

Regional Differences and Tribal Use of American Indian/Alaska Native Cancer Data in the Pacific Northwest

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Abstract In the Pacific Northwest, cancer is a leading cause of morbidity and mortality for American Indians and Alaska Natives (AI/AN). Misclassification of AI/AN race in state cancer registries causes cancer burden to be underestimated. Furthermore, local-level data are rarely available to individual tribes for use in health assessment and program planning. We corrected race coding in the cancer registries of Idaho, Oregon, and Washington using probabilistic record linkage to a file derived from patient registration records from Indian Health Service and a large urban clinic. We calculated cancer incidence and mortality measures by state, comparing AI/AN to non-Hispanic White (NHW) race. Record linkages identified a high prevalence of misclassified race. Differences in AI/AN cancer patterns were identified across the three state region. Compared to NHW, AI/AN experienced disproportionate late stage rates of some screen-detectable cancers. The correct classification of race is a crucial factor in cancer surveillance and can reveal regional differences even within a relatively small area. The availability of local-level cancer data can help inform tribes in appropriate intervention efforts.

Keywords Cancer · Incidence · Incidence-based mortality · American Indian/Alaska Native · Misclassification

The findings and conclusions in this report are those of the authors and do not necessarily represent official positions of NCI or IHS.

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Background

In the Pacific Northwest, cancer is a leading cause of morbidity and mortality for American Indian and Alaska Native (AI/AN) people [1, 2]; however, misclassification of AI/AN race in state cancer registries causes cancer burden to be underestimated. Previous reports have demonstrated that AI/AN are incorrectly classified in administrative data sources more frequently than other racial/ethnic groups [3], and the prevalence of racial misclassification may range from 30% to 70% [3–5]. The miscoding of race may be especially problematic for groups with relatively small populations such as AI/AN, since undercounting of even a small number of cases can drastically affect population-based rate estimates. The underestimation of cancer measures hinders tribal health leaders' ability to plan and implement appropriate cancer control measures. Furthermore, AI/AN-specific cancer data are rarely available to individual tribes at a geographic level that is meaningful for local health assessment and program planning.

According to 2008 intercensal population estimates, AI/AN comprise about 1.7% of the state population in both Idaho and Oregon and 1.9% of Washington's population. Approximately 6.4% of the nation's AI/AN population resides in this three-state region [6]. There are 43 federally recognized tribes in the Pacific Northwest: five in Idaho, nine in Oregon, and 29 in Washington. Tribes range in size from a few hundred to over 9,000 members.

The Indian health delivery system in the Northwest is comprised of a combination of Indian Health Service (IHS) direct service clinics, tribally operated programs, and three urban Indian clinics [7]. Clinical services vary widely by tribe; some tribes have only a single medical provider available once or twice per week, while others offer complete ambulatory and public health services, including lab, dental,

optical, and pharmacy on-site. A few tribes have no direct clinical services at all and instead contract out all health care for their members. All IHS, tribal, and urban health facilities in the Northwest provide only outpatient care; there are no inpatient centers within the Indian health system where AI/AN patients could receive cancer-related diagnostic, treatment, or surgical services.

The Northwest Portland Area Indian Health Board (NPAIHB) is a tribal organization governed by the 43 federally recognized tribes of Idaho, Oregon, and Washington. Tribal governments appoint a delegate to represent them on the board which meets on a quarterly basis. The delegates guide the priorities and programs at the NPAIHB. In response to a recognized need for better AI/AN surveillance data to inform public health programs and priorities, the Northwest Tribal Registry Project (“Registry Project”) was formed by the NPAIHB in 1999. The project was designed to increase the quality of surveillance data on AI/AN through record linkage studies with the Northwest Tribal Registry.

Record linkage methods with IHS registration data have been shown to mitigate the effects of inaccurate race data in cancer registries [4, 8–11] and other disease surveillance systems [5, 12, 13]. IHS eligibility for AI/AN people is based on enrollment in a federally recognized tribe, making patient registration records a data source of individuals of known AI/AN race. Federal IHS funding also supports several health clinics that serve AI/AN living in urban areas, though registration data from urban sites are not routinely collected by IHS administration. The purpose of this study was to examine misclassification of AI/AN race in the state cancer registries of Idaho, Oregon, and Washington by linking cancer cases to a list of IHS and urban AI/AN patients. We then calculated measures of cancer burden among AI/AN and non-Hispanic Whites in each state to examine regional variations over a recent 5-year period. We describe ways in which cancer surveillance data obtained through these methods have been analyzed and disseminated to tribes and used for a variety of cancer control efforts in the Pacific Northwest.

