

The High Burden of Cancer Among American Indians/Alaska Natives in Wisconsin

Mary Foote, MS; Rick Strickland, MA; Samantha Lucas-Pipkorn, MPH; Amy Williamson, MPP; Lauren Lamers, MPH

ABSTRACT

Objective: American Indians/Alaska Natives (AI/AN) who live in the Northern Plains, including Wisconsin, face disproportionate cancer disparities. This report examines cancer incidence and mortality based on residence in Contract Health Service Delivery Areas (CHSDA) to assess disparities between AI/ANs and other racial populations in Wisconsin.

Methods: To improve identification of the AI/AN race, incidence data were linked with Indian Health Service (IHS) patient records. Analysis further focused on residents of IHS CHSDA counties. Age-adjusted cancer incidence and mortality rates (2007-2011) were calculated by sex and major cancer sites. AI/AN rates were analyzed for both statewide and CHSDA residency in comparison to statewide white rates and comparable national rates.

Results: In comparison with whites, AI/ANs in CHSDA counties had higher incidence rates of cervical (3.5 times), liver (3.2), lung (2.3), and kidney cancers (2.1), and higher mortality rates for liver (2.7), kidney (2.2) and lung (1.9) cancers. Although there were similar rates of prostate cancer incidence between the 2 populations, AI/ANs were 1.9 times more likely to die from the disease.

Conclusions: AI/AN individuals in Wisconsin CHSDA counties experience the highest cancer incidence rate of any racial group for both genders combined and for females. This population also has the highest mortality rate among all racial groups for both males and females. To meet the Wisconsin Comprehensive Cancer Control Plan 2015-2020 and Healthy People 2020 goals of lowering cancer incidence and mortality rates, the disproportionate cancer burden among AI/ANs needs to be addressed.

The Indian Health Service (IHS) is the primary vehicle through which the federal government provides health services to AI/ANs. However, limited funding for IHS and other barriers to care may result in limited access to health services. Several studies have reported dramatic regional variation in cancer incidence and mortality, especially higher rates of cancer in the Northern Plains states including Wisconsin.²⁻⁵ *Cancer in North America 2007-2011*, a North American Association of Central Cancer Registries publication presenting data from 32 state cancer registries (meeting data standards and with sufficient AI/AN populations), shows that Wisconsin has the fifth highest incidence rates for males and third highest for females, as well as the highest lung cancer incidence rates for both males and females.⁶

BACKGROUND

Cancer Incidence among American Indians/Alaska Native

American Indians and Alaska Natives (AI/AN) face persistent disparities in health status and health care, including barriers to obtaining screening, health care, and treatment of cancer.¹

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Author Affiliations: Cancer Reporting System, Wisconsin Department of Health Services Bureau of Health Informatics, Madison, Wis (Foote); Cancer Health Disparities Initiative, UW Carbone Cancer Center, Madison, Wis (Strickland, Williamson); Great Lakes Inter-Tribal Epidemiology Center, Lac du Flambeau, Wis (Lucas-Pipkorn); University of Wisconsin Population Health Institute, Menominee Tribal Clinic, Keshena, Wis (Lamers).

Corresponding Author: Mary Foote, MS, Epidemiologist, Wisconsin Cancer Reporting System, 1 W Wilson St, Rm 118, Madison WI 53703; phone 608.261.8874; fax 608.266.2431; e-mail mary.foote@dhs.wi.gov.

Wisconsin Cancer Reporting System

The Wisconsin Cancer Reporting System (WCRS) is a population-based registry guided by a state statutory mandate to collect, manage, and analyze cancer data on Wisconsin residents. In 1994, WCRS became part of the National Program of Cancer Registries, funded by the Centers for Disease Control and Prevention. Over 30,000 newly diagnosed cancer cases were reported to WCRS for the most recent reportable diagnosis year.⁷

This report examines cancer incidence and mortality data based on residence in Contract Health Service Delivery Areas (CHSDA) to assess disparities between AI/AN, and other racial populations in Wisconsin. To meet the Wisconsin Comprehensive Cancer Control Plan 2015-2020 and Healthy People 2020 goals of lowering cancer incidence and mortality rates, the disproportionate cancer burden among American Indians needs to be addressed.

