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Documentation of the Cancer Research Needs of American Indians and Alaska Natives

Cancer Control Science Program, Division of Cancer Prevention and Control, National Cancer
Institute

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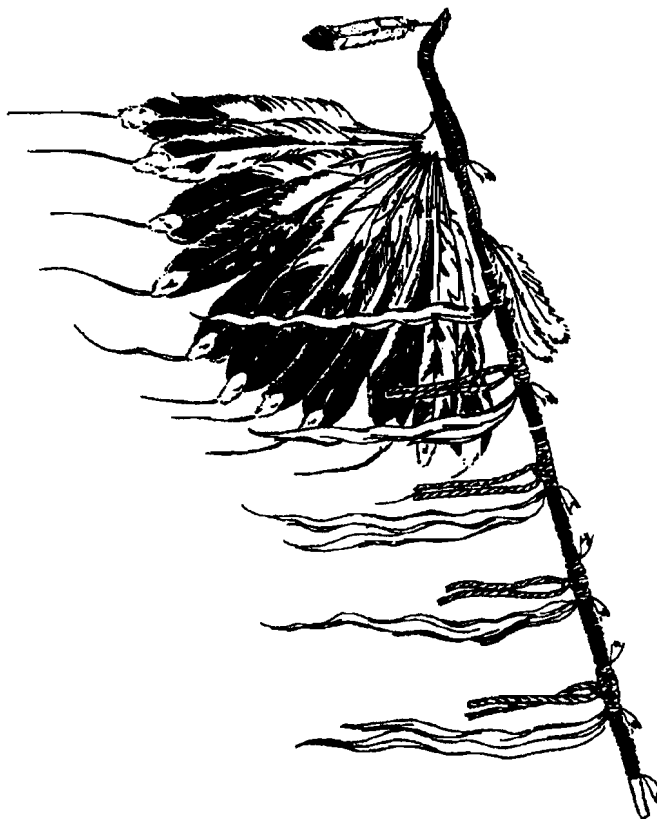
**Documentation of the Cancer
Research Needs of American
Indians and Alaska Natives**

Linda Burhansstipanov, DrPH, CHES
Native American Cancer Control
Special Populations Studies Branch

Connie Dresser, RDPH, LN
Nutrition Interventions
Public Health Applications Research Branch

Cancer Control Science Program
Division of Cancer Prevention and Control
National Cancer Institute
Bethesda, Maryland

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FOREWORD

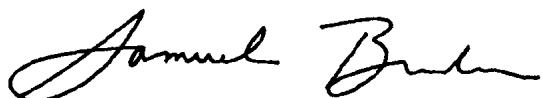
The National Cancer Institute is committed to reducing cancer incidence and mortality among Indigenous Peoples. The commitment to reduce the suffering and death from cancer has been intensified where people suffer disproportionately from cancer or appear to be underserved. The Native American Cancer Control Initiatives are an important expression of this commitment.

The NCI Division of Cancer Prevention and Control has compiled an overview of NCI-supported Native American projects and they are detailed in this publication. Last year a workshop was held to encourage NCI Cancer Centers to link up with those concerned with the health of Native Americans and to train scientists to apply for grants in this area. A meeting was held in the summer of 1993 to discuss cancer control research among these populations. As long ago as 1987, NCI began to formally address the programs and activities needed to fulfill these goals. We hope that the overview of cancer among Indigenous Peoples provided in this book spurs targeted research.

We hope the reader will find this book has a useful emphasis on nutrition as it relates to cancer prevention and control. This is an important area. All lifestyle issues are interwoven with economics and in many cases also influenced by tradition. Nutrition and smoking certainly are influenced by both. NCI is encouraging innovative research that focuses on increased access to and consumption of fruits and vegetables and fiber to reduce the risk not only of cancer, but also the risk of cardiovascular disease, obesity and diabetes.

The NCI acknowledges the Sovereign Rights of the Indian Nations and wishes to work with these Nations in improving the quality of life, particularly in reducing cancer incidence and mortality, among Indigenous Peoples.

Finally, this monograph presents concepts that will assist in the establishment of culturally relevant and, hence, acceptable programs. There is extreme variability in these groups and we hope this book helps to sensitize program planners to this fact.

A handwritten signature in black ink, reading "Samuel Broder". The signature is fluid and cursive, with the first name "Samuel" and last name "Broder" clearly distinguishable.

Samuel Broder, M.D.

Advisory Task Force

Ronny Bell, MEd
University of North Carolina
Park Gymnasium
Department of Foods/Nutrition
Greensboro, NC 27412

Cecelia Fire Thunder
Oglala Sioux Community
P.O. Box 920
Martin, SD 57551

Felicia Hodge, DrPH
American Indian Cancer Control Project
1918 University Avenue, suite 214
Berkeley, CA 94704

Carol Marquez-Baines, MPH
American Indian Health Care Assn.
245 East 6th Street, suite 499
St. Paul, MN 55101

Anne M. Walker, MS
Executive Director
Alaska Native Health Board
1345 Rudakof Circle, suite 206
Anchorage, AK 99508
(907) 337-0028

NCI Staff

Linda Burhansstipanov, DrPH
SPSB, CCSP, DCPC
National Cancer Institute
9000 Rockville Pike
EPN, room 240
Bethesda, Maryland 20892

Connie Dresser, RDPH, LN
Nutritional Cancer Research
Populations Studies and Cancer Research
Applications of Prevention and Early
Detection Section, PHARB, CCSP, DCPC
National Cancer Institute
9000 Rockville Pike
EPN, room 241
Bethesda, Maryland 20892

Clarissa Wittenberg
Senior Writer
Office of Cancer Communication
National Cancer Institute
9000 Rockville Pike
Building 31, 10 A
Bethesda, Maryland 20892

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Internal (NCI) Reviewers:

George A. Alexander, MD
Carolyn Clifford, PhD
Thomas Glynn, PhD
Peter Greenwald, MD, DrPH
Marianne Haenlein, PhD
Susan Pilch, PhD
Carol Shapiro
Edward Sondik, PhD
Gloria Stables, MS, RD
Clarissa Wittenberg, MSW

External Reviewers:

Thomas Becker, MD, PhD
Ronny Bell, MEd
Trula Breuninger, RD, MPH
Richard E. Clark
Leslie Cunningham-Sabo, MS, RD
Mark Dignan, PhD
Tim Gilbert, MPH, RD
James W. Hampton, MD
Felicia Hodge, DrPH
Yvonne Jackson, PhD, RD
Martin Mahoney, PhD
Barbara Stillwater, PhD
Karen Strauss, MS, RD

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PREFACE

Purpose

The **purpose** of this publication is to provide a resource and reference to assist in the formulation of culturally acceptable cancer prevention and control research projects or programs. It is a *brief* overview of the cancer problem among American Indian and Alaska Native People living in urban, rural, reservation and village sites. It is not designed to be read from cover to cover, but rather that the reader will utilize appropriate sections which may assist in the formulation of a cancer prevention and control program for one's local Native community. This document is neither all encompassing nor comprehensive, but rather is an introduction to the cancer problem as it currently exists among American Indians and Alaska Natives. Because specific tribal information is rarely available, reservations, urban Indian clinics and other tribal settings are encouraged to collect and record cancer data for their community.

This publication is the first of a series of monographs which focus on Native Americans. Monograph #1, *Documentation of the Cancer Research Needs of American Indians and Alaska Natives* provides an overview of cancer among Indigenous Peoples. The monograph has three sections: the initial section is a brief overview of cancer among Indigenous Peoples; the second section describes the role of nutrition in cancer prevention and control; and, the third section is an overview of NCI-supported Native American projects and activities. It is designed to be used as a resource or reference to assist in the formulation of culturally competent cancer prevention and control research projects or programs.

Target Audience for this Publication

This monograph is primarily designed for use by Native and non-Native cancer researchers. Basic information on cancer data and cancer research is included to assist the researcher who is new to the field. Information in this publication may also be of assistance to health care providers, tribal health planners, health educators, public health nutritionists, community health representatives, and other similar professionals working with American Indian or Alaska Native populations in developing and designing cancer prevention and control research proposals, programs, and/or materials.

The information from this publication may benefit Native researchers in the development and implementation of cancer intervention programs in urban, rural and/or reservation settings. It may assist in the development of culturally competent Native American survey instruments for the collection of accurate data. It may also be useful in the development of culturally sensitive Native American cancer education materials and programs to be used in innovative research interventions.

