may also choose to not self-report AI/AN race due to fear of racism, or because they associate with multiple race groups. Data collection and health facility intake staff may be hesitant to ask people to identify their race. Because cancer registries generally rely on medical or death records to complete race and ethnicity information, it is often unknown how that information was originally collected. In various Northwest disease registries, racial misclassification of AI/ANs can range from 15-50%[6].

One way that racial misclassification can be addressed is through record linkages. The Northwest Tribal Epidemiology Center (the EpiCenter) conducts regular linkages with a range of disease surveillance systems, by matching a list of known AI/ANs – the "Northwest Tribal Registry", derived from Indian Health Service, tribal, and urban clinic registration lists – to identify AI/ANs in those registries who are incorrectly coded as another race or missing race information altogether. Since 2003, cases of racial misclassification identified through linkages with the state cancer registries of Idaho, Oregon, and Washington have been reported back to them so that the state data can be corrected. The correction of AI/AN race data is widely supported by both tribal health leaders and our state partners, and is seen as an important step toward improving the quality and availability of health data for Northwest tribal people.

Disparities

"I think that the next time the decision makers...decide they are going to go to their doctor, I think we should put them all on a deferred or on a waiting list for 90 days and let them sit at home and worry about it. Let them feel that lump for 90 days....Maybe you want to go into town for a regular routine physical. Put yourself on a six month waiting list....The next time you want to go to the dentist, wait a year."

Bob Brisbois, Executive Director,
Spokane Tribe of Indians

Courtesy: 2002 President's Cancer Panel

Health disparities are loosely defined as inequalities in health between different groups of people. Disparities may include differences in how many people in a group develop a certain health condition, or how often a disease results in death. Racial and ethnic health disparities are more than mere differences; they are generally viewed as an issue of social justice, representing unfair and unwarranted inequities. The elimination of racial and ethnic health disparities was highlighted in January 2000 as an overarching priority of Healthy People 2000, a national initiative of the Department of Health and Human Services (DHHS)[7]. National health improvement objectives continue to focus on eliminating disparities.

In this report, we present data to compare AI/ANs to non-Hispanic whites, the most common race/ethnicity group in the Pacific Northwest. For most conditions, the non-Hispanic white population has better health status than other races and ethnicities, thus this is a common comparison population chosen when examining health disparities.

Regional Variation

Most data presented in this report are aggregated from cases reported in Idaho, Oregon, and Washington. Cancer patterns may vary by state or by smaller geographic region such as individual tribal groups. For example, cancer incidence rates for AI/ANs in Idaho are substantially lower than AI/AN rates in Oregon and Washington. However, the goal of this report is to describe the region as a whole, rather than to focus on these differences. State- and tribal-level data are available in several other reports produced by the Northwest Portland Area Indian Health Board[8-9].

Some data in this report are presented at the county level (Figures 9-10, 21-22), to show some of the regional variation across the three-state area. Note that these measures do not directly represent the membership of any particular tribe or reservation because they include all AI/ANs (regardless of tribal affiliation) residing in a particular county at the time of diagnosis or death. However, data for counties located near or on reservations may correlate closely with cancer patterns for those tribal communities. It is important for tribal leaders and community members to apply their own knowledge of their communities in considering how well these data represent their populations.

Quinault Rainforest, Olympic National Park, Washington

SECTION II: INCIDENCE

Incidence is a measure of how frequently a disease occurs in a population. An incidence rate is the number of new cases in a specified population over a period of time, usually one year. It is usually expressed "per 100,000" population per year. A cancer incidence rate of 500 can be interpreted as "if you followed 100,000 people in this population for one year, you can expect about 500 of them to develop cancer."

$$Incidence\ rate = \frac{New\ cancers}{Population\ at\ risk} \times 100{,}000$$

The risk of developing cancer increases with age, so if one population contains relatively more older people than another population, their cancer rates would not be comparable (the older population's rate would look much higher). In this report, all incidence rates are **age-adjusted** to the 2000 U.S. standard population in order to remove the effects of different age distributions. This allows for a more direct comparison of rates between different populations.

Methods

"I have seen the face of cancer change over time in my community. When I first started working with Suquamish people about 9 years ago the cancer cases all involved tribal elders. Since then, it seems to be mostly people in their 30's and 40's who are being diagnosed with cancer. Also, I first saw liver cancers, but now there are different cancers, and no two people have the same diagnosis. Genital, pancreatic, jaw, throat, breast, colorectal and brain are the most recent cases that I can recall."

Leslie Wosnig,
Health and Policy Administrator,
Suquamish Tribe,
NPAIHB Delegate

The following cancer incidence data were collected from the state cancer registries of Idaho, Oregon, and Washington. Each of these registries is a member of the National Program of Cancer Registries (NPCR) and adhere to data quality standards set by the North American Association of Central Cancer Registries (NAACCR). Prior to analysis, each registry was matched to the Northwest Tribal Registry to identify racially misclassified AI/AN cases (see Background, p. 13). Analyses also include cases identified as AI/AN by the cancer registry, whether or not they were contained in the Northwest Tribal Registry.

Five years of data were combined for most estimates (2003-2007). Two maps at the end of this chapter present county-level incidence rates, and for these we combined 8 years of data (2000-2007) in an attempt to obtain a greater number of cases for analysis. Even still, many counties had very few AI/AN cases. Rates based on fewer than 5 cases are not presented (suppressed), and those based on fewer than 10 cases are shaded to indicate that the rate is particularly unstable (i.e., apparent differences may be a result of random fluctuation, rather than true variation).

Cancer sites were coded and grouped according to standard methods presented in the Surveillance Epidemiology and End Results (SEER) site recode for ICD-O-3 definition (Appendix F). Following current standards in cancer reporting, we only present data on invasive cases, with the exception of urinary bladder (where *in situ* cases are also included). **Invasive** refers to cancer that has spread beyond the layer of tissues in which it developed, versus ***in situ*** (or non-invasive) cancer, in which the cancer cells are found only in the place where they first formed. National Center for Health Statistics bridged-race population estimates 2003-2007 were used for population-at-risk denominators[3]. All rates were age-adjusted to the 2000 U.S. standard population.

Data Summary

Fig. 3 - Most commonly diagnosed cancers among Northwest AI/ANs of both sexes, 2003-2007

Cancer Site	Percent of cases
Lung & Bronchus	14.7%
Colorectal	10.7%
Non-Hodgkin Lymphoma	4.8%
Kidney & Renal Pelvis	4.4%
Bladder	3.2%
Oral Cavity & Pharynx	2.9%
Liver	2.8%
Pancreas	2.7%
Thyroid	2.4%
Leukemia	2.2%
Stomach	2.2%
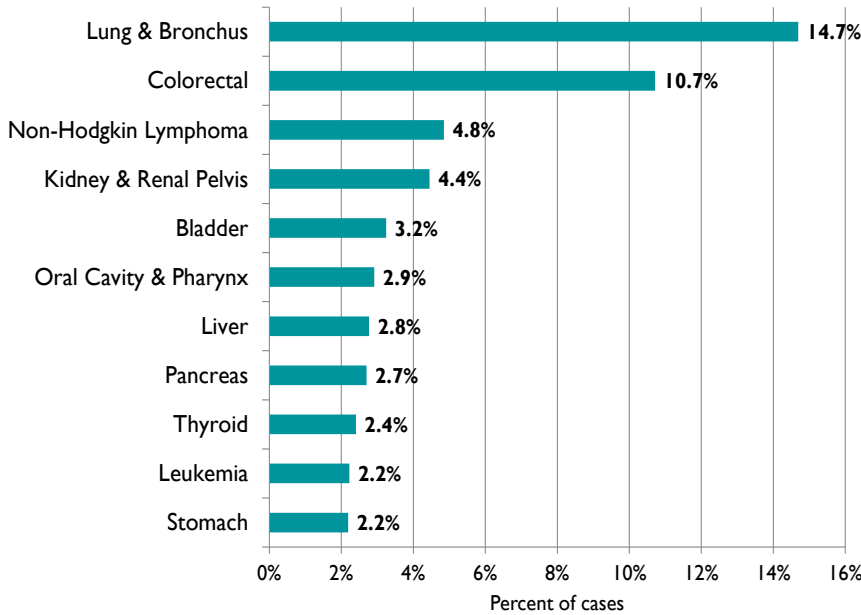
Figure 3 displays the most commonly diagnosed cancer sites among the Northwest AI/AN population for both sexes combined (sex-specific sites such as prostate and breast are excluded). Lung cancer is the most common, comprising 14.7% of newly diagnosed cases.

For all sites combined, the average annual cancer incidence rate for Northwest AI/ANs is 430 per 100,000, which is significantly lower than the non-Hispanic white rate of 483 per 100,000. Figure 4 shows incidence rates for the five leading cancer sites for AI/ANs and non-Hispanic whites. Lung and colorectal cancer rates among AI/ANs are slightly higher than corresponding site-specific rates for non-Hispanic whites, while the rate of bladder cancer is somewhat lower for AI/ANs.

Fig. 4 - Age-adjusted cancer incidence rates, selected sites, Northwest AI/ANs and non-Hispanic whites (NHW), 2003-2007

Site	AI/AN	NHW
Lung & Bronchus	72.1	66.9
Colorectal	48.8	44.2
Non-Hodgkin Lymphoma	21.5	21.2
Kidney & Renal Pelvis	17.3	14.2
Bladder	14.1	23.0

Rate per 100,000

Data Summary

Fig. 5 - Most commonly diagnosed cancers among Northwest AI/AN males, 2003-2007
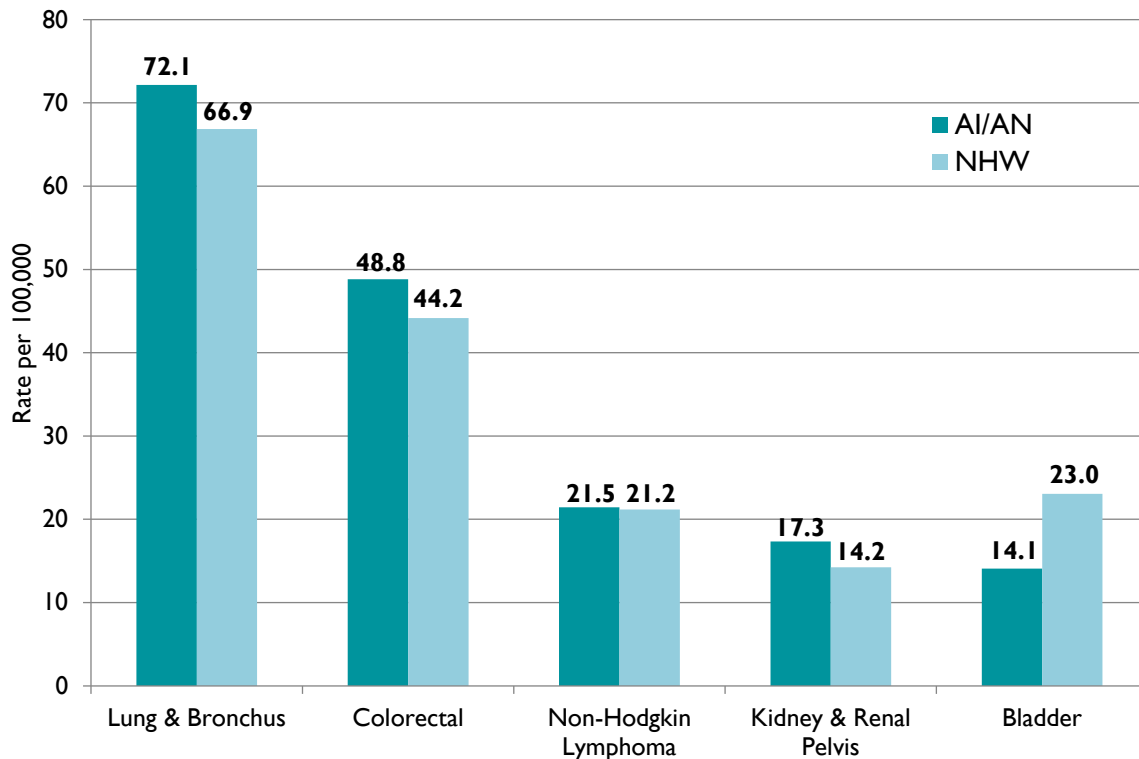
Cancer Site	Percent of cases
Prostate	21.7%
Lung & Bronchus	14.8%
Colorectal	12.0%
Non-Hodgkin Lymphoma	5.8%
Kidney & Renal Pelvis	5.6%
Bladder	5.2%
Oral Cavity & Pharynx	4.0%
Liver	3.9%
Stomach	2.7%
Leukemia	2.7%
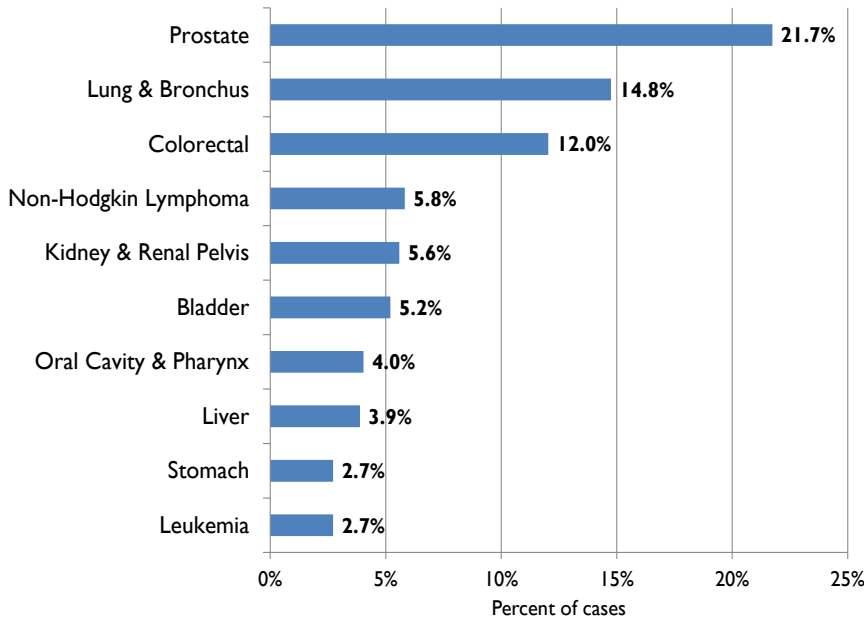
Figure 5 shows leading incident cancer sites for AI/AN men. Figure 6 displays incidence rates for leading sites among males with comparisons to rates for non-Hispanic white males. The overall cancer incidence rate for AI/AN males is 454 per 100,000, which is significantly lower than the rate for non-Hispanic white males (548 per 100,000). Prostate cancer leads diagnoses in men (21.7% of new cases), followed by lung and colorectal cancers (14.8% and 12.0%, respectively).

