Facing Cancer in Indian Country:
The Yakama Nation and Pacific Northwest Tribes

President's Cancer Panel
2002 Annual Report

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health
National Cancer Institute

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Prepared by:
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for The President's Cancer Panel

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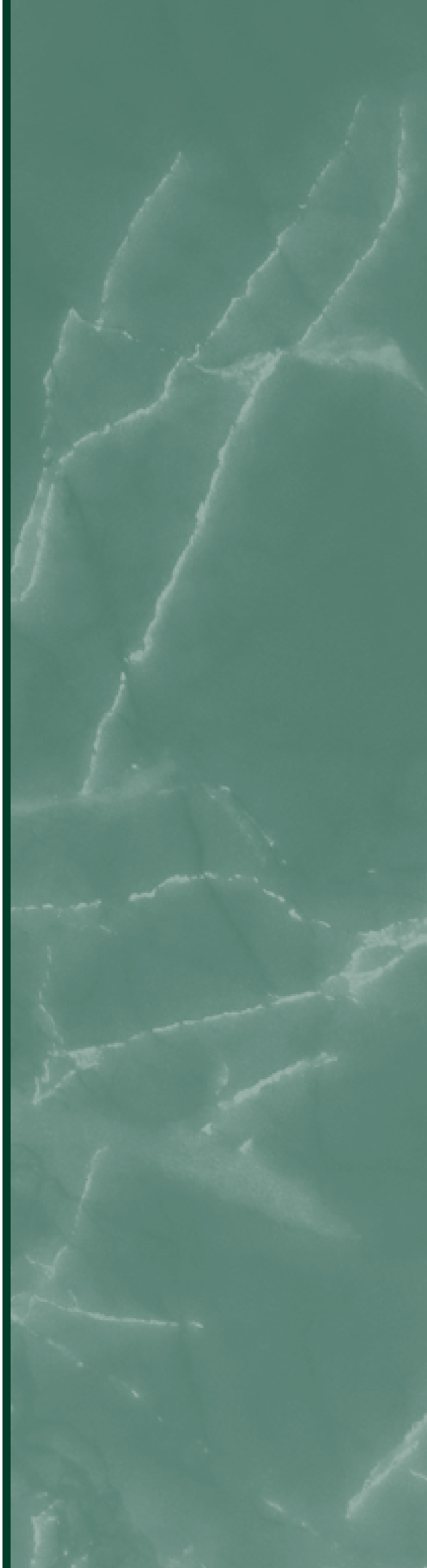

This report is submitted to the President of the United States in fulfillment of the obligations of the President's Cancer Panel to appraise the National Cancer Program as established in accordance with the National Cancer Act of 1971 (P.L. 92-218), the Health Research Extension Act of 1987 (P.L. 99-158), the National Institutes of Health Revitalization Act of 1993 (P.L. 103-43), and Title V, Part A, Public Health Service Act (42 U.S.C. 281 et seq.).

The President's Cancer Panel

Immediate Past Chair and Member:
Harold P. Freeman, M.D.
Director
The Ralph Lauren Center for Cancer Care and Prevention
New York, NY 10035

This report was commissioned under the direction of Dr. Harold P. Freeman.

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PRESIDENT'S CANCER PANEL

NATIONAL CANCER PROGRAM NATIONAL CANCER INSTITUTE NATIONAL INSTITUTES OF HEALTH
DEPARTMENT OF HEALTH AND HUMAN SERVICES

The President
The White House
Washington, DC 20500

Dear Mr. President:

No matter who you are or where you live, a diagnosis of cancer is devastating. Knowing—or suspecting—that you or a loved one has cancer and being unable to access prompt and appropriate care is an unconscionable human cruelty.

In July 2002, the President's Cancer Panel was invited to visit the Yakama Nation in Washington State to learn about cancer occurring among the Yakama and other Native American tribes in the Pacific Northwest region of our Nation.

Moving and troubling testimony was received from nearly 40 cancer survivors, family caregivers, physicians and other medical personnel, outreach workers, health care administrators, and cancer researchers. They described in detail an Indian health system hobbled by longstanding, severe underfunding, inadequate infrastructure and staffing, and the maze of complex and arcane requirements of the Indian Health Service (IHS) system. These problems frequently cause needed cancer care to be delayed for months at the patient's peril—and even denied entirely.

Indian communities have inadequate resources to conduct cancer education, encourage cancer screening and prevention, and help patients obtain cancer-related care, either within the IHS system or in the non-Indian community. Important but remediable cultural misunderstandings by care providers and patients alike often complicate the provision of cancer care, and simply reaching cancer care facilities from remote reservation areas is itself a major barrier. All of these issues are made worse by the widespread poverty and limited educational and economic opportunities common to Indian communities.

Mr. President, although our Nation now faces many serious challenges to our national security and fiscal well-being, we must not shirk the responsibility of our Government to provide necessary cancer and other health care to the first Americans.

Facing cancer in Indian Country should not be more arduous than it is elsewhere in our Nation. I respectfully submit the attached report and recommendations to help meet our national obligation and alleviate the unnecessary suffering that Native American people with cancer and their families now endure.

Sincerely,

Harold P. Freeman

Harold P. Freeman, M.D.
Immediate Past Chair and Member

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Executive Summary

Every person in America should have access to prompt and appropriate screening and treatment for cancer. No individual—or group of people—should suffer the fear and despair of knowing, or suspecting, that their body harbors a deadly cancer and be unable to receive life-saving care. Yet for many American Indians and Alaska Natives in the Pacific Northwest region of our Nation, lack of cancer screening and treatment—or dangerously delayed care—is the norm, not the exception.

In accordance with its charge to monitor the development and implementation of the National Cancer Program and report promptly to the President on barriers to the Program's fullest execution, Dr. Harold P. Freeman, representing the President's Cancer Panel, traveled to the reservation of the Confederated Tribes and Bands of the Yakama Nation in Washington State. Representatives from the Yakama Nation and other Pacific Northwest tribes described their cancer experiences and discussed barriers to cancer care.

For two days in July 2002, testimony was received from tribal elders and members of tribes in Alaska, Idaho, Oregon, and Washington, many of whom are cancer survivors or family caregivers. Additional testimony was provided by Native and non-Native health care and social service providers; officials of the Indian Health Service (IHS); community epidemiologists and researchers; advocates; State legislative staff; and others. In total, nearly 40 people shared their experiences and described key issues affecting cancer incidence, mortality, and care in this region.

“One of the things that is very difficult for outsiders to understand is the relationship between the fish and the people. The tribal people will tell you that they are the salmon. Salmon is the first food for many of the babies born here, and from birth to the death of the body, the people and the salmon share each other's lives. Many religious and cultural practices are centered on salmon.”

Christine Walsh, B.S.N., E.P.H.N.*, Project Coordinator, Contaminated Subsistence Fish Project, Indian Health Service; Member, Rosebud Lakota (SD) and Oneida (NY) Tribes, Washington*

Economic and Physical Environments of Pacific Northwest Native Americans

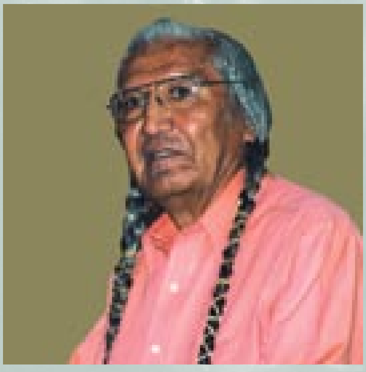
Many Pacific Northwest tribal lands are located in remote areas with little industry or educational opportunity. Poverty and unemployment are exceptionally high and educational achievement is lower than that of the general population. Native-owned and -operated businesses, including a number of casinos, have thus far been unable to lift the overall economic status of these tribal communities.

Many tribal people of the region continue to depend on the fish, game, roots, and berries native to the area for the majority of their diets. For several of the tribes, fish—particularly salmon—from the Columbia River system is the principal source of dietary protein and is consumed at levels far exceeding the fish intake of the general population. A deep respect for the natural environment is a central element of the culture and belief systems of many Northwest tribes.

However, the Yakama and other Native Americans and Alaska Natives of the Pacific Northwest also live in areas having some of the Nation's highest levels of man-made radioactive and chemical contamination. Chief among these is the Hanford nuclear facility in south-central Washington, adjacent to the Yakama Reservation. Other reservations in the Northwest are subject to contamination from nuclear weapons production sites, uranium mines, and other hazards related to the nuclear weapons industry. Extensive chemical contamination has been found throughout the Columbia River Basin and adjacent lands. Some of the sources of contamination are unknown, but much comes from agricultural chemicals and cattle farming waste runoff. The tribes believe their life-long exposure to these contaminants has increased the number of cancers occurring in tribal communities. To date, few studies have been done to determine the causative or contributory relationships between food, air, and water contamination and the cancers being experienced by these Native populations.

Cancer Among the Yakama and Other Pacific Northwest Tribes

National data suggest that cancer incidence among Native Americans is lower than the national average, but that their mortality from cancer is higher than average. Information on the exact magnitude of the cancer burden among Native Americans is both incomplete and compromised by significant levels of racial misclassification, underreporting of cancer cases, the reluctance of many Native Americans to provide personal information to researchers or cancer surveillance personnel, and insufficient and underutilized databases, among other problems. Recent record linkage studies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> “[We] have in our front yard down here the oldest and largest nuclear facility that has...bombarded this area with radioisotopes for 60 years. And we do not know what has happened to the gene pool of the Yakama Nation.”

***Russell Jim**, Manager, Environmental Restoration Waste Management Program; Tribal Elder, Yakama Nation, Washington*

> “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....”

***Geneva Charley**, Community Health Information Specialist, Warm Springs Tribe, Oregon (membership 3,944, median age 23.9 years)* conducted by tribal organizations and grantees suggest that cancer incidence is higher than national data suggest. Higher mortality appears to be due to late-stage diagnosis and limited health care access.

Health Care Infrastructure and Financing

Except for small numbers of tribal members who have private insurance or coverage under a plan for tribal employees, Pacific Northwest Native Americans must rely on the Indian Health Service (IHS) clinics and health stations for direct (primary) care, and on separately funded contract (specialty) care for all other services, including cancer care and most cancer screening. In many tribes, contract care is administered by the tribe, while direct care facilities are operated by IHS. Both, however, are grossly underfunded to meet the health care needs of the population. For many tribes, funding for specialty care is exhausted, or nearly so, months before the end of the fiscal year. When this occurs, only patients at risk of life or limb (designated as Priority 1) receive such care, and even then care may be delayed. The Yakama tribal contract health program has operated on Priority 1 status for the past two to three years.

In addition, many reservation residents live far from the nearest IHS or tribal primary health facility, and the nearest cancer care is often hundreds of miles away. Some tribes have no health facilities at all. Urban Indians, who comprise more than half of the Native American population in the Pacific Northwest (and the Nation) are served by only three Indian health clinics in the region; some receive care at other publicly-funded health centers. They have no access to specialty care unless they are Medicaid-eligible, Medicare beneficiaries, have private insurance, or return to the reservation of the tribe in which they are enrolled.

Increasingly, individual Native Americans and IHS health facilities are relying on Medicaid, Medicare, and other publicly-funded health services to try to cover the cost of care needed by tribal members. Yet continuing decreases in Medicaid funding to States and uncertainties regarding Medicare reimbursements to facilities and individual providers are reducing the number of providers willing to care for these patients. These funding problems, and accompanying infrastructure and staffing insufficiencies, result in health care rationing that causes many Indian cancer patients to be diagnosed only when their disease is advanced and

“We only have four physicians taking appointments. That leaves approximately 5,000 plus patients per doctor. When you talk about cancer prevention, how can one prevent cancer when you cannot even keep up with the onslaught of patients coming through that door? When you cannot get an appointment for two months?”

Rex Quaempts, M.D., *Family Physician, Indian Health Service; Member, Yakama Nation, Washington*

“There are some tribes...completely without health facilities of any sort and this is a shame that in this day and age that we allow this to go on.”

Tom Lang, Sr., *Colorectal and Throat Cancer Survivor; Councilman, Metlakatla Alaska Indian Community; Elder, Tsimpsean Tribe, Alaska* untreatable. Further, this situation reinforces the belief held by many Native Americans that a cancer diagnosis is a death sentence; some avoid seeking care for suspicious symptoms out of fear or resignation.

Cultural and Information-Related Barriers to Cancer Care

Some Native people also hesitate to engage the health care system, particularly providers outside the IHS system, due to cultural and language barriers. Even within the IHS system, many of the available physicians are foreign nationals who are temporary and are unfamiliar with Native American cultures and beliefs. Building a relationship of trust and mutual respect with the health provider is often extremely difficult under these circumstances. In addition, many non-Indian providers are unwilling to include traditional health practices or Native ceremonies in hospitals or in the course of other cancer care even when it is possible to do so without jeopardy to the patient's treatment.

Many Native Americans believe that it is inappropriate to discuss cancer, which still carries a strong stigma in Native communities. Modesty among Native women prevents many from seeking cancer screening and care. Lower literacy, particularly among older individuals, complicates communication about cancer and other health issues, and culturally appropriate educational materials are scarce. Most Native languages do not even include a word for "cancer."

Conclusions

The attached report is not an exhaustive review of the complex issues described by those who testified. However, based on the testimony and subsequent further information gathering, opportunities exist to address cancer care barriers related to health services funding and infrastructure deficits, cultural issues, information and training needs, and geographic barriers to care. Specifically:

The Cancer Burden of the Yakama and Other Pacific Northwest Tribes Cannot Be Separated from Their History and Current Circumstances

Cancer occurs in humans who live in specific human circumstances. In large measure, the widespread poverty and limited economic opportunities experienced by Native

"I just 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**, Business Council,*
Spokane Tribe, Washington

"...if the doctors would treat us as individuals instead of lump us all in one category....I think a lot of them come and think that we are all to act this way or be this way but we are not like that."

***Tina Kalama Aguilar**, Caregiver,*
Warm Springs Tribe, Oregon

Americans are the driving force behind many of the health status and coverage problems facing tribal people. Lower socioeconomic status and the circumstances that typically characterize it—poor housing, low income, limited education, greater environmental and occupational exposures, limited access to information and communication technologies, insufficient access to transportation services—are associated with later stage cancer diagnosis and higher mortality. Commonly, people living under these conditions suffer from excessive stress and feelings of hopelessness and isolation. Thus, it is highly likely that the history leading to the current living and health care situations of the Yakama and other Pacific Northwest tribes has influenced not only the cancers occurring in these populations, but the distrust many Native Americans feel toward non-Indian health care providers.

Health Care Funding for Pacific Northwest Tribes Is Seriously Inadequate

IHS funding is appropriated annually at the discretion of Congress and is not adequate to meet the health care needs of Native American people. This ongoing funding deficit is a major factor in cancer-related and other disparities experienced by Native populations. The Institute of Medicine (IOM) has stated that closing the gap on health disparities for this population will require a national recommitment; especially in the form of increased Federal funding that would allow patients timely access to specialty care. According to IHS officials, in the Pacific Northwest, IHS health care budgets for reservation-based American Indians and Alaska Natives are based neither on current census figures nor on actual numbers of patients served. These funding inadequacies are the root of major barriers to preventive cancer care, early detection, diagnostic services, the most appropriate treatment (including treatment provided in clinical trials), and supportive and end of life care.

Medicaid and Medicare funding levels and continuing disparities in rural versus urban reimbursement levels are exacerbating an already critical funding shortage. Funding issues make it exceedingly difficult to attract and retain health care providers in remote rural areas. Insufficient funding also results in excessive patient loads, lack of up-to-date equipment, inadequate staff support, professional isolation, and untenably low incomes that contribute to the problem.

“...social and cultural things are critical because sometimes the relevance or the importance of follow through, the importance of communicating to the patients the critical nature of the diagnosis or the way it may impact their lives is going to be quite different for each culture.”

***Thomas Boyd, M.D.**, Medical Oncologist, Yakima Regional Cancer Center, Washington*

“Undercounting affects how resources are allocated and that, in turn, affects the level of health resources available to us and how they are allocated.... Another challenge is overcoming the misperception that all American Indians’ and Alaska Natives’...health care is covered by the United States Government. We all know that this just is not so.”

***Ruth Jensen**, Northwest Tribal Cancer Control Project; Member, Klinquit Nation, Alaska*

Although urban American Indians and Alaska Natives comprise more than half of the Native American population, IHS budget allocations for their care equal approximately one percent of the total IHS budget. The solution to this problem is not to reallocate the current IHS budget, but to increase IHS funding to provide a level of service to urban Indians that is at least commensurate with the average level-of-need funding for reservation-based Native Americans.

The June 2002 preliminary report of the Restructuring Initiative Workgroup—a constituent-dominated group of tribal leaders, representatives of tribal and urban Indian health programs, national Indian organizations, and Federal employees—provides a blueprint for a five-year plan to restructure Indian health care. Among other recommendations, the report indicates that IHS appropriations should be removed from the discretionary funding pool and that funding levels should increase to $5 billion by 2007.

Greater Synergies Should Be Achievable with Existing Health Care Resources in the Pacific Northwest

The limitations of current IHS funding and health care infrastructure are clear. However, a number of other health care resources are available in the region, such as community health centers, migrant health centers, neighborhood health centers, other Federally-funded health facilities, State and local grant-supported health programs, and the private provider network. Through collaborative efforts, it should be possible to achieve greater synergy among the available resources to better serve the Native American population. Such collaborations might result in enhanced joint buying power for services such as pathology or radiology, and coordinated patient tracking systems, among other possible benefits to all participants. It was suggested that tribes be made more aware of non-profit clinics in their geographic areas. In addition, technical assistance in grant writing could help tribes expand the scope of cancer-related health services and culturally appropriate cancer information available to Indian people.

Moreover, a recent IOM report urges the Federal Government to provide leadership in coordinating government roles and resources to improve health care quality. Medical facilities serving Native Americans are one of several categories of Federally-operated programs the IOM believes should serve as laboratories for developing innovative quality improvement models. This report may prove useful in suggesting promising strategies for collaboration and health care quality improvement in the Pacific Northwest.

Culturally Appropriate Cancer-Related Education Is an Urgent Need

To increase the tribes' knowledge about cancer prevention and treatment, and to dispel fatalism about cancer among Native populations, culturally appropriate and widespread public education is needed. Many do not know that cancer is the second leading cause of death among Native Americans. Speakers also emphasized the need for education on personal health and lifestyle behaviors that influence disease risk, including cancer risk. This education, they stressed, should begin with youth. Educational materials that incorporate visual learning are needed, as are print materials written at the average reading level of the target populations. Importantly, education and awareness must be accompanied by health system capacity; it is unethical to create demand for services without the infrastructure and staffing to meet the demand.

