

Improving Cancer Incidence Estimates for American Indians in Wisconsin

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ABSTRACT

Objectives: The purpose of this study was to improve the measurement of cancer incidence among American Indians in Wisconsin and compare incidence rates with state and national incidence rates.

Methods: The Wisconsin Cancer Reporting System (WCRS) entered into a data linkage project with CDC and the Indian Health Service (IHS) to improve classification of American Indian cancer cases in Wisconsin. WCRS data were linked to IHS patient registration files to identify American Indian cases that were misclassified as a non-Indian race for the years 1998-2002. American Indian age-adjusted rates and rate ratios for major cancer sites were compared before and after the linkage, and with statewide and national rates.

Results: The age-adjusted incidence rate for all cancer among American Indians increased from the pre-linkage rate of 386.3 per 100,000 to the post-linkage rate of 471.7 per 100,000, a statistically significant increase. The post-linkage rate was over twice the comparable Surveillance Epidemiology and End Results (SEER) national rate among American Indians at 233.6 per 100,000. Post-linkage American Indian incidence rates for male colorectal and female lung cancers were higher than those for the state average.

Conclusions: In contrast to earlier data, the linkage results show that American Indians had similar cancer incidence compared to the general population in Wisconsin, and over twice as high as national SEER American Indian rates. Post-linkage rates resulted in more accurate site-specific and geographically focused cancer incidence rates to help target the national

and state priorities of addressing disparities among American Indians.

BACKGROUND

Cancer Incidence among American Indians

National publications presenting National Cancer Institute (NCI) Surveillance, Epidemiology and End Results (SEER) national data have reported cancer incidence among American Indians as the lowest among all racial and ethnic groups.^{1,2} However, many central cancer registries acknowledge limitations with surveillance data for American Indian and Alaska Native populations, including race misclassification leading to the underestimation of cancer incidence for some minority groups, which may mask wide variations in cancer incidence by state and region.^{3,4} Numerous studies have documented the underestimation of the cancer burden due to misclassification,⁵⁻⁹ ranging from 49% misclassification in the state of Washington to negligible in New Mexico.^{5,6} To address the challenge of obtaining more accurately classified cancer data for American Indians, the Centers for Disease Control and Prevention (CDC) and the Indian Health Service (IHS) are currently conducting a national data linkage project with National Program of Cancer Registries (NPCR) central cancer registries.¹⁰

Spirit of EAGLES is an American Indian/Alaska Native (AI/AN) leadership initiative on cancer that addresses comprehensive tribal cancer control through partnerships with the Network for Cancer Control Research among AI/AN populations, tribes, cancer centers, Cancer Information Service, and the American Cancer Society. In 2002, they conducted a cancer surveillance project in Wisconsin to assess the accuracy of AI/AN cancer data reported to WCRS by Wisconsin health care facilities. The results demonstrated only 28 (50%) of the 56 American Indian cancer cases collected for the project and diagnosed in 2001 were found in the WCRS database. Of the 28 cases already reported, 7 (25%) were not reported as American Indian. In total, 35 of the 56 cases (62.5%) were either not in the registry at all or were misclassified.¹¹

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Results from linkage projects reported by the Northwest Tribal area and Minnesota, among other states, also have documented American Indian incidence rates as underestimated when based on routine case submission to cancer registries; these same organizations reported enhanced rates after linking to IHS registration databases.^{6-9,12}

American Indians and Alaska Natives in Wisconsin

The US Census reported that the American Indian/Alaska Native population in Wisconsin was 47,228 for the year 2000, comprising 0.9% of the state population.¹³ For this study, SEER*Stat, a statistical software from the NCI, provided a bridged-race population estimate of 53,196 American Indians/Alaska Natives for the year 2000.¹⁴ American Indians comprise almost 100% of the American Indian and Alaska Native population in Wisconsin, while only approximately 225 people in Wisconsin were identified as Alaska Native.¹⁵ Therefore the exclusive term American Indian was used for the focus of this project. Today, the Indian Health Service (www.ihs.gov) provides health care to members of federally recognized American Indian Tribes through directly administered federal facilities and by funding tribally operated health programs. All tribes in Wisconsin have chosen to receive IHS funds directly and operate their own tribal health centers. Access to IHS-supported medical care is governed by set criteria most commonly related to enrollment in a federally recognized tribe. Specific criteria for enrollment in a federally recognized tribe are determined by each tribe.