Although it is the number one site, the rate of prostate cancer among AI/AN males is substantially lower than the rate for non-Hispanic whites. AI/AN males have a slightly increased rate of colorectal cancer, while lung, lymphoma, and kidney cancer rates are similar between the two populations.

Fig. 6 - Age-adjusted cancer incidence rates, selected sites, Northwest AI/AN and non-Hispanic white (NHW) males, 2003-2007

Site	AI/AN	NHW
Prostate	106.0	154.1
Lung & Bronchus	76.9	76.4
Colorectal	59.6	50.7
Non-Hodgkin Lymphoma	24.2	25.7
Kidney & Renal Pelvis	21.9	18.9

Rate per 100,000

Data Summary

Fig. 7 - Most commonly diagnosed cancers among Northwest AI/AN females, 2003-2007

Cancer Site	Percent of cases
Breast	27.4%
Lung & Bronchus	14.6%
Colorectal	9.6%
Endometrium	5.6%
Non-Hodgkin Lymphoma	4.0%
Thyroid	3.6%
Kidney & Renal Pelvis	3.4%
Cervix	2.9%
Pancreas	2.8%
Melanoma of the Skin	2.4%
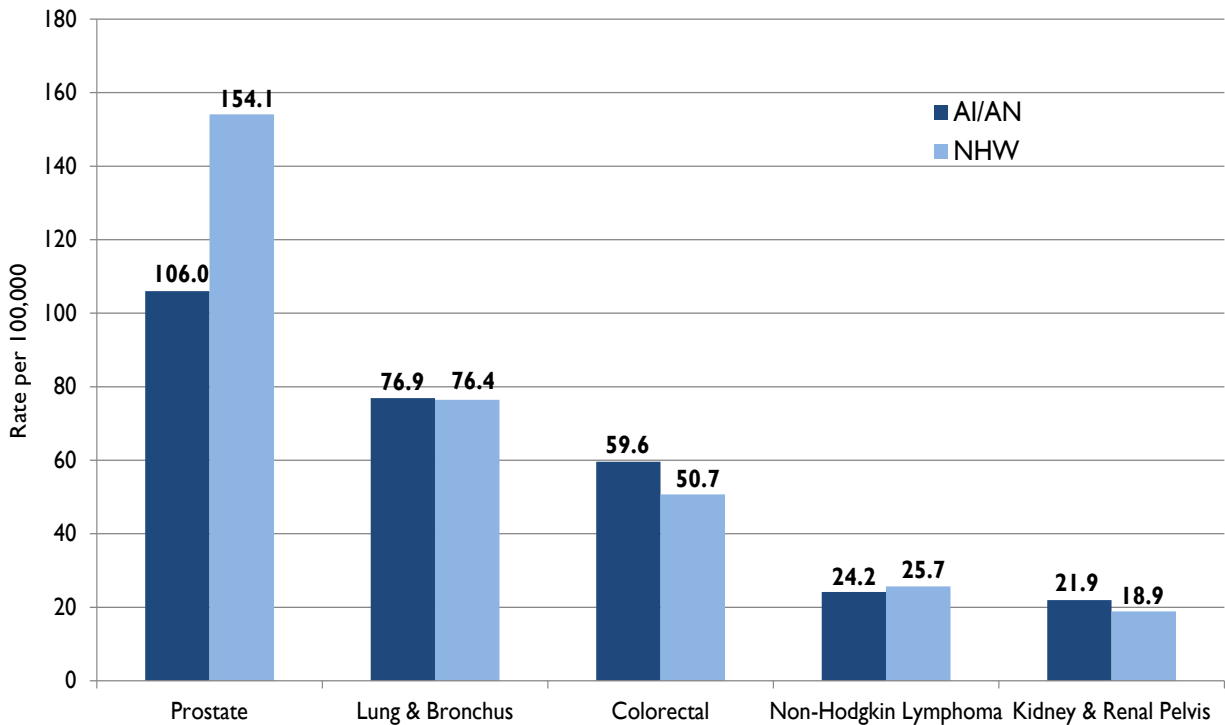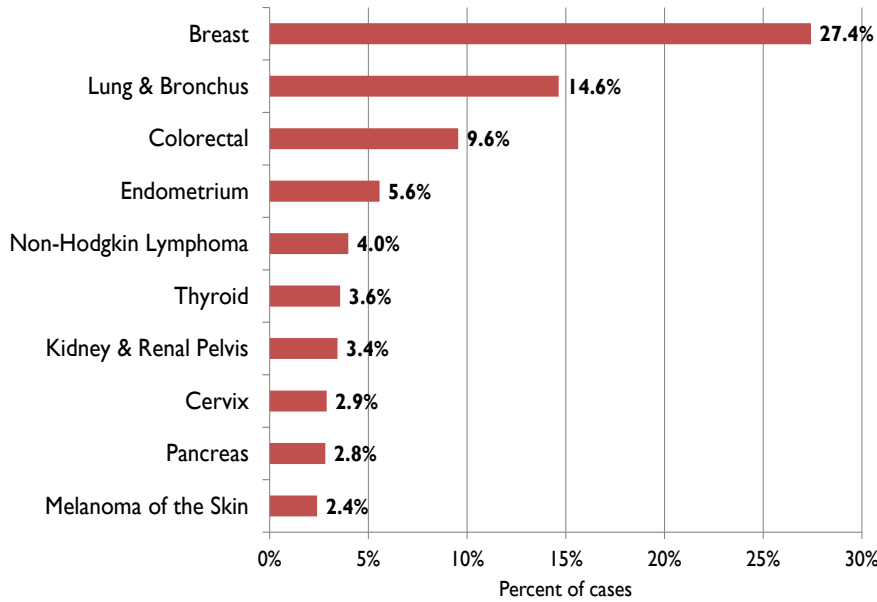
Figure 7 shows leading cancer sites among AI/AN women, and Figure 8 displays the incidence rates of leading sites and how they compare with non-Hispanic white females. The overall cancer incidence rate for Northwest AI/AN females is similar to the rate for non-Hispanic white females (416 vs. 436 per 100,000, respectively). Breast cancer represents over one in four cancers diagnosed in AI/AN women (27.4%). Lung (14.6%) and colorectal (9.6%) cancers are the second and third most common sites, respectively.

The breast cancer rate is lower among AI/AN women compared to non-Hispanic whites. The rate of female lung cancer rate is slightly higher, while colorectal, endometrial, and lymphoma rates are similar between the two groups.

Fig. 8 - Age-adjusted cancer incidence rates, selected sites, Northwest AI/AN and non-Hispanic white (NHW) females, 2003-2007

Site	AI/AN	NHW
Breast	104.1	130.5
Lung & Bronchus	70.1	60.0
Colorectal	41.2	38.7
Endometrium	22.1	23.6
Non-Hodgkin Lymphoma	18.8	17.5

Rate per 100,000

Data Summary
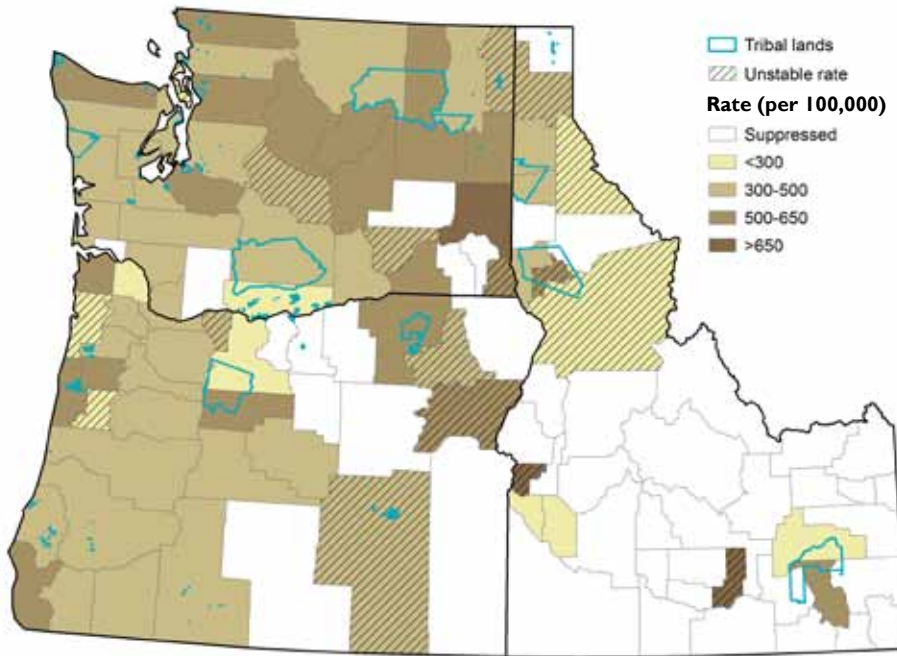
Figure 9 shows all-site cancer incidence rates by county of residence at the time of diagnosis. The highest rates can be seen across parts of central and eastern Washington, and lower rates on average in much of Idaho.

Figure 10 displays the ratio of AI/AN all-site incidence rates for each county compared to the statewide rate for all races combined. This measure answers the question "is the AI/AN rate in this county higher or lower than the state average for all people?" For the majority of counties, the AI/AN rates are similar to statewide rates (light yellow shading). Four counties have significantly lower rates (green shaded counties with asterisks), and seven counties, mostly in Washington, have significantly higher rates (red shading with asterisks).

Fig. 9 - AI/AN cancer incidence rates by county of residence, all sites combined, 2000-2007

Fig. 10 - Cancer incidence rate ratios: AI/ANs compared to statewide average for all races combined, 2000-2007
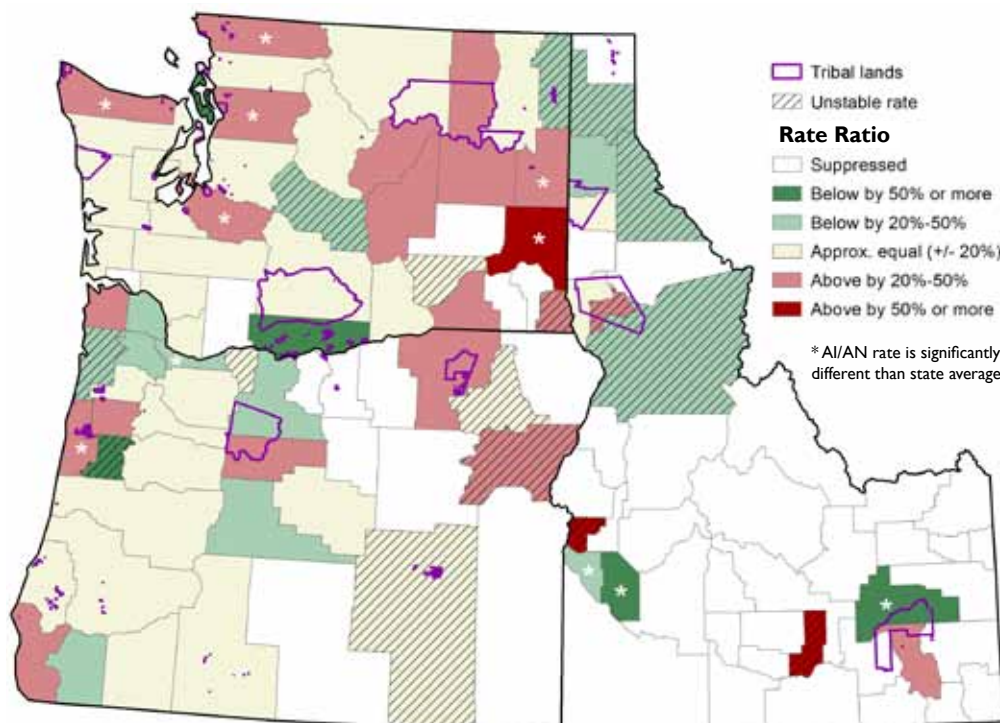
Umatilla Rock, Dry Falls, Grand Coulee, Washington

SECTION III: CANCER SCREENING / STAGE AT DIAGNOSIS

Cancer screening tests are designed to detect cancer at an early stage, before symptoms appear. The primary purpose of screening is early detection – the possibility of finding cancer at an early stage, when it is easier to treat or cure. Effective screening tests:

- Find cancer before there are symptoms
- Screen for a cancer that is easier to treat and cure when found early
- Have few false-negative and false-positive results
- Reduce the likelihood of dying from cancer

By these criteria, not all cancers are ideal for screening, and for many other cancers, an appropriate screening test does not exist. The most common screen-detectable cancers are breast, cervical, colorectal, and prostate.