Methods

The Northwest Tribal Registry (NTR) is an enumeration of the AI/AN population in the Portland IHS administrative area (Idaho, Oregon, and Washington) which is maintained and regularly updated by the NPAIHB’s Registry Project. This registry is derived from the Portland Area IHS registration file and includes all AI/AN who received services from a federally operated IHS or tribal health care facility in the area between 1986 and December 2009. This data source is known to underrepresent certain subpopulations of AI/AN who have not accessed care through the IHS, most notably those living in urban areas [14]. Through a

partnership with the Seattle Indian Health Board, we supplemented the NTR data with the AI/AN patient registry of the area’s largest urban Indian health clinic.

We used the probabilistic linkage software Link Plus (version 2.0; Atlanta, GA), developed by the Centers for Disease Control and Prevention, to compare the AI/AN patient list against the Cancer Data Registry of Idaho (1992–2008), the Oregon State Cancer Registry (1996–2009), and the Washington State Cancer Registry (1992–2009). Each of these registries adheres to quality control standards set by the North American Association of Central Cancer Registries [15] and had been matched against state death certificate files to improve ascertainment of vital status and cause of death prior to our linkages. Cancer cases that matched with the Indian patient registration file were reported to cancer registry staff to correct inaccurate race data at the state level. Linkage methods have been described in more detail elsewhere [11, 14].

Cancer frequencies, incidence rates, incidence-based mortality rates, stage-specific rates, and rate ratios were calculated for the period 2003–2007, the most recent 5-year period considered complete by all three cancer registries as of the linkage date. In this report, incidence data include invasive cancers (behavior code 3), plus in situ urinary bladder cases. Primary site and histology data were coded according to the International Classification of Diseases for Oncology Third Edition (ICD-O-3) [16]. We aggregated primary cancers into site groups according to the SEER site recode for ICD-O-3 definition [17]. Incidence-based mortality calculations included patients in the cancer registry with cancer indicated as the cause of death, coded using SEER Cause of Death recode definitions [18], and date of last follow-up between 2003 and 2007. Incidence-based mortality was restricted to incident cases diagnosed in 1996 or later, since this was the earliest year of incidence data available in all three state registries. Stage of disease was coded according to SEER Summary Staging 2000 [19]; unless specified, unstaged cancers were included throughout the analysis. Late-stage and early-stage incidence rates were calculated for three screen-detectable cancer sites for which there are accepted screening recommendations for a given age/gender group [20, 21]. These calculations were restricted to the appropriate age/gender grouping recommended for screening to better approximate the population that should be receiving routine screening, as opposed to those at high risk who are likely to be screened at younger ages. For the calculation of stage-specific rates, regional and distant stages were combined to present a measure of disseminated disease (“late stage” diagnoses), and in situ and localized stages were collectively considered “early stage,” with the exception of cervical cancer, for which in situ cases are not reportable and thus “early stage” refers only to localized cancers. To arrive at the most complete population-based estimates for AI/AN, we included in analyses all matched

cases, plus non-matched records coded as AI/AN in the state cancer registry. National Center for Health Statistics bridged-race population estimates 2003–2007 (vintage 2008) were used for population-at-risk denominators. These census-based estimates bridge multiple-race population counts to single-race categories, thus adjusting population estimates for individuals who self-select more than one race [6]. All incidence rates were age-adjusted to the 2000 U.S. standard population in 5-year age groupings; confidence intervals were calculated by the gamma method described by Fay and Feuer [22]. Rate ratios (RR) with 95% confidence intervals are presented as a comparative measure of incidence and mortality rates between AI/AN and non-Hispanic White (NHW) populations within each state. For stage at diagnosis analyses, rate ratios present late- versus early-stage measures within the two race groups being compared. Statistical significance of differences was assessed by RRs differing significantly from 1.0 ($p < 0.05$). All data management and statistical analyses were conducted using SAS software (version 9.1; SAS Institute Inc., Cary, NC).