Additionally, education is one avenue for addressing many Indian peoples' deep distrust of cancer treatment, and of data collection and research. This distrust has been (and continues to be) reinforced by insensitive and disrespectful treatment of American Indians and Alaska Natives at the hands of non-Indian health care providers, and by research that has provided no direct benefit to the tribes.

Native American Patients with Cancer and Those at Risk for Cancer Need Assistance Navigating the Health Care System

Navigating the cancer care system can be overwhelming even for those who are well-educated, well-informed, and well-insured. For those with less education, fewer resources, and from cultures outside of the medical mainstream, finding and accessing appropriate services across the cancer care continuum—from prevention to survivorship and end of life—can be particularly difficult. Native Americans in the Pacific Northwest need patient navigators or similar assistance to help them find, arrange for, and reach cancer screening, treatment, and supportive services; establish eligibility for financial assistance; obtain and understand needed cancer information; manage cancer care-related paperwork; and reach across cultural gaps. Such assistance is crucial to keep people from dropping out of the health

“[We need] some special place that will especially work with us as American Indian people....To get that money to do that was the hard thing. They said, ‘No, they don't need that. They don't need that prevention and education. What they need is research.’ Yes, we do, but we also need this other track alongside of it to help us.”

Julia Davis-Wheeler*, Tribal Council, Nez Perce Tribe, Idaho*

“We never had anyone advocate to us to get a second opinion. We never had anyone tell us that we should know more about what we are doing. We both just jumped in [with] both feet and had our surgeries...no counseling when we were first diagnosed, no care providers, no home visitors, no information on special needs like diet or how to dress your wounds or where to go for therapy or related services...no assistance for transportation and no support group.”

Anita Pimm Swan*, Breast Cancer Survivor and Wife of Bladder Cancer Survivor, Yakama Nation, Washington*

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> “For the Quinault Nation there is a clinic in Queets, but it is only open on Wednesdays. That is not much help to people who need medical care other days of the week. There is no clinic on the Hoh Reservation at all. Child care for these women, if they need to get to a doctor’s appointment, is a very difficult issue. Many of them have no phone. There are a number of homes in isolated areas on the reservations where there is no electricity.”
>
> ***Denise Brennan**, Women’s Health Clinic Worker, Port Angeles, Washington*

system. Those at greatest risk may include older patients who have little contact with and are fearful of the health care system, individuals with limited health literacy, and those in isolated areas with limited transportation and telephone service. Individuals also may ignore their own health needs to care for other family members and as they struggle to overcome the daily rigors of life in poverty.

Rural, Geographically Isolated, and Poor Tribal Members Need Transportation Assistance and Reimbursement for Fuel Costs

The prevalence of poverty in Native communities, lack of personal transportation, and the burden of fuel costs are significant barriers to cancer care that must be addressed. Options for resolving this issue could include developing cooperative ride services organized and supported jointly by the tribes, churches, the American Cancer Society, IHS, health departments, or other local groups; and fuel cost reimbursement by IHS or Medicaid.

Positive Elements of the Working Relationship Between the Yakama Nation, Other Pacific Northwest Tribes, and the Regional IHS Office May Be Applicable Elsewhere in the Country

From the information available to the Panel, it is not clear how representative the working relationships among the Yakama, other Pacific Northwest tribes, and the Portland Area IHS may be of other IHS-tribal relationships. However, certain characteristics of these relationships appear to be quite productive and may be applicable in other parts of the Nation. More than 20 years ago, the Pacific Northwest tribes joined together to work as a single unit with IHS; this decision appears to have contributed to a productive working relationship between IHS and the tribes. The ongoing involvement of and consultation with the tribes in policy and operational decisionmaking appear to have been critical elements in this success.

Similarly, the IHS-tribal agreement that led to the building of the Warm Springs health center in Oregon and a concurrent infusion of health care resources may provide a model for increasing the quality and quantity of health services available to specific tribes or coalitions of tribes. Absent substantially increased IHS funding, such strategies may result in total health resources that would more closely approximate actual tribal health care needs.

More Complete and Accurate Cancer Data on Pacific Northwest Indians Are Critically Needed

Without question, better data on the cancer burden borne by Pacific Northwest Indians must be gathered on a regular and systematic basis, with full protection of confidential patient information. These data are crucial to (1) support health care funding and staffing requests and grant applications; (2) clearly identify causative and contributing factors to the cancers being experienced by tribal populations; (3) identify important regional and tribal differences in cancer incidence, survival, and mortality; and (4) inform the development of culturally appropriate education, prevention, and clinical interventions. It is essential that the urban Indian population be included in expanded data collection efforts. Wider and more consistent use of the IHS Resource and Patient Management System (RPMS) may provide a vehicle for improving Native American cancer and other health data in the Northwest. The need for more accurate and complete cancer-related data is not limited to the Pacific Northwest tribes, but is an issue for Native Americans nationwide.

“...if we are going to learn more about this disease we are going to have to allow ourselves to be studied...so we can figure out our denominators and numerators...it is very important that we allow those doors to open again.”

Rex Quaempts, M.D., *Family Physician, Indian Health Service; Member, Yakama Nation, Washington*

Researchers Have a Responsibility to Involve Tribes in Study Design and Provide Useful Data to Them

Those who conduct studies of tribal populations and collect cancer-related data must provide such data and the results of intervention studies and demonstrations to the tribes involved. Tribes should have access to data without restriction and in a format that will be useful in planning and managing their health care services. To dispel resistance to research, tribes should be involved in study design and approval processes, and researchers must provide security regarding personal identifiers. The methodology used in the Northwest Tribal Registry data linkage studies may be a useful model in this regard.

Further Study Is Needed on the Extent and Effect of Contamination in the Columbia River Basin, but Action Can Be Taken Now

The serious environmental issues in this geographic region are important to both Indian and non-Indian residents of the area. Additional investigation of environmental effects (e.g., how chemicals are metabolized and may lead to cancer; studies of radiation effects on cancers other than thyroid; assessment of the combined risks of chemical and radioactive contamination on people eating fish from the Columbia River) would help to quantify more clearly the magnitude of cancer risk associated with these exposures and identify specific cancers most associated with exposures. Yet the need for additional research should not preclude action; it appears that enough evidence exists to act on some of the identified problems. Presenters testified that elsewhere in the country, in areas less contaminated than the Columbia River Basin, environmental clean-up activities already have been initiated. While a plan has been developed to clean up the Hanford nuclear site, it will be several years before any actual containment or removal of radioactive waste begins.

Targeted Programs Are Needed to Strengthen the Science Education of Native American Youth and Promote Careers in Health Care

The issue of cultural dissonance with health care providers was cited repeatedly, and treatment provided by Native American health care professionals is seen as the best possible solution to this problem. A major stumbling block to achieving this goal appears to be the inadequate quality of the science education most Native American children receive, and the lack of sufficient encouragement and financial support for seeking a career in the health professions. Strategies for addressing this issue might include greater involvement in tribal education by the National Cancer Institute's Science Enrichment Program and similar programs sponsored by other governmental or academic entities; scholarships that include a requirement to practice in Native communities for a specified period of time (similar to the National Health Service Corps); support networks for college and graduate students pursuing health careers; and financial incentives that will enable Native American health professionals to establish and maintain financially viable careers in rural areas.

Recommendations

Facing cancer in Indian Country should not be any more arduous than it is elsewhere in the United States. Both rapid action and additional study are needed to address the complex health care funding, health services, cultural, and environmental issues that face this population.

1. Funding for Indian health care through the Indian Health Service (IHS) must be increased to improve access to cancer preventive, diagnostic, and treatment services, as well as the primary care services that are the gateway to appropriate cancer care. Ideally, Indian health care should become an entitlement program so that funding levels are adjusted for inflation and the buying power of IHS funding is not eroded.
2. The U.S. Department of Health and Human Services (DHHS) should convene a meeting of its involved agencies, including the Health Resources and Services Administration (HRSA), IHS, the Centers for Medicare and Medicaid Services, and other public health care funders and providers (e.g., Department of Veterans Affairs) to determine how greater synergy and cost efficiencies can be achieved among existing publicly-funded health care entities to improve cancer-related care to Native Americans. The potential for closer working relationships between HRSA-funded community health centers and IHS is of special interest. The results of the meeting should provide the basis for new regional collaborations between health services resources in the Pacific Northwest and elsewhere in the country.
3. Patient navigator programs should be established to help Native American cancer patients and those at risk for cancer enter the health care system, establish eligibility for assistance programs for which they qualify, and access the medical and supportive services needed for effective care.
4. The Congress should rapidly reauthorize the Indian Health Care Improvement Act to, among other provisions, provide funding to help Native Americans more fully utilize Medicaid, Medicare, and other public health services for which they are eligible, as described in bills recently under consideration.
5. Recent actions and future plans for Medicare and Medicaid reimbursement and service adjustments should be re-examined given (1) the increasing dependence of IHS- and tribally-operated health services on patient care revenues from these programs, and (2) the impact further adjustments may have on rural health care access and provider capacity nationwide.
6. Increased efforts should be undertaken to develop more accurate data on the cancer burden being experienced by Native Americans in the Pacific Northwest. This is an issue germane to Native Americans nationwide. Urban Indians must be included in future data collection efforts, and ways must be found to address widespread current concerns about research and data collection among American Indian and Alaska Native people.
7. The potential benefit of the Pacific Northwest tribes' united approach to working with IHS Area Offices should be explored for its application in other parts of the Nation.
8. The Warm Springs-IHS joint venture should be considered as a potential model for improving health system capacity and more fully meeting tribal health care needs in other parts of the country.
9. Additional research is needed to better understand the possible relationships between environmental exposures and cancer in Pacific Northwest Native Americans. Such investigations should include studies of the impact of exposure to radioactive and chemical contaminants (both alone and in combination) on this population, particularly on the risk for cancers other than thyroid cancer.

Overview

The President's Cancer Panel, created by the National Cancer Act of 1971, is charged to monitor the development and implementation of the National Cancer Program (NCP) and to promptly advise the President of any delays or blockages in the rapid execution of the Program.

In 2000 and 2001, following its evaluation of the evolution and current status of the NCP[1]—including its public and private research and delivery components—the Panel undertook a series of seven regional meetings to explore in greater detail the barriers that keep all Americans from receiving the most appropriate cancer care. At the conclusion of the meetings, testimony had been received from every State and territory in the Nation. This testimony and resulting recommendations were presented to the President in the Panel's March 2002 report.[2]

At the fifth of these regional meetings, held in Los Angeles, California, on February 1 and 2, 2001,[3] testimony on the cancer burden being experienced by members of the Yakama Nation and other Pacific Northwest American Indian tribes was presented by Mr. Joe Jay Pinkham, a Yakama tribal elder and cancer survivor. At that meeting, he extended an unprecedented invitation to the President's Cancer Panel to visit the Yakama Nation and learn firsthand about the cancer experiences, cancer care, and related issues of the Yakama and other Pacific Northwest tribal people.

On July 29 and 30, 2002, Dr. Harold P. Freeman, representing the President's Cancer Panel, visited the Yakama Nation Reservation, located near Toppenish, Washington. The meeting was attended by Yakama tribal elders and members; elders and members of tribes in Alaska, Idaho, Oregon, and Washington; Native and non-Native health care and social service providers; officials of the Indian Health Service (IHS); community epidemiologists and researchers; advocates; State legislative staff; and others. In all, 39 people provided testimony.

This report summarizes the meeting testimony as well as background information presented to and collected both prior to and subsequent to the meeting. While this document represents a synthesis of research, relevant data are in many cases limited or absent. Therefore, this report principally reflects the testimony provided. The majority of the report is specific to the Yakama Nation, and situations encountered by the Yakama are described in the most detail. Where the circumstances of other Pacific Northwest tribes are known to be similar to or different from those of the Yakama, this is indicated. Likewise, where the circumstances of the Yakama or other Pacific Northwest tribes are similar to those of most American Indians and/or Native Alaskans in the United States, this also is noted.

The Yakama Nation and Other Pacific Northwest Tribes

Forty-three (43) Federally-recognized American Indian tribes are based in Idaho, Oregon, and Washington, the three States covered by the Portland Area IHS Service Unit (see Appendix). Nearly all have tribal lands in one of these

States. Total tribal membership numbers nearly 79,000 people. The Confederated Tribes and Bands of the Yakama Nation is comprised of 14 smaller groups totaling 9,564 enrolled members, and the Yakama are the largest tribe in the Pacific Northwest. Other Pacific Northwest tribes, some of which also are confederations of smaller groups, vary considerably in size. The smallest is the Kootenai Tribe of Idaho, with 113 enrolled members.

Location and Land Area

Many of the Indian people in the Pacific Northwest, and elsewhere nationwide, live on or near reservations located in some of the most remote and impoverished areas of the country (Map 1). Many large land areas have rudimentary road, sanitation, utility, telephone, and other basic systems.

The Yakama Nation Reservation covers 1.39 million acres of land in southeastern Washington. Of the enrolled membership, 75 percent live on the reservation, and an estimated 96 percent of tribal members live within 30 miles of Toppenish, the town in which the IHS health center is located. A small percentage of the population lives some distance from the reservation, mostly near traditional Indian fishing grounds along the Columbia River.

The reservation of the Confederated Tribes of Colville in northeastern Washington also is large (1.3 million acres). Approximately 42 percent of the tribe's membership lives off of the reservation. Population centers are small, few, and dispersed across the 70-mile width of the reservation. The Confederated Tribes of Warm Springs Reservation (640,000 acres) in north-central Oregon is home to about 85 percent of the tribe's 3,944 members. Smaller reservations in the Portland IHS Service Area include those of the Idaho Nez Perce and Kootenai tribes (about 90,000 acres combined, with the population clustered in three areas), the Duck Valley and Fort Hall Reservations in southern Idaho, and the Umatilla and Quinault Reservations in Oregon and Washington, respectively. Some tribes, particularly those along the western coasts of Washington and Oregon have very small reservation lands.

Nationwide, it is estimated that 56 percent of American Indians and Alaska Natives live in urban settings and the remaining 44 percent live in rural areas.[4] Portland Area IHS officials believe this estimate approximately reflects the residency pattern of the total population of individuals from any American Indian and Alaska Native tribe who live in the three Pacific Northwest States. The trend toward urbanization has been affected by several factors, including the end of mandatory reservation living, military service during wars, the granting of U.S. citizenship to Indians in 1924, reservation economies, Federal tribal relocation and termination policies, and the 1960s civil rights movement. At the same time, the population of some reservations is increasing as a growing number of tribal members return to their communities.

Government

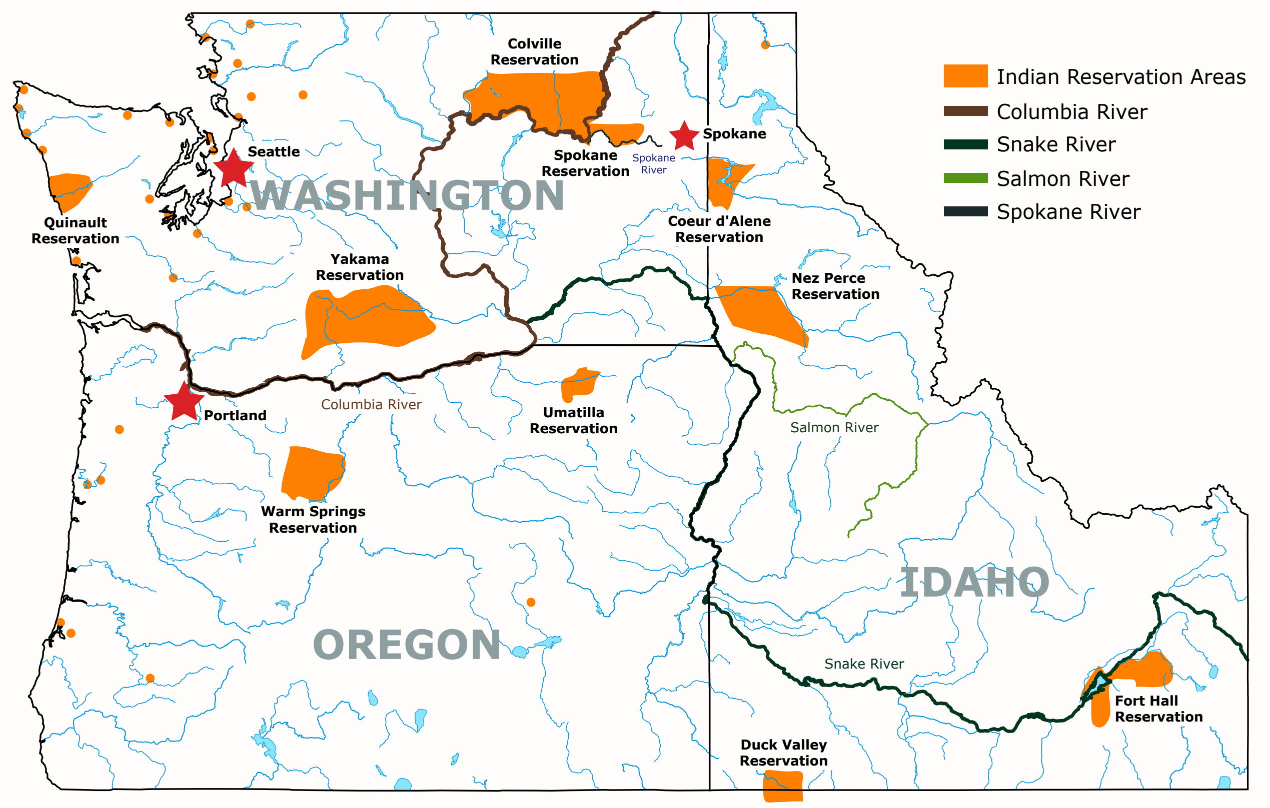
Each American Indian and Alaska Native tribe is a sovereign nation with independent powers of government. The Yakama Nation has its own governing documents that provide for an elected General Council and Tribal Council made up of tribal elders. Tribal members aged 18 years and older are entitled to vote. Government affairs are conducted through standing committees that report directly to the Tribal Council Executive Board. The Council oversees legislative matters that affect the reservation and the people. They advise, suggest, approve, and disapprove the various activities of tribal programs, including health and human services, natural resources, law and justice, education, housing, and other programs. Each of the other Pacific Northwest tribes also has its own system of government; many of these are based on a similar council/committee structure.

Federally-recognized tribes' relationship to the United States Government is on a government-to-government basis. At the same time, individual Indians are at once citizens of the United States and citizens of a sovereign nation within U.S. borders.