Wisconsin tribal health centers provide either direct health services (those provided on site or by their employers) or Contract Health Services (CHS). CHS are services provided by contracted health care professionals and are administered in accordance with IHS policies and regulations. A Contract Health Service Delivery Area (CHSDA) is the geographic area within which CHS funds are made available to those Indians who live on or near Indian reservations. These geographic areas usually constitute a county or group of counties and often include reservation and off-reservation trust land within these counties. In Wisconsin, there are 11 CHSDA areas encompassing 33 of the 72 counties. CHSDA counties are distributed throughout 4 (Western, Northern, Northeastern, and Southern) of the 5 Department of Health and Family Services designated regions (Figure 1). The Southeastern region has no CHSDA counties, but includes Milwaukee, Waukesha, and Racine counties with sizeable American Indian populations, and contributes approximately 14% of American Indian cancer cases.

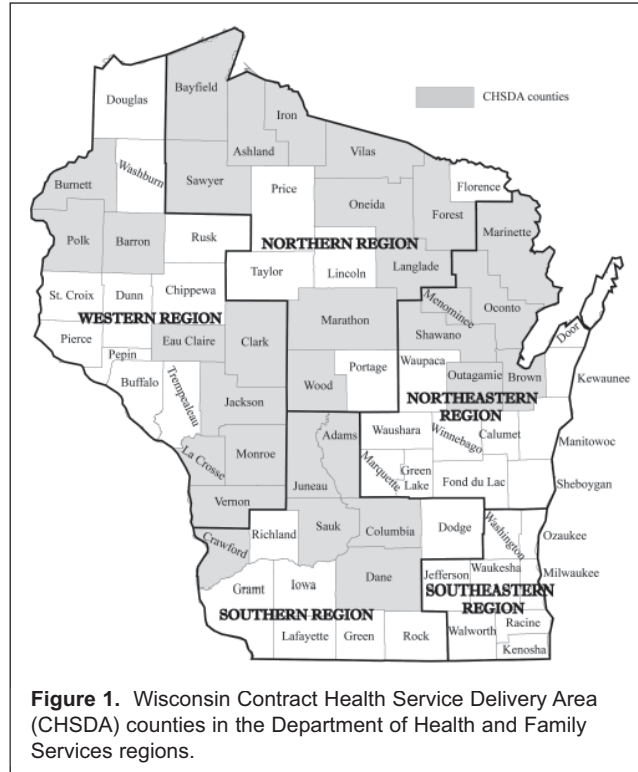


Figure 1. Wisconsin Contract Health Service Delivery Area (CHSDA) counties in the Department of Health and Family Services regions.

Wisconsin has 13 federally recognized tribes and urban Indian centers: Bad River Tribe, Forest County Potawatomi, Gerald Ignace Indian Health Center, Ho-Chunk Nation, Lac Courte Oreilles Tribe, Lac du Flambeau Tribe, Menominee Nation, Oneida Nation, Red Cliff Tribe, Sokaogon Chippewa Tribe, St. Croix Tribe and the Stockbridge-Munsee Tribe, and the United Amerindian Center. Each tribe maintains a unique government, language, and spiritual and health practices. The geographic distribution of American Indians in Wisconsin shows 64% reside in the Northern and Northeastern regions of Wisconsin. Approximately 45% reside in metropolitan areas. The largest population, 14%, live in Milwaukee County.¹³

Overview of Cancer Registries in the United States

There currently are 2 major cancer surveillance systems of population-based registries in the United States: The SEER Program and the NPCR. The SEER program of cancer registries began collecting data in 1973 and is a primary component of the NCI's Surveillance Research Program. The SEER program currently collects and publishes cancer incidence and survival data from 14 population-based registries and 3 supplemental registries covering approximately 26% of the US population. For this analysis, national data were calculated from the most current SEER data from 13 registries comprising the Public Use Data Base for Expanded

Races. Registries are selected for the SEER program based on 2 major criteria: the ability to operate a high quality population-based registry, and their “epidemiologically significant population subgroups.” See <http://seer.cancer.gov/registries> for a complete description of all the SEER registries.

SEER standards for data collection have established a 98% case ascertainment (locating cancer cases in hospital files) and a follow-up rate of 95% for survival data. The SEER program is the only comprehensive source of population-based information that collects patient survival data.