The Native American Populations

When the National Cancer Institute (NCI) specifies, "Native American", the following populations are included: American Indians, Alaska Natives, Native Hawaiians and American

Samoans. This publication focuses on two of these populations: American Indians and Alaska Natives only. Subsequent publications will focus on Native Hawaiians and American Samoans.

Limitations of this Publication

This monograph is the first of a series of proposed publications which are designed to be of assistance to program planners, researchers and Tribal Councils and Boards. It is not possible to include everything one needs to know about the research process in one monograph. For your information, the suggested monographs include the following:

- Monograph #1: Documentation of the Cancer Research Needs of American Indians and Alaska Natives
- Monograph #2: Documentation of the Cancer Research Needs of Native Hawaiians and American Samoans
- Monograph #3: Cancer Risk Factors among Native Americans
- Monograph #4: Planning Cancer Prevention Research Projects among Native American Populations
- Monograph #5: Initiating Local Native Support for Cancer Prevention and Control Programs
- Monograph #6: Participation with and recruitment of Native Americans in Clinical Trials and other types of Research Projects

Since a future monograph is planned to focus on cancer risk factors among Native Americans, this monograph is limited in its discussion of those factors. The only risk factors which are included in any detail are dietary (Section II, Chapters 6, 7, and 8).

The Special Populations Studies Branch of NCI has planned to produce a *Bibliography of Native American Cancer and Cancer-related Literature* in the near future. This would include listings of references which will be of assistance to the researcher and others. The proposed Bibliography will not focus on Native American diet. For that reason, Section II of this monograph includes an extensive list of references on dietary components and cancer. Appendices "G" and "H" include additional resources.

Recommended Resources

For general cancer information, the reader is referred to the Cancer Information Services which are located throughout the country. The toll free telephone number is 1 (800) 4-CANCER or 1 (800) 422-6237. Another excellent resource is *Cancer Statistics Review: 1973-1989* (NIH Publication number 92-2789) for a clear description of how NCI calculates rates and for comprehensive tables of cancer data.

Native American-specific cancer information is available through Dr. Sarah Valway's work, *Cancer Mortality among Native Americans in the United States; Regional Differences in Indian Health, 1984-1988; Trends Over Time, 1968-87*). This publication was released in 1992 and is available from the Cancer Prevention and Control Program located in Indian Health Service Headquarters West, Albuquerque, New Mexico. Their phone number is 1 (505) 766-5557.

The proceedings from the 1989 First National Conference on Cancer in Native Americans are published in the *American Indian Culture and Research Journal* (volume 16, number 3, 1992) which is published at UCLA.

For listings of Native American cancer publications, Dr. James Justice, who is with the Native American Research and Training Center, University of Arizona, has multiple works available which list American Indian bibliographies and literature.

Data Issues

At the present time, there is a dearth of accurate data on cancer among American Indians and Alaska Natives which is accessible to Indigenous Peoples. The National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results (SEER) database is a basic resource for information about cancer incidence and mortality rates. The geographic areas comprising the SEER Program's database, represent an estimated 9.6% of the United States population.¹ American Indian residents from Arizona were added in 1980. The New Mexico SEER Registry includes American Indians and Alaska Natives from both New Mexico and Arizona which contain about 19 percent of the American Indian population, but these data are not representative of American Indians elsewhere. This poses difficulties due to a high rate of variation in Native American culture and lifestyle patterns, i.e., smoking prevalence, access to medical care, and the poverty level. For example, American Indians who live in Arizona and New Mexico rarely use tobacco, and therefore lung cancer rates from the New Mexico SEER Registry cannot be uniformly generalized to represent other Native Americans. For the present, SEER rates must be read for Native American populations with this caution in mind. While developing a cancer program for Indigenous Peoples from geographic areas outside of SEER regions, such as the North Central States (sometimes referred to as the Northern Plains), researchers must rely on statistics from federal agencies such as the Indian Health Service and National Center for Health Statistics.

TERMINOLOGY

Age-adjusted rate: Cancer risk increases with age. The purpose in calculating an "age-adjusted rate" is to remove the effect of age differential to allow for comparisons of rates among different population groups. For example, cancer mortality rates in Florida and North Dakota need to be adjusted for age if they are to be compared. Florida has a higher proportion of older people than does North Dakota. Thus, a higher unadjusted rate of cancer would be observed in that state versus in North Dakota. Age adjustment takes into account the different population structures and allows comparisons of rates. (see "rate" below; for additional descriptions of age adjustment, see reference #2²)

Alaska Native: The term collectively refers to Eskimos, Aleuts and American Indians who are indigenous to Alaska.

All Races: This is a phrase which is used to describe the entire U.S. Population (including American Indians, Aleuts, Eskimos, whites, black Americans, Asians, Hispanics, Latinos, Native Hawaiians, et al).

American Indian: This includes enrolled members of Federal and/or state recognized tribes as well as people who are self-identified as "American Indian" on the U.S. Census. The degree of Indian blood in these self-identified Indians is not known. Many tribes have a tribal-specific blood quantum requirement (e.g., one-quarter) for membership; some tribes have a simple descentance requirement.³

Benign: not recurrent; not malignant; mild;⁴ (an adjective) in pathology terms, refers to non-malignant, usually in reference to tumors.

Blood Quantum: Indicates the percentage of American Indian or Alaska Native. For example, a mother who is 50 percent or one-half blood quantum is half American Indian and half some other race. If this mother and a white father parent a child, the child has a blood quantum of 25 percent or one-quarter. Some persons may be of mixed American Indian tribal descentance and must indicate their principal tribe on Census and other questionnaires.

ABBREVIATIONS

CDC	Centers for Disease Control and Prevention
IHS	Indian Health Service
NCHS	National Center for Health Statistics
NCI	National Cancer Institute
NHANES	National Health and Nutrition Examination Survey
NIH	National Institutes of Health
Pap	Papanicolaou (smear or test)
SEER	Surveillance, Epidemiology, and End Results (Program)
SES	Socioeconomic status

Carcinogen: Any cancer-causing substance or agent.

Carcinoma: A cancer that arises in the epithelial cells. These cells are in skin and other tissues that cover external and internal body surfaces.

Federally Recognized Tribes: Refers to the relationship between certain Indian tribes and the Federal Government. Federal recognition can be obtained by satisfying the criteria of the Federal Acknowledgement Process administered through the U.S. Department of the Interior, by Federal statute enacted by Congress, or by federal court decree. Federally recognized tribes and their members are eligible for the special programs provided by the United States for Indian people because of their status as Sovereign Nations of Indians.³

Federal Definition of "American Indian": "Any person who is a member of an Indian tribe, as defined in subsection (d) hereof, except that, for the purpose of sections 102, 103, and 20 (c) (5), such terms shall mean any individual who (1) irrespective of whether he or she lives on or near a reservation, is a member of a tribe, band, or other organized group of Indians, including those tribes, bands, or groups terminated since 1940 and those recognized now or in the future by the state in which they reside, or who is a descendant, in the first or second degree, of any such members, or (2) is an Eskimo or Aleut or other Alaska Native, or (3) is considered by the Secretary of the Interior to be an Indian for any purpose, or (4) is determined to be an Indian under regulations promulgated by the Secretary."⁵

Incidence: Refers to a rate, based on identification of new cases of a specific disease occurring during a certain period in a defined population; usually expressed as new cases per 100,000 population per year, (see "rate" below).

Indian Country: (a) all land within the limits of any Indian reservation under the jurisdiction of the U.S. government; (b) all dependent Indian communities within the borders of the U.S.; (c) all Indian allotments (U.S. Congress, Indian Country Statute of 1948 (18 USC, 1151))

Indian Territory: This refers to Oklahoma lands which the U.S. Government historically set aside for American Indian tribes.

Indian Tribe: Any Indian tribe, band, nation, rancheria, pueblo or other organized group or community, including any Alaska Native village or group or regional or village corporation as defined in or established pursuant to the Alaska Native Claims Settlement Act (85 Stat. 688), which is recognized as eligible for the special programs and services provided by the United States to Indians because of their status as Indians. A tribe may be federally-recognized, state-recognized, or self-recognized and/or federally terminated.

Indigenous Peoples: The inhabitants of the North American continent prior to 1492; Living or occurring naturally in a specific area or environment⁶; The First Americans.