Results

Among new cancer cases in the three state registries that had not previously been sent for linkage with Indian health data (diagnosis years 2008–2009), 279 out of 686 matched cases were coded as non-AI/AN in the primary race field (40.7% misclassified). The misclassification prevalence among new matches varied by state: 40.0% in Idaho, 24.2% in Oregon, and 45.8% in Washington. These cases were most commonly coded in the cancer registries as White (77.4%) or unknown race (18.6%). None of these cases had AI/AN race indicated in any of the secondary race fields. Matched cases were reported to cancer registry staff so that race coding could be amended prior to the public release of annual statistical files. Previous linkages with IHS and urban patient data had ascertained the majority of incorrect race data for cancers diagnosed prior to 2008.

Of the 2,743 total AI/AN cancers included in the present analyses (diagnosis years 2003–2007), 1,671 cases had a match in the Indian patient registry file (60.9%), and the remaining 1,072 (39.1%) were coded as AI/AN in the cancer registry but did not match a record in the Indian patient dataset. Staging information was not applicable or missing for 230 cases (8.4%). The most common cancer sites for AI/AN by number of incident cases were female breast (29.7% of female cancers), prostate (21.2% of male cancers), lung and bronchus (13.9%), and colon–rectum (10.5%). Site-specific incidence-based mortality for AI/AN was led by lung and bronchus (26.0% of cancer deaths), female breast (13.0% among females), colon–rectum (10.7%), and pancreas (6.5%).

Within the Northwest region, some differences in cancer patterns can be seen by state (Tables 1, 2 and 3). Incidence rates among AI/AN varied by state, though rates for NHW were generally more similar across the three states (Table 1). Idaho AI/AN had lower rates of all-site invasive cancer (309 per 100,000) than either Oregon or Washington AI/AN (406 and 468 per 100,000, respectively). In general, site-specific rates for AI/AN also reflected a similar pattern, with Idaho having the lowest incidence, Washington having the highest, and AI/AN rates being somewhat lower than those for NHW overall. The one exception was a significantly higher rate of colorectal cancer among Washington AI/AN (56 per 100,000) compared to Washington NHW (44 per 100,000; rate ratio = 1.28). In all three states, AI/AN had lower rates of prostate cancer relative to NHW.

Less variation was seen in incidence-based mortality rates for AI/AN (Table 2). In Washington, cancer mortality among AI/AN (200 per 100,000) was higher than NHW (162 per 100,000; rate ratio = 1.23). Incidence-based mortality among Idaho AI/AN was approximately equal to the NHW estimate, a notable finding in light of the fact that the rate of new cancers was 35% lower than NHW for this population. The between-state pattern for AI/AN mortality did not follow that for incidence: Idaho AI/AN had slightly higher female breast cancer mortality than Oregon (28 vs. 19 per 100,000, respectively), and the highest colorectal cancer mortality rate among AI/AN in the three states (24 per 100,000; RRs not significantly different than 1.0). Oregon AI/AN had greater lung and bronchus mortality than their counterparts in the other two states, representing the highest site-specific mortality rate in the region (65 per 100,000). Again, these estimates were unstable due to small numbers, and the confidence intervals around rate ratios did not differ from 1.0. Washington AI/AN had significantly elevated mortality due to female breast and colorectal cancers, compared to NHW (RR = 1.49 and 1.49, respectively).

Table 3 presents rates of late-stage (regional and distant) and early-stage (in situ and localized) diagnosis by state and race for female breast, cervical, and colorectal cancers, restricted to the age groups recommended for screening. In general, AI/AN had less favorable ratios of late-stage to early-stage cancers, compared to Northwest NHW. Oregon AI/AN had the highest proportion of colorectal cancers diagnosed at a late stage (74.7% among those ages 50 and older) and the most marked disparity in late-stage to early-stage ratios compared to NHW (RR = 2.5 vs. 1.4, respectively). Idaho AI/AN females had the highest rate of female breast cancers diagnosed in late stages (124 per 100,000), and early-stage breast cancer rates were lower among AI/AN than NHW in all three states. Rates of late-stage cervical cancer were also elevated among AI/AN in Oregon and Washington.

