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# American Indian and Alaska Native Cancer Data Issues

LINDA BURHANSSTIPANOV, JAMES W. HAMPTON, AND  
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## INTRODUCTION TO CANCER AS AN ISSUE AMONG AMERICAN INDIANS AND ALASKA NATIVES<sup>1</sup>

Cancer is a growing problem among American Indians and Alaska Natives. Unfortunately, both non-Native and First Nations peoples are less aware of the growing cancer dilemma than they are of alcohol, violence, diabetes, and other well-promoted and widely dispersed conditions within Native communities. In the second half of the twentieth century, cancer has become the leading cause of death for Alaska Native women and is the second leading cause of death among Alaska Native men.<sup>2,3,4</sup> In fact, cancer is currently the third leading cause of death for all North American Natives<sup>5</sup> and is the second leading cause of death among American Indians (both sexes) over age 45.<sup>3</sup> The disease is the third most cited reason for hospital stays among Indian Health Service beneficiaries served by the Alaska Area Native Indian Health Service.<sup>3</sup> Cancer rates, previously reported as less frequent in American Indian and Alaska Natives, have been increasing throughout the last twenty years.<sup>4</sup> Incidence rates among Alaska Natives have exceeded "U.S. All Races" rates for most cancer sites.<sup>6</sup> Rates are increasing similarly for Canadian bands.<sup>7</sup>

Within Native American communities, health programs continue to focus on alcoholism and diabetes, although cancer is responsible for more deaths than either of these conditions.<sup>8</sup> Because the word *cancer* is not indigenous, it translates into some Native languages as "the disease for which there is no

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cure” or “the disease that eats the body.” Many tribes regard cancer as a white man’s disease because of its rarity before European contact. For many Native cancer patients, the disease is not discussed and is considered a form of punishment, shame, and guilt. A few tribes consider the patient’s suffering necessary in order to ensure the health of the other tribal members (they wear the pain so that their community will be spared). Some tribal members living with cancer—infected with the cancer spirit—are considered contagious and are ostracized by their communities. Other tribal members refuse cancer treatment surgery for fear that their body and spirit will be incomplete, leaving them incapable of finding their ancestors when they move to the other side (death).<sup>9</sup>

#### NATIONAL CANCER DATA LIMITATIONS AFFECTING NATIVE AMERICAN STATISTICS

Accurate data are needed to set health priorities and to develop innovative cancer programs for American Indians and Alaska Natives. Accurate statistics are critical for epidemiologic research and for the design, implementation, and evaluation of public health interventions.<sup>10</sup> Policymakers, researchers, and health care professionals at all levels (federal, state, and local) rely on national federal databases as accurate sources of information. Existing national databases, such as the U.S. census population figures, National Center for Health Statistics mortality data, National Cancer Institute Surveillance, Epidemiology, End Results (SEER) Program, and National Indian Health Service (IHS) are cited as reputable sources for cancer information about American Indians and Alaska Natives. However, each national cancer database has limited epidemiological information on all American Indians and Alaska Natives. This alarming deficiency needs to be acknowledged when these data sources are utilized for statistical purposes. These databases fail to describe accurately several underserved populations due to: (1) racial misclassification; (2) underreporting; (3) coding errors; (4) inclusion of insufficient population numbers; and (5) regional limitations for data collection. Cancer is underreported for American Indian and Alaska Native populations. Other ethnic groups, including Hispanics, Native Hawaiians, and Vietnamese, also have had reporting problems.<sup>11,12,13,14</sup> Databases referred to as good within this document refer to those that, for the most part, have addressed at least four of the five limitations described above.

#### DATABASE QUALITY VARIES AMONG TUMOR REGISTRIES

The quality of databases varies among racial groups and among geographic regions of the country. For example, the data from the New Mexico Tumor Registry are among the more comprehensive and accurate recorders of cancer incidence among American Indians. Since its inception, the New Mexico Tumor Registry director continues to recognize the need for accurate data collection from underserved populations, including American Indians and Hispanics (race is self-reported). As a result, the data collection protocol

implemented accurately describes the ethnicity of persons living in New Mexico. Survival data are available only for these American Indian populations.

At the present time, the two states with the highest American Indian population (Oklahoma and California),<sup>15</sup> both have significant racial misclassification errors, resulting in underreporting among Native Americans living in those states.<sup>16,17</sup> Similar database undercounts of Native American cancer rates have been reported for the northwestern states (Oregon, Washington, and Idaho) and the north central states (Montana and Wyoming).<sup>18,19</sup> The CDC funding of state tumor registries ideally will help improve the data in states with a high population of American Indians.

#### DATA SEQUESTRATION ON AMERICAN INDIANS AND ALASKA NATIVES IN "OTHER" CATEGORY

Cancer data are available for whites and blacks but not for American Indians or Alaska Natives. This is due in part to the smaller size of Native populations in comparison to the population of these larger racial groups. Native Hawaiians and American Samoans have a similar problem. Indigenous populations are included in the "other" category when cancer data are discussed. As a result, unusual cancer patterns among specific groups of peoples are overlooked. There are cases in which data are summarized into major racial categories to permit comparisons and analyses for cancer priorities within racial groups (African Americans, Caucasians, American Indian/Alaska Natives, Asian/Pacific Islanders, etc.). However, it is difficult to develop a community-based cancer prevention and control program with such lumped data, since the American Indian community's cancer priorities are quite different from those included under the broad category of "other." When statisticians discuss cancer incidence or mortality rates, the comparisons usually are limited to blacks and whites (and occasionally Hispanics).<sup>20</sup> When race and ethnicity are included in statistical analyses, several disconcerting findings are discovered. For example, the racial or ethnic group with the highest breast cancer incidence rate is Native Hawaiian. The racial or ethnic group with the highest cervical cancer incidence rate is Alaska Native. The racial or ethnic group with the highest gallbladder incidence rate is southwestern American Indian.<sup>21</sup> This information could not be distinguished from "other" category data.

#### HETEROGENEITY OF NATIVE AMERICAN COMMUNITIES AND "MASKING" VARIABILITY

There is no single national database that accurately presents comprehensive cancer data for American Indians. As a result, multiple databases, including the Indian Health Services, must be relied upon to supply the overall cancer data for American Indians and Alaska Natives.

Age-adjusted cancer incidence and mortality rates vary significantly among American Indians and Alaska Natives of different tribal affiliations

and geographic areas.<sup>22</sup> Accurate tumor registry data are needed to determine which cancer sites are priorities within a given community. Conclusions about cancer incidence cannot be drawn from one region for all American Indians and Alaska Natives.

The New Mexico database (mentioned earlier) is the most commonly used aggregation for NCI reports. It is part of the SEER national database which is reputedly representative of the total U.S. population. When regional data are examined, however, it is clear that the New Mexico SEER data are not representative of American Indians living in other regions of the country. The New Mexico SEER data include the Apache Reservation communities of White River and San Carlos in Arizona and Mescalero Apache (New Mexico), Tohono O'Odham and Pima (communities from Sells and Sacaton, Arizona), and Navajo (communities on the Navajo Reservation in northwestern New Mexico and northeastern Arizona).

According to the Indian Health Service statistics from 1989–1993, the four IHS areas that continued to report significantly lower rates (Phoenix, Tucson, Navajo, and Albuquerque) are located in Arizona and New Mexico. Five of the nine IHS areas had age-adjusted breast cancer mortality rates that were similar to other U.S. rates. When 1989–93 IHS age-adjusted breast cancer mortality data are compared with previously published breast data, they indicate that breast cancer mortality rates among American Indians in geographic regions other than Arizona and New Mexico gradually are increasing and becoming similar to other U.S. rates for breast cancer. American Indian women in these areas no longer are benefiting from statistically significant lower breast cancer mortality. The “U.S. All Races” breast cancer mortality rate was 27.1. The 1989–1993 female age-adjusted breast cancer mortality rates for the IHS areas located in geographic regions other than the Southwest follow in Table 1.<sup>23</sup>

The significantly lower breast cancer incidence data of Native peoples living in New Mexico and Arizona do not apply to other geographic and tribal regions, which are experiencing breast cancer incidence similar to white populations. This is of particular concern because the National Cancer Institute (NCI) Surveillance, Evaluation, and End Results (SEER) incidence data for

**Table 1**  
**1989–1993 Female Age-adjusted Breast Cancer Mortality Rates**  
**for IHS Areas with No Known Data Problems**  
**(Underreporting Indian Race on Death Certificates)**

IHS Areas Outside of AZ and NM		IHS Areas Within AZ and NM	
Aberdeen IHS (ND, SD, NE, IA)	26.3	Phoenix (AZ)	11.5
Billings IHS (MT, WY)	25.6	Albuquerque (NM)	10.3
Alaska IHS (AK)	21.4	Navajo (AZ/NM)	9.4
Nashville IHS (e.g., NC, TN, MS, FL, PA, ME, GA)	20.0	Tucson (AZ)	4.2
Bemidji IHS (WI, MN, MI)	14.2		

Native peoples are based on Arizona and New Mexico only and are used misleadingly to describe Native peoples living in other geographic regions.<sup>24</sup> The heterogeneity of lifestyle, culture, and traditions among Native communities prevents reporting statistics from one culture area and applying it to the entire population. Lifestyle variations may be regional. Southwestern American Indian communities seldom smoke cigarettes, whereas in the Northern Plains, smoking cigarettes is very common. Lung cancer is a consequence of cigarette smoking and may account for the differences in regional lung cancer incidence data.<sup>25,26,27</sup>

## AMERICAN INDIAN CANCER INCIDENCE, MORTALITY, AND SURVIVAL DATA

### **Historical Perspective**

At the turn of this century, cancer was considered a rare disease among American Indians.<sup>28</sup> The disease was so rare that some authors suggested that American Indians never had cancer.<sup>29</sup> However, skeletal remains found in archeological investigations of Indian burial grounds in Alaska and New York suggest that cancer occasionally was present in Native communities.<sup>30</sup> American Indian and Alaska Native elders have reported that cancer was not a common disease among their people. In the past twenty years, however, nearly every American Indian and Alaska Native community has experienced substantial exposure to this dread disease.<sup>31</sup>

Being cognizant of the data limitations described earlier, examples of the cancer sites identified to be of most concern among American Indians and Alaska Natives include: lung, colorectal, breast, prostate, uterine, cervix, stomach, pancreas, and gallbladder.<sup>13</sup>

### **Age-Adjusted Cancer Incidence Rates**

American Indians in the SEER database were shown to have a lower cancer incidence rate than "U.S. All Races."<sup>30,32,33,34,35,36</sup> The American Indian populations included within that database are comprised primarily of Native peoples living in Arizona and New Mexico. When compared with other racial groups, the incidence of cancer among American Indians living in Arizona and New Mexico is low. The incidence rate for "all cancer sites combined" for both sexes is less than one-half that of whites (157.3 per 100,000 person years, compared to the white rate of 359.2).

Previous studies typically have identified lower cancer incidence rates among American Indians than among whites. Such studies include Gaudette's research within the Northwest Territories<sup>37</sup> and Young's studies in Manitoba<sup>38</sup> and Ontario, Canada.<sup>39</sup> Neither the data problems nor the racial classification accuracy difficulties these researchers encountered is known.

Most research conducted in Arizona and New Mexico consistently indicates lower cancer incidence. These databases generally are those accepted as

accurately classifying race and ethnicity. These studies include Edison's work in New Mexico,<sup>40</sup> Nutting's review of screening policies among Southwestern American Indian communities,<sup>41</sup> Sorem's research in the Southwest among the Zuñi,<sup>42</sup> and Black's work with tri-ethnic populations in New Mexico.<sup>43</sup> In addition, SEER data from the New Mexico Tumor Registry consistently include cancer incidence rates for Native Americans as lower than other racial groups, such as whites and blacks.<sup>44</sup> According to the New Mexico SEER Tumor Registry (an accurate database with very few racial misclassifications), American Indians living in New Mexico and Arizona have incidence rates for stomach, uterine cervix, primary liver, and gallbladder cancers that are higher than for the "U.S. All Races." American Indians have the highest gallbladder cancer incidence rate (10.9) of any racial group.<sup>45</sup>

Nutting conducted an Indian Health Service-wide review of cancer incidence among American Indians and Alaska Natives (1980–1987).<sup>46</sup> This study was known to have errors, but was the best data available at the time. Based upon those data, American Indians and Alaska Natives have lower cancer incidence rates than do whites.

Mahoney's work with the Seneca in New York<sup>47</sup> has been accepted by the tribal council as racially accurate. Those data indicate lower cancer rates (almost all sites) among the Seneca than among other New York area communities.

In contrast, Lanier's work in Alaska among the Inuits, Athabaskans, and Aleuts identifies elevated cancer rates.<sup>48</sup> Lanier is recognized by both Natives and non-Natives to collect and record data and findings accurately. Her work consistently is of high quality and typically has few racial misclassifications or ICD coding errors. Data from the Alaska Native Tumor Registry indicate that Alaska Natives have excessive cancer incidence of the cervix, uterus, colorectal, gallbladder, kidney, oral cavity, and pharynx. An asterisk in Table 2 below indicates the highest incidence rate of any racial group, such as African American, white, and so on.

Likewise, Welty's work indicates a higher than "US All Races" rate for lung cancer among the Northern Plains American Indian Nations.<sup>49</sup> The data within the northern plains states (e.g., South Dakota) are considered to have few racial misclassifications and regarded as accurately reflecting the area's cancer problems.

### **Cancer Mortality Rates**

Cancer mortality rates also have been identified as lower than whites' in multiple research studies, as Horner's work in North Carolina shows.<sup>50</sup> There are major racial misclassifications among tribes throughout the East Coast and it is not known how accurate the data were in this study. However, based upon the databases accessible to Horner, American Indians in North Carolina have lower cancer mortality rates than whites living in that region.

Mao conducted a review of Canadian national data<sup>51</sup> and concluded that aboriginal peoples had lower mortality rates than did whites. The quality of Canadian data has been questioned by several of the First Nations for having multiple racial misclassifications.

Mahoney also studied cancer mortality of the Seneca in New York and found lower rates than for whites from the same region.<sup>52</sup> His data were accepted by the Seneca tribal council as accurate. Creagan's review of U.S. national data<sup>53</sup> also indicated lower mortality data. However, the national data have numerous racial misclassifications, leaving the database highly suspect. The National Center for Health Statistics also shows a lower cancer mortality rate among American Indians than among whites and blacks. Again, this database is considered to have multiple racial misclassifications and to underreport cancer among Native peoples (see Table 2).

**Variable Incidence Rates among First Nation's Peoples.** The American Indian data from the New Mexico Tumor Registry provide an excellent overview of cancer incidence for indigenous peoples living in Arizona and New Mexico. However, according to NCI-supported research projects implemented by the Indian Health Service

**TABLE 2**  
**Age-Adjusted (1970 U.S. Standard) Cancer Incidence Rates per 100,000**  
**Population by Race and Cancer Site, 1977-1983**

(♀ refers to females; ♂ refers to males)

Cancer Incidence Site	AK Nat. ♀	AK Nat. ♂	Am Ind. (AZ&NM only) ♀	Am Ind. (AZ&NM only) ♂	SEER White ♀	SEER White ♂	SEER Afr. Am. ♀	SEER Afr. Am. ♂
Breast <sup>a</sup>	44.2	Unk	21.7	Unk	93.3	Unk	74.9	Unk
Cervix uteri	*28.0	NA	20.5	NA	8.6	NA	19.5	NA
Colorectal	*65.2	61.0	10.0	10.6	44.9	64.5	45.9	56.4
Gallbladder	*14.7	*6.7	*14.7	6.4	1.6	0.9	1.2	0.8
Kidney	*11.0	*11.4	7.3	8.1	4.5	10.7	4.5	9.7
Oral cavity and pharynx	*15.7	17.2	1.3	3.0	7.1	17.6	7.6	*24.0
Pancreas	9.6	10.1	4.5	7.1	7.9	11.6	*11.4	*17.0
Prostate	NA	34.5	NA	37.6	NA	73.6	NA	*126.0
Stomach <sup>b</sup>	8.4	22.4	13.8	22.3	5.8	13.3	8.6	22.5
Liver <sup>c</sup>	2.0	10.8	1.1	4.1	1.2	3.1	1.9	5.3

a. The racial group with the highest breast cancer incidence rate is Native Hawaiians (108.5).

b. The racial group with the highest stomach cancer incidence rate for females is Native Hawaiians (28.8) and for males is Japanese (41.3).

c. The racial group with the highest liver cancer incidence rate is Chinese (females=3.9; males=20.8).



(IHS), cancer incidence rates among different IHS areas varied significantly for specific cancer sites. A brief review of these data clearly illustrate the variability of cancer incidence rates among IHS areas. Examples of IHS age-adjusted incidence data (age-adjusted to 1970 U.S. population) from 1982–1987 follow.<sup>54</sup>

**Breast Cancer Incidence Rates.** See Table 3 for examples of variables for breast cancer incidence rates.

**Cervical Cancer Incidence Rates.** It is obvious from Table 4 that the data's quality is suspect, as per the large confidence intervals (the larger the confidence interval, the more questionable the data). Cervical cancer incidence rates are high among all nations when compared with other races. Alaska Native populations (Aleut, Athabaskan, and Inuit) consistently have higher cervical cancer incidence than do other American Indian populations.

American Indian women do not appear to have a high prevalence of many of the risk factors commonly associated with cervical neoplasia among non-Native populations.<sup>55</sup> It is not known if genetics plays a more significant role in cervical cancer in American Indian women than it does in non-Native women. Research is needed to improve understanding of the risk factors and the determinants of cervical cancer incidence among American Indians and Alaska Natives.

**Colorectal Cancer Incidence Rates.** According to Table 5, Alaska Natives living in Alaska have the highest age-adjusted colon and rectum cancer incidence rate per 100,000 population for both sexes (Alaska, 1977–83) compared to any other racial group. Among the Alaska Native populations (Athabaskan, Aleut, and Inuit), unusual rates are noted both within the same sub-population and between sexes. This unusual variability generates several questions regarding the risk factor behaviors of these men and women.<sup>56</sup> As is seen in all tribal incidence data, several of the confidence intervals are exceptionally large.

**Gallbladder Cancer Incidence Rates.** Table 6 indicates that gallbladder cancer incidence rates are disproportionately high among both Native males and females. The incidence rates for whites, both sexes, is 1.3 per 100,000 people, compared with an incidence of 10.9 for American Indians living in Arizona and New Mexico and 10.6 for Alaska Natives.<sup>20</sup> Gallbladder cancer is 8.4 times more likely to occur in a Native person than in a white person.

The incidence rates for gallbladder cancer are higher among women than men. Gallbladder cancer is approximately nine times more likely to occur in an American Indian or Alaska Native woman than in a white woman.

**Lung Cancer Incidence Rates.** A quick review of the lung cancer incidence data in Table 7 indicates why it is inappropriate to use New Mexico data (which includes American Indians living in Arizona and New Mexico) to generalize about other Native population groups. In the following table, those data include the Apache, Navajo, and Tohono O'Odham nations. The lung cancer incidence among these southwestern tribes is much lower than those peoples living in Alaska and the northern plains.

**TABLE 3**  
**Age-adjusted (1970 Standard) Breast Cancer (ICD Codes 174.0-174.9)**  
**Incidence rates per 100,000 female population and 95% C.I. for each of the**  
**selected seven nations for which databases have few racial**  
**misclassification errors**

(♀ refers to females; ♂ refers to males)

ALEUT	APACHE	ATHA- BASKAN	ESKIMO	NAVAJO	SIoux	TOHONO O'ODHAM
♀ n=3,834	♀ n=12,781	♀ n=4,474	♀ n=17,252	♀ n=89,815	♀ n=27,348	♀ n=14,360
40.1 (0.0-81.4)	26.2 (9.7-42.8)	106.1 (48.3-163.9)	50.7 (30.4-70.9)	28.7 (21.8-35.6)	57.9 (40.0-75.7)	18.5 (5.7-31.3)

Source: Nutting et al., 1993.

**TABLE 4**  
**Age-adjusted (1970 Standard) Cervical Cancer (ICD Codes 180.0-180.8)**  
**Incidence rates per 100,000 female population and 95% C.I. for each of the**  
**selected seven nations for which databases have few racial**  
**misclassification errors**

(♀ refers to females; ♂ refers to males)

ALEUT	APACHE	ATHA- BASKAN	ESKIMO	NAVAJO	SIoux	TOHONO O'ODHAM
♀ n=3,834	♀ n=12,781	♀ n=4,474	♀ n=17,252	♀ n=89,815	♀ n=27,348	♀ n=14,360
29.7 (0.0-61.9)	31.8 (14.1-49.5)	39.4 (4.1-74.8)	33.1 (17.9-48.3)	26.3 (19.7-32.8)	29.2 (17.7-40.6)	41.7 (21.5-62.0)

Source: Nutting et al., 1993.

**TABLE 5**  
**Age-adjusted (1970 Standard) Colorectal Cancer (ICD Codes 153.0, 164.1, 169.0) Incidence rates per 100,000 population and 95% C.I. for each of the selected seven nations**

(♀ refers to females; ♂ refers to males)

ALEUT	APACHE	ATHA-BASKAN	ESKIMO	NAVAJO	SIOUX	TOHONO O'ODHAM
♀ n=3,834	♀ n=12,781	♀ n=4,474	♀ n=17,252	♀ n=89,815	♀ n=27,348	♀ n=14,360
89.9 (26.9-152.9)	13.0 (0.1-25.8)	96.2 (31.9-160.5)	116.1 (80.9-151.3)	10.7 (6.4-15.0)	19.4 (8.7-30.2)	9.4 (0.0-20.0)
ALEUT	APACHE	ATHA-BASKAN	ESKIMO	NAVAJO	SIOUX	TOHONO O'ODHAM
♂ n=3,953	♂ n=12,134	♂ n=4,612	♂ n=17,789	♂ n=84,502	♂ n=26,144	♂ n=13,632
114.8 (47.3-182.3)	9.3 (0.0-19.9)	40.4 (4.8-75.9)	53.2 (32.7-73.7)	9.3 (5.3-13.3)	24.7 (12.6-36.8)	1.3 (0.0-3.8)

Source: Nutting et al., 1993.

**Prostate Cancer Incidence Rates.** According to Table 8, the prostate incidence rates are low among both American Indians living in Arizona and New Mexico (37.6/100,000) and Alaska Natives (34.5/100,000) in comparison with other races. Tribal data show a range of incidence rates from 3.3 to 91.8. The lowest prostate cancer incidence rate is 3.3 for the Apache.

**Stomach Cancer Incidence Rates.** Stomach cancer incidence rates, as shown in Table 9, are high among American Indians when compared with whites and higher among males than females.

**Age-Adjusted Cancer Mortality Rates**

According to the National Center for Health Statistics, American Indians experience excessive mortality rates from uterine, cervix, and gallbladder cancers when compared with "U.S. All Races." The annual age-adjusted cancer death rates (156/100,000) for the Alaska Indian Health Service (IHS) area

**TABLE 6**  
**Age-adjusted (1970 Standard) Gallbladder Cancer (ICD code 156.0)**  
**Incidence rates per 100,000 population and 95% C.I. for each of the**  
**seven nations**

(♀ refers to females; ♂ refers to males)

ALEUT	APACHE	ATHA-BASKAN	ESKIMO	NAVAJO	SIoux	TOHONO O'ODHAM
♀ n=3,834	♀ n=12,781	♀ n=4,474	♀ n=17,252	♀ n=89,815	♀ n=27,348	♀ n=14,360
0	20.5 (5.0-35.9)	0	27.6 (10.2-44.9)	10.8 (6.3-15.4)	5.9 (0.1-11.7)	33.4 (13.5-53.4)
ALEUT	APACHE	ATHA-BASKAN	ESKIMO	NAVAJO	SIoux	TOHONO O'ODHAM
♂ n=3,953	♂ n=12,134	♂ n=4,612	♂ n=17,789	♂ n=84,502	♂ n=26,144	♂ n=13,632
0	0	9.2 (0.0-27.2)	3.8 (0.0-9.1)	3.9 (1.3-6.4)	4.7 (0.0-10.0)	5.3 (0.0-12.8)

Source: Nutting et al., 1993.

exceed those of the “U.S. All Races” (132/100,000).<sup>6</sup> Alaska Natives have excessive mortality from cancers of the uterine, cervix, colorectal, esophagus, gallbladder, kidney, nasopharynx, and salivary glands (see Table 10). Colorectal, breast, pancreas, and cervical cancers are the most frequent causes of cancer death among Alaska women. Stomach cancer mortality rates are excessive for Alaska Native males when compared with white males. Alaska Natives have the highest mortality rates of any racial group for cancers of the oral cavity, colorectal, gallbladder, endometrial, and renal carcinoma.

### Five-Year Relative Survival from Cancer

The relative five-year survival data for American Indians are among the poorest for all cancer sites combined of any racial group in the United States. When compared to non-Indian peoples in the Southwest, American Indians' cancer diagnosis—even in its early stages—results in poorer survival.<sup>57</sup> Survival data are based on American Indian residents in the New Mexico and

**TABLE 7**  
**Age-adjusted (1970 Standard) Lung Cancer (ICD Codes 162.2-162.9)**  
**Incidence rates per 100,000 population and 95% C.I. for each of the**  
**seven nations**

(♀ refers to females; ♂ refers to males)

ALEUT	APACHE	ATHA-BASKAN	ESKIMO	NAVAJO	SIOUX	TOHONO O'ODHAM
♀ n=3,834	♀ n=12,781	♀ n=4,474	♀ n=17,252	♀ n=89,815	♀ n=27,348	♀ n=14,360
101.7 (37.2-166.3)	8.3 (0.0-17.7)	111.3 (50.1-172.4)	53.2 (30.5-75.9)	4.6 (1.6-7.6)	34.1 (20.0-48.1)	17.9 (3.5-32.3)
ALEUT	APACHE	ATHA-BASKAN	ESKIMO	NAVAJO	SIOUX	TOHONO O'ODHAM
♂ n=3,953	♂ n=12,134	♂ n=4,612	♂ n=17,789	♂ n=84,502	♂ n=26,144	♂ n=13,632
92.3 (34.7-149.8)	6.1 (0.0-14.6)	88.4 (36.3-140.5)	106.1 (77.3-134.8)	13.1 (8.4-17.9)	46.2 (29.7-62.7)	10.5 (0.2-20.9)

Source: Nutting et al., 1993.

Arizona only. According to the data in the following, American Indians are less likely to be alive five years after diagnosis than are whites.

Table 11 summarizes survival data for American Indians and whites. According to the data in this table, American Indians have the poorest survival rates of any racial group for almost every cancer site included in the table. The zero survival from pancreatic cancer is true for people of all races. In about one-half of the diagnosed cases of pancreatic cancer, the cancer already has spread to other organs. This results in an overall five-year survival of just 3.2 percent for all races. Little improvement has been seen in five-year relative survival for liver cancer since the mid-1970s. The overall five-year relative survival for stomach cancer in all races is only 17 percent, but improves to 55 percent for cancers detected at the localized stage.<sup>43</sup>

Published survival data are unavailable for Alaska Natives. As of July 1995, survival data for Alaska Natives were in the process of being organized into a summary report. An Alaska Native Tumor Registry collected data from 1969 to 1983. Due to the low number of cancer cases (less than one hundred per year), however, the registry lost its funding for several years. The Alaska Native

**TABLE 8**  
**Age-adjusted (1970 Standard) Prostate Cancer (ICD Codes 174.0-174.9)**  
**Incidence rates per 100,000 male population and 95% C.I. for each of the**  
**seven Nations**

(♀ refers to females; ♂ refers to males)

ALEUT	APACHE	ATHA- BASKAN	ESKIMO	NAVAJO	SIoux	TOHONO O'ODHAM
♂	♂	♂	♂	♂	♂	♂
n=3,953	n=12,134	n=4,612	n=17,789	n=84,502	n=26,144	n=13,632
47.3 (5.7-89.0)	3.3 (0.0-9.7)	91.8 (37.6-146.0)	19.4 (6.7-32.1)	26.5 (19.9-33.1)	32.5 (18.6-46.6)	29.7 (12.1-47.4)

Source: Nutting et al., 1993.

Tumor Registry was reestablished through funding by the National Cancer Institute from 1989–1993 and was in the process of collecting information on incidence, follow-up, stage at diagnosis, and treatment. Unfortunately, the registry lost its funding again in 1993. It is not known how these invaluable data will be attained in the future.<sup>58</sup>

The low survival from cancer of American Indians reported by the National Cancer Institute (NCI) SEER data suggest that American Indian cancer patients experience the disease differently than other ethnic populations. More investigation needs to be done to explore the causative factors such as genetic risk factors, late detection of cancer, poor compliance with recommended treatment, presence of concomitant disease, or lack of timely access to state-of-the-art diagnostic and/or treatment methods.<sup>59</sup> Some types of cancer (uterine, cervix) may act differently within Native peoples and Native cultures and may affect the way people respond to cancer and cancer programs. By studying specific cancer sites that are elevated among Native peoples, information may be acquired to help people of all races. In addition, data reflecting American Indian communities that have effectively avoided specific cancers might shed some light on some protective factors of health behavior, diet, or environment.

#### INFLUENCES ON PARTICIPATION IN EARLY DETECTION SCREENING PROGRAMS

##### **Lack of Access to Culturally Acceptable Cancer Services**

The Indian Health Service (IHS) plays the primary role in providing services for American Indians and Alaska Natives. IHS is perceived by many Natives as a culturally acceptable health care provider. However, the IHS lacks sufficient

**TABLE 9**  
**Age-adjusted (1970 Standard) Stomach Cancer (ICD Codes 151.0-150.9)**  
**Incidence rates per 100,000 population and 95% C.I. for each of the seven**  
**nations**

(♀ refers to females; ♂ refers to males)

ALEUT	APACHE	ATHA-BASKAN	ESKIMO	NAVAJO	SIoux	TOHONO O'ODHAM
♀	♀	♀	♀	♀	♀	♀
n=3,834	n=12,781	n=4,474	n=17,252	n=89,815	n=27,348	n=14,360
6.9 (0.0-20.5)	7.9 (0.0-17.0)	7.3 (0.0-21.5)	12.2 (0.7-23.7)	10.9 (6.5-15.4)	11.3 (2.9-19.7)	10.9 (0.0-22.1)
ALEUT	APACHE	ATHA-BASKAN	ESKIMO	NAVAJO	SIoux	TOHONO O'ODHAM
♂	♂	♂	♂	♂	♂	♂
n=3,953	n=12,134	n=4,612	n=17,789	n=84,502	n=26,144	n=13,632
37.4 (4.1-70.7)	13.4 (1.3-25.5)	15.3 (0.0-37.0)	28.9 (13.9-43.9)	10.8 (6.5-15.1)	11.3 (3.3-19.2)	12.2 (1.1-23.3)

Source: Nutting et al., 1993.

budget, personnel, facilities, and resources to provide quality comprehensive cancer screening services to all urban and reservation Indians without collaboration from other agencies such as CDC and state health departments. Medical services are not always available to the consumer and are among the more common reasons for not using their services. For example, breast cancer screening has been assessed through the 1989 Survey of American Indians and Alaska Natives (SAIAN), which was a subset of the National Medical Expenditure Survey. The SAIAN found that only 23 percent of the women reported ever having had a mammogram.<sup>60</sup> When last reported in May of 1993, the IHS had a nationwide total of only fourteen dedicated mammography machines. Only two IHS areas had contracts for mobile mammography services.<sup>61</sup> Clearly, the majority of American Indian women belong in the medically underserved category, and are underscreened for breast cancer.

Another common complaint regarding IHS services is its inaccessibility. For example, American Indians living in the rural New York area (for instance, on

**TABLE 10**  
**A Selected Age-Adjusted (1970 U.S. Standard) Cancer Mortality Rates per**  
**100,000 Population by Race and Cancer Site, 1977–1983**

(♀ refers to females; ♂ refers to males)

Cancer Mortality Site	AK	AK	Am	Am	SEER	SEER	SEER	SEER
	Nat.	Nat.	Ind.	Ind.	White	White	Afr.	Afr.
	♀	♂	♀	♂	♀	♂	Am. ♀	Am. ♂
Breast <sup>a</sup>	12.8	unk	9.0	unk	26.7	unk	26.9	unk
Cervix uteri	*12.5	NA	5.5	NA	3.2	NA	8.7	NA
Colorectal	*27.2	22.1	8.0	10.1	18.4	*25.6	20.3	25.4
Gallbladder	*6.3	1.4	3.6	*1.5	1.2	0.6	0.9	0.5
Kidney	*4.4	*6.7	2.0	3.5	2.1	4.6	1.8	3.9
Oral cavity and pharynx	*6.3	*10.2	1.3	2.3	1.8	5.1	2.4	9.9
Pancreas	*10.3	9.3	4.2	5.3	6.8	10.4	9.3	*13.9
Prostate	NA	11.4	NA	11.8	NA	21.1	NA	*44.0
Stomach <sup>b</sup>	7.0	17.2	4.3	7.6	3.6	7.6	6.5	14.9
Liver <sup>c</sup>	2.6	15.2	1.1	3.1	1.3	2.7	2.1	5.6

- a. The racial group with the highest breast cancer mortality rate is Native Hawaiians (37.8)  
b. The racial group with the highest stomach cancer mortality rate for females is Native Hawaiians (14.5) and for males is Native Hawaiians (32.1)  
c. The racial group with the highest liver cancer mortality rate is Chinese (females=3.8; males=16.6)

Source: Department of Health and Human Services, PHS, NIH, NCI, 1992.

the Seneca Reservation) must travel more than 500 miles one way to access IHS services in Cherokee, North Carolina. American Indians living in Denver must travel 390 miles one way to Ignacio to obtain IHS services.<sup>62</sup> Some American Indians choose convenience over culturally acceptable services and those who have access to private health insurance are also likely to use this service instead.

### Changes in Lifestyle

As mentioned earlier, cancer rates appear to be increasing among American Indians and Alaska Natives. Through assimilation over time, American Indians have adopted Western lifestyles, which are conducive to cancer, and many forms of behavior-related cancer have increased throughout Indian country (lung, colorectal, and stomach). For this reason, the foci of several



**TABLE 11**  
**Five-Year Cancer Relative Survival (%) by Race and Cancer Site, 1975–84**

(♀ refers to females; ♂ refers to males)

Survival and Cancer Site	AK	AK	Am	Am	SEER	SEER	SEER	SEER
	Nat.	Nat.	Ind.	Ind.	White	White	Afr.	Afr.
	♀	♂	(AZ&NM only) ♀	(AZ&NM only) ♂	♀	♂	Am. ♀	Am. ♂
Breast	NA	NA	*49.7	unk	75.7	unk	62.8	unk
Cervix uteri	NA	NA	65.1	NA	67.2	NA	*61.3	NA
Colorectal	NA	NA	*42.3	*33.0	53.6	52.8	47.6	42.8
Gallbladder	NA	NA	*6.4	*3.0	9.4	9.4	8.6	8.9
Kidney	NA	NA	*36.2	*39.2	51.8	51.9	55.6	49.4
Oral cavity and pharynx <sup>a</sup>	NA	unk	*28.0	54.6	47.2	45.8	*28.0	
Pancreas	NA	NA	*0.0	*0.0	2.7	3.0	4.8	3.3
Prostate	NA	NA	NA	*51.4	NA	69.8	NA	62.0
Stomach <sup>b</sup>	NA	NA	12.0	*4.7	18.7	15.1	18.6	17.2
Liver <sup>c</sup>	NA	NA	unk	unk	6.5	2.8	6.7	2.1

- a. The racial group with the poorest survival from oral cavity and pharynx cancer for females is Native Hawaiians (36.4)
- b. The racial group with the poorest survival from stomach cancer for females is Filipino (8.4)
- c. The racial group with the poorest survival from liver cancer for both sexes is Japanese (females=3.7; males=1.2)
- The asterisk identifies the poorest survival rate of any racial group.

Source: Department of Health and Human Services, PHS, NIH, NCI, 1992.

ongoing cancer prevention and control programs in collaboration with American Indian communities are to assist those communities in undertaking lifestyle changes that may help prevent cancer.

**Risk Factors**

Risk factors for each of the more common cancer incidence sites have been identified. Since the majority of the cancer risk factors released by national organizations and agencies are based on white or black populations, they may not apply to American Indians and Alaska Natives. Therefore, it is not known which of the identified factors are risks for people of all races and which factors are a result of poverty. As cited earlier, a larger proportion of First Nations peoples live in poverty than do people of other races.<sup>63</sup>

Risk factors may be regional and may depend on particular lifestyles prominent in that area. Welty has shown that the high rate of smoking (56 percent for men and 48 percent for women) among the Sioux living in North and South Dakota are related closely to their high lung cancer mortality rates. Intensive smoking cessation and prevention programs are likely to have the greatest impact on reducing such preventable cancer deaths within their community.<sup>64</sup> Similar programs in New Mexico, where the incidence and risk factors are less, may not fare as well.

Risk factors may also vary among racial groups. Preliminary research indicates that risk factors for cervical dysplasia in American Indian women differ from those identified for the same cancer site in Southwestern Hispanic and non-Hispanic white women (for example, presence of HPV infection, multiple sexual partners throughout lifetime). Such research emphasizes the need to investigate ethnic differences in uterine and cervical cancer development.<sup>65</sup>

### **Barriers to Participation in Cancer Prevention and Control Programs**

In comparison to other ethnic groups, American Indians and Alaska Natives seldom utilize early cancer detection screening programs. They also are rarely recruited to participate in clinical trials or state-of-the-art treatment programs. When recruited, they typically are not retained throughout the duration of the study, but withdraw and cannot be evaluated. There are numerous barriers which explain these low utilization and participation rates.<sup>66</sup>

Barriers affecting American Indian and Alaska Native participation in cancer early detection and screening programs include poverty and psychosocial, sociocultural, and policy barriers. There are numerous policy barriers specific to Indian country. While American Indian nations have a unique, sovereign relationship to the federal government, state governments have not been tolerant of American Indian sovereignty issues in the past. These federal government-to-tribal-government relations often are strained by bureaucratic budget cuts by the Office of Management and Budget, which have significant and devastating impacts on American Indians' health care through the IHS hospitals, traditional Indian medicine, and tribal health services. These policy barriers can only be addressed through the successful implementation of culturally competent cancer prevention and control programs. When the projects are completed, modifications and outcome recommendations can be prepared as policies and submitted to the tribal communities for their approval. Only if the community can be brought into the planning will a program be successful.

Poverty has multiple, confounding effects on life priorities, from health problems other than cancer (such as alcohol/substance abuse, violence, suicide, and diabetes) to a lack of medical insurance to a want of transportation to a medical facility. Obviously, these barriers affect people of all colors who live in poverty and are not racially or ethnically specific. Psychosocial factors also affect people of all colors and include, but are not limited to, education level, knowledge about health and disease, language or nonverbal communi-

cation styles, and fear of using health services based on cultural practices or unpleasant past medical experiences. Examples of psychosocial barriers among American Indian women are related to misconceptions about breast cancer and/or the lack of breast cancer education. Some of the identified misconceptions might be a result of dispersed cancer education materials written at a very high literacy level (most National Cancer Institute materials are written for persons with an average of grade eleven or higher reading skills), whereas the average reading comprehension of large segments of the target population (within all ethnic groups) may be as low as grade five.

Sociocultural barriers include culturally irrelevant cancer education and recruitment materials, culturally specific beliefs about cancer (for example, to discuss the disease is to invite the cancer spirit into one's body), and other such misconceptions.

Culturally competent interventions are needed to find acceptable strategies of addressing these barriers. For example, the Native American Women's Wellness through Awareness (NAWWA) project being implemented in Denver and Los Angeles provides Native Sisters who assist in personalizing the cancer screening process.<sup>67</sup> For example, one woman requested that she be accompanied to a sweat on the evening of her mammography screening so that she could participate in a cleansing and spiritual ceremony to help eradicate evil cancer spirits which may have been introduced during screening. The Los Angeles site also has had clients who requested that a female medicine woman be present to smudge and bless the woman both prior to and following early detection breast cancer screening.

### BEHAVIORAL CANCER RISK FACTORS

Most cancers have external causes and to a great extent are preventable by practicing a healthy lifestyle. Likewise, other factors and behaviors are associated strongly with increased risk for developing cancer, such as a high fat/calorie and low fiber diet, habitual tobacco use, poverty, and so on. Unfortunately, the factors and behaviors that are associated with increased risk have escalated among First Nations peoples since World War II.

Thirty-five percent of all cancer fatalities in the United States are attributed to diet.<sup>68</sup> Dietary behaviors such as consuming chemo-preventive foods like fresh fruits and vegetables assist in preventing many forms of cancer. A 1990 report evaluating the USDA's Food Distribution Program stated that approximately 65–70 percent of the Native Americans living on reservation received either food commodities or food stamps. A typical household included an average of 3.2 persons, 40 percent of the families were one- or two-person households, and 8.5 percent were single-parent homes. The households generally included children and older adults aged 60 and over. The average level of education attained was the tenth grade. More than 50 percent of the adults worked, were looking for work, or were laid off and were looking for work. Most of the households were poor by any conventional standard and had transportation difficulties.<sup>69</sup> With the advent of the Indian Health Service (since 1955) and the USDA program, access to nutritional foods on reserva-

tions has improved.<sup>70</sup> However, Indian people who subsist on the USDA commodities programs frequently have access to five servings of fruits and vegetables a week which is insufficient to provide protective benefits to the body, according to biomedical models and National Institutes of Health dietary guidelines.

Habitual tobacco use is estimated to be responsible for about 30 percent of cancer in people of all races and is responsible for causing 90 percent of all lung cancer.<sup>71</sup> Based upon Behavioral Risk Factor Surveillance System data from 1985–1989, Native communities in the northern states and urban areas are more likely to be habitual tobacco users than are people of other races (50–80 percent of individuals from selected American Indian communities in Montana are habitual tobacco users).<sup>72,73</sup>

Poverty is a well-known risk factor for cancer. More than one-quarter (28 percent) of American Indian and Alaska Native people of all ages live in poverty, which is more than twice the national average. Almost two-thirds (61 percent) of American Indian and Alaska Native elders live in poverty.<sup>74</sup>

These are just a few examples of factors, lifestyles, and behaviors related to cancer risks. Obviously, if such behaviors and conditions continue, the cancer incidence and mortality rates will continue to rise among First Nations.

#### WHAT ARE SOME OF THE REASONS FOR THIS LACK OF AWARENESS?

This general lack of awareness is due partially to racial misclassification in statistical data collection, which subsequently has underestimated the number of cancer incidence and mortality cases. As a result, providers are misinformed about the significance of cancer within specific Native communities and are less aggressive in their efforts to identify and refer cancer symptoms. Federal agencies, such as the National Cancer Institute (NCI), until recent years were more likely to discount cancer as a problem. Since their primary data sources are from Arizona and New Mexico (where Native American cancer incidence and mortality rates are lower than for Indian communities from other parts of the United States), the institute was less apt to publicize this health problem. Unfortunately, only one-third of the fifty state health departments directly support or sponsor cancer prevention and control services for American Indians and Alaska Natives, reinforcing the misconception that cancer is not a health problem.<sup>75</sup> There have been very effective health education campaigns that have raised awareness and concern within a community. These campaigns include, but are not limited to, alcohol and substance abuse, domestic violence, diabetes prevention, and education. Other health problems, such as alcoholism and domestic violence, are very visible and effects of these behaviors are widely dispersed among Native communities; consequently, cancer is not considered particularly problematic.

Although cancer is a growing problem, its incidence and mortality rates are lower among First Nations people than within other racial groups. Survival from most cancer sites, however, is the poorest of any racial group. As discussed earlier, many American Indian and Alaska Native cultural beliefs discourage open discussion of the disease.

These issues, along with many others affecting cancer prevention and control efforts within First Nations communities, are discussed and prioritized within the 1992 National Strategic Plan for Cancer Prevention and Control to Benefit the Overall Health of American Indians and Alaska Natives, developed by the Network for Cancer Control Research among American Indian and Alaska Native Populations and published in a special National Cancer Institute Monograph.<sup>76</sup> The plan warned this special population that cancer was a major public health problem in their community and that steps should be taken to inform them of this change in cancer epidemiology.

#### NETWORK FOR CANCER CONTROL RESEARCH AMONG AMERICAN INDIAN AND ALASKA NATIVE POPULATIONS

The Special Populations Studies Branch (SPSB) of the National Cancer Institute (NCI) supported the initiative and development of a Network for Cancer Control Research among American Indian and Alaska Native Populations. The mission of this network was to “improve the health of American Indian and Alaska Native peoples by reducing cancer morbidity and mortality to the lowest possible levels and to improve cancer survival through cancer control research.” The Network functioned as an empowered, independent organization and assisted the NCI in achieving its year 2000 objectives for American Indians and Alaska Natives. From the latter part of 1991 through 1992, the Network for Cancer Control Research among American Indian and Alaska Native Populations prepared and wrote a National Strategic Cancer Plan to control cancer in this special population. The purpose of this plan was to enhance the awareness of federal agencies, other funding organizations, the Indian Health Service, health care deliverers and researchers about the special problems of cancer in American Indian and Alaska Native populations. The plan’s focus was to recommend actions and outcomes to assist federal agencies in formulating special initiatives to address the increasing incidence of cancer in American Indians and Alaska Natives. The federal plan was presented to the director of NCI, the director of IHS, and the national board of directors of the American Cancer Society, and was published in a National Cancer Institute monograph.

During 1993 and 1994, as part of its continuing efforts to reduce cancer morbidity and mortality, the Network for Cancer Control Research among American Indian and Alaska Native Populations completed a modified strategic plan for cancer control for state health departments. This achieved greater significance as the Congress moved to shift federally controlled funding to the states in the form of block grants. State agencies need to be better informed of strategies of collaboration with tribes and nations within their boundaries and how to address the cancer prevention and control needs of this special population.<sup>77</sup>

#### CONCLUSIONS

The data on cancer among American Indian and Alaska Native communities are sparse and riddled with racial misclassification errors, resulting in the underreporting of cancer incidence and mortality. Selected geographic regions of the

country, such as New Mexico, Alaska, or South Dakota, have access to databases that are considered to be of good or excellent quality. When cancer data are reviewed for these regions of the country, there is great diversity in the cancer incidence rates among Native American nations. This essay highlights seven tribal nations and specific cancer sites. For each cancer site, variable incidence rates are noted among the tribes. Although the Native American cancer databases have many quality problems, those data are the best available to communities to plan and develop culturally competent cancer prevention and control programs.

## NOTES

1. The National Cancer Institute has released incidence and mortality data that are more recent than those published in this article (see B. A. Miller, L. N. Kolonel, L. Bernstein, J. L. Young, G. M. Swanson, D. W. West, C. R. Key, J. M. Liff, C. S. Glover, G. A. Alexander, L. Coyle, B. F. Hankey, L. A. G. Ries, C. L. Kosary, A. Harras, C. Percy, and B. K. Edwards, *Racial/Ethnic Patterns of Cancer in the United States 1988–1992*, National Cancer Institute (Bethesda, MD: NIH Pub. No. 96-4104). However, due to less than twenty-five cancer cases of American Indians from Arizona and New Mexico, the majority of the tables for specific cancer sites (e.g., prostate, lung, breast) in the book have no data for Native peoples. Earlier data are used so that some numbers and rates can be reviewed by the reader.

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