The NPCR, in which WCRS participates, was first funded in 1992 under the Cancers Registries Amendment Act. Currently, CDC funds a total of 49 statewide and territorial cancer registries. NPCR registries represent 96% of the US population. The NPCR registries are expected to collect cancer incidence data on at least 95% of the cancer cases diagnosed or treated in their state or territory. Survival data are not collected by NPCR registries. WCRS, like many NPCR registries, works within a “passive system” of data collection; facilities are required to report all malignant cancer cases (except basal and squamous skin cancers and in situ cervical cancers) to the central state cancer registry in a specified time frame (within 6 months of diagnosis for hospitals, for example). For complete WCRS reporting requirements see <http://dhfs.wisconsin.gov/wcrs/index.htm>.

WCRS has collected cancer incidence data since 1976 as first mandated by Chapter 255.04, Wisconsin Statutes. Starting in 1994, WCRS entered into a cooperative agreement with CDC and became part of the NPCR. The North American Association of Central Cancer Registries (NAACCR) has estimated WCRS’s case ascertainment completeness at 95%. The NAACCR completeness estimation is a national standard described in more detail at www.naacr.org.

All NPCR registries annually report their incidence data to CDC. Data from SEER registries are also reported to their respective NPCR state cancer registries for inclusion in the state cancer data submitted to CDC. Since 2000, the 2 federal programs have combined incidence data in a collaborative publication, the *US Cancer Statistics: Incidence and Mortality*. However, for the years covered in this analysis, SEER was the primary national database providing racial categories, including American Indians. SEER is the oldest and most widely cited national cancer database, and currently used by the American Cancer Society, for example, for estimates of national cancer incidence.

METHODS

Data Sources

As part of the national linkage program between IHS and NPCR registries, WCRS worked with the IHS Division of Epidemiology and Disease Prevention to link cancer case records with IHS patient registration files.¹⁰ Access to IHS-supported medical care is governed by set criteria most commonly related to enrollment in a federally recognized tribe and criteria for enrollment may vary between tribes. IHS databases include Native Americans who have used IHS services at any time since IHS’s electronic medical record system was established. American Indians and Alaska Natives were not included in the database if they never used IHS facilities. The data from IHS included only variables for the purpose of probabilistic linkage and did not include diagnostic information or record of services received.

The data from WCRS contained cancer cases diagnosed among Wisconsin residents from 1985 through 2002 in 2 files. The first contained identifying information (such as name, date of birth, address) for the purpose of matching by project staff approved to work with confidential data. The other file contained clinical cancer information (site and stage at diagnosis) by age and gender, for analytical purposes. All staff directly involved with the confidential data signed appropriate IHS and WCRS confidentiality agreement forms. The WCRS cancer case records were linked to IHS files for the single purpose of identifying or reclassifying WCRS cases as American Indian.

WCRS-IHS Record Linkage

The linkage project conducted probabilistic matching of cancers cases from 1998 through 2002 in the WCRS state cancer registry with IHS patient registration records. In probabilistic matching, the computer assigns a score to a potential match indicating a probability that the identified match is in fact correct. Records are matched by comparing personal identifying information for each record in an attempt to determine whether 2 or more records pertain to the same person.¹⁶

To assess and improve the accuracy of American Indian case ascertainment, CDC staff working for IHS linked the IHS patient registration files to WCRS files. This analysis focused on data from the most recently matched 5-year period (January 1, 1998 through December 31, 2002). The probabilistic matching was performed using Link Plus, a public domain software package developed by the CDC Division of Cancer Prevention and Control. Link Plus uses name, social security number, date of birth, and sex as match-

Table 1. Distributions for American Indians by Sources of Identification, Wisconsin, 1998-2002