Figure 1. Wisconsin Contract Health Service Delivery Area (CHSDA) Counties in the Department of Health Services Regions



Oneida Nation, Forest County Potawatomi, Red Cliff Band of Lake Superior Chippewa, St. Croix Chippewa, Sokaogon Chippewa (Mole Lake), and Stockbridge-Munsee.

Challenge of Data Collection

The collection of accurate data on cancer incidence among AI/ANs is hampered by misclassification of this population in cancer case reports.¹¹ To rectify misclassification and the tendency to report the AI/AN race as white, WCRS and other state cancer registries in the United States routinely link cancer case data to the IHS patient record registry.¹² In Wisconsin, of the 1005 invasive cancers diagnosed among AI/ANs in 2007-2011, approximately 15% were newly identified through the IHS linkage. The other method used to reduce misclassification is to restrict the selection of cases to residents in IHS CHSDA counties.^{6,13} In Wisconsin, 62% of the 2011 AI/AN population of 68,745 reside in the 32 CHSDA counties. Of the 1005 reported cancer cases for this population during 2007-2011, 75% (761) were among residents of CHSDA counties. Nationally, 64% of the AI/AN population reside in 637 CHSDA counties, and linkage

METHODS

American Indians and Alaska Natives in Wisconsin

The US Census indicated the self-reported AI/AN 2010 population (single or in combination) in Wisconsin was 69,386.⁸ For this study, SEER*Stat, statistical software from the National Cancer Institute (NCI), provided a bridged-race population estimate of 68,745 AI/ANs for the year 2011.⁹ American Indians make up almost 100% of the AI/AN population in Wisconsin; only approximately 225 people in Wisconsin were identified as Alaska Natives.¹⁰ The IHS (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. 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. CHSDA counties are designated by IHS and contain or are adjacent to federally recognized tribal lands. In Wisconsin, there are 32 CHSDA counties in the state (Figure). There are 11 federally recognized tribes in Wisconsin, each with unique government, language, and health practices. These are the Bad River Band of Lake Superior Chippewa, Ho-Chunk Nation, Lac Courte Oreilles Band of Lake Superior Chippewa, Lac du Flambeau Band of Lake Superior Chippewa, Menominee Tribe of Wisconsin,

studies indicate more accurate race classification and higher proportions of this population in CHSDA counties.⁷ Racial classifications for mortality data are ascertained from information recorded on death certificates and are not currently subject to the same corrective adjustments as incidence data (although NPCR-IHS linkage is currently underway and will be available in the future). Mortality data in this report are, therefore, potentially more underestimated than are incidence data.

Data Sources and Statistical Methods

Cancer cases diagnosed during 2007 through 2011 were selected from WCRS for Wisconsin and from SEER*Stat incidence files for the United States. Mortality data for deaths during 2002-2011 were drawn from SEER*Stat public use mortality files. Age-adjusted rates were calculated for all racial groups, including AI/ANs in CHSDA counties and the entire state. All rates, expressed per 100,000 population, were directly age adjusted to the 2000 United States standard population using SEER*Stat. Rates were calculated for all sites combined and for the 13 most frequent cancer incidence sites and 9 most common cancer mortality sites among AI/ANs.

Cancer registry incidence records (state and national) were linked with patient registration files from the IHS. Incidence data refer to invasive cancers, with the exception of the urinary blad-

Table 1. Cancer Incidence by Sex and Race, for Contract Health Service Delivery Areas (CHSDA), Wisconsin and United States

Wisconsin												
	Male and Female				Male				Female			
	Rate	Lower CI	Upper CI	Count	Rate	Lower CI	Upper CI	Count	Rate	Lower CI	Upper CI	Count
All races	471.2	468.8	473.7	148,854	533.0	529.1	536.8	77,158	426.9	423.7	430.1	71,696
White	461.3	458.8	463.8	137,566	518.9	515.0	522.8	71,275	420.2	416.9	423.5	66,291
African American	544.1	530.0	558.4	6,512	680.8	655.6	706.7	3,501	448.6	431.9	465.6	3,011
AI/AN, CHSDA	576.3	531.8	623.3	761	600.2	525.2	681.9	340	570.5	513.8	631.4	421
AI/AN, Total	483.4	450.6	517.8	1,005	503.7	449.3	562.1	459	476.1	434.1	520.9	546
Asian/Pacific Islander	291.8	271.7	312.8	976	311.3	277.1	348.1	410	288.0	262.8	314.8	566