Cancer staging is used to describe the extent to which a cancer has spread in a patient's body, and is often used as a way to assess prognosis (the probable outcome of the disease). Cancers that have not spread beyond the local organ are ge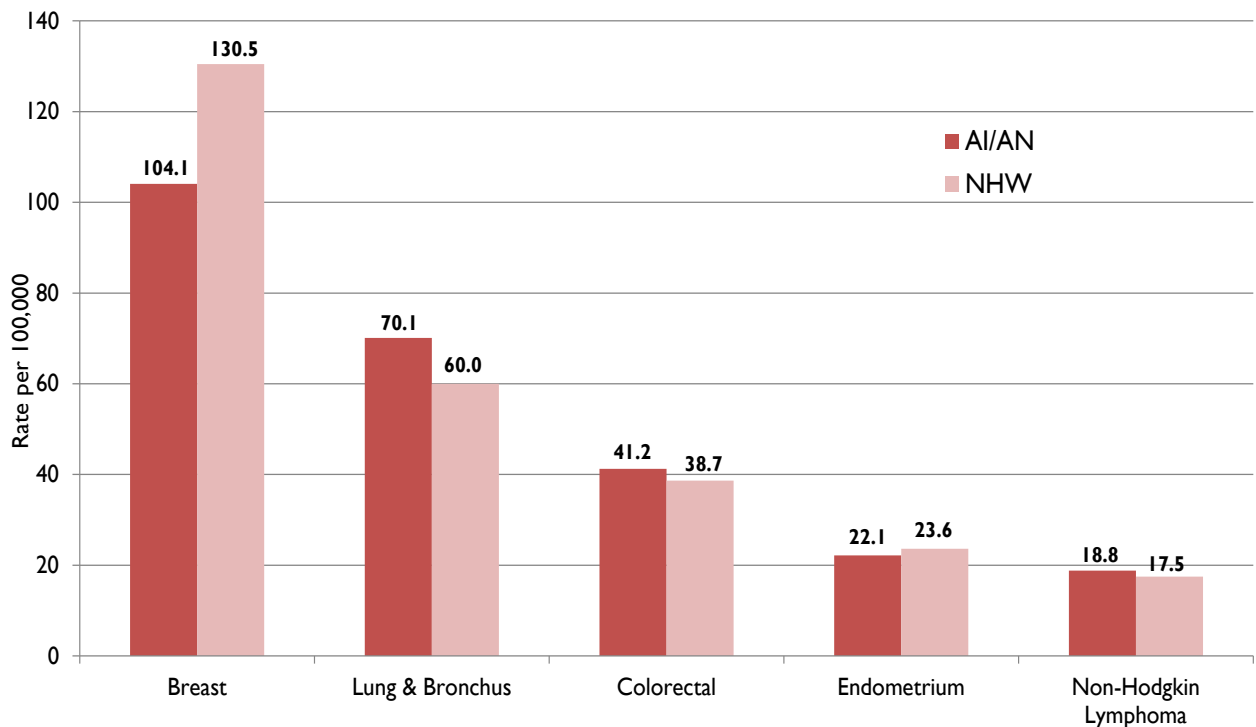nerally more treatable, with a better prognosis. Cancers that have divided and spread beyond the primary site (called metastasis) are likely to have a poorer outcome for the patient.

In this report we present cancer screening and stage at diagnosis data for three cancer sites – breast, cervical, and colorectal. All three of these sites have effective screening tests and there are generally agreed-upon national recommendations on who should be screened and how often. Although an inexpensive screening test also exists for prostate cancer - the Prostate Specific Antigen (PSA) test - the evidence is insufficient to conclude that it is effective in preventing deaths; thus screening and staging data for prostate cancer are not presented in this report.

Methods

Screening
The screening information in this report is collected from two sources: Government Performance and Results Act (GPRA) measures reported for the Portland Area by the Indian Health Service, and Behavioral Risk Factor Surveillance System (BRFSS) survey results from each Northwest state. The GPRA measures provide a clinic-based estimate of screening coverage for the Northwest AI/AN population that receives health care through I/T/U facilities. BRFSS estimates the prevalence of screening in the general population through self-reported survey responses. Because of the differences in data collection methods and the specific questions asked, the results are not directly comparable. Below we describe the two data collection systems in more detail.

The Government Performance and Results Act requires federal agencies to show that they are using their funds effectively toward meeting their missions. Each agency sets its own priorities and goals for improving performance, and develops its own measures to assess progress. The following cancer screening measures and definitions are used by the IHS to assess how well clinics are doing at providing recommended screening tests to appropriate patients[10].

"I have made a public challenge at the NPAIHB board meetings for my brothers and sisters over 50 to get their colonoscopy screening. I called them out and asked for a show of hands for those over 50 – and those who have been screened. I felt good about doing this because I have had my screening; you just have to make the appointment and go and do it."

Andy Joseph, Jr.,
Colville Tribal Business Council,
NPAIHB Chairman

- *Cervical Cancer Screening* - Proportion of female active clinical patients ages 21-64 with a documented Pap test within the past three years.
- *Breast Cancer Screening* - Proportion of female active clinical patients ages 52-64 with a documented mammogram within the past two years.
- *Colorectal Cancer Screening* - Proportion of active clinical patients ages 51-80 with any of the following colorectal cancer screenings documented: Fecal Occult Blood Test (FOBT) or Fecal Immunochemical Test (FIT) during the report period; flexible sigmoidoscopy or double contrast barium enema in the past five years; or colonoscopy in the past ten years.

Screening services that patients receive at other (non-I/T/U) facilities are often not recorded in their I/T/U medical record; thus, many GPRA measures may under-report of the actual screening coverage of the AI/AN population.

The BRFSS is a state-based system of health surveys funded by CDC that collects information on health risk behaviors, preventive health practices, and health care access. It is a telephone survey conducted among adults in all 50 states, and is statistically weighted to make the results generalizable to the whole population. The three cancer screening measures that we use in this report are based on the following definitions:

- *Cervical Cancer Screening* - Proportion of women ages 18+ who have had a Pap test within the past three years.
- *Breast Cancer Screening* - Proportion of women ages 50+ who have had a mammogram within the past two years.
- *Colorectal Cancer Screening* - Proportion of adults ages 50+ who have ever had a sigmoidoscopy or colonoscopy.

Stage at diagnosis

Cancer stage information in this report was coded according to the SEER Summary Staging 2000 guidelines, which is the method used by all state cancer registries for tumors diagnosed since 2001[11]. In this system, stage at diagnosis can be defined with these general categories:

- *Localized* cancer is limited to the organ in which it started and has not spread beyond it
- *Regional* cancer has spread beyond the primary organ to nearby organs, tissues, or lymph nodes
- *Distant* cancer involves cells that have broken away from the primary tumor, spread to other parts of the body, and have begun to grow at the new location
- *Unstaged* or *unknown* is coded when there is not enough information to indicate a stage

The stage at diagnosis data in this section are restricted to the sex and age groupings to which current screening guidelines apply: men and women ages 50 and older for colorectal cancer, and women ages 50 and older for breast cancer. Cervical cancer screening is recommended for women starting about three years after first intercourse but no later than age 21[12]. For cervical cancer stage-at-diagnosis measures, we include all ages because very few cases were diagnosed in women under age 20.

Data Summary

Fig. 11 - Prevalence of cancer screening, IHS GPRA and state BRFSS surveys, 2010
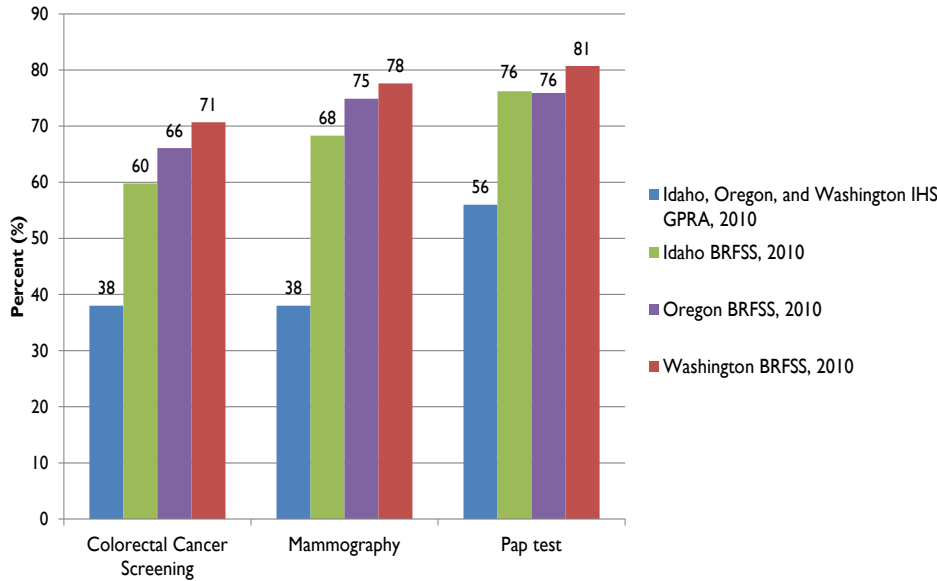
See p. 26 for definitions.
Data sources: IHS Area Summary Report, GPRA 2010[13]; CDC BRFSS data online, 2010[14]

Fig. 12 - Colorectal cancer (ages 50+) stage at diagnosis, Northwest AI/ANs and non-Hispanic whites (NHW), 2003-2007
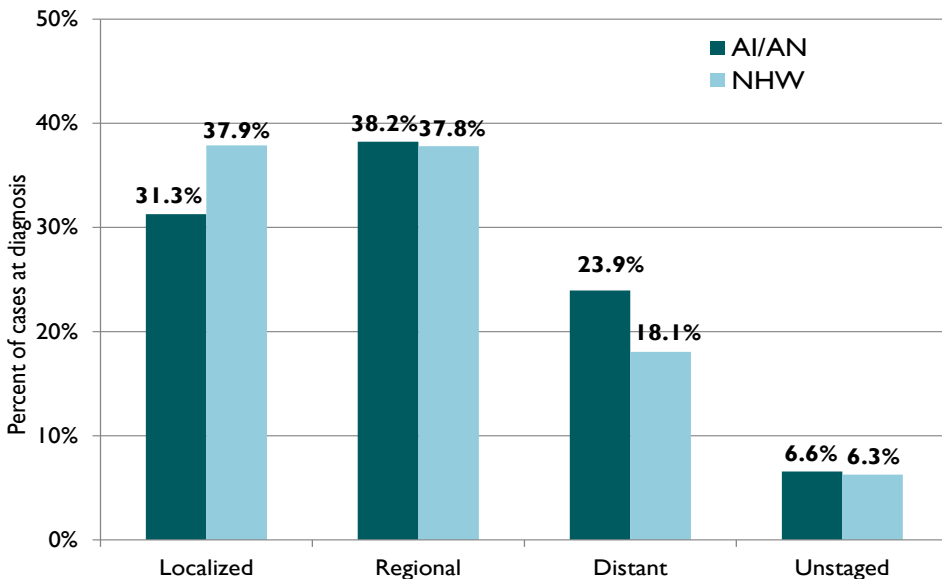
Figure 11 presents cancer screening prevalence figures for Northwest I/T/U patients and the general populations of Idaho, Oregon, and Washington. Fewer than 40% of active IHS patients received appropriate colorectal screening in 2010 (38%), and the same proportion of women had documented mammography within the past two years. Cervical cancer screening was somewhat higher (56%), though still relatively below state-level numbers for all races combined. Self-reported results from statewide BRFSS surveys show higher cancer screening coverage for all sites in the general population. However, it is important to keep in mind that the numbers are not directly comparable between the two systems due to different collection methods. This is particularly true for the colorectal screening measure, where the definitions differ substantially.

Figures 12, 13 and 14 show that Northwest AI/AN cancer patients tend to be diagnosed at later stages than their non-Hispanic white counterparts. For colorectal cancer (Fig. 12), only 31.3% of AI/AN cases are diagnosed as localized, versus 37.9% in non-Hispanic whites. Regional stage diagnosis percentages are similar, but the percentage of later stage distant cancers are higher among AI/ANs, at 23.9%, versus 18.1% for non-Hispanic whites.

Data Summary

SECTION III: STAGE AT DIAGNOSIS / CANCER SCREENING

Fig. 13 - Breast cancer (ages 50+) stage at diagnosis for Northwest AI/AN and non-Hispanic white (NHW) females, 2003-2007
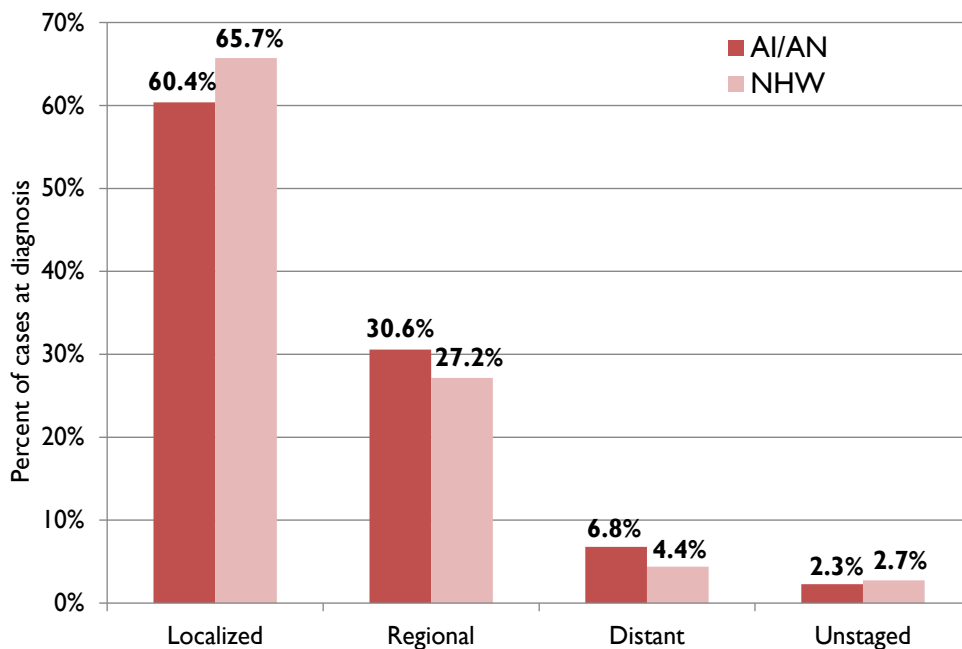
Breast cancer diagnoses among AI/ANs are also generally made at later stages (Fig. 13), although the disparities are not as pronounced as with colorectal cancer (Fig. 12). Approximately 60% of breast cancer diagnoses for AI/AN women are localized versus 65.7% for non-Hispanic whites. Percentages for both regional (30.6% vs. 27.2%) and distant (6.8% vs. 4.4%) cancer diagnosis are slightly higher among AI/AN women.

