



Bulletin No. 11

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## Accuracy of Race/Ethnicity Data for HIV/AIDS Cases Among Alaska Natives

HIV infection and AIDS are reportable conditions in Alaska. Cases reported to the Section of Epidemiology are recorded in the HIV/AIDS Reporting System (HARS). As of June 2002, there were 847 non-duplicated reported cases of HIV/AIDS in the Alaska HARS database of which 176 cases were recorded as American Indian/Alaska Native (AI/AN).

### Are cases of HIV/AIDS in Alaska Natives underreported in Alaska due to misidentification of race/ethnicity?

Studies reporting misidentification of AI/AN in disease surveillance databases and death certificates<sup>1-3</sup> have been cited as evidence that misidentification of race/ethnicity is a source of underreporting of HIV/AIDS among AI/AN. Underreporting is of concern because funding allocations are influenced by disease prevalence, services are most effective if tailored to the specific populations in need, and community awareness of risk is influenced by the epidemiology of a disease. In Alaska, where Alaska Natives are the largest minority group and where there is an extensive health care system serving Alaska Natives almost exclusively, less misattribution of race/ethnicity occurs than in the contiguous U.S. In 2002, the Section of Epidemiology undertook an assessment of the accuracy of the race/ethnicity data recorded for Alaska HIV/AIDS cases.

### Methods

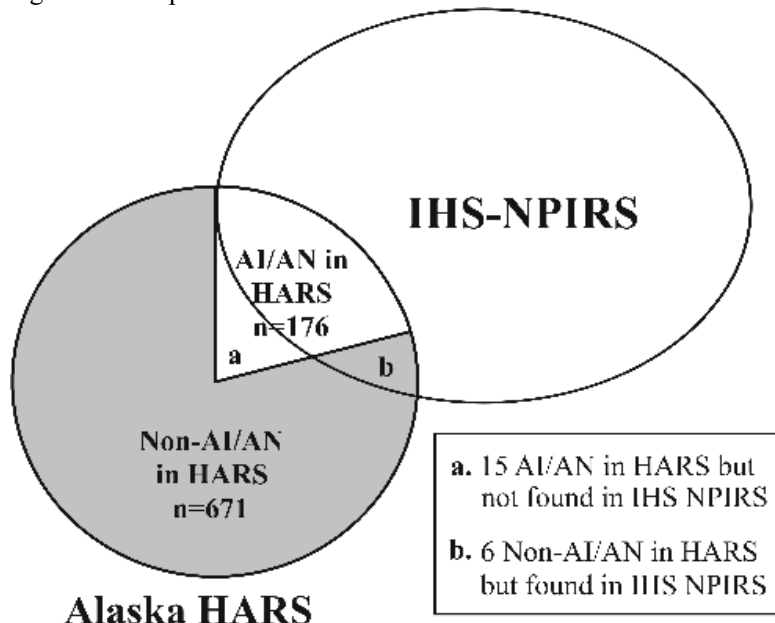
State of Alaska birth and death records were examined for corroboration of race/ethnicity of reported HIV/AIDS cases. The Section of Epidemiology then participated in a study conducted by the Centers for Disease Control and Prevention (CDC) in collaboration with the Indian Health Service (IHS) National Epidemiology Program, IHS Area Offices, and selected other state and local health departments whereby HARS databases were cross-matched against the IHS National Patient Information and Reporting System (IHS NPIRS), a database of 2.47 million patients who have received health services in tribal or IHS facilities nationwide. This database is presumed to have high sensitivity for correctly assigning AI/AN race/ethnicity for IHS and tribal health beneficiaries. The cross-match between Alaska HARS data and an electronic copy of the IHS NPIRS was conducted in June 2002 at the Section of Epidemiology with technical assistance provided by the CDC project staff. Integrity® "Ascential Software" was used to compare the HARS data against the IHS NPIRS, using a probabilistic record linkage algorithm.

### Results

When the 847 Alaska cases in HARS were cross matched with the IHS NPIRS, five cases listed in HARS as White and one case listed as Hispanic had an exact match in the IHS NPIRS indicating that race/ethnicity had been inaccurately coded in HARS for these six individuals. This represents a 3.3% misidentification of AI/AN cases in the Alaska HARS database [ $6/(176 + 6) = 3.3\%$ ]. Of these six cases, all are male; four are identified in the IHS NPIRS as American Indian, two as Alaska Native. In the IHS NPIRS, tribal affiliation for each of these six individuals is coded as "Indian - Non-tribal member" indicating there was no proof of enrollment in, or descent from a member of, a federally recognized tribe at the time of diagnosis. In the earlier examination of State vital records, five of these six individuals had no Alaska birth record; one had a birth record indicating a father of Alaska Native ancestry. For two deceased individuals, race/ethnicity was noted as White in the death registry. Only one of the six had a tribal or IHS facility listed as the facility of diagnosis: four had Anchorage private physicians as the diagnosing provider; one was diagnosed at a rural primary care clinic. Race/ethnicity for these six cases has now been changed to AI/AN in the HARS database.

Fifteen (15) of the 176 cases recorded in Alaska HARS as AI/AN had no match in the IHS NPIRS. Of these 15 cases, nine have strong corroborating evidence that they are AI/AN: for four cases there are birth records indicating Alaska Native parentage; seven cases were diagnosed at a tribal health or IHS facility; and four are listed as Alaska Native on death certificates.

Figure 1. Overlap of Alaska HARS Cases and IHS-NPIRS Data



### Discussion

The Alaska race/ethnicity misidentification rate of 3.3% is much lower than rates of misclassification reported from an examination of AIDS surveillance data in Seattle<sup>4</sup> (62%), more recent studies of STD surveillance data in Oklahoma<sup>1</sup> (21%-32%), and death certificate data in Washington<sup>2</sup> (14.7%). Race/ethnicity for AI/AN is not subject to misattribution in Alaska to the extent seen

elsewhere. Very few cases of HIV/AIDS among AI/AN residents of Alaska have been undercounted due to misidentification of race/ethnicity.

The recorded race/ethnicity of an individual may vary from one data source to another due to recording error, variation in self-report, or variation in method of ascertaining race/ethnicity. Data on race/ethnicity are especially subject to error when ascertained by observation or surname rather than by self-report. Race and ethnicity data are best obtained by asking the patient (or family member of a decedent) to self-identify rather than to rely on observation. While the IHS NPIRS is a very helpful database for evaluating the accuracy of AI/AN race/ethnicity data, the absence of a name in the IHS NPIRS is not sufficient justification to discount AI/AN race/ethnicity since not all tribal facilities provide patient data for inclusion in the IHS NPIRS.

References:

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(Contributed by Penelope Cordes, PhD and Alison Bell, MD, Section of Epidemiology, HIV/STD Program.)