| | IHS Only* | | WCRS Only* | | Both IHS/WCRS* | | Total | |
|----------------------------|-----------|------|------------|------|----------------|------|-------|------|
| | No. | % | No. | % | No. | % | No. | % |
| All Cancer | 129 | 20.0 | 209 | 32.5 | 306 | 47.5 | 644 | 100 |
| Sex | | | | | | | | |
| Male | 71 | 55.0 | 103 | 49.3 | 159 | 52.0 | 311 | 48.3 |
| Female | 58 | 45.0 | 106 | 50.7 | 147 | 48.0 | 333 | 51.7 |
| Age at Diagnosis | | | | | | | | |
| Under 25 | 6 | 4.6 | 17 | 8.1 | 10 | 3.3 | 33 | 5.1 |
| 25-44 | 19 | 14.7 | 30 | 14.2 | 32 | 10.5 | 81 | 12.6 |
| 45-64 | 60 | 46.5 | 75 | 35.5 | 121 | 39.5 | 256 | 39.7 |
| 65 and over | 44 | 34.1 | 87 | 41.6 | 143 | 46.7 | 274 | 42.5 |
| DHFS Region | | | | | | | | |
| Northeast | 65 | 50.4 | 83 | 39.7 | 150 | 49.0 | 298 | 46.3 |
| North | 26 | 20.2 | 43 | 20.6 | 88 | 28.8 | 157 | 23.4 |
| Southeast | 13 | 10.1 | 53 | 25.4 | 23 | 7.5 | 89 | 13.8 |
| South | 9 | 7.0 | 12 | 5.7 | 11 | 3.6 | 32 | 5.0 |
| West | 16 | 12.4 | 18 | 8.6 | 34 | 11.1 | 68 | 10.6 |
| Health Service Area | | | | | | | | |
| CHSDA | 98 | 76.0 | 125 | 59.8 | 267 | 87.2 | 490 | 76.1 |
| Non-CHSDA | 31 | 24 | 84 | 40.2 | 39 | 12.8 | 154 | 23.9 |
| Cancer Site | | | | | | | | |
| Colorectal | 11 | 8.5 | 24 | 11.5 | 46 | 15.0 | 81 | 12.6 |
| Lung and Bronchus | 17 | 13.7 | 29 | 13.9 | 57 | 18.9 | 103 | 16.0 |
| Breast (female) | 18 | 13.9 | 30 | 14.3 | 31 | 10.1 | 79 | 12.3 |
| Prostate | 20 | 15.5 | 19 | 9.1 | 35 | 11.4 | 74 | 11.5 |

IHS=Indian Health Services; WCRS=Wisconsin Cancer Reporting System; CHSDA=Contract Health Service Delivery Areas.
 Source: Wisconsin Cancer Reporting System, Bureau of Health Information and Policy, Department of Health and Family Services
 * IHS Only represents cases in IHS enrollment file but not coded as American Indian in WCRS file; WCRS Only represents cases not in IHS enrollment file but coded as American Indian in WCRS file; Both IHS/WCRS represents cases in IHS enrollment file and coded as American Indian in WCRS file.

ing variables. Records that were perfectly matched on those variables were assigned a perfect score. For records matched with some uncertainty, a clerical review was performed by WCRS staff to resolve those cases. Persons enrolled in the IHS as non-American Indian were not included in the linked file.

Statistical Analysis

Cancer incidence cases were first designated by the source of American Indian identification. Three groups were established: cases identified as American Indian in both WCRS and IHS records (Both IHS/WCRS); cases identified as American Indian in the IHS records but not in WCRS case records (IHS Only); and cases identified as American Indian in WCRS records but not in IHS records (WCRS Only). The latter designation was included because American Indians may not be registered with the IHS. In calculating the pre-linkage age-adjusted rates, only American Indian cases identified by WCRS

were included in the incidence rates. Post-linkage rates included all cases identified by WCRS and/or IHS.

Descriptive statistics (Table 1) were calculated based on the 3 sources of American Indian identification described above: Both IHS/WCRS, IHS Only, and WCRS Only. The descriptive comparisons by sex, age at diagnosis, cancer site, stage at diagnosis, and geographic location (residence at diagnosis) were limited to frequency counts and proportions because of the small number of cases. Average annual age-adjusted incidence rates were calculated using the direct method for years 1998-2002, standardized to the 2000 US population (Table 2, Figure 2). The small size of the American Indian population and small number of cancer cases required limiting rates to more common cancer sites and all cancers combined. Rates were calculated using SEER*Stat, which produces age-standardized incidence rates and 95% confidence intervals for state and national level data. SEER*Stat incidence rates are calculated from a bridged single race