Tribal Membership

American Indian and Alaska Native tribes determine tribal membership at their sole discretion based on an individual's Native ancestry ("blood quantum") and historical circumstances. An enrolled tribal member whose grandparents were American Indian or Alaska Native, without other known genetic admixture, is considered to be of "full blood quantum," whereas a tribal member with only two of four grandparents entirely of American Indian or Alaska Native heritage is considered to be of 50 percent blood quantum.Variations in the percentage of blood quantum among an enrolled tribal member's ancestors result in different degrees of blood quantum.[5] A substantial number of tribes require 25 percent blood quantum for membership, but this varies somewhat across the country and may be as low as one-eighth blood quantum in very small tribes and/or for those deemed to be descendants of tribal members. For purposes of eligibility for Federally-funded programs, an Indian usually is defined as a "person meeting two qualifications: (a) that some of his ancestors lived in America before its discovery by Europeans, and (b) that the individual is recognized as an Indian by his or her tribe or community."[6] As will be described in detail later in this document, tribal membership or tribal descent is crucial to gain access to IHS-funded health and other services.

Map 1. Indian Reservations in Washington, Oregon, and Idaho



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> “One of the things that is very difficult for outsiders to understand is the relationship between the fish and the people. The tribal people will tell you that they are the salmon. Salmon is the first food for many of the babies born here, and from birth to the death of the body, the people and the salmon share each other’s lives. Many religious and cultural practices are centered on salmon.”

***Christine Walsh, B.S.N., E.P.H.N.**, Project Coordinator, Contaminated Subsistence Fish Project, Indian Health Service; Member, Rosebud Lakota (SD) and Oneida (NY) Tribes, Washington*

World View and Spiritual Life

It is important to recognize the wide diversity in beliefs and traditions among the many tribes of the Pacific Northwest, as well as tribes elsewhere in the country. However, the testimony presented suggests that the Yakama and other Pacific Northwest tribes share with other indigenous peoples a number of similarities in their world view and spirituality.[7] Among the perspectives common to many tribes are appreciating the spiritual essence of all people, the relationships between all people and the environment, respect for all living things, and for human beings’ place in the web of life. Family and family well-being are highly valued. Responsibility to one’s community is a central value. In addition, the role of spirituality in health is recognized. Harmony among the mind, body, spirit, and environment is seen as a requirement for individual and community health, and for attaining balance in one’s life and life choices.

The Yakama and other Pacific Northwest tribes have a deep spiritual connection to the land that is a foundation of their societal and personal philosophies and codes of conduct. Beyond that, however, they see themselves, literally and organically, as a part of and one with the land and environment.

Lifestyle Traditions

A considerable number of the Yakama and other Pacific Northwest tribal members continue to follow the traditional fishing, hunting, and gathering lifestyle of their forebears. Fish are the principal subsistence source of protein. The salmon is considered a sacred animal and is consumed in the greatest quantity. Other fish commonly caught for food include white sturgeon, mountain whitefish, rainbow trout, steelhead, and euchalon. Most of the fish come from the Columbia and Snake Rivers and their tributaries. The tribes hunt elk, deer, turkeys, and other game. Some tribes raise buffalo for food. Berries, roots, and medicinal plants are gathered regularly in their seasons. These traditional foods and medicines are integral parts of the culture, as are prayer and a holistic approach to health. For example, sweat lodges, special buildings in which dry heat is produced much as in a sauna, are used for spiritual exploration, prayer, and therapy for specific health problems.

Economic Conditions

The Pacific Northwest tribes, like most other Native Americans, remain among the poorest populations in the country. Many of their reservations are in isolated areas with extremely limited economic activity and educational opportunities. In part due to discrimination, Native Americans often have difficulty competing for available jobs or are limited to low-paid service jobs. The 1997 Current Population Survey[8] reveals that Indians live in poverty at a level nearly three times that of the rest of the population. The tribes are not uniformly poor, but even those with some prosperous members have large pockets of poverty on the reservation. The majority of urban Indians also are poor.

A misconception exists among many non-Indians that since passage of the Indian Gaming Regulatory Act (IGRA, P.L. 100-497), tribes that have built casinos are self-sufficient, even wealthy. This may be true in few cases, but in order to build casinos, most tribes have taken on partners and considerable debt, and most have not reached a level of profitability sufficient to raise the overall socioeconomic status of the tribe. In fact, recent articles in the press have maintained that it is primarily the non-Indian partners and investors who are making money from casino operations.[9,10] In addition, concerns have been raised about both the economic and social costs of casinos to the communities in which they are located.[11] Some tribes are using casino profits to improve fire and rescue services, provide hearing aids and other items not covered by IHS, and support social programs. In other cases, tribes also have made per capita distributions of net revenues to enrolled members, as permitted under plans required under IGRA and approved by the Bureau of Indian Affairs (BIA).

Many tribes in the Pacific Northwest have developed businesses, seeking to improve their economic conditions by creating local industry and employment opportunities. For example, the Yakama derive revenue from the national and international sale of fruit grown on reservation lands. The tribe recently opened a casino and has ventured into the promotion of sporting events in the region. Other revenue-producing activities include the production and sale of forest products, and ownership and/or management of fish hatcheries, a recreational vehicles park, a food market, and an industrial park. These enterprises employ several hundred tribal members and non-Natives in the area. Even with these ventures, however, the unemployment rate on the reservation is estimated at more than 80 percent, and average annual income is under $7,000.[12]

Among the other Northwest tribes, forestry, farming, and animal husbandry (including hatcheries) are principal sources of financial support. For example, the Colville tribe relies on forestry and some agricultural production, including orchards and vineyards. The majority of existing service jobs come from the IHS, BIA, and the tribal government. Unemployment is estimated at 50 to 60 percent, and annual family income is less than $10,000.[13]

The Warm Springs tribe is the largest employer in north-central Oregon; the tribal government employs about 400 people, and about 550 people work in a tribally-owned and -operated resort and a forest products business. The IHS and BIA also employ some tribal members. Despite these employment opportunities, the unemployment rate is high, and average annual per capita earned income is estimated at about $4,000. In recent years, per capita distributions of profits from tribal enterprises have supplemented earned income by approximately $2,000 per tribal member.[14]

For a number of the tribes in northern Idaho, farming, logging, and animal husbandry provide livelihoods for some members, and some find jobs in local industries (forestry, grain farming, cattle raising, and hydroelectric power projects) and through Federal and tribal agencies. Unemployment remains extremely high, however, and only half of the population earns more than $7,000 annually.[15]

Education

The educational status of adult American Indians and Alaska Natives in the Northwest varies greatly. According to 1990 census data, 71.5 percent of adult Indians over age 25 in the IHS Portland Service Unit had a high school education; in the same population group, only 8.6 percent had a Bachelor's degree or higher.[16] A considerable number of older individuals have had very limited formal education.

The number and quality of educational opportunities also varies considerably among tribes in the Pacific Northwest. Some of the tribes operate their own schools, while others rely on local public school systems. The vast majority of Indian students attend public schools.

The Yakama Tribal Council has been very supportive of efforts to improve the educational achievement of Indian students. Although most students attend public schools, the Yakama have established a tribal school that promotes learning styles and curriculum content designed to meet Indian students' needs; the junior/senior high school is accredited by the State of Washington as a private school. The tribe also established a scholarship program, and has operated several Head Start preschools. Several post-high school educational institutions are relatively close to the reservation; these include Yakima Valley Community College, Heritage College, and Central Washington University.[17] Some students are being trained to work as technicians in the fish hatcheries, where they also receive mentoring and help in continuing their education.

The reservations in Northern Idaho are served by the public school systems, with some students attending high school at a boarding school in Salem, Oregon. The area offers many post-high school educational opportunities within a 45-minute drive from most reservation communities, including several four-year public and private universities and a community college.[18] However, the high school completion rate among the youth of many tribes is quite low compared to the national average of 85 to 87 percent.[19] For example, only half of students on the Warm Springs Reservation complete the 12th grade. Some Warm Springs students attend BIA boarding schools away from the community. For those who complete high school, further educational opportunities are available at the Central Oregon Community College in Bend and at the Oregon State University campus in Cascade, in addition to adult education and other classes offered in the reservation communities.[20]

Similarly, the dropout rate is high among Colville youth, who (like students from many tribes) endure long bus and/or ferry rides to reach schools off of their reservation; a General Educational Development (GED) program attempts to address this problem. The reservation has a school for students in grades one through eight, and for students who want to continue formal education beyond high school, community college extension classes are available at several locations on the reservation.[21]

Yakama tribal members noted that Indian students who seek higher education far from the reservation often suffer from feelings of loneliness and isolation that sometimes become too much to tolerate. In addition, students may have difficulty because their high school academic preparation was not sufficiently rigorous. Without the support of other Indian students or special supportive efforts by the college or university, the college completion rate among Native students tends to be lower than the national average of 51 percent.[22]

Nationally, an increasing number of tribes are, with partial Federal support, establishing their own institutions of higher learning to help preserve their languages and cultures and provide a learning environment designed for the needs of Indian students. Federal funding has been uneven, however, and many of these schools are struggling to provide students with quality faculty, and up-to-date textbooks and computer equipment.[23]

Legal History of Indian Health Care

The health care available to the Yakama and other Pacific Northwest tribes has been profoundly influenced by treaties, laws, and Executive Orders enacted over nearly 150 years. Through the Treaty of 1855,[24] the Yakama Nation ceded 11.5 million acres of its tribal lands to the U.S. Government in exchange for certain protections and concessions. These included fishing, hunting, gathering, and grazing rights, an annuity to be paid over 20 years, and the construction and maintenance of shops, mills, schools, and a hospital with the personnel to operate them, also for a period of 20 years. Similar treaties were executed in 1855 with other Pacific Northwest tribes, and these are much like treaties executed with hundreds of other tribes throughout the country beginning in the 1830s.

The cession of most of the land that now comprises the United States, as codified in these treaties, is the basis for the Federal Government's obligation to provide health care services to Native Americans. It also is the basis of the intensely held belief among Native Americans that these services are not provided free—that is, that the tribes paid in advance for these services, with the premium prepayment in the form of land.[25] Though the first separate funding specifically for Indian health (other than for smallpox vaccination programs) was identified in an appropriation act in 1911, the 1921 Snyder Act[26] was the first legislation providing continuing authority for Congress to appropriate funds specifically for the "relief of distress and conservation of health of Indians." The Snyder Act was passed in response to recognition of the seriously declining health of Indian populations, and designated Indian health care as a Federal function administered by the BIA and subsequently (via the Transfer Act, 1954), by the IHS of the Department of Health, Education and Welfare, now known as the Department of Health and Human Services (DHHS).

The Indian Self-Determination and Education Assistance Act of 1975 (P.L. 93-638) provided that Indian tribal governments could, upon request, take over the operation of any BIA or IHS function. Many tribes have taken advantage of these provisions to manage their health and educational programs and control the expenditure of allocated IHS funds, including administrative funds.

The following year, the Indian Health Care Improvement Act of 1976 (P.L. 94-437) was enacted based upon findings that the health status of American Indians and Alaska Natives continued to rank far below that of the general population. Since its initial passage, the Act has been amended (reauthorized) and extended several times. Provisions of the initial Act and amendments expressed the Government's obligation and intent to ensure that the health of Indian people is elevated to the highest possible level, to achieve the maximum participation of Indian people in Indian health programs, and to provide the resources necessary to achieve these goals. The 1992 reauthorization (P.L. 102-573) included 69 objectives taken from Healthy People 2000 and required the IHS to utilize Epidemiology Centers to carry out these provisions and to report annually on success in meeting these objectives. The most recent reauthorization of the Act expired on September 30, 2000, but was extended for one year to provide Congress time to consider provisions of reauthorization legislation. At this writing, none of the proposed Indian Health Care Improvement Act reauthorization bills has reached the floor for a vote.

Trust Responsibility of the U.S. Government

Among the Yakama and other Pacific Northwest tribes—as among Native Americans generally—there is a deep conviction that the U.S. Government has failed to honor its treaties and the trust responsibilities that flow from the treaties. For example, the Treaty of 1855 with the Yakama guaranteed the right to take fish at all usual and accustomed places. This guarantee has been threatened by a series of 12 dams built over the last half century, some of which eliminated a number of traditional fishing areas.

Specific to health care, the consistent and severe underfunding of Indian health programs is cited as a major example of the Government's failure to honor its obligations to Indian people. One speaker maintained that the Government's trust responsibility for appropriate health care for American Indians should extend beyond the Department of the Interior and the IHS to all DHHS agencies, including the National Institutes of Health (NIH) and the National Cancer Institute (NCI).

Cancer Among the Yakama and Other Pacific Northwest Tribes

The Yakama and other Pacific Northwest tribes have become increasingly concerned about the number of cancer cases being diagnosed in tribal members in recent years, and the number of premature deaths due to cancer. In these Native cultures, elders are the tribe's governmental, societal, and spiritual leaders, and are crucial to passing on cultural traditions and spiritual beliefs and practices to the younger generations. Thus, early deaths rob the tribe of the people who perform these vital functions. Whereas previously, cancer was neither discussed nor its diagnosis shared—sometimes not even with family members—the Yakama and neighboring tribes have decided that cancer must become a more open issue if it is to be addressed effectively. At this meeting, a number of participants, including three tribal elders, spoke publicly about their own cancer, in some cases for the first time.

"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**, Yakama Nation, Washington*

Apparent Cancer Burden

Cancer is the second leading cause of death among Native Americans, exceeded only by heart disease. Much of the available national data suggest that cancer incidence among Native Americans is lower than the national average for all races combined, but this assessment in part reflects the younger average age of the Native population (27.8 years versus 35.8 years, U.S. All Races[27]). Most cancers occur at older ages, and Native Americans have fewer individuals in the older age groups compared with the general population. Cancer mortality among Native people, however, appears to be higher than national averages. A number of studies have observed that during the past three decades, Native American cancer incidence and mortality rates have been increasing, and that American Indian and Alaska Native cancer survival rates are the lowest of any ethnic group.[28] Limited data indicate a five-year cancer survival rate for Native Americans nationally of 36 percent, compared with 47 percent among other Americans.[29,30] Lower survival and

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> “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....”

***Geneva Charley**, Community Health Information Specialist, Warm Springs Tribe, Oregon (membership 3,944, median age 23.9)*

higher mortality are believed to be associated with late-stage diagnosis due to limited access to care, particularly specialty care.

It is recognized, however, that tribes have diverse physical environments, genetic heritage, lifestyles, and diets that may markedly affect the frequency and types of cancer they develop and their survival and mortality from those diseases.[31] In addition, data on quality of cancer care for Native Americans remains scarce. Disturbingly, however, one study of time elapsed from diagnosis to first cancer-directed surgery for Native women with breast cancer in New Mexico and Arizona found that regardless of age, disease grade and stage, distance to care, and poverty level, American Indian women were nearly four times more likely than non-Hispanic White women to receive their first surgery more than six months after diagnosis.[32] The effect of such disparity on survival is obvious.

The exact magnitude of the cancer burden among the Yakama and other Pacific Northwest tribes has been difficult to ascertain due to limited data and small numbers of cases. Available data indicate that in the IHS Portland Service Area, the 1994–1996 age-adjusted overall cancer death rate (also adjusted for racial miscoding on death certificates) was 126.4 per 100,000 population, slightly lower than the U.S. All Races average of 129.9, but higher than the IHS average of 116.6 for all American Indians and Alaska Natives.[33]

The most common cancers afflicting Pacific Northwest tribal populations are those of the lung, breast, prostate, and colon/rectum. Data for 1994–1996 indicate that lung and breast cancer mortality rates in the IHS Portland Service Area exceeded the U.S. All Races rates by nearly 10 percent, colorectal cancer mortality was almost 13 percent higher, and the cervical cancer mortality rate was almost 2.6 times higher. The prostate cancer rate among Native men in the three-State area was 16 percent lower than the U.S. All Races rate.[34]

Few studies have been conducted specific to urban Indian health status, but available data indicate that this population is faring poorly on every health status measure, including cancer.

Data Issues and Sources

Policy makers at all levels rely on national databases as accurate, representative sources of information, yet no single, reliable national cancer database exists for American Indians and Alaska Natives. The several existing sources of Native American cancer incidence and mortality data vary considerably in their data collection methodologies and other features, but all share two significant limitations: they are incomplete and of uncertain reliability.

By some estimates, racial misclassification of Native Americans may be as high as 40 to 60 percent nationwide.[35] In a small population such as American Indians/Alaska Natives, even moderate misclassification can have a large effect on the accuracy of cancer-related data. At both State and national levels, racial/ethnic misclassification of Native people is recognized as a major problem; speakers noted that commonly, a person is "born Indian, but dies White." This often occurs when hospital or other health care providers hesitate to add to the stress of the family of a sick or dying patient by asking if he or she is Native American and instead make assumptions based on appearance or surname. In some cases, there may be no response category for "Native American/Alaska Native" on death certificate or hospital intake forms. Members of tribes that are State-recognized but not Federally-recognized may not identify themselves as Native American.[36] In addition, a speaker suggested that health providers completing hospital intake forms may hesitate to ask for racial identification out of concern that the patient believes identifying as Native American will result in inferior care.

Other key issues compromising the quality of data on Native Americans include undercounting, coding errors, insufficient sampling to achieve statistical power that would permit conclusions, and tribes' small populations and specific geographic areas of residence.[37] As a speaker noted, to address disparities in Indian health, three things are necessary: determining who is American Indian/Alaska Native, measuring health accurately, and providing data in a way that will inform decisionmaking.

Indian Health Service

Using its computerized Resource and Patient Management System (RPMS), IHS compiles data on total population served, number of medical encounters, diagnosis, treatment, and utilization of selected services provided in its facilities to enrolled members of Federally-recognized tribes and their descendants. Clinic- and encounter-based RPMS data are recorded and collected using a standard format that allows analysis of data across States and regions. However, in the Pacific Northwest States, only IHS-operated facilities enter data into the RPMS consistently and in accordance with DHHS guidelines. RPMS is likely to include data on care by specialists to whom patients are referred only if a bill comes back to the IHS facility for payment. Care provided to Indian patients on Medicaid is not captured by the system. In addition, some "contracted" tribes that manage their own health programs with consultation from IHS may use RPMS but are not required to enter data into the system in the same manner as in IHS-run facilities. "Compacted" tribes that operate their health facilities entirely independently are not required to use RPMS at all. Thus, while the RPMS seems to provide an established platform for improving data on care provided to Native Americans, it currently is underutilized and used inconsistently.

IHS computes Native American incidence and mortality rates for specific diseases using census and vital event data as denominators, which introduces the data quality issues described below. Service population estimates, in conjunction with health status and other measures, provide the basis for determining IHS allocation of base budget increases. Currently, service population estimates are still based on 1990 census figures (adjusted based on projected births and deaths); it is unclear when IHS will begin to use 2000 census data as the basis for service population estimates. Allocations of Indian Health Care Improvement Act funds are based on the user population (defined as persons who have received services at least once at an IHS health facility in the most recent three years) rather than the service population.