Fig. 14 - Cervical cancer (all ages) stage at diagnosis for Northwest AI/AN and non-Hispanic white (NHW) females, 2003-2007
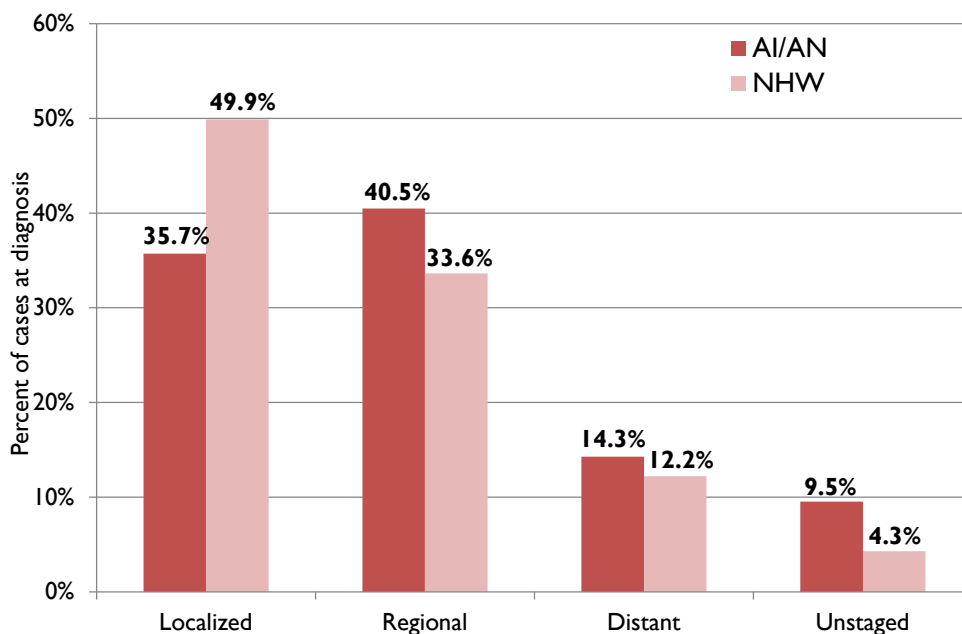
Cervical cancer diagnoses also occur later among AI/AN women than among non-Hispanic whites (Fig. 14). While nearly half of all cervical cancers among non-Hispanic whites are localized at diagnosis, only 35.7% of AI/AN women are diagnosed at this early stage. AI/ANs have higher percentages than non-Hispanic whites for both regional (40.5% vs. 33.6%) and distant (14.3% vs. 12.2%) stage cervical cancer.

Mt. Rainier, Washington

SECTION IV: MORTALITY

Mortality, or the death rate, is a population-level measure of the risk of dying from a certain condition. Mortality is an important statistic used to assess the effectiveness of secondary prevention programs (such as cancer screening). A mortality rate is a calculation of the number of deaths occurring in a specified population over a period of time, usually one year. Like incidence rates, mortality is usually expressed "per 100,000" population per year.

$$\textit{Incidence based mortality rate} = \frac{\textit{Cancer deaths}}{\textit{Population at risk}} \times \textit{100,000}$$

This report presents **incidence-based mortality**, using information collected by the three state cancer registries. Cancer registries collect information on cancer patients who have died from hospital reports and death certificates, and this information is associated with factors about the cancer onset (such as primary site and stage at diagnosis). Thus, each death in this report is associated with a person who was included in the cancer registry.

As is the case with incidence, the risk of dying from cancer increases with age, so it is important to age-adjust mortality rates to a standard population in order to accurately compare two different groups of people.

Methods

"The only statistic I was given to bring here is out of the last 40 deaths in Warm Springs, 15 of them [37.5%] were due to cancer...we are catching them too late...our people need to understand that. The way to help them to understand that is to increase awareness...."

Judith Charley, Community Health Information Specialist, Warm Springs Tribe, Oregon

Courtesy: 2002 President's Cancer Panel

Incidence-based mortality data were collected from the state cancer registries of Idaho, Oregon, and Washington. Prior to analysis, each registry was matched to the Northwest Tribal Registry to identify racially misclassified AI/AN cases (see Background, p. 13). Each cancer registry had also completed linkages with state death certificates to record information on cancer patients who had died. Analyses include cases identified as AI/AN by the cancer registry and those that matched with the Northwest Tribal Registry.

Mortality calculations include patients in the cancer registry with cancer indicated as the cause of death and date of last follow-up between 2003 and 2007. Incidence-based mortality was only calculated for those cases where there was a primary cancer diagnosed in 1996 or later, since this was the earliest year of incidence data available in all three state registries. Two maps at the end of this chapter present county-level mortality rates, and for these we combined 8 years of data (2000-2007) to obtain greater numbers for analysis. Many counties had very few AI/AN cancer deaths; rates based on fewer than 5 cases are not presented (suppressed), and those based on fewer than 10 cases are shaded to indicate that the rate is particularly unstable.

Cancer deaths were coded and grouped using SEER Cause of Death recode definitions[15] (Appendix G). National Center for Health Statistics bridged-race population estimates 2003-2007 were used for population-at-risk denominators[3]. All rates were age-adjusted to the 2000 U.S. standard population.

Data Summary

Fig. 15 - Percent of cancer deaths by site among Northwest AI/ANs of both sexes, 2003-2007

Lung & Bronchus **31.3%**
Colorectal **12.8%**
Pancreas **7.8%**
Non-Hodgkin Lymphoma **5.0%**
Esophagus **4.6%**
Leukemia **3.8%**
Liver **3.6%**
Stomach **3.4%**
Kidney & Renal Pelvis **3.4%**
Oral Cavity & Pharynx **3.0%**

Percent of cancer deaths
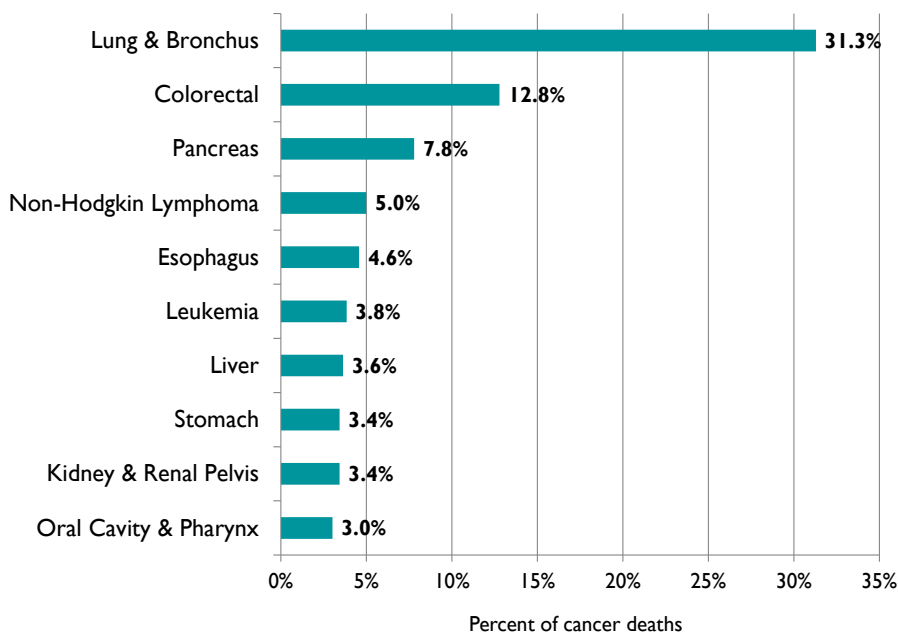
Fig. 15 shows the most common cancer mortality sites among AI/ANs for both sexes combined. Nearly a third of all cancer deaths (31.3%) among Northwest AI/ANs are due to lung and bronchus cancers. The next most common cancer that caused AI/AN deaths was colorectal at 12.8%. Note that these two are also the most commonly diagnosed cancers among AI/ANs (see Figure 3). Pancreatic cancer, while only the 8th most common type of cancer diagnosis among AI/ANs, was the third-leading cause of cancer death, at 7.8%.

The overall cancer mortality rate among Northwest AI/ANs is 202 per 100,000, which is significantly higher than the rate for non-Hispanic whites, at 133 per 100,000. Figure 16 presents age-adjusted cancer mortality rates for the leading sites seen in Figure 15. For the top five sites, AI/ANs have elevated mortality compared to non-Hispanic whites. In particular, the colorectal cancer mortality rate for AI/ANs (21.9 per 100,000) is nearly twice that of non-Hispanic whites (11.6 per 100,000).

Fig. 16 - Age-adjusted cancer mortality rates, selected sites, Northwest AI/ANs and non-Hispanic whites (NHW), 2003-2007

Rate per 100,000

AI/AN
NHW

Site	AI/AN	NHW
Lung & Bronchus	55.3	43.7
Colorectal	21.9	11.6
Pancreas	12.4	9.9
Non-Hodgkin Lymphoma	8.7	4.9
Esophagus	7.3	4.2

Data Summary

Fig. 17 - Percent of cancer deaths by site among Northwest AI/AN males, 2003-2007

Site	Percent
Lung & Bronchus	31.6%
Colorectal	15.2%
Prostate	9.9%
Pancreas	8.1%
Esophagus	7.5%
Non-Hodgkin Lymphoma	5.7%
Oral Cavity & Pharynx	4.6%
Liver	4.6%
Kidney & Renal Pelvis	4.6%
Stomach	4.2%
Leukemia	4.2%

Percent of cancer deaths

Northwest AI/AN males have a cancer mortality rate of 216 per 100,000, significantly higher than non-Hispanic white males (155 per 100,000). The leading causes of cancer death among AI/AN males, as shown in Figure 17, are from lung, colorectal, prostate, pancreas and esophagus. Lung and bronchus cancer accounts for nearly one in three (31.6%) cancer-related deaths.

Figure 18 shows again that mortality rates for leading causes of cancer death are higher for AI/ANs males than for non-Hispanic white males. Particularly striking disparities exist for colorectal and prostate cancer, where AI/AN rates are between 2 and 2.5 times higher.

Fig. 18 - Age-adjusted cancer mortality rates, selected sites, Northwest AI/AN and non-Hispanic white (NHW) males, 2003-2007

Rate per 100,000

Site	AI/AN	NHW
Lung & Bronchus	59.1	51.2
Colorectal	30.4	12.8
Prostate	23.1	9.2
Pancreas	12.0	10.9
Esophagus	12.1	7.1

Data Summary

Fig. 19 - Percent of cancer deaths by site among Northwest AI/AN females, 2003-2007

Site	Percent of cancer deaths
Lung & Bronchus	26.5%
Breast	13.0%
Colorectal	9.1%
Pancreas	6.4%
Ovary	5.2%
Non-Hodgkin Lymphoma	3.7%
Leukemia	3.0%
Cervix	2.9%
Stomach	2.4%
Liver	2.4%
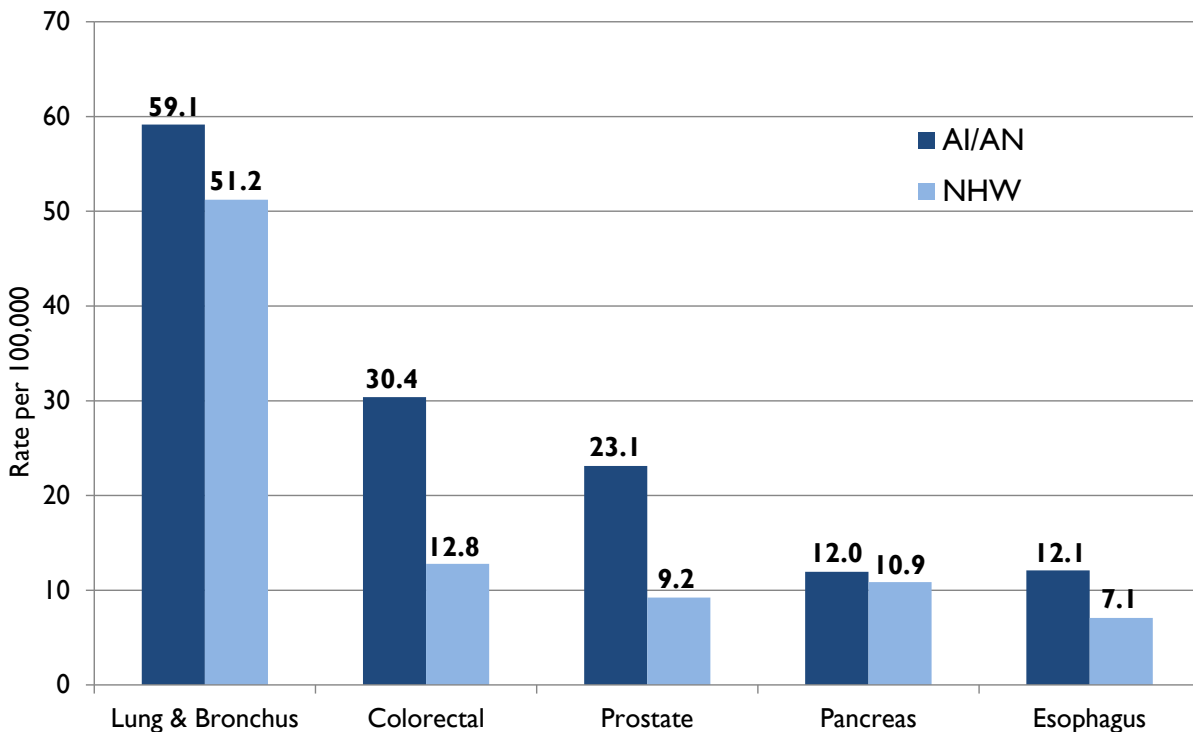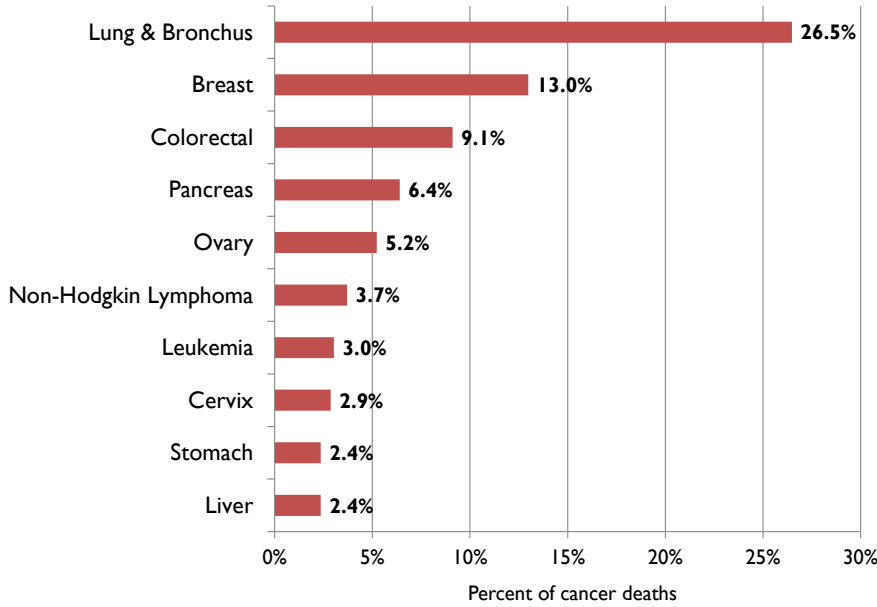
For all sites combined, AI/AN females have a cancer mortality rate of 192 per 100,000. This is significantly higher than the mortality rate for non-Hispanic white females in the Northwest (111 per 100,000). The leading causes of cancer death among AI/AN females, as shown in Figure 19, are lung, breast, colorectal, pancreatic and ovarian cancers. Lung and bronchus cancers account for a slightly lower percentage of cancer-related deaths for AI/AN women (26.5%) than for men (31.6%, see Figure 17).