Table 2. Wisconsin Pre- and Post-Linkage, American Indian Age-Adjusted Incidence Rates Compared to Wisconsin and SEER Incidence Rates, Major Cancer Sites with Lower and Upper Confidence Intervals, 1998-2002

| | Wisconsin American Indian Pre-Link* | Wisconsin American Indian Post-Link* | Wisconsin All Races* | National SEER American Indian* | National Seer All Races* |
|--------------------------|-------------------------------------|--------------------------------------|-------------------------|--------------------------------|--------------------------|
| All Sites | | | | | |
| Male | 501.6 (432.8, 581.5) | 604.4 (530.5, 689.1) | 564.6 (560.4, 568.9) | 255.4 (242.7, 268.8) | 553.3 (551.6, 555.0) |
| Female | 318.5 (277.9, 364.2) | 389.6 (344.7, 439.7) | 427.4 (424.1, 430.8) | 220.5 (210.8, 230.7) | 413.5 (412.2, 414.8) |
| Total | 386.3 (350.4, 425.5) | 471.7 (432.5, 514.5) | 482.6 (480.0, 485.2) | 233.6 (255.6, 241.6) | 469.7 (468.6, 470.7) |
| Bronchus and Lung | | | | | |
| Male | 68.1 (45.1, 103.1) | 85.9 (59.3, 124.5) | 85.1 (83.4, 86.8) | 42.7 (37.5, 48.6) | 77.9 (77.2, 78.5) |
| Female | 66.3 (47.7, 90.6) | 77.3 (57.2, 103.1) | 51.7 (50.5, 52.8) | 23.6 (20.3, 27.3) | 49.0 (48.5, 49.4) |
| Total | 67.2 (52.5, 85.5) | 80.4 (64.2, 100.1) | 65.6 (64.6, 66.6) | 31.8 (28.9, 35.0) | 61.1 (60.7, 61.4) |
| Colorectal | | | | | |
| Male | 94.5 (65.5, 135.7) | 105.4 (75.2, 147.5) | 67.5 (66.0, 69.0) | 36.7 (31.9, 42.0) | 62.1 (61.5, 62.7) |
| Female | 36.5 (32.2, 55.6) | 41.1 (26.9, 61.1) | 47.5 (46.4, 48.6) | 32.2 (28.4, 36.4) | 46.0 (45.6, 46.4) |
| Total | 59.5 (45.5, 77.3) | 67.1 (52.3, 85.6) | 56.3 (55.4, 57.2) | 34.2 (31.2, 37.4) | 52.9 (52.6, 53.3) |
| Breast | | | | | |
| Female | 67.1 (50.7, 88.7) | 89.2 (67.8, 133.7) | 135.7 (133.8, 127.6) | 54.8 (50.2, 59.7) | 134.4 (133.7, 135.1) |
| Prostate | | | | | |
| Male | 122.5 (88.5, 168.8) | 154.7 (117.6, 203.6) | 167.0 (164.2, 168.8) | 50.3 (44.7, 56.6) | 173.8 (172.8, 174.7) |

Sources: Wisconsin Cancer Reporting System, Bureau of Health Information and Policy, Department of Health and Family Services and Surveillance, Epidemiology and End Results (SEER) program, Division of Cancer Control and Population Sciences, National Cancer Institute.

* Rates are per 100,000 population and age-adjusted to the 2000 US Standard population. Confidence intervals in parentheses are 95% for rates.

category derived from the self-reported multiple race categories in the 2000 US Census. The bridged estimates and methodology appear on the National Center for Health Statistics Web site.¹⁴

The rates among American Indians were compared with the rates for the total population of Wisconsin by using the standardized incidence ratio (SIR). SEER*Stat calculated each SIR from the ratio of American Indian cases to the number of cases found in the same age-specific groups in the general state population (Table 3).

RESULTS

Source of Identification of Cancer Cases Among American Indians in Wisconsin

Table 1 shows the selected characteristics of 644

American Indian cancer cases by the source of race identification. Of all cancers among American Indians in the study, 20% were identified through the IHS linkage and were previously misclassified in WCRS records as races other than American Indian or unknown. Cancer cases identified by the WCRS but not found in the IHS files comprised 32.5%, and cases identified as American Indian in both IHS and WCRS records contributed less than half, or 47.5%, of the incidence cases.

It should be noted that the WCRS file of cancer case records were linked to IHS files for the single purpose of identifying or reclassifying WCRS cases as American Indian. All demographic, geographic, and cancer information in Table 1 originate from the WCRS files. The 3 categories of IHS Only, WCRS Only, and Both

IHS and WCRS are mutually exclusive categories, and distinguishable only as the source of identification for American Indian cases.