United States												
	Male and Female				Male				Female			
	Rate	Lower CI	Upper CI	Count	Rate	Lower CI	Upper CI	Count	Rate	Lower CI	Upper CI	Count
All races	460.4	459.7	461	2,001,481	529.4	528.4	530.5	1,033,837	411.3	410.5	412.2	967,644
White	468.9	468.2	469.6	1,628,476	532.1	530.9	533.2	840,730	424.4	423.4	425.3	787,746
African American	480.8	478.6	482.9	208,379	600.9	597.0	604.7	110,040	398.8	396.3	401.4	98,339
AI/AN, CHSDA	319.3	311.8	326.9	7,934	348.1	335.9	360.7	3,774	301.9	292.4	311.7	4,160
AI/AN, Total	235.1	230.2	240.1	10,362	259.3	251.3	267.5	4,991	219.9	213.7	226.2	5,371
Asian/Pacific Islander	306.7	304.9	308.4	121,493	331.0	328.2	333.9	55,972	293.0	290.7	295.3	65,521

Data are for years 2007-2011. Rates are per 100,000 population and age-adjusted to the 2000 U.S. standard population.

Abbreviations: AI/AN, American Indians/Alaska Natives.

Sources: Wisconsin Cancer Reporting System, Office of Health Information, Division of Public Health, Department of Health Services, and Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat. US Incidence - SEER 18 Regs Research Data, Nov 2013 Sub (2000-2011). SEER counts are based on data from 18 registries to represent a national estimate. Data accessed November, 2014.

Table 2. Cancer Mortality by Sex and Race, for Contract Health Services Delivery Areas (CHSDA), Wisconsin and United States

Wisconsin												
	Male and Female				Male				Female			
	Rate	Lower CI	Upper CI	Count	Rate	Lower CI	Upper CI	Count	Rate	Lower CI	Upper CI	Count
All races	174.6	173.2	176.1	55,901	212.6	210.1	215.1	29,278	148.4	146.6	150.3	26,623
White	172.6	171.1	174.1	52,731	210.0	207.5	212.5	27,638	146.8	144.9	148.6	25,093
African American	236.0	226.2	246.1	2,508	296.0	278.1	314.6	1,315	195.7	184.2	207.6	1,193
AI/AN, CHSDA	252.2	220.0	287.3	270	320.2	257.3	391.7	139	215.1	177.7	257.3	131
AI/AN, Total	216.8	193.0	242.6	371	262.4	218.0	312.0	187	191.4	162.9	223.0	184
Asian/Pacific Islander	103.1	90.6	116.6	291	120.2	98.2	144.9	138	93.1	78.1	109.8	153

United States												
	Male and Female				Male				Female			
	Rate	Lower CI	Upper CI	Count	Rate	Lower CI	Upper CI	Count	Rate	Lower CI	Upper CI	Count
All races	173.8	173.6	174.0	2,847,364	211.6	211.3	212.0	1,488,124	147.4	147.2	147.7	1,359,240
White	173.3	173.1	173.5	2,440,835	209.8	209.4	210.1	1,278,795	147.5	147.3	147.8	1,162,040
African American	206.4	205.7	207.1	325,388	269.3	267.9	270.7	167,469	169.0	168.2	169.9	157,919
AI/AN, CHSDA	158.0	154.7	161.4	9,743	190.0	184.2	196.0	5,081	135.2	131.2	139.3	4,662
AI/AN, Total	120.0	117.8	122.2	13,770	145.2	141.4	149.0	7,252	102.1	99.5	104.8	6,518
Asian/Pacific Islander	107.8	107.0	108.6	67,371	131.0	129.6	132.5	34,608	91.5	90.4	92.5	32,763

Data are for years 2007-2011. Rates are per 100,000 population and age-adjusted to the 2000 U.S. standard population.