Figure 20 shows that site-specific cancer mortality rates for women are again higher for AI/ANs than for their non-Hispanic white counterparts, though the magnitude of disparities is different for women than for men. Lung and bronchus

Fig. 20 - Age-adjusted cancer mortality rates, selected sites, Northwest AI/AN and non-Hispanic white (NHW) females, 2003-2007

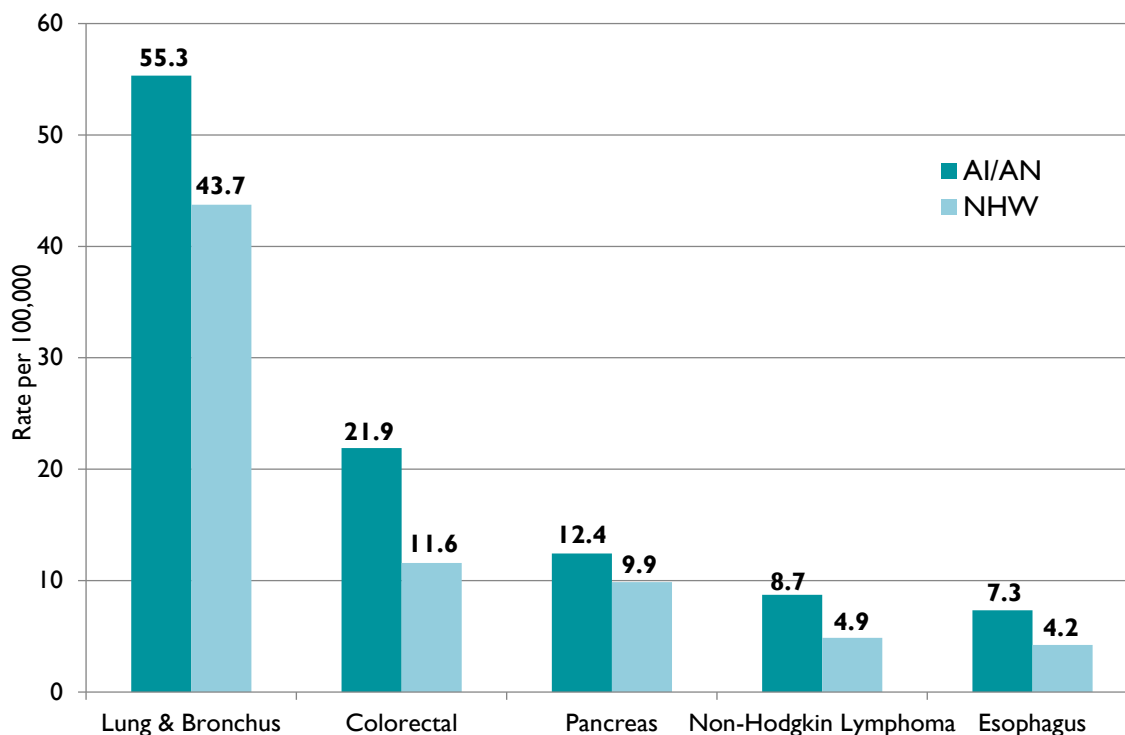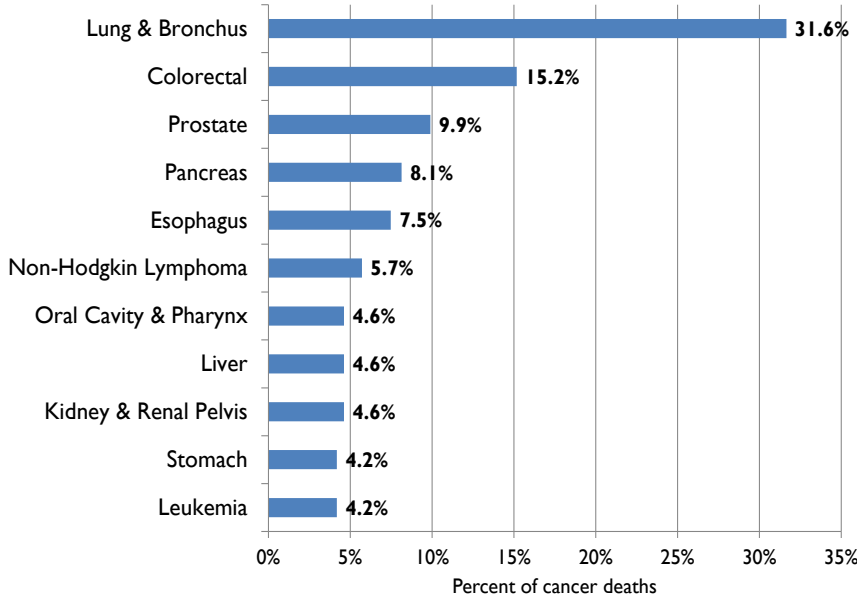| Site	AI/AN	NHW
Lung & Bronchus	53.4	36.1
Breast	23.9	8.9
Colorectal	16.5	10.0
Pancreas	12.6	8.5
Ovary	9.6	6.1

Rate per 100,000

SECTION IV: MORTALITY
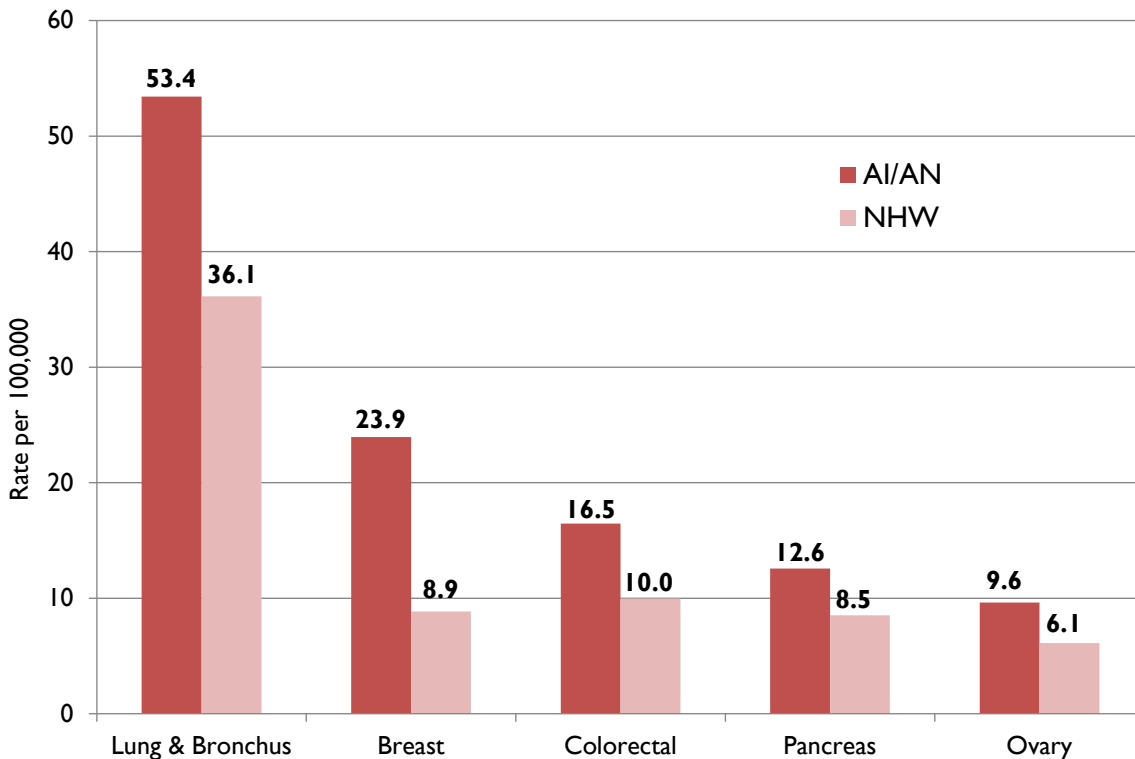
Fig. 21 - AI/AN cancer mortality rates by county of residence, all sites combined, 2000-2007
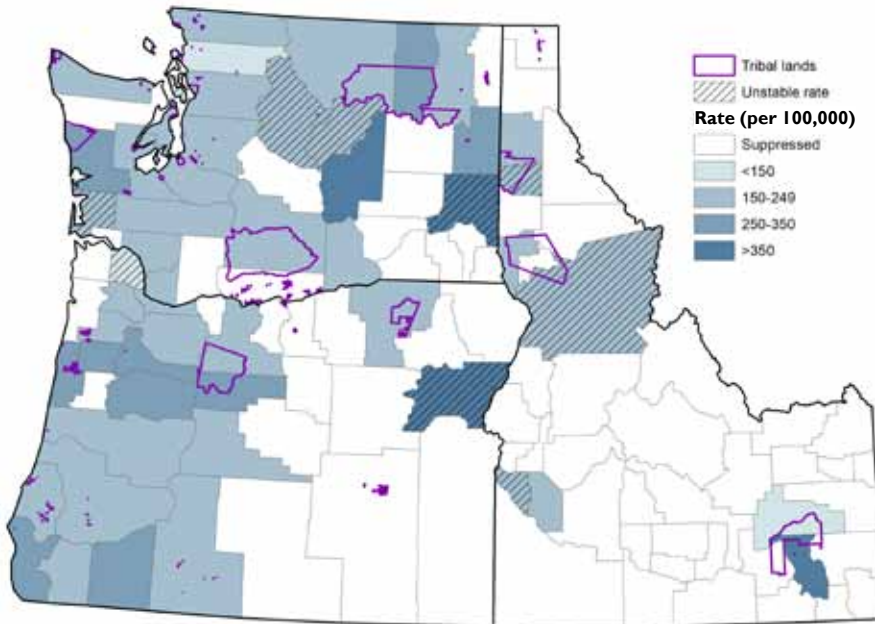
Fig. 22 - Cancer mortality rate ratios: AI/ANs compared to statewide average for all races combined, 2000-2007
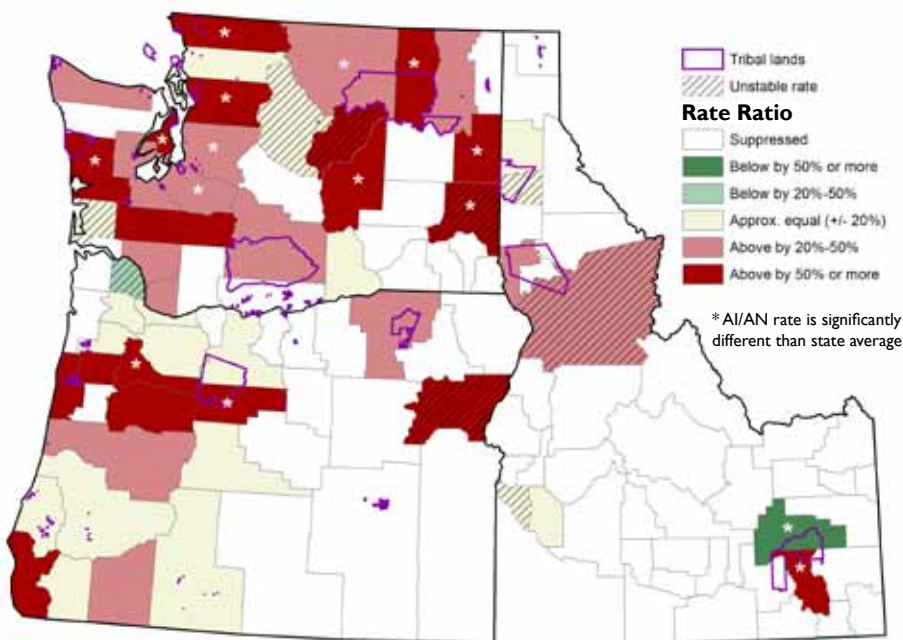
cancer mortality among AI/AN women is 50% higher than that for non-Hispanic white women, while AI/AN and non-Hispanic white male rates are more similar (approx. 15% higher for AI/AN males vs. non-Hispanic white males, Fig. 18). A disparity is also seen in the breast cancer mortality rate, which is 2.7 times higher for AI/AN than for non-Hispanic white women.