Geographically, approximately 50% of the cases identified in the IHS Only and Both IHS/WCRS combined files were residents from the Northeast region in Wisconsin. By comparison, <40% of American Indians identified in the WCRS Only file resided in the Northeast region. The WCRS Only file contributed 25% of American Indian cases from the Southeast region compared with 10% from the IHS Only file and 7.5% from the Both IHS/WCRS files. In examining the CHSDA, it was not surprising that 76% of cases in the IHS Only file and 87% of cases in Both IHS/WCRS files were from CHSDA counties, in contrast to only 60% of the cases in the WCRS Only file.

Cancer Site Distribution by Source of Identification

Cancer sites among the 644 American Indian cases were compared by the 3 sources of identification as displayed in Table 1. The numbers were small for reliable conclusions regarding statistical differences but descriptive comparisons show certain patterns. Prostate cancers were approximately 50% higher among the IHS Only group (15.5%) compared with the WCRS Only group (9.1%) and Both IHS/WCRS groups (11.4%). Although the IHS Only group had a 10% higher proportion of men, the magnitude of prostate cancer is greater than would be expected if comparable for the 3 groups.

Pre- and Post-Linkage Age-Adjusted

Cancer Incidence Rates

Figure 2 shows that for all cancers, the post-linkage incidence rate among American Indians is approaching Wisconsin's total incidence rate (472 and 483 per 100,000, respectively). The post-linkage rate is over twice as high as the SEER national rate for American Indians/Alaskan Natives (234 per 100,000). The cancer incidence rate among American Indian men is also higher than the Wisconsin total male population rate (604, compared with 565 per 100,000).

Table 2 presents the age-adjusted cancer incidence rates before and after the IHS linkage. Virtually all cancer sites reflect a post-linkage increase. For Wisconsin American Indians, the all sites incidence rate increased from a pre-linkage rate of 386.3 to a post-linkage rate of 471.7 per 100,000, statistically significant based on the confidence intervals. The largest post-linkage increase in incidence rates among American Indians was a 33% increase in female breast cancer and the second largest increase was a 26% increase in prostate cancer, but neither increase reached statistical significance.

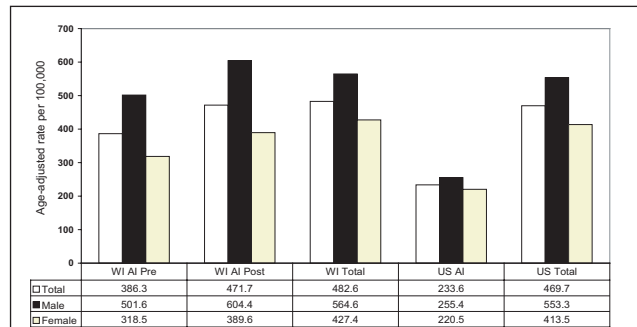


Figure 2. Wisconsin and national cancer incidence rates, all sites. Pre- and post-linkage, American Indian (AI) and all races, 1998-2002. Sources: Wisconsin Cancer Reporting System, Bureau of Health Information and Policy, Department of Health and Family Services and Surveillance, Epidemiology and End Results (SEER) program, Division of Cancer Control and Population Sciences, National Cancer Institute.

Table 3. Selected Standardized Incidence Ratios: Incidence Rates for American Indians in Wisconsin Compared With Those for the General Population in Wisconsin, 1998-2002

| Cancer Site | Before Linkage | | After Linkage | |
|-------------------|----------------|-------|---------------|-------|
| | Men | Women | Men | Women |
| All Sites | 0.89 | 0.74 | 1.07 | 0.91 |
| Colorectal | 1.40 | 0.77 | 1.56 | 0.86 |
| Lung and Bronchus | 0.80 | 1.28 | 1.01 | 1.50 |
| Breast | — | 0.49 | — | 0.66 |
| Prostate | 0.73 | — | 0.93 | — |

Source: Wisconsin Cancer Reporting System, Bureau of Health Information and Policy, Department of Health and Family Services.
Rates are per 100,000 and age-adjusted to the 2000 US standard population. Standard Incidence Ratios are based on cancer incidence rates calculated before and after the linkage of data from the Indian Health Service and the Wisconsin Cancer Reporting System. A Standard Incidence Ratio of 1.0 means rates are the same for the American Indian population and the general population.