Malignant: Virulent; growing worse; resisting treatment, said of cancerous growths; tending or threatening to produce death; harmful.⁴ An adjective; in pathologic terms, refers to cancer, a cellular growth which is tending or threatening invasion, destruction and tendency to spread; opposed to benign tumors.

Metastasis: Movement of bacteria or body cells (especially cancer cells) from one part of the body to another; change in location of a disease or of its manifestations or transfer from one organ or part to another not directly connected. The usual application is to the manifestation of a malignancy in a secondary growth arising from the primary growth in a new location. Spread is by the lymphatic or blood stream.⁴ Spread of cancer cell from a primary tumor to sites elsewhere in the body.

Morbidity: State of being diseased. The number of sick persons or cases of disease in relationship to a specific population.⁴ Illness; can also refer to morbidity rate, which is the number of illnesses occurring during a certain period of time, usually a year, per unit of population, usually 1,000 or 10,000 or 100,000; usually expressed as the number of new illnesses per 100,000 population per year. (See "rate" below)

Mortality: Death; refers to a rate based on the number of deaths occurring during a certain period in a defined population; rates are calculated as number of deaths per 100,000 population per year. (See "rate" below)

Native American: The term collectively includes American Indians, Alaska Natives, and Native Hawaiians. However, in this publication, the term only refers to American Indians and Alaska Natives.

Non-Natives: Refers to people who are not recognized as or do not identify themselves as American Indian or Alaska Native.

Person-years: Person-years may be used as the denominator for the computation of incidence or mortality rates. Person-years of observation are frequently used as denominators in the computation of rates in prospective studies. They take into consideration both the number of persons who were observed and the duration of observation of each person. For example, five persons who remain under observation for twenty years contribute one hundred person-years of observation and one hundred persons who are observed for one year also contribute one hundred person-years of observation.⁷

Population-based: Disease incidence and mortality data based on the number of persons in a given geographic location.

Rate: Rates form the essential ingredients of vital statistics methods. For mortality, the numerator of a death rate for some period of time is a count of deaths during that time period as reported to local and, subsequently, to national authorities. The denominator is the population at risk during that time period as determined by census, special population enumerations, and the reporting and recording of births.⁸ Rates differ from ratios, proportions and percentages in that which their numerators are accumulated over a period of time (usually a year), their denominators are static figures estimating the population at one point in time.² Refers to the force of a disease in a population; is similar to risk of developing a disease. Rates are calculated by including the number of new cases of disease which occur in a population (the numerator) in a given period of time, and dividing that number by a denominator which includes both persons at risk to develop the disease and time at risk. If 50 new cases of cancer occurred in a population of 5,000 people during a one-year period, the crude (unadjusted) incidence rate would be $50 \div 5000$ person-years, or 0.01 cases per person-years.

years. Through simple multiplication, this rate can be defined in terms of a standard denominator, such as 100,000 per person-years. Thus, 0.01 cases per person-year = 1000 cases per 100,000 person years. A high rate implies a strong force of a disease in a population. This term is commonly used in reference to both morbidity and mortality (see above). For additional information on rates and rate calculations, see reference #2 and #8).

Relative survival rate: The relative survival rate is calculated using a procedure described Ederer, Axtell and Cutler (1961). This involved adjusting the observed survival rate for expected mortality. The relative survival rate represents the likelihood that a patient will not die from causes associated specifically with their cancer at some specified time after diagnosis.¹

Reservation: The geographic area set aside by treaty or other law for a federally recognized Indian tribe, including Pueblos, rancherias, or colonies, informal reservations in Oklahoma, Alaska Native regions established pursuant to the Alaska Native Claims Settlement Act (43 U.S.C. 1601 et seq.).³

Reservation State: A state in which there is at least one federally recognized Indian reservation or tribe(s) and in which IHS provides services or fiscal support for health care for eligible Indians.³ As of 1992, there are 33 such states.

Sarcoma: A cancer of mesenchymal origin found in tissue (e.g., muscles, bone, cartilage).

Self-determination: A policy established in 1975 with the Indian Self-Determination and Education Assistance Act (Public Law 93-638) to encourage maximum Indian participation in the planning, conduct, and administration of Federal programs and services provided for Indians by Indian Health Service (IHS) and Bureau of Indian Affairs (BIA), by transferring responsibilities for these programs and services from the Federal Government to tribal governments which were established under the Indian Reorganization Act (25, USC 461-479).³

Terminated Tribes: Refers to Federal policy after World War II and continuing into the 1960's, formally repudiated by Congress in 1989, which had several components: (1) induced resettlement of thousands of reservation Indians to urban centers where they were to be trained and employed; (2) the transfer of major functions, responsibilities, and jurisdiction over Indians to states from the Federal Government; and (3) the termination of the Federal relationship with specific tribes, including ending services and distributing tribal assets to tribal members.³

Tribal Enrollment Number: Each tribe determines the criteria by which individuals are accepted as a member of the tribe. In many tribes it is a minimal blood quantum, such as 25 percent, or one-quarter. In a few, it is proof of Indian ancestry. In others it is proof of ancestors being included on the Department of the Interior's Records from the late 1800's and early 1900's which was to register all "legal" Indians. An example of an illegal Indian is one who committed a crime and was not allowed to be listed or counted in the Department of Interior's book. Each tribe, as a Sovereign Nation, determines its own criteria for acceptance of tribal members to be included on tribal enrollment books. All entries on these books receive enrollment numbers.

Tribal Trust Land: Lands held in trust for Indian tribes and administered for their mutual benefit by the Federal Government.³

93-638 Clinics: Health clinics owned and operated by Native Americans, tribes or Alaska Native Health Corporations; a health clinic which is owned, staffed, and managed by local tribal communities. The 1975 Indian Self-Determination Act, P.L. 93-638 and the 1976 Indian Health Care Improvement Act, P.L. 94-437 as amended, allow for higher resource levels to expand health services, to build and renovate medical facilities, and for the construction of safe drinking water and sanitary disposal facilities. These "638" clinics may receive part of their funding from the IHS. **Note:** some American Indian and Alaska Native owned and operated clinics are *not* 93-638 clinics.

93-638 Contracts: Indian and owned and operated clinics who are contracted via the 93-638 process; contracts between Indian tribes or tribal organizations and Federal agencies (i.e., IHS and BIA), under which tribes assume planning, operation, and administration of programs and services for Indians from the Federal Government.³

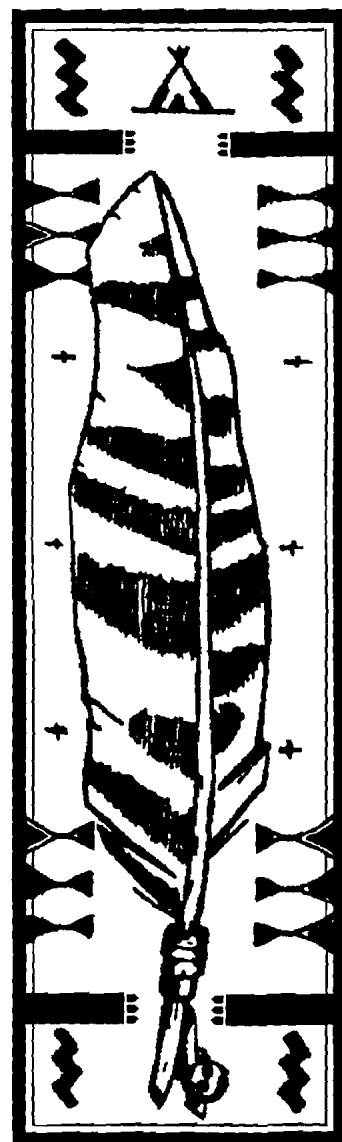
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SECTION I

OVERVIEW OF CANCER AMONG INDIGENOUS PEOPLES

The first section of this publication provides an overview of American Indian and Alaska Native populations, a description of cancer databases and their limitations, an explanation of cancer incidence, mortality and survival data for American Indians and Alaska Natives, clarification regarding the regional variation of cancer among Indigenous Peoples from different geographic regions and tribal affiliations. The last chapter of this section provides a summary chart of risk factors for the eight cancer sites which are common among Native Americans and a brief discussion of tobacco use among Native Americans.