Figure 21 shows all-site AI/AN cancer mortality rates by county of residence at the time of diagnosis. Several of the counties with the highest mortality also have relatively high incidence rates (see Fig. 9). Due to small numbers, data for many counties is suppressed or unstable.

Figure 22 displays the ratio of AI/AN all-site mortality rates for each county compared to the statewide rate for all races combined. Similar to Fig. 10, this measure assesses whether the AI/AN mortality rate in a particular county is higher, lower, or about equal to the state average for all people. Many counties, particularly throughout Washington, have AI/AN mortality rates that are higher than the state average by 20-50% or more. Only two counties (Bingham County in Idaho and Columbia County in Oregon) had AI/AN mortality rates below the state average. Statistically significant differences are noted by asterisks.

Shoshone-Bannock Arena, Fort Hall, Idaho

SECTION V: TRENDS

Trends are used to measure changes in disease patterns over time, and are often used to assess whether the occurrence of a condition is improving or worsening in a population. Cancer trends are influenced by many factors, including screening (which may increase incidence rates but decrease mortality over time), advances in treatment, and lifestyle or environmental factors. One simple way to look at trends is to plot annual rates over a range of years and determine whether the slope of the line is going up, down, or remaining generally flat.

Average annual percent change (APC) describes, on average, how much a rate has changed per year over a period of time. A positive APC corresponds to an increasing trend, a negative APC to a decreasing trend, and a number near 0 indicates that there is no change over time. A statistical test can be applied to determine whether the APC differs significantly from the null value of 0.

Methods

Annual incidence and mortality rates were calculated using the same case inclusion criteria and methods discussed in earlier chapters (see pp. 18, 32) then plotted over time to assess trends. This chapter presents incidence trends for all sites combined, as well as trends for several selected sites, between 1996 and 2007. Overall and site-specific mortality trends are presented for years 2000-2007. Since the earliest diagnosis year available is 1996, mortality rates for years 1996-1999 are not presented as these would be based on a limited group of people who were diagnosed and died within a few years' span. This would result in artificially low mortality rates for those early years, potentially leading to an apparent increasing trend, which may not be accurate.

Annual percent change is presented for all-site incidence and all-site cancer mortality rates. An asterisk (*) indicates that the trend is statistically significant (i.e., different from zero). These calculations were obtained by fitting a linear regression line to the natural logarithms of the annual rates[16]. APCs were also calculated for individual sites, and any significant trends are mentioned in the narrative describing each graph. Additional trend data are presented in Appendix E.

Data Summary

As seen in Figure 23, overall cancer incidence rates for Northwest AI/ANs have fallen over the past decade. Compared to non-Hispanic whites, incidence for AI/ANs decreased more rapidly, at an average of -1.4% per year (vs. -0.2% per year for non-Hispanic whites). Prostate cancer incidence for AI/AN men also decreased significantly and more rapidly than that for non-Hispanic white men, at -3.4% per year (vs. -0.8% for non-Hispanic whites). Although it is difficult to see on the chart, breast, lung, and colorectal incidence among AI/ANs also decreased slightly, but not significantly, over this time period. Site-specific APC data are presented in Appendix E.

Figure 24 shows that overall cancer mortality rates have remained relatively stable for both AI/ANs and non-Hispanic whites since 2000 (APCs not significantly different than zero). Lung cancer mortality in this period decreased faster among AI/ANs than for non-Hispanic whites (significant trend of -4.6% per year, vs. -0.9%; see Appendix E). Of the sites presented, mortality rates for AI/ANs decreased slightly over time with the exception of female breast which rose at a rate of 7.9% per year (trend not significant). Site-specific mortality APCs are presented in Appendix E.

Fig. 23 – Trends in cancer incidence, Northwest AI/ANs and non-Hispanic whites (NHW), 1996-2007

NHW Annual Percent Change: -0.2%

AI/AN Annual Percent Change: -1.4%*

Rate per 100,000

Legend:
- AIAN Overall*
- NHW Overall
- AIAN Prostate (male)*
- NHW Prostate (male)
- AIAN Breast (female)
- NHW Breast (female)*
- AIAN Lung
- NHW Lung*
- AIAN Colorectal
- NHW Colorectal*

* APC is significantly different from 0 (p<.05)
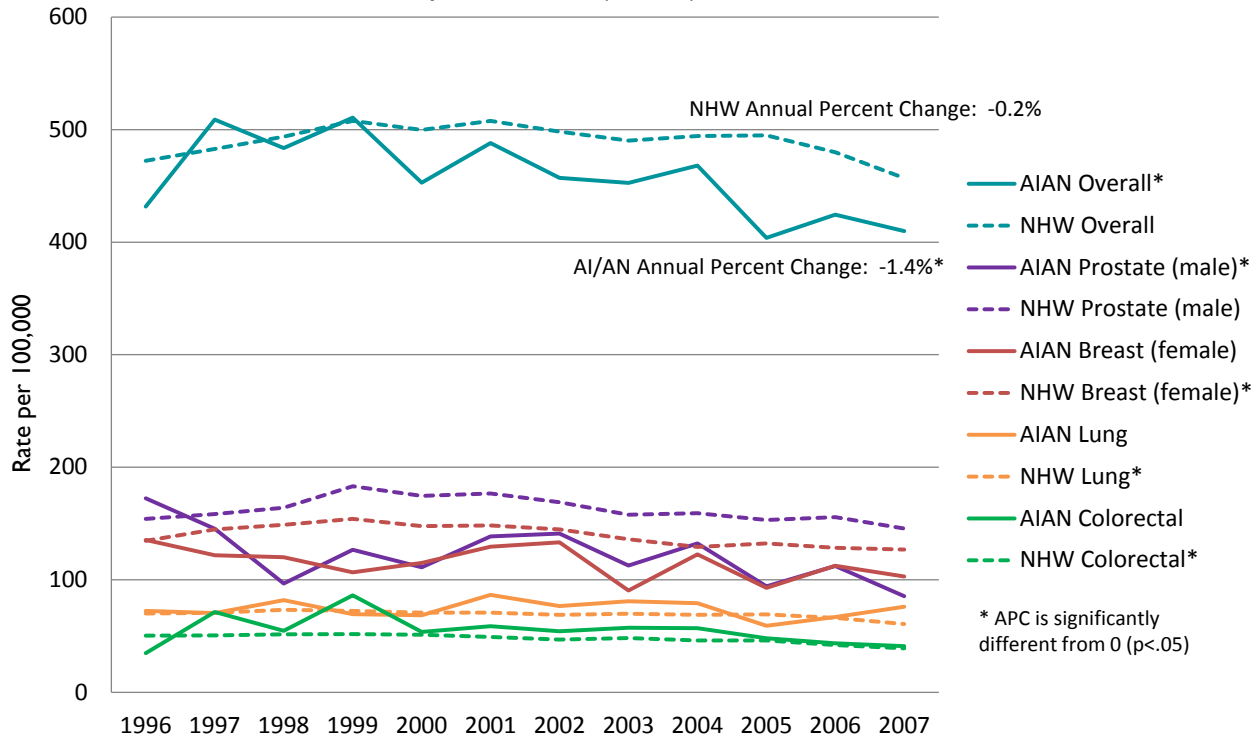
Fig. 24 – Trends in cancer mortality, Northwest AI/ANs and non-Hispanic whites (NHW), 2000-2007

AI/AN Annual Percent Change: -0.7%

NHW Annual Percent Change: +0.7%

Rate Per 100,000

Legend:
- AIAN Overall
- NHW Overall
- AIAN Lung*
- NHW Lung
- AIAN Colorectal
- NHW Colorectal
- AIAN Breast (female)
- NHW Breast (female)
- AIAN Pancreas
- NHW Pancreas

* APC is significantly different from 0 (p<.05)
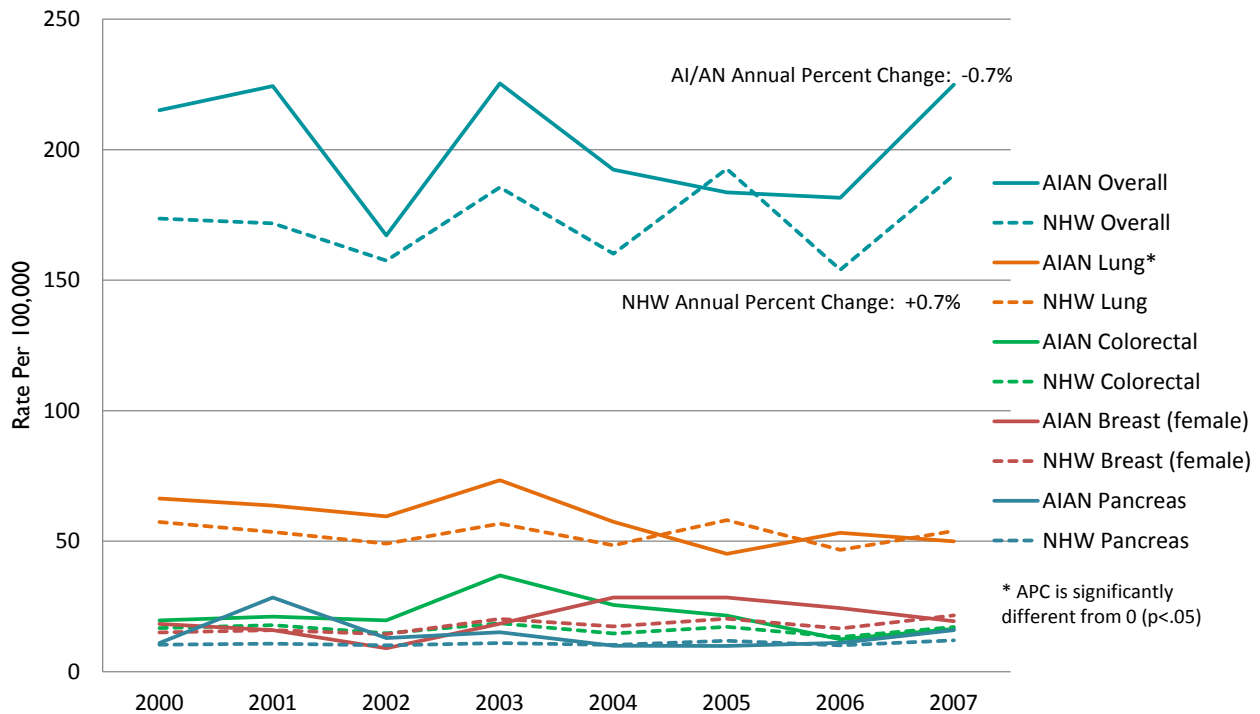
Siletz Tribal Dance House
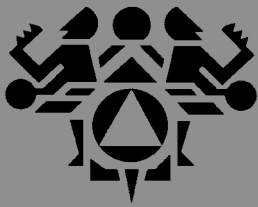
SECTION VI: DISCUSSION & RECOMMENDATIONS

Discussion

"Our traditional lifestyle includes healthy low-fat diets, active lifestyles, spiritual priorities, and tobacco used for sacred and not recreational purposes. This can still work for us today to prevent heart disease, diabetes, and cancer."

Stella Washines,
Yakama Nation Tribal Council,
NPAIHB Delegate

Many agencies do not report cancer data specifically for the AI/AN population, or race-specific numbers may be aggregated nationally where they are less meaningful for individual tribes and local program planning. Additionally, many data sources are hindered by incomplete or inaccurate data due to racial misclassification, which results in under-counting AI/AN cancer cases and deaths. This report attempts to address both shortcomings, by providing comprehensive measures of AI/AN cancer burden at a regional level from cancer registries which have been routinely corrected for misclassified race. Ongoing cancer control efforts in the Northwest have greatly increased the awareness of cancer in tribal communities. This report is meant to further that effort, by providing relevant and accessible data to inform and guide Northwest tribes in the development of appropriate prevention, intervention, and research programs.

On the whole, AI/AN cancer incidence rates and patterns in the Northwest are similar to those for the non-Hispanic White population. For both AI/ANs and non-Hispanic whites, lung and colorectal cancer lead new diagnoses for both sexes, and prostate and breast cancer are the most commonly diagnosed among males and females, respectively. Some differences are seen in site-specific incidence rates, where lung cancer incidence is slightly higher among AI/AN women vs. non-Hispanic white women (difference not significant), but both prostate and breast cancer rates are significantly lower for AI/ANs.

Cancer screening remains one of the most marked cancer-related disparities, where data show that only 38% of I/T/U clinic users are up-to-date on colorectal and breast cancer screening, and 58% of women have had cervical cancer screening. This lag in screening is likely reflected in the excess proportions of late-stage diagnoses for these cancers, and greater cancer mortality. Because mortality from colorectal, breast, and cervical cancer is preventable through screening, this is one area where additional education, awareness, and resources would be well-targeted.

Another notable disparity is seen in female lung cancer mortality: the AI/AN rate is nearly 50% higher than that for non-Hispanic white females, while male AI/ANs experience only slightly elevated mortality from this cause compared to their male non-Hispanic white counterparts. Public health efforts should continue to focus on the leading cause of this deadly cancer through the expansion of smoking prevention and cessation programs.

The trend results indicate that cancer incidence and mortality rates for AI/ANs are decreasing over time, and for some sites, show more favorable projections than among the non-Hispanic white population. One exception is breast cancer mortality among AI/AN women which has increased by almost 8% per year between 2000 and 2007, although the trend is not statistically significant and may be due to random variation. Because cancer is often a slowly developing disease and is relatively rare in the population, trend patterns viewed over only an 8- or 12-year period should be interpreted cautiously to avoid drawing inaccurate conclusions with limited data.