Census Data

The U.S. Census data that supply the denominator for determining cancer rates are based on self-reported racial/ethnic status, and it is difficult to know how accurate such reports may be. In the 2000 census, the population identifying as American Indian or Alaska Native numbered approximately 2.48 million (0.87 percent of 281,421,906 total U.S. population[38]). However, 4.1 million people (1.46 percent) self-identified as American Indian/Alaska Native alone or in combination with other races.[39]

In the Pacific Northwest States, the percent of the population that identified as Native American alone (Washington—1.6 percent; Oregon—1.3 percent; Idaho—1.4 percent) or as American Indian/Alaska Native alone or in combination with other races (Washington—2.7 percent; Oregon—2.5 percent; Idaho—2.1 percent)[40] is greater than their percentage of the U.S. population overall, with rare counties having substantially larger Native populations (e.g., Ferry County, Washington—18.3 percent).[41] Nonetheless, with such small numbers, it is unlikely that State-level data provide an accurate picture of cancer incidence and mortality among Native Americans in the region compared with the rest of the population.

Vital Event Statistics

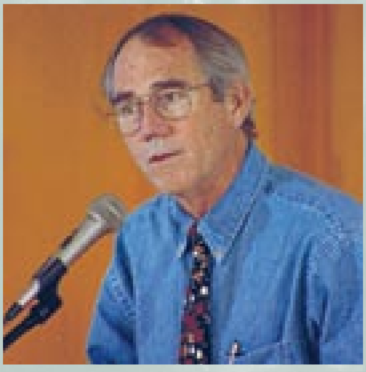
American Indian and Alaska Native vital event statistics used by the IHS and others are derived from data compiled annually by the National Center for Health Statistics (NCHS) at the Centers for Disease Control and Prevention (CDC). NCHS obtains birth and death records for all U.S. residents from State departments of health, based on information reported on official State birth and death certificates. The data are therefore subject to the degree of accuracy of reporting by the States to NCHS (which performs edit checks and imputes values for non-responses). To determine death rates, IHS adjusts for the younger average age of the American Indian/Alaska Native population and additionally adjusts for known miscoding of Indian race on State death certificates. Misclassification on death certificates tends to be greatest in areas distant from traditional Indian reservations.[42]

SEER and CDC Cancer Registries

The NCI's Surveillance, Epidemiology, and End Results (SEER) population-based cancer registry program was expanded recently[43] and with this expansion now covers approximately 42 percent of the Native American population nationally. However, of the Pacific Northwest States (Washington, Oregon, Idaho), only the Seattle-Puget Sound area (13 counties) of Washington is covered by SEER. According to 2000 census data, this population includes approximately 57,000 persons who self-identified as American Indian/Alaska Native alone, and almost certainly some percentage of 161,000 persons reporting ancestry in two or more races. A limited number of patterns of care studies have linked SEER and IHS data files, and in some cases sampled medical records, but to date, these have focused on Native Americans in New Mexico, Arizona, and South Dakota.[44] Thus, although it is cited as perhaps the best source of data on cancer in Native Americans, SEER still lacks significant direct relevance to Pacific Northwest American Indians/Alaska Natives, since generalizations from one Indian population to another (and one geographic region to another) cannot be made with confidence.

> “I used to have braids...but after I started getting chemotherapy I started losing my hair so I had to have it cut off. It is very devastating, you know, especially when you follow your belief, your religion, which requires you to have hair.”

***Frederick Ike, Sr.**, Lymphoma Survivor; Vice Chairman, Tribal Council, Elder; Yakama Nation, Washington; Died 2003*



“In this era, if you write to any funding organization and say things are bad here, we need more money, you are just out of luck. You have got to be able to justify and the best way...is by having good data.”

Dee Robertson, M.D., M.P.H., *Advisor to the Director, Northwest Portland Area Indian Health Board, Oregon*

The CDC also supports State cancer registries through the National Program of Cancer Registries (NPCR) and jointly funded the SEER expansion through a memorandum of understanding with NCI. The Washington, Oregon, and Idaho State cancer registries all are supported with NPCR enhancement program funding and have achieved certification through the North American Association of Central Cancer Registries. The Oregon State Cancer Registry has participated in a record linkage study in collaboration with the Northwest Tribal Registry of the Northwest Portland Area Indian Health Board (NPAIHB, see below) designed to more accurately determine the cancer burden of American Indians and Alaska Natives residing in Oregon. The Cancer Data Registry of Idaho is using geocoded cancer case data in conjunction with geographic information systems (GIS) to measure distances from residences to cancer treatment to help explain differences in treatment and outcome. Unfortunately, the coding in rural areas is at the census tract or ZIP code level. This limitation, in addition to misclassification issues, has made these studies minimally useful for identifying or explaining cancer disparities experienced by reservation Indians in the State.

Centers for Medicare and Medicaid Services (CMS)

CMS is a health care payment system, and maintains a national claims database on all Medicare beneficiaries. Medicare data have been used by a number of researchers nationwide to study patterns of care for various diseases in specific populations; these data appear to have been used minimally to study care provided to older Native Americans. CMS also administers the Medicaid program; aggregated claims data are available at the State level and can be accessed by tribal organizations. These data can be obtained by population group, age, and diagnosis, however, because some of the tribal populations are small, it is possible that data at this level of detail might enable identification of individuals. In addition to potentially violating Federal privacy rules[45] concerning patient data, personal identification is an issue of concern to many tribal people.

Northwest Portland Area Indian Health Board

The NPAIHB houses the tribally-operated Northwest Tribal Epidemiology Center (the Epi Center). The Epi Center was developed in response to the tribes’ needs for accurate health data that would enable them to make informed decisions about funding allocations in tribally-operated health facilities and for outreach activities.

In 1999, NCI funded the NPAIHB to develop the Northwest Tribal Registry Project. The Project's objectives are to better ascertain the incidence and prevalence of diseases, including cancer, primarily among reservation-based Northwest American Indians and Alaska Natives and to assess the causes and magnitude of racial misclassification. Through an interagency agreement with IHS, the tribally-controlled registry has begun conducting record linkage studies comparing data from the Portland Area IHS Merge Registration File, State cancer registry data, and data from other sources, including tribal enrollment registries and health facility enrollment data. The potential also exists to link data to sources such as private provider data files. Individual identifiers are removed after the linkage, and no tribe-specific data are provided to the cancer registries.

According to speakers from the Epi Center reporting on the project, a three-State linkage study revealed many additional cases of cancer among Native Americans that the States had originally classified as non-American Indian/Alaska Native, nearly doubling overall cancer rates compared with previous computations. In addition, the study found substantially higher percentages of kidney, skin, and oral cavity cancers among Yakama Indians compared with non-Yakama Native Americans in the region.

Unlike previous linkage studies, the Northwest Tribal Registry Project has a longitudinal focus on building trend data. It is planned to conduct these linkage studies annually, and to use the data to inform intervention development and increase awareness of Native American presence in State cancer registries to help minimize misclassification. Though these studies are an important step toward improving the accuracy of cancer incidence and mortality estimates among Pacific Northwest American Indians and Alaska Natives, a major shortcoming is the omission of data on urban Native Americans, who comprise more than half of the Native population in the region. They were not included because accurate information on the total population of urban Indians was not available to use as a denominator in calculating cancer rates.

The Epi Center conducts a number of other Indian-specific data collection and research efforts. For example, it has developed a set of clinical performance measures on which about 26 of the Northwest tribes and a number of IHS programs now report. Cancer screening is one of the identified measures. In addition, the Epi Center uses the RPMS as a source of data on diagnosis and treatment in IHS health facilities.

"...we are dying out here. We have got people that are dying around us and from the time that I have been on Council...I cannot even count how many people we have lost....The time is going by so fast, by the time we get finished with another study we will not be here."

***Julia Davis-Wheeler**, Tribal Council, Nez Perce Tribe, Idaho*

“...if we are going to learn more about this disease we are going to have to allow ourselves to be studied...so we can figure out our denominators and numerators...it is very important that we allow those doors to open again.”

Rex Quaempts, M.D., *Family Physician, Indian Health Service; Member, Yakama Nation, Washington*

The CDC-funded Northwest Tribal Behavioral Risk Factor Surveillance Survey (BRFSS) collects information on cancer risk behaviors and other health risk factors in seven selected Pacific Northwest tribal communities. The BRFSS normally is a telephone survey; however, because a considerable number of Native Americans in the Northwest do not have telephones, all of the interviews were conducted face-to-face. Tribal councils' support for the study was instrumental in achieving a high level of participation by tribal members.

Finally, several NIH-funded research activities are underway through the Epi Center's Native American Research Centers for Health. A representative of the Epi Center noted that all of these projects, as well as a number of others not cancer-related, are operated on a core budget of about $78,000.

Other Data Collection Efforts

An NCI-funded chart review and data linkage study is being conducted by an IHS environmental health nurse to identify cancer cases among the Yakama. The goal of the study is to develop baseline data that might substantiate the wide-spread observation that cancer is becoming more common among tribal members, assess the level of misdiagnosis, and conduct a linkage study similar to that of the Northwest Tribal Registry Project to develop more accurate incidence and prevalence data. The RPMS is queried using ICD-9 (Inter-national Classification of Diseases, Ninth Revision) cancer diagnosis codes, then chart reviews are conducted on the identified cases to determine the method of diagnosis and type of treatment prescribed.

Data Collected by Individual Tribes

Some of the tribes collect their own cancer data, but are reluctant to share it with others. One presenter indicated that while his tribe knows its cancer rates, the elders decided not to reveal this data at the Panel meeting because they did not know if it would be used in a way that would prove detrimental to the tribe. Such concerns keep unavailable what may be among the best data on the Indian cancer burden.

Resistance to Research and Data Collection

The concerns noted above regarding cancer data collection and its use highlight the resistance of many tribes to participating in research studies of their populations. Some of this resistance is related to fear of providing personal or tribal information to the U.S. Government, including the IHS. Some tribes also do not participate in the Northwest

Tribal Registry project for fear that they will be compared unfavorably with other tribes.

A large measure of resistance, however, is due to previous experiences in which tribes allowed themselves to be studied, but received no report of the study results, or received data presented in a format that was not useful. This was referred to as "helicopter research"—that is, the researchers dropped in, took what they needed, and flew away again without providing any benefit to the tribe. One such case involved a health status study of the Western Shoshone near Yucca Mountain, Nevada (a proposed nuclear waste storage site). A presenter indicated that the young researcher, who was working toward her degree, copyrighted the resulting report, precluding the tribe from using the data for its own purposes.[46] The speaker additionally expressed anger that the researcher's education, of which the study was a part, was being supported by the funding agency involved; this was seen as an example of the ways non-Indians have enriched themselves at the expense of Native Americans.

Many tribes strongly resist providing genetic information for research purposes in the belief that the information will be used against them in some way. Tribes also are concerned that researchers will use the information to develop drugs or other products that will lead to personal enrichment but provide no benefit to the tribe. A speaker maintained that the Human Genome Project is studying indigenous peoples because their genetic make-up remains pure (i.e., relatively little admixture with other populations has occurred). However, he believes the motivation for the study is largely economic—so that the genetic information can be patented and sold, and so that non-Indians can learn to repair their own DNA, which has been damaged by exposure to agricultural and other chemicals.

At this time, the Portland Area Institutional Review Board (IRB), a joint effort of the IHS, the Federal Government, and the NPAIHB is the only IRB in the area. This IRB must approve any population-based studies that would involve Indian people. A speaker indicated that some Yakama wish to establish their own IRB so that they can decide for themselves the value of proposed research involving their people and the types of studies that are needed. Speakers also noted moderate interest in strengthening relationships with certain university researchers in the region and developing a tribal environmental health advisory committee to help the tribe develop its own research agenda based on studies it believes are needed.

"We need to have someone not only get the data...but do something with that data. Something that is productive. Something that causes services to become available to us. Something that causes the Indian Health Service to have more care providers for us."

***Anita Pimm Swan**, Breast Cancer Survivor and Wife of Bladder Cancer Survivor, Yakama Nation, Washington*

Possible Environmental Influences on the Northwest Native American Cancer Burden

Tribes throughout the Northwest have been concerned for many years about contamination of their water, food supply, land, and air. Several speakers expressed the widely held belief that chemical and radioactive contamination is responsible for many of the cancers being experienced by tribal members. A considerable number of the tribal members who testified described numerous cases of cancer among parents, grandparents, siblings, children, and aunts and uncles, as well as their own cancer history. Though anecdotal, the testimony raises questions as to the likelihood of environmental influences and/or the possibility of undiscovered familial cancer syndromes (i.e., genetic predispositions). Little is known about familial cancer patterns in American Indian/Alaska Native communities, but 8 to 12 percent of Native breast cancer patients studied in Alaska, Arizona, and South Dakota reported having a first-degree relative with the disease.[47]

Chemical Contaminants

The principal sources of chemical contamination of Northwest tribal lands are believed to be agricultural and industrial areas in the United States that drain into the main rivers and streams in the Columbia River system, including the Columbia, Spokane, Snake, and several other rivers. Much of the contamination is believed to come from subsurface water flowing from cattle farms and from chemicals used on leased reservation land. The leases, up to 99 years in duration, are controlled by the BIA, so the tribes cannot prohibit the use of pesticides and other chemicals on the land. It also is suspected, but unproven, that a substantial amount of chemical contamination in the water and soil originates in Canada.

In 1988–1989, the U.S. Environmental Protection Agency (EPA) conducted a national survey of water contamination.[48] The Columbia River was one of the selected test sites. The fish in the river were found to be heavily contaminated with dioxins. Dioxins have been shown to be uniformly carcinogenic in animals and the most potent form (2,3,7,8-TCDD) is classified as a known human carcinogen by the International Agency for Research on Cancer.[49] An EPA reassessment of dioxin's effects[50] classifies these compounds as a "likely human carcinogen" and also confirms that they can cause human immune system damage and interfere with regulatory hormones, among other serious effects. Dioxins are produced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"Those chemicals are at the bottom of Commencement Bay...the salmon have been different now. They are not all normal....Some of these salmon come back so deformed you would not even recognize them. Some of them come back with sores all over their bodies. Some come back into our watershed with no skin but you never see that in the news...."

***Iatel**, Breast and Stomach Cancer Survivor, Quinault Tribe, Washington*


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"...when the Creator first created mankind as us Natives on this land, at that time everything was clean. There was no sickness. Today we have all different kinds of illness that is coming upon us and it is making our peoples leave the world."

***Elsie Dick**, Elder, Yakama Nation, Washington* and released into the air principally through the incineration of waste, and are released directly into water via the bleaching process used by paper mills, herbicide production, and certain other manufacturing processes. These compounds are stored in fatty tissue and bioaccumulate up the food chain (i.e., dioxin particles fall onto water or plants that are consumed by animals or fish that then are eaten by humans). Dioxins have a half-life of approximately seven years, meaning that only half of a given exposure to dioxin will have become non-toxic in seven years. Apart from its natural degradation over time, the only other means of ridding it from the body are through its transfer to the placenta or breast milk, both of which dose the fetus or infant heavily relative to its body weight. Most dioxins in the human diet come from animal products—beef, dairy products containing fat, fish, and poultry. The amount of dioxin varies with the amount of fat in the food source (e.g., more in salmon than in flounder). The World Health Organization has stated that some populations may be exposed to higher levels of dioxins because of their diets, including high consumers of fish in certain parts of the world.[51]

Because of the subsistence consumption of fish by local tribes, the EPA study finding caused immediate concern. The tribes were doubly concerned by the findings because the EPA tested only a small sample of fish that were not collected at traditional Indian fishing sites, nor were they the species most commonly eaten by the river tribes. Therefore, an accurate assessment of risk could not be determined.

To obtain better data on the extent of contamination of this primary protein source, the Columbia River Inter-Tribal Fish Commission, with the help of the river tribes (Yakama, Nez Perce, Umatilla, and Warm Springs) launched its own fish consumption survey. Professional interviewers questioned the participants in person to ascertain the types and quantities of fish consumed by tribal members. It was discovered the average weighted mean consumption of fish for adults was 62.3 grams per day—nearly nine times the amount of fish consumed on average by the general population (7.5 grams/day). Average daily fish consumption for many tribal members exceeded 500 grams/day.

Both the tribes and the EPA were highly alarmed once the average levels of fish consumption were understood. A fish tissue survey was undertaken[52] using the most sophisticated methods and several different laboratories to analyze the most commonly eaten varieties (both whole fish and filets)

“...you cannot tell a population who depend on the fish, who have lived with the fish for all eternity, that they cannot eat their fish. There is no alternative acceptable protein and the cultural risk for this type of communication is not acceptable.”

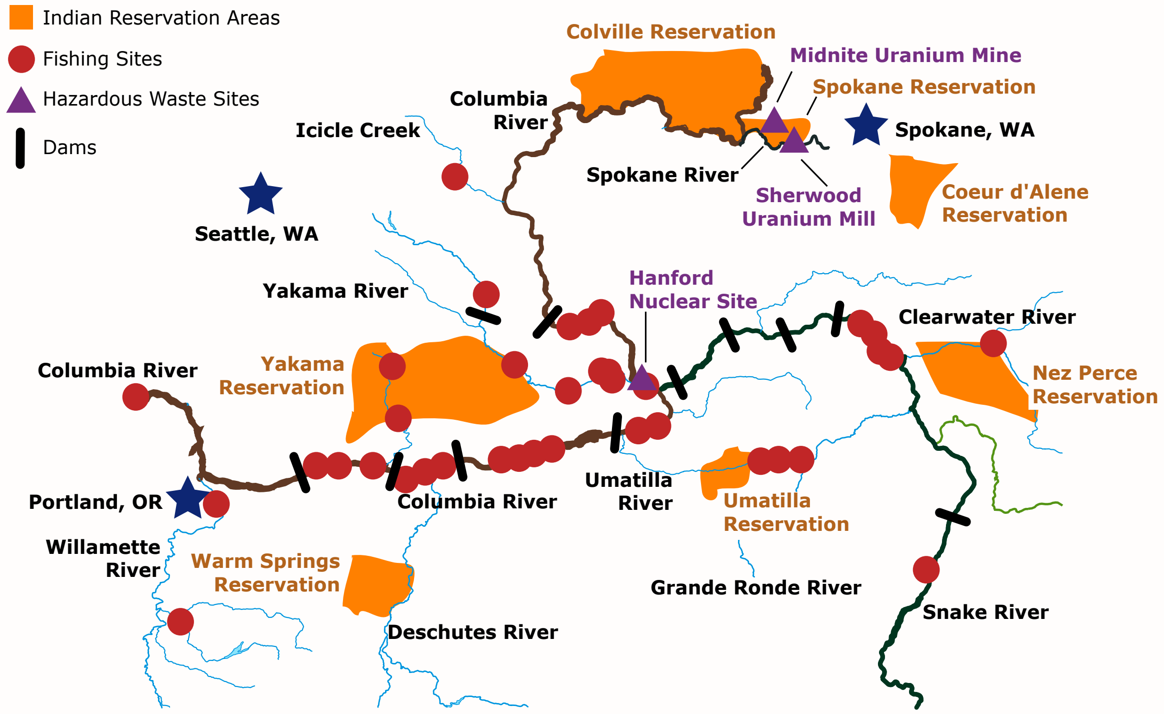
Christine Walsh, B.S.N., E.P.H.N., *Project Coordinator, Subsistence Fish Research Project, Indian Health Service; Member, Rosebud Lakota (SD) and Oneida (NY) Tribes, Washington*

“One of the scientists we met with the other day... was from EPA. She said, ‘If you eat 100 pounds of fish a year out of the Columbia River, we could not guarantee how long you would live.’”