Abbreviation: AI/AN, American Indians/Alaska Natives.

Source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Mortality - All COD, Aggregated With State, Total U.S. (1990-2011), National Cancer Institute, released July 2014. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

der (bladder), which includes in situ cancers. Data for the primary cancer site and histology were coded according to the International Classification of Diseases for Oncology (ICD-O-3) edition in use at the time of diagnosis, and then categorized according to SEER site

groups.¹⁴ The underlying cause of death was coded according to the International Classification of Diseases, 10th Revision (ICD-10).¹⁵ Mortality data are not currently linked to IHS records. Consistent with previous practice, this report shows the standard mortality rates

Table 3. Cancer Incidence for Whites and CHSDA American Indians/Alaska Natives, Wisconsin

Cancer Site	White		AI/AN		AI/AN/White Rate Ratio
	Rate	Count	Rate	Count	
All sites	461.3	137,566	576.3 ^a	761	1.2
Lung and bronchus	59.3	17,803	133.7 ^a	150	2.3
Prostate	134.7	19,406	132.3	74	1.0
Breast	124.9	19,415	118.5	95	0.9
Colon and rectum	40.6	12,252	#58.2	72	1.4
Kidney and renal pelvis	16.2	4,807	#34.4	50	2.1
Non-Hodgkin Lymphoma	20.6	6,111	23.8	26	1.1
Oral cavity and pharynx	11.1	3,357	#19.5	29	1.8
Cervix uteri	5.4	719	#18.9	17	3.5
Liver and intrahepatic bile duct	5.2	1,585	#16.6	19	3.2
Ovary	13.0	2,026	16.4	13	1.3
Leukemia	15.9	4,635	16.1	22	1.0
Pancreas	12.2	3,703	13.9	15	1.1
Uterus	28.1	4,537	26.6	24	0.9

Data are for years 2007-2011. Rates are per 100,000 and age-adjusted to the 2000 US standard population.

^a The rate ratio indicates that the rate is significantly different than the rate for whites ($P < 0.05$).

Abbreviations: CHSDA, Contract Health Service Delivery Area; AI/AN, American Indian/Alaska Natives (CHSDA counties).

Source: Wisconsin Cancer Reporting System, Office of Health Information, Division of Public Health, Department of Health Services.

Table 4. Cancer Mortality for Whites and CHSDA American Indians/Alaska Natives, Wisconsin

Cancer Site	White		AI/AN		AI/AN/White Rate Ratio
	Rate	Count	Rate	Count	
All malignant cancers	177.0	104,173	257.5 ^a	510	1.5
Lung and bronchus	46.7	27,178	87.7 ^a	174	1.9
Colon and rectum	15.7	9,396	23.8 ^a	41	1.5
Breast	22.0	7,174	27.6	32	1.2
Prostate	25.7	5,999	45.8 ^a	19	1.8
Liver and intrahepatic bile duct	4.6	2,692	12.6 ^a	27	2.7
Pancreas	11.1	6,526	11.2	24	1.0
Kidney and renal pelvis	4.4	2,606	9.8 ^a	22	2.2
Non-Hodgkin Lymphoma	7.2	4,281	9.0	16	1.2
Leukemia	8.1	4,744	8.1	15	1.0

Data are for years 2002-2011. Rates are per 100,000 and age-adjusted to the 2000 US standard population.

^a The rate ratio indicates that the rate is significantly different than the rate for whites ($P < 0.05$).

Abbreviations: CHSDA, Contract Health Service Delivery Area; AI/AN, American Indian/Alaska Natives (CHSDA counties).

Source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Mortality - All COD, Aggregated With State, Total U.S. (1990-2011), National Cancer Institute, released July 2014. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

as reported from death certificates, and thus are potentially subject to misclassification and underreporting.

Wisconsin's relatively small American Indian population limits mortality analyses to major sites, and the small number of cancer cases requires aggregation for confidentiality restrictions and acceptable statistical reliability. Accordingly, incidence data were aggregated by the most recent 5-year interval. Mortality data for all cancers was reported by a 5-year interval, but mortality data by site required a 10-year interval. Using age-adjusted incidence and mortality rates, we calculated standardized rate ratios for AI/ANs using whites for the comparison. Rate ratios (RRs) were calculated using

SEER*Stat, and 95% confidence intervals (CIs) for age-adjusted rates and RRs were calculated based on statistical methods described by Tiwari et al.¹⁶

RESULTS

During 2007-2011, the likelihood of being diagnosed with cancer varied greatly by race as shown in Table 1. In Wisconsin, incidence rates for AI/ANs in CHSDA counties were approximately 19% higher for both sexes than when calculated for this population statewide. During that period, 1005 AI/AN cancer cases were diagnosed in Wisconsin with an incidence rate of 483.4 (per 100,000), and 761 cases were diagnosed in CHSDA counties, with an incidence rate of 576.3. The cancer incidence rate for AI/ANs in CHSDA counties was the highest of any racial group for both genders combined and females. For AI/AN males, the rate was second highest to African American males, but the difference was not statistically significant.

Cancer incidence rates among all AI/ANs in Wisconsin were approximately twice as high as national rates for total cases and 80% higher for CHSDA cases. Comparing Wisconsin CHSDA and non-CHSDA counties, the incidence rate for whites in CHSDA counties was 459.7 (CI, 455.6-463.7) and, for non-CHSDA counties, 470.3 (CI, 467.2-473.5). The incidence rate for AI/ANs in CHSDA counties was 576.3 (CI, 531.8-623.3), but 308.3 for AI/ANs in non-CHSDA counties (CI, 256.8-355.2). Data are not shown for this comparison.

Table 2 shows the risk of dying from cancer differed markedly among racial groups in Wisconsin, which also is true nationally. The age-adjusted mortality rate for AI/AN people in Wisconsin was approximately 16% higher for residents of CHSDA counties than statewide, but this difference is not statistically significant. AI/ANs living in CHSDA counties in Wisconsin had the highest mortality rates among all racial groups for the years analyzed—for men, women and both sexes combined. Nationally the comparable mortality rates for AI/ANs (CHSDA) were lower than rates for whites and African Americans.

Tables 3 and 4 present Wisconsin cancer incidence and mortality rates by site for whites statewide and AI/ANs in CHSDA coun-

ties. All remaining results refer to CHSDA counties only. Rates for all cancer combined and the most common cancers are presented. AI/ANs in Wisconsin had statistically significantly higher incidence rates of all cancer sites combined, lung, colorectal, kidney, oropharyngeal, liver, and cervical cancers than whites. The degree of disparity varied by site; AI/ANs were twice as likely to have lung and kidney cancer, as shown in Table 3. Cervical cancer and liver cancers were 3 times more common, and oral cancer was almost twice as common. They also had similar incidence rates of breast and prostate cancers compared with whites.

Table 4 shows that this population had a 50% higher mortality rate for all cancers combined compared to whites. They experienced equal or higher mortality rates for all cancer sites shown and were approximately twice as likely to die from cancers of the lung or kidney, and 2.7 times as likely to die from liver cancer—the site with the largest disparity.

DISCUSSION

Shift in Surveillance Data

Nationwide, AI/ANs historically have been reported as having lower rates of cancer than other racial groups, except for Asian/Pacific Islanders, but according to various state and national data the reported rates have been increasing in recent years.^{6,13,17} The rates may have been underreported because of past misclassifications and flaws in collecting cancer data. WCRS and many other state cancer registries currently link data with IHS records and use data from CHSDA counties as the current “gold standard” in data collection for this racial group.⁷

High Cancer Rates in Northern Plains

Previous research has identified cancer disparities among AI/AN in the Northern Plains region. In the Northern Plains, AI/ANs have a higher cancer incidence rate than do whites, and the highest incidence and mortality rates compared with AI/ANs in other regions of the United States. Northern Plains AI/ANs have an increased risk of developing and dying from lung, colorectal, breast, cervical, and prostate cancers.^{2-5,16} Some of this variation may be due to differences in social and environmental factors, which in turn lead to differences in alcohol use, obesity, and smoking—risk factors found to be more prevalent in the Northern Plains region.^{2,16}

Behavior Risk Factors

Behavior Risk Factor Surveillance (BRFS) data for Wisconsin have shown smoking prevalence among AI/ANs as high as 40% to 50%, although more recent studies found lower rates closer to 30%.^{18,19} Moreover, compared to other racial/ethnic groups, AI/AN high school students had the highest prevalence of tobacco use during 2008-2012 (40%), although lower than the prevalence for 2000-2004 years (55%).²⁰ Ceremonial use of tobacco is in the context of traditional American Indian culture, but the health

consequences of commercial tobacco use are well known, and tribal communities are working to reduce smoking.²¹ In addition to lung cancer, smoking is a significant factor in cancers of the throat, mouth, nasal cavity, esophagus, stomach, pancreas, kidney, bladder, and cervix, as well as acute myeloid leukemia.²² The 2013 Wisconsin BRFSS estimate for obesity prevalence among AI/ANs was 38%.¹⁹ The 2011-2013 Youth Risk Behavior Survey data show a 51% prevalence for drinking among AI/AN high school students, higher than other racial/ethnic groups of that age.²³

Socioeconomic Risk Factors

Individual behaviors alone do not explain differences in health status between groups. Healthy People 2020 documents the leading social determinants of health and describes a range of personal, social, economic, and environmental factors that contribute to individual and population health. Many AI/ANs live in communities that are economically depressed and have lower levels of insurance coverage.²⁴ In Wisconsin, AI/ANs have a higher poverty rate than whites (28% and 10%, respectively) and a lower employment rate (67% and 83%, respectively).²⁵ They generally have a lower prevalence of screening for colorectal, breast, and cervical cancer, which largely determine the stage at diagnosis, treatment options and, in some cases, survival and clinical outcomes.^{26,27} The National Cancer Institute reports that AI/ANs have the lowest national 5-year survival rate for all cancers combined among all races.²⁸

Limitations

Results of this analysis should be interpreted within the context of certain limitations. WCRS is a passive system of data collection in that all data are reported by medical facilities throughout the state. The original quality of data rests on proficiency at the reporting facilities. Final incidence data from WCRS are compilations of reported case submissions, subject to state and national standard edits, consolidated if reported from multiple sources, and linked to IHS registration lists. The SEER*Stat bridged-race population estimates used as the rate denominator are based on the self-reported race information from the US Census. However, the rate numerator is based on secondary identification of race reported to WCRS from facility reporters and from linkage to IHS files. The different methods of racial identification may have unknown inconsistencies. The data linkage fails to correct those AI/AN cases misclassified in WCRS records and not enrolled in the IHS files. The relatively small AI/AN population in Wisconsin limits analysis, and caution is warranted in highly specialized interpretations of the limited data. Despite limitations, the magnitude of the disparity, continuity of rates over many years, and the consistency with rates in other states in the Northern Plains region, indicate the surveillance data are valid and useful for data-driven public health planning, interventions, and policy development.

CONCLUSIONS AND NEXT STEPS

The results of this study confirm the need for increased efforts to address individual-level behavior changes, as well as policy and system-level changes that promote healthy lifestyles and increased access to cancer screening and treatment.

Cancer control has become a priority for American Indian tribes in Wisconsin, as cancer surveillance data have revealed high rates of cancers. Cancer control programs such as the Spirit of EAGLES²⁹ have been initiated to increase awareness within AI/AN communities to better address the prevention, screening, and treatment priorities of Wisconsin tribes. Coalitions such as the Wisconsin Native American Tobacco Network³⁰ collaborate with AI/AN communities to promote cessation, prevent commercial tobacco abuse, and reduce second-hand smoke exposure. Progress has been made: High school youth smoking rates have decreased, but more needs to be done. Expanded preventive programs (smoking cessation, nutritional and activity programs) and increased access to screening (Pap screening, computed tomography (CT) lung cancer screening, prostate cancer screening) suggest that current rates of cancer mortality could decrease within a generation.

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