CHAPTER 1: INTRODUCTION AND BACKGROUND

CHAPTER OBJECTIVES:

- DESCRIBE NATIVE AMERICAN CULTURAL PRACTICES WHICH MAY AFFECT CANCER PREVENTION AND CONTROL RESEARCH PROJECTS
 - DELINEATE AMERICAN INDIAN AND ALASKA NATIVE DEMOGRAPHICS
 - DESCRIBE NATIVE AMERICAN ISSUES RELATED TO ACCESS TO MEDICAL SERVICES
-

INTRODUCTION

This first chapter includes a brief overview of current conditions among American Indians and Alaska Natives, as well as a summary of cultural features, beliefs, demographics, and access to health care services. The criteria for inclusion of information in this introductory section are relevancy to cancer prevention and control programs among American Indians and Alaska Natives.

Brief overview of cancer among American Indians and Alaska Natives

According to the New Mexico SEER Registry, American Indians living in New Mexico and Arizona have incidence rates for stomach, cervix uteri, primary liver, and gallbladder cancers that are higher than for U.S. population. American Indians experience excessive mortality rates from cervical and gallbladder cancers when compared with SEER white rates. The cancer survival rates for American Indians are among the poorest of any racial group in the United States. The five-year relative survival data collected among American Indians are poorer for all cancer sites combined. Compared to non-Indian peoples in the Southwest, even when cancer is diagnosed in early stages (i.e., Stage II), when stage at diagnosis and treatment is considered, survival from cancer for American Indians is poor.¹ Survival data are from American Indians living in New Mexico and Arizona only, and data are not yet available for American Indians or Alaska Natives in other parts of the country.

Data from the Alaska Native Tumor Registry suggest that Alaska Natives have excessive cancer incidence of cervix uteri, colon and rectum, gallbladder, kidney, nasopharynx, oral cavity and pharynx. The annual age-adjusted cancer death rates

(156/100,000) for the Alaska Indian Health Service (IHS) Area exceed those of the U.S. All Races (132/100,000)². Alaska Natives have excessive mortality from cancers of the cervix uteri, colon and rectum, esophagus, gallbladder, kidney, nasopharynx, and salivary glands. Colorectal, breast, pancreas and cervical cancers are the most frequent causes of cancer death among Alaska women. Stomach cancer incidence and mortality are excessive for Alaska Native males when compared with white males. Alaska Natives have the highest mortality rates of any racial group for cancers of the oral cavity, colon and rectum, gallbladder, corpus uteri, and renal system. Survival data for Alaska Natives living in Alaska are in the process of being collected, but presently are unavailable.

The poor survival rate of American Indians reported by the National Cancer Institute (NCI) suggests that American Indian cancer patients experience the disease differently from those in Non-Native populations. To further explore these issues, factors such as genetic risk factors, late detection of cancer, poor compliance with recommended treatment, presence of concomitant disease, or lack of timely access to state-of-the-art diagnostic and/or treatment methods should be investigated.

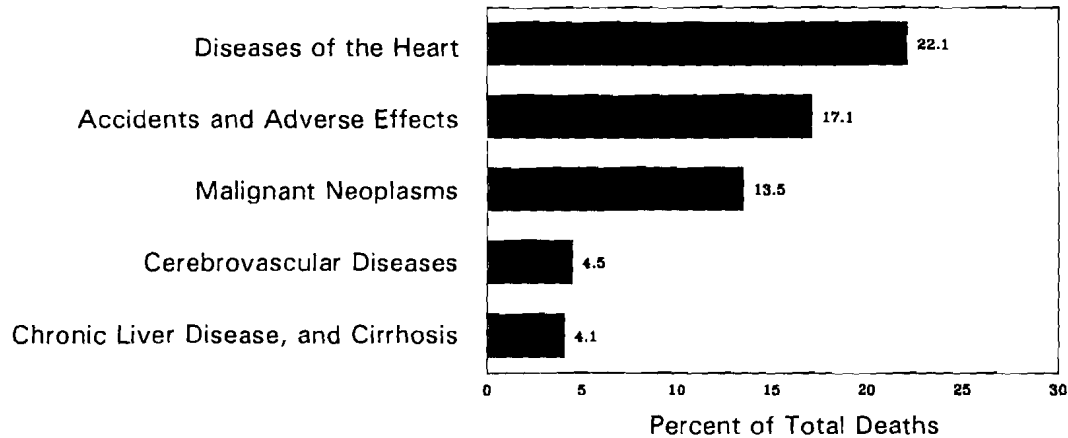
By studying cancer within American Indian and Alaska Native populations, scientists have the opportunity to learn about the disease itself which may be of assistance to people of all races. For example, cervical cancer incidence rates are high among American Indian women when compared with white women from the same geographic regions. However, American Indian women do not appear to have many of the risk factors which are commonly associated with cervical neoplasia among non-Native populations³. It is not known if genetics play a more significant role in cervical cancer within American Indian women as compared to non-Native women. Research is needed to improve understanding of the risk factors and the determinants of cervical cancer incidence among American Indians and Alaska Natives. Such data would benefit women of all races.

BACKGROUND ON AMERICAN INDIANS AND ALASKA NATIVES

At the turn of this century, cancer was a rare disease among American Indian people.⁴ According to a number of articles reviewed at the beginning of this century (Levin 1910), American Indians *never* had cancer.⁴ This was an erroneous conclusion, however, since cancer has been identified in skeletal remains found in archaeological investigations of Indian burial grounds.

The leading causes of death among American Indians and Alaska Natives in 1986-1988 for all IHS Areas are illustrated on Graph 1.1 on the following page.⁵ Although American Indians and Alaska Natives continue to experience low cancer incidence rates in comparison with other racial groups such as whites, blacks, and Asians, within the last few generations, cancer has become the leading cause of death for Alaska Native women, and is the second leading cause of death among American Indian women.^{6,7} Within the last thirty years, cancer has become the third leading cause of death for American Indians and Alaska Natives of all ages,⁸ and it is the second leading cause of death among American Indians over age 45 years.⁶

Graph 1.1: Leading Causes of Death: All IHS Areas for Calendar Year 1986-1988⁵



National Strategic Plan for Cancer Prevention and Control to Benefit the Overall Health of American Indians and Alaska Natives

Individuals who are interested in cancer research priorities among Indigenous Peoples may find the "*National Strategic Plan for Cancer Prevention and Control to Benefit the Overall Health of American Indians and Alaska Natives*" to be of assistance. This plan was prepared by the National Cancer Institute-supported *Network for Cancer Control Research among American Indian and Alaska Native Populations*. The purpose of this plan was to enhance the awareness in federal agencies and in others (e.g., State Departments of Public Health) about the problems of cancer among American Indian and Alaska Native populations. The Plan includes:

- An executive summary
- Introduction
- Overview of the Plan's issues and recommendations for federal agencies
- Action items
- Outcome measures

Cancer among Indigenous Peoples is emphasized in the Plan in its discussions of the poor cervical and breast cancer survival rates, the lack of access to early detection services, the lack of Indigenous health care providers and researchers, and the cultural barriers which interfere with effective cancer prevention and control programs. This Plan is included in its entirety in Chapter 12 of this publication.

Health Priorities among American Indians and Alaska Natives

Although cancer is an increasing health problem among Indigenous Peoples, a wide variety of health issues compete for attention within most Native American communities. It is challenging to raise "cancer" on the health agenda of Native communities where health priorities include alcohol/substance abuse, violence, accidents, suicide, diabetes, obesity, and cardiovascular disease. In addition, "cancer" as a problem is competing against poverty, shelter, unemployment, clothing needs, and access to sufficient nutritional foods such as fruits and vegetables for one's family and neighbors.

Despite the many cultural strengths associated with tribal membership, the current health status of American Indian and Alaska Native Peoples is significantly inferior to that of non-Indian populations. For example, general mortality rates from tuberculosis are 780 percent greater among American Indians than the U.S. rate; alcoholism are 663 percent greater for American Indians than for the U.S. population, accidents are 295 percent greater among Indigenous Peoples, diabetes is 268 percent greater than among U.S. population, homicide rates are 134 percent greater among American Indians, and suicide rates are 95 percent greater among Native Peoples than among U.S. populations.⁵

DEMOGRAPHICS

The Bureau of the Census has prepared a detailed analysis of 1990 American Indian Alaska Native data which is tentatively scheduled to be available during the latter part of 1993. The 1990 Census data were utilized in the following section when feasible. Some descriptive information is based on 1980 Census if specific 1990 data have not yet been released by the Census Bureau.

