



News From The EpiCenter

Northwest Tribal Epidemiology Center – Northwest Portland Area Indian Health Board

September–November 2000



Northwest Tribal Registry Project: Improving the Accuracy of Health Status Rate Calculations

State health registries collect an array of health status information on their residents. One health registry may focus on cancer, another on sexually-transmitted diseases, and still another on deaths. Most collect basic demographic information, such as name, date of birth, social security number, as well as diagnostic and treatment information.

and in urban areas, their relatively small numbers further limit the visibility of AI/AN in the public eye, leading to racial misclassification in everyday settings. The combination of these two factors, small population size and undercounting, results in reported disease rates that are of questionable validity.

The Northwest Tribal Registry Project seeks to redress the effects of missing or incorrect race data in the state health registries and to better define the population of AI/AN throughout the Northwest states of Idaho, Oregon, and Washington. The Northwest Tribal Registry is composed of a demographic listing of primarily Northwest AI/AN that can be linked to various health data sets. In the linkage process, an anonymous statistical file is generated that is used in standard rate calculations to determine better estimates of death and disease among Northwest AI/AN. The major advantage of the Northwest Tribal Registry is that it increases the reliability of rate calculations. By exploring the relative proportion of AI/AN who are misclassified in state systems, and comparing that information with tribal data (e.g., blood quantum), better data on disease patterns can be understood and used to benefit tribal health efforts.

This information is used by the states to: (1) identify disease trends for subpopulations of people, and (2) allocate resources to target areas if a particular condition is found to occur at an excessive rate.

Despite this valuable information, the state health registries often contain incorrect race data on their residents, including American Indians and Alaskan Natives (AI/AN). However, measuring the health status of AI/AN is not a straightforward task for several reasons. First, AI/AN comprise a small portion of the overall population. For statistical reasons, measures of disease rates for smaller populations generally have more variability than those for larger populations. Second, although AI/AN live both on reservations

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Northwest Tribal Registry Project Update

To learn more about the leading causes of death and the cancer burden for Northwest American Indians and Alaskan Natives (AI/AN), the Northwest Tribal Registry Project recently completed mortality and cancer registry data linkage studies with Washington, Idaho, and Oregon. After analysis of the results, we found that racial misclassification was a significant problem in state registries. The following tables describes the overall racial misclassification for these registries over the last several years:

Racial Misclassification Rates

	Washington	Idaho	Oregon
Cancer	47.3%	50.3%	66.3%
Mortality (Death)	13.1%	9.6%	16.6%

The largest predictor of misclassification appears to be blood quantum. People with lower blood quantum were more likely to be recorded as white or Caucasian in these registries. Another factor appears to be urban residence.

The issue of misclassification will become more complex in the coming decades. The advent of multiple-race reporting forms will provide additional challenges for a public health system already operating with limited resources, and will require more cooperation with tribal entities to ensure quality data standards. The Northwest Tribal Registry Project is building the infrastructure that will help bridge tribal, state, and federal data systems; conducting the data linkages provides a means to measure trends in Indian health status.

For further information on the Northwest Tribal Registry Project, contact Lisa DeRoo, Staff Epidemiologist, at (503) 228-4185 or lderoo@paihb.org.



How Many Indians Are There?

And who decides who is Indian?

It comes as a surprise to many that there are several competing definitions for who is considered American Indian and Alaskan Native (AI/AN). Depending on the criteria used, the count of AI/AN can fluctuate substantially. These varying counts can impose statistical biases in the calculations of disease rates for AI/AN communities. Diseases may then falsely appear to be more common or less common, depending on the population size used.

The federal and state definitions for AI/AN are often different from the enrollment criteria for the tribes. Indian Health Service (IHS) considers a person to be Indian for the purposes of eligibility if they meet one of three criteria:

- Member of a federally recognized tribe.
- Primary or secondary descendant of a tribal member.
- Declared to be Indian by the Secretary of the Interior.

Government agencies are often unaware that tribes individually determine their membership criteria. Agencies also operate under the assumption that there is one standard blood quantum that tribes use. In reality, while one tribe may have a minimum blood quantum of one level, another may have a higher or lower minimum quantum. Some may recognize the degree of total Indian blood, while others may carry adoption clauses that affect the membership process. Some tribes may have no quantum, and others may utilize unique cultural rules, such as matrilineal versus patrilineal heritage. With nearly 600 federally-recognized tribes ranging in size from 100 to 500,000 members, it is unlikely that a universal standard will ever be adopted. The major point of consideration is that the population discussed by federal and state governments may have characteristics that are different from the populations recognized as AI/AN by the tribes.