Table 2 also shows the pre- and post-linkage rates in relation to Wisconsin and national rates for all races and American Indians. Across the 4 leading cancer sites, post linkage rates for female lung cancer and male colorectal cancer among American Indians were significantly higher than rates for the Wisconsin general population.

By way of national comparisons, the SEER incidence rate for all cancers among American Indians was 233.6 per 100,000, or less than half the Wisconsin post-linkage rate (471.7). For lung cancer, the post-linkage Wisconsin American Indian female rate (77.3) exceeded state and national female rates (51.7 and 49.0, respectively) for all races by 50% and exceeded the national rate for American Indian women (23.6) by over

300%. For colorectal cancer incidence, the post-linkage Wisconsin American Indian male rate exceeded the state male rate for all races by 57% and surpassed the national American Indian male rate by almost 300% (105.4 compared with 67.5 and 36.7, respectively).

Standardized Incidence Ratios for American Indians Compared with Total Population in Wisconsin

Table 3 provides SIRs for comparing pre- and post-linkage incidence in Wisconsin's American Indian population to the statewide population. The pre-linkage SIRs for American Indian men demonstrates rates lower than state average rates for all sites, lung, and prostate cancers (SIRs ranged from .73 to .89) while higher for colorectal (SIR=1.40). However, all post-linkage SIRs for American Indian men exceeded or closely approached the state average (SIRs ranged from .93 to 1.56). Although the female post-linkage rate for all sites remained lower than the state average rate (SIR=.91), the difference was reduced in magnitude compared to the pre-linkage rate (SIR=.74).

DISCUSSION

Geographic Patterns in Sources of Identification

The pattern of increased American Indian cancer cases identified by this linkage suggests there are potential deficiencies in current registry data collection methods unless supplemented by secondary data linkages. The extent of misclassification varies by geographic regions within Wisconsin. The WCRS misclassified cases for years 1998-2002 (IHS Only) were more frequently located in the Northeastern part of the state and were more often residents of CHSDAs. The Northeast region has the highest concentration of American Indians in Wisconsin and is home to the largest tribes in the state. The Southeastern region of Wisconsin has no CHSDA counties and therefore fewer IHS recipients. The Southeastern region of Wisconsin is more highly urbanized than other regions of the state. It is speculated that a higher percentage of American Indians living in this region may be employed in positions covered by private insurance. Consequently these individuals would be able to seek medical care outside of Tribal or Urban Indian Health Centers. In those circumstances, information on their cancer cases would not be reported to the IHS. However, information on those cancer cases would be captured through reporting to the WCRS.

Variations in Misclassification by Cancer Site

Estimates for American Indian incidence rates in Wisconsin increased for all cancer sites examined as a result of data linkage to IHS patient files. The post-link-

age increase for all cancers combined among American Indians was statistically significant. The post-linkage rate for American Indian men exceeded the state rate for men of all races but did not reach statistical significance. Male colorectal and female lung cancer pre-linkage rates among American Indians in Wisconsin were already marginally higher than state rates for all races combined, and the post-linkage rates increased to reach statistical significance. This may suggest more complete and timely reporting practices for those cancers often treated in hospital settings and comprehensive treatment centers, compared to outpatient treatment centers.

The post-linkage female breast cancer rate among American Indians in Wisconsin remains lower (89.2 compared to 135.7) than for Wisconsin in general and this could be related to the low mammogram screening rates for American Indian women, as widely reported in the Wisconsin Behavioral Risk Factor Surveillance System.

Regional Variation in Cancer Mortality in the United States

Previous studies have consistently shown the highest cancer mortality among American Indians in the IHS Northern Plains region, which includes Wisconsin, when compared to other IHS regions in the United States (East, Southwest, and Pacific Coast).^{3,17} Mortality rates in the Northern Plains were highest of all 4 regions for lung, colorectal, breast, cervical, and prostate cancers. By contrast, lung cancer mortality was lower among the Southwest and East regions, primarily attributed to variability in tobacco use. Smoking prevalence among American Indians/Alaska Natives in the Northern Plains during 1997-2000 was 44%, compared with 21% in the Southwest.¹⁸