Age

In 1986-1988, the life expectancy at birth for nine of the IHS service areas (including Alaska) was 70.1 years, which was 4.9 years less than the 1987 estimate of 75.0 for U.S. All Races population.⁵ Only 5.6 percent of people who were self-identified as American Indians and Alaska Natives on the 1990 Census were older than 65 years of age. Approximately 14 percent of whites were over 65 years of age. At the time of the 1990 Census, a lower percent of American Indian and Alaska Native women (6.5 percent) were 65 years or older compared with American Indian and Alaska Native males (4.8 percent).⁹

According to the 1980 Census, the median age of American Indians a decade ago was 23.4 years, which is almost seven years younger than the average U.S. population figure of 30 years. Indians living on reservations were even younger, with a median age of 19.7 years. The median age of Alaska Natives was 21 years, compared with 26 years for the total Alaska state population and with 30 years for the average U.S. population. The life expectancy of Alaska Natives was 67 years.¹⁰

Poverty

In 1989, twice as many American Indians and Alaska Natives (30.9 percent) as the total U.S. population (13.1 percent) lived at or below the poverty level. The percent of whites living at or below poverty level in 1989 was 9.8 percent. The median family income in 1989

for Indigenous Peoples was \$20,025. The white median family income was \$31,435 in 1989.¹¹ Similar to other Native American groups, the socioeconomic conditions of Alaska Natives are poor. In 1980, approximately one-fourth of Alaska Native families lived below the poverty level.

Employment

According to the 1990 Census, 62.1 percent of Indigenous Peoples 16 years and older are in the labor force, of which 10.3 percent are in the armed forces and 14.4 percent are unemployed. The unemployment percent for whites was 5.2.¹¹ The unemployment rates among Indians living on reservations was higher than for Indians living in urban areas. A large proportion of American Indians have left reservations to get jobs that pay enough to support families.

Education

According to 1990 Census data, 65.5 percent of all American Indians and Alaska Natives age 25 and over completed at least four years of high school and 9.3 percent possess a bachelor's degree or higher. In comparison, 77.9 percent of whites complete high school or higher and 21.5 percent have a bachelor's degree or higher.¹¹ Approximately 85 percent of Indian youth attend public schools, 10 percent attend Bureau of Indian Affairs (BIA) schools, and 5 percent attend private schools.

Based upon 1980 Census, 18 percent of Alaska Natives ages 25 year or older had less than five years of elementary school, as compared with 2.6 percent of U.S. whites. Of the Alaska Natives 25 years or older, 46 percent had completed high school, in comparison to eighty-three percent statewide. Less than 4 percent of Alaska Natives were college graduates, in comparison with 21 percent statewide.¹⁰

Geographic Distribution - American Indians

There were approximately one million Native People on the continent at the time of Columbus; at the turn of this century there were only 200,000.¹² Today, the "American Indian" (which includes all tribes and clans of peoples who are Indigenous to continental U.S.) has the smallest number of people among identified racial groups in the United States. Approximately 1.9 million people (0.8 percent of the U.S. population) were self identified as American Indians and Alaska Natives on the 1990 U.S. Census.¹³ Although over 700 tribes of Indigenous Peoples originally inhabited this land, at least 200 tribes have become extinct. In 1988 the Bureau of Indian Affairs Federal Register listed and recognized approximately 500 tribes of Native People in the U.S.

Each of the surviving federally recognized tribes has its own unique and diverse culture and many are acknowledged by U.S. Congress as Sovereign Nations. In addition, there are hundreds of tribes which are recognized by individual states, but not by the federal government. An Act of Congress is required to formally "recognize" a tribe today. Many tribes no longer possess reservation or trust lands and several tribes share a single reservation. A map which illustrates the location of federal reservations is included in Figure 1.1 and the locations of the twelve Alaska Native Health Corporations is included in Figure 1.2.

Figure 1.1 The location of federally - recognized reservations and tribes.

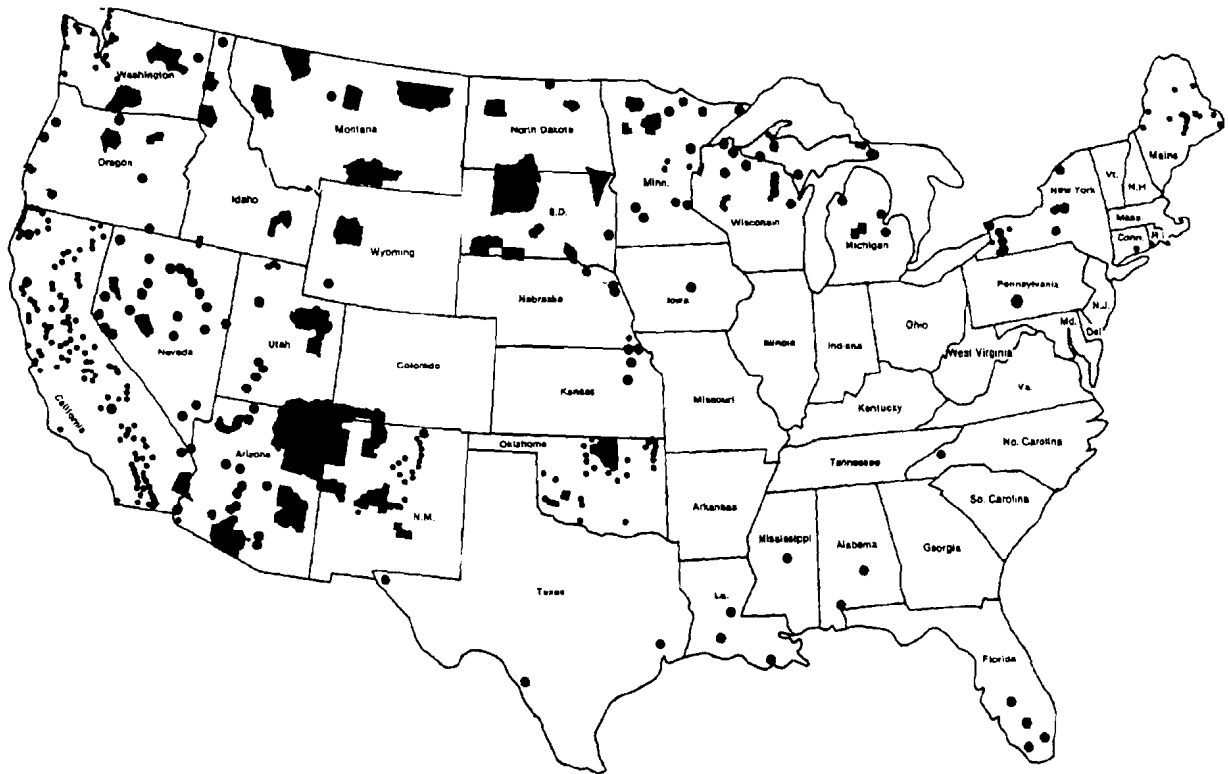
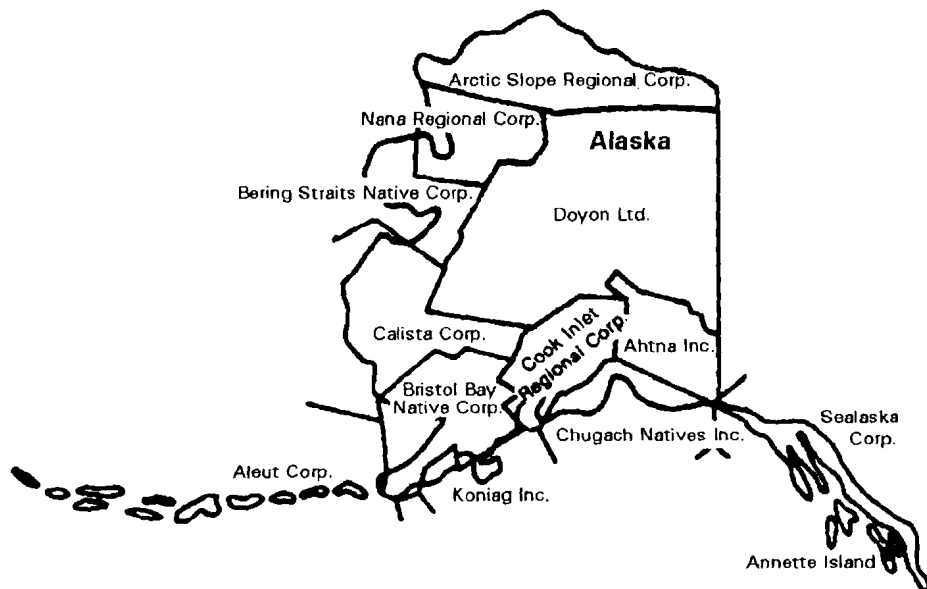


Figure 1.2 The location of Alaska Native Health Corporations.