Bob Brisbois, *Business Council, Spokane Tribe, Washington* for more than 130 chemicals; 92 of these were detected in the fish samples. The survey found that contamination is widespread throughout the Columbia River system; of the many samples taken at numerous locations (see Map 2), there were no uncontaminated fish, and contaminants also were found in the eggs of certain varieties of salmon. For reasons not yet understood, the highest concentration of contaminants was found in the Hanford reach of the Columbia River. Of the contaminants found, those of most concern include polychlorinated biphenyls (PCBs) and Arochlors, dioxins, furans, hexachlorobenzene, inorganic arsenic, and pesticides. Among the pesticides detected, DDT, which was banned 20 years ago, was found in its original state as well as in a metabolized but still toxic form, DDE.

The total cancer risk for all chemicals combined was estimated by the EPA Region 10 Office at approximately one in 1,000.[53] According to a speaker, this risk is a thousand-fold higher than risk levels that previously have prompted EPA regulatory action, and that clean-up already is underway at areas less contaminated than the Columbia River Basin. Another speaker indicated that for Indian people who eat fish in accordance with their dietary customs, the risk of a fatal cancer may be as high as one in 50. He observed, *"If this happened in the suburbs of Cincinnati, people would be in penitentiaries today and it would be cleaned up very soon."* With a grant from the U.S. National Institute for Environmental Health Sciences, the Yakama are now producing a series of videos to try to raise health care provider and tribal awareness of the fish contamination and suggest ways to minimize chemical exposure while still adhering to traditional dietary patterns.

Map 2. Traditional Fishing Sites Included in the Columbia River Basin Fish Contaminant Survey



Source: U.S. Environmental Protection Agency. (2002).
Columbia River Basin Fish Contaminant Survey 1996-1998 (EPA 910-R-02-006). Seattle, WA: EPA, Region 10.
Available on the Internet at http://yosemite.epa.gov/r10/oea.nsf/Reports/Reports.

A speaker from the Spokane Tribe indicated that recently, and after many years of negotiation, the EPA finally had agreed formally that water quality standards for the tribe would be the same as those for the remainder of the State, a significant step toward cleaning up contaminants in the tribe's water supply, which include PCBs, lead, furans, and dioxins.

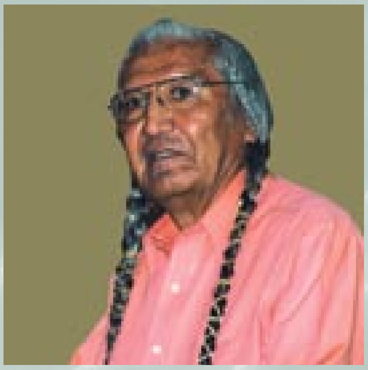
Other tribes (Colville, Pullayup) have become involved in pilot projects under the EPA Brownfields Economic Redevelopment Initiative. A brownfield is defined by EPA as "a site, or portion thereof, that has actual or perceived contamination and an active potential for redevelopment or reuse."[54] Several such pilot projects are underway in the Pacific Northwest States on reservations or nearby lands.

Radioactive Contaminants

Of equal concern, a number of the Pacific Northwest tribes live adjacent to or in the dispersion paths of several major sources of radioactive contamination. The most infamous of these is the Hanford nuclear weapons production site in south-central Washington, which contains the greatest quantity of radioactive waste in the country. Plutonium, which has a half-life of 24,000 years, was produced at Hanford for nearly 30 years, beginning in 1943. During that time, there were multiple releases of radioactive iodine-131 gas into the air, water contaminated with radioactive compounds was released routinely into the Columbia River, and some 45 billion gallons of contaminated liquids were dumped above ground at the site. An estimated two million people in the area were exposed, many of them Native Americans.[55] A speaker stated that in the 1960s, Hanford was discharging more than 20 million curies of radionuclides into the Columbia River annually. By comparison, the Three Mile Island nuclear reactor in Pennsylvania released approximately 20 curies annually.

According to current estimates, the Hanford site still contains 53 million gallons of plutonium waste stored in leaking underground tanks, nearly 2,300 tons of spent fuel, four and a half tons of plutonium, 25 million cubic feet of solid waste, and 38 billion cubic feet of contaminated soil and groundwater.[56] In addition to plutonium, the waste contains strontium, cesium, and other radioactive elements.

A speaker indicated that thousands have sued the Government's Hanford contractors for harm to health associated with the plant's operations. A negative judgment in a suit



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> "Plutonium is one of the most hazardous materials in existence. One invisible speck inhaled into the lungs can cause cancer. Hanford produced 74 tons of plutonium."

***Russell Jim,** Manager, Environmental Restoration/ Waste Management Program; Elder, Yakama Nation, Washington*


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“About five years ago, a tribal member on the river reported to the tribal game wardens that after working late into the evening hanging fish to dry after they sliced them, they turned the lights out to go to their house, and looked back and the fish were glowing...my wife woke me up at 10:30 after cutting fish and asked me if I want to come out and see the glowing fish. And I said, ‘No, I am going to eat them anyway.’”

Russell Jim, *Manager, Environmental Restoration/ Waste Management Program; Elder, Yakama Nation, Washington*

brought by the Yakama and others in 1996 recently was overturned on appeal, and the plaintiffs hope that a future verdict will be favorable. The speaker noted that the same appeals court recently held that there is no safe threshold for ionizing radiation, a statement supported by scientific and legal authorities.[57] A Government-sponsored report released in September 2001[58] concluded that tribal radiation doses had been underestimated by a factor of 15 in the 1996 Hanford lawsuit, and that tribal members in the Hanford reach of the Columbia River were the most severely affected of all people.

Two major studies of the Hanford situation have been conducted. The Hanford Environmental Dose Reconstruction (HEDR) Project began in 1987 by the U.S. Department of Energy and later was transferred to the CDC due to conflict of interest concerns. The National Academy of Sciences characterized the 1993 study report[59] as incomplete and based on questionable methods. The CDC also sponsored the Hanford Thyroid Disease Study. Begun in 1989, its final report was released in June 2002. With limited data and a study design that relied on assessments of dose-response relationship rather than using an external control group, the study could draw few conclusions. However, the study found that compared with the general population, Northwest U.S. residents with childhood radiation exposures from Hanford had similar risk levels for thyroid cancer and other thyroid diseases regardless of their radiation dose.[60] Importantly, due to small numbers, neither HEDR nor the Hanford Thyroid Disease Study included Native Americans, and the tribes in the area remain unconvinced that the thyroid cancer and other thyroid disease experienced by their families is unrelated to radioactive exposures from Hanford. To date, no studies of possible relationships between radioactive exposure from Hanford and other cancers have been conducted.

The Yakama Nation has been involved in activities related to the Hanford clean-up process for many years, proposing and participating in a variety of impact assessment projects and participating in the Hanford National Resources Trustee Council. Construction of a new waste treatment complex at Hanford began in September 2002, but even test processing of plutonium waste will not begin until at least 2007.[61] According to a speaker, the clean-up plan for the area will create a permanent storage facility at Hanford and reclassify massive amounts of certain high level waste as “incidental waste,” eliminating the requirement to dispose of it in the most secure manner. The Yakama Nation filed suit to block this reclassification plan. The clean-up plan also would permanently restrict access to the land affected, which the tribe saw as a violation of the Treaty of 1855.

Hanford is not the only source of radioactive contamination on tribal lands in the Pacific Northwest. For example, the open-pit Midnight uranium mine (an EPA Superfund site) is located on the Spokane Reservation. The mine supplied uranium for nuclear bombs beginning in the late 1950s. Reclamation of the site, including the processing and disposal of mine waste and contaminated water, has for years been a major issue for the Spokane tribe. The deposit and flow of contamination from the mine affects the tribe's lands, subsistence food supply, and its water supply from the Spokane River. The Sherwood uranium mill also is on the Spokane Reservation; though long closed and ostensibly "reclaimed," a tribal representative indicated his belief that radioactive contaminants were not fully removed or contained. Moreover, the Spokane Indians are one of the "down-winder" tribes that for many years were subject to radioactivity released into the air from these sources.

"We have two of our elders dying this week of cancer or undergoing treatment and we do not know the cause of that cancer. I lost my mother, I lost my grandfather, I lost my grandfather on my father's side. My grandmother had two different types of cancer....In my wife's family there has been several cancer deaths...."

***Bob Brisbois**, Business Council, Spokane Tribe, Washington*

Other Possible Environmental Influences

Speakers indicated that although tobacco has been used in ceremonies for centuries, cigarette smoking was, until the last few decades, relatively rare in most tribes. Currently, however, American Indians/Alaska Natives have the highest smoking rates in the country (41 percent)[62] and while national smoking rates have fallen steadily since 1965, smoking prevalence among American Indians/Alaska Natives has been nearly unchanged for about two decades.[63]

Several speakers at the meeting testified that the use of smokeless tobacco (chew or snuff) is a significant problem, particularly among young men. National data indicate that American Indian/Alaska Native men are more likely than any other group to use smokeless tobacco.[64]

Some of the larger tribes appear to have policies and arrangements for safe disposal of auto batteries, motor oil, paint, solvents, and other domestic and industrial use items and chemicals, but it is unclear how consistently residents and businesses adhere to these policies or use available services. If not disposed of properly, these items may be contributing to soil and water contamination in the region.

Health Services Funding, Infrastructure, and Cancer Care Services

As is true for any population, the cancer burden borne by Pacific Northwest American Indians and Alaska Natives is influenced by the health services funding, health care infrastructure, and cancer care services that are available, accessible, and culturally acceptable. Many of the challenges to cancer care for the Yakama Nation and other tribes in the region are problems common to rural areas—physician undersupply, low reimbursements compared to urban areas, poor access to primary and specialty care, fragmentation of care, poor access to clinical research, geography/distance from care, cultural and social issues, and poverty. In the case of Native Americans, however, some of these problems are exacerbated by limitations of the Indian Health Service programs and unique features of the relationship between tribal governments and U.S. Federal and State Governments.

It recently has been observed that "the Indian health system continues to try to meet the Federal trust responsibility to provide health care for American Indians and Alaska Natives despite significant shortfalls in funding, resources, and staff.... The growth in the prevalence of chronic diseases in this population is a crisis for the IHS, which was originally designed as a hospital-based, acute care system and is currently severely underfunded..."[65] The IHS system is heavily oriented to the provision of reservation-based primary care, with virtually all specialty services arranged through referral by the physician or a case manager.

The total IHS budget for Fiscal Year 2002 was $2.8 billion, but tribal leadership has estimated that a budget adequate to meet Indian health care needs would approach $18 billion.[66] The inadequacy of IHS funding is further apparent when per capita expenditures for health care are compared with other Federal programs that provide or finance health services, and with average per capita expenditures nationwide (Figure 1). As the graph indicates, per capita health care expenditures for Native Americans are far below that of any other reference group, including Federal prison inmates.

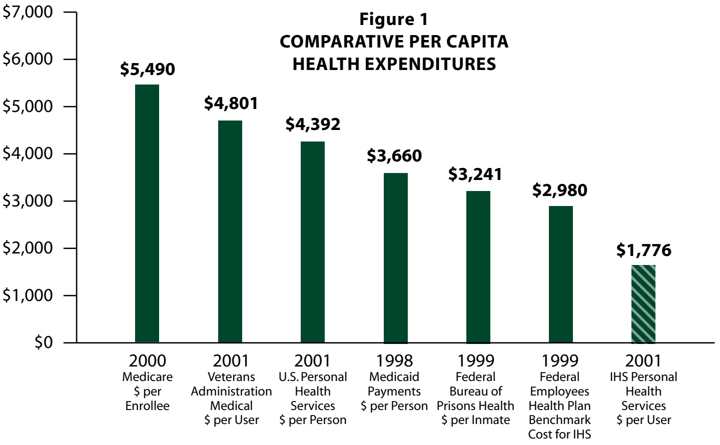

Figure 1
COMPARATIVE PER CAPITA HEALTH EXPENDITURES

Sources: The Restructuring Initiative Workgroup for the IHS. Transitions 2002: A 5-Year Initiative to Restructure Indian Health, Preliminary Report–June 5, 2002; U.S. General Accounting Office. Federal Prisons: Containing Health Care Costs for an Increasing Inmate Population, Testimony, April 6, 2000, page 1.

Over the past decade, health care delivery for Northwest American Indians and Alaska Natives has evolved from a centralized, IHS-maintained system to a system that is dispersed, complex, and diverse. Under the provisions of the Indian Self-Determination and Education Assistance Act of 1975, tribes can elect to manage and operate IHS health facilities and services. At this time, half of the 14 IHS-funded primary health centers in the Portland Area Indian Health Service Unit are operated by the tribes served, while the other half continue to be operated by IHS.

IHS health care services are funded through two mechanisms:

(1) *Direct care* includes primary care services provided at tribal health centers, clinics, and health stations. Though each IHS facility has a designated delivery area, a person who is a member of any Federally-recognized tribe can receive direct care at any IHS primary care center.

(2) *Contract health services* (CHS) includes care or services of any type not available at the primary care centers. Care provided through a tribe's CHS typically is strictly limited to enrolled tribal members and descendants living in the CHS catchment area.

As with the primary care centers, the IHS manages and operates some CHS programs. However, where the tribe has elected to administer the program itself (as have the Yakama), IHS monies still fund the CHS program, but the tribe has full authority to structure and manage the program and to decide what services are covered.

Direct Care

The majority of health care provided to Federally-recognized Pacific Northwest tribal members and descendants is funded by the IHS. For some tribes, IHS services are the only source of care, and the scope of direct care services available varies significantly.

Yakama Nation

The ambulatory care center located on the Yakama Nation Reservation, the Yakama Indian Health Center, is the largest stand-alone clinic in the IHS network nationwide. It is owned and operated by IHS, but a representative of the Yakama tribe sits on the center's governing board that makes decisions regarding operations, staffing, and other administrative matters.

Primary (direct) care at the Yakama IHS health center is funded to serve a four-county catchment area, but a significant number of American Indian and Alaska Native people from outside the catchment area use the center's services. In the past three years, members of 105 tribes have received care at the clinic. The clinic is funded at 51 percent of actual need based on a user population of 11,700. However, the clinic actually serves nearly 22,000 patients. Treating these additional patients exacerbates the severe underfunding problem that already exists, since the budget in reality covers only about 25 percent of the medical needs of those being served.

The health center provides primary care, suturing, basic burn care, x-ray, basic laboratory services, dental care, mental health, substance abuse, and pharmacy services. Pap smear and prostate-specific antigen (PSA) cancer screening tests can be performed, but mammography, colposcopy, flexible sigmoidoscopy, and colonoscopy are not offered. No other cancer diagnosis or treatment services are provided at the health center.

As of January 2003, the Yakama health center employed five board-certified physicians, one of whom serves half time as medical administrator. A physician working under contract (12 hours per week) does not take appointments, treating urgent care patients only. Additional physicians are needed, but recruiting efforts have been hampered by the same disincentives that are common to rural health: heavy patient loads, isolated location, quality of life concerns (e.g., frequent on-call duty), limited professional contact and continuing education opportunities, and low reimbursements.

"We only have four physicians taking appointments. That leaves approximately 5,000 plus patients per doctor. When you talk about cancer prevention, how can one prevent cancer when you cannot even keep up with the onslaught of patients coming through that door? When you cannot get an appointment for two months?"

Rex Quaempts, M.D., *Family Physician, Indian Health Service; Member, Yakama Nation, Washington*

A speaker noted that a physician at the Yakama health center recently left to work at the nearby Farmworker's Clinic; his patient load dropped from 5,000 to 1,500.

In addition to the physician staff, the center employs one half-time and four full-time pharmacists; one part-time and two full-time pharmacy technicians; six full-time dentists; a dental hygienist and nine dental assistants; an x-ray technician; a clinical psychologist; a counselor; two social workers; and one half-time and two full-time advanced nurse practitioners. In addition, the center has a phlebotomist, three medical technicians, four public health nurses, a contract optometrist, a physical therapist, an audiologist, and a health educator. Recently, one of the public health nurses was assigned to a new patient navigator program developed since the meeting. Tribal employees working at the clinic include a psychiatric nurse practitioner, a dental hygienist, and a doctor and nurse working under contract.

A second, smaller reservation clinic is located at White Swan, some 20 miles west of Toppenish. Unlike the Yakama Indian Health Center, the clinic at White Swan is not accredited. A new ambulatory clinic in White Swan is scheduled to open in 2006, and a new dental clinic will open in 2003.

The IHS does not provide ambulance/rescue services as part of direct care, but the Yakama Nation owns and operates around the clock three ambulances that are staffed by emergency medical technicians (EMTs). One vehicle is located in Toppenish, the others are stationed at White Swan. The EMTs currently are not certified to start intravenous lines. A non-tribal community ambulance service also responds to 911 calls on the reservation; the tribe will pay the ambulance service for the call if the patient has an alternative payor that can be billed, and the situation is deemed to have been a true emergency. Otherwise, it is an out-of-pocket cost to the patient.

The Yakama Nation operates a home health program staffed by registered nurses who are a crucial link between the health system and tribal individuals and families. They explain the importance of preventive and medical interventions in a culturally appropriate manner, and encourage the use of available health services. The nurses monitor medication regimens, including pain management; assist patients in obtaining prescription refills; take vital signs; and conduct physical and visual patient assessments. Though they are not trained in oncology, they do provide assistance to cancer patients. Program staff noted the need to expand hospice care as the need for these services is growing. The home health nurse manager meets regularly with the IHS primary care physicians to apprise them of patients' status. Like a number of other tribes, the Yakama also employ Community Health Representatives (CHRs) who can help set up patient appointments, provide patient transportation, conduct limited home visits, and provide social support.