Epidemiologists, those who study disease trends, often use the number of AI/AN reported by the US Census in rate calculations. However, the Census counts, which come from self-reported, mail-in data, may be inaccurate. Conversely, IHS verifies status by asking applicants to provide proof of tribal membership, or primary or secondary ancestry. Tribes use the most rigorous screening criteria, with enrollment officers present to verify AI/AN ancestry, birth certificates, and so forth. Because disease rate calculations rely upon Census data, an unknown level of statistical bias is present in these calculations.

The Northwest Tribal Registry Project Sheds Light on the Issue

The Northwest Tribal Registry Project hopes to provide one way to assess the effect of different population sizes on disease rate calculations. The Registry originated from Northwest Indian health care program patient record data (i.e., people who accessed services from a Northwest Indian health program). In addition, currently the project is asking the tribes to consider including tribal enrollment data in the Registry. This will allow tribe specific health status measurements to be made. In this way, rates can be compared between those who are tribal members only, those who are considered AI/AN by the federal government, and those who were self-identified as AI/AN in the US Census.

Important policy questions must be addressed given the variability in eligibility definitions. The US has adopted treaties with tribes that invoke a unique government-to-government status not found for other ethnic minority groups. Tribal leaders are elected by enrolled members and carry the responsibility to represent the tribe in official discussions. When these discussions involve allocation of health resources, it is important that these leaders have available accurate health status information. If this health status information is incorrect because the wrong population of AI/AN people was used in the rate calculations, resources may be allocated incorrectly.

Northwest Tribal Registry Project Future Plans

Understand the prevalence of misclassification in state Medicaid and Medicare files

Investigate potential associations between blood quantum and health status

Link more tribal enrollments with the Northwest Tribal Registry to improve the accuracy of the data resulting from data linkages

New Maternal and Child Health Epidemiologist to Join Northwest Tribal Epidemiology Center

In recognition of the state-of-the-art work being done at the Northwest Tribal Epidemiology Center (*The EpiCenter*), the Centers for Disease Control and Prevention (CDC) recently assigned a high level Maternal and Child Health (MCH) Epidemiologist to work at *The EpiCenter*. Jim Gaudino, MD, MS, MPH, will begin work at *The EpiCenter* in November 2000. Dr. Gaudino's work will focus on elucidating the factors involved in the recently reported reduction in infant mortality among Northwest tribes. Dr. Gaudino, Dee Robertson, MD, MPH, Director of *The EpiCenter*, and Lisa DeRoo, MPH, Staff Epidemiologist, documented this reduction in a recent publication. (For a copy of this publication, contact Chandra Wilson, Project Assistant, at (503) 228-4185.)

Dr. Gaudino is currently the Lead MCH Epidemiologist and Clinical Associate Professor for the CDC Division of Reproductive Health and the University of Washington School of Public Health, respectively. His areas of expertise are pregnancy; fetal, infant, and child health

epidemiology; and the prevention of adverse health outcomes, risk behaviors, and injuries among women, infants, children, and adolescents. His experience in MCH epidemiology is extensive and includes: (1) evaluating the impact of major health initiatives, such as the state-wide implementation of Washington's immunization registry and child health education computer system; (2) developing and directing the Washington state-based MCH epidemiology program; and (3) designing, managing, and evaluating surveillance systems for MCH-related diseases, conditions, and risk factors of public health importance.

The Northwest Portland Area Indian Health Board and *The EpiCenter* welcome Dr. Gaudino. You can contact Dr. Gaudino at (503) 228-4185 after November 7, 2000. If you have any questions in the meantime, contact Dr. Robertson at the same telephone number. 



It's a healthy, happy baby girl! Josephine Rose Lutz was born to Tam Lutz, Indian Community Health Profile Project Specialist, and Ed Lutz on May 23, 2000. Congratulations!! Tam, Ed, and now Josephine are Lummi tribal members.