There are 314 federal reservations and trust lands, 217 Alaska Native village statistical areas, 12 Alaska Native regional corporations, and 17 tribal jurisdiction statistical areas (which used to be referred to as the "historic areas of Oklahoma, excluding urbanized areas").¹⁴

About one-half of the American Indian population lived in the West in 1980, 27 percent in the South, 18 percent in the Midwest, and 6 percent in the Northeast (1990 Census data unavailable).¹⁰

American Indian people reside in every state. According to the 1990 Census, the states which have over 50,000 self-identified American Indians include the following: Oklahoma (252,420), California (242,164), Arizona (203,527), New Mexico (134,355), Alaska (85,698), Washington (81,483), North Carolina (80,155), Texas (65,877), New York (62,651), Michigan (55,638), and South Dakota (50,575).¹⁵

According to 1990 Census, the ten largest American Indian tribes are Cherokee (308,132), Navajo (219,198), Chippewa (103,826), Sioux (103,255), Choctaw (82,299), Pueblo (52,939), Apache (50,051), Iroquois (49,038), Lumbee (48,444), and Creek (43,550). Tribal members report residence in states in addition to the location of their home reservation. For example, 42.5 percent of the Sioux live in South Dakota, which is the location of Pine Ridge and Rosebud reservations. In addition, 7.3 percent of the self-identified Sioux on the 1990 Census live in California, 6.8 percent live in North Dakota, and 5.3 percent live in Minnesota.¹⁶

American Indians on Reservations

A reservation is an area of land held in trust by the federal government reserved for Indian use. However, according to the 1990 Census, of the 637,533 people living on Indian reservations, 60.9 percent are Indians and 39.1 percent are non-Indians. The Secretary of the Interior is the trustee for the U.S. federal government and the Bureau of Indian Affairs is responsible for the administration and management of Indian trust lands to the trustee.¹⁷

Contrary to popular opinion, according to the 1990 Census, only 19.8 percent of all American Indians live on a Federal reservations. According to the 1990 Census, the ten largest reservations and their respective populations are listed in Table 1.1.¹⁷

To illustrate the poverty level experienced by people living on those reservations a few data are presented:¹⁰

- Almost one-fourth of American Indian housing units lacked complete plumbing facilities.
- At least 50 percent of the homes on three of the largest reservations--Hopi, Tohono O'Odham, and Navajo--were without an indoor toilet.
- More than half (56 percent) of the American Indian housing units on ten of the largest reservations had no telephone.
- Sixteen percent of all American Indian housing units on reservations lacked electric lighting.
- Nearly 50 percent of the American Indian housing units on the Hopi and Navajo were without electric lighting.

Table 1.1 Ten Largest American Indian Reservations

10 Largest Reservations	Total Population	Native American Population
Navajo and Trust Land AZ, NM UT	148,451	143,405 (96.6%)
Pine Ridge and Trust Lands NE SD	12,215	11,182 (91.5%)
Fort Apache AZ	10,394	9,825 (94.5%)
Gila River AZ	9,540	9,116 (95.6%)
Tohono O'Odham AZ	8,730	8,480 (97.1%)
Rose Bud and Trust Land SD	9,696	8,043 (83.0%)
San Carlos AZ	7,294	7,110 (97.5%)
Zuni Pueblo AZ NM	7,412	7,073 (95.4%)
Hopi and Trust Lands AZ	7,360	7,061 (95.9%)
Blackfeet MT	8,549	7,025 (82.2%)

American Indians in Urban and Rural Areas

It is estimated that approximately 20 percent of American Indians live on tribal trust lands, 8 percent live on Historic Areas of Oklahoma, and another 3 percent live in Alaska Native Villages or rural areas.

Over 70 percent of the American Indian population lives off reservation or tribal trust lands, and over half live in urban areas. In the early 1950's, the Bureau of Indian Affairs monitored the "Relocation Program for American Indians" with the stated purpose of improving the status of living. Today, some urban Indian survivors of the 1950 Relocation Program are "second generation" to the city life and may or may not possess traditional cultural behaviors. Others are first generation urban residents. Some Indian people "migrate" back and forth from urban areas and to home reservations.

Indian people come to the cities for different reasons. Perhaps the most common reason is to secure employment. Others are forced to temporarily move to the city to obtain medical treatment that is not available on their home reservation. Or, as part of a rehabilitation program, a reservation American Indian may live in an urban area for six months to a year to maintain sobriety before returning to the home reservations.

Geographic Distribution - Alaska

Approximately one-third of Alaska Natives live in urban areas, primarily Anchorage, Fairbanks, and Juneau. The other two-thirds of the Alaska Native population live in one of more than 200 rural villages with populations of 50 to 1,000 people. Alaska Natives also live in the "lower 48" states, especially the northwestern states and California.

Tribes and Bands - Alaska

The 1990 Census enumerated 85,698 American Indians, Eskimos and Aleuts living in Alaska. Approximately one-seventh of Alaska's population is Native. Over one-half of these are Eskimo, approximately one-third are American Indian and slightly more than one-tenth are Aleut. The two main Eskimo groups are Inupiat and Yupik. The primary language among many of these groups is the Native tongue rather than English. The primary American Indian tribes living in Alaska are Athapaskan, Tlingit, Tsimshian, and Haida.¹⁰

According the 1990 Census, the ten largest Alaska Native Village Statistical Areas follow:¹⁷

Table 1.2 Ten Largest Alaska Native Village Statistical Areas

10 Largest Alaska Native Village Statistical Areas	Total Population	Alaska Native Population
Bethel	4,674	2,986 (63.9%)
Kotzebue	2,751	2,067 (75.1%)
Barrow	2,763	1,771 (64.1%)
Dillingham	2,017	1,125 (55.8%)
Hooper Bay	845	811 (96.0%)
Mountain Village	674	614 (91.9%)
Emmonak	642	591 (92.1%)
Point Hope	639	587 (91.9%)
Unalakleet	714	584 (81.8%)
Selawik	596	569 (95.5%)

ACCESS TO HEALTH SERVICES

Little data exist which describe access to health care. Although American Indians and Alaska Natives are eligible to receive comprehensive health services free of charge from the Indian Health Service (IHS), over half of Indigenous Peoples do not utilize IHS services. For those who do not take advantage of IHS facilities, the more common reasons are that they have medical insurance or that no IHS facility is accessible. For example, American Indians or Alaska Natives living in California (which is a reservation state and the state with the second largest number of Indigenous Peoples) cannot utilize IHS facilities because none exist within the state. A brief description of health care services is provided.

The Indian Health Service (IHS)

The Indian Health Service (IHS) was established under the Transfer Act of 1954 (Public Law 83-568). This act mandated that the "conservation of Indian health all functions,

responsibilities, authorities, and duties relating to the maintenance and operation of hospital and health facilities for Indians be administered by the Surgeon General of the U.S. Public Health Service." Based on this act, the Indian health program was transferred from the Bureau of Indian Affairs (BIA) to the Indian Health Service, which became the major provider of Federal health services to American Indians and Alaska Natives. The 1975 Indian Self-Determination Act (Public Law 93-638) gave tribes the capability of contracting, as well as the options of staffing, managing, and controlling, their own health programs. These latter programs are commonly referred to as "93-638 contracts".

The National Indian Health Service (IHS) is charged with providing health and medical services to American Indians and Alaska Natives (predominately in the 33 reservation states). It also provides the central organizational focus for cancer prevention and control services in this hard-to-reach/access population. The IHS program consists of tribal and federally operated hospitals, clinics and health centers as well as an extensive contract health services component. The mission of IHS is to raise the health of Native Peoples to the highest possible level.

Perhaps because of these public laws, it has been erroneously assumed that the IHS has the sole responsibility of providing health care to all American Indians and Alaska Natives, either directly, or through P.L. 93-638 contracts. Although the IHS has the primary responsibility, it cannot accomplish its mission without collaboration with other federal agencies.