Other Pacific Northwest Tribes

Some of the other larger tribes have health centers that provide a similar range of primary care services, though the scope of services may vary somewhat. For example, the Warm Springs clinic is staffed to provide cardiology, nephrology, and optometry services. A number of smaller tribes have only health stations that are staffed by a nurse. Some, such as the Hoh and the Quinault, have no primary care services available on the reservation on a regular basis. Speakers testified that it recently has been possible to take breast cancer screening clinics to some of these populations with support from a foundation grant.

Urban Indians

Urban Indian primary care clinics in the Pacific Northwest are located in Seattle and Spokane, Washington, and in Portland, Oregon. The Seattle program is by far the largest of the three clinics and provides a broader range of services that includes dental care and behavioral and community health services. These clinics serve a highly diverse population of American Indians and Alaska Natives from many tribes and cultures who live in urban areas. The clinics also serve non-Natives. Much like a community health center, they operate on a sliding fee scale, and no one is refused service. In 2002, 83 percent of those receiving services were below 200 percent of Federal poverty level guidelines.[67] To an even greater extent than the reservation clinics, the urban centers are limited by IHS underfunding—just over one percent of the IHS budget is allocated to urban Indian primary health,[68] despite the fact that 56 percent of Native Americans live in urban settings.

Contract Health Services (CHS)

Health services not provided at the primary care centers must be obtained through referral to CHS. Each tribe is allotted CHS funding according to its "share" of regionally allocated dollars. As noted earlier, these funds can be

"I just 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, *Business Council, Spokane Tribe, Washington*

“It took me six months to get a referral out because I am not a Quinault but I lived in their service area, [and] my Quileute tribal service area could not give me the referral because I was out of jurisdiction of their service unit. Things like that need to be looked into and addressed because a lot of times we cannot marry someone from our own reservation because we are all related in one way or another so you have to go look outside of your reservation to go marry someone you are not related to.”

Ann Penn-Charles, *Breast Cancer Survivor; Community Health Representative, Hoh Indian Tribe, Washington*

administered by the tribe or by IHS. The funds may be administered by non-medical staff who arrange patient referrals for imaging studies, specialty or hospital services, nursing home or hospice care, or other care according to instructions from a primary care physician. If a tribe’s direct care center offers a relatively narrow range of services, then a greater number of services must be funded with CHS dollars.

Typically, only enrolled members and (if authorized by the tribe) tribal descendants are eligible for care through a tribe’s CHS. Other individuals may be included at the tribe’s discretion. This rule can create a situation in which a person living on the reservation of a tribe other than the one in which he or she is enrolled will have to return to the home tribe’s catchment area to receive contract care services.[69] For example, a pregnant woman may have to go back to her tribe for prenatal care and delivery so that she can access obstetric and hospital care. Children may be registered with the mother’s or father’s tribe according to each tribe’s laws; this decision will affect the child’s access to contract health services for life.

Specific to cancer, a person may have to return to his/her tribe’s CHS catchment area for screening (if not available at the primary health center) and diagnostic care; if diagnosed, the patient may have to leave his or her family for an extended period in order to receive treatment. In some cases, depending upon where an individual lives outside of the tribe’s catchment area, a tribal member may be able to access some CHS services in his/her area of residence, provided the tribe has funds set aside to serve members further from the reservation. According to an IHS official, in this situation such persons may not be able to obtain all needed cancer care services because of their cost.

Yakama Nation

Yakama tribal members and descendants residing in the CHS program’s catchment area (six counties in Washington State and two communities in Oregon, although IHS funding covers only four counties) are eligible to receive contract health services. CHS also is available to members of other Federally-recognized tribes who are permanent residents on the reservation and others who live off of the reservation but who are full-time employees of the Yakama Nation, the local BIA office, or the local IHS clinic.[70]

Reduced staffing and a growing patient population have forced the IHS-operated Yakama Indian Health Center to reduce the scope of services provided as part of direct care. For example, the center can no longer perform flexible sigmoidoscopy to screen for colorectal cancer, because the test requires too much of a physician's time and there are too few support staff to maintain the proper cleanliness of the equipment. Therefore, this procedure must be paid for with CHS funds. The center never has been staffed to perform colonoscopy; patients needing this test are referred to CHS.

Yakama health center providers perform Pap smears and PSA tests, and the center pays the laboratories that evaluate these screening tests out of its IHS budget. If a patient has an abnormal finding, however, any further diagnostic procedures or testing must be obtained through a referral to the Yakama tribal CHS.

Like most IHS health centers, the Yakama health center has no mammography machine, so screening and diagnostic mammograms are performed at either community hospitals or a local radiology facility. Yakama women who receive screening mammograms through CHS must go to the facility with which the tribal CHS has a contract. When limited CHS funding is reserved for those with life-threatening conditions (see below), no woman receives screening mammography unless she has an alternate source of payment (e.g., Medicare, Medicaid, private insurance), a family history of breast cancer, or is symptomatic. Those who are CHS-eligible but have an alternate payment source still must tell the CHS they are receiving a screening mammogram in order for CHS to pay any amounts not covered by the alternate payor.

Yakama women not eligible for CHS may receive a mammogram or a Pap smear through a Centers for Disease Control and Prevention (CDC) Breast and Cervical Cancer Early Detection Program (BCCEDP) grant administered locally by the Yakima Health District, but they must meet the program's eligibility requirements. The number or percent of eligible women who receive mammography services through this program is not known. The CDC grant will reimburse the Yakama primary care center for the cost of performing or evaluating Pap smears provided to eligible women.

Non-cancer acute care hospital services are available at three community hospitals, one of which is in Toppenish. The others are in the city of Yakima, approximately 20 miles from Toppenish. Patients with diagnosed or suspected cancer are referred to one of the two cancer treatment centers in

"Looking at the 2000 data, we did approximately 1,100 Pap smears. We have about 5,000 women who should have had a Pap smear....We had about a ten-month period there where we were unable to provide screening mammograms....Fortunately the CDC grant came through and we have started picking up the pace on getting women screened."

Rex Quaempts, M.D., *Family Physician, Indian Health Service; Member, Yakama Nation, Washington*

“...change the restrictions on this funding...so that an insurance type program can be designed by the American Indian for the American Indian that will give every man and woman and child born with an inherent right to be an American Indian a card that will...give the card holder the right to have access to all available facilities and doctors throughout America.”

Tom Lang, Sr., *Colorectal and Throat Cancer Survivor; Councilman, Metlakatla Alaska Indian Community; Elder, Tsimpsean Tribe, Alaska*

Yakima (Yakima Regional Cancer Care Center and North Star Cancer Center) or to the University of Washington. The Yakima Regional Cancer Care Center also has a number of outreach clinics, some up to 60 miles from the cancer center, but winter weather in the area can make it difficult for patients and physicians alike to reach these facilities.

Access to cancer treatment clinical trials appears to depend on the oncologist to whom a patient is referred by CHS. According to a speaker, the cancer centers in Yakima have been participating in clinical research for approximately 13 years, including NCI-sponsored trials of the Southwest Oncology Group and the National Surgical Adjuvant Breast and Bowel Project, as well as industry-sponsored trials. With the exception of the NCI Study of Tamoxifen and Raloxifene (STAR) cancer prevention trial, in which four Yakama women have been enrolled, little information was available on the extent of Yakama or other Northwest tribal participation in other cancer prevention or treatment trials; it was estimated that Native Americans comprise no more than five percent of trial participants. This limited participation is due to several barriers, including co-morbid conditions that may preclude eligibility, patient distrust and resistance to “experimental” therapy, lower educational levels that are associated with reduced willingness to participate, and the constraints and economics of travel to the cancer centers. Limited data at the national level suggest that participants in clinical trials typically are college educated and have high incomes,[71] and that American Indians and Alaska Natives who have less than a college degree are rarely included in any type of cancer clinical trials.[72]

Contract health funds are seldom sufficient for all of a tribe’s health care needs, and funds often are extremely limited—or entirely exhausted—before the end of the fiscal year (ending September 30). At the time of the meeting, for example, Yakama contract health dollars were only available to fund severe medical emergencies (Priority 1—referred to as “life, limb, or function” cases). Yakama CHS personnel stated that although they have had funds sufficient to treat all of their Priority 1 patients, they only have been able to treat Priority 1 patients for the last two or three years. Thus, only individuals with life-threatening situations are actually able to receive care. According to Yakama CHS officials, patients with suspicious mammograms, abnormal Pap smears (high grade dysplasia or cancer *in situ*), and elevated PSA levels (depending on PSA level and age) are designated Priority 1.

This may not be the case in other tribal CHS programs. Under these circumstances, patients in some tribes may receive a referral for contract health services, but he or she may not actually receive the needed care for several months—or may not receive it at all. Tribal staff indicated that there is an appeal process through which a cancer patient may be able to receive chemotherapy despite the scarcity of CHS funds. Palliative and hospice care is likely to be seen as a comfort measure that would not be covered by CHS.

Further, patients who are referred for care when the CHS budget is exhausted are obligated to tell the provider that he/she will not be paid until the next fiscal year. Under these conditions, many area providers refuse to take contract care patients. This situation delays needed care and places great stress on the patient. From a financial standpoint, this situation means that the tribe's health budget, which already is grossly underfunded, begins each fiscal year with a deficit.

In the past fiscal year, Yakama CHS was only able to pay for 35 percent of the care requested. This is consistent with the national average—in FY 2002, almost two-thirds of the care needed by American Indian and Alaska Native families but not available through IHS- or tribally-operated direct care programs was denied.[73]

Other Pacific Northwest Tribes

Although far less information was provided on CHS services in other tribes, the Yakama's experience appears to be similar to that of other larger tribes. At some of the smaller clinics, basic x-ray and laboratory services may not be available, and therefore may also require contract health support. Compared with the Yakama, members of smaller and more isolated tribes may have to travel much further to access specialty health care, including cancer care services.

Urban Indians and Alaska Natives

American Indians and Alaska Natives living in urban areas do not have access to contract health services unless they return to the CHS catchment area of their tribe. The urban clinics provide referrals to specialty care and may assist patients in applying for Medicaid or other public programs if eligibility seems likely; otherwise, unless they have private health coverage, urban Natives are liable for the cost of any specialty care they may require.

IHS and CHS—Payors of Last Resort

Since IHS budgets are so constrained, IHS- and tribally-operated facilities must aggressively seek other sources of payment for services provided to tribal members. IHS officials clarified that IHS- and tribally-operated CHS are “payors of last resort.” This means that every other possible payment source will be billed before IHS or CHS assumes responsibility for the cost of services. At the Yakama health center and tribal CHS, potential payors are billed in the following order: private primary insurance, private secondary insurance, Medicare, Medicaid, Medicare supplemental insurance, IHS direct care, tribally-managed CHS. However, if a person is a Medicare beneficiary, the provider bills Medicare directly, and CHS pays for any costs not covered by Medicare. The Yakama tribal CHS will pay these balances even if they are not for Priority 1 medical situations, but other CHS programs may not. In addition, the primary health center can bill the CDC screening program for Pap smears provided to eligible women.

Non-IHS Funding for Health Services Provided to Tribal Members

CDC Breast and Cervical Cancer Early Detection and Treatment Programs

The Yakama Nation has been one of a relatively small number of tribes receiving care through a grant from the Breast and Cervical Cancer Early Detection Program (BCCEDP). Women who are eligible for the program (those aged 40 to 65 years with incomes at or below 200 percent of the Federally-established poverty level) are referred to local hospitals or a radiology facility for mammograms. As noted earlier, Pap smears most often are performed at the Yakama health center. According to an IHS official, the State of Washington BCCEDP is trying to secure funding to cover Pap smears for eligible women 18 to 39 years old).

Prior to passage of the Native American Breast and Cervical Cancer Treatment Technical Amendment Act of 2001,[74] Indian women with abnormalities detected through the screening program were not covered by the Breast and Cervical Cancer Treatment Act (P.L. 106-354) and had to seek follow-up diagnostic services and treatment through the tribal CHS. With passage of the amendment, women who are screened through the program and who have abnormal Pap smears or mammograms are presumed eligible for Medicaid coverage of all diagnostic and treatment services needed in connection with the detected abnormality. It should be noted that for all women covered by the Treatment Act, Medicaid coverage ends at the conclusion of initial cancer treatment; routine follow-up care is not covered. To date, no Yakama woman has received cancer treatment through the Treatment Act. Information on other tribes in this regard was not provided.

Medicaid and Medicare

Medicaid

Medicaid provides a substantial safety net for the poorest Native Americans, but many who could receive benefits do not realize they are eligible. They may not understand the process and paperwork associated with establishing eligibility, and also may resent having to apply for welfare to get services they believe should be paid for by IHS.

The Yakama and other Pacific Northwest tribal members are eligible for Medicaid if they meet State eligibility requirements. At the Yakama health center, if it appears that an individual is eligible for Medicaid, a patient registration clerk instructs the patient to visit the local welfare office located in Wapato, approximately 10 miles from the clinic. Generally, patients are responsible for getting to the welfare office and filing their own forms for Medicaid coverage, but the clinic sometimes assists patients with no means of transportation. However, Yakama tribal CHS officials indicated that a CHS staff member is available to assist patients with applications and makes home visits to help people complete application materials. Eligibility determinations can be made at the time of application, but it normally takes 30 days to receive a Medicaid card. Speakers indicated that other tribes often experience much longer waiting periods. During the waiting period, patients at the Yakama health center can still receive direct care services and if they are CHS-eligible, referrals for specialty care. The center then bills Medicaid when the appropriate paperwork is completed; the center's business office and the tribal CHS can submit claims for cost recovery for up to three years.

Just over 4,000 primary care patients (persons who have used clinic services at least once in the past three years) at the Yakama health center are on Medicaid, and the clinic is heavily dependent on reimbursements from this payment source. However, Medicaid enrollment, and therefore Medicaid patient care revenue, has been declining due to lower reimbursement levels and tightening eligibility

> “You wait six months for that Medicaid to get placed. If you have to go through surgery and...chemo and radiation sometimes it takes longer and it is that much more days that the cancer is spreading.”
>
> ***Ann Penn-Charles,*** *Breast Cancer Survivor, Community Health Representative, Hoh Indian Tribe, Washington*

requirements. The Yakama health center would like to have a staff person in the clinic who could assist patients in establishing eligibility. For this to occur, Washington State would have to place an employee at the facility; this person could also assist people in qualifying for food, utility (including telephone), and other assistance. Health center personnel indicated that they intend to pursue this arrangement with the State.

A speaker noted that tribes often are not recognized as sovereign nations, but are considered subpopulations of counties or States. Medicaid funding is allocated based on total State population. The State then reimburses claims by IHS- or tribally-operated health facilities for care provided to Native American Medicaid-eligible persons. The Federal Government covers 100 percent of the cost of providing Medicaid services to Native Americans, so no State Medicaid matching funds are required to care for Indians on Medicaid.[75] In some cases, however, when Natives sought Medicaid- or Medicare-funded services outside of an IHS facility, they were refused and told that they must go through IHS. In this way, a speaker maintained, the State takes advantage of the extra funding it receives by counting Native Americans in its population total, but the tribes do not receive commensurate benefit. The health centers would prefer that State allocations for Native Americans come directly to the tribes so that they, rather than the State, can control their expenditure.

Medicare

Patients aged 65 years and older are eligible for Medicare if they (or their spouse) previously were employed and paid Social Security taxes for the minimum number of quarters required of beneficiaries. Some of the Yakama and other tribal members who were lifelong subsistence fishermen, for example, cannot receive Medicare because they did meet this requirement. Those who have been employed and made the requisite contributions are contacted by the local Social Security Office upon reaching age 65.

Approximately 1,170 Yakama health center patients are 65 years of age or older. Of this population, 32 percent receive Medicare benefits.[76] A small percentage (four percent) receive Medicare Part A (hospital services) only, have no other payment source for health services, and either cannot afford or choose not to pay Part B (ambulatory and physician services) premiums, which exceed $50 per month. Thirty-two (32) percent of elderly Yakama Medicare beneficiaries are paying the Part B premium out-of-pocket. In addition, approximately 15 percent receive both Medicare and Medicaid. According to Kaiser Family Foundation information, Medicaid will provide Part B premium payment for defined groups of low-income Medicare beneficiaries.[77] Only 14 percent of all elderly Yakama have a combination of Medicare and some form of private insurance that would reduce their liability for out-of-pocket health care costs.

A tribal elder and colon cancer survivor from Alaska testified that he was experiencing rectal bleeding when he went to the health center on his reservation. After a preliminary test, he was referred to another facility 250 miles away for additional testing—five weeks later. A recently retired commercial fisherman, this individual had become eligible for Medicare and for Medicaid under the Alaska system. He decided to seek treatment outside of the IHS system in Ketchikan, Alaska, where he was diagnosed and treated promptly. Eighteen months later, he was diagnosed with throat cancer and treated at the University of Washington. He is now cancer free. Though his physicians referred to him as "double lucky," he stated, *"I do not think luck had anything to do with it. What had to do with it was my little card here—something that a majority of American Indians do not have. It was this card that got me into a system where the doctor...said, 'You have a choice.' He gave me a list of all the doctors on the West Coast."*

Similar bills introduced in the House and Senate (H.R. 1662 and S. 212, respectively) in 2001 would have reauthorized and amended the Indian Health Care Improvement Act (IHCIA) to, among other provisions, provide funding directly to tribes, tribal organizations, and urban Indian organizations to increase American Indian/Alaska Native awareness and utilization of Medicare and Medicaid, provide assistance with program-related paperwork, provide transportation assistance to enable patients to reach application or enrollment offices, and establish a sliding fee scale for premiums based on ability to pay. A Senate IHCIA reauthorization bill (S.556) introduced in the 108th Congress likewise includes funding for these services.

The Pacific Northwest States have some of the lowest Medicare reimbursement rates in the country (Figure 2). Low Medicare reimbursement levels are causing growing numbers of providers to cease accepting Medicare patients. Reimbursements were reduced by 5.4 percent in 2002. Rapid congressional action averted a 5.7 percent cut scheduled for 2003, instead increasing payments by 1.6 percent.

"The very, very first Americans... all we want is to have number one care like everybody else. And that is what we should get. But every year Indian Health Service is cut. Every year. And they tell us to go to get our alternate resource insurance and Medicaid and Medicare. I said, 'We never signed a treaty for Medicare or Medicaid or alternate resource.'"

Janice Clements, *Chair, Health and Welfare Committee, Warm Springs Tribe, Oregon*

Figure 2: Average Annual Medicare Payments per Beneficiary

Rank	State	Average Payment
	US Average	$5,490
41	Idaho	$3,959
42	Washington	$3,921
46	Oregon	$3,829

Source: Centers for Medicare and Medicaid Services, Fiscal Year 2000.

