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# Data Sources for Cancer Statistics among American Indians/Alaska Natives

CHARLES R. KEY AND THOMAS M. BECKER

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## INTRODUCTION

Few published data have addressed the descriptive epidemiology of cancer among various American Indian tribes nationwide, and risk factor information on a site-specific or tribal-specific basis is almost nonexistent in published reports. Nonetheless, with appropriately guided searches, a tenacious researcher of health care information can be directed to specific data sources on cancer among American Indians/Alaska Natives in various parts of the country. In this chapter, we will discuss some of these data sources, their access, and their limitations.

## METHODOLOGY

A study of the descriptive epidemiology of cancer or any other disease generally starts with the calculation of *incidence rates*, which are based on the number of newly diagnosed cases in a defined population during a specified period of time, or *mortality rates*, which are based on the number of deaths during a specified

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period. Crude rates, obtained simply by dividing the number of cases (numerator) that occur during a specified period of time by the total population at risk (denominator), are seldom informative, because they do not take into account any variation in the distributions of ages in the different populations that one wants to compare. Indian groups in the United States tend to have young populations; crude rates for most tribes typically are very low, because the denominators are weighted with relatively large numbers of young persons who have not yet reached the ages at which cancers occur most frequently.

To calculate age-specific rates for direct comparisons among different groups or with rates in published reference populations, one must know the size and the race/ethnic-sex-age distribution of the population at risk as well as those same demographic characteristics and the diagnostic classification of *all* newly diagnosed cancer cases or cancer deaths in that population during the specified time period. Age-specific rates typically are presented as tables or graphs of separate numerical values for each of sixteen or more five-year age groups (0–4, 5–9, 10–14 . . . 70–74, 75–79, 80–84, 85+).

Age-standardization or “age-adjustment” of site-specific incidence and mortality rates allows presentation of a complex set (or curve) of age-specific rates for a particular cancer as a single summary statistic. It represents the annual number of cases that would occur in 100,000 members of the standard population *if* the disease occurred within each age group of the standard population at the age-specific rates found in the study population.

Age-standardized rates from different populations or from the same population during different time periods cannot be compared directly unless they use the same standard. Recent publications of the National Cancer Institute (NCI) use the 1970 United States standard million population; earlier reports used 1920, 1940, and 1960 United States standard populations. *Cancer Incidence in Five Continents*, published every five years by the International Agency for Research on Cancer (World Health Organization), uses a “world” population standard (which has a younger median age than the 1970 United States standard) and a “truncated” standard (only ages 35 through 64 years) for international comparisons.

Communication among investigators and users of cancer data relating to Native Americans could be facilitated by consistent use of uniform methods and/or clear descriptions of case ascertainment, diagnostic classification and group-

ing, population determination, rate calculation, and rate standardization.

## INCIDENCE DATA

### **Indian Health Service Patient Data Systems**

In the future, computerized patient data systems already in place within the Indian Health Service should become a major data source that is most complete and most representative of the nature and magnitude of diverse cancer problems in heterogeneous Indian groups nationwide. Up to now, most IHS reports have emphasized administrative or workload measures such as numbers of clinic visits, hospital admissions, discharges, or days (length of stay) for selected diagnoses. These measures are somewhat informative, but converting them into valid incidence rates requires extensive verifying, editing, merging, and formatting of the original data sets. Potentially these patient data systems will facilitate complete ascertainment and matching of cases or deaths from specific populations at risk that can be defined from rosters of patients served by an IHS area or service unit.

### **New Mexico Tumor Registry**

Since much of the published cancer incidence data for American Indians in the United States is from the New Mexico Tumor Registry (NMTR), the NMTR's population-based cancer surveillance system will be described in some detail. Located at the University of New Mexico (UNM) Cancer Center, the NMTR works with the Indian Health Service (IHS), the Arizona Central Cancer Registry, and NCI to maintain databases of cancer cases occurring in the American Indian populations of New Mexico and Arizona. At the end of 1989, these databases spanned twenty-one years and contained records of more than six thousand cases. About four hundred newly diagnosed cases are added each year.

The total number of cancer cases registered by NMTR is over 97,000, and the total is growing by more than five thousand newly diagnosed cases each year. Cancer is a reportable disease in New Mexico by regulation of the Department of Health. NMTR has worked to locate, review, and abstract medical records of all

cancer cases diagnosed among all New Mexico residents since 1969. Because Arizona did not have a statewide cancer registry, the IHS in 1969 asked NMTR to include all Navajo Area IHS hospitals (including the ones in Arizona), and in 1980 IHS and NCI asked NMTR to include the rest of the IHS facilities in Arizona. Many, but probably not all, records from the 1969–80 era were identified and retrieved from archives and were abstracted into the database.

Major funding for NMTR comes by contract from the Cancer Statistics Branch, Division of Cancer Prevention and Control, NCI. NMTR is one of the nine population-based cancer registries that make up NCI's Surveillance, Epidemiology and End Results (SEER) program. The SEER program monitors changes in cancer incidence, extent of disease at diagnosis (stage), treatment, and survival in five states (Connecticut, Hawaii, Iowa, New Mexico, and Utah) and four metropolitan areas (Atlanta, Detroit, San Francisco, and Seattle), which represents a sample comprising about 10 percent of the United States population. NMTR is the SEER program's primary source of cancer data relating to American Indians and Hispanics.

Working with local hospital medical records personnel, circuit-riding tumor registrars from NMTR schedule visits to each facility for case-finding, abstracting, and follow-up. Abstracted data items include information about the patient (birth date, sex, tribe, place of residence), the cancer (diagnosis date, anatomic site, histologic type, grade, size, amount of direct extension to adjacent organs or structures, lymph node involvement, and metastatic spread to distant sites), the treatment (surgery, radiation, chemotherapy, but not specific regimens, schedules, or doses), and the outcome (vital status at annual intervals; data and cause of death, if deceased). These items are abstracted according to guidelines and coding rules established and monitored by the SEER program. Standard case-finding procedures cover medical laboratories, radiation therapy centers, and vital records offices in addition to hospital sources. Within hospitals, the primary case-finding sources are pathology reports, treatment logs, and indices maintained by medical records departments.

With careful attention to the protection of confidentiality, the Certified Tumor Registrars (CTRs) collect the data and input them directly into files on portable (laptop) microcomputers using a locally produced dBase III software system: PC DaSH (Patient Cancer Data System for Hospitals). PC DaSH software can also be

used for some basic analytical functions, including the production of subfiles, lists, sorted lists, frequency distributions, cross-tabulations, and survival rate calculations.

The NMTR master file is maintained on a Hewlett-Packard 3000 minicomputer in a secure data management facility at the UNM Cancer Center, using Cancer Information Management System (CIMS) software created at the Michigan Cancer Foundation. Hospital-specific data sets are extracted from the master file and placed on personal computer diskettes, allowing a wide variety of analyses and reports to be made with PC DaSH at the local hospital. Larger data sets from the statewide database, including all major data elements except personal-identifier information, are available to the hospitals for comparative studies.

Each year, NMTR prepares routine and special reports for three IHS areas (Albuquerque, Navajo, and Phoenix) and their major clinical facilities. Epidemiologists of the cancer prevention and control staff at IHS Headquarters West in Albuquerque verified a high level of completeness of New Mexico Indian cancer cases by cross-checking NMTR files with IHS patient data systems and original hospital records. Because of admissions to non-IHS facilities, ascertainment of the Arizona Indian cancer cases is not as complete as ascertainment in New Mexico. This situation will improve in the near future as the Arizona Central Cancer Registry expands its coverage in Arizona hospitals and incorporates data from IHS and NMTR.

Published age-specific and age-adjusted cancer incidence rates for New Mexico Indians are calculated using denominators interpolated from 1960, 1970, and 1980 United States Census Bureau population reports. Rates for recent years are not published, because detailed 1990 census data are not yet available. Rates for individual tribes and groups of tribes or IHS areas and service units will be published in collaboration with IHS and the tribes when credible subgroup population counts by sex and age are compiled from census reports, IHS patient service statistics, or special surveys. For a variety of reasons (census undercounting; tribal rolls that include persons living in distant cities), population counts from tribal sources often are larger than comparable census counts. Use of the larger population counts (denominators) would result in lower calculated rates. Sometimes it is useful to calculate rates using all of the available denominators to assess the range of resulting values.

Figures 1 and 2 illustrate average annual age-adjusted cancer

incidence rates (1970 United States standard population) for New Mexico Indians compared to rates for New Mexico Hispanics and non-Hispanic whites ("Anglos") in the nineteen-year period, 1969 to 1987. New Mexico Indians had incidence rates for all sites combined that were 40 to 50 percent lower than for non-Hispanic whites.

Age-specific and age-adjusted (world and truncated standard populations) cancer incidence rates for New Mexico Indians can be found in *Cancer Incidence in Five Continents*, volumes 3, 4, and 5 [1,2,3]. Age-specific and age-adjusted (1970 United States standard population) cancer incidence and mortality data for New Mexico Indians are published in NCI Monograph number 57 (*Surveillance, Epidemiology, and End Results: Incidence and Mortality Data, 1973-77*) [4]. Age-adjusted rates (1973-77; 1978-81) are in NIH Publication number 85-1837 (*SEER Program: Cancer Incidence and Mortality in the United States, 1973-81*) [5]. Numerous journal publications by UNM faculty members and NCI staff members address specific cancer topics based on these data sets assembled by NMTR [6,7,8,9].

### **Alaska Natives**

Anne Lanier and colleagues [10,11,12] have published several reports describing cancer incidence and mortality in the Alaska Native populations, which include Eskimo, Aleut, and Indians.

### **Other Native American/American Indian Groups**

Relatively low cancer incidence rates have been reported for Native Americans of western Washington [13], but misclassification of race may have resulted in undercounts of Native American cancer cases. Cancer incidence among members of the Seneca Nation of Indians is low in comparison to the general population of New York State [14,15].

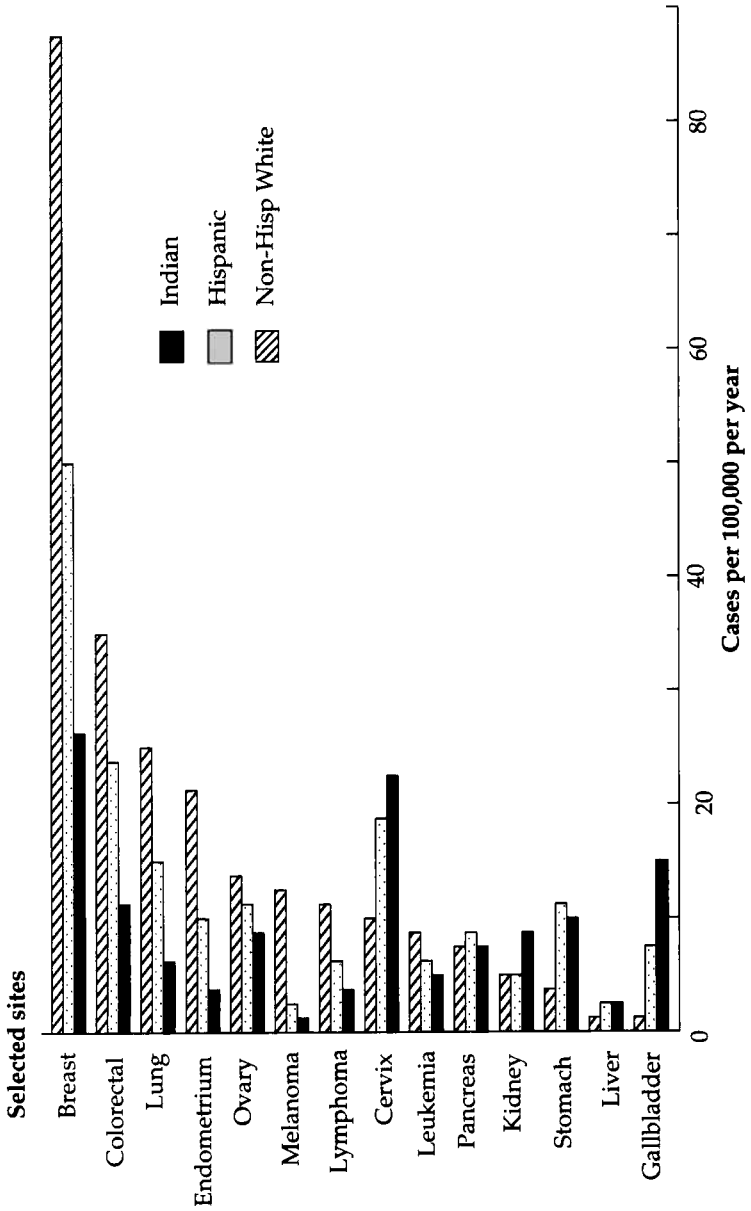


FIGURE 1. Cancer Incidence, New Mexico Females (New Mexico Tumor Registry, 1969-87)



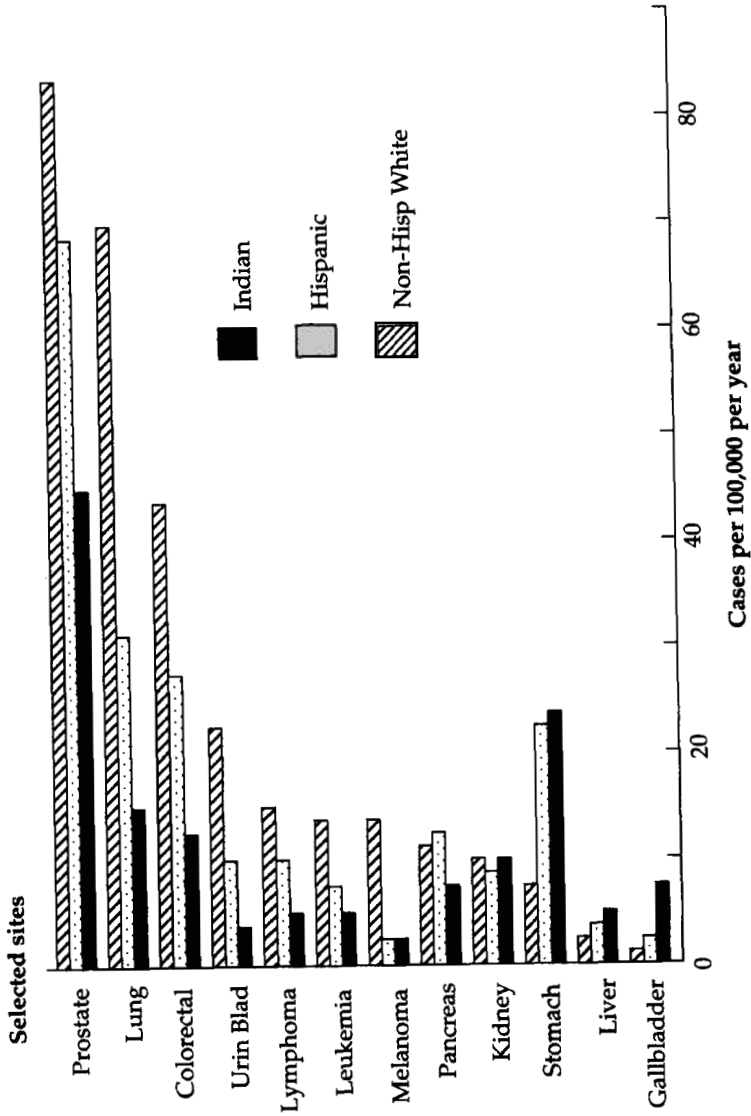


FIGURE 2. Cancer Incidence, New Mexico Males  
(New Mexico Tumor Registry, 1969-87)

## MORTALITY DATA

### State Vital Records

Every state health department maintains birth and death records for its population, coded by the decedent's name, underlying cause of death, contributing causes of death, age at death, and ethnic/racial affiliation. For certain states with large American Indian populations, the state nosologist(s) will code American Indian ethnic status in the appropriate fields on the death record, but their reports may not include ethnic-specific analyses. Some states consistently record tribal affiliation as part of the death record. Thus, if denominators (tribal sizes) are known, researchers may be able to calculate ethnic- and tribal-specific crude cancer mortality rates for American Indians based on mortality data sources. If denominators include information about the sex and age composition of the populations of interest, age-specific and age-adjusted rates can be calculated. In the absence of denominator data, the proportional distribution of major cancers may provide useful insights.

Mortality data as collected by state vital statistics bureaus are not without problems, including misclassification of ethnic status, misclassification of cause(s) of death, and errors in other descriptive data erroneously included in death certificates. For specific cancer sites, misclassification issues have been well addressed by Percy et al. [16]. In addition to these predictable sources of bias from state vital records, we have shown that American Indians are more likely than non-Indians to have their deaths assigned to the category "symptoms, signs, and ill-defined conditions." In New Mexico, a large proportion of the state's American Indian population lives in remote areas with often limited access to modern health care facilities. Chronically ill persons who are isolated from a modern health care system are more likely to have their deaths assigned to "cause of death, unknown" codes, which are then assigned by vital records under symptoms, signs, and ill-defined conditions (ICD 9 code 780 to 799). For predominantly rural American Indians in this state, the rates of death ascribed to symptoms, signs, and ill-defined conditions are seven-fold higher than for whites [17]. If a substantial proportion of these American Indians' deaths were caused by undiagnosed cancers, a significant amount of bias would result from rate calculations for cancer-related deaths. This problem is not specific to American Indians in

New Mexico, since large minority populations in other states also show high rates of death from symptoms, signs, and ill-defined conditions [17].

In New Mexico, ethnic identification of American Indians in state vital record data does not appear to be as problematic as in some states, where genetic admixture and tribal eligibility are not as clearly defined as in this state. Using state vital data collected on cancer mortality for specific sites over a twenty-five-year period, we have shown substantial rate differences in cancer mortality among the state's major ethnic populations (table 1). We have also used the same vital records tapes to examine ethnic differences in mortality from several other causes, including unintentional injury, ischemia, heart disease, rheumatic heart disease, respiratory diseases, homicide and suicide, and infectious diseases [17,18,19,20,21,22,23,24].

### **Indian Health Service Reports**

The Indian Health Service routinely publishes analyses of cancer mortality statistics for all Indian Health Service areas in yearly summaries [25,26,27]. These data are also valuable in providing some insight into the heterogeneity of cancer patterns among American Indians nationwide. In the Indian Health Service population, cancer is the third leading cause of death, accounting for approximately 11 percent of all Indian deaths for 1980–82 [28]. IHS data show that the cancer mortality rate, on the average, is lower than that of United States all races, although considerable variability exists among IHS areas. For certain areas, including the northern Plains, north-central United States, Alaska, and south-central states, American Indian/Alaska Native cancer mortality exceeds that of United States all races. In addition, site-specific excesses in cancer mortality are apparent for lung cancer in northern Plains American Indians, stomach cancer in the Southwest IHS areas, and cervical cancer in all IHS service areas [29].

### **State-Specific Cancer Mortality Reports**

In addition to state vital records data and Indian Health Service reports, several researchers have examined their state's mortality experience and published their findings on cancer mortality. Most

**TABLE 1**  
**Age-Adjusted\* Cancer Mortality Rates for New Mexico's**  
**American Indians, Hispanics, and Non-Hispanic Whites**  
**for Selected Sites, 1958-82**

<b>Site</b>	<b>1958 -62</b>	<b>1963 -67</b>	<b>1968 -72</b>	<b>1973 -77</b>	<b>1978 -82</b>
<i>Lung (Male)</i>					
American Indian	5.3	4.7	9.0	7.7	10.8
Hispanic	10.1	14.5	18.2	20.1	28.8
Non-Hisp. White	30.1	34.6	48.3	56.6	62.9
<i>Lung (Female)</i>					
American Indian	1.6	1.9	5.6	2.3	4.2
Hispanic	4.8	5.3	12.7	12.7	11.2
Non-Hisp. White	4.5	6.8	10.8	17.9	19.9
<i>Stomach (Male)</i>					
American Indian	12.8	13.9	16.0	17.5	16.1
Hispanic	32.6	21.4	23.6	15.3	16.1
Non-Hisp. White	13.6	7.8	6.0	5.9	6.2
<i>Stomach (Female)</i>					
American Indian	6.1	5.8	3.1	4.1	9.4
Hispanic	17.8	10.5	12.7	9.4	8.9
Non-Hisp. White	5.3	3.3	4.2	3.8	3.8
<i>Cervix (Female)</i>					
American Indian	3.8	9.8	7.8	5.9	7.7
Hispanic	10.6	9.8	8.1	7.6	4.4
Non-Hisp. White	7.0	5.0	4.5	4.0	2.2

TABLE 1 (cont'd)

Site	1958 -62	1963 -67	1968 -72	1973 -77	1978 -82
<i>Symptoms, signs, and ill-defined conditions (male)</i>					
American Indian	155.1	173.3	129.5	139.4	115.6
Hispanic	95.3	80.8	52.3	56.9	58.3
Non-Hisp. White	58.3	42.9	31.9	49.1	49.2
<i>Symptoms, signs, and ill-defined conditions (Female)</i>					
American Indian	105.0	138.1	93.4	80.4	81.7
Hispanic	64.9	40.9	27.9	31.1	30.9
Non-Hisp. White	18.9	16.8	17.7	23.9	27.9

\* Age-adjusted to the 1970 U. S. standard population.

of these mortality data are from Alaska, North Carolina, and New York, although the cancer experience in New Mexico's American Indians has also been summarized recently [9]. In Alaska from 1960 to 1969, standardized mortality ratios (SMRs) were high for Alaska Natives from cancers of the nasopharynx, salivary gland, liver, gallbladder, esophagus, and cervix [30]. Low SMRs were found for breast, uterus, and bladder cancer, and for melanoma. Among the Seneca of New York, low proportionate mortality ratios (PMRs) were recorded for all cancers combined from 1969 to 1984 [31]. However, for specific sites such as the cervix, PMRs were elevated [31]. In North Carolina, American Indians had higher cancer mortality rates than local whites for the following cancers: cervix, prostate, and male genital organs [32].

These mortality data sources, like the incidence data discussed above, provide clinicians and public health planners with descriptive information needed to help plan cancer prevention and control programs. A more thorough exploration of cancer mortality data from vital records tapes should be encouraged to help de-

scribe the patterns of cancer among American Indians nationwide. Such data will provide a base for further studies on cancer etiology among American Indians and Alaska Natives nationwide.

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