The Indian Health Service coordinates services through its 11 regional administrative units which are called IHS Area Offices. The Office of Health Program Research and Development in Tucson is also considered an Area Office even though it functions differently than the other 11 Areas. In the Fall of 1990, the Area Offices consisted of 136 service units, of which 58 were operated by tribes. As of 1990, tribes operated 7 hospitals, 89 health centers, 3 school health centers, 64 health stations, and 173 Alaska Village Clinics and the IHS operated 43 hospitals, 66 health centers, 4 school health centers, and 51 health stations.

In addition to these health facilities, the IHS partially funds 34 urban Indian programs. Of these, 28 are medical clinics.⁶ The 12 IHS Area Offices covering 33 reservation states are: Aberdeen, Alaska, Albuquerque, Bemidji, Billings, California, Nashville, Navajo, Oklahoma, Phoenix, Portland, and Tucson.

Although Indian Health Services are not limited to reservation-based Indians, the IHS clinical facilities are usually found on or near reservations and receive the majority of health funds. American Indians and Alaska Natives live in all fifty states, but the Indian Health Service provides services in the following 33 states which are designated "reservation states":

Table 1.3 The 33 Reservation States

Reservation States (33)		
Alabama	Maine	North Dakota
Alaska	Massachusetts	Oklahoma
Arizona	Michigan	Oregon
California	Minnesota	Pennsylvania
Colorado	Mississippi	Rhode Island
Connecticut	Montana	South Dakota
Florida	Nebraska	Texas
Idaho	Nevada	Utah
Iowa	New Mexico	Washington
Kansas	New York	Wisconsin
Louisiana	North Carolina	Wyoming

Survey of American Indians and Alaska Natives (SAIAN) - Access to Care Survey Items

The National Medical Expenditure Survey (NMES) II Household Survey provides extensive information on health expenditures by or on behalf of American families and individuals, the financing of these expenditures, and each person's use of services. The NMES is a research project of the Center for General Health Services Intramural Research, Agency for Health Care Policy and Research. This same survey instrument was administered as the Survey of American Indians and Alaska Natives (SAIAN) and was implemented in 1987 to 6,500 individuals who lived on or near federally recognized reservations in 33 states. A multistage area probability sample design was used.¹⁸ According to the SAIAN, persons who identified a facility not operated by the Indian Health Service as their usual source of care were more likely to have had an appointment, to have traveled shorter distances, and to have waited less time to be seen than those who reported using the Indian Health Services as their usual source of care.¹⁸ Many IHS-eligible persons identified a facility not supported by the Indian Health Service as their usual source of care. This was found most often for those who had private health insurance or relatively higher income.

Urban American Indians and Health Services

In 1976, Congress passed the Indian Health Care Improvement Act (Public Law 94-437) which addressed the health deficiencies of Indians living on reservations and in urban areas. Title V of this law, "Health Services for Urban Indians", is directed at improving the health status of urban Indians. In 1992 there were 34 urban Indian health programs in 19 states receiving Title V IHS funding and two additional programs in Oklahoma funded as "demonstration projects" under the IHS. Although 54-68 percent of the American Indians and Alaska Natives primarily reside in the urban areas, less than 2 percent of the total IHS budget is allocated to urban Indian clinics. As of December 1992, only one individual from IHS headquarters was assigned to urban health programs. The 34 urban Indian clinics which receive partial support from IHS are listed in Appendix A.

DISCUSSION

"Many challenges are facing American Indian and Alaska Native communities, and certainly one of the most important is their well-being: the health of their people, their cultural traditions and their environment. Many Indian people are rediscovering traditional perspectives that are relevant in addressing these challenges. The importance of balance in their lives, in their communities and with their environment is once again being seen as playing a vital part in the process of health promotion, disease prevention, and community development...The historical record is clear. No one can make Indian and Alaska Native communities do something they do not wish to do. It is Indian people who are ultimately responsible for their own communities, and it is Indian people who will determine what level of health Indian people will achieve and maintain." (Stanford Center for Research in Disease Prevention. *Restoring Balance: Community-directed Health Promotion for American Indians and Alaska Natives*. Stanford, California. (Library of Congress Catalog Card Number 92-93511) 1992, p. xiii.

Native Cultures

The health status of Native American groups cannot be fully understood apart from their history or their present social conditions. As with all other minority groups within the broad American population, poverty and education play major roles. Certainly, there have been many misconceptions about American Indians and Alaska Natives. All too often contemporary media carries news only of the disturbances and not the triumphs of Native American people. All too often the public perception is distorted, sometimes in a highly romanticized or very negative direction. It is time to reexamine these attitudes and to conduct new assessments of the factors at play in determining the health and life expectancy of these groups. The cultural information supplied here is relative to the issues that should be considered in developing sensitive and acceptable health education programs and research endeavors.

There are reasons to hope that Native Americans with their growing political expertise will be able, as other groups have, to develop and implement culturally acceptable social and health programs. The fact remains that today, the health, welfare and education of Native Peoples fall below the national average.⁵

Fortunately, progress has been made in some areas toward self-determination and independence. Many American Indians and Alaska Natives are currently participating in an empowerment movement with the goal of expressing themselves as stronger, confident, self-reliant Peoples proud of their beautiful and diverse cultures. In the 1930's through to the early 1960's, many Native People denied their heritage for fear of prejudice and other forms of alienation. However, since the latter 1960's, there has been a resurgence of American

The Surveillance, Epidemiology, and End Results (SEER) Program was initiated in 1973 by the National Cancer Institute (NCI) to collect cancer data on a routine basis from designated population-based cancer registries in various areas of the country. The geographic areas comprising the SEER Program's data base represent an estimated 9.6 percent of the United States population and include states or counties such as Connecticut; Detroit, Michigan; Iowa; New Mexico; Utah; San Francisco/Oakland, California; Hawaii; Atlanta, Georgia; and Seattle-Puget Sound, Washington.

The SEER program (1) provides estimates of cancer incidence and mortality in the United States; (2) monitors annual cancer incidence trends to identify unusual changes in specific forms of cancer occurring in population subgroups defined by geographic, demographic, and social characteristics; (3) provides continuing information on changes over time in the extent of disease at diagnosis, trends in therapy, and associated changes in patient survival; and (4) promotes studies designed to identify factors amenable to cancer control interventions, such as: a) environmental, occupational, socioeconomic, dietary, and health-related exposures; b) screening practices, early detection and treatment; and c) determinants of the length and quality of patient survival.

The SEER areas are responsible to record information from all death certificates on which cancer is listed as a cause of death for residents dying in or outside the coverage area. They also collect new cases and register malignant neoplasms with the exception of certain histologies for cancer of the skin. SEER records data on all newly diagnosed cancers, including selected patient demographics, primary site, morphology, diagnostic confirmation, extent of disease, and first course of cancer-directed therapy. SEER also provides active follow-up on all living patients except those with in situ cancer of the cervix uteri. This and other information is submitted to NCI twice a year. A quality control program has been implemented to ensure quality.

SEER registries are regarded as being among the best sources of cancer data. However, New Mexico is the only SEER site that contains a sufficient number of American Indians (19 percent of all Indian people live in Arizona and New Mexico) and represents a reasonable sample within its SEER population. These data are useful for local tribes that include, but are not limited to, the Navajo, Hopi, Mescalero Apache, Jicarilla Apache, Ute, Pascua Yaqui, and nineteen Pueblo tribes (e.g., Zuni, Acoma, Santo Domingo). However, given the uniqueness of different American Indian and Alaska Native tribes and clans, New Mexico data are not representative of the populations from other regions. This will be illustrated in Chapter four.

NATIONAL CENTER FOR HEALTH STATISTICS

DATA LIMITATIONS: (1) INCLUDE INSUFFICIENT NUMBERS OF AMERICAN INDIANS AND ALASKA NATIVES ON NATIONAL SURVEYS SUCH AS THE NHIS; AND (2) RACIAL MISCLASSIFICATION.

The Centers for Disease Control and Prevention's National Center for Health Statistics has a variety of data including, but not limited to, mortality statistics, results from the National Health Interview Survey, and the National Death Index.

Undercount of Native Americans

Many American Indians and Alaska Natives did not participate in the Census even though Census personnel made repeated attempts to contact them. Lack of Native participation by Native People was due to several reasons. Native People migrate from rural villages or reservations to the urban area to find employment. Jobs such as fire fighting in Washington, lumbering in Montana, and fishing in Alaska are seasonal and may require migration for several months at a time. Other Natives purposely did not participate in the Census in protest to a long history of broken U.S. governmental commitments and in recognition of their own Indian Nations' sovereignty.