Likewise, recent legislation averted reimbursement cuts for 2004 and 2005. The impact of this legislation on the existing shortage of physicians in rural states, such as those in the Pacific Northwest, remains to be seen.

Department of Veterans Affairs (VA)

Approximately 250 Yakama are veterans, but the closest veterans health facility is in Walla Walla, Washington, about 120 miles from the reservation, so this population receives health care through IHS. The VA cannot be billed for care provided to veterans outside of a VA facility. A small VA clinic is being established in Toppenish, but veterans will have to travel to Walla Walla to complete required paperwork before they can be seen at the Toppenish clinic.

Tribal Health Insurance

Native and non-Native employees of the Yakama Nation are covered by an insurance policy administered by the tribe (self-insurance). This plan covers approximately 800 people. Many of the Yakama insured under the plan continue to obtain primary care services at the Yakama health center, but the center is not permitted to bill the plan for reimbursement. If tribal employees seek health services outside of IHS, the health plan reimburses the provider for care received and the tribal CHS, though separate from the tribal employees health plan, pays any copayment or deductible that would be owed by the patient. Therefore, Yakamas employed by the tribe have the option to obtain cancer screening and treatment services and other specialty care outside of the IHS/tribal CHS system.

Private Health Insurance

Limited opportunities for jobs that provide employer-sponsored health benefits and low incomes have limited Native Americans' access to private insurance. Nationally, only half of non-elderly American Indians and Alaska Natives have employment-based or other private health insurance, and 30 percent are uninsured.[79] After Hispanics, non-elderly Native Americans are least likely to have health insurance.[80] About 2,150 Yakama (nearly 25 percent) have some form of private insurance (e.g., Blue Cross/Blue Shield), only half of the national average for Native peoples.

Other Federally-funded Health Centers

American Indians and Alaska Natives can access care at most Federally-funded health programs, such as community health centers (CHCs). In fact, some CHCs may offer a greater variety of services and provide assistance with Medicaid applications; they also may enable Native patients to obtain referrals to specialty care more easily than through IHS clinics and tribal CHS. However, presenters testified that many Native Americans hesitate to go to CHCs or other non-Indian facilities and instead go to IHS clinics because they are familiar with the system and believe they will be treated with more understanding and respect.

Barriers To Care

Funding

IHS and Payor-related Financial Barriers

As detailed above, the most important barrier to care for Native Americans in the Pacific Northwest (and elsewhere) is insufficient health care funding. Nonetheless, Indian health overall has improved since 1973—life expectancy has increased by more than 12 years, and death rates from a number of targeted conditions have dropped dramatically. But it is no secret nor is it denied that IHS funding is woefully inadequate and that health care costs, including those for cancer care, are controlled by limiting access. Further, because Indian health is not an entitlement program, increasing costs due to medical inflation (10 to 12 percent annually) and a growing beneficiary population (2.5 percent/year[81]) are not covered automatically. As a result, IHS buying power continues to be eroded and little progress has been made in closing the gap in per capita health care expenditure between IHS and other beneficiary populations or the national average, as indicated by the Federal Employees Health Plan Disparity Index Study (FDI).[82] The FDI is a pricing model developed by a workgroup of tribal and Indian health leaders that uses the Federal Employees Health Benefit Plan (FEHBP) as the primary benchmark. Its objective is to determine the funding that would be required to provide equitable health services to Native Americans. The IHS allocates the Indian Health Care Improvement Fund to tribes using results from the model.

The national average IHS funding for Indian health care is approximately 60 percent of need.[83] For some tribes, IHS funding covers a much smaller percentage of need. For example, health funding to the Muckleshoot tribe of Washington covers only 29.5 percent of tribal health needs as measured by the FDI. The Yakama Nation is funded at 51 percent of need; though it is the largest tribe in the Pacific Northwest, it is one of the less well funded. Additionally, as in the case of the Yakama, the patient population statistics used to derive the tribes' percent-of-need funding estimates may be vastly understated. With no increases in their core budgets, IHS health facilities are increasingly dependent on reimbursements from other payors, principally Medicare and Medicaid, but these reimbursements have been cut significantly.

Some Yakama and other tribal members have private insurance, but neither can this source of revenue be counted upon. If the patient is a member of a health maintenance organization (HMO) or preferred provider organization (PPO), including Medicare supplemental policyholders, IHS or tribal organizations may not be able to bill for services provided because they are not considered part of the provider network. Revenues from privately insured patients are not necessarily higher than those from public payors; private insurers quickly adjust their reimbursements to mirror Medicare payment levels. Moreover, Native American patients with private insurance or Medicare often come to the Yakama health center for medications or dental services not covered by their health plan.

In the early 1990s, the Warm Springs tribe established a joint venture demonstration project with the IHS, authorized under the Indian Health Care Improvement Act, to improve the health care capacity and funding available to tribal members and descendants living on or near the reservation. Using funds obtained partially through a ten-year tax-exempt bond offering (as permitted by the Indian Tax Status Act), as well as some of its own resources, the tribe constructed a new health center on its geographically isolated reservation. The tribe owns and maintains the facility, but it is made available to the IHS through a no-cost 20-year lease. IHS equips, staffs, and operates the health center. The joint venture had a dramatic effect on the tribe's CHS budget; once fully operational, previously CHS-funded services such as optometry, pediatric dentistry, and enhanced diagnostic services were shifted to the IHS recurring base budget without reducing the CHS budget. The CHS program was then able to cover all of the care needed by the tribe and even have some dollars for reserves. Although it took several years to bring to fruition, the joint venture was made possible in part because of a strong working relationship between the Warm Springs leadership and IHS.

Provider-related Financial Barriers

Providers are becoming increasingly reluctant to accept IHS, Medicaid, or Medicare reimbursements for services provided to patients (especially new patients) with these payment resources. It was reported that some physicians are leaving the area, and that some older physicians are simply retiring early. The result is delayed care for patients, and the loss of already scarce providers, particularly specialists in rural areas.

Although the Yakama clinic has its own pharmacy, some medications (e.g., certain injectable medications, some of the more expensive antibiotics, antidepressants, and asthma medications) are not available there. Patients who are prescribed such medications must try to obtain them at local pharmacies. At the time of the meeting, the local newspaper reported that several area pharmacies would no longer accept prescription orders from Medicaid patients because of low reimbursements.[84] Therefore, Indian and non-Indian patients alike who are on Medicaid now have fewer places at which to obtain needed medicines.

Patient-centered Financial Barriers

IHS funding limitations sometimes cause patients to refuse care because they fear being liable for charges not covered by IHS/CHS. Speakers indicated that CHS patients must sign a form agreeing to pay for services not covered, although Yakama CHS employees indicated that this is not the case if the patient's condition is an emergency, CHS is notified, and the medical situation falls within CHS priorities. Signing such an agreement can be a humiliating experience if an individual knows that if charges are incurred, he or she will have no way of paying. Speakers reported that some tribal members have had their outstanding bills sent to a collection agency. If they choose, those with health bills may qualify for a personal loan from the tribe that usually must be repaid within five years; but for many, repaying such a loan also is an impossibility.

Infrastructure—Facilities, Equipment, and Staffing

The average age of IHS facilities is 32 years; many facilities are more than 60 years old and one-third require replacement. The Yakama recently received IHS funding to build a new clinic at White Swan. Other facilities require substantial renovation to function effectively as ambulatory care centers. As noted earlier, even the larger health centers in the Pacific Northwest do not have mammography machines, other


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> “The system barriers begin with the long wait from the time of the call for [an] initial visit to the primary care at the clinic, then the search for specialists who will provide tests, a greater wait for insurance funding, or a patient has to sign an agreement to pay privately for diagnostic tests when they have absolutely no expectation of ever being able to pay that bill, which then of course contributes [to] a sense of powerlessness, embarrassment, and stigmatizing by feeling poor and unable to receive services as others appear to have. And often what they do is they will not come back.”

Kay Maples, *Social Worker, North Star Cancer Center, Yakima, Washington* equipment, or the staff necessary to provide cancer screening and other cancer-related services. Yakama health center providers make limited use of computers because the equipment they have is slow and access to servers is limited. A single fiber optic link was established with the help of a special grant.

Chronic staffing shortages at Indian health clinics due to budget constraints and difficulties in recruiting providers to remote areas result both in appointment delays that can exceed six months and waits of several hours at the clinic even when one has an appointment. Long waits can be particularly difficult for older or very ill patients. Sometimes patients may wait all day to be seen, only to be told to return another day. This situation is a major disincentive to participation in the health care system.

Staffing shortages also limit the range of services available at IHS or tribal health facilities, requiring patients to need CHS referrals for cancer screening, diagnosis, and treatment, and non-cancer care. As earlier sections detailed, patients may never receive needed services if CHS funds are depleted or may receive services too late to save their lives. In addition to the funding issues, care can be delayed because there are too few specialists to serve the population. In this regard, a speaker pointed out that the city of Yakima used to have five gastroenterologists but now has only two; waiting time for an appointment is now six weeks to three months.

Provider supply and CHS funding issues contribute to fragmentation of care. An IHS primary care physician at the Yakama health center expressed his frustration that Yakama cancer patients are referred out to other providers, often distant from the reservation, and thereby lose the continuity of care and support that he believes is a critical part of the primary care provider's role. Patient records are maintained at the primary care center used by the tribal member; when he or she must travel to other sites for care, records are often lost in transit.

Native Americans at the Yakama meeting expressed a strong preference to be treated by Native health care providers, but few are available. Attracting young American Indians and Alaska Natives to health careers has been a significant challenge. Most lack the fundamental science education, social support, self-confidence, and resources to pursue careers in the health professions. All of these areas will need to be addressed to develop a cadre of Native health professionals in Indian Country. Suggestions included strengthening primary and secondary school science curricula, building support networks for university students, and taking advantage of a State-level tuition repayment program that currently is being utilized primarily by non-Natives. In addition, to retain Native providers in rural and reservation areas, it must be possible to establish and sustain a financially viable career. Yakama health center providers participate actively in community health fairs to encourage young people to consider medical and health care administrative careers and show that success is possible.

Cultural Barriers

Attitudes about Cancer and Health

Fatalism about cancer is very strong in Native populations, because their experience has been that nearly everyone who develops cancer dies from it. As a result, interest in screening may be limited, because cancer is viewed as a death sentence and people fear the disease, its treatment, and treatment costs. Having cancer still carries a strong stigma for many American Indians and Alaska Natives and can be a major barrier to prompt care and family support. Many believe that stress can cause illness, including cancer. Presenters noted that cancer education and screening interventions that emphasize finding illness are at odds with Native health attitudes that focus on promoting wellness and harmony. Cancer education has been difficult in part because of the lack of communication infrastructure on many reservations. Many do not have telephones, and most communication is by word of mouth. For this reason, outreach by CHRs or similar workers is critical to reach residents in remote areas.

Reluctance to Engage the Health Care System

Several speakers stated that many Native Americans in the Northwest hesitate to go to hospitals because they have suffered extremely hostile and insensitive treatment by hospital personnel. They attributed this treatment to racial discrimination and the low reimbursements providers receive from IHS. Those who have had little contact with the health care system may find the facilities and machinery intimidating and frightening.

Importantly, to provide effective health care to Native Americans, providers must be willing to meld Western and Native health practices and beliefs. IHS facilities have always understood this need and have found ways to allow the participation of traditional healers and traditional ceremo-


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“. . .I am a second time go around with a brain tumor....The hardest part is going through with my family, my spouse. I feel like at times they get sick [of it] and don't want to be around me. They do not want to hear the negative talk sometimes because I am planning a funeral and I tell them this, do it like that, do this, the way I was taught as a little girl.”

Rhonda Billy, *Brain Tumor Survivor; Yakama Survivor Support Group, Yakama Nation, Washington*


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“...in a spiritual sense it means very much to our people to have a tie to the land, to be able to know that there are medicines on Mother Earth that we can draw upon...and when the rest of the world does not understand that in a holistic sense then it becomes a barrier.”

Anthony Washines, *Chair, General Council; Elder, Yakama Nation, Washington*

“...trust has to be established no matter who the provider is and sometimes that can take a lot of time.... Unfortunately, cancer does not always give us that sort of time line...having the system already integrated together with the specialists would be a big advantage in terms of trying to establish that trust...so that the appropriate interventions for cancer can be made.”

Thomas Boyd, M.D., *Medical Oncologist, Yakima Regional Cancer Center, Washington*

“...they had drained out five liters of liquid from her stomach. They found a tumor that was the size of a grapefruit and four more that were the size of walnuts...and all of this, you know, I think could have been prevented if they would have listened to what she said about her stomach hurting.... I am thankful that the IHS is there, but, you know, when a person hurts in their body a lot of times they think they are there for drugs.”

Tina Kalama Aguilar, *Warm Springs Tribe, Oregon, describing the experience of a friend with ovarian cancer*

nies in conjunction with modern medical care. Non-Indian facilities often are unwilling to make this important extra effort, creating a significant barrier to care.[85]

Some patients resist going even to tribally-administered CHS because they are required to fill out a government form with identifying information and are distrustful of the health care system, including IHS, and the U.S. Government as a whole. Further, cancer has not been a high priority for many Native Americans, who may be more concerned with daily needs and with health problems such as diabetes, heart disease, substance abuse, and unintentional injuries. For all of these reasons, speakers indicated, patients may only come to the clinic or hospital when they are in significant pain or incapacitated. In such cases, when the cause of the problem is cancer, the disease is likely to be advanced.

Cultural Incompatibility with Health Care Providers

Native Americans, particularly women, are quite private and are extremely hesitant to discuss matters having to do with their bodies, especially with strangers. Community health education events often separate the genders if details of bodily functions or body parts must be discussed. This modesty affects Native women’s willingness to be screened for cancer or to discuss symptoms they may be having with providers, especially those who are male and/or not Native Americans. Native American men also do not like to undergo invasive or embarrassing procedures or disclose physical problems, choosing instead to endure pain or other symptoms.

Incompatibility with providers can take many forms. A speaker explained that some State personnel have dual roles that can complicate the provision of effective care. She recounted a situation in a northwestern Washington county in which a non-Native social worker at a State agency known to have poor relationships with Native American and other ethnic people also was a nurse practitioner assigned to perform women’s health examinations on Native and other underserved women. According to the speaker, the State agency was perplexed as to why Native women resisted undergoing examinations by this individual.

Many of the physicians or other health care providers in rural areas are foreign medical graduates, and speakers testified that building a relationship of trust with the provider, so essential to effective health care for Native Americans, can be particularly challenging because of cultural and language differences. Overcoming trust issues is made more difficult by the fact that many of these physicians only remain in underserved communities for a limited period, usually two years. It was suggested that all non-Native providers serving American Indian and Alaska Native patients receive cultural proficiency training, and that performance in this area be made a criterion in the accreditation process for hospitals and clinics. Speakers further suggested that providers and researchers be trained in how to build trust with patients, and that funds to support such training should be built into grant budgets.

In addition, speakers urged that more CHRs or similar workers be recruited and that their skill and knowledge levels be elevated to support an expanded role in reaching Native Americans with culturally appropriate cancer information and encouraging them to use available cancer-related services.

Language/Literacy and Information Issues

Some Native Americans, especially older individuals, have limited English skills, and a large majority has had limited education. Speakers indicated that many of these individuals are likely to feel comfortable receiving services within the IHS network, but may need an interpreter when services are needed from community hospitals, cancer centers, or other non-Native care providers. However, if the interpreter lacks sufficient education and health literacy to understand and accurately translate information about a diagnosis or procedure to be performed, the patient may hesitate or refuse to accept needed care. A meeting participant stated that many older Native Americans are fearful of hospitals and medical equipment.

Understanding of cancer and its prevention and treatment also is hampered by the fact that of the 217 indigenous languages spoken today in the United States, few, if any, include a word for “cancer.”[86] Many Native people do not know that cancer is the second leading cause of death for American Indians and Alaska Natives.

At this time, little written cancer education material is available that is both culturally appropriate and matches the literacy level of most of the population. As indicated earlier, a large percentage of adult Pacific Northwest Indians have not completed high school, and many elders have far less formal education. IHS officials believe that to be most effective, print materials should be written at the sixth grade level, and that most educational materials should be designed

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“In 1998...I was diagnosed with breast cancer...I went through chemo reluctantly. I do not wish that on anybody. I went through radiation and now I am four years on tamoxifen and I have one more year follow-up for cancer care....But in December 2000, I was diagnosed with cardiomyopathy...the cancer treatment is very invasive so they do not tell you these are possible problems that can occur. So now I am a heart patient.”

Patricia Ike, *Breast Cancer Survivor, Yakama Nation, Washington* for visual learners and the oral transfer of information (e.g., videos, conferences, story telling, support groups, and talking circles), in keeping with Native oral language traditions. Speakers reported that materials produced by the Native C.I.R.C.L.E. (Cancer Information Resources Center and Learning Exchange) program co-sponsored by NCI and the Mayo Comprehensive Cancer Center have been found useful. The crucial role of CHRs or similar workers in meeting with people in their homes to provide cancer and other health information was reiterated.

The testimony presented also suggested that newly diagnosed cancer patients may not be receiving sufficient information on treatment options, short- and long-term side effects of treatment, how to obtain needed supportive services, and other important information. The testimony of a breast cancer survivor who also is the wife of a bladder cancer survivor described these problems starkly, particularly since she and her husband were receiving cancer treatment at the same time:

> *"…we never had anybody advocate to us to get a second opinion. We never had anyone tell us that we should know more about what we are doing. We both just jumped in [with] both feet and had our surgeries... no counseling when we were first diagnosed, no care providers, no home visitors, no information on special needs like diet or how to dress your wounds or where to go for therapy or related services...no assistance for transportation and no support group."*

Presenters also emphasized the need to reach young people with cancer prevention information (e.g., regarding tobacco use, exercise, diet); some suggested that doing so effectively will require re-instilling traditional Indian beliefs (e.g., self-responsibility, the essential importance of inner harmony and balance, and the belief that the body is a gift to be treasured and protected) from which they feel many young people have strayed.

Distance from Care/Transportation

Native American patients in the Pacific Northwest almost always are referred to specialists for cancer care and typically must travel long distances to reach diagnostic services and treatment. Little information is available to indicate whether Indian patients who live in remote areas are being offered all appropriate treatment options. For example, due to distance from care and provider concerns about patient adherence to a treatment regimen, it is feared that women with breast cancer may not be offered lumpectomy and radiation as an alternative to mastectomy.