Northwest Tribal Epidemiology Center Welcomes a New Staff Epidemiologist

Lisa DeRoo, MPH, recently accepted her invitation to join the Northwest Portland Area Indian Health Board (NPAIHB) as the new Staff Epidemiologist for the Northwest Tribal Epidemiology Center (*The EpiCenter*). As the Staff Epidemiologist, Lisa will provide expert epidemiologic support for many of *The EpiCenter*'s projects, including the Indian Community Health Profile Project, the Infant Mortality Study (see above article), and the Fetal Alcohol Syndrome Surveillance Project (see article on page 4).

Lisa already has experience in epidemiology in Indian Country. She recently collaborated with Dee Robertson, Director of *The EpiCenter*, and Jim Gaudino (see above article) to document the recent decrease in infant mortality among Northwest American Indians and Alaskan Natives. In addition to her work in studying infant mortal-

ity, Lisa has studied the utilization of health care services by Alaskan Natives at village clinics and regional hospitals. Lisa is currently a PhD candidate at the University of Washington School of Public Health.

In addition to her epidemiologic support, one of Lisa's first projects will be to play a key role in applying for the Native American Research Center for Health grant that is due at the end of this year. With Lisa's input, NPAIHB is confident that the grant proposal will help us bring the Research Center to the Northwest.

Feel free to contact Lisa at (503) 228-4185. For a copy of the infant mortality article that Lisa co-authored, please contact Chandra Wilson, Project Assistant, at the same telephone number. 

Northwest Tribal Dental Support Center

The Northwest Portland Area Indian Health Board is proud to announce that Indian Health Service awarded the Northwest Tribal Epidemiology Center with the Dental Support Center grant.

If you would like further information, contact us at (503) 228-4185, and watch for the next issue of this newsletter.

Northwest Tribal
Epidemiology Center

Projects and Activities

Community Health
Training

Fetal Alcohol Syndrome
Surveillance Project

Health Status Objectives

Indian Community Health
Profile Project

Northwest REMS Cancer
Assessment Project

Northwest Tribal Dental
Support Center

Northwest Tribal Diabetes
Surveillance Project

Northwest Tribal Registry
Project

REMS Support and
Training

REMS Surveillance
Capacity Project

Stop Chlamydia! Project

California Area Diabetes
Surveillance Project

Fetal Alcohol Syndrome Surveillance Project to Begin Soon

Fetal Alcohol Syndrome (FAS) is a medical condition that occurs when a baby is exposed before birth to alcohol consumed by the mother. It can result in growth deficiencies, delayed development, facial abnormalities, heart defects, and arm and leg abnormalities. The diverse problems that result from FAS are difficult to manage. For example, heart defects may require surgery to help correct. An FAS child may also exhibit hyperactive behavior and learning disabilities.

To help reduce the incidence of FAS in Indian Country, the Indian Health Amendments of 1992 required Indian Health Service (IHS) to develop a program that would reduce the incidence to less than 2/1,000 births. Since the 1980s, IHS has awarded the University of Washington (UW) Fetal Alcohol and Drug Unit with special funding to study FAS. Despite this funding no surveillance system has been established by the UW program to determine whether the occurrence of FAS is increasing,

decreasing, or staying the same. To develop an approach to measure accurately the occurrence of FAS, the FY 2000 Interior Appropriations Committee Conference Report stated that the UW FAS program should collaborate with the Northwest Portland Area Indian Health Board (NPAIHB).

In July 2000, NPAIHB received funds from IHS to begin a one-year FAS Surveillance Project. The Project will be administered by the Northwest Tribal Epidemiology Center (*The EpiCenter*) in cooperation with UW. The goal of the Project will be to assess the current level of FAS among Northwest tribes and to reduce the level through effective programs.

The EpiCenter is currently searching for a Project Specialist who will run the Project. If you would like further information on the Project, contact *The EpiCenter* at (503) 228-4185. 

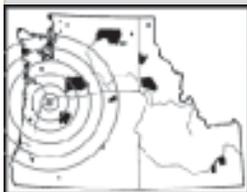
Did you know?

- During 1994-1996, 4.5% of Indian mothers drank during pregnancy (as reported on birth certificates) compared to 1.5% of US ALL Races mothers.
- The percentage of Indian mothers who drank increased with age, except Indian mothers in the under 18 age group drank more than Indian mothers in the 18 to 19 age group.

(*Trends in Indian Health 1998-99*. US Department of Health and Human Services)

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