Discrepancy Between SEER National Data and Wisconsin Data

There are over 500 federally recognized tribes and over 100 state-recognized tribes, each of which has its own unique culture.¹⁹ Great diversity exists in culture, political organizations, and general health status among tribes in the United States. The enormous variation across tribes imposes limitations on drawing conclusions from currently available statistics. Kelley et al reported "striking differences" in cancer incidence patterns between 2 American Indian populations in Alaska and New Mexico.²⁰ Dramatic differences between national incidence rates from SEER compared with regional and state rates may be explained as a function of this tribal variation. Overall, cancer incidence among American Indians is more than 2 times higher in Wisconsin than in the geographic areas

participating in the SEER program. National data from SEER registries and supplemental areas (California, New Mexico, and Arizona for example) may reflect lifestyles and behavioral risk factors, not to mention health care practices, unique to those states or at least not indicative of Wisconsin. The Minnesota state cancer registry, Minnesota Cancer Surveillance System, also found the American Indian rate for all cancer increased by a third (from 398 to 538, per 1000) for years 1998-2002 as a result of data linkage with IHS. The Minnesota state registry also reported post-linkage rates for all major cancers (lung, colorectal, breast, prostate) at least twice as high as comparable SEER American Indian rates.²¹ Based on regional mortality data, cancer appears to be unusually common among Northern Plains Indians in general.¹⁷ Previous surveillance studies have concluded there is no national database providing accurate comprehensive cancer data for American Indians.²²

LIMITATIONS

The SEER*Stat bridged population estimates used as the incidence rate denominator reflects the American Indian population that was self-reported in the 2000 US Census. The numerator is derived from 2 central sources (WCRS and IHS) of racial identification from medical records. IHS enrollment is more restrictive than self-reported census identification, but also provides potential benefits to those who are enrolled. This raises the possibility that the linkage projects may calculate standardized incidence rates from different methods of racial identification between the numerator and denominator. The recent work with the Great Lakes Inter Tribal Council to increase tribal reporting has demonstrated that certain cancer cases, particularly those diagnosed or treated in non-hospital settings, were not reported during the 1998-2002 period covered in this report.¹¹ American Indians in Wisconsin not enrolled in the IHS files could not be reclassified through this linkage and may still be misclassified in the WCRS records. In this study, approximately a third of American Indian cancer cases in Wisconsin (identified by WCRS) were not found in IHS patient files. Lastly, other health indicators and previous studies have consistently shown the highest cancer mortality among American Indians in the Northern Plains region, including Wisconsin, compared to other regions in the United States.^{3,17} The post-linkage rates appear more consistent with published mortality data and therefore serve to correct the previous underestimation of American Indian cancer incidence rates.

Quality and Completeness of Facility Reporting

There are no national standards for the identification of

race/ethnicity of patients during admission to hospitals. In recognition of this problem, the American Hospital Association, Health Research and Educational Trust, has issued the Toolkit for Collecting Race, Ethnicity and Primary Language Information from Patients to help facilities standardize their collection of patient race and ethnicity (available at www.hretdisparities.org).

WCRS operates within a "passive" system of data collection; facilities in Wisconsin are required to report cancer cases to WCRS. Some health care facilities in Wisconsin lack well-defined, standard procedures for the collection of racial/ethnic data; WCRS receives cancer data of varying quality and timeliness. Because some American Indian cancer patients are treated in non-IHS facilities, systemic improvements in collecting patient racial and ethnic data at the facility level are needed for further improvement in cancer statistics from WCRS.

CONCLUSIONS

The pattern of increased incidence identified by the linkage suggests there is misclassification in current data collection that can be addressed by data linkages. The magnitude of the initial misclassification varied most obviously by geographic location and by cancer site. The accuracy of racial classification was previously unverifiable except through costly re-abstracting or auditing of hospital records. Data linkage is a timely and inexpensive method of reconciling inconsistencies and increasing identification of American Indian cancer cases.²³⁻²⁵ As direct reporting to WCRS by tribes in Wisconsin increases, and all currently reporting facilities become more standardized in collecting racial/ethnic cases, the need for secondary sources of identification could be greatly reduced or eliminated.

The higher incidence rates for largely preventable lung cancer among American Indian women and early detectable colorectal cancer among American Indian men have implications for educational and screening programs currently being navigated in the Wisconsin Comprehensive Cancer Control Plan (www.wicancer.org). The unequal burden of cancer among racial groups is a focus of current state and national efforts in cancer prevention and control. As the WCRS state cancer registry strives to eliminate misclassification and underreporting of American Indian cancer incidence, the IHS linkage project enhances data for more accurate guidance of cancer control programs through state and local levels.

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