A considerable number of the Yakama live at some distance from the IHS health clinic in Toppenish and even further from cancer care in Yakima. Because of the high level of poverty, a substantial proportion of the population lacks reliable transportation or the money to pay for gasoline. This issue becomes especially important when repeated trips are required to receive radiation therapy. Speakers pointed out that a 60-mile round trip from the reservation to one of the Yakima cancer centers, five days a week for six weeks is an untenable financial burden for many. Access to both primary and specialty care, particularly in the winter, is worse for some of the Pacific Northwest tribes that are more geographically isolated, have poorer road systems, and fewer personal vehicles than the Yakama. For example, the Quinault Nation in northwest Washington can only access health services one day a week at a distant clinic. There also is no clinic on the Hoh Indian Reservation, and the nearest hospital is 36 miles away.

> “Our nearest specialized health care delivery systems are in Bend, which is 60 miles south of Warm Springs, [and] Portland which is 120 miles west, and so we have a very big problem just with transportation alone. They cut just last week providing people gas money to make their appointments...we are a long ways from everywhere.”

Geneva Charley, *Community Health Information Specialist, Warm Springs Tribe, Oregon*

Conclusions

The testimony received at this dialogue with the Yakama Nation provides only a snapshot of some of the many, exceptionally complex issues facing Indian health care overall, and the issues involved in better understanding and addressing the cancer burden and cancer care issues of the Yakama and other Pacific Northwest tribes. While this report is not an exhaustive review of the situation, it describes some of the limits of current knowledge and points to the need for specific information that would help in addressing some of these issues. At the same time, knowledge is seldom complete, but this reality must not preclude action. Opportunities exist to better understand cancer in Pacific Northwest tribal communities and steps to improve cancer-related care are possible.

The Cancer Burden of the Yakama and Other Pacific Northwest Tribes Cannot Be Separated from Their History and Current Circumstances

Cancer occurs in humans who live in specific human circumstances. It has been noted that, particularly among indigenous peoples, dispossession—of land, culture, language, religious beliefs, and labor—is at the root of health disparities.[87] In large measure, the widespread poverty and limited economic opportunities experienced by Native Americans are the driving force behind many of the health status and coverage problems facing tribal peoples.[88] Lower socioeconomic status and the circumstances that typically characterize it—poor housing, low income, limited education, greater environmental and occupational exposures, limited access to information and communication technologies, insufficient access to transportation services—are associated with late-stage cancer diagnosis and higher mortality.[89,90,91] Commonly, people living under these conditions suffer from excessive stress and feelings of hopelessness and isolation. Thus, it is highly likely that the history leading to the current living and health care situations of the Yakama and other Pacific Northwest tribes has influenced the cancers occurring in these populations and been a major factor fostering the distrust of many Native Americans toward non-Indian health care providers.

Health Care Funding for Pacific Northwest Tribes Is Seriously Inadequate

IHS funding is appropriated annually at the discretion of Congress and is not adequate to meet the health care needs of Native American people. This ongoing funding deficit is a major factor in cancer-related and other disparities experienced by Native populations. The Institute of Medicine (IOM) has stated that closing the gap on health disparities for this population will require a national recommitment, especially in the form of increased Federal funding that would allow patients timely access to specialty care.[92] According to IHS officials, in the Pacific Northwest, IHS health care budgets for reservation-based American Indians and Alaska Natives are computed using neither current census figures nor actual numbers of patients served. In terms of cancer care, these funding inadequacies are the root of major barriers to cancer prevention, early detection, and diagnostic services; the most appropriate treatment (including treatment provided in clinical trials); and supportive and end of life care.

Medicaid and Medicare funding levels and continuing disparities in rural versus urban reimbursement levels are exacerbating an already critical funding shortage. Funding issues make it exceedingly difficult to attract and retain health care providers in remote rural areas. Insufficient funding also results in excessive patient loads, lack of up-to-date equipment, inadequate staff support, professional isolation, and untenably low incomes that contribute to the problem.

Although urban Indians and Alaska Natives comprise more than half of the Native American population, IHS budget allocations for their care total approximately one percent of the total IHS budget.[93] The solution to this problem is not to reallocate the current IHS budget, but to increase IHS funding to provide a level of service to urban Indians that is at least commensurate with the average level-of-need funding for reservation-based Native Americans.

The June 2002 preliminary report of the Restructuring Initiative Workgroup[94]—a constituent-dominated group of tribal leaders, representatives of tribal and urban Indian health programs, national Indian organizations, and Federal employees—contains more than 50 recommendations for a five-year plan to restructure Indian health care. The recommendations center on removing IHS from the discretionary funding pool, improving funding levels (to $5 billion by 2007), influencing the internal and external environments in which Indian health operates, realigning the system, improving accountability for quality of care, and guaranteeing culturally appropriate health care.

Greater Synergies Should Be Achievable with Existing Health Care Resources in the Pacific Northwest

The limitations of current IHS funding and health care infrastructure are clear. However, a number of other health care resources are available in the region, such as community health centers, migrant health centers, neighborhood health centers, other Federally-funded health facilities, State and local grant-supported health programs, and the private provider network. Through collaborative efforts, it should be possible to achieve greater synergy among the available resources to better serve the Native American population. Such collaborations might result in enhanced joint buying power for services such as pathology or radiology, and coordinated patient tracking systems, among other possible benefits to all participants. It was suggested that tribes be made more aware of non-profit clinics in their geographic area. For example, a community health center is located within a few miles of the Yakama health center in Toppenish. In addition, technical assistance in grant writing could help tribes expand the scope of cancer-related health services and culturally appropriate cancer information available to Indian people.

Further, a recent IOM report[95] urges the Federal Government to provide leadership in coordinating government roles and resources to improve health care quality. Medical facilities serving Native Americans are one of several categories of Federally-operated programs the IOM believes should serve as laboratories for developing innovative quality improvement models. This report may prove useful in suggesting promising strategies for collaboration and health care quality improvement in the Pacific Northwest.

Culturally Appropriate Cancer-Related Education Is an Urgent Need

To increase the tribes' knowledge about cancer prevention and treatment options, and to dispel fatalism about cancer among Native populations, culturally appropriate and widespread public education on cancer is needed. Many do not know that cancer is the second leading cause of death among Native Americans. Speakers also emphasized the need for education on personal health and lifestyle behaviors that influence disease risk, including cancer risk. This education, they stressed, should begin with youth. Educational materials that incorporate visual learning are needed, as are print materials written at the average reading level of the target populations. Importantly, education and awareness must be accompanied by health system capacity; it is unethical to create demand for services without the infrastructure and staffing to meet the demand.

Additionally, education is one avenue for addressing many Indian peoples' deep distrust of cancer treatment, and of data collection and research. This distrust has been (and continues to be) reinforced by insensitive and disrespectful treatment of American Indians and Alaska Natives at the hands of non-Indian health care providers, and by research that provided no direct benefit to the tribes.

Native American Patients with Cancer and Those at Risk for Cancer Need Assistance Navigating the Health Care System

Navigating the cancer care system can be overwhelming even for those who are well-educated, well-informed, and well-insured. For those with less education, fewer resources, and from cultures outside of the medical mainstream, finding and accessing appropriate services across the cancer care continuum—from prevention to survivorship or end of life—can be a particularly difficult journey. Native Americans in the Pacific Northwest need patient navigators or similar assistance to help them find, arrange, and reach cancer screening, treatment, and supportive services; establish eligibility for financial assistance; obtain and understand needed cancer information; assist with cancer care-related paperwork; and reach across cultural gaps. Such assistance is crucial in efforts to keep people from dropping out of the health system. In Native populations, those at greatest risk may include older patients who have little contact with and are fearful of the health care system; individuals with limited health literacy, and those in isolated areas with limited transportation and telephone service. Individuals may ignore their own health needs to care for other family members and in their struggles to overcome the daily rigors of life in poverty. Based on the testimony provided, the National Cancer Institute's Center to Reduce Cancer Health Disparities is working with the Yakama and Portland Area IHS to develop navigation programs that can be implemented and sustained in both reservation and urban settings.

Rural, Geographically Isolated, and Poor Tribal Members Need Transportation Assistance and Reimbursement for Fuel Costs

The reservations of many of the Pacific Northwest tribes are in geographically isolated areas far from cancer care centers, and in some cases, from the nearest primary care facility. Given the prevalence of poverty in these communities, lack of personal transportation and the burden of fuel costs are significant barriers to cancer care that must be addressed. Options for resolving this issue could include developing cooperative ride services organized and supported jointly by the tribes, churches, the American Cancer Society, IHS, health departments, or other local groups; and fuel cost reimbursement by IHS or Medicaid. According to a speaker, one such collaborative transportation service, People for People, currently is operating in the southeast Washington area. Proposed language in a recently introduced Indian Health Care Improvement Act reauthorization bill would provide for transportation reimbursement.

Positive Elements of the Working Relationship Between the Yakama Nation, Other Pacific Northwest Tribes, and the Regional IHS Office May Be Applicable Elsewhere in the Country

From the information reviewed, it is not clear how representative the working relationships among the Yakama, other Pacific Northwest tribes, and the Portland Area IHS may be of other IHS-tribal relationships. However, certain characteristics of these relationships appear to be quite productive and may be applicable in other parts of the Nation. For example, more than 20 years ago, the Pacific Northwest tribes joined together to work as a single unit with IHS; this decision appears to have contributed to a productive working relationship between IHS and the tribes. The ongoing involvement of and consultation with the tribes in policy and operational decision-making appear to have been critical elements in this success.

The IHS-tribal agreement that led to the building of the Warm Springs health center in Oregon and concurrent infusion of health care resources may provide a model for increasing the quality and quantity of health services available to specific tribes or coalitions of tribes. Absent substantially increased IHS funding, such strategies may result in total health resources that would more closely approximate actual tribal health care needs. It is recognized, however, that all tribes do not have the financial resources to invest in such a project or secure a bond issue. In addition, to be useful on a larger scale, it will be necessary to find ways to expedite the administrative, policy/legislative, fiscal, and construction processes to bring services to tribal communities more rapidly than was possible in Warm Springs. Section 818 of the Indian Health Care Improvement Act provides the legislative authority for such projects, though no funds have been appropriated for this purpose in recent years. Provision for these joint ventures is likewise included in proposed legislation to reauthorize the Indian Health Care Improvement Act.

More Complete and Accurate Cancer Data on Pacific Northwest Indians Are Critically Needed

Without question, better data on the cancer burden borne by Pacific Northwest Indians must be gathered on a regular and systematic basis, with full protection of confidential patient information. These data are crucial to (1) support health care funding and staffing requests and grant applications; (2) clearly identify causative and contributing factors to the cancers being experienced by tribal populations; (3) identify important regional and tribal differences in cancer incidence, survival, and mortality; and (4) inform the development of culturally appropriate education, prevention, and clinical interventions. It is essential that the urban Indian population be included in expanded data collection efforts. Expanded use of the IHS Resource and Patient Management System (RPMS) may provide a vehicle for improving Native American cancer and other health data in the Northwest. However, the need for more accurate and complete cancer-related data is not limited to the Pacific Northwest tribes, but is an issue for Native Americans nationally.

Researchers Have a Responsibility to Involve Tribes in Study Design and Provide Useful Data to Them

Those who conduct studies of tribal populations and collect cancer-related data must provide such data, and the results of intervention studies and demonstrations, to the tribes involved. Tribes should have access to data without restriction and in a format that will be useful in planning and managing their health care services. To dispel resistance to research, tribes should be involved in study design and approval processes, and researchers must provide security regarding personal identifiers.

The methodology used in the Northwest Tribal Registry data linkage studies appears to be a useful model in this regard.

Further Study Is Needed on the Extent and Effect of Contamination in the Columbia River Basin, but Action Can Be Taken Now

The serious environmental issues in this geographic region are important to both Indian and non-Indian residents of the area. Additional investigation of environmental effects (e.g., how chemicals are metabolized and may lead to cancer; studies of radiation effects on cancers other than thyroid; assessment of the combined risks of chemical and radioactive contamination on people eating fish from the Columbia River) would help to quantify more clearly the magnitude of cancer risk associated with these exposures and identify specific cancers most associated with exposures. Yet the need for additional research should not preclude action; it appears that enough evidence exists to act on some of the identified problems. Presenters testified that elsewhere in the country, in areas less contaminated than the Columbia River Basin, environmental clean-up activities already have been initiated. Although plans have been made for clean-up at the Hanford nuclear site, it will be several years before any actual containment or removal of radioactive waste begins.

Targeted Programs Are Needed to Strengthen the Science Education of Native American Youth and Promote Careers in Health Care

The issue of cultural dissonance with health care providers was cited repeatedly, and treatment provided by Native American health care professionals is seen as the best possible solution to this problem. A major stumbling block to achieving this goal appears to be the inadequate quality of the science education most Native American children receive, and the lack of sufficient encouragement and financial support for seeking a career in the health professions. Strategies for addressing this issue might include greater involvement in tribal education by NCI's Science Enrichment Program and similar programs sponsored by other governmental or academic entities; scholarships that include a requirement to practice in Native communities for a specified period of time (similar to the National Health Service Corps); support networks for college and graduate students pursuing health careers; and financial incentives that will enable Native American health professionals to establish and maintain financially viable careers in rural areas.

Recommendations

Facing cancer in Indian Country should not be any more arduous than it is elsewhere in the United States. The exact magnitude of the cancer-related problems of the Pacific Northwest tribes is not clearly known, but there is little doubt that Native Americans in the region urgently need assistance to receive timely and appropriate cancer screening, cancer information, and cancer care services. Both rapid action and additional study are needed to address the complex set of health care funding, health services, cultural, and environmental issues that face this population.

1. Funding for Indian health care through the Indian Health Service (IHS) must be increased to improve access to cancer preventive, diagnostic, and treatment services, as well as the primary care services that are the gateway to appropriate cancer care. Ideally, Indian health care should become an entitlement program so that funding levels are adjusted for inflation and the buying power of IHS funding is not eroded.

2. The U.S. Department of Health and Human Services (DHHS) should convene a meeting of its involved agencies, including the Health Resources and Services Administration (HRSA), IHS, the Centers for Medicare and Medicaid Services, and other public health care funders and providers (e.g., Department of Veterans Affairs) to determine how greater synergy and cost efficiencies can be achieved among existing publicly-funded health care entities to cost effectively improve cancer-related care to Native Americans. The potential for closer working relationships between HRSA-funded community health centers and IHS is of special interest. The results of the meeting should provide the basis for new regional collaborations between health services resources in the Pacific Northwest and elsewhere in the country.

3. Patient navigator programs should be established to help Native American cancer patients and those at risk for cancer enter the health care system, establish eligibility for assistance programs for which they qualify, and access the medical and supportive services needed for effective care.

4. The Congress should rapidly reauthorize the Indian Health Care Improvement Act to, among other provisions, provide funding to help Native Americans more fully utilize Medicaid, Medicare, and other public health services for which they are eligible, as described in bills recently under consideration.

5. Recent actions and future plans for Medicare and Medicaid reimbursement and service adjustments should be re-examined given (1) the increasing dependence of IHS- and tribally-operated health services on patient care revenues from these programs, and (2) the impact further adjustments may have on rural health care access and provider capacity nationwide.

6. Increased efforts should be undertaken to develop more accurate data on the cancer burden being experienced by Native Americans in the Pacific Northwest. This is an issue germane to Native Americans nationwide. Urban Indians must be included in future data collection efforts, and ways must be found to address widespread current concerns about research and data collection among American Indian and Alaska Native people.

7. The potential benefit of the Pacific Northwest tribes' united approach to working with IHS Area Offices should be explored for its application in other parts of the Nation.

8. The Warm Springs-IHS joint venture should be considered as a potential model for improving health system capacity and more fully meeting tribal health care needs in other parts of the country.

9. Additional research is needed to better understand the possible relationships between environmental exposures and cancer in Pacific Northwest Native Americans. Such investigations should include studies of the impact of exposure to radioactive and chemical contaminants (both alone and in combination) on this population, particularly on the risk for cancers other than thyroid cancer.

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Appendix

Federally-Recognized Native American Tribes Served by the Portland Area Indian Health Service

State	Tribe	Members
Idaho	Coeur d'Alene Tribe	1,741
	Kootenai Tribe of Idaho	113
	Nez Perce Tribe of Idaho	3,525
	Northwest Band of Shoshoni Nation of Utah (affiliated with Fort Hall)	426
	Shoshone-Bannock Tribes of the Fort Hall Reservation	4,443
		Total 10,248
Oregon	Burns Paiute Tribe Indian Colony of Oregon	311
	Confederated Tribes of Coos, Lower Umpqua, and Siuslaw Indians of Oregon	670
	Confederated Tribes of the Grand Ronde	4,617
	Confederated Tribes of the Siletz Reservation	3,430
	Confederated Tribes of the Umatilla Reservation	2,051
	Confederated Tribes of Warm Springs Reservation	3,944
	Coquille Tribe of Oregon	744
	Cow Creek Band of Umpqua Indians of Oregon	1,133
	Klamath Indian Tribe of Oregon	3,330
		Total 20,230
Washington	Confederated Tribes of the Chehalis	642
	Confederated Tribes of Colville	8,644
	Confederated Tribes and Bands of the Yakama Nation	9,564
	Cowlitz Indian Tribe	N/A*
	Hoh Indian Tribe of Washington	157
	Jamestown S'Klallam Tribe of Washington	492
	Kalispel Indian Community of Kalispel Reservation of Washington	310
	Lower Elwha Tribal Community of the Lower Elwha Reservation	775
	Lummi Tribe of Washington	3,774
	Makah Indian Tribe of Washington	3,279
	Muckleshoot Indian Tribe of Washington	1,606
	Nisqually Indian Tribe	487
	Nooksack Indian Tribe of Washington	1,355
	Port Gamble Reservation	958
	Puyallup Tribe of Washington	2,219
	Quileute Tribe of Washington	678
	Quinault Tribe of Washington	2,580
	Samish Indian Tribe of Washington	750
	Sauk-Suiattle Indian Tribe of Washington	230
	Shoalwater Bay Tribe of Washington	240
	Skokomish Reservation	846
	Snoqualmie Tribe	N/A**
	Spokane Tribe of Washington	2,268
	Squaxin Island Tribe of Washington	684
	Stillaguamish Tribe of Washington	181
	Suquamish Indian Tribe of the Port Madison Reservation	852
	Swinomish Indians of Washington	751
	Tulalip Tribes of Washington	3,296
	Upper Skagit Indian Tribe of Washington	705
		Total 48,323
	TOTAL ENROLLMENT ALL TRIBES	**78,801**

* Cowlitz Indian Tribe is a newly recognized tribe and does not have an official enrollment number.
** No number provided.

Source: Bureau of Indian Affairs, October 2002.

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