Table 1 Selected age-adjusted invasive cancer incidence rates (per 100,000) and RR by state, AI/AN and NHW, 2003–2007

| | AI/AN rate (95% CI) | NHW rate (95% CI) | AI/AN/NHW RR (95% CI) |
|-------------------|----------------------|----------------------|-----------------------|
| All sites | | | |
| Idaho | 308.8 (265.0, 358.7) | 475.2 (469.8, 480.5) | 0.65 (0.51, 0.79) |
| Oregon | 406.1 (375.7, 438.6) | 470.8 (467.6, 474.0) | 0.86 (0.79, 0.93) |
| Washington | 467.8 (444.0, 492.8) | 492.2 (489.5, 494.9) | 0.95 (0.90, 1.0) |
| Breast (female) | | | |
| Idaho | 87.5 (57.9, 129.7) | 120.5 (116.8, 124.3) | 0.73 (0.38, 1.08) |
| Oregon | 90.4 (73.0, 111.4) | 130.9 (128.6, 133.2) | 0.69 (0.50, 0.88) |
| Washington | 115.1 (100.7, 131.3) | 132.1 (130.3, 134.0) | 0.87 (0.75, 0.99) |
| Colon and rectum | | | |
| Idaho | 34.5 (20.7, 55.3) | 43.6 (42.0, 45.2) | 0.79 (0.37, 1.21) |
| Oregon | 41.4 (31.9, 53.2) | 44.9 (43.9, 45.9) | 0.92 (0.69, 1.15) |
| Washington | 55.8 (47.6, 65.4) | 43.7 (42.9, 44.5) | 1.28 (1.14, 1.42) |
| Lung and bronchus | | | |
| Idaho | 45.9 (30.4, 67.9) | 59.0 (57.1, 60.9) | 0.78 (0.43, 1.13) |
| Oregon | 79.1 (65.4, 95.1) | 68.3 (67.1, 69.5) | 1.16 (0.99, 1.33) |
| Washington | 73.9 (64.1, 84.9) | 68.0 (67.0, 69.0) | 1.09 (0.96, 1.22) |
| Prostate (male) | | | |
| Idaho | 86.8 (53.8, 138.4) | 168.3 (163.7, 173.0) | 0.52 (0.13, 0.91) |
| Oregon | 91.3 (69.0, 120.4) | 143.0 (140.4, 145.6) | 0.64 (0.40, 0.88) |
| Washington | 117.2 (99.1, 138.7) | 158.1 (155.9, 160.4) | 0.74 (0.60, 0.88) |

Rates exclude non-urinary bladder in situ cases and are adjusted to 2000 U.S. standard population

CI confidence interval, RR Rate ratios, AI/AN American Indians and Alaska Natives, NHW non-Hispanic White

Table 2 Selected age-adjusted cancer incidence-based mortality rates (per 100,000) and RR by state, AI/AN, and NHW, 2003–2007

| | AI/AN rate (95% CI) | NHW rate (95% CI) | AI/AN/NHW RR (95% CI) |
|-------------------|----------------------|----------------------|-----------------------|
| All sites | | | |
| Idaho | 187.5 (151.7, 229.9) | 182.7 (179.4, 186.0) | 1.03 (0.84, 1.22) |
| Oregon | 209.6 (186.7, 234.7) | 191.8 (189.7, 193.8) | 1.09 (0.99, 1.19) |
| Washington | 200.0 (183.5, 217.7) | 162.0 (160.4, 163.5) | 1.23 (1.15, 1.31) |
| Breast (female) | | | |
| Idaho | 28.2 (10.7, 61.4) | 19.7 (18.3, 21.3) | 1.43 (0.69, 2.17) |
| Oregon | 18.6 (10.8, 30.7) | 20.7 (19.8, 21.7) | 0.90 (0.45, 1.35) |
| Washington | 24.7 (17.5, 34.2) | 16.6 (16.0, 17.3) | 1.49 (1.19, 1.79) |
| Colon and rectum | | | |
| Idaho | 24.3 (12.4, 43.7) | 16.6 (15.7, 17.7) | 1.46 (0.91, 2.01) |
| Oregon | 22.8 (15.7, 32.4) | 18.1 (17.5, 18.7) | 1.26 (0.94, 1.58) |
| Washington | 21.3 (16.2, 27.8) | 14.3 (13.9, 14.8) | 1.49 (1.25, 1.73) |
| Lung and bronchus | | | |
| Idaho | 42.8 (27.4, 64.9) | 49.7 (48.0, 51.5) | 0.86 (0.48, 1.24) |
| Oregon | 65.0 (52.3, 80.1) | 58.1 (57.0, 59.2) | 1.12 (0.92, 1.32) |
| Washington | 53.7 (45.4, 63.4) | 49.7 (48.8, 50.5) | 1.08 (0.93, 1.23) |