The "Race" and "Ethnicity" survey items

A major limitation of U.S. Census and other questionnaires is the question asking about "race". The resulting number of American Indians and Alaska Natives change depending on the phrasing of the question. For example, the U.S. Census racial question allows American Indians and Alaska Natives to identify their ancestry rather than requiring blood quantum or tribal enrollment numbers. Hahn (1992) states that there is an overcount of American Indians when self-identity or ancestry are used in Census data. In a 1980 re-interview study, 41 percent of persons who identified themselves as American Indian had reported themselves as white in the 1980 census. Also in the 1980 census, while an estimated 6.8 million persons reported American Indian ancestry, only 1.2 million reported American Indian race ... only 73 percent of those reporting American Indian race claimed American Indian ancestry".⁴

Blood quantum is not always a clear indication of American Indian Alaska Native status. For example, someone who has 1/16 of Native bloodline may mark American Indian or Alaska Native on the Census, but live in accordance with mainstream lifestyles. Many Native People fear that non-Natives who identify themselves as Indians will try to gain access to tribal benefits, such as health services and special educational programs. This also raises the unresolved issue that ancestry, cultural identity and blood quantum are frequently but erroneously used as equivalent indicators of racial status.

Tribal enrollment may also present confusion. People who are of mixed Indian blood may be enrolled in multiple tribes. When completing the U.S. Census questionnaire, the instructions specify that the principal tribe be listed first on the questionnaire. When interpreting and summarizing data, the Census only includes the first tribe listed in its analysis, losing important information about behaviors which may be inherent to "secondary" tribal affiliations. Misclassification of cultural and lifestyle behaviors occur when the individual is active in more than one tribe. Tribal behaviors are diverse and may have a significant impact on the presence or absence of cancer risk factors.

NCI SURVEILLANCE, EPIDEMIOLOGY, AND END RESULTS DATA (SEER)

DATA LIMITATIONS: (1) MOST SEER TUMOR REGISTRIES HAVE RACIAL CLASSIFICATION ERRORS; AND (2) SOUTHWESTERN DATA CANNOT BE GENERALIZED TO NATIVE PEOPLES LIVING IN OTHER REGIONS.

epidemiologic research and for the design, implementation, and evaluation of public health interventions.¹

Limitations of national databases which affect *most* underserved populations (e.g., Native Hawaiians, Vietnamese, Hispanic) include one or more of the following:

- Racial misclassification
- Undercounting
- Coding errors (universal to people of all races)
- Inclusion of insufficient numbers of the racial group to formulate conclusions
- Data collection in selected geographic regions which cannot be generalized to Peoples in other areas

The quality of databases varies among racial groups and among geographic regions of the country. For example, the data from the New Mexico Tumor Registry are among the more comprehensive and accurate records of cancer among American Indians and Alaska Natives. New Mexico Tumor Registry staff recognized the need to collect accurate and precise data on all people, including underserved populations, such as American Indians and Hispanics. As a result, data collection protocol was implemented which accurately ascertains the race and diagnosis of the cancer patient. Other tumor registries may not have had the same level of interest to incorporate similar techniques until recent years. Collection of accurate racial information is now a higher priority in tumor registries, such as the Fred Hutchinson Cancer Research Center.

THE U.S. CENSUS DATA

DATA LIMITATIONS: (1) UNDERCOUNT OF AMERICAN INDIANS AND ALASKA NATIVES; AND (2) RACIAL/ANCESTRY SURVEY ITEMS.

The Census Bureau produces published and unpublished statistics from its censuses and surveys for states, counties, cities, etc. and from the decennial census, for smaller areas down to the size of a city block.² The results of enumeration of people and their housing units every ten years provides an overview of the population size and distribution, socioeconomic and housing characteristics.

The Census Bureau has been collecting information on American Indians as a separate group since 1860, but Indians living in Indian Territory and on reservations were not included in population counts until the 1890 Census.³ In preparing for the 1990 Census, the Census Bureau established liaisons with more than 300 tribal governments in their attempt to include all American Indian and Alaska Native people in the Census. Among urban and rural dwelling Native Peoples, one in six households received the long questionnaire. However, on reservations and in Native Villages, although one in two households were to receive the long questionnaire, many households were excluded. The Census estimated that racial minorities were undercounted by approximately 6 percent in the 1980 Census. The estimated undercount of minorities in the 1990 Census was at least as high.

CHAPTER 2: LIMITATIONS OF EXISTING CANCER DATA AMONG AMERICAN INDIANS AND ALASKA NATIVES

CHAPTER OBJECTIVES:

- DESCRIBE THE LIMITATIONS OF NATIONAL CANCER DATABASES
 - IDENTIFY THE TYPES OF DATA WHICH NEED TO BE COLLECTED
-

INTRODUCTION

Policy makers, researchers, and health care professionals at all levels (federal, state and local) rely on national databases as accurate, representative sources of information. Existing national databases, such as the U.S. Census population counts, National Center for Health Statistics mortality data, National Cancer Institute Surveillance, Epidemiology, and End Results (SEER) Program, and National Indian Health Service, are cited as reputable sources for cancer information. However, each national cancer database has limitations when used for American Indians and Alaska Natives which need to be acknowledged when these data sources are utilized.

There is no single national database that accurately presents cancer-related data for Indigenous Peoples. As a result, multiple databases must be relied upon to assess the cancer problem among American Indians and Alaska Natives. The heterogeneity of American Indian and Alaska Native populations and their lifestyles has contributed to difficulties in drawing conclusions about the reported lower incidence of cancer in Indigenous Peoples than in other minority groups. This database limitation is not specific to American Indians and Alaska Natives, but affects most racial groups.

The Limitations of Regional and National Databases

The types of cancer data that are available for U.S. whites and blacks are unavailable for the majority of Native Americans, Hispanics, Vietnamese, and so on. The diversity of American Indian populations greatly limits generalizing available cancer data to all tribal groups.

Based upon the limited data, cancer appears to be accelerating throughout Indian Country, and is worse in Alaska and the Northern states. Accurate data are needed to set health priorities and develop innovative cancer programs. Accurate statistics are critical for

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until recent years. Traditional healers and medical doctors occasionally work cooperatively with one another, and are greeted with great welcome and relief by Native patients.

Social Structure

Native cultures have strong social structures. The family is the focal point of most activities and practices. Within the family unit, the woman is highly esteemed because she gives the gift of life. The woman is typically the caretaker of the family who places the needs of family members before her own. Likewise, the male is traditionally viewed as the protector of the home and the local tribal community. Children are viewed as blessings from the Creator and are included in almost every tribal activity rather than being kept at home to be watched by non-family persons. Elders are cherished as resources of vast knowledge and experience; it is expected they will help educate the young about tribal practices, histories, and ceremonies which are verbally passed from one generation to another. Each of these family member roles can be constructively integrated within a cancer research project.

Although symbolism is common among Native People, specific symbols usually have different connotations among the different tribes. Circles, such as "the Circle of Life" and the "Medicine Wheel", have multiple positive meanings among tribal communities as do the Four Directions - East, South, West and North. Non-Natives should be cautious about using symbols because of the diversity of interpretation and connotations among tribes.

Demographic Considerations

The researcher or program planner needs to be apprised of demographics while designing a cancer project. For example, it is inappropriate to plan to implement a telephone survey on the Navajo reservation where over 74.5 percent of the population do not have access to a telephone. Since the poverty rates are high, research projects which generate employment as well as train Indigenous Peoples in new fields and increase empowerment are more welcomed in tribal communities than are projects that send non-Natives to a reservation or Indigenous Health Clinic to implement the research project. The education level is low among many indigenous Peoples, which requires that research materials, such as statement of consent or intervention pamphlets, be written at a literacy level that most residents can understand. The previous description of demographics is a compilation of national data. Local Native data are different and require collaboration with Native communities to obtain accurate demographic information for the local target population. Such data are essential to identify appropriate cancer intervention settings and methodology.

SUMMARY

This first section was an overview of American Indian and Alaska Native Peoples' present condition as well as a brief summary of background information. Although most people living in the U.S. are aware of Indigenous Peoples through movies and other media, their Hollywood image differs from their actual living situations. Descriptive information was provided which may complement cancer risk factors, incidence, mortality, and survival data which are further explained in subsequent chapters.

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