Discussion

Cancer patterns may differ by state, region, and tribe within the Pacific Northwest, and these variations are largely hidden in this report. Tribe-level cancer data are difficult to report due to small numbers of cases leading to wide statistical variability. Where there were adequate numbers of cases, we did provide AI/AN rates at the county level to demonstrate some of the differences by geography. The maps in this report are intended to provide an additional level of relevance to Northwest tribes, but not to attribute geographic or environmental causes to the results. Additional data reports at the state and tribal levels are available through NPAIHB's IDEA-NW/Tribal Registry project[9].

Recommendations

The causes of the disparities seen in this report are complex and not thoroughly understood. However, cultural and language barriers, poverty, educational and employment opportunities, continuity of care in a fractured system, lack of insurance and access to care most certainly all play a role. In light of these results, we offer the following recommendations:

1.   Promote increased collaboration and partnership between the Indian Health Service, tribes, tribal and urban health programs, tribal epidemiology centers, research institutions, and other public health partners to translate these data into targeted, meaningful, and culturally-appropriate cancer control programs.

2.   Increase cancer screening through culturally relevant education and outreach, clinical tracking system utilization, and decreased barriers to patients, including greater participation in state Breast and Cervical Cancer Early Detection programs. Promote increased training for health care providers in the latest screening recommendations and best practices.

3.   Focus on prevention including smoking prevention and cessation and lifestyle modification. Policy and programs promoting wellness and prevention should be holistic and comprehensive, with a multi-disciplinary approach (for example, diabetes and cancer programs collaborating on work plans).

4.   Develop and implement clinical tracking systems for cancer screening, diagnostic, and treatment follow-up to improve clinical quality and continuity of care and to enable increased surveillance of patient outcomes.

5.   Continue meaningful partnerships with state cancer registries to ensure data quality, accessibility, and ongoing surveillance to inform tribal cancer control efforts.

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Final stage of totem - Quileute Tribe

SECTION VII: CANCER RESOURCES

Regional

Smoking Salmon, Warm Springs, OR

Improving Data & Enhancing Access - Northwest (IDEA-NW) Project
NPAIHB Program with regional and local data for Northwest Tribes
www.npaihb.org/epicenter/project/improving_data_enhancing_access_northwest_idea_nw
503-416-3261

Northwest Tribal Comprehensive Cancer Program (NTCCP)
NPAIHB Program with educational information and resources for Northwest Tribes
www.npaihb.org/programs/nw_tribal_cancer_control_project
503-416-3295

Cancer Data Registry of Idaho
http://www.idcancer.org/

Oregon State Cancer Registry
http://public.health.oregon.gov/DiseasesConditions/ChronicDisease/Cancer/oscar/

Washington State Cancer Registry
https://fortress.wa.gov/doh/wscr/

Cancer Lifeline
Providing programs and resources to support people in all stages of the cancer process; serves the Puget Sound area and 16 western Washington counties
http://www.cancerlifeline.org/
800-255-5505

Indian Health Service, Division of Epidemiology and Disease Prevention

Federal agency with national data and reports on cancer and other health issues

www.ihs.gov/epi/index.cfm?module=epi_cancer_main

505-248-4132

Spirit of EAGLES (Education, Advocacy, Grants, Leadership, Elders, Scholarships)

American Indian non-profit with educational information, resources, and community grants based at the Mayo Cancer Center

www.nativeamericanprograms.org/index-spirit.

507-266-3064

Native CIRCLE (Cancer Information Resource Center and Learning Exchange)

American Indian non-profit with free AI/AN educational materials based at the Mayo Cancer Center

www.nativeamericanprograms.org/index-circle.html

507-284-1544

Native American Cancer Research

American Indian non-profit with educational information and resources

www.natamcancer.org

800-537-8295

American Cancer Society

Non-profit with educational information and resources

www.cancer.org

800-227-2345

National Cancer Institute

Federal Agency with educational information and grants supporting cancer research

www.cancer.gov

800-422-6237

CancerCare

Non-profit with educational information and resources

www.cancercare.org

800-813-4673

SECTION VII: CANCER RESOURCES

Appendix A - Definitions

Cancer A term for diseases in which abnormal cells divide without control and can invade nearby tissues. May also be called a malignancy or tumor.

Cancer Staging

Localized Cancer that is limited to the organ in which it started and has not spread beyond it.

Regional Cancer that has spread beyond the primary organ to nearby organs, tissues, or lumph nodes.

Distant Cancer that involves cells that have broken away from the primary tumor, spread to other parts of the body, and have begun to grow at the new location.

Unstaged The staging code assigned when there is not enough information to indicate a stage.

Cancer Behavior

In situ Abnormal cells that are found only in the layer of tissue in which they developed. Most in situ cancers are reportable to state cancer registries, but they are generally not counted in surveillance statistics (with the exception of bladder cancer).

Invasive Cancer that has spread beyond the layer of tissue in which it developed and is growing in to surrounding, healthy tissues. May also be called infiltrating cancer.

Incidence The number of new cases of a disease occurring in a population during a specified period of time.

Mortality The number of deaths in a population during a specific period of time. Mortality rate may also be called the death rate.

Age-adjustment A technique used to adjust rates to a standard population which allows populations with different age structures to be more accurately compared. May also be called age-standardization. Rates that are not age adjusted are called crude rates.

Unstable rate A rate which is based on only a few cases or deaths and should be interpreted with caution. With unstable rates, it is difficult to distinguish between random fluctuation and true changes in rates or patterns of diseases.

Confidence interval A numerical range around a measurement that conveys how precise the measurement is. A 95% confidence interval means that there is a 95% chance that the true rate falls between the lower and upper bounds (conversely, there is a 5% chance that the true rate is outside those limits). If the confidence intervals for two rates do not overlap, they may be said to be significantly different.

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Annual percent change	The average annual change over time, expressed as a percent of the rate. The APC is one statistic that is used to measure trends, or the change in rates over time.
Racial misclassification	Information on a patient's race that is recorded inaccurately or is missing, for example, an AI/AN cancer patient being coded as "white" in a state cancer registry.
IHS	Indian Health Service. U.S. Department of Health and Human Services agency providing health care to Native American and Alaskan Native peoples.
I/T/U	Indian Health Service/Tribal/Urban. The three types of clinical facilities comprising the Indian health care system. IHS facilities are operated directly by the IHS, tribal facilities are operated by tribes through contract or compact with IHS, and urban facilities provide services to urban AI/ANs not residing on or near an Indian reservation.
GPRA	Government Performance Results Act. A federal mandate to monitor the performance of federal agencies according to specific health and treatment guidelines. Several clinical GPRA measures are used by IHS to assess how well clinics provide recommended cancer screening tests to appropriate patients.
NAACCR	North American Association of Central Cancer Registries. A professional association that develops and promotes uniform data standards for cancer registration and certifies population-based cancer registries.
NCHS	National Center for Health Statistics. A CDC program that collects a range of U.S. public health statistics.
NPCR	National Program of Cancer Registries. A CDC program that collects data on the occurrence of cancer through state-based central cancer registries.
SEER	Surveillance Epidemiology and End Results. A program of the National Cancer Institute that collects and disseminates information on cancer incidence, prevalence and survival from specific geographic areas representing 28% of the US population.

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Appendix B - Incidence Data Tables

Data source: Cancer Data Registry of Idaho, Oregon State Cancer Registry, and Washington State Cancer Registry. Restricted to invasive and *in situ* bladder cases only.

Table 1 - Counts and percent of most commonly diagnosed cancer sites among Northwest AI/ANs, 2003-2007

Site	n	%
Lung & Bronchus	403	14.7%
Breast (Female)	400	14.6%
Colorectal	294	10.7%
Prostate (Male)	280	10.2%
Non-Hodgkin Lymphoma	133	4.8%
Kidney & Renal Pelvis	122	4.4%
Bladder	89	3.2%
Endometrium (Female)	81	3.0%
Oral Cavity & Pharynx	80	2.9%
Liver	76	2.8%
Pancreas	74	2.7%
Thyroid	66	2.4%
Leukemia	61	2.2%
Stomach	60	2.2%
Melanoma of the Skin	59	2.2%
Cervix (Female)	42	1.5%
Brain	38	1.4%
Multiple Myeloma	37	1.3%
Ovary (Female)	34	1.2%
Esophagus	31	1.1%
Larynx	15	0.5%
Hodgkin Lymphoma	15	0.5%
Vulva (Female)	12	0.4%
Testis (Male)	12	0.4%
All other sites combined	229	8.3%
Total	**2743**	**100.0%**

Table 2 - Average age-adjusted cancer incidence rates, selected sites, Northwest AI/ANs and non-Hispanic whites, 2003-2007

Site	AI/AN			Non-Hispanic White		
	Rate	CI Lower	CI Upper	Rate	CI Lower	CI Upper
Overall	**429.7**	412.1	448.0	**482.8**	480.7	485.0
Lung & Bronchus	**72.1**	64.7	80.3	**66.9**	66.1	67.7
Colorectal	**48.8**	42.9	55.5	**44.2**	43.5	44.8
Non-Hodgkin Lymphoma	**21.5**	17.6	26.1	**21.2**	20.7	21.6
Kidney & Renal Pelvis	**17.3**	14.1	21.3	**14.2**	13.9	14.6
Bladder	**14.1**	11.1	17.9	**23.0**	22.6	23.5
Pancreas	**12.0**	9.2	15.5	**11.0**	10.6	11.3
Oral Cavity & Pharynx	**11.3**	8.8	14.7	**4.1**	3.9	4.4
Liver	**11.1**	8.5	14.5	**11.6**	11.3	12.0
Stomach	**11.0**	8.2	14.7	**10.3**	10.0	10.6
Leukemia	**8.8**	6.5	11.9	**13.0**	12.7	13.4
Thyroid	**7.8**	5.9	10.4	**5.2**	5.0	5.5
Melanoma of the Skin	**7.8**	5.7	10.6	**27.1**	26.6	27.6

All rates are per 100,000 population with 95% confidence interval (CI) bounds

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Table 3 - Counts and percent of most
commonly diagnosed cancer sites
among Northwest AI/AN males,
2003-2007

Site	n	%
Prostate	280	21.7%
Lung & Bronchus	190	14.8%
Colorectal	155	12.0%
Non-Hodgkin Lymphoma	75	5.8%
Kidney & Renal Pelvis	72	5.6%
Bladder	67	5.2%
Oral Cavity & Pharynx	52	4.0%
Liver	50	3.9%
Leukemia	35	2.7%
Stomach	35	2.7%
Pancreas	33	2.6%
Melanoma of the Skin	24	1.9%
Esophagus	22	1.7%
Multiple Myeloma	20	1.6%
Brain	19	1.5%
Thyroid	14	1.1%
Larynx	12	0.9%
Testis	12	0.9%
Hodgkin Lymphoma	10	0.8%
All other sites combined	111	8.6%
Total	**1288**	**100.0%**

**Table 4 - Average age-adjusted cancer incidence rates, selected sites,
Northwest AI/ANs and non-Hispanic white males, 2003-2007**

Site	AI/AN			Non-Hispanic White		
	Rate	CI Lower	CI Upper	Rate	CI Lower	CI Upper
Overall	**454.4**	426.1	484.8	**547.8**	544.7	550.9
Prostate	**106.0**	92.4	121.7	**154.1**	152.4	155.7
Lung & Bronchus	**76.9**	64.9	91.1	**76.4**	75.3	77.6
Colorectal	**59.6**	49.3	72.1	**50.7**	49.8	51.6
Non-Hodgkin Lymphoma	**24.2**	18.2	32.3	**25.7**	25.0	26.3
Kidney & Renal Pelvis	**21.9**	16.5	29.5	**18.9**	18.3	19.5
Bladder	**22.2**	16.6	30.1	**39.9**	39.1	40.7
Oral Cavity & Pharynx	**16.0**	11.2	22.9	**16.2**	15.6	16.7
Stomach	**14.8**	9.7	22.4	**7.5**	7.2	7.9
Liver	**13.6**	9.7	19.7	**6.4**	6.0	6.7
Leukemia	**10.8**	6.9	17.0	**16.7**	16.1	17.2

All rates are per 100,000 population with 95% confidence interval (CI) bounds

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Table 5 - Counts and percent of most commonly diagnosed cancer sites among Northwest AI/AN females, 2003-2007

Site	n	%
Breast	399	27.4%
Lung & Bronchus	213	14.6%
Colorectal	139	9.6%
Endometrium	81	5.6%
Non-Hodgkin Lymphoma	58	4.0%
Thyroid	52	3.6%
Kidney & Renal Pelvis	50	3.4%
Cervix	42	2.9%
Pancreas	41	2.8%
Melanoma of the Skin	35	2.4%
Ovary	34	2.3%
Oral Cavity & Pharynx	28	1.9%
Leukemia	26	1.8%
Liver	26	1.8%
Stomach	25	1.7%
Bladder	22	1.5%
Brain	19	1.3%
Multiple Myeloma	17	1.2%
Vulva	12	0.8%
Esophagus	9	0.6%
Hodgkin Lymphoma	5	0.3%
All other sites combined	122	8.4%
Total	**1455**	**100.0%**

Table 6 - Average age-adjusted cancer incidence rates, selected sites, Northwest AI/AN and non-Hispanic white females, 2003-2007

Site	AI/AN			Non-Hispanic White		
	Rate	CI Lower	CI Upper	Rate	CI Lower	CI Upper
Overall	**415.8**	393.1	439.5	**435.6**	432.7	438.6
Breast	**104.1**	93.4	115.8	**130.5**	128.9	132.1
Lung & Bronchus	**70.1**	60.5	80.9	**60.0**	58.9	61.1
Colorectal	**41.2**	34.2	49.5	**38.7**	37.8	39.6
Endometrium	**22.1**	17.3	28.2	**23.6**	23.0	24.3
Non-Hodgkin Lymphoma	**18.8**	14.0	24.9	**17.5**	16.9	18.1
Kidney & Renal Pelvis	**13.5**	9.8	18.4	**10.2**	9.8	10.7
Pancreas	**12.9**	9.1	18.1	**10.5**	10.0	11.0
Thyroid	**11.4**	8.4	15.5	**15.1**	14.6	15.7
Cervix	**9.1**	6.5	12.9	**6.4**	6.0	6.7
Melanoma of the Skin	**8.4**	5.7	12.4	**24.4**	23.7	25.0

All rates are per 100,000 population with 95% confidence interval (CI) bounds

Appendix C - Stage at Diagnosis Data Tables

Data source: Cancer Data Registry of Idaho, Oregon State Cancer Registry, and Washington State Cancer Registry. Restricted to invasive cases only.

Table 7 - Colorectal cancer stage at diagnosis counts and percent, Northwest AI/AN and non-Hispanic white adults ages 50+, 2003-2007

	AI/AN		Non-Hispanic White	
Stage	**n**	**%**	**n**	**%**
Localized	81	31.3%	7994	37.9%
Regional	99	38.2%	7981	37.8%
Distant	62	23.9%	3812	18.1%
Unstaged	17	6.6%	1323	6.3%
Total	259	100.0%	21110	100.0%

Table 8 - Breast cancer stage at diagnosis counts and percent, Northwest AI/AN and non-Hispanic white females ages 50+, 2003-2007

	AI/AN		Non-Hispanic White	
Stage	**n**	**%**	**n**	**%**
Localized	160	60.4%	19177	65.7%
Regional	81	30.6%	7923	27.2%
Distant	18	6.8%	1282	4.4%
Unstaged	6	2.3%	796	2.7%
Total	265	100.0%	29178	100.0%

Table 9 - Cervical cancer stage at diagnosis counts and percent, Northwest AI/AN and non-Hispanic white females (all ages), 2003-2007

	AI/AN		Non-Hispanic White	
Stage	**n**	**%**	**n**	**%**
Localized	15	35.7%	768	49.9%
Regional	17	40.5%	518	33.6%
Distant	6	14.3%	188	12.2%
Unstaged	*	*	66	4.3%
Total	*	100.0%	1540	100.0%

* Data on fewer than 5 cases is suppressed

Appendix D - Mortality Data Tables

Data source: Cancer Data Registry of Idaho, Oregon State Cancer Registry, and Washington State Cancer Registry. Incidence-based mortality among cases diagnosed 1996 or later.

Table 10 - Counts and percent of cancer death by site among Northwest AI/ANs, 2003-2007

Site	n	%
Lung & Bronchus	301	26.0%
Colorectal	123	10.6%
Breast (Female)	77	6.6%
Pancreas	75	6.5%
Non-Hodgkin Lymphoma	48	4.1%
Prostate (Male)	45	3.9%
Esophagus	44	3.8%
Leukemia	37	3.2%
Liver	35	3.0%
Kidney & Renal Pelvis	33	2.8%
Stomach	33	2.8%
Ovary (Female)	31	2.7%
Oral Cavity & Pharynx	29	2.5%
Brain	17	1.5%
Cervix (Female)	17	1.5%
Multiple Myeloma	17	1.5%
Bladder	12	1.0%
Endometrium	9	0.8%
Larynx	7	0.6%
Melanoma of the Skin	6	0.5%
Thyroid	6	0.5%
All other sites combined	156	13.5%
Total	**1158**	**100.0%**

Table 11 - Average age-adjusted cancer mortality rates*, selected sites, Northwest AI/ANs and non-Hispanic whites, 2003-2007

Site	AI/AN			Non-Hispanic White		
	Rate	CI Lower	CI Upper	Rate	CI Lower	CI Upper
Overall	**201.7**	189.2	215.0	**133.5**	132.4	134.6
Lung & Bronchus	**55.3**	48.8	62.6	**43.7**	43.1	44.4
Colorectal	**21.9**	17.9	26.7	**11.6**	11.2	11.9
Pancreas	**12.4**	9.6	16.1	**9.9**	9.6	10.2
Non-Hodgkin Lymphoma	**8.7**	6.2	12.1	**4.9**	4.7	5.1
Esophagus	**7.3**	5.2	10.3	**4.2**	4.0	4.4
Leukemia	**5.4**	3.6	8.1	**5.3**	5.1	5.5
Liver	**5.9**	3.9	8.7	**2.7**	2.5	2.8
Kidney & Renal Pelvis	**5.3**	3.5	7.8	**3.0**	2.8	3.1
Stomach	**5.2**	3.4	7.8	**2.4**	2.3	2.6
Oral Cavity & Pharynx	**4.5**	2.9	6.9	**2.0**	1.9	2.1

* Incidence-based mortality rates; all rates are per 100,000 population with 95% confidence interval (CI) bounds

Table 12 - Counts and percent of cancer death by site among Northwest AI/AN males, 2003-2007

Site	n	%
Lung & Bronchus	144	25.6%
Colorectal	69	12.3%
Prostate	45	8.0%
Pancreas	37	6.6%
Esophagus	34	6.0%
Non-Hodgkin Lymphoma	26	4.6%
Kidney & Renal Pelvis	21	3.7%
Liver	21	3.7%
Oral Cavity & Pharynx	21	3.7%
Leukemia	19	3.4%
Stomach	19	3.4%
Brain	11	2.0%
Bladder	7	1.2%
Larynx	7	1.2%
Multiple Myeloma	6	1.1%
Thyroid	5	0.9%
All other sites combined	71	12.6%
Total	**563**	**100.0%**

Table 13 - Average age-adjusted cancer mortality rates[*], selected sites, Northwest AI/AN and non-Hispanic white males, 2003-2007

Site	AI/AN			Non-Hispanic White		
	Rate	CI Lower	CI Upper	Rate	CI Lower	CI Upper
Overall	**216.2**	196.0	238.4	**154.9**	153.4	156.4
Lung & Bronchus	**59.1**	48.6	71.9	**51.2**	50.4	52.1
Colorectal	**30.4**	22.6	40.5	**12.8**	12.4	13.2
Prostate	**23.1**	16.2	32.5	**9.2**	8.9	9.6
Pancreas	**12.0**	8.0	18.2	**10.9**	10.5	11.3
Esophagus	**12.1**	8.1	18.3	**7.1**	6.8	7.4
Non-Hodgkin Lymphoma	**10.8**	6.5	17.5	**6.1**	5.8	6.3
Oral Cavity & Pharynx	**6.7**	4.0	11.8	**2.8**	2.6	3.0
Stomach	**6.4**	3.6	11.7	**3.2**	3.0	3.4
Kidney & Renal Pelvis	**6.2**	3.7	11.2	**4.0**	3.7	4.2
Liver	**5.3**	3.1	9.7	**4.0**	3.7	4.2
Leukemia	**5.0**	2.7	9.7	**6.8**	6.5	7.1

[*] Incidence-based mortality rates; all rates are per 100,000 population with 95% confidence interval (CI) bounds

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Table 14 - Counts and percent of cancer death by site among Northwest AI/AN females, 2003-2007

Site	n	%
Lung & Bronchus	157	26.4%
Breast	77	12.9%
Colorectal	54	9.1%
Pancreas	38	6.4%
Ovary	31	5.2%
Non-Hodgkin Lymphoma	22	3.7%
Leukemia	18	3.0%
Cervix	17	2.9%
Liver	14	2.4%
Stomach	14	2.4%
Kidney and Renal Pelvis	12	2.0%
Multiple Myeloma	11	1.8%
Esophagus	10	1.7%
Endometrium	9	1.5%
Oral Cavity and Pharynx	8	1.3%
Brain	6	1.0%
Bladder	5	0.8%
All other sites combined	92	15.5%
Total	**595**	**100.0%**

Table 15 - Average age-adjusted cancer mortality rates[*], selected sites, Northwest AI/AN and non-Hispanic white females, 2003-2007

Site	AI/AN			Non-Hispanic White		
	Rate	CI Lower	CI Upper	Rate	CI Lower	CI Upper
Overall	**191.9**	175.8	209.2	**111.0**	109.6	112.4
Lung & Bronchus	**53.4**	45.0	63.1	**36.1**	35.3	36.9
Breast	**23.9**	18.5	30.6	**8.9**	8.5	9.3
Colorectal	**16.5**	12.1	22.1	**10.0**	9.5	10.4
Pancreas	**12.6**	8.7	17.7	**8.5**	8.1	8.9
Ovary	**9.6**	6.3	14.2	**6.1**	5.8	6.4
Non-Hodgkin Lymphoma	**7.3**	4.4	11.5	**3.8**	3.5	4.0
Liver	**5.8**	3.1	10.0	**1.4**	1.2	1.5
Leukemia	**5.5**	3.1	9.4	**3.9**	3.6	4.2
Stomach	**4.2**	2.2	7.6	**1.7**	1.5	1.8
Cervix	**3.7**	2.1	6.5	**1.0**	0.9	1.1

[*] Incidence-based mortality rates; all rates are per 100,000 population with 95% confidence interval (CI) bounds

Appendix E - Trends Data Tables

Data source: Cancer Data Registry of Idaho, Oregon State Cancer Registry, and Washington State Cancer Registry. Incidence calculations restricted to invasive and *in situ* bladder cases only.

Table 16 - Annual percent change in cancer incidence, selected sites, Northwest AI/ANs and non-Hispanic whites, 1996-2007

Site	Annual percent change	
	AI/AN	Non-Hispanic White
Overall	-1.38*	-0.21
Prostate (male)	-3.42*	-0.81
Breast (female)	-1.91	-1.29*
Lung & Bronchus	-0.40	-1.00*
Colorectal	-1.91	-2.08*

*APC is significantly different from zero (p<0.05)

Table 17 - Annual percent change in cancer mortality[†], selected sites, Northwest AI/ANs and non-Hispanic whites, 2000-2007

Site	Annual percent change	
	AI/AN	Non-Hispanic White
Overall	-0.74	0.66
Lung & Bronchus	-4.59*	-0.91
Colorectal	-4.69	-1.29
Breast (female)	7.90	4.36
Pancreas	-3.86	1.38

[†] Incidence-based mortality
*APC is significantly different from zero (p<0.05)

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Appendix F - Site Recode ICD-O-3 Definitions

Table 18 - SEER site recode ICD-O-3 definition (1/27/2003)		
Cancer Site	**ICD-O-3 Site**	**ICD-O-3 Histology (Type)**
All Sites Combined	C00-C80	All except benign neoplasms
Oral Cavity and Pharynx	C00-148	excluding 9140, 9590-9989
Digestive System		
Esophagus	C150-159	excluding 9140, 9590-9989
Stomach	C160-169	excluding 9140, 9590-9989
Colon and Rectum	C180-C189, C199, C209, C260	excluding 9140, 9590-9989
Liver	C220	excluding 9140, 9590-9989
Pancreas	C250-259	excluding 9140, 9590-9989
Respiratory System		
Larynx	C320-329	excluding 9140, 9590-9989
Lung and Bronchus	C340-349	excluding 9140, 9590-9989
Skin excluding Basal and Squamous		
Melanoma of the Skin	C440-449	8720-8790
Breast	C500-509	excluding 9140, 9590-9989
Female Genital System		
Cervix Uteri	C530-539	excluding 9140, 9590-9989
Corpus Uteri (Endometrium)	C540-549	excluding 9140, 9590-9989
Ovary	C569	excluding 9140, 9590-9989
Vulva	C510-519	excluding 9140, 9590-9989
Male Genital System		
Prostate	C619	excluding 9140, 9590-9989
Testis	C620-629	excluding 9140, 9590-9989
Urinary System		
Urinary Bladder	C670-679	excluding 9140, 9590-9989
Kidney and Renal Pelvis	C649,C659	excluding 9140, 9590-9989
Brain	C710-719	excluding 9140, 9530-9539 and 9590-9989
Endocrine System		
Thyroid	C739	excluding 9140, 9590-9989
Other Endocrine including Thymus	C379,C740-C749,C750-C759	excluding 9140, 9590-9989
Lymphoma		
Hodgkin Lymphoma	All primary sites with histology codes 9650-9667	
Non-Hodgkin Lymphoma	All sites with histology 9590-9596, 9670-9729; and except for sites C420, C421 and C424 all other sites with histology 9823 or 9827	
Myeloma		9731-9732, 9734
Leukemia	All sites with histology 9733, 9742, 9800-9820, 9826, 9831-9948, 9963,9964; for sites C420, C421 and C424 only, histology 9823 or 9827	
Kaposi Sarcoma (ICD-10 only)	All primary sites with histology code 9140	

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Appendix G - Cause of Cancer Death Recode Definitions

Table 19 - SEER cause of death recode 1969+ definition (9/17/2004)		
Cancer Causes of Death	**ICD-9 (1979-1998)**	**ICD-10 (1999+)**
All Malignant Cancers	140-208, 238.6	C00-C97
Oral Cavity and Pharynx	140-149	C00-C14
Digestive System		
Esophagus	150	C15
Stomach	151	C16
Colon and Rectum		
Liver	155.0, 155.2	C22.0, C22.2-C22.4, C22.7, C22.9
Pancreas	157	C25
Respiratory System		
Larynx	161	C32
Lung and Bronchus	162.2-162.5, 162.8-162.9	C34
Skin excluding Basal and Squamous		
Melanoma of the Skin	172	C43
Breast	174-175	C50
Female Genital System		
Cervix Uteri	180	C53
Corpus Uteri (Endometrium)	182	C54
Ovary	183	C56
Vulva	184.1-184.4	C51
Male Genital System		
Prostate	185	C61
Testis	186	C62
Urinary System		
Urinary Bladder	188	C67
Kidney and Renal Pelvis	189.0-189.1	C64-C65
Brain and Other Nervous System	191, 192	C70, C71, C72
Endocrine System		
Thyroid	193	C73
Other Endocrine including Thymus	164.0, 194	C37, C74-C75
Lymphoma		
Hodgkin Lymphoma	201	C81
Non-Hodgkin Lymphoma	200, 202.0-202.2, 202.8-202.9	C82-C85, C96.3
Myeloma	203.0, 238.6	C90.0, C90.2
Leukemia	204-208	C90.1, C91-C95
Kaposi Sarcoma (ICD-10 only)	N/A	C46

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