Rates are based on incident cases diagnosed 1996 through 2007 and are adjusted to 2000 U.S. standard population

CI confidence interval, RR Rate ratios, AI/AN American Indians and Alaska Natives, NHW non-Hispanic White

Table 3 Selected screen-detectable cancer age-adjusted rates (per 100,000) and RR by stage and state, screening-recommended age groups, AI/AN, and NHW, 2003–2007

| Site | State | AI/AN | | | NHW | | |
|-----------------------------|------------|--------------|--------------|------------------------------------|------------|-------------|------------------------------------|
| | | Late stage | Early stage | RR (late/early stage) ^a | Late stage | Early stage | RR (late/early stage) ^a |
| Breast (female, ages 50+) | Idaho | 123.7 | 190.2 | 0.65 (0.0, 1.38) | 114.7 | 276.7 | 0.41 (0.34, 0.48) |
| | Oregon | 105.9 | 189.0 | 0.56 (0.13, 0.99) | 110.7 | 326.9 | 0.34 (0.30, 0.38) |
| | Washington | 102.7 | 225.6 | 0.46 (0.14, 0.77) | 117.0 | 329.2 | 0.36 (0.32, 0.39) |
| Cervix (female, ages 18+) | Idaho | ^b | ^b | – | 3.6 | 4.6 | 0.79 (0.51, 1.07) |
| | Oregon | 4.4 | ^b | – | 3.6 | 4.4 | 0.82 (0.64, 1.00) |
| | Washington | 8.5 | 4.5 | 1.87 (1.08, 2.66) | 3.7 | 4.5 | 0.81 (0.67, 0.95) |
| Colon and rectum (ages 50+) | Idaho | 48.4 | 54.3 | 0.89 (0.0, 1.81) | 79.0 | 57.3 | 1.38 (1.30, 1.46) |
| | Oregon | 101.1 | 40.0 | 2.53 (1.97, 3.08) | 83.2 | 60.5 | 1.38 (1.33, 1.42) |
| | Washington | 100.9 | 73.8 | 1.37 (1.05, 1.68) | 79.8 | 57.6 | 1.39 (1.35, 1.42) |

Rates are adjusted to 2000 U.S. standard population. SEER Summary Stage 2000 was used for staging; late stage = regional and distant, early stage = in situ and localized

^a With 95% confidence intervals in parentheses

^b Rates based on fewer than 5 cases are suppressed

RR Rate ratios, AI/AN American Indians and Alaska Natives, NHW non-Hispanic White

Discussion

The correct classification of race is a crucial factor in cancer surveillance and cancer control. Systematic record linkages with Indian health data have proven to be an effective means to minimize the effects of race misclassification on population-based estimates [11]. Cancer patterns among AI/AN vary widely by geographic region across the USA [23, 24], and as we demonstrate, important regional differences may exist even within a relatively small area.

AI/AN people in the Pacific Northwest and elsewhere report lower prevalence of cancer screening than the general population [25], which may be reflected in excess late stage diagnosis of screen-detectable cancers among age groups recommended for routine screening and greater cancer mortality. State-level screening prevalence estimates for AI/AN are not widely reported, likely due to small sample sizes and nonresponse rates. In a 2001 Tribal Behavioral Risk Factor Surveillance System (BRFSS) of selected Northwest American Indian tribes, 19% of respondents reported having a fecal occult blood stool test in the past year, 28% reported having a sigmoidoscopy in the past 5 years, 80% of females had had a Pap test in the past 3 years, and 62% of females reported mammography in the past 2 years [26]. These cancer screening prevalence figures were lower than Idaho, Oregon, and Washington general population estimates from state BRFSS surveys. In prior studies examining both self-reported screening behavior and late stage diagnoses of breast, cervical, and colorectal cancers, correlations were seen at the state level between lower screening prevalence

and higher late-stage tumor incidence [27]. These findings agree with our results demonstrating greater rates of late-stage coupled with lower early-stage tumor diagnoses among AI/AN for several screen-detectable cancers and excess breast and colorectal cancer incidence-based mortality.

State and regional measures may also shed light on screening and access-to-care patterns at the state level. Tribal and IHS clinics in the Northwest have limited capacity to provide certain cancer screening tests, and all mammography and colonoscopy procedures are referred to facilities outside the Indian health system. The CDC's National Breast and Cervical Cancer Early Detection Program is operated in every state and provides no-cost breast and cervical cancer screening to income-eligible women through contracted providers [28]. Access to this program for eligible AI/AN women is likely enhanced when their tribal clinics are participating providers, with enrollment and referral resources readily available. As of the time of this writing, only two of nine Oregon tribes are actively using the state breast and cervical program to screen eligible women; in Idaho, three of five tribes are contracted, and the majority of Washington tribes provide services through this program (E. Vinson, personal communication, January 31, 2011). All three urban Indian clinics in the area are contracted providers. In addition, Washington provides colorectal screening services through its colon health program. State variations in late stage diagnoses of breast, cervical, and colorectal cancer among AI/AN may be partially explained by state-level differences in the availability of programs such as these.

Many other factors are likely to influence screening program utilization, including geography, provider recommendations for screening, and personal beliefs; these factors may or may not be correlated at the state level.

Due in part to improved surveillance data on the burden of cancer in AI/AN people [23], cancer control efforts in the Northwest have greatly increased the awareness of cancer in tribal communities. NPAIHB's Northwest Tribal Comprehensive Cancer Program, funded since 1998, supports a Tribal Cancer Coalition which has grown from a small group of seven individuals to meetings numbering around 30–50 people. The coalition's chairwoman for the past 6 years, Stella Washines (Yakama Nation), credits this program for advancing awareness in tribal communities. "Ten years ago, cancer was not discussed. Now there are education forums, community screening events, and people are willing to talk about their cancer experience. There are tribal cancer support groups to turn to." In 2002, the Yakama Nation hosted a President's Cancer Panel, during which members of this and other Northwest tribes provided important testimony furthering the discussion of cancer disparities and experiences in Indian Country [2]. Cancer remains a high priority today; NPAIHB's tribal delegates identified cancer as the number one priority in their 2010 strategic plan.

Although data are not presented here due to small population sizes and confidentiality issues, we provided local-level data to tribes, using Contract Health Service Delivery Areas (CHSDAs) as the geographic unit of analysis. Contract Health Service Delivery Areas typically include counties that overlap with, or are adjacent to, Indian reservations and are assigned by the federal government for the purposes of determining individual eligibility for various services through IHS [29]. Rates calculated in this way were often unstable due to small numbers and population sizes; however, we did demonstrate some substantial variation in incidence, mortality, and stage distributions across tribes. Tribal health leaders have reported using these CHSDA-level cancer data for grant reporting and applications, education at community health events, health assessment, and program planning. However, we are limited in providing cancer data specific to the membership of individual tribes, and CHSDA-level measures may be less meaningful for some tribes than for others. Our CHSDA-level analysis methods capture any AI/AN residing in a CHSDA region (regardless of affiliated tribe), and many CHSDA boundaries overlap between multiple tribes [29]. Furthermore, not all Northwest tribes have an IHS or tribal clinic, thus reducing the likelihood that their tribal members are accurately represented in the NTR, and subsequently, in central cancer registries. Our linkage and analysis methods would be improved by the addition of tribal enrollment lists in cancer linkages, an approach which has been

shown to supplement ascertainment of AI/AN cases above IHS enrollment records [10, 30].

Ensuring the accuracy and completeness of surveillance data continues to be an important strategy to inform prevention and early detection activities. Our findings contribute to the overall picture of cancer burden on AI/AN people nationally, and reveal some heterogeneity within the Pacific Northwest region. The improved quality and availability of local-level cancer data can help inform states and tribal communities in a range of cancer control efforts.

Acknowledgments The authors are grateful to the staff of the Urban Indian Health Institute, Cancer Data Registry of Idaho, and Oregon and Washington State Cancer Registries, for their collaboration and linkage-related support. Grant support for this project was received from National Cancer Institute's Surveillance Research Program, contract #HHSN261201000335P, and the Indian Health Service Division of Epidemiology and Disease Prevention.

Conflict of interest The authors declare that they do not have a